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Everyone Counts: Community-Based Health Information Systems

A Reference Compendium on the Collection, Analysis and Use of Data for Accountability in Health

Edited by

David R. Marsh • Katherine Kaye
Karen LeBan • James E. Sarn

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PREFACE

Accountability in Health

The many authors of this compendium recognize that our teachers gave us useful methods and perched us securely on the shoulders of science's giants. The lenses that focused the following vignettes of accountability in health, however, were the families in our service populations. We are grateful to them, and we hope they think well of us. We hope we have faithfully represented what they did and how they changed their children's previous risks and exposures to disease and death.

Enabling families to save their children brings to light knowledge that some families have possessed and practiced for generations. The age of such knowledge does not diminish the excitement of recognizing it in the course of being helpful, kind and accountable to the thousands from whom we learn.

Kindness seems an unattainable value as names and faces of desperately impoverished families pass by, rapidly and in great numbers. Our respect and concern may not always be transmitted personally by thoughtfully formulated words and actions. Meetings, reports, plans, surveys, statistics, budgets, and travel often eclipse the affective aspects of working with families who want to save their children.

Although affection keeps us coming back to the families, our donors' concerned generosity conspires with families' informed expectations to make accountability our preeminent value. In effect, the work presented here deals principally with *accountability* to our service populations in terms of their health outcomes.

Warren Berggren, MD, DrPH
Gretchen Berggren, MD, MS
Hopital Albert Schweitzer, Haiti

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Introduction

The Compendium

Health for All (1978) and the Child Survival Revolution (1984) have been the motivating visions for the international development community for more than two decades. Health for All (HFA) depends principally on the implementation of comprehensive primary health care (PHC) programs to extend preventive and curative care to all segments of the population. Child Survival (CS) programs focus on providing greater accessibility, particularly for children and women, to a few simple but highly effective interventions (GOBI-FF: growth monitoring, oral rehydration, breast-feeding, immunization, food supplements and family planning). Both of these global health strategies rely heavily on the use of community-based programs and interventions to provide accessible, affordable and culturally acceptable health services.

Although there is significant documentation for the effectiveness of HFA/PHC and CS programs, large segments of the populace in developing countries do not have adequate health services. There remains considerable debate as to which approach or which combination of program components can achieve the ultimate cost-effectiveness, cost-efficiency and cost beneficial protection for needy populations. Equally as important, there is also substantial uncertainty as to which approach or combination will have the best long-term sustainability for developing countries.

Private voluntary and non-governmental organizations, such as Save the Children, frequently are requested by local leaders or donor organizations to develop programs and extend services to needy, by-passed communities. With minimal resource levels and major socioeconomic obstacles, PVO/NGO programs have proven to be extraordinarily successful. The October 1994 worldwide Bangalore Child Survival Conference (Community Impact of PVO Child Survival Efforts: 1985-1994) concluded that "The findings of this conference are startling in demonstrating the dramatic global effectiveness, efficiency and impact of the strategies and interventions developed by the USAID-PVO partnership in reducing morbidity and mortality of children and women" and that "...PVO child survival activities (are) among the most cost effective of development technical assistance."

A key force in the development of the effectiveness and efficiency of PVO child survival programs has been the interest of USAID in providing resources for monitoring, evaluation and technical assistance. Through the assistance of Johns Hopkins University and USAID, the PVO child survival programs have developed impressive planning, implementation, management and evaluation capabilities. Significantly improved surveying techniques and health information systems have been one of the principal elements of these institutional strengthening activities.

This compendium is designed to capture some of the more important approaches to health information systems utilized to improve primary health care and child survival programs. It attempts to summarize the key approaches and issues related to the development and implementation of effective information systems.

At the Bangalore Conference, population-based health information systems emerged as one of the most effective and promising approaches to improved program management and impact evaluation. Population-based health information systems have also demonstrated significant achievements in improved equity, cost-effectiveness and program impact in a number of Save the Children primary health care and child survival programs. For these reasons, the compendium goes into significant detail on the rationale and development of a population-based health information systems.

The *History* chapter presents the evolution of the concept of community-based health information systems, at least in the 20th century. The chapter, *Rationale*, explains the idea of community-based health information systems from multiple perspectives. From theory to current practice, the *Field Applications* chapter presents the

recent experience of Save the Children and other organizations in community-based health information system. Not surprisingly, practice does not always perfectly reflect theory, but the differences are instructive.

The *Methods* chapter includes a variety of tools that support community-based health information systems. Included are practical papers describing the theory and/or demonstrating the practice of quantitative and qualitative techniques for utilizing, explaining or refining information from the HIS. Next, the *Alternative Health Systems* chapter reflects on the appropriateness of utilizing the population-based and other various HIS approaches. Interestingly, the indications of alternative systems are extremely narrow, thereby further supporting, albeit indirectly, the wide applicability of population-based systems. The final chapter, *Computers*, reviews the ever widening niche that computers can play in managing, analyzing, and even guiding response to information. Prominently featured is Save the Children's software program, *ProMIS*, which manages and analyzes health data for individuals and communities. The *Conclusions* summarizes the findings, highlighting remaining challenges and next steps.

The Audience

The Compendium is intended to inform, motivate and guide an array of cadres in international health towards utilizing appropriate health information systems. It is particularly important for high level decision makers responsible for the public's health to be aware of the operational issues and program benefits related to effective use of HIS programs. Potential and actual funders will recognize the wisdom of USAID's support of HIS strengthening activities which contributed significantly to improving the impact of Child Survival projects. Program implementors, such as private voluntary and non-governmental organizations, will hopefully benefit from the experiences of and the tools recommended by those that have gone before or worked along side them. Government counterparts at the facility, district, regional and national levels, will benefit from this straight-forward advocacy for universal coverage and care according to need. Ultimately, however, the intended beneficiary of this compendium is the one who, till now, has been overlooked and remains outside current health systems.

* * *

Compiling this Compendium depended upon a host of field staff and headquarters staff, organizers, writers, editors, programmers, interns, epidemiologists, friends, and mentors. This list certainly will be incomplete, but some names include: 1) Drs. Warren and Gretchen Berrgren, Dr. Sherry Guild, Gita Pillai, Mary Beth Powers and Donna Sillan for their contributions towards the development of HIS; 2) Save the Children field staff, particularly members of the Bangladesh field office which pioneered HIS; 3) the authors who contributed to this collection; 4) Christine Burns, Caroline Connolly, James Coplit, Maria Granata, Judith Raines, Jessica Rose and Vandana Sundaram who devoted countless hours in the production of this book and, finally, 5) the communities, the ultimate beneficiaries.

Historical Development: Theory and Practice of Health Information Systems

To understand community-based health information systems, one must first grasp community-based approaches to public health. Their stories are intertwined. A scenario of a medical encounter illustrating good and bad clinical practice will, by extension, introduce good and bad public health practice as well. The essence of good community-based practice is then examined. Finally, some brief historical remarks are presented about this approach to the health of the public.

A Medical Consultation

Suppose you are ill and see a doctor. You might be surprised at what happens. A good physician might not just treat your symptoms. Rather, she might inquire about seemingly unrelated matters and conduct a physical examination, in part, distant from the offending organ. Then she might perform laboratory investigations of uncertain relevance, and prescribe treatment which, indeed, may not be exactly what you had in mind.

This doctor-patient interaction introduces by way of analogy the activities of the community health practitioner. Professor Wyon has eloquently compared and contrasted the tasks of the public health physician and the clinician.[1] Each gathers data, interprets them, and makes recommendations -- whether his concern is for a defined population or an individual.

Now suppose in the above example, you were, indeed, very ill with fever and shaking chills. A careless physician might respond to your complaint by taking your temperature and prescribing aspirin for the fever. The careful physician, on the other hand, would discover that you had been coughing, that you had signs of chest congestion, and that you, in fact, had pneumonia. She discovered and treated this potential life-threatening condition because she looked beyond the presenting problem; beyond what was immediately apparent.

Community Health

How does this relate to a community's health? What if the public health practitioner assessed and responded only to readily visible "community" issues? Just as this resulted in poor medical practice in the above example, so it would lead to poor community medicine practice. Experience has shown that those at greatest risk and those with the worst health are often the least visible, just like the pneumonia hidden in your chest. These people are unseen because they are too poor to afford the health system, too uninformed to recognize their risk, too powerless to make decisions on their or their dependents' behalf, too distant to access the health system, and so on. The public health practitioner who only considers evidence that is immediately apparent risks drawing erroneous conclusions.

Denominators

Epidemiologists speak of "numerator analysis" and "denominator analysis." The former refers to collecting counts of health events often from a health facility, i.e., numbers of cases of diarrhea seen at a District Hospital per month. These service-based statistics provide a partial, but incomplete and possibly dramatically inaccurate, picture of the diarrhea problem surrounding the Hospital. For example, a cholera epidemic could ravage an inaccessible corner of the District while low numbers of diarrhea cases survive to reach the facility.

"Denominator analysis," on the other hand, deals with *rates* of health events. Rates depend on numerators, the counts, and *denominators*, the population at risk. Not until one grasps the implications of denominators does one fully understand the community-based approach. For example, consider villages A, B, and C from which 30, 35, and 50 malnourished children, respectively, attend a nutritional rehabilitation center. Numerator analysis identifies village C with the greatest and village A with the least child malnutrition problem.

Suppose you were concerned enough about all the counts to investigate further by visiting all the households in each village to identify and characterize the nutritional status of each inhabitant. You uncovered a malnutrition problem far greater (and different) than you had

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expected. Villages A, B, and C really have 90, 75 and 60 malnourished children under age 5. Village A actually has the greatest number of malnourished children. And its problem is more than childhood malnutrition alone because half of the children were not even seeking medical care! The population-based approach allows you to identify all affected individuals, many of whom were previously invisible to the health system because of its incomplete **coverage**.

When you were in the villages, you were also counting everyone (i.e. taking a census) as well as assessing the children. You found that the total populations of villages A, B, and C were 900, 500, and 1200. Thus, their malnutrition *rates* per thousand inhabitants are 100 (90/900 x 1000), 150 (75/500 x 1000), and 50 (60/1200 x 1000), for villages A, B, and C, respectively. Village B actually has the greatest malnutrition problem after correcting for the denominators. When the number of health events *per population base* is known, one can **compare** and rank communities by their health status.

You will want to refine the numerator according to your question. For example, if you are interested in severe malnutrition, consider only counting "children less than 36 months of age with modified Gomez classification III malnutrition." You will also refine the denominator according to the principle of risk (i.e., the group at risk for malnutrition or the group from which the malnourished children arise, such as those less than 24 months). Indeed, this principle of risk begs continual refinement. For example, suppose the malnutrition rates in each of our three villages were twice as high for girls as for boys? This suggests that gender bias may play a role in the **causation** of malnutrition in these communities.

Community-Based Approach

These three principles of *coverage, comparison,* and *causation* undergird the population- or community-based approach. Incomplete coverage means an incomplete health system (recall the pitfalls of an incomplete physical examination). Inability to compare means an impaired ability to measure the effect of a community's health program, such as comparing two strategies or comparing one strategy's effect over time. Unclear notions of causation and risk impede understanding health phenomena and targeting interventions.

Recent History

Wyon[2] traces the roots of the census-based approach to health care back 70 years to the Peking Union Medical College where John B. Grant and others extended the health care system to households. He then cited a generation of work by John E. Gordon: household surveillance for scarlet fever in Romania in the 1930s, epidemiologic surveillance during World War II and, finally, the Khanna Population Study[3] in the 1950s and 1960s in rural Punjab, India measuring the impact of household level services on fertility and mortality. Soon to follow was Kielmann and Taylor's Narangwal health services experiment, also in Punjab during the 1960s and 1970s.[4]

Meanwhile, Sidney Kark and others developed the concept of community-oriented primary care first in South Africa during the 1940's and 1950's and later in Jerusalem during the 1960's.[5] Essential to this concept were the following: (1) combining epidemiologic and clinical skills for a defined population; (2) community involvement for specific interventions and (3) measurable impact.[6]

We have included three papers from a seminal Epidemiologic Surveillance Symposium. Frederiksen[7] and other epidemiologists[8,9,10] debated the applicability of census-based approaches to public health. Based on his observations from Uttar Pradesh, India, First Frederiksen reported an exponential decay in health facility attendance with increasing distance between residences and the facility. In addition, he cited the re-emergence of malaria in Ceylon coinciding with replacing house-to-house surveillance with health center-based surveillance. Thus, he boldly proposed a multi-purpose household level surveillance system akin to the then familiar uni-purpose model in public health for malaria eradication. Possible aims included: providing family planning services, conducting surveillance for public health threats such as plague and cholera, measuring demographic trends and, of course, eradicating malaria. He poignantly observed that his proposal depended on a census-based

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approach. While fertility rates could be calculated on the basis of a population sample, the reduction of fertility required services with wide coverage.

Not all experts agreed with Frederiksen. Dunn,[5] the harshest critic, was skeptical of the affordability of a program of such broad scope (i.e., " a continual census"). Moreover, he noted that Frederiksen's model was the most expensive of surveillance systems for two reasons. First, the model actively sought data rather than passively awaited the information. Second it both analyzed these data and responded to them. Aside from cost issues, Dunn noted that not all health events (i.e., helminthiases) were amenable to surveillance.

Taylor[6] cautiously favored testing Frederiksen's notion of adding house-hold delivery of family-planning services to malaria control activities because he recognized the need for repeated person-to-person contact in this sensitive area. His major reservation concerned the qualitative differences between spraying an inanimate surface for mosquito abatement Vs. the delicate interpersonal tasks of motivating, advising, and following up couples for family planning. He felt that this strategy might be effective to initiate family planning services in response to a pre-existing demand. Taylor was uncomfortable with the supervisory effort required to reach less motivated potential beneficiaries or provide follow-up to acceptors.

Wray[10] endorsed Frederiksen's notion enthusiastically, citing personal experience at Bangkok's Ramathibodi Medical School. Indeed, Wray pushed the model further. Rather than viewing "epidemiographic surveillance as an adjunct to health care. . . [he considered it to be] as a necessary part of the health care delivery system." While Fredericksen and Taylor gingerly added selected services, mainly family planning, to the house-hold information system, Wray would wrap the community's entire health system around it! Furthermore, he would use such prototypes to teach community medicine to medical and nursing students. Wray noted the following: (1) the health and demographic baseline data would contribute to problem identification; (2) continuous surveillance flexibly would allow for special studies; (3) screening for malnutrition or tuberculosis could be performed in the field; (4) chronic medications and follow-up could best be provided at the house-hold level and (5) rigorous quantitative program evaluation would be possible. His second example, from the SEATO Cholera Research Laboratory (now the International Centre for Diarrheal Disease Research-Bangladesh), stressed the need for defined populations to measure cholera vaccine efficacy. In summary, Wray defended a census-based approach to health services as foundational to improving a population's health. Furthermore, he noted the opportunities for both the training of health personnel and the research of locally relevant health problems.

The 1978 Alma Ata Declaration[11] codified much of the above experience as Primary Health Care: universal coverage at the house-hold level of essential services as a strategy towards equity in health. The notion has stimulated much health system dialogue and experimentation in the developing world. Millions of lives have been saved. Berggren, Ewbank, and Berggren's attached paper,[12] Reduction of Mortality in rural Haiti through a Primary-Health-Care Program, exemplifies such an impact. They estimated an annual saving of 495 years of life per 1000 inhabitants among a defined population of less than 9000.

But hundreds of millions in the poorest countries of Africa, Asia, and Latin America remain outside their health systems. Indeed, wealthy countries are not spared such inequities. Increasingly, further health care reform relies on strategies evoking "defined communities" or "universal coverage" in both developing[13] and developed[14,15,16,17] countries. The experience of Save the Children and other private voluntary organizations in community-based health information systems has much to offer in informing this debate.

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Summary

In less developed countries, where the needs are greatest and the resources are least, attempts to extend conventional health services through conventional health facilities fail to reach the bulk of the population in rural areas. In such circumstances it is proposed that the planning, implementation, and evaluation of an integrated system of domiciliary health services be based on a multi-purpose system of surveillance of births, deaths, disease, and migration.

Thus, systems of epidemic and demographic surveillance could be incorporated into a multi-purpose system of epidemiographic surveillance for the eradication, or the maintenance of eradication, of smallpox and malaria as well as the critical evaluation and rational programming of other health services and family planning activities.

The accelerated feedback of epidemiologic and demographic information would guide the programmed responses of auxiliary field personnel of categorical or multipurpose campaigns, until the more conventional and comprehensive concepts of health services become feasible in the advanced stages of modernization. The systems of epidemographic surveillance and categorical campaigns would be phased out when the evolution of health needs and the development of health resources permit the realization of the ideal comprehensive health services. [eds.]

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EPIDEMOGRAPHIC SURVEILLANCE

HARALD S. FREDERIKSEN, M.D.

As defined in the preamble of the constitution of the World Health Organization, *"health . . . is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity."* But by this definition health is an absolute and utopian concept, which ignores the relative and evolutionary nature of health services.

The planning of services and investments in the health sector of a multisectoral system for the acceleration of economic and social development must be based on an understanding of the quantitative and qualitative evolution of feasible goals and optimal programs in the context of evolving needs and resources at successive stages of development. Accordingly, Hanlon (1964) has provided the following workable definition of health services: *"Public health is dedicated to the common attainment of the highest level of physical, mental and social well-being and longevity consistent with available knowledge and resources at a given time and place. It holds this goal as its contribution to the most effective total development and life of the individual and his society."*

EVOLUTION OF HEALTH SERVICES

Rational planning of health services must take note of the evolution of health needs and resources in the context of economic, social, and demographic transition. Disease tends to occur in definable patterns that reflect the level of modernization of society. Where the patterns of disease are not compatible with the process of modernization, we can attempt to modify them to patterns that are compatible with a modernizing society, both by direct and indirect health measures.

The ideal health policy would attempt to optimize short-term and long-term plans. Manpower and organization of the health services, designed to attack the most prevalent diseases most amenable to attack, would evolve with the needs and resources in the complex process of economic, social, and demographic transition.

The schematic outline of the evolution of health services in the context of the evolving patterns of disease and sets of circumstances (Table 1) is based on the empirical profiles of relative development (Figure 1).

The profile of relative development permits the setting of tentative but realistic targets, as well as tentative but realistic budgets, for health services in the context of needs and resources. Such empirical targeting and budgeting permits the minimization of costs or the maximization of benefits by permitting analyses of alternative budgets and targets to be based on the empirically derived targets as well as

budgets. The method and its application have already been more fully described elsewhere (Frederiksen 1967).

Obviously, the extension of curative medicine through the classic physician-patient relationship is not the most effective, efficient, or feasible approach in the earliest stages of development. When the primary objective is the maximum reduction in death, disease, and disability; and when endemic diseases are rampant, but actual and potential health resources are insufficient for a personal and curative approach, it is necessary to adopt impersonal and preventive approaches (Table 1 and Figure 1).

In the early stages of development mass campaigns are a more feasible, effective, and efficient approach for large-scale extension of categorical health services. Health may also be an incidental but significant by-product of economic and social development; for example, specific improvements in nutrition of minor cost but major benefit.

Only in the more advanced stages of development is it feasible to extend curative medicine to all through the classic physician-patient relationship. Of course, the level of development is not homogeneous nationwide. Certain regions, notably the capital city, may be relatively advanced, requiring or permitting a different approach than that necessary and feasible for the extension of health services to the masses in the rural areas.

THE LIMITS OF CENTRIPETAL SYSTEMS

The health center remains the conventional and favored approach for the extension of health services to the bulk of the population in rural areas of less developed countries, sometimes regardless of economic, demographic, or social circumstances or realities. Because the concept of a health center is so elusive, a network of health centers may give the comfortable illusion or facile promise of national coverage by a comprehensive and integrated, preventive and curative, system of health and medical services, but only until the objectives and functions are defined in time and place. A comprehensive and integrated system of curative and preventive medicine is the unquestionable and universal goal, but can the goal be achieved, even realistically contemplated, in the early stages of development?

Ignoring idealistic visions of imaginary attributes, in the actual practice of less developed countries many health centers are simply or primarily outpatient clinics for medical relief. Of course, the health center may serve as a base of operations for a campaign against a specific disease. However, aside from the possible sharing of space for offices, warehouse, garage, and a laboratory, the functional relationships between the centrifugal preventive and the centripetal curative activities are usually minimal and incidental in nature. For this reason, the evaluation of the sphere of influence of the static health facility is focused on the typical centripetal activities, which offer medical relief and very occasionally a little preventive medicine to those who are willing and able to come to the health center.

In India, for example, health centers combining preventive as well as curative services are to be established in such numbers that eventually all inhabitants should be within five miles of a health center or sub-center. A more elaborate network of centers hardly being feasible in the near future, the question arose whether medical relief is in fact such a powerful attraction that all or most inhabitants would be willing or able to walk or be carried up to five miles for medical relief. This question led to the study of the power of attraction of six dispensaries in the Benares District, in the State of Uttar Pradesh.

The rural population served by these six dispensaries is homogeneously distributed, with a density of more than 500 inhabitants per square mile. The topography of the area is typical for the Gangetic plain, of which the area forms a part. Three of the dispensaries under study practiced the indigenous or Ayurvedic system of medicine and the other three the modern or allopathic system. For each visit, the date of attendance, name, age, sex, diagnosis, and residence were recorded. It was also noted whether the patient attended in person or whether his illness was reported by proxy.

Obviously attendance should be considered in the context of the population to be served. With a homogeneous distribution of the population, this was most readily achieved by the calculation of the attendance per square mile, grouped by the distance of the residence from the dispensary. It became apparent that a substantial proportion of the attendance was "by proxy," which led to separate calculations of the attendance per square mile for those who attended in person and "by proxy." Those who attended "by proxy" were too old, too young, or too sick to attend in person.

The findings were substantially the same for the six dispensaries, for which reason the presentation of data (Tables 2a and 2b and Figure 2) is limited to the attendance at the allopathic dispensary in the village of Cholapur, situated ten

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miles north of Benares City, since data were available in greater and more reliable detail.

There is an inverse exponential relation between the daily attendance in person per square mile and the distance of the residence from the dispensary. If it is accepted that the total attendances in person and "by proxy" within one-half mile of the dispensary would tend to underestimate the morbidity in that locality, and if it is further accepted that the morbidity should be more or less evenly distributed throughout the area (at least in the absence of any epidemic and with an even distribution of the population), then it follows that less than 3.5 percent of those ill within five miles of the dispensary receive personal attention at the dispensary (Table 2a). It is evident that a sick person is more likely to attend in person only when he lives within one-half mile of the clinic.

By the way, if it is thought that the attendance from within one-half mile of the dispensary would overstate the morbidity in the area, the attendance per square mile form 0.5 to 1.5 miles might be accepted as the norm. In this event the findings remain essentially the same. The attendance still declines exponentially with distance and only a minute fraction of those sick within a five-mile radius seek attention at the dispensary either in person or by proxy (Table 2b).

Similar studies of the power of attraction of static curative facilities in geographically and ecologically distinct parts of India provide independent confirmation of the general validity of the findings in the Gangetic Plain.

Applying my method of analysis to basic data from Mysore State provided by Achuthan, Javare Gowda, and Nanjundiah (1964), and also to basic data from other regions of India provided in four prior reports cited by them, produces essentially similar findings: *the attraction of a center decreases at a geometric rate as the distance of the client increases at an arithmetic rate.*

It seems reasonable to assume that the inverse relationship between attraction and distance will generally hold true elsewhere. Of course, the particular rate of loss in power of attraction will vary with the nature or mix of the system of transportation as well as the distance of the residence of the client from the center.

It is evident that a system of health services, to achieve total coverage of the population by a network of static facilities in the walking stage of transportation, would require the location of such facilities in such numbers that the bulk of the population would live within a mile of medical relief. Even with the most economical structures and equipment, and with the maximum substitution of auxiliary personnel for professional staff, it will take considerable time and resources to achieve adequate coverage of a country by an integrated system of preventive and curative services through a network of health centers. Obviously, such an ambition becomes realistic only at a somewhat advanced stage of social and economic development. To some extent, improvement in transportation could substitute for increased proximity of the health center and availability of health manpower. But better transportation is also a matter of time and modernization.

NEED FOR CENTRIFUGAL SYSTEMS

The barriers to the extension of health and family planning programs include the lack of basic data on births, deaths, disease, and migration without which it has been quite difficult to successfully plan, implement, and evaluate basic services in rural areas of less developed countries. Moreover, the static facilities have been too few and the motivation of the populace too little to cause them to come and get preventive services from a facility some distance away from their residence.

Whereas medical relief might be offered conveniently in a static facility, it would not be realistic to expect attendances for preventive services, when even medical relief has such limited power of attraction. But the primary health services need not be restricted by the walls of a building. Medical relief might be considered as an incidental aspect of a health center, which might be viewed as the base of operations for certain essential health services to prevent epidemics and control endemics throughout the area.

Malaria eradication has been extended to many countries, even though the infrastructure of basic health services has been inadequate, by devising house-to-house systems of surveillance for the detection and eradication of residual or new foci of malaria.

It was thought that once transmission had been interrupted and the reservoir of infection depleted, active search for fever cases by periodic house visits might no longer be necessary, and that adequate vigilance to prevent resumption of transmission might be maintained solely by the examination of febrile patients at a network of health centers to rule out malaria. But what seemed possible has not proved to be feasible.

In theory, an existing network of health centers could be of such fine mesh that all or most inhabitants would visit a nearby center when medical attention is needed. All febrile patients could be examined for malaria parasites, or at least when a build-up in the fever rate is recorded. Thus any imported case or at least the secondary cases would be detected with such promptness that appropriate measures would not permit an epidemic to result in the re-establishment of endemic malaria.

In fact, in Ceylon, where malaria had been eradicated, the maintenance of malaria eradication was turned over to the network of general health centers. Even though Ceylon has a fairly well-developed system of health centers, they failed to detect the re-emergence of malaria sufficiently early to prevent the explosive re-establishment of epidemic malaria there. Thus, to eradicate malaria, Ceylon will have to start all over again.

Much the same disaster, only on a much larger scale, has happened to India. Areas of India, with some 100 million population, had reached the final phases of malaria eradication, but have since reverted to the early phases of the program for lack of adequate provisions for the consolidation and maintenance of malaria eradication.

Similar problems have arisen in connection with smallpox eradication in India and elsewhere.

Therefore, health and family planning programs need and want low-cost, practical, and multi-purpose systems of surveillance to spot births, deaths, disease, and migration as a basis for the successful extension and maintenance of malaria and smallpox eradication as well as the extension of family planning to rural areas beyond the reach of health centers.

FEASIBILITY OF SURVEILLANCE

At an early stage of development, we might aspire to a system of preventive services to reduce some of the most prevalent causes of mortality and morbidity area-wide through use of an army of auxiliaries for the house-to-house extension of stereotype health services beyond the reach of static facilities.

Where health centers had failed to eradicate malaria or smallpox for lack of an adequate sphere of influence, campaigns extending residual spraying of insecticides or vaccinations house-to-house have been dramatically successful in interrupting transmission at low cost per capita.

However, special surveillance programs for the maintenance of malaria or smallpox eradication are difficult to justify on an indefinite basis, particularly when the single disease in question appears to be quite non-existent.

Maintenance of malaria eradication requires house-to-house surveillance to supplement notification of fever cases (or malaria cases) by curative facilities, until the static facilities approach total coverage of the population or until extinction of the malaria parasite renders further vigilance redundant. Neither of these can be promised in the near future.

The maintenance of smallpox eradication, in the absence of an adequate system of routine reporting of smallpox, and also fully developed epidemiological and local health services, requires house-to-house surveillance or the achievement and maintenance of a high level of immunity by periodic vaccination and revaccination of more than 80 percent of the population, in all age groups and in all areas of the country.

Although surveillance is required to insure that the interruption of transmission of malaria and smallpox is maintained, this does not mean that maintenance of malaria and smallpox eradication could not be effectively integrated into a general health service. Certain essential health services, requiring total coverage, may be jointly more successful in maintaining a dynamic approach to health problems.

For example, family planning has made a good start in some cities of some countries, but relatively little has been accomplished in areas outside the immediate localities served by health centers. A separate effort to obtain vital statistics and to identify clients for family planning would be costly. But it would cost little more to collect data for several programs through a multi-purpose system of surveillance. Based on known costs of malaria surveillance, it is estimated that such a system of multi-purpose surveillance, once operating routinely, will cost on the order of 10 to 25 cents (U.S.) per capita per annum. Thus, the costs of such a multi-purpose system of surveillance would be only a small fraction of the total costs of these programs.

Thus, we have a potential solution for the problem of extending family planning and maintaining malaria or smallpox eradication, if and when the latter are achieved. Where, in contradistinction to a sampling procedure, the house-to-house approach has been necessary to achieve eradication for lack of an adequate infrastructure of basic health services, the house-to-house approach may also be necessary for the maintenance of eradication; i.e., until interruption of transmission is

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synchronized worldwide, or until conventional and comprehensive health services achieve adequate coverage nationwide.

ORGANIZATION OF SURVEILLANCE

Whenever a domiciliary system of surveillance has been established to reduce the reservoir of malaria and to confirm the eradication of malaria by the house-to-house approach, the opportunity exists to transform the single-purpose organization for the surveillance of malaria into an integrated multi-purpose domiciliary health service.

The current system of malaria surveillance, which is operational in some 30 countries with total coverage rather than a sampling coverage, serves as prototype for the multi-purpose system of surveillance. The integrated system would be designed to collect demographic as well as epidemic data and serve family planning as well as the general health services. In addition to the periodic house-to-house service for cases of malaria, the system would collect the leading symptoms of any disease or death, and the age and parity of the mother of any birth, and the age and sex of any new arrival. This information would be sufficient to plan, direct, or evaluate basic health and family planning services.

Although the malaria surveillance system serves as prototype for the multi-purpose system of surveillance, it should be noted that this system is not simply an attempt to "piggyback" on-going malaria programs. Rather, when the separate system of malaria surveillance has been eliminated along with the disease or when the government is not willing or able to support a separate system, the multi-purpose system would serve malaria eradication as well as all other health and family planning services equally. Finally, the same information on births, deaths, disease, and migration can be used over and over again by different parts of the Ministry of Health, and other agencies, and still would not be diminished by any one use to the detriment of any other use.

Auxiliary staff, as the basic tier of the district health organization, each with a single function serving multiple purposes, under the supervision of a hierarchy of semi-professional and professional staff with no clinical inclinations or responsibilities, could extend the essential health services over the entire area.

House visitors with the single function of asking a few questions could serve multiple purposes. By periodic visits, the house visitors could cover 1,000 to 2,000 households each. From such periodic visits the district health service could obtain epidemic and demographic intelligence serving, among other things, family and economic planning as well as the maintenance of eradication of both malaria and smallpox.

An additional example of the need for, and utility of, a domiciliary system of epidemic and demographic surveillance is indicated by the fact that, in endemic situations, the reporting of smallpox is the exception rather than the rule despite, or because of, requirements for compulsory isolation of cases in an isolated hospital. In such circumstances, "pox surveys" (surveys of the prevalence of pockmarked individuals) provide a method of identification of the epicenters and mainstreams of transmission of endemic smallpox, as shown for Bolivia (Figure 3, Table 3).

More important, "pox surveys" may constitute the only method of confirmation whether the last cycle of a mass campaign has in fact been successful in interrupting transmission. Only if accuracy and completeness of the system of reporting could be established would the absence of reported cases indicate the interruption of transmission. In fact, major epidemics of smallpox have been overlooked, ignored, and denied, even in urban areas of less developed countries. As confirmation of an apparent interruption of transmission, "pox surveys" could establish the absence of pockmarked individuals born since the last cycle of mass vaccination.

Of course, the tabulation of the leading symptoms of death and disease would serve as an early warning network for any epidemic disease, allowing appropriate and timely actions to the extent necessary or desirable and feasible. For example, in areas where cholera or plague are occasional problems, this system would allow action directed against a new focus before the problem becomes overwhelming.

Birth data, recorded by the first echelon, might identify mothers with two or more sons as potential candidates for a visit by a second echelon of subprofessional staff, specialists in the theory and practice of family planning.

The increments in median or average parity of women by single year age groups would approximate the age-specific fertility rates and indicate the need for and the impact of family planning programs. Couple with possible questions concerning the desired family size and the use of contraceptives, the incidence of unwanted pregnancies and the demand for family planning can be distributed by age and parity in time and place to

facilitate planning and implementation as well as the evaluation of area-wide family planning programs.

In contradistinction to sampling approaches, which underlie the estimation of vital statistics, the surveillance system would lead to the identification of all potential clients area-wide. Birth rates cannot be reduced on a sample basis; action programs require total coverage area-wide for success.

An accumulation of potential clients for family planning would lead to a visit by the family planning agent to probe and develop motivation. Subsequently, a nurse or midwife or other personnel qualified in the insertion of IUD's might make a house visit to provide IUD's to those who want and qualify for one. Alternatively, the interested and qualified women would be referred to a health center. Another alternative would be to put potential clients on a list for the monthly delivery of pills, possibly by the surveillance agent, who makes monthly visits to inquire about births, deaths, disease, and migration.

Moreover, the system would serve a number of statistical purposes of interest to economic as well as family planners. Information obtained by this independent system for the collection of data on births and deaths could be matched with registration data to prepare estimates of under-registration. The data collected would allow more sophisticated analyses of fertility trends by age and parity, and also of mortality trends by age, sex, and leading symptoms. Of course, the data would allow the mapping of morbidity rates, birth rates, death rates, migration rates, and growth rates by time and place, indicating the relative urgency and success of action by area.

Last but not least, the system of surveillance allows for the possibility of conducting special sample surveys. The multi-purpose surveillance agents might ask one additional question each round, for example, at every tenth household of every tenth hamlet. A different question might be asked each round. These questions might be on any appropriate topic of particular interest to any part of the Ministry of Health of the host government, including appropriate questions concerning the knowledge, attitudes, and practices relating to health or family planning.

Additionally or alternatively, such special sample surveys might measure height and weight, which along with age and sex, would indicate nutritional status. Edema, if present, would also be measured. The National Communicable Disease Center has incorporated such nutritional surveys into their system of smallpox surveillance in West Africa (Miller 1970). The results of such nutritional surveys have successfully guided relief operations and could serve as a basis for developing nutrition programs or agricultural policies.

CALIBRATION OF SURVEILLANCE

The successful utilization of auxiliary staff to extend a multi-purpose system of epidemic and demographic intelligence requires an effective and efficient system of supervision. It cannot be assumed that lowly paid staff with limited education will be highly motivated spontaneously. To insure total coverage of services house-to-house on a large scale, it will be necessary to transform the layers of supervision into an unbroken chain of effective supervision.

The mixed history of success in previous attempts to collect demographic data by periodic house visits indicates the need for careful selection, training, and supervision of personnel and also the need for continuous verification of the validity of the data collected.

Effective supervision of auxiliary house visitors is in part achieved by the introduction of a system of "serial inspection," which requires systematic sampling by successive echelons of supervision to periodically verify the findings of preceding echelons of supervision, whether the house visitors have in fact noted or missed symptoms and vital events in samples of households in hamlets in their areas of jurisdiction.

Since all levels of supervision can verify the validity of the reported findings of all previous levels of supervision by going to the same households first inspected by the first layer of supervision, it is quite difficult, if not impossible, for bogus data to escape detection. Even if several layers of inspection are bogus, ultimately an honest man at a higher level will detect the series of falsifications and report the need for new management and strengthened supervision. To reduce collusion sampling should be systematic; for example, inspections at every tenth house using the numbering of houses by the malaria campaign. All villages and hamlets should be covered in systematic rotation.

Actually in those parts of India where "serial inspection" had been substituted for less structured systems of supervision, the output per house visitor has promptly doubled, as indicated by unpublished personal observation of fever cases detected before and after, with and without, serial inspection.

Of course, there are other approaches to the evaluation of the efficiency and effectiveness of stereotype activities of any army of auxiliaries. The

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most appropriate approach in the given instance depends upon the nature of the programs and the features essential for its success.

In addition to serial inspection, there are a number of practical approaches to the supervision of operations and the quantitative evaluation of results. For example, the coverage of surveillance in time and space becomes readily apparent by tabulation of numbers and rates of cases, births, and deaths detected in each locality and in each round of visits by each surveillance agent. Apparent gaps in such tabulations would pinpoint candidates for spot checks as a crosscheck of the system of serial inspection.

In India, such tabulation by hamlets of the fever cases (detected by a surveillance agent each fortnight, as evidenced by the fortnightly submission of blood films from the reported fever cases) demonstrate gaps in coverage, both in time and space, although the number of specimens obtained, in relation to the population of the area, by far exceeds any norms established for the surveillance of malaria (Table 4). Note that, in the absence of a routine system of serial inspection and tabulation by hamlets of output, the annual blood examination rate per 100 population declined with distance from the base of operations and residence of worker (Figure 4).

Evidently, routine supervision as well as operations tend to lag with distance from the base or residence. This natural tendency confirms the urgency of objective and systematic methods of supervision as outlined.

Moreover, critical evaluation of costs and benefits or the cost-effectiveness of static health facilities could be based on the calculation of morbidity, mortality, and natality rates as well as attendance rates by distance of residence from the health center, once serial inspection and tabulation by hamlets of output confirm that the completeness of coverage by the domiciliary system of epidemic and demographic intelligence is not affected by distance from the health center.

Systematic supervision is required not only to achieve, but also to evaluate the completeness in the coverage of surveillance for the detection of births, deaths, disease, and migration. Serial inspection and tabulation by hamlets of vital events are useful or essential for the calibration of the sensitivity of the surveillance system, without which it cannot be proven, for example, whether a reduction in the birth rate reflects a collapse of the system of surveillance or success of the system of family planning; and whether the failure to find malaria constitutes failure of surveillance or success of eradication.

Since the very failure of surveillance tends to give programs of control or eradication a semblance of success, the routine calibration of sensitivity of the system for the detection of births, deaths, disease, and migration is proposed as a basic step in the evaluation of programs for family planning or the eradication of diseases. Instead of assuming that the quantity and quality of surveillance is adequate, the probability of missing births, deaths, or cases of disease, with the given quantity and quality of surveillance operations, should be routinely estimated as a prerequisite for any evaluation of demographic trends or the epidemiological significance of any cases.

DISCUSSION

Where the health needs are greatest the health resources are least. There, we have to make a choice. Either we can choose to further reduce morbidity and mortality through a comprehensive attack, both on major and minor health problems, by extending a complex and costly system of curative and preventive medicine, but only to selected parts of the population, i.e., those in the key centers. Or we can choose to further reduce morbidity and mortality by selective attack, only on major causes of disease and death, through selective categorical or multi-purpose campaigns using low cost methods and largely auxiliary personnel to extend preventive health services, and, if desired, family planning services, to all parts of the population, nationwide.

In early stages of development we cannot have it both ways. If we prefer to give priority to comprehensive geographic but selective functional coverage, rather than vice versa, we should use our resources in the most effective and efficient manner in order to have the greatest impact on morbidity and mortality of the total population.

Certain health measures that become feasible on a large scale only at later stages of development would be deferred, if necessary, to allow full scale immediate attacks on the most prevalent diseases that are most amenable to prevention. The development of institutions and professions would be phased to obtain the greatest immediate impact on the current problems. During early stages of development the most successful attack on the overwhelming health problems might require greater reliance on categorical mass campaigns against specific health problems and less reliance on the more complex and costly general

health services that are conventional in the most affluent countries.

The proposal for a system of multiple surveillance is based primarily on the quantitative and qualitative deficiencies of static health facilities and secondarily on the underutilization of such facilities where they do exist in rural areas of developing countries.

The utilization of health facilities is in part determined by the knowledge, attitudes, and practices of the public as well as the limited availability and accessibility of the facilities. The exponential decline in the attendance at health centers, inversely with the distance from the residence, suggests that ready availability and accessibility, or home delivery, of services would tend to serve more of those passively willing to accept but not actively willing to seek health or family planning services at any distance.

The concept of multiple surveillance proposes to collect, process, and feed back objective and subjective data to make the responses of services more appropriate and acceptable, and also more effective and efficient. Epidemographic surveillance may be a necessary prelude to the development of health services in certain less developed countries, that is if we wish to accelerate and escalate effective attacks on the major health problems during early stages of development, when health resources are inadequate for a more conventional and comprehensive development of health services.

Multiple surveillance may be an essential, although only transitional, phase in the development of health services; nevertheless a health service based on a series of systems for multiple surveillance, accelerated feedback, and reflexive response is neither qualitatively nor quantitatively an adequate substitute for the development of the more conventional comprehensive health services centered around regional hospitals and primary health centers. However, health services that are comprehensive geographically, as well as functionally, are not feasible until later stages of modernization. Thus, selective campaigns could and should be phased out only as static facilities can provide services that are comprehensive, both geographically and functionally.

Multiple surveillance would be phased out possibly over several decades, as soon as the selective categorical approach is no longer necessary or desirable. The evolution of the goals and types of health services reflects the evolution of objective and subjective health needs and the development of health manpower and facilities, both of which change in the context of the complex process of modernization. Such specific factors as the development of vital registration, education, and transportation are also immediate and important determinants of the quantitative and qualitative evolution of health services.

Even if the system of epidemographic surveillance might temporarily become the predominant source of basic data for planning, implementing, and evaluating health and family planning services, it would hardly be the sole source of such data for all purposes of the many types of health activities.

Special information on the knowledge, attitudes, and practices of the public concerning health and family planning might require special surveys that could not or should not be incorporated into the multiple surveillance system. Finally, the large scale nature of the surveillance operations to provide relevant and timely data for routine activities might make the special collection of the additional data by the routine system of surveillance impractical or inconvenient.

The proposal for the simultaneous solution of problems, for example, relating to the maintenance of malaria eradication and the extension of family planning in rural areas of less developed countries remains to be fully developed. Moreover, the feasibility and utility of particular elements of the proposal remain to be tested and demonstrated in a series of pilot projects in the field situations of one or more developing countries. But the system of malaria surveillance serves as a successful prototype for the concept of multiple surveillance.

Although there are some differences in kind as well as degree, the evolution of a system of multiple surveillance from the single system of malaria surveillance is a matter of incremental rather than fundamental change. At one time in India alone the homes of about 200 million persons were being visited fortnightly for purposes of malaria eradication. The costs of this single purpose system of surveillance was only a few cents (U.S.) per capita per annum.

Ultimately, it should be emphasized that the utility and feasibility of the surveillance system will depend upon the relevance of the data collection, and the promptness of the feedback. The type of data to be collected and processed will depend upon the feasibility and utility of applying the data to guide specific action programs.

The nature and scope of programs will dictate the type, coverage, and frequency of data collection. The urgency and magnitude of the data needs may require the computerization of data

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tabulation and analysis to accelerate the feedback of relevant information. Of course, steps to accelerate the collection and transmission of data will also be required. Direct transmission of basic data from the field to the central tabulating point might parallel the hierarchical submission of data for supervisory purposes.

Incidentally, the feedback of data may serve to monitor the surveillance system as well as guide the action units of the health services. The computer might identify peculiar inconsistencies, as well as regularities, causing supervisory staff to concentrate early and effectively on potential disciplinary problems.

More important, accelerated feedback would aid the rapid identification of the nature and magnitude of the basic health problems to guide either premeditated responses from disciplinary teams based at the static health facilities or stereotype responses from auxiliary field personnel of categorical or multi-purpose campaigns.

SUMMARY

In less developed countries, where the needs are greatest and the resources are least, attempts to extend conventional health services through conventional health facilities fail to reach the bulk of the population in rural areas. In such circumstances it is proposed that the planning, implementation, and evaluation of an integrated system of domiciliary health services be based on a multi-purpose system of surveillance of births, deaths, disease, and migration.

Thus, systems of epidemic and demographic surveillance could be incorporated into a multi-purpose system of epidemographic surveillance for the eradication, or the maintenance of eradication, of smallpox and malaria as well as the critical evaluation and rational programming of other health services and family planning activities.

The accelerated feedback of epidemiologic and demographic information would guide the programmed responses of auxiliary field personnel of categorical or multi-purpose campaigns, until the more conventional and comprehensive concepts of health services become feasible in the advanced stages of modernization. The systems of epidemographic surveillance and categorical campaigns would be phased out when the evolution of health needs and the development of health resources permit the realization of the ideal of comprehensive health services.

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TABLE 1

Stages in the Evolution of Environmental Health Problems, Predominant Patterns of Disease, Scope of Health Services, and the State of Nutrition

Stages of society	Environmental health problems	Predominant patterns of disease	Goals, type, and scope of health services	Actual or potential state of nutrition
Traditional	Largely rural environment with contamination of water and food; proliferation of insects and rodents; and periodic food scarcities.	Endemic infections, parasitisms, infestations, and nutritional deficiencies.	Indigenous systems of medicine based on traditional practices and beliefs.	Undernutrition as a result of food scarcities in a subsistence economy with practices and preferences of food production and consumption of a traditional, but youthful, society.
Early Transitional	Largely rural environment with contamination of water and food; proliferation of insects and rodents; adulteration of foods and drugs and food scarcities.	Endemic infections, parasitisms, infestations, and nutritional deficiencies.	Medical relief and family planning in key centers, control of endemic diseases and environmental sanitation in selected areas and the nationwide extension of categorical health services (malaria and smallpox eradication) requiring only minimal cooperation from the public and only minimal judgment from auxiliary staff with stereotype duties (residual spray and vaccination).	Potential improvements in nutrition in the areas of the monetary economy through possible modifications of social, economic, and agricultural policies favoring the consumption of a variety of nutritious foods; facilitating the extension of modern practices of agriculture, food technology and marketing, nutrition education, child feeding, and school l programs to the min of the population within the scope of the nutrition programs of the health, education, and agricultural services.
Late Transitional	Rural environment still resembles that of traditional society, whereas the urban environment resembles that of modern society.	Endemic diseases prevail at reduced levels in rural areas, whereas the disease patterns of urban areas resemble those of modern society.	Comprehensive and integrated systems of preventive and curative health and medical services in key centers with nationwide extension of medical relief, family planning, nutrition, basic sanitation, health education, and communicable disease control.	Continuing improvement of nutrition as by-product of economic growth and as result of progressive extension of nutrition programs nationwide, including the production of protein-rich foods and the fortification of staples.
Modern	Largely urban environment with pollution of air, water, and food by automotive exhausts; household, industrial, and atomic wastes; insecticides and pesticides; plus hazards from indiscriminate promotion or use of cigarettes, alcohol, food additives, new drugs, and narcotics.	Broncho-pulmonary and cardiovascular diseases, malignant neoplasias, mental illness, accidents, and obesity.	Nationwide extension of complex systems of comprehensive and integrated, preventive and curative health and medical services, requiring a prosperous society and enlightened public, as well as ample health manpower, qualified to exercise independent judgment.	Overnutrition as a result of an abundance of foods in an industrial economy of an affluent, sedentary, and ageing [sic] society.

TABLE 2a

Daily Attendance at the Allopathic Dispensary, Cholapur Village,[1] *Benares District, U.P., May and June 1963, by Distance of Residence from the Dispensary*

		Distance of residence from dispensary (miles radius of concentric circles)						
		0-0.5	0.5-1.5	1.5-2.5	2.5-3.5	3.5-4.5	4.5-5.5	Total 0-5.5
Area[2]	Square miles between concentric circles	0.8	6.3	12.6	18.8	25.1	31.1	94.7
Daily attendance	Total	9.1	41.1	15.4	5.4	2.8	0.4	74.2
	"By proxy"	3.5	22.2	7.4	3.4	1.7	0.3	38.3
	In person	5.6	18.9	8.0	2.0	1.1	0.1	35.7
Daily attendance per square mile	Total	11.4	6.5	1.2	0.3	0.1	0.0	0.8
	"By proxy"	4.4	3.5	0.6	0.2	0.1	0.0	0.4
	In person	7.0	3.0	0.6	0.1	0.0	0.0	0.4
Index of daily attendance per square mile	Total	100.0	57.3	10.7	2.6	1.0	0.1	7.0
	"By proxy"	38.4	31.0	5.2	1.6	0.6	0.1	3.5
	In person	61.6	26.4	5.5	1.0	0.4	0.0	3.5

[1] 600 inhabitants.

[2] More than 500 inhabitants per square mile.

SOURCE: Frederiksen, H., Maintenance of malaria eradication, *Bull. Nat. Soc. Ind. Mal. Mosq. Dis.* 11 (1963): 191-197, and republished by WHO in WHO Malaria Series, No. 429, February, 1964.

TABLE 2b

Index of Daily Attendance per Square Mile at the Allopathic Dispensary in Cholapur Village by Distance of Residence, Assuming Attendance from 0.5 to 1.5 Miles Distance as the Norm

Distance of residence from dispensary in miles	0 - 0.5	0.5 - 1.5	1.5 - 2.5	2.5 - 3.5	3.5 - 4.5	4.5 - 5.5	Total 0 - 5.5
Index of attendance per square mile	175.4	100.0	18.5	4.6	1.5	0.1	12.3

SOURCE: Same as Table 2a.

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TABLE 3

Prevalence of Pockmarked and Unvaccinated Individuals, by Age Group and Population Density in 11 Provinces of the Highland Plateau of Bolivia, 1958

Percent pockmarked (p) and not vaccinated (nv), by age group (years)

Province	Sample	All ages (not age adjusted)		0-4		5-9		10-19		20-39		40 and over		All ages (age adjusted)[1]		Population density per sq. km
		p	nv	p	nv	p	nv	p	nv	p	nv	p	nv	p	nv	
Manco Kapac	179	31.3	35.1	5.0	55.0	8.5	23.4	21.7	19.6	50.0	38.9	76.6	60.0	32.4	39.4	60.3
Comacho	1,637	30.1	49.4	1.6	-	10.6	-	23.5	-	45.9	-	55.8	-	27.5	-	32.5
Omasuyos	997	21.5	35.8	.6	56.1	6.9	14.7	16.8	20.4	37.1	42.7	49.1	55.1	22.1	37.8	31.4
Los Andes	1,525	14.6	34.4	.4	68.4	2.6	16.3	5.1	23.0	24.5	28.9	46.1	52.0	15.7	37.7	30.9
Dalence	1,786	5.1	30.9	.3	77.8	1.6	31.9	3.3	8.5	13.5	17.0	19.0	23.8	7.5	31.8	13.6
Ingavi	1,384	13.7	29.8	0	66.2	2.7	18.5	5.9	9.5	28.0	28.9	38.7	52.4	15.1	35.1	12.2
Aroma	812	12.7	30.7	1.0	66.7	3.3	40.1	7.6	6.3	28.3	37.0	27.7	38.3	13.6	37.7	9.5
Abaroa	130	9.2	47.7	0	95.5	0	72.2	11.1	48.1	16.3	18.6	10.0	35.0	7.5	53.9	5.1
Pacajes	1,849	9.5	35.0	0	73.2	2.0	33.9	5.5	23.5	16.9	26.2	40.0	62.9	12.9	43.9	4.8
Poopó	320	6.3	17.2	0	60.0	1.5	16.9	.7	5.4	18.8	30.1	27.8	27.8	9.8	28.0	4.8
Sabaya	476	3.6	35.1	0	82.8	0	48.3	0	14.2	6.9	19.6	15.6	35.9	4.5	40.2	.6

[1] Age adjusted by averaging age-specific rates for the age groups: 0-4, 5-9, 10-19, 20-39, and 40 and over.

SOURCE: Frederiksen, H., Strategy and tactics for smallpox eradication, *Public Health Reports* 77 (1962): 617-622.

TABLE 4

Blood Smear Collection by Locality and Fortnight, in the Bichwa Section, for the Year 1963

Locality	Population	Month and fortnight																								Total smears	Smears per 100 population
		1		2		3		4		5		6		7		8		9		10		11		12			
		I	II	I	II	I	II	I	II	I	II	I	II	I	II	I	II	I	II	I	II	I	II	I	II		
Jalosal	435																				7					7	2
Landura	88																									0	0
Hanspur	331							1													4		6			11	3
Jamuna	123													1							1		4		1	7	6
Karapani	118																						2			2	2
Ransali	63							2	1					1			4			3	7	6	3			27	43
Passanini	183								2												1	1	1	1		6	3
Chitalbag	133																						2			2	2
Najhota	69																					1	1			2	3
Belkera	239							3					2	2		3	1					3				14	6
Haraia	190			1		1		3			4	1	3	1	9	5			2		7	4	8	3	3	55	29
Bichal	137							1						7	3		4		1		4	1	1	1		23	17
Bichwa Farm	197		5	5		5		5	4		6	7	11	19	22	18	13	2	9	8	9	2	14	3		167	85
Bichwa Tarao	265							3	1	2	1	2	3	1	2				3						1	19	7
Tukri Farm	283	4	1	5	6	3	5	4	14	8	18	5	5	13	31	22	20	3	2	20	20	22	6	11	6	254	90
Kaivhuly	285		2	4	14	7	7	6		2	6	9	3	11	18	14	6	12	13	13	21		9	6	3	186	65
Golapipal II	204		1	2	8	6	7	1	1	3	4	5	5	1	10	12	1	7	20	3	15	9	9	5	4	139	68
Golapipal I	224		1	2	1		11	6	5	4	2	4		2	2	8		4	3	9		3	1	5	3	76	34
Total	3,567	4	10	19	29	22	30	35	28	19	41	33	32	59	97	82	49	28	53	56	96	52	67	35	21	997	28

SOURCE: Malaria Eradication Program for India

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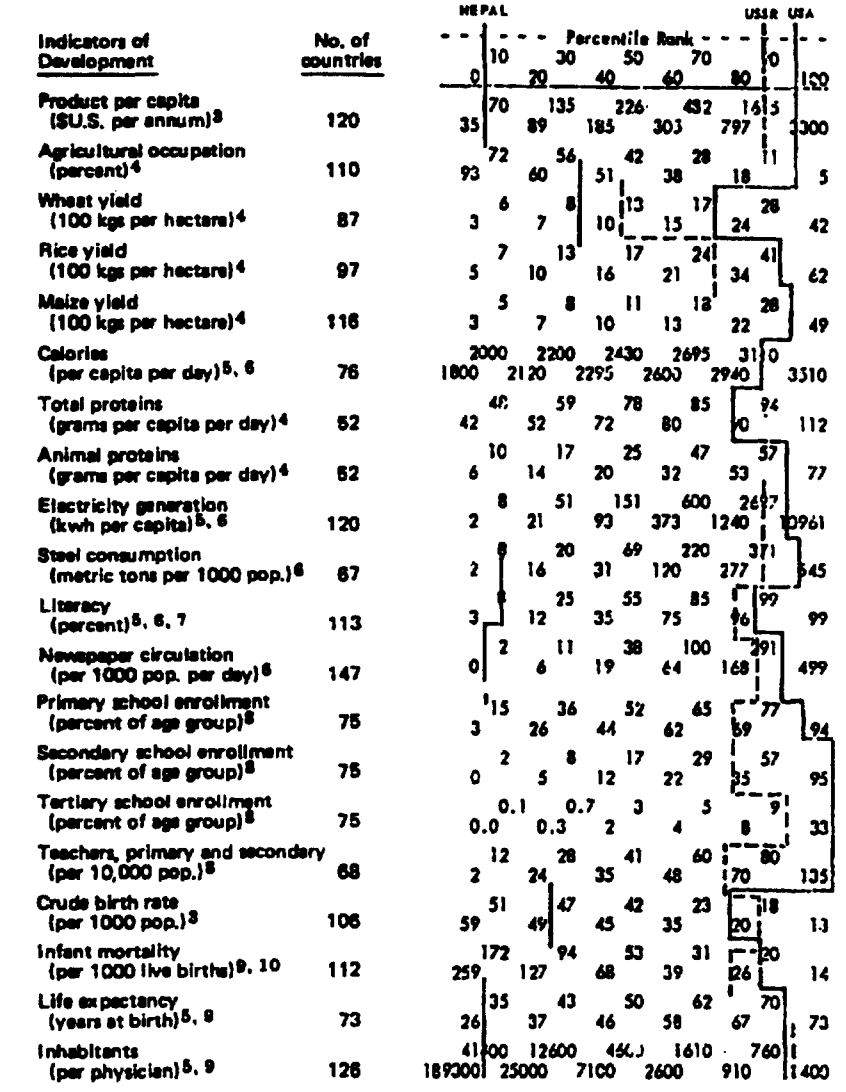
FIG. 1. Profiles of the relative development of Nepal,[1] USSR,[1] and USA[1] in comparison with 10 levels in the global grid of sectoral development[2]



[1] As indicated by histogram.

[2] As indicated by the deciles in the rankings of indicators from the latest year and the maximum number of countries for which comparable data are available.

[3] Population Reference Bureau, December, 1965.

[4] Food and Agriculture Organization, *Production Yearbook*, 1964.

[5] A.I.D. Economic Data Books, 1964.

[6] United Nations, *Statistical Yearbook*, 1964.

[7] Ginsburg, N. *Atlas of Economic Development* (Chicago and London: Univ. of Chicago Press, 1961).

[8] Harbison, F., and Myers, C. A., *Education, Manpower and Economic Growth: Strategies of Human Resource Development* (New York: McGraw-Hill, 1964).

[9] United Nations, *Demographic Yearbook*, 1964.

[10] Countries with virtually complete reporting or estimated rates.

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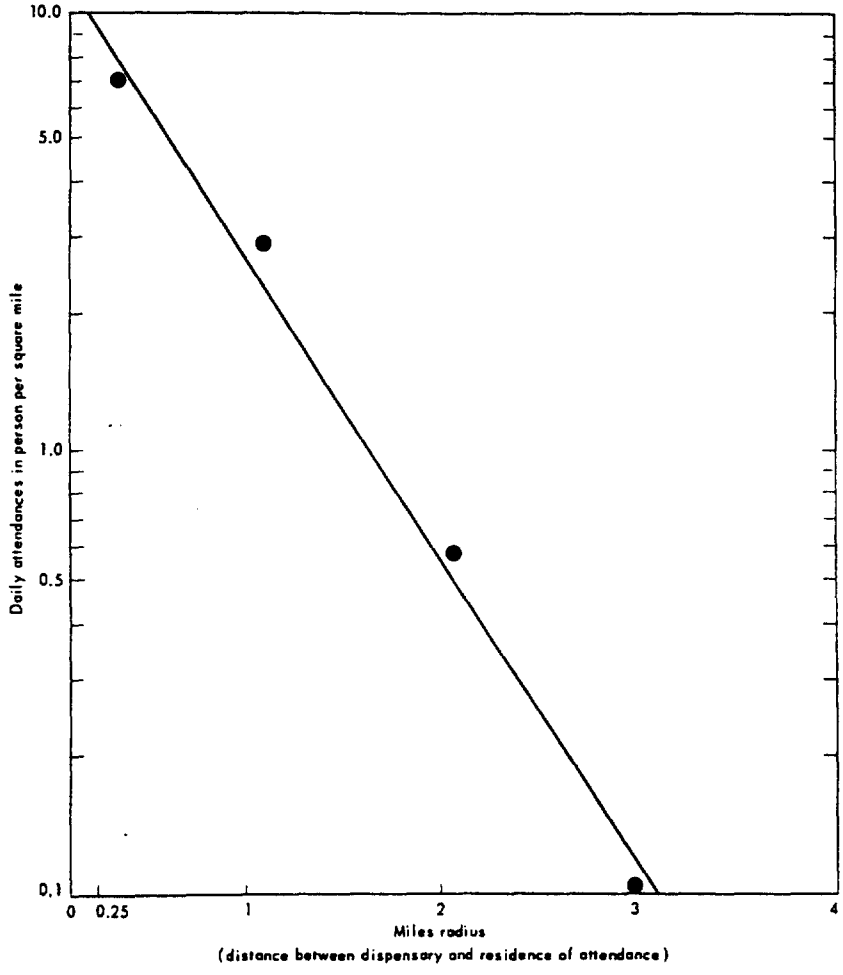
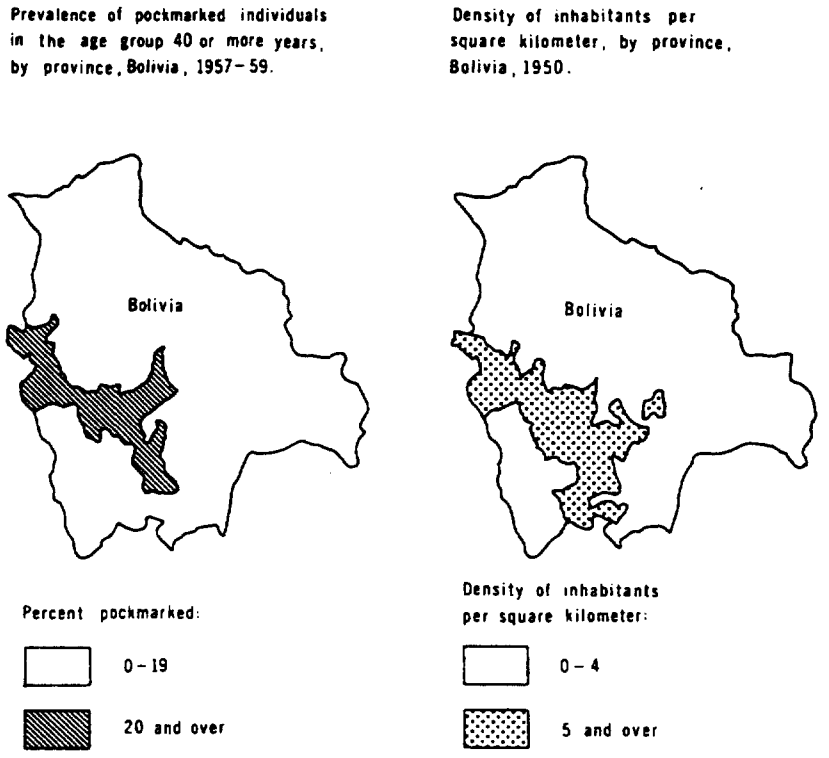
FIG. 2. Daily attendance in person at the allopathic dispensary, Cholapur Village, Benares District, Uttar Pradesh, May and June, 1963, per square mile by miles radius from the dispensary



SOURCE: Frederiksen, H., Maintenance of malaria eradication, *Bull. Nat. Soc. Ind. Mal. Mosq. Dis.* 11, No. 5-6 (1963): 191-197, and republished by WHO in WHO Malaria Series, No. 429 (February, 1964).

FIG. 3. Prevalence of pockmarked individuals and density of inhabitants



SOURCE: Frederiksen, H., Strategy and tactics for smallpox eradication, *Public Health Reports* 77, No. 7 (1962):617-622.

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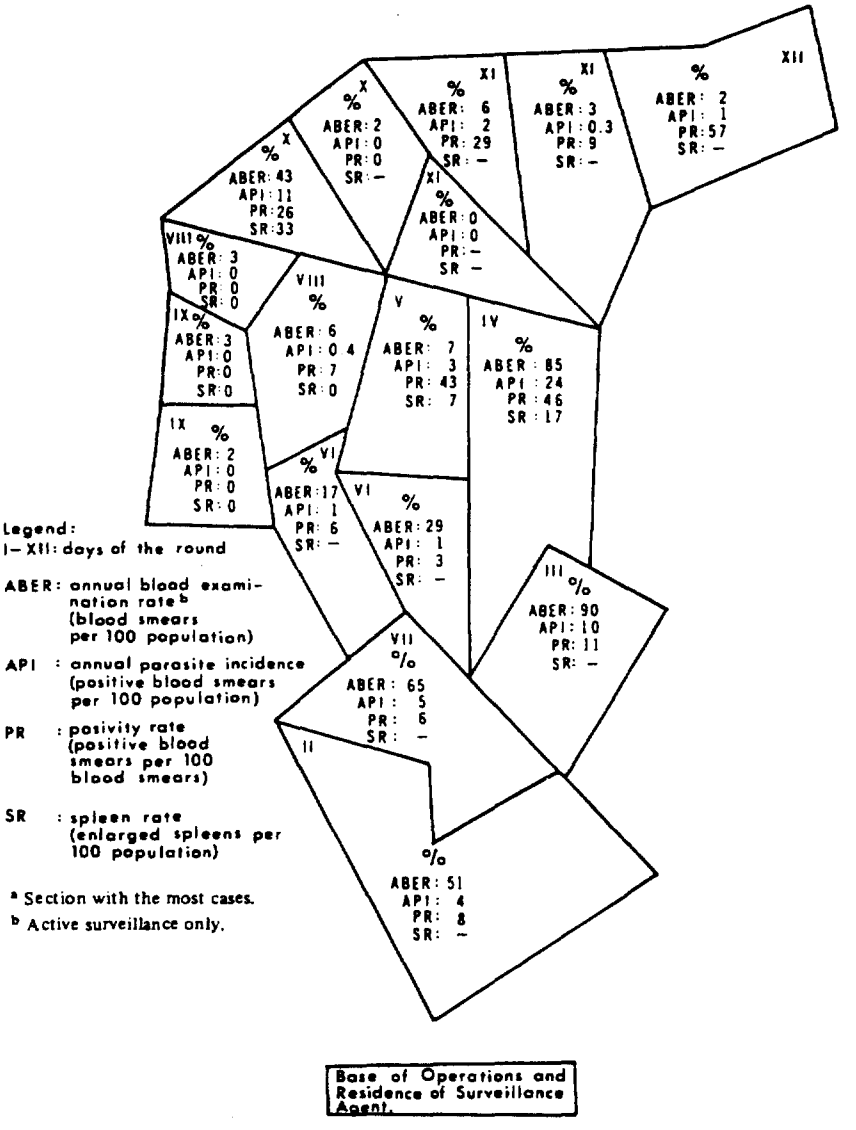
FIG. 4. The coverage by active surveillance and the detection of malaria in 17 localities of surveillance section Bichwa,[a] Rudrapar Unit, 1963



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Summary

Dr. Frederiksen's proposed "epidemiographic surveillance" rests on: (1) total population surveillance; (2) expansion of existing population-based networks (for malaria control, for example) to cover other diseases and malnutrition as well as to provide demographic data; and (3) a domiciliary health system to respond to the information.

This ideal objective is unrealistic from several perspectives. The extraordinary costs of conducting a "continual census" are unlikely affordable by most developing countries even if the per capita costs are low. The supervisory effort required to maintain a chain of valid information would be prodigious. Moreover, continuous surveillance would not serve all health needs, such as community helminthiasis which is better assessed through periodic surveys. Finally, surveillance has been interpreted more narrowly by thoughtful public health practitioners as the watchful collection, analysis, interpretation, and dissemination of important health information - exclusive of the response to this information. Further dialogue on this and all points is needed. [eds.]

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LIMITATIONS OF EPIDEMOGRAPHIC SURVEILLANCE

FREDERICK L. DUNN

My comments on Dr. Frederiksen's paper follow careful second and third readings that have left me with a somewhat less enthusiastic impression than gained by my first rapid reading of "Epidemographic Surveillance." Reflection and rereading convince me that Frederiksen's proposals do not cover very much new ground and that the one idea which is really new may not be practicable.

The essential points he makes, explicitly or implicitly and always with special reference to developing ("less developed") countries, seem to be these: 1) Continuing *total-population* surveillance of diseases (malaria, smallpox, and others) that contribute significantly to morbidity and mortality is needed. 2) The activities of existing surveillance networks – especially those for malaria and smallpox – should be extended to cover other diseases and nutritional disorders (mentioned in passing on page 20) *and to provide basic demographic data.* In addition, new surveillance programs, as they are established, should be developed as similar multi-purpose systems. 3) Given the deficiencies of present "centripetal" rural health services, new centrifugal services should be devised – for example, "an integrated system of domiciliary health services" (page 27) – and these should be based on the data provided by multi-purpose surveillance.

Regarding point 1), the need for continuing communicable disease surveillance has been widely accepted for at least two decades (Langmuir 1963); this is of course a global need, a necessity in "developed" as well as developing countries. At issue is whether this continuing surveillance need be "active" as well as "passive" at the total-population level, or principally passive at that level with active data-collecting limited to periodic sampling. I shall touch on this issue again later.

Point 2) is not new in general conception, namely, that existing surveillance activities should be broadened to encompass additional health problems. Dr. Frederiksen notes, indeed, that the National Communicable Disease Center has incorporated nutritional surveys into the West African smallpox surveillance program. The *new* element appears to be the suggestion that demographic data should also be gathered within the surveillance network.

As early as 1960 S.C. Seal expressed similar ideas about rural health problems and needs in a paper entitled "Integrated general health survey in India" (submitted to the World Health Organization Expert Committee on Health

Statistics, Geneva, 5-10 December 1960, and later published by WHO) (Seal 1965). The introduction to his paper includes these remarks:

> Specialized surveys must involve a considerable amount of duplication and unnecessary expenditure of public funds and effort, besides disturbing people with repeated visits from different workers. In view of these considerations, schemes for general health surveys have found increasing favour in recent years.
>
> In a tropical country like India with high population density, diversity of climatic, racial, religious and socio-economic conditions, afflicted with many endemic and epidemic diseases and with relatively poor and varied standards of sanitation and public health in its different regions and communities, it is all the more imperative that health and morbidity surveys should include studies of these diverse factors (i.e. environmental and socio-economic) *as well as of family characteristics and population growth* if they are to facilitate the planning of better and more balanced health services. (italics mine)

Seal continues with a detailed description of an integrated health survey; his findings are of considerable interest in the light of Frederiksen's proposals. The fundamental difference between the mechanism for gathering health and demographic data described by Seal and that proposed by Frederiksen is important; the health survey involves sampling at one "point in time" (or at periodic intervals) while the surveillance approach calls for continuous (or at least regular) "house-to-house" coverage of the total population.

Frederiksen is therefore suggesting that health and demographic data be collected in much more intensive and comprehensive fashion than is possible in a sampling survey and that these data be put to direct use (as part, it seems, of the surveillance activity), for example in the identification of potential clients for family planning. He does, however, fall back on sampling survey techniques for certain purposes, suggesting that they be used within the surveillance system to gather information concerning knowledge, attitudes, and practices relating to health or family planning (page 20 [of Fredericksen's article]). No one can deny that Frederiksen's proposal for total-population coverage is an ideal objective. Obviously total coverage would provide the most complete health data and access to all possible candidates for family planning. The principal issue to be considered, therefore, is this: How practicable is the "epidemographic" surveillance proposal?

Frederiksen maintains that it *is* practicable, technically, administratively, and financially. In response to his arguments I can offer only intuition; perhaps this is all that anyone can offer until a large-scale pilot effort in multi-purpose surveillance is undertaken – a venture that I assume the author has in mind. He fully acknowledges the difficulty of supervision, but believes that this can be handled as in existing malaria surveillance programs. This is not a totally persuasive argument because administration and supervision in at least some malaria surveillance efforts has been far less than optimal, as some of the faltering malaria eradication programs in the past decade bear witness. With regard to expense Frederiksen bases his optimistic estimates on the cost of malaria surveillance. I am not qualified to comment on this matter, but I would point out that the great malaria surveillance effort in India, involving some 200 million persons, was maintained for only a rather limited time at that level of coverage, and surveillance at that level was not inexpensive ("a few U.S. cents per capita per annum" multiplied by 200 million is a considerable sum, particularly for a developing country). The multi-purpose surveillance program, on the other hand, would have to be continued (with varying emphasis through time) for an extended period, probably many years. Thus the large capital expenditures that total-population surveillance entails would be required every year for many years. One of the original justifications for total-population malaria surveillance, as for the malaria eradication programs as a whole, was that these would be short-term efforts – requiring large but short-term capital investments – in contrast to malaria control which implies a continuing though lesser drain on financial resources.

The image that keeps coming to my mind is that a multi-purpose total-population health and demographic surveillance program would be comparable to a national census operating *continuously* rather than once every 10 years. The substantial costs and administrative problems posed by a decennial census, even one limited in scope to very few questions per household, are the imponderables that raise doubts about the practicability of the "epidemographic

surveillance" proposal. I hope other commentators and Dr. Frederiksen will further discuss this matter of practicability.

Part of point 3) mentioned at the beginning of these comments – that new centrifugal health services need to be devised – is important but also widely accepted by those concerned with meeting rural health needs. The weak power of attraction of the rural health center, so nicely illustrated by Frederiksen's Indian data, has long been recognized. Seal, for example, made the same point in his 1960 working paper: "It was also found during rural surveys that nearly 40% of the population do not try to get any treatment [i.e., "qualified medical advice"] for their common illnesses" (Seal 1965: 179). Indeed, since Frederiksen's primary purpose is to outline a surveillance proposal it seems rather unnecessary to devote such a large portion of his paper to the already widely recognized problem of underutilization of centripetal rural health facilities.

In passing I must take issue with one generalization. Near the beginning of his paper Frederiksen says: "Disease tends to occur in definable patterns that reflect the level of modernization of society." I should have preferred something like this: "Disease tends to occur in definable patterns that are related to, among other factors, the degree that a society has abandoned tradition in favor of the industrialized, scientific, urban model of the technologically advanced countries." The original sentence, as it stands, seems to relate disease patterns directly and solely to "modernization," whatever that may be; hence the suggested addition of "among other factors." "Modernization" is a most unfortunate term for it implies that a society in 1970 may not be "modern" – that is, current, in the present, characteristic of the present time – but all living societies are of course equally "modern."

I must also comment on several points that, in my opinion, should have been raised in the paper. Since the concept of surveillance is the central theme I think the presentation would have been improved by some discussion of "surveillance" as such. Little or no consideration is given to kinds of surveillance, or to the distinction between "active" and "passive" data collecting. And in particular I would have liked to find a statement of Frederiksen's position with respect to the rather different interpretations of the scope of surveillance that are expressed by Langmuir (1963) and by Pampana (1963). Langmuir's definition of surveillance follows: "Surveillance, when applied to a disease, means the continued watchfulness over the distribution and trends of incidence through the systematic collection, consolidation and evaluation of morbidity and mortality reports and other relevant data. Intrinsic in the concept is the regular dissemination of the basic data and interpretations to all who have contributed and all others who need to know. The concept, however, does not encompass direct responsibility for control activities. These traditionally have been and still remain with the state and local health authorities." Pampana, on the other hand, extends the conceptual scope of surveillance much further so that surveillance comes "to consist of two series of activities, one purely epidemiological, the other remedial" (Pampana 1963: 358). Frederiksen seems to favor Pampana's interpretation, but I would welcome more discussion on this point and especially on how it may relate to the question of practicability.

I am sure that costs for purely epidemiological surveillance and for combined epidemiological-remedial surveillance will always be radically different, the latter much greater. With respect to demographic surveillance, for example, costs would skyrocket if the total-population program were extended beyond collecting of vital statistics to identification of clients for family planning and then to "remedial" activities, such as actual family planning and IUD insertions. Frederiksen refers to "echelons" at several stages in his discussion but left me with no clear impression about their nature or even whether all echelon activities are to be regarded as part of the surveillance program.

While I am on the subject of surveillance as a concept, I wish to add that surveillance techniques were developed in response to a need for data on disease of the acute communicable type. The surveillance method has particular value in following the potentiality epidemic disease, the disease that undergoes relatively rapid changes in prevalence, incidence, and geographic distribution. Surveillance is an economical and necessary procedure in data gathering for such diseases. On the other hand, for the mass endemic diseases, especially those that are caused by bisexual parasites (Macdonald 1965) – the helminthiases – surveillance is less practicable or necessary. Instead, periodic sampling surveys in a particular region can provide the needed basic data upon which to ground public health and preventive

measures. Surveillance, in the strict sense, is not applicable or economically justifiable for such diseases as ascariasis, schistosomiasis, hookworm disease, trichuriasis, and filariasis (or for such moderately to highly prevalent asexual infections as those that cause the common diarrheal diseases, amoebiasis, and Chagas' disease). Admittedly, sampling surveys for these diseases can be administered through a national surveillance program, but the surveys do not thereby become "surveillance." I should have liked to have seen discussion in the paper of this enormously important category of disease, which, together with nutritional disorders, constitutes a total health burden far greater than that imposed by most acute communicable diseases combined (except malaria). Mass endemic parasitic and infectious diseases and mass nutritional disorders, linked as they are to agricultural productivity, economic development, social well-being, and physical and psychological maturation, figure prominently in rural health planning; but it is through effective and regular sampling surveys rather than through continuous total-population surveillance that the basic data on these diseases and disorders is best collected.

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Summary

Experiences with a Health Information and Service System (HISS) in Thailand and lessons from the Pakistan-SEATO Cholera Research Laboratory support Dr. Frederiksen's model of "epidemiographic surveillance."
A defined population of approximately 50,000 at Amphur Bang Pa-In (one hour from Bangkok) is presently the site of health systems research through the Ramathibodi Medical School. Community surveillance provides the information necessary for the following: designing appropriate health services; evaluating such experiments; research and teaching medical and nursing students. Household surveillance allows the health system to collect baseline data, organize special studies and provide domiciliary services such as screening, medicine refills, education, follow-up and publicity. Systems approaches guide data collection and handling, as well as services.
The cholera research facility in Matlab maintains a population of approximately 200,000 people under weekly surveillance. It has provided valuable lessons in supervision, training, data processing, community participation and, especially, research.
Important issues for future epidemiographic surveillance are cost-effectiveness, staff recruitment and training, integration with existing health care system, and start-up costs. [eds.]

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A HEALTH INFORMATION AND SERVICE SYSTEM

JOE D. WRAY, M.D.

An invitation to contribute to a symposium-discussion of Dr. Harald Frederiksen's paper was most welcome because I have been thinking along remarkable parallel lines and agree enthusiastically with his suggestions regarding the potential value of "epidemographic surveillance." Before moving on to discuss the topic, however, I would like to make explicit acknowledgment of the contribution he makes in the first part of his paper in presenting his data concerning the effect of distance upon the utilization of health care facilities. He has provided "hard facts" to substantiate the "clinical impressions" held by many of us that the effective range of health care facilities is indeed limited. His findings ought to be sobering to everyone concerned with the delivery of health care to rural populations in developing countries throughout the world and, among other things, provide one compelling argument in favor of the establishment of an epidemographic surveillance system.

SOME SIMILARITIES OF APPROACH

The parallel in our thinking mentioned above includes even the genesis of the idea. His concept was inspired by his experience in malaria eradication in India. My own ideas have similar roots. In early 1968, not long after arriving in Thailand, I first encountered a Malaria Eradication Program (MEP) in the "Active case detection phase." On hearing that the MEP "home visitors" were in monthly contact with *every family* in a district, it dawned on me that here was a system with a remarkable potential for collecting health relevant information and, at the very least, ought to be collecting reliable data on births and deaths.

Over the months since then I have continued to think about this, still along lines quite parallel to those of Frederiksen. In considering such an information gathering system as a part of a health care delivery system, and the functions which it might fulfill, in addition to obtaining birth, death, and migration data, most of those mentioned by Frederiksen occurred to me also. These include the collection of other kinds of information, as well as the provision of certain health services to the population under surveillance.

Yet another parallel worth noting here is the fact that our estimates of the cost of operating such a system are also quite similar to those of Frederiksen. It appears that it would be possible to establish such a system in rural Thailand at a cost of around 25 cents (U.S.) per capita per year.

SOME DIFFERENCES IN APPROACH

My own thinking about the establishment of such a system has been shaped by my involvement in a Community Health teaching program in the new Ramathibodi Medical School in Bangkok. The program is being developed by members of the clinical departments of the medical school, working together with officials of the Ministry of Health, to establish in a rural district a site which can be used to provide practical learning experiences in community health care for medical and nursing students and be used also for research in health care delivery. The site selected, Amphur Bang Pa-In, about one hour north of Bangkok, has a population of approximately 50,000 people scattered through 146 villages, served by one physician, one public health nurse, four midwives, and three sanitarians. The program is only now getting under way and many aspects of it are still in the planning stages. This includes our version of an epidemographic surveillance system, which we are tentatively calling a Health Information and Service System (HISS).

First, if we are indeed to be able to carry out rigorous experiments in the delivery of health care, and to attempt to develop simple reproducible programs which might be used elsewhere in Thailand, then it obvious that we must have reliable information concerning the effectiveness of such programs. The possibility that the HISS may furnish the data for such evaluation is immediately apparent. No less apparent, however, is the fact that this will not be possible unless the objectives of such experimental approaches are defined in measurable terms and the necessary measurements can be carried out, in the field, by the surveillance agents.

The second important function of the HISS anticipated in the Community Health Program in Amphur Bang Pa-In derives from its role in the teaching activities in community health for medical and nursing students. I have recently expressed my strong conviction that if teaching programs in community medicine are to compete with the teaching of clinical medicine for the interest and attention of medical students, it is imperative that ways be found to demonstrate the benefits of community health activities to the students (Wray 1970b). The challenge here is imposing. Results prompt, and often dramatic, are readily apparent on the wards of the clinical services of good teaching hospitals. The results of community health activities are neither prompt nor readily apparent and only rarely dramatic. Yet, if we are to make an impression on the students, we *must* compete with the clinical departments: some attempt must be made to demonstrate, as convincingly as possible, that such activities are worthwhile. Here too, then, we hope that the HISS can play a role not mentioned by Frederiksen.

A third difference in our approach to epidemographic surveillance in Bang Pa-In is explicit in the title of the paper: such a system can and indeed ought to be an integral part of a health care delivery system. This is also implicit in Frederiksen's paper, although he does not make it as explicit as we feel is warranted. Rather than thinking of epidemographic surveillance as an adjunct to health care, we think of it as a necessary part of the health care delivery system, and hope to integrate it in the manner indicated in the sketch shown in Figure 1. As the sketch suggests, there is an important and continuing role for such a system in medical care activities, as well as in preventive and promotive programs.

1. *Baseline data.* Among other things, we expect the HISS to provide an adequate census, basic vital data, and simple information, about morbidity and mortality as well as health behavior, which will be useful in the medical care programs. We also expect it to provide information concerning target populations and, again, vital data, for the preventive-promotive programs. These functions are spelled out quite adequately in Frederiksen's paper.

2. *Special studies.* As suggested by Frederiksen, once the HISS is established and functioning efficiently in collecting the primary information regularly from the total population, then the same system can be used to obtain other kinds of information needed at less frequent intervals or only occasionally. The HISS man could ask one additional question, on some special topic, of the total population each month, or he could spend an equal amount of extra time in asking several questions of a specified sample of the, total population. Such questions could be asked on an annual or semi-annual basis to provide evidence of changes in concepts or practices. In planning our program, for example, we hope to use the system to obtain data concerning health behavior, including the utilization of health care facilities and personnel, health expenditures, and as suggested by Frederiksen, knowledge, attitudes, and practices concerning family planning as well as other preventive or promotive health programs. Repeated questions, at intervals, will provide evidence of change – or the absence thereof.

3. *Screening programs.* Given the regular contact with the total population that will be provided by HISS, the possibility of screening for certain problems or health care needs comes quickly to mind. At the same time, we are in complete agreement with Frederiksen that the addition of tasks beyond those

directly related to the collection of information must be done with careful thought and extreme care in order to avoid impairing the information-gathering efficiency of the system. Hence, we do not intend to begin to include such activities until after the system is well established, has proven its effectiveness, and the team members know their roles well and are comfortable in them.

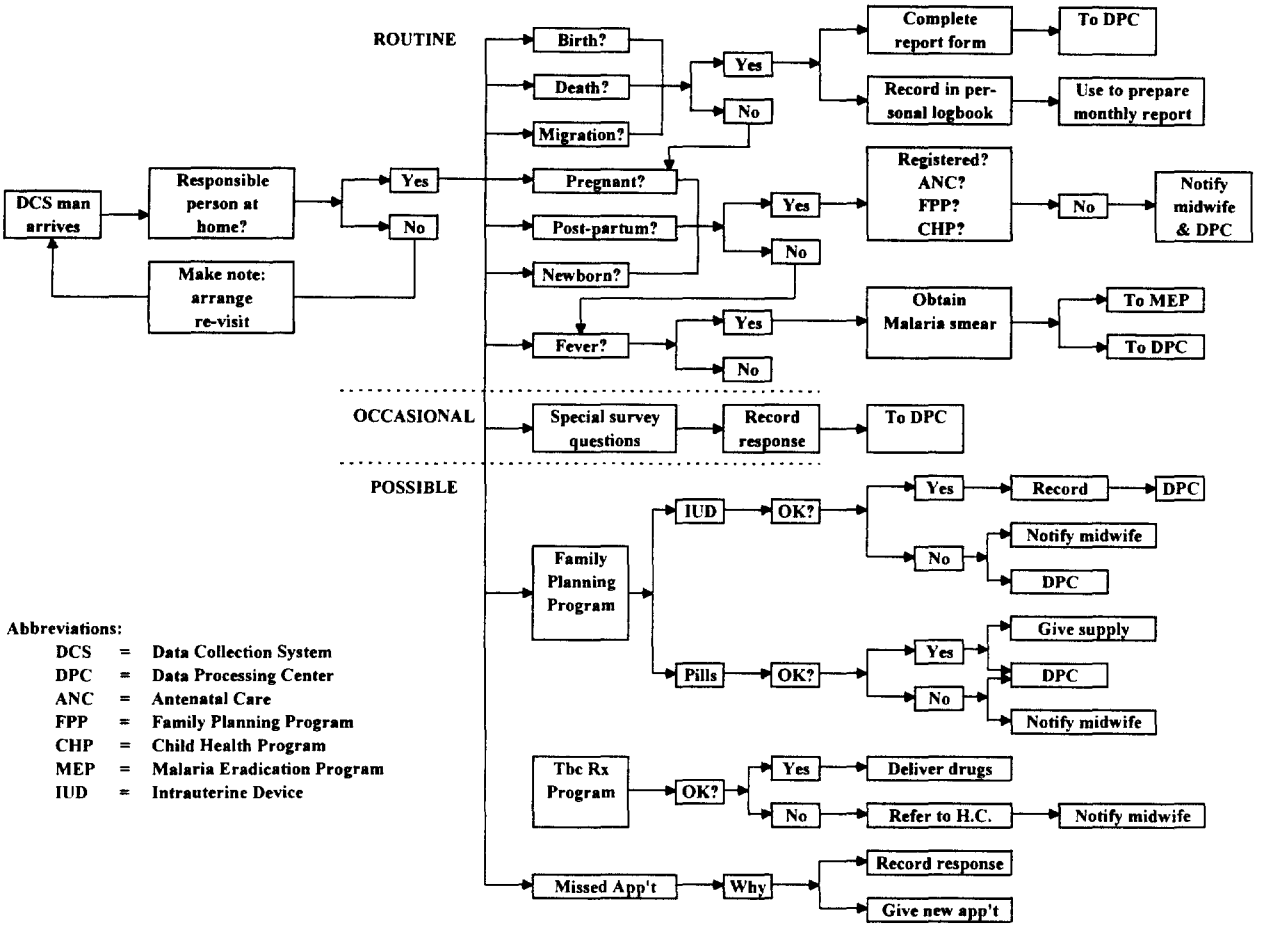
Once that stage is reached, however, we feel that it will not be too difficult to add such activities to the program. On the medical care side, our thinking is still in the preliminary stages, but as Frederiksen suggests, it is obvious that the surveillance team can screen fever cases for malaria. In addition we are exploring the idea of screening for tuberculosis suspects by questioning for symptoms. Reports from India suggest that "some 90 to 95 percent of all sputum-positive cases in a community could be diagnosed by a case-finding program based on symptoms of the disease" (Banerji 1965). It seems altogether possible that the surveillance team could identify individuals with clinical symptoms and refer them to the health care facilities for further diagnostic studies. The unknown variable in such an attempt is the number of "false positives" that might be identified in such a screening approach, but there is undoubtedly a risk that their number might be considerable – and overwhelm the rest of the system. It is unlikely, however, that the proportion would exceed that of negative blood smears collected in the MEP's: 97.4 percent here in Thailand (Rogosh 1970).

On the preventive side, it is clear that the surveillance team could identify candidates for antenatal care, for family planning programs, and for well child supervision. We lack Frederiksen's confidence that it would be practical for the HISS man, unassisted, to identify children with protein-calorie malnutrition (PCM). In 1968 and 1969, students in our Community Health Program carried out house-to-house surveys in rural villages of Thailand. They carried scales and a device for measuring height with them to weigh and measure the pre-school children in order to screen for PCM. This was quite satisfactory as a screening procedure, *per se* (Jelliffe 1966 & Wray 1970a), and gave us satisfactory information concerning the prevalence of various degrees of PCM in the pre-school population. However, it was a cumbersome and time-consuming procedure and we are reluctant to impose the task on the surveillance team member. On the other hand, our experience suggests that they may be able to help. This year a different approach was tested. The students, rather than carrying scales and measuring devices from house-to-house, made arrangements in advance for some central collecting point in each district, usually at a school, where the children might be weighed and measured *en mass*. Then, as they made their house-to-house survey, they invited parents to take their pre-school children to the collecting point at a fixed time. The response of parents to this request was generally quite satisfactory. As might have been predicted from Frederiksen's data concerning the effects of distance, the response depended on how far the parents had to travel to the "collecting points." In those communities where the school was less than a kilometer or so from most of the homes, over 90 percent of the families responded to the request. Hence, we feel that the surveillance team can play a role in screening for malnutrition if there is proper planning and careful attention to the distance factor. At prearranged times, the HISS team members could invite parents to take their children to a central point for screening and then, in collaboration with other members of the health care team, make the measurements necessary for adequate screening purposes. A factor favoring the feasibility of such an approach is the fact that such screening needs to be carried out only at relatively infrequent intervals. Once a year would probably be sufficient – much better, at the very least, than no screening at all – although once every six months would be more desirable.

4. *Services and publicity*. As we envision it, delivering services to the population with which they are in regular contact is one of the strongest potential economic justifications for development of the HISS system. On the clinical side, for example, we believe that once a patient has been identified as tuberculous and ambulatory treatment is well established, then the HISS team member could deliver his drugs on a monthly basis. We feel, in fact, that any person with a chronic illness requiring continuous medication could conceivably be given his monthly supply of the medication by the surveillance team members. Similarly, on the preventive side, we believe the team members should be able to deliver a monthly supply of anovulatory "pills" to women practicing family planning once they are enrolled in a program and are well established – say after three months of participation.

Another type of service which could be provided by the HISS team is in the follow-up of patients enrolled in preventive programs who miss appointments. In this case, the health center personnel responsible for the program would "flag" the name of the family or the individual who missed an appointment on the list of the team member in the

FIG. 2. Data collection system flow chart for Bang Pa-In



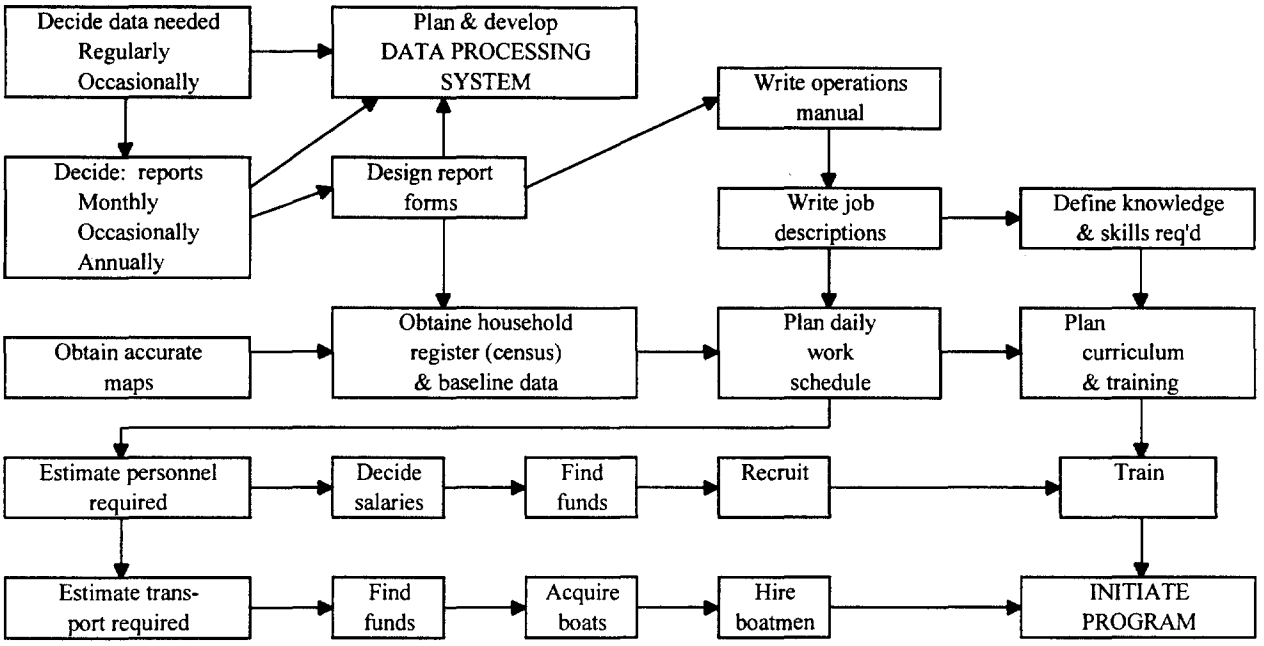
district. Then, as the HISS man makes his rounds, he could ask the family or individual why the appointment was missed, make an appointment for the next meeting of the program, and notify the relevant health center personnel. This could save a considerable amount of time which would otherwise be required for adequate follow-up home visiting of missing program participants.

Finally, since the HISS man is in contact with the total population at regular intervals, it is obvious that he could deliver notices or other kinds of publicity regarding health center programs and activities, either to the total population or to selected target populations at regular intervals.

5. *Follow-up and evaluation.* As indicated earlier, we feel that the collection of complete, reliable information for the evaluation of health care activities is probably the single most important function of the HISS. This will begin, of course, with the relatively simple measurement of changes in vital rates of various kinds. The effectiveness of health care activities will also be reflected by rates of participation in the various preventive and promotive programs, by changes in patterns of health care utilization as well as health care expenditures. Adequate evaluation will require that some of the measurements be obtained at frequent intervals, while others will be collected much less often. As also indicated earlier, however, this will be possible only if the objectives of the health care programs are sufficiently specific and reliable measures of effectiveness have been defined in advance and are carried out regularly over a period of time.

Here it is appropriate to mention that my own suggestion for the interval between visits should be one month. A longer interval might be adequate for the collection of much of the information needed and this of course would mean the system would be less expensive to operate. A monthly visit, however, would produce more reliable information, would be essential if some of the services mentioned above are to be provided, and would provide more opportunities for special studies. These reasons, I feel, would fully justify the added costs.

FIG 3. PERT sketch for the health information and services system in Bang Pa-In



PLANNING A HEALTH INFORMATION AND SERVICE SYSTEM

The sketch in Figure 1 has already indicated how we hope to integrate the HISS into the overall health care delivery system in the Community Health Program in Amphur Bang Pa-In. In planning the HISS, we are attempting to use some of the modern techniques of management and have taken a few preliminary steps in this direction. Tables 1 and 2 present a tentative systems analysis approach to the operational phase of the two central elements of the program: the information collection system and the information processing system. The tables are self-explanatory, and, to repeat, they are tentative. For anyone contemplating the establishment of such a system, however, we do recommend this exercise, in that it is useful to point up the elements which must be taken into consideration and the steps which must be taken before such a system can be placed in operation.

A second planning effort resulted in the HISS "task flow chart" shown in Figure 2. It represents an attempt to indicate the activities which will be carried out by the HISS agents in the field, and an effort was made to separate those which will be done routinely, those which will be done routinely, those which will be done occasionally, and to indicate some of the possible service activities.

Finally, Figure 3 is a sketch of a preliminary, rough PERT[1] diagram which suggests the chronologic sequence of the steps which must be taken in order to initiate the HISS.

LESSONS FROM THE PAKISTAN-SEATO CHOLERA RESEARCH LABORATORY

Anyone contemplating the establishment of an epidemographic surveillance system would be well advised to examine the experience of the Pakistan-SEATO Cholera Research Laboratory (CRL) in their field study area in East Pakistan. There the staff of the CRL have established a surveillance system which is quite similar to that proposed by Frederiksen and the results are most impressive. It was established in order to meet a specific, essential research need. The CRL intended, as one of its major research functions, to carry out reliable tests of the effectiveness of cholera vaccines in an area in which cholera was highly endemic. They realized from the beginning, therefore, that if this were to be done, it would be necessary to collect accurate information on a longitudinal basis from a large population exposed to the risk of cholera. This

[1] Program Evaluation Review Technique.

in turn led to recognition that a continuous, dependable surveillance system would be required. They have developed just that – a system which is in regular, reliable contact at *weekly* intervals with over 200,000 people in the district of Matlab southeast of Dacca (Mosely, Alauddin Chowdhury, Aziz & Mosley 1969).

It is not my role to describe their system, nor is there space here to do it justice; however, it does seem appropriate to mention some of the lessons which I learned on visiting there.

1. *Supervision.* Frederiksen, in presenting his proposal for epidemographic surveillance, has quite correctly laid great emphasis on the importance of supervision of the surveillance agents in the field. The CRL system in Matlab illustrated this beautifully. Their system is multi-layered. In the echelon immediately above the field agents there is a field supervisor for every four or five agents. The supervisors are responsible for checking the information from their districts on a continuous basis. The echelon above that consists of the field director and his two deputies, who have transportation readily available, and carry out spot-checks throughout the entire district at irregular and unannounced intervals. In addition, the data processing staff systematically query all reports turned in which are in any way peculiar or inconsistent.

2. *Training of field agents.* In preparing field staff to work in their project, CRL staff have relied almost entirely on on-the-job training rather than on formal courses. The system was established initially on a small scale and supervisory staff and the field agents learned together in the process of getting the program going. As the program expanded and additional staff became necessary, new team members learned their roles by working with agents already in the field for approximately two months, and then moving on to their own area.

3. *Work Load.* There are 54 field agents in the CRL system, who cover a population of more than 2000,000 in the Matlab area. One man, therefore, is able to provide *weekly* surveillance of around 4,000 people in an area which is fairly thickly settled.

4. *Data processing.* One of the more impressive features of CRL system is that in spite of the huge population under constant surveillance and the large volume of data produced each month, the Laboratory is able to handle this with a small staff and simple data processing equipment. Five staff members, one keypunch, one verifier, and one sorter-counter are sufficient to handle the routine reports, although a computer is used for certain special studies.

5. *The quid pro quo.* Another impressive feature of this system is the quality of cooperation from the population under observation. The staff there attribute this degree of cooperation, I am sure correctly, to the fact that the CRL is providing a service to the population that is highly valued. This has come about because the CRL staff realized in the beginning that adequate testing of cholera vaccine would require exposing a large control population to the risk of cholera. They felt obliged, therefore, to establish in the study district a small hospital which could provide adequate treatment for the clinical cases of cholera which did occur either in the control or in the vaccinated populations. Over the years, this facility has demonstrated its effectiveness in handling this problem and the local population, without any question, is extremely grateful to have it easily accessible. Hence, when they cooperate with the surveillance team members, they are well aware that something is provided to them in return for this cooperation. Incidentally, when problems do arise, the surveillance staff members do not hesitate to remind the population that the continued presence of the hospital in their district is fully dependent on the continued success of the surveillance operation..

6. *The role of the indigenous midwife.* In developing the Matlab system, the CRL staff were aware that they would require disciplined, literate agents in the field. On the other hand, they were equally aware of the need to have local people from each village actively involved in the study. As a result they carefully selected an indigenous midwife, or dai, in each village to serve as an extension of the regular surveillance agent in keeping track of illnesses and vital events in the village. Most of these women are not literate, but they do know what is going on in their village and as the surveillance agent visits the village each week, it is the midwife who tells him what has happened in the village during the past week, which the agent then confirms by visiting the households concerned.

7. *Conviction, commitment, and the "scientific method."* A visit to Matlab is thoroughly provocative. As noted earlier, the CRL staff developed their surveillance system because they wanted to test certain hypotheses regarding cholera vaccines and this required reliable information about the occurrence of cholera in a large population, over a long period of time. So, they developed a system that would provide this information. Such a procedure seems simple and straightforward. A

question remains unanswered: why is this so rarely done in "public" or "community" health programs?

PROBLEMS OF IMPLEMENTATION

There is no doubt that a number of obstacles must be overcome if a Health Information and Service System is to be established and to function effectively in a health care delivery system. Among the most outstanding are the following:

1. *Costs.* In Western countries where the annual per capita expenditures for health care are expressed in the hundreds of dollars, Frederiksen's assertion, and my own, that such a system can be operated at a cost of less than 25 cents (U.S.) per capita per year, makes the matter of costsseem negligible. This assumption, however, ignores the fact such a sum might almost equal the total health care budget for rural populations in many parts of the world (Bryant 1970). Consequently, there is a very real need for a clear demonstration of the effectiveness and utility of such a system before it is likely to be widely accepted in developing countries.

Once such demonstrations have been carried out, however, the chances of obtaining adequate support ought to be reasonably good. Such an assertion is based on the precedent of the active case detection phase of Malaria Eradication Programs in many countries of the world. They have shown that it *is* economically possible. Epidemographic surveillance will be somewhat more costly, but the benefits should be many times greater. Hence, if the budget makers could be persuaded to support the MEP's they should be susceptible to persuasion for this purpose.

2. *Field staff and discipline* Recruitment and training of an adequate staff as well as the establishment of good work discipline in the operation of the program will obviously be critical to its success. Proper supervision will be essential. No less essential are precise job descriptions as well as carefully written, specific operations manuals for the various levels of staff involved in the program. The SEATO-CRL experience, however, has demonstrated clearly that it can be done. They have also shown that formal training, in classes, is unnecessary and that, in fact, training can be better accomplished on the job.

3. *Integration with the health care system.* If the potential contributions of the HISS to other elements of the health care delivery system are to realized, then integration with those elements is essential. Clearly, much of this integration must take place in the minds of the various members of the health care team. Beyond that, the cooperation which must be forthcoming from the population being served is, in no small measure, dependent on what they perceive to be its value to them. This, in turn, will depend on the gradually increasing effectiveness of the total health care system, combined with efforts to make clear to the formal and informal leaders and the population at large the relationship between the HISS and other elements in the system. Meanwhile, efforts must be made to make the members of the HISS team feel that they are true members of the total health care team, and, at the same time, help the other health personnel appreciate the contribution HISS field staff are making. This will be facilitated if the information collected is processed promptly, made available to the health care team and used, and the HISS staff are kept aware of their contributions to the overall success of the health programs.

4. *The cost of "tooling up."* However modest or immodest that the cost of operating such a program may be, the investments required to plan and initiate it are likely to be much greater. Here we are referring especially to the investment of human time and energy necessary to carry out the detailed planning which will be required or, for example, to obtain the household register from the total population which will be essential for such a system. Figure 4 is an attempt to depict graphically a rough estimate of the magnitude of the differences in the inputs required for various phases of such a program. This particular graph was drawn with general health care programs in mind, but it is quite applicable to the problems involved in the development of an epidemographic surveillance system. We are not yet sure how the extra inputs which will be required can be provided in Bang Pa-In, but among other things, we expect to utilize the energy of medical and nursing students in our program in Bang Pa-In, to help get things started. In the meantime, if we have any hope of making such a system reproducible elsewhere, we will be compelled to find ways of developing it within the constraints of available resources, human and otherwise

THE VALUE OF EPIDEMOGRAPHIC SURVEILLANCE OR A HISS

Dr. Frederiksen spelled out in considerable detail his ideas of the possible contributions of such a system to the health care of rural populations in developing countries and these have been further elaborated in this paper. They include both direct service to those populations in dealing with specific,

TABLE 1

A Systems Approach to the Health Information and Services System in Bang Pa-In

Operation Phase

Inputs	Processes	Outputs
Trained personnel a. Supervisors b. Field staff	Visit all homes in BPI at regular intervals	Completed routine data collection forms
Operations manual	Interview responsible person in household	Completed special survey data collection forms
Daily work schedule and maps	Collected information: a. Routine (total population) b. Special (total or sample)	Monthly report by each field staff member
Data collection forms a. Routine b. Special	Record information on prepared report forms	Notification forms for programs: ANC EPP WCP MEP
Transportation system	Return reports to DPC at regular intervals (daily or weekly)	(Services delivered)
Household register and baseline data	Monthly review meeting	
("Flag" lists for program follow-up)	(Carry out program follow-up activities)	
("Flag" lists for health care services)	(Deliver medications as part of health care services)	

Note: -- Future activities in parenthesis

TABLE 2

A Systems Approach to the Data Processing System in Bang Pa-In

Operation Phase

Inputs	Processes	Outputs
Household register	Record births, deaths, and migration data on household register	Routine a. Birth Date, sex Term, premature, still births Maternal age, parity living children ANC Delivery: who, where
Operations manual	Punch birth, morbidity, death data on IBM cards	
Report & notification forms	Record new pregnancies & other follow-up data on "notification form"	b. Deaths: Age, sex Cause Terminal care
IBM cards, data processing equipment	Code, punch, tabulate results of special surveys	
Trained personnel	Monthly review meeting	c. Migration: Age, sex In, out, where
		d. Notifications: New pregnancies New EPP candidates New WCP candidates
		e. Program participation rates
		Special: a. Morbidity Specific illnesses Accidents Symptoms Days of illness
		b. Health care Utilization of facilities Expenditures Program participation Knowledge

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important health problems, as well as furnishing reliable data that are vital to those responsible for health planning.

Some years ago, in the first "International Lecture" at the National Institutes of Health (McDermott 1964), Dr. Walsh McDermott identified five stages in the growth of medical care and he made a distinction between the first three, which he characterized as essentially non-continuous, non-personal, or indirect methods of applying the biomedical sciences, and the fourth and fifth, which involve "the regular delivery of medical services to people as individuals." Implicit in the latter was the idea that this delivery would be carried out by physicians. He defined the fourth stage as "the type of medicine that can be practiced by a physician situated in a remote outpost," and the fifth stage as the kind of medicine than can be practiced in modern urban societies with the facilities and economic support that one might expect there.

It would appear that if the service functions of an epidemographic surveillance system as proposed by Frederiksen, or the health information service system described here, could be carried out effectively, then they would offer a feasible and potentially useful transitional stage between the non-personal, noncontinuous delivery of medical care, and the physician based stages of medical care described by Dr. McDermott. They would provide certain services on a personal, continuing basis – by a non-physician.

It is our intention in Bang Pa-In to justify the introduction of such a system on the basis that it is essential for purposes of evaluation of experiments in health care delivery and as a necessary element in our teaching programs We hope, however, that in the long run we will be able to demonstrate that such a system is economically feasible, that it is reproducible, that it contributes in a number of critically important ways to the delivery of health care and that it should, in fact, be considered a necessary part of any health care system.

The two most serious health problems in the developing world are excessive population growth and malnutrition in pre-school children. *The solutions to both of these problems depend ultimately on changes in maternal behavior.* For the first, it is the mother, for the most part, who takes the required actions for effective family planning; for the second, it is the mother who must finally provide the proper nutrition to the child. On a global level, it is clear that hundreds of millions of women must make such changes – and it is equally clear that today most of these women simply are not touched by a health care system which might teach them and help make possible such changes. Adding an element to the health care system which would *reach out* and establish contact with these women is a potentially crucial step in the right direction.

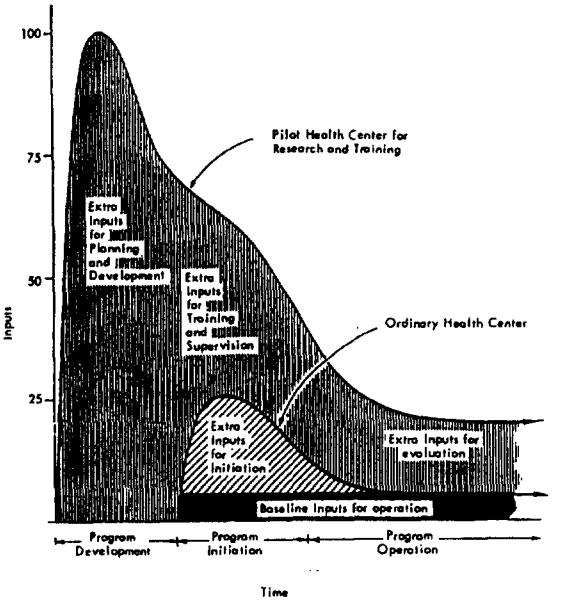

FIG. 4. Variations in input requirements with time, distinguishing among the phases of program development, program initiation, and program operation. The assumption is that all three phases would be carried out at the Pilot Health Center Level, while only the second two, initiation and operation, are required at the ordinary health center level. This is obviously a generalization; the ratio of the difference in inputs required in the different phases would vary from one health care program to another. The intent is to indicate: 1. Inputs required at the Pilot H. C. level, where program methodology is to be developed and tested, are substantially greater than those required at the ordinary H.C. level. 2. Inputs required for program initiation and requirements for initiation are, in turn, greater than those required for operation.

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Copyright 1991 Massachusetts Medical Society. All rights reserved. Reproduced by permission, Berggren, WL et al. Reduction of mortality in rural Haiti through a primary health-care program. **N Engl J Med** 1981; 304: 1324-1330.

REDUCTION OF MORTALITY IN RURAL HAITI THROUGH A PRIMARY-HEALTH-CARE PROGRAM

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ABSTRACT

Deaths and their causes in a rural Haitian population of 8820 were studied through hospital records, death registration, a disease survey, and health surveillance. The results were used in selecting eight diseases for the delivery of health services by village-level health workers. The impact of the services was measured by monitoring annual age-specific and disease-specific mortality rates and by comparing them with officially estimated national mortality rates. Mortality rates fell progressively during five years, to levels only one fourth as high as the national estimates. The fall in mortality was associated principally with services that prevented deaths due to tetanus, malnutrition, diarrhea, and tuberculosis. The total program of hospital and village health services saved 495 years of potential life per thousand population per year. Most of the saving was attributable to preventive services. The program eventually served more than 115,000 persons, and it has been replicated by other agencies for an additional 135,000 Haitians. (N Engl J Med. 1981; 304: 1324-30.)

Primary-health-care programs for rural populations in less-developed countries are now being implemented and reported by governments, international agencies, and private voluntary organizations.[1-8] These reports show that better methods are needed to assess a population's health needs, to distribute services equitably, and to measure the impacts of programs. Our report describes methods for reaching these goals and measures the impact of a program on the health of a population in rural Haiti. The need for brevity makes it impossible to describe the background and methods in as much detail as can be provided in reports dealing with a single disease such as tuberculosis, tetanus, or malnutrition. However, we have tried to mention the characteristics that are essential to an understanding of the results that we obtained.

BACKGROUND

According to several criteria, the Republic of Haiti, occupying the western end of the island of Hispaniola, is the Western Hemisphere's poorest nation. Haiti's 5 million citizens had a mean annual gross national product of only $280 per capita in 1978[9]; they have a high prevalence of chronic malnutrition,[10,11] an infant mortality rate of 150 per thousand live births, a life expectancy of 47.5 years at birth, and a birth rate of 37 per thousand population.[12,13] Approximately 80 per cent of Haitians live in rural areas and derive their living directly from agriculture. Agricultural production appears to be constantly threatened by erosion and periodic droughts and hampered by primitive farming methods.

The Albert Schweitzer Hospital, a 140-bed general hospital funded by private donations and the Grant Foundation of Pittsburgh, Pennsylvania, and operated by permission of the government of Haiti, opened in 1956 in Deschapelles, Haiti. It presently serves a population of more than 115,000 rural Haitians living in a district of 380 km^2. The hospital annually provides approximately 70,000 outpatient consultations, 3000 hospital admissions, and 60,000 patient-days of hospital care. Although outpatient consultations are primarily for curative care of patients with disease, the hospital provides such preventive services as health education, screening for tuberculosis and malnutrition, and immunization against tetanus, diphtheria, pertussis, and tuberculosis during the consultations. All curative and preventive services are provided for a token fee, and the receipts from these fees supply 3 per cent of the hospital's annual budget. In 1968, the hospital instituted a Department of Community Health to provide preventive services free of charge in the villages to all inhabitants of the hospital district.[14]

The purpose of the Department of Community Health was to improve the health of the people inhabiting the hospital district. To accomplish this end, the Department set out to deliver appropriate health and nutrition services at the village level. Achievement of this goal required identification of the health problems, identification of the persons at risk for each problem, and planning and provision of appropriate services for the persons at risk.

The Department's plan of action entailed performing all three functions simultaneously and gathering data to evaluate the impact of the services. Through this plan, all members of a defined population are identified and counted, the members needing certain health or nutrition services are identified and served, all deaths are identified, and the cause is certified. From these data the rates of births, deaths, and certain diseases can be calculated. The rates and annual changes in the rates are analyzed to plan services and to evaluate the impact of the program on the population's health.

Such systematic and iterative gathering and interpretation of health information from a defined population is called health surveillance; this process and the provision of health services are mutually supporting aspects of the Albert Schweitzer Community Health Program and are performed concurrently by the same personnel. This report will show how health surveillance and health services, in concert with the services offered by the hospital, saved lives and increased the population's life expectancy. The results reported are from a population, measured by census, that grew from 8820 residents in 1968 to 9612 in 1972. After 1969, the services that produced the results were extended progressively to neighboring populations; by 1979, all 115,000 people inhabiting the hospital district were served. Data collection and analysis were restricted to the original census-tract population as an economy measure.

METHODS

Description of the Population and Vital-Registry System

The first persons to benefit from the health surveillance-health services program were the 8820 residents of 23 villages in a 28-km^2 area surrounding the hospital. Residents of this census tract were persons who lived within its boundaries for at least six months of the year and infants who were born of resident mothers.

Births, deaths, and migrations of residents were reported by community collaborators selected from among volunteers in each village. Each collaborator was responsible for a neighborhood of 100 families. Reports from collaborators were verified through home visits conducted by members of the professional staff. Causes of reported deaths were certified by a physician who based his diagnoses on information gathered from the family of the deceased, from hospital records, and in 18 per cent of the cases, from autopsy results. Deaths were registered by underlying cause, with the *International Classification of Diseases* List A, 1965 revision,[15] used for tabulation purposes.

Assessment of Service Needs from Mortality and Morbidity Information

In order to assess needs for service as revealed by available morbidity information, hospital records on work performed before 1968 were studied. This study indicated that tetanus was the most common cause of admission, accounting for 13 per cent of all admissions; that cases of malnutrition were the greatest consumers of days of hospital care, accounting for 23 per cent of the total annual number of hospital days; and that tuberculosis and diarrhea were the greatest consumers of ambulatory-clinic services, accounting for 25 per cent and 18 percent of outpatient consultations, respectively. Since the precise size of the denominator population from which patients with these diseases were admitted was not known, no inferences about the incidence of specific diseases in the hospital district were drawn.

The prevalence of tuberculosis was studied by examination of the entire census-tract population. A survey in 1969 tested the skin reactivity of residents to intermediate-strength purified protein derivative of tuberculin (PPD), which was administered intradermally by jet injector. Persons with at least 10 mm of induration at the injection site after 48 hours were examined clinically and with chest x-ray films. Eighty-two per cent of the residents had all the relevant tests. Persons with lymphadenopathy or x-ray shadows that were characteristic of tuberculosis were presumed to have tuberculosis; they were treated on an ambulatory basis with antituberculosis drugs and were followed with repeated x-ray films and sputum examinations for at least 18 months. A patient's treatment was stopped when follow-up examinations were negative for six months. The presumed cases were treated with self-administered isoniazid, 300 mg per day, and aminosalicylic acid, 12 g per day, for 18 to 24 months. Children were given appropriately smaller doses.

For further assessment of the population's needs for service, deaths of census-tract residents during the first year of surveillance were analyzed according to category of underlying cause. In addition, recent mortality rates among infants and children were measured from retrospective interviews of all mothers in the census tract. The 2570 mothers reported 2144 deaths among their 7743

live-born children, and cross-tabulation of these data provided estimates of annual mortality rates (Berggren W, et al. Unpublished data).

Mortality and morbidity information from health surveillance, surveys, hospital records, and maternity histories indicated that malnutrition, diarrhea, tuberculosis, and tetanus should be target disease categories for preventive services. Prevention of tetanus required immunization of the population -- a service that was easily expanded to include prevention of measles, pertussis, diphtheria, and poliomyelitis with little increase in cost. Although these four diseases caused no mortality among the study population during 1968, they are known to occur in epidemics that may cause considerable morbidity and mortality (Berggren W, et al. Unpublished data). The health services were therefore designed to prevent deaths due to eight categories of target disease: malnutrition, diarrhea, tuberculosis, tetanus, pertussis, diphtheria, measles, and poliomyelitis.

Malaria was not among the target diseases because it was well controlled by the National Malaria Eradication Service[16] through house spraying and chloroquine distribution. No cases of malaria were diagnosed among the census-tract population in 1968.

Description of Services

Eight categories of preventive services were offered to the population and were delivered at quarterly neighborhood gatherings or "health rallies" held at strategically located "rally posts." A rally post was easily accessible to 1000 to 1500 inhabitants. A community collaborator personally invited each inhabitant to attend the rally post closes to home. On rally days, the collaborators were assisted by a physician or nurse and by five to 10 auxiliaries in delivering the eight categories of services described below. The few persons requiring medical attention were treated by the physician at the rally or were referred to the hospital.

Lessons in Health and Nutrition

Residents arriving at a health rally were seated in groups of 20 to 30 persons and were given 15-minute illustrated talks on nutrition, sanitation, or other health-related topics. The lessons were taught in the vernacular by nurses, physicians, or auxiliary health workers, and they covered such topics as disposal of excreta, breast feeding, the frequency and content of child feeding, the availability of family planning, or the method of oral rehydration for treatment of diarrhea. Parents were given a "Road-to-Health" card for each child in order to teach them that the child must gain weight.

Targeted Supplemental Feeding

Supplemental feeding was used as emergency home treatment of severely malnourished children who were discovered through weight monitoring. In order to identify those in need of supplemental feeding, all children six years old or younger were weighed, measured, and examined for pretibial edema at the time of each rally; weights were recorded graphically on Road-to-Health cards, which were kept by the child's parents.[17] Fourteen per cent of the rally appointments were missed, and home visits were performed in such cases to record the child's weight.

Children were categorized according to the Gomez classification with the Harvard standard of weight for age.[18,19] Children with third-degree malnutrition or negative weight increments either received supplementary food or were referred to a "mothercraft center" for rehabilitation. According to these criteria, about 5 per cent of the children up to six years old were eligible for supplementation.

The supplementary food package consisted of 1.2 kg of powdered skimmed milk fortified with oil and sugar in proportions (by weight) of 4:1:1.[20] The daily ration contained approximately 350 kcal and 20 g of protein. The children were followed at a fortnightly clinic held on the hospital grounds and were resupplied until they gained weight at a rate equal to that of Boston children of the same age or were no longer classified as having Grade III malnutrition.

Demonstration Education

Since management of malnutrition over the long term requires the efforts of educated and motivated parents, a program of demonstration and education was instituted to expand and reinforce the lessons on nutrition that were taught at the health rallies. This method, developed by the Haitian Bureau of Nutrition, involved parents in the rehabilitation of their malnourished children.[21,22] Mothers of children who were underweight for their ages were given supervised practice in appropriate child feeding, and they witnessed the therapeutic effectiveness of such feeding in community nutritional education and rehabilitation centers, which were sometimes called mothercraft centers.[21-

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[23] Centers were established in local homes and employed foods, utensils, and methods of preparation that were familiar to the mothers. Underweight children attended a center six days per week for 13 weeks, receiving a balanced and calorically adequate diet. Mothers or guardians of the enrolled children attended for one day per week in rotation. By participating in the work of the center, they learned that the usual adult one-meal-per-day regimen had to be supplemented with frequent feedings in young children, and they practiced preparing adequate meals from indigenous, inexpensive foods.

Each center served a neighborhood of 400 to 600 families. New groups of 24 to 30 mothers and their underweight children were recruited every three months until all mothers of children weighing less than 80 per cent of the expected weight for their ages had attended one three-month session. The nutrition teacher and the center's utensils were then moved to another area.

Oral Rehydration

Oral rehydration of the children with diarrhea was taught at health rallies, in nutrition centers, and in the ambulatory clinics of the hospital. Parents were shown how to prepare a rehydration solution[24] from locally available sea salt, sucrose, and potable water, using the large spoon, empty rum bottle, and bottle cap that are present in every rural home as measuring utensils. Lime juice, which is traditionally esteemed for its flavor and supposed medicinal value, was also added to the rehydration fluid. Parents were instructed to administer the solution by cup or spoon, to continue breast feeding, to recognize signs of dehydration, and to bring dehydrated or vomiting children to the hospital.

Screening and Treatment for Tuberculosis

In addition to the survey for tuberculosis described above, routine chest x-ray films were taken of malnourished children who did not gain weight after adequate feeding in a nutrition center. Patients with presumably active tuberculosis thus diagnosed were treated with isoniazid and paraaminosalicylic acid, and were followed up with clinic and home visits. During the visits, urine was tested for evidence of paraaminosalicylic acid excretion, attention was paid to patients who were not taking their medication or were not attending the monthly clinic, and patients and their families were counseled as necessary.

Deworming

Piperazine citrate syrup, 100 mg per milliliter, was administered at health rallies. Children six months to three years old were given 15 mil of the syrup in a single dose; older children received 20 ml. This treatment had a twofold purpose. Heavy burdens of ascaris worms were reduced, and the observation of passage of large numbers of worms was of benefit in maintaining parental interest and attendance.

Immunization

Children three months to four years old were inoculated with diphtheria-pertussis-tetanus toxoid (DPT) and were given trivalent poliomyelitis vaccine. Three doses of DPT were given at one-month intervals, and a fourth dose was given one year after the third. Two doses of oral trivalent poliomyelitis vaccine were given with an interval of two months. Children one year old or older were given measles vaccine unless they had been born before January 1967, which was the end of the last measles epidemic. Persons older than six years were inoculated with three doses of tetanus toxoid at intervals of one to three months.

All inhabitants of the hospital district were vaccinated with bacillus Calmette Guérin (BCG) if the PPD test resulted in less than 5 mm of induration after 48 hours.

Skin testing, vaccination, and recording were all done by auxiliaries, who were supervised by a nurse or physician. New residents (immigrants and neonates) were identified by the village volunteers, given immunization cards, and immunized at the health rallies.

Support of the Traditional Birth ttendant

Eighty-five per cent of mothers delivered their babies in their homes, usually with the assistance of a traditional birth attendant (TBA). The hospital supplied 175 TBAs with sterile razor blades, cord ties, and umbilical dressings. These items were packaged, sterilized, and distributed monthly at meetings of TBAs. To receive supplies, a TBA had to attend five training sessions given by the hospital's professional staff and to demonstrate an ability to use the materials correctly.[25]

TBAs instructed parents to take the baby and the immunization card of the mother to the hospital soon after birth so that BCG vaccine could be administered. Neonates whose mothers were

incompletely vaccinated against tetanus were given prophylactic tetanus antitoxin in addition to routine BCG vaccination.

Personnel

The clinical services of the 140-bed hospital were staffed by a radiologist, three pediatricians, three internists, three surgeons, 30 nurses, 60 auxiliary nurses, and several technologists and many auxiliary personnel who worked in the laboratory, x-ray facility, pharmacy, record room, business office, housekeeping department, and other areas. The Community Health Program was eventually provided to the entire hospital district of 115,000 people by a rural sanitary officer, two nurses, three physicians, 30 full-time auxiliaries, and 60 community collaborators.

The health auxiliaries were recruited from among local farmers with sufficient skill in reading and writing to execute the routine reports. Many of them began working as collaborators. The training was progressive in that new recruits first worked for two to three months on a daily-hire basis and received on-the-job training in specific tasks such as census taking, weighing, measuring, recording, and injecting vaccines. On-the-job training involved one task at a time, performed under the supervision of the professional staff. The recruit was given maximum experience in performing one task before a different duty was taught. By the time a recruit acquired sufficient training to be considered for employment on a full-time basis, his or her personal commitment to community-health work had been adequately demonstrated. As auxiliaries became expert in their tasks, some of them were given responsibilities that included training and supervision of their juniors.[26]

In general, the community collaborators volunteered their time. However, they were paid for two days for each rally (one day for preparation) and for days spent working on the annual census.

RESULTS

Combined Impact of Hospital Services and of Health Surveillance and Health Services

The health and lives of census-tract residents were protected by easy access to the hospital and free preventive care through the health services. One can measure the effect of this protection by comparing the census tract with the rest of Haiti. We made this comparison on the basis of mortality rates, deaths averted, and years of life saved.

Age-Specific Mortality Rates

Annual age-specific mortality rates in the census-tract population were far below the mortality rates estimated for the total population of Haiti. In 1972, for example, the one-to-four year mortality rate in the census tract was less than one third of the national estimate, and the infant mortality rate was only one fifth of the national estimate (Table 1). Mortality rates at the ages of five to 39 years were only one sixth as high as the national estimates.[12,13]

Deaths Averted by the Program

If the national age-specific mortality rates are applied to the age distribution in the population of the census tract, the resulting expected number of deaths for 1972 would be 171.1. Only 72 deaths were observed in 1972 -- 99 fewer than expected. It is assumed that this difference is caused by the health services offered in the census tract, and that the services therefore averted the deaths.

Years of Expected Life Saved

In order to calculate the number of years of expected life that were saved by the health services, we make certain assumptions. The 99 residents whose deaths were averted in 1972 can be expected to die at a rate determined by their age and by their health care. We can assume that if the health-care services provided by the hospital and its Department of Community Medicine had ceased at the end of 1972, residents of the census tract would have continued to die at the same annual rate found in their birth cohorts in the rest of Haiti. Therefore, the number of years of expected life saved in each age group by 1972 is equal to the number of deaths averted in each age group multiplied by the national life expectancy of that age group.[28] Summation of these products reveals that a total of 4758 years of expected life were saved during 1972. Division of this sum by the midyear population shows that 495 years of expected life were saved per thousand population.

Impact of Health Surveillance and Health Services

By 1972, life expectancy at birth in the census-tract population had increased to 66.4 years --

18.9 years above the national level (Table 1). This difference resulted from the combined impact of the hospital services and the health surveillance and health services. The hospital services probably achieved their maximum impact during the 12 years before the health surveillance and health services began. The impact of health surveillance and health services is therefore reflected in the changes in mortality rates after 1968. The earliest data for comparison are for 1968, when registration of births and deaths was instituted. Comparing 1968 with 1972 underestimates the impact of health surveillance and health services, since the mortality rates during 1968 were almost certainly lowered by the program of surveillance and services. However, even this underestimate indicates considerable impact.

The effect of health surveillance and health services may be estimated by a calculation of the change in target-disease-specific death rates between 1972 and 1968 (Table 2). From 1968 to 1972, deaths due to malnutrition, diarrhea, and tuberculosis declined by 50 per cent or more, and the five other target diseases caused no mortality at all (Table 2). Mortality rates for the target diseases taken as a group declined by 55 per cent from 1968 to 1972; meanwhile, mortality rates for all other (nontarget) diseases declined by only 35 per cent.

With the target-disease-specific mortality rates of 1968 and the 1972 population size, the expected number of deaths due to target diseases in 1972 is 41, whereas the observed number was 19. Thus, assuming that the services caused the

Table 1. Measures of Mortality Trends during 14 Years in the Albert Schweitzer Hospital Census Tract in Comparison to Haitian Estimates for 1972.*

AGE GROUP	CENSUS TRACT							NATIONAL ESTIMATE
YR	RETROSPECTIVE		PROSPECTIVE					
	1958-1962	1963-1967	1968	1969	1970	1971	1972	1972
Infants †	174	110	55	68	47	37	34	150
1-4	24	14	11	7	9	5	6	23
5-9	8	3	3	2	1	4	1	6
10-14	NA	NA	2	<1	1	1	<1	4
15-39	NA	NA	3	4	2	2	2	11
40-64	NA	NA	19	9	9	13	9	20
≥65	NA	NA	90	73	67	65	69	110
All	NA	NA	13	9	8	9	8	18 ‡
Life expectancy (S.E.) §	NA	NA	57.1 (1.1)	61.9(1.3)	64.7(1.1)	63.8(1.1)	66.4(1.1)	47.5

* All rates are expressed as the number of deaths per thousand population per year. Five-year mean annual mortality rates for 1958-1962 and 1963-1967 were calculated from retrospective maternity histories. Prospective rates for single years were calculated from tabulated births and deaths registered during health surveillance. The national estimate was obtained from a multi-round demographic survey conducted from 1971-1973.[13] NA denotes not available.

† Infant mortality is expressed as the number of deaths of children 11.9 months old or younger per thousand live births.

‡ Standardized to 1972 census-tract population.

§ These figures are the actual life expectancies observed in the population during these years. The standard errors should be used to test whether the underlying risks of dying changed significantly between years. These standard errors were calculated with the formula given by Keyfitz,[27] with the variance of the death rate in each age group based on the Poisson distribution because of the small number of deaths.[29] With these values for the standard errors, the life expectancies in each of the four years from 1969 to 1972 are significantly greater than the corresponding value in 1968 ($P<0.01$).

differences between the 1968 and 1972 rates, the lives of 22 persons, who are expected to live an additional 1064 years, were saved (Table 3). This benefit amounts to an annual saving of 111 years of expected life per thousand population.

The full impact of health surveillance and health services is underestimated not only by the use of 1968 as a base line but also by the use of the census tract to calculate mortality rates in rural Haiti in 1968. Since 1956, the hospital clinics had provided many of the same services[29] that the health surveillance and health services began to deliver at the village level in 1968. The hospital services naturally had the greatest impact on persons who lived close enough to the hospital to make use of them. Therefore, some of the effect accomplished by the hospital in the census tract would be produced by health surveillance and health services in areas that were more distant from the hospital. The hospital's program of routine tetanus vaccination is a clear example of this problem. Before 1968, tetanus immunization was available only to schoolchildren and persons who came to the hospital clinics and was therefore effective only for the schoolchildren and for that proportion of the clinic's patients who returned after intervals of a month or more to complete the series of injections. Thus, the program's impact on mortality rates was concentrated in the population living in closest proximity to the hospital -- i.e., the inhabitants of the census tract.

In order to estimate the impact of the extension of the tetanus-vaccination program beyond the census-tract population, it is necessary to estimate the death rate from tetanus before immunization began. Two such estimates of the tetanus mortality rate are available for neonates, who constitute the group with the highest risk. The rate of hospitalization for tetanus among neonates in the hospital district in 1967 was 64 per thousand live births.[14] This figure is certainly an underestimate of tetanus-specific mortality, since the case-fatality rate in the absence of treatment is almost 100 per cent, and since many affected persons from the hospital district never reached the hospital. The hospital's antenatal-vaccination program was initiated at the end of 1961, and it is estimated from maternity histories collected in the census tract that the tetanus-specific mortality rate for that year was 145 per thousand live births. This figure is therefore a reasonable estimate of the tetanus-specific infant-mortality rate among a nonvaccinated rural Haitian population.

Table 2. Disease-Specific Mortality Rates by Year in the Albert Schweitzer Hospital Census Tract from 1968 to 1972.

Disease Category	ICDA No.*	Deaths		Mortality Rates†					Reduction of Mortality Rate
		1968	1972	1968	1969	1970	1971	1972	1968-1972
									%
Malnutrition	267.0-268.0	19	9	2.2	1.5	0.5	1.0	0.9	59
Diarrhea	9.1-9.2	11	6	1.2	0.7	0.9	0.6	0.6	50
Tuberculosis	11.0-17.9	7	4	0.8	0.4	0.1	0.5	0.4	50
Tetanus	37.0	2	0	0.2	0.0	0.0	0.0	0.0	100
Subtotal, all target diseases‡	---	39	19	4.4	2.6	1.5	2.1	2.0	55
Subtotal, all other diseases	---	73	53	8.4	6.7	6.6	6.3	5.5	35
Total, all diseases	---	112	72	12.8	9.3	8.1	8.5	7.5	41

* *International Classification of Diseases*, List A number, 1965 revision.

† Expressed as the number of deaths per thousand persons per year.

‡ Target diseases included malnutrition, diarrhea, tuberculosis, tetanus, pertussis, diphtheria, measles, and poliomyelitis.

Table 3. Deaths Due to Malnutrition, Diarrhea, Tuberculosis, or Tetanus and Years of Life Saved by Health Surveillance and Health Services in the Albert Schweitzer Hospital Census Tract, 1972.

Age Group	No. of Expected Deaths	No. of Observed Deaths	No. of Averted Deaths	Percentage of Expected Deaths Averted	Life Expectancy at Mean Age of Group	Years of Life Saved
yr					yr	
0-1	11	3	8	73	51.0	408
1-4	11	5	6	55	55.0	330
5-9	4	2	2	50	53.8	108
10-14	1	0	1	100	50.2	50
15-39	5	1	4	80	39.5	158
40-64	3	3	0	0	21.4	0
≥65	6	5	1	17	9.8	10
Total	41	19	22	54	—	1064*

* 111 years of life per one thousand person-years

Using each of the above estimates of the tetanus-specific infant mortality in turn, and assuming a constant birth rate of 37 per thousand population (approximately that of the census tract), we can estimate that the tetanus-vaccination program prevented between 2.4 and 5.4 neonatal deaths per thousand population per year. Based on the national life expectancy of 51 years, our estimates show that the savings are between 122.4 and 275.4 person-years of expected life per thousand population. With these savings added to those attributed to health surveillance and health services in the census tract, the estimated total savings attributable to the new programs are between 233 and 386 years of life per thousand population, or between 47 and 78 per cent of the total savings. Of the two, 78 per cent is the more likely estimate of the proportion of lives saved by the health surveillance and health services outside the census tract.

Discussion

Health impact is defined in this report as changes in mortality rate that are associated with the provision of health services. The study shows associations in time, age group, place (Table 1), and specific disease category (Tables 2 and 3) between the provision of services and the decline of mortality rates. A demonstration of these associations does not prove that the health services caused lower mortality rates, but since all four types of association are in agreement, they strongly support the hypothesis of causality.

Socioeconomic factors were not monitored during the study period, but there is no reason to believe that they changed substantially or that this population is unrepresentative of the total population of Haiti. For example, the prevalence of malnutrition of Grades II and III among census-tract children in 1968 was similar to that found in studies of the national population.[10,11] Housing appeared to be just as poor and crowded in the census tract as it was in other rural areas of Haiti. Food preparation in the family was carried out in the manner that is customary in all areas of Haiti: on the ground in unsanitary shelves that were poorly supplied with water for washing hands or utensils. Latrines were few, infrequently used, and poorly maintained. Less than half the population had easy access to a protected water supply. Therefore, if there were notable differences in socioeconomic levels between the census tract and the rest of the country, these differences were not reflected in practices affecting health.

We measured the program's impact on mortality by converting the changes in mortality rates to the number of lives (or years of expect life) that were saved per thousand population. These measures can be conveniently used to compare the effectiveness of alternative health programs.[28] The use of years of expected life saved per thousand population emphasizes the importance of protecting younger members of the population, who can be expected to live longer than older persons.

The hospital services and the health surveillance-health services program together lowered age-specific mortality rates, saved 10.4 lives per thousand population, lengthened life expectancy, and annually saved 495 years of life per thousand population. About 50 to 80 per cent of the probable total impact of the program outside the census tract can be attributed to health surveillance and health services.

Health planners in low-income countries must seek ways to deliver more effective health services to the largest number of people within the constraints of limited budgets. For example, the Haitian Ministry of Health has a current annual operating budget of only about $2.75 per capita. In addition, they have about $2.90 per capita to be used for the capital expenditures, training, and other costs associated with extension of the health system. International aid provides a great deal of the development funds.

This paper demonstrates that health surveillance and health services reduced mortality effectively even in a population that already had access to an established hospital. The average annual cost of adding health surveillance and health services

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to the hospital services for the five-year period studied here was only $1.60 per inhabitant per year. This amount includes some program-development costs and the initial training costs. Inflation and extension of the program to more distant populations have increased the cost of this program, just as they have increased the cost of alternative approaches. However, a relatively low cost is ensured by the program's dependence on locally recruited village-level health workers.

Since 1972, when the expatriate director of the program was succeeded by a Haitian physician, the population covered by the health surveillance-health services program of the Albert Schweitzer Hospital has reached 115,000. Similar programs have been initiated by private organizations to serve 20,000 persons in another rural area and 80,000 in an urban slum. This latter program is now receiving additional funds from the United States Agency for International Development. A pilot project in a rural area with a population of 33,000 was initiated by the Haitian Department of Public Health, Division of Family Hygiene. This project studied the impact of health surveillance and health services combined with different levels of expenditure for clinical services. It demonstrated that the presence of clinical services did not add to the impact of health surveillance and health services.[8] The cost figures for the government program are comparable to those for the program reported here.

Health surveillance and health services are designed to ensure that scarce resources are used efficiently to attack the most frequent and serious preventable diseases in the population. They accomplish this goal in two ways. In the first place, the use of village-level health workers makes it possible to ensure complete coverage of the population without incurring large expenses. Secondly, the data from the surveillance system make it possible to keep the program focused on the high-priority needs of the population. For example, the data from the census tract indicate that after 1972 the nutrition centers had reached all the mothers of malnourished children, that the prevalence of the original target diseases had decreased, and that there was a resurgence of malaria. This kind of information can guide changes in the program so that the services provided reflect the needs of the population rather than the habits or preferences of the providers. In these ways, health surveillance and health services provide the key to cost effective use of the more expensive and scarce resources of health professionals and the supplies and equipment that they require.

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Rationale: Why Community-Based?

Epidemiology is the study of the distribution and determinants of disease among human populations; literally, it is "the study of what is on the people" (from the Greek, *epi, demos,* and *ology*). Epidemiology undergirds community-based health programs and their supporting information systems. Ethical and economical program content is guided by epidemiology as are the related management, research and policy implications.

We have used "the five e's" to communicate five key facets of community-based health information systems: epidemiology, equity, empowerment, effectiveness and efficiency. Epidemiology is the foundation. Equity and empowerment comprise the ethical dimension of our population-based programs. Effectiveness and efficiency, or the ratio between effect and cost, comprise the economic dimension (Figure 1). Guided by epidemiology, the ethical and economic imperatives drive related management, research and policy questions.

This model embraces the key requisites of Primary Health Care. **Affordable** programs must be cost-**effective**. Equitable programs target risk groups and must be **accessible**. And programs that empower communities will also be **acceptable** since communities participate in guiding them.

Equity

In every community there are groups whose needs are relatively neglected: women and girls; the poorest members and ethnic minorities. For example, in rural areas of Bangladesh, the risk of dying from severe malnutrition is twice as high for girls as for boys. In one of Jakarta's slums, 37% of children from the poorest families are moderately to severely malnourished versus 19% of children from the most affluent families. In Sudan, traditionally powerful ethnic groups were receiving 120% of standard food rations.

Without information from all segments of the community, these inequities could not have been demonstrated. Unless samples are extremely large and rigorously selected, they are likely biased against minorities and the most mobile or isolated residents. Without enumerating and collecting data on <u>every member</u> of a community (or at least on all members of specific risk groups), identifying and responding to those in greatest need is not possible.

A census-based monitoring system helps avoid what the *State of the World's Children -1991*[1] called the "fallacy of the average: "

> Average levels of immunization coverage, educational achievement, or under-five mortality . . . can and do mask serious disparities of many kinds — between boys and girls, between urban and rural, between different regions of a country, between different ethnic or cultural groups, and especially between different economic strata of society... A national under-five mortality rate of 50 can mean 30 for the majority in the mainstream of the nation's life and 150 among the ethnic minorities, the geographically isolated, or the politically disenfranchised . . . The monitoring process should therefore focus more on measuring how many fall how far below the average, and on identifying who they are, where they are, and why they are being marginalized by progress ... This kind of monitoring is more likely to lead to a reaching-out to the unreached ...

Talyor[2] defends "Surveillance for Equity in Primary Health Care" in his attached paper. Citing experience in China, India, Haiti, and elsewhere, he observed that health systems that reached every household in a community could demonstrate improved health among the unhealthiest members. Information from such surveillance galvanizes communities, nations, and donors to action.

Empowerment

Residents are empowered by a community-based information system if: (1) they are involved in its development and implementation; (2) they

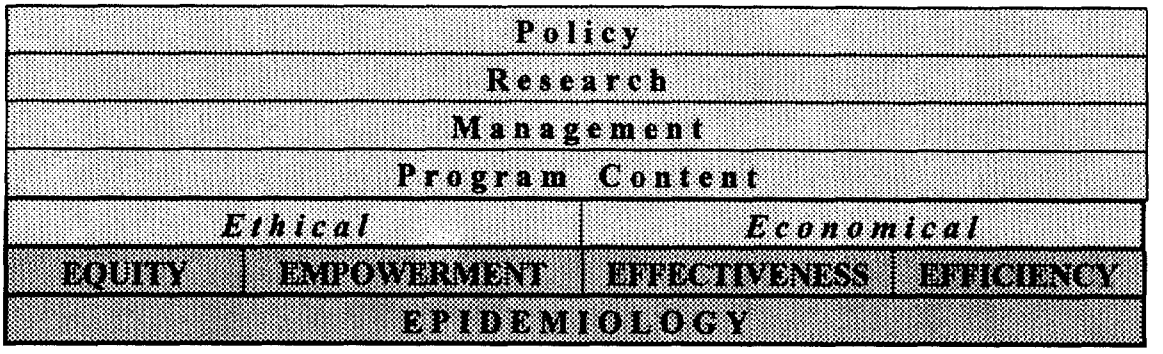

Figure 1. Community-based health information system: foundational principles supporting multiple uses

receive and have the ability to interpret the information it generates and (3) the health interventions meet the needs identified by the information system.

A prerequisite for step one of empowerment, however, is enfranchisement. That is, a community will not support the development of a health information system unless it is perceived to address important local problems. Community priorities are not necessarily those that Child Survival or other health interventions can address. For example, community residents often want water, curative care or interventions against endemic diseases beyond the scope of most programs. Thus, it is important for service providers either to incorporate into their programs or to advocate for interventions which address these felt needs. They must also illustrate to community members, through population-based health information, how other interventions (perhaps not identified by the community) can also save community lives.

Kaye's paper, "Urban Health from the Perspective of a NGO: Lessons Learned from a Case Study in Jakarta, Indonesia" (in *Field Applications* chapter), is relevant. Here, community residents in a poor section of Jakarta indicated, at the start of an early Save the Children Child Survival Project, that their major health problem was dengue. Although interventions against dengue were not initially planned as part of the Child Survival Project, SC health program managers opted for outreach workers distributing a mosquito larvicide (Abate) during home visits to promote other Child Survival interventions. Using data derived from the community HIS, program managers illustrated to community leaders in a series of fora conducted throughout the program that immunizable diseases were responsible for much child mortality in their areas and that program interventions were saving children's lives. By the end of the program, community leaders wanted to designate part of their small endowment fund to help institutionalize a Health Coordinator position within the municipal health department. This person would supervise community outreach workers (similar to that previously provided by Save the Children staff) and afford community representatives a channel through which complaints could be aired if municipal health personnel failed to staff the local monthly community health posts.

Community support for an information system also entails active participation in selecting outreach workers and detailing their workload (e.g., household visit schedules) and compensation. Community members should also have input into how outreach workers will be supervised in collecting data, in communicating with families, and in delivering services. For community empowerment to occur, supervision must also focus on ensuring that data are regularly fed back to the community (ideally to all groups) and that community members are trained in the interpretation of data (e.g., through use of simple, graphic techniques).

Unless those community groups who traditionally have been disenfranchised are involved in collection, review and interpretation

of data and in decision-making, it is unlikely that community empowerment will lead to greater equity. In Bangladesh, Save the Children learned that Village Development Committees were quickly dominated by the powerful village elite, whose decisions tended to maintain the *status quo*. When the Field Office development approach shifted towards promoting women's development throughout he establishment of Women's Savings Groups, it became easier to ensure that information was indeed shared with those who most needed to act upon it — poor women. This does not imply, however, that the Field Office chose to collect data on and communicate with poor women only. With respect to some health problems (e.g., infectious diseases, obstetric complications), more affluent groups were at equal or greater risk than the poorest groups. Demonstrating to these more powerful groups that they were as much at risk as their poorest neighbors can sometimes build a greater community cohesion and increase resolve to attack a common problem.

Effectiveness

Because Save the Children is a development agency rather than a research organization, the census-based approach has been viewed mainly as a tool to increase outreach. Nevertheless, data from census-based systems in several countries have been used to facilitate program evaluation and research. As sources of longitudinal data on identified individuals and families, census-based systems are valuable epidemiological tools to measure program impact.

Three conclusions recently put forth by a working group from the National Research Council (in *Effects of Health Programs on Child Mortality in Sub-Saharan Africa)* provide a strong rational for using census-based data in evaluating the impact of child survival projects, especially on child mortality:

- Declines in mortality rates should remain the ultimate indicator of the effectiveness of child health interventions in Africa;
- More emphasis should be given to age-specific mortality rates in stating program goals; and
- There is a need for more long-term studies that include regular collection of vital statistics, routine surveys of service utilization and quality of care.

Mortality rates can certainly be estimated through surveys. However, unless samples are very large and selected adequately to represent minority groups, it is difficult reliably to assess changes in infant, child and maternal mortality or to determine whether rates differ between groups. In the long run, a census-based system — which affords the opportunity to improve service delivery — may be no more expensive than a series of large surveys.

Equally important, having longitudinal data on identified individuals allows measuring the impact of specific interventions on mortality and nutritional status. A recently concluded external final evaluation of a Bangladesh Child Survival project observed "an astonishing wealth of data documenting project activities, participation, coverage rates, and outcomes. . . Thanks to the [computerized information system] it was even possible to prepare estimates of infant mortality by cause, which revealed, among other things, that deaths from immunizable diseases declined substantially."[3]

The rich longitudinal data base also facilitates answering questions of interest to the scientific community. For example, Khan and Dearden[4] measured the association between fertility and membership in a women's savings groups. They found that group members were more likely to use modern contraceptive methods and had lower fertility than non-members.

Other applications of longitudinal data include examining the temporal distribution of health events. Such inquiries generate explanatory hypotheses and guide programmatic response. The clustering of winter births in Nasirnagar, Bangladesh (Figure 2), for example, may relate to the cultural practice of marriages after the November-December harvest. Perhaps physical proximity stimulated by colder weather and a sense of nutritional well-being also play roles.

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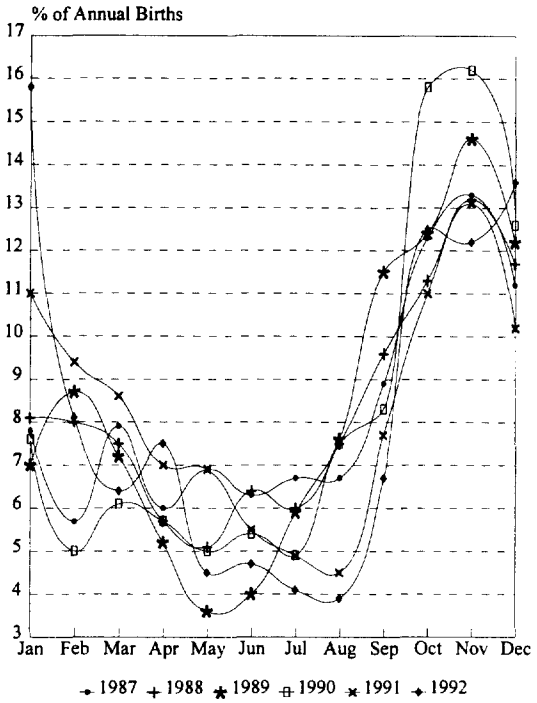

Figure 2. Births in Nasirnagar, Bangladesh by Month (1987-1992)

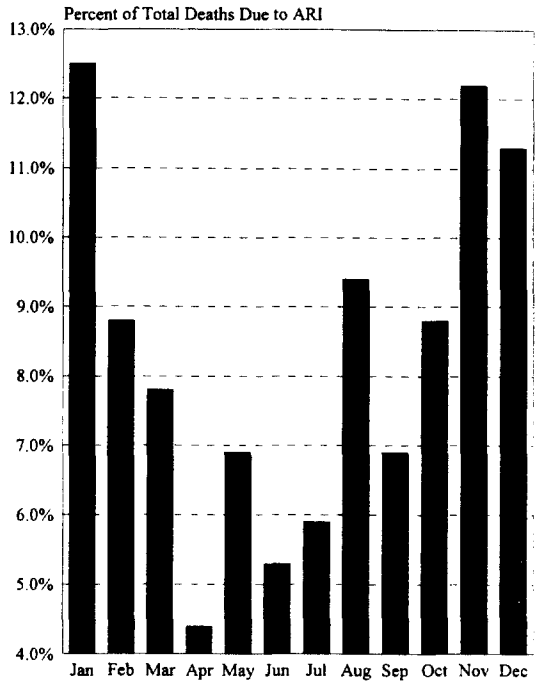

Figure 3. Deaths (%) Due to ARI by Month, Nasirnagar, Bangladesh (1987-1992)

The similar clustering of respiratory deaths in children under age three years in Bangladesh (Figure 3) underscores the need to train mothers and program staff in case management prior to cooler weather.

From the perspective of a service provider operating under time-constrained Child Survival grants, Save the Children attests that programs which implement census-based monitoring systems meet their objectives more quickly than those which rely on data from surveys alone. A note of caution requires distinguishing between program effectiveness from program sustainability. Unless outreach workers can be sustained after the end of external funding, the census-based system will not endure. On the other hand, if the census-based system effectively led to changed health behavior and health services utilization, some improvement will last with or without the system.

Efficiency

In any health program, it is important to weigh the costs of monitoring and evaluation systems against other program components, notably services. Generalizing the costs of census-based systems is difficult because of their variability from one setting to another. Key determinants of cost are whether outreach workers are volunteers or salaried, the intensity of supervision and the frequency of home visiting.

A "minimal" census-based information system might track indicators related to only one or few events that had the greatest impact on health status. For example, if all pregnancies were identified (possibly through twice annual sweeps through the community), pregnant women could be counseled on prenatal and delivery care. As they were revisited through subsequent sweeps, the outcome of their pregnancy could be recorded, and they could be counseled on early infant care. None of SC's field offices, however, have yet to apply such a stream-lined approach.

The costs of implementing and maintaining a census-based information system should certainly be recorded and analyzed. Such analysis should be in relation to the cost of service delivery in areas with and without such systems. The accompanying article by Zayan et al[5] compares the costs of immunization in an area where the population had been enrolled into a community-based information system to those

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where the population had not been enrolled. Costs of immunization were significantly lower in the area where the population had been enrolled, and the coverage was higher.

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Summary

***Background**: Recent global political and economic adjustments have threatened progress towards equity in health for vast populations. Equity is the "distribution of benefits according to demonstrable need;" surveillance is "an information system to identify emerging problems promptly so as to respond rapidly with appropriate action."*
***Methods**: Reviewing experience in developing countries, the author assesses health programs' equity, effectiveness, and efficiency.*
***Results**: China's barefoot doctors provided continual health care to their neighbors lowering infant mortality from 200 to 30-50/1000 live births. Local health cooperatives stressed preventive activities and the equitable distribution of food. With privatization, half of the 2,000,000 barefoot doctors became fee for service with resulting drops in immunization coverage and an over-medicated public. In response, the Mother and Child Health Model Counties Program, rediscovering the pursuit of equity, has reached 200 million in China's 300 poorest counties. In Indian Punjab, fortnightly visits to households with infants and every other month visits to households with children 1-3 years of age halved infant mortality. Villages responded to population-based malnutrition data by establishing feeding centers in low-caste areas. In Haiti, child mortality was reduced by 75% after surveillance allowed targeting of tetanus toxoid vaccination and other services.*
***Conclusions**: Where data are poor, distribution of births, deaths and child growth can be used as direct measures of equity. Verbal autopsies provide sufficient cause-specific information for management decisions. Every home should be visited at least annually, more often in poorest areas. Equity and efficiency need not be at odds (i.e., measles outbreaks will continue until poor pockets are protected). Integrating child survival and family planning is most essential where conditions are the worst. Community-based surveillance can make societal action contagious as peer pressure facilitates behavioral changes spreading through a group. Surveillance prompts communities, governments and donors to respond to greatest needs. [eds.]*

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SURVEILLANCE FOR EQUITY IN PRIMARY HEALTH CARE: POLICY IMPLICATIONS FROM INTERNATIONAL EXPERIENCE

CARL E. TAYLOR*

Equity in distribution of health care is a generally desired but elusive ethical norm. This paper presents evidence from international experience showing that equity is not only morally right, but it can also help make primary health care effective and efficient. Epidemiological methods of surveillance can use equity indicators to improve health care for poor populations. It is gratifying when a practical and effective management tool fits synergistically with a moral imperative. The management paradigm is that a health problem in a population can be controlled by: identifying subgroups among whom disease and risk are concentrated, defining priority problems, determining underlying causation and implementing corrective interventions.

Three recent shifts in public policy support the need for more attention to equity. First, in developed countries there seems to be ambivalence and reversal of earlier altruistic concerns for equity, especially since there are 35 million Americans with no health care coverage. Second, in the past decade many developing countries have been forced by 'economic adjustment' policies to cut public financing of health care by a third or more, severely reducing services for the poor. Third, China and Eastern Europe are engaged in equally drastic 'political adjustments' resulting in abrupt collapse of health systems that were designed to promote equity.

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The operational definition of equity used in this paper is, distribution of benefits according to demonstrable need rather than on the basis of political or socioeconomic privilege. This definition differs from the usual less specific notion of 'promoting fairness' and focuses on disparities in health status rather than equality of inputs or access.[1,2] Surveillance is defined as an information system to identify emerging problems promptly so as to respond rapidly with appropriate action.[3] The methodology grew out of surveillance for specific infections and high-risk pregnancy monitoring.

The Alma Ata slogan 'Health for All by the Year 2000'[4] implies political commitment to promote equity. Recent WHO policy statements reaffirm health for all as 'a foundational objective for WHO'.[5,6] Multiple successful demonstrations show that health can be improved greatly under conditions of extreme poverty.[7] The content of programmes depends on local circumstances but we now have a methodology to develop community based services anywhere. Relevant data are presented in this paper from projects in developing countries and from China's shifting national experience to show that a consistent characteristic of effective programmes is equity.

FLEXIBLE PROCESS OF SURVEILLANCE FOR EQUITY

1. For systematic monitoring each population subgroup should be the designated responsibility of a unit of the health system guided by a management framework at district level.[8,9] The process should start by registering all families.

2. Sustainable primary health care depends on continuing dialogue between health workers and community leaders starting with a joint situation analysis to agree on priorities based on available information and simple surveys.[4,9] Estimation of fertility, mortality and approximate causes of death can be obtained by simple retrospective 'verbal autopsy' methods which are adequate for management purposes.[10]

3. Continuing data gathering for equity indicators should not attempt research level rigor but focus on monitoring high risk subgroups among whom health problems are concentrated. For the poor and least educated local health workers should provide surveillance. More educated families can be taught to do much of their own surveillance and initiate their own care.

4. Surveillance should trigger feedback for prompt action on priority problems. The data can help health workers and community leaders decide how to generate and use resources, balance public and private activities and adjust the relative roles of health and community workers.

5. Where data are poor distribution of births, deaths and child growth can be used as direct measures of equity. To stimulate community involvement data need to be presented in a simple form to be believable as equity indicators. So much effort and money go into the usual reporting of demographic data that it may be more efficient to use surveys such as RAP (Rapid Assessment Procedures)[11] and simple demographic surveys.[12] Periodic surveys can also be used to follow local priorities, practices and attitudes that influence causation or control. Timing can be flexible because equity indicators do not change as rapidly as for epidemic diseases.

6. In order for the data to cover all subgroups every home should be visited at lease once a year and more frequently in the poorest areas. Child growth should be measured in each major nutritional season. Community surveys provide more useful denominator based information than the usual monthly growth monitoring which often does not include the most malnourished children or result in relevant action.[13]

7. Where health development is more advanced other methods and indicators can be selected but the principles are similar. Periodic analyses and feedback of surveillance data should be provided for administrators, community leaders and health personnel to adjust priorities and adapt interventions in a collaborative process which commits them to action. While encouraging self-reliance the health system should retain sufficient control to ensure equity and quality and to guide training, supervision and resource flow.

PRACTICAL ISSUES IN IMPLEMENTATION

1. Reaching those at greatest risk requires simple and low-cost interventions. Three types of intervention need to be balanced in child survival programmes in developing countries.[14] First, a few public health interventions, such as mass immunizations and some environmental control measures, can be effectively imposed on whole populations. National surveillance can follow coverage and impact. Second, for many interventions, community health workers can be

trained in family surveillance for early identification and treatment of major causes of death, such as pneumonia and diarrhea in children or malaria and other endemic diseases.[9] While most monitoring is initiated by health workers mothers and volunteers can be trained to provide primary screening. Third, modifications of individual and societal behavior are needed to change underlying causal factors such as: hygiene practices, child care, lifestyle, sexual activities, nutritional practices and environmental conditions. The health of individuals depends on the health of the community. Community-based surveillance can make societal action contagious as behavioural changes spread through a group with peer pressure to change cultural norms. Social mobilization should use culturally appropriate communication methods to help communities solve their own health problems.

2. An apparent dilemma identified by management experts is how to balance equity and efficiency.[1] Care for the most needy tends to be expensive and difficult. It may seem efficient to focus on people who can be easily reached and convinced even though they are better off. The dilemma applies only when input and output indicators are used to measure services or coverage. Equity and efficiency tend to be complementary if more important outcome or impact measures are used. Measles outbreaks will occur even with high immunization coverage if there are pockets of unimmunized children in poor areas. Oral rehydration therapy may be used by a high proportion of families but most diarrhoea deaths will continue among the poor. Similar disparities occur with childhood pneumonia, nutritional interventions, family planning, etc. Simply adding more services contributes less than reaching families with the greatest health problems.

3. Surveillance for equity can resolve concerns stimulated by Maurice King's article[15] about the so-called 'demographic trap'. He recommended that people in a 'trap shut' position should let children die to protect future generations and eco-sustainability. He does not deal with ambiguities of how such difficult decisions will be implemented in traditional cultures with the most intractable population problems. Deaths of children are mostly in poor families with the least educated mothers and the most babies. The alternative more realistic policy accepted by most countries and the UN agencies recognizes that integration of health and family planning services is most essential where conditions are worst.[16,17] Contrary to King's claims, practical field studies[18,19] show two-way interactions so that when a child's life is saved parents are helped to see that they do not need to have many children and that family planning can help increase the chances for child survival. Surveillance for equity can focus synergistic health and family planning services on needy families with the most children.[18]

4. Another dilemma is how to combine equity and community participation. Established community leaders can manipulate resources so that new inputs go first to their families and constituents. Systematic exclusion of the poor is greatest when people have to pay for part of their care. Three mechanisms for preventing discrimination require top-down intrusion into community decision-making. First, knowledge is power and feedback about where deaths and malnutrition are concentrated encourages community pressure on leaders to respond. Second, targets for equitable distribution set at district level can require local leaders to meet government norms to provide care where needs are demonstrated. Third, where economic and political adjustment policies have caused socialized health systems to collapse countries are increasingly turning to local self-financing mechanisms. Present extreme financial constraints require efficient use of outside funds. Community-based surveillance for equity is a direct way to make sure that international and national subsidies go to those in greatest need. International funding should include conditionalities to ensure care for the most deprived. The marginal costs are not great. Recent UNDP Human Development Reports have calculated that all social services for the poor in an average developing country would cost 3-5% of GNP.[20]

5. Surveillance for equity can help neutralize the artificial polarization between proponents of 'comprehensive' and 'selective' primary health care.[21] Surveillance has helped make selective programmes effective. Comprehensive programmes should also learn how to set priorities and focus activities[22] and surveillance for equity provides a data base for such decisions. National and international planners may offer a plethora of priorities but the community should determine their sequence and timing. The health system can define entry points so that activities chosen by the people lead naturally to other programmes shown to be important by surveillance.[18]

6. Surveillance indicators should be simple and measurable. The European region of WHO has tried to define quality of life indicators but an

example of the need to simplify indicators is experience in London where resources are allocated to areas where mortality is greatest.[23]

7. Since the capacity to select appropriate indicators and organize surveillance and action tends not to be available at local level in most developing countries, a feasible alternative is to do field research in community-based longitudinal study areas with professional guidance from academic centres. Priorities and measurement methods can be adapted by multi-disciplinary teams using the demonstration area as a model for extension to adjoining regions.[24] International and national networks can help build capacity for regional problem solving.[25] The International Commission on Health Research[26] stressed the need for 'country specific essential health research' to adapt scientific knowledge to local needs with equity being a primary goal.

PRAGMATIC INTERNATIONAL FIELD EXPERIENCE

Many international examples show how equity can promote community based primary health care. Lessons can be learned from China where the earlier priority given to equity was reversed in the past decade but efforts are again being made to retrieve past benefits. Project results from other developing countries will be briefly summarized.

Before liberation health conditions in China were among the worst in the world but after liberation they improved greatly during three decades when ideological commitment to equity permeated all decisions. With GNP per capita less than $100 per year China brought child mortality down almost to the level of developed countries. (Figure 1) Many reports in the 1970s tried to explain China's success[27,28,29] which involved almost a quarter of the world's population. One of the most perceptive observers of China's health transition was Dr. Ma Haide (George Haterm), the architect of national campaigns to control venereal diseases and leprosy. He attributed the mortality reduction to the 'constant day-to-day availability of health care that works year-in-and-year-out' as provided by barefoot doctors.[30] Local health cooperatives gave priority to preventive activities and equitable distribution of food reduced severe malnutrition.[31] Being part of the community, barefoot doctors maintained surveillance of their neighbours with an information system that was in their heads.

Since quality of care depended on local funding, however, disparities developed between regions with differing economic resources. A third of the million deaths every year are among the 12% of the population in remote and minority areas.[31] Even so, the simplest and lowest cost health care had great impact if it reached everyone. Infant mortality plateaued at over 50 per 1000 live births in poor provinces and about 30 in the more affluent ones.[32] But this was still vastly better than earlier levels of about 200 in all parts of the country. The quality of medical care was less important than availability of preventive measures to all without social or cost barriers.

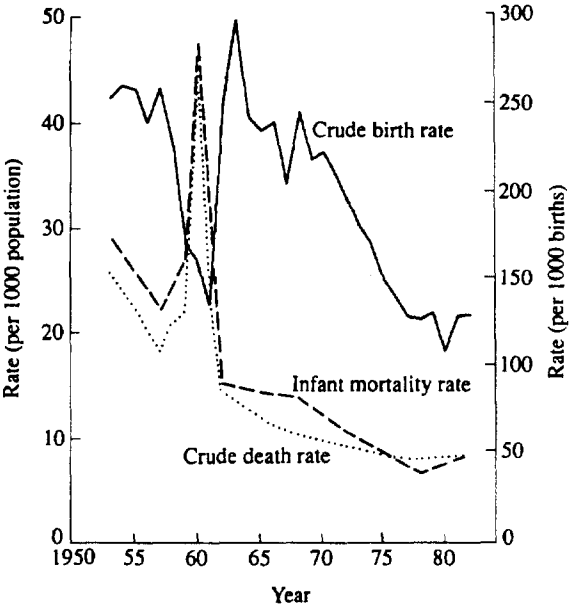

FIGURE 1 *Mortality and fertility in China, 1950–1980*

China's experience during the economic reforms of the past decade illustrates emerging dilemmas. The shift to private enterprise resulted in an apparent reversal of earlier priority given to equity. The Ministry of Health's Mother and Child Health (MCH) Model Counties Project, supported by UNICEF, provided an opportunity to learn how to adapt services to the new economic policies. The principles outlined above were validated by my personal involvement with this unique experiment. Starting in 1982, ten counties worked with schools of public health and medicine to improve maternal and child health. After two years the project was expanded to 33 counties, then to 95 and in 1988 to 300 of the poorest counties in China.[33] It now

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reaches over 200 million people.[34,35] Some conclusions are:

1. The economic reforms of the 'contract responsibility system' turned farmland over to families and eliminated the financial base of the commune health system and workpoints to remunerate health workers. Half of the two million barefoot doctors became mid level village doctors and they now get paid mainly through fee for service private practice.[34-36]

2. The Model County Project focused on training and systematizing management through surveillance applied to cost-effective interventions. Eight of the original ten model counties evolved low-cost procedures to extend simple services from an experimental township to the whole county and health conditions rapidly improved. The two counties that showed little improvement put their resources and effort into building a county hospital for women and children but improved village services in only the most accessible townships.

3. In most of China attention shifted from preventive to curative services as upgrading of village doctors concentrated on clinical training and credentialling examinations. Mao's slogans 'Put Prevention First' and 'Serve the People' were de-emphasized. The model county programme provided training for village doctors including monitoring for: priority diseases, child growth and high-risk pregnancy. Lessons from experience in the present mixed economy may be more transferable to other countries than the unique communal health system proved to be.[32]

4. Village doctors get much of their income from selling medicines and this results in serious problems of over-medication.[36] Multiple antibiotics and other drugs for simple colds and diarrhoea contribute to iatrogenic diseases, such as deafness in children from overuse of streptomycin and gentamycin.[37,38]

5. Privatization of local financing interfered even with the national immunization programme. Since families had to pay village doctors a fee for each immunization[39] it was found in the first year that in poor counties with fees as low as 5 fen (2 cents) immunization rates remained below 50% while in more affluent counties with fees above 30 fen (10 cents) coverage was over 90%. A contract system proved popular and achieved over 90% coverage in every province by 1988.[40] The contract provided all immunizations for about 7 yuan ($2) and if a child developed any of the six diseases they received free care plus an indemnity of about 100 yuan ($30). Now even more systematic surveillance is needed because epidemics of paralytic poliomyelitis have occurred in unimmunized groups.

6. To re-emphasize equity the Ministry of Health has issued a directive that by the year 2000, 70% of the counties should re-establish health cooperatives that are locally financed.

The Narangwal project[18,41] in the Indian Punjab demonstrated the effectiveness of regular surveillance and care by village-based auxiliary nurse midwives. Groups of study villages received different combinations of interventions to control infections and malnutrition and child mortality dropped in 3 years by about half in comparison with control villages which used government services.[41] The surveillance system was designed to gather research data but field experience proved that it was the most cost-effective way to identify and care for health problems. Reanalysis of the data shows considerable specificity in the periodicity of effective surveillance related to age. Where each house was visited every 2 weeks infant mortality dropped by half but villages with visits every 2 months had little improvement in infant deaths (Figure 2). By contrast, for children of 1-3 years of age, mortality reduction was very good with a 2-month surveillance interval, probably because mothers were better able to monitor indicators in older children (Figure 3). Use of preventive services among children of low-caste and landless families increased as compared with higher status families (Table 1). When presented with growth monitoring data village leaders collected food at harvest time from land-owning farmers for feeding centres which they decided to locate in low-caste areas. Integrated services cost about $2 (US) per capita per year.[18,19]

A parallel project in five clusters of villages showed that integration of family planning and MCH services improved both equity and cost-effectiveness when surveillance focused on the most needy families.[18,19] Before the project, 13% of low-caste women had practiced family planning. After 3 years of integrated services, among women who had not previously used family planning, the ratio shifted with 39% of low-caste women becoming regular users compared to 33% of high-caste women (Table 2). Theoretical discussions of population pressure had little impact but a convincing entry point for family planning was when a baby's life was saved.

In Haiti, an extension program from the Schweitzer Hospital[42] reduced child mortality to just one-quarter of earlier levels in a rural valley with greatest impact on neonatal tetanus, malnutrition,

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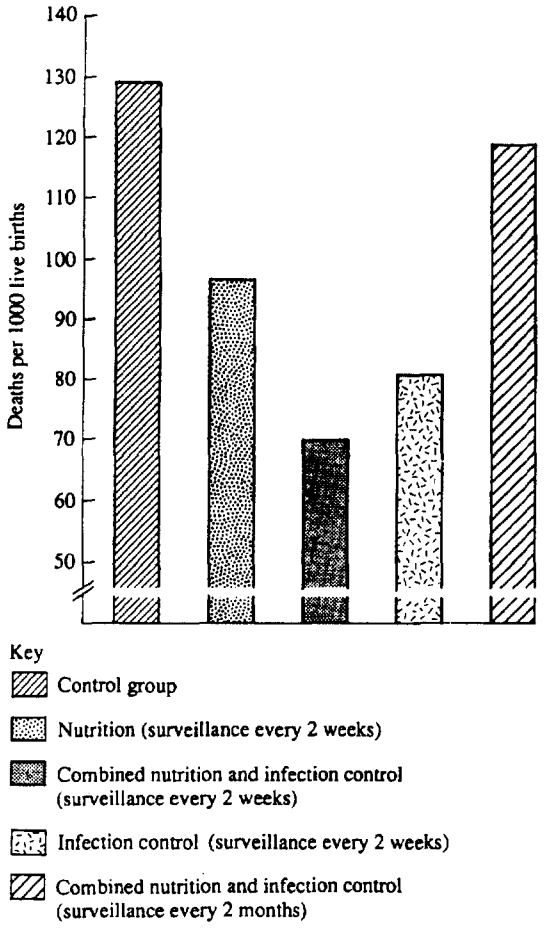

FIGURE 2 *Infant mortality rates in groups of Punjab villages receiving different types of child health services*

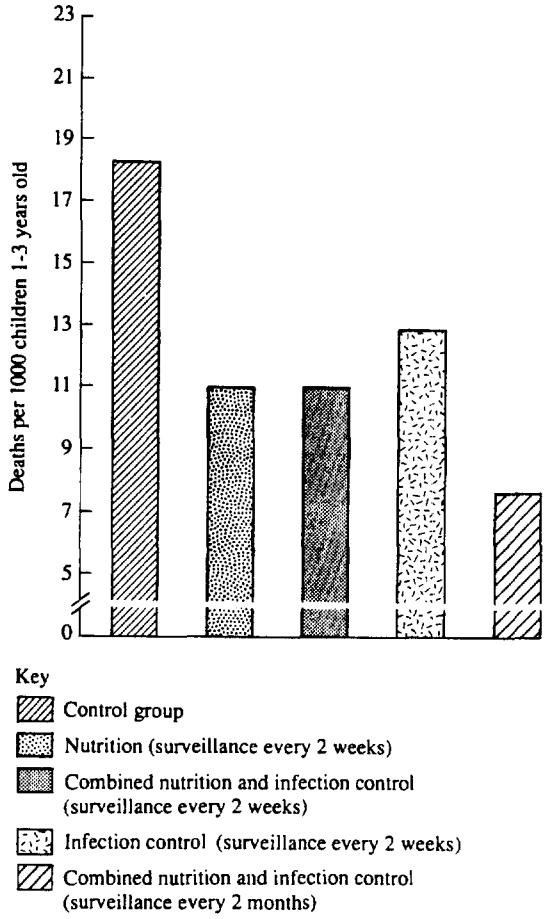

FIGURE 3 *Child mortality rates (1-3 years) in groups of Punjab villages receiving different types of child health services*

diarrhoea and tuberculosis. Tetanus toxoid immunization of pregnant women and the capacity to provide specific care for priority problems became effective only when total registration of the population made regular surveillance possible. This community programme cost $1.60 per capita per year.

Community members themselves organized and maintained surveillance in the Kakamega Project which become a model for community-based primary health care in Kenya.[43] Community workers gathered and analyzed their own information and at their own initiative the people targeted services to the poorest and most remote areas. Services for a population of 140,000 were paid for by local communities with government health centres providing technical backstopping.

One of the most effective health projects in the world is at Jamkhed, in a desperately poor area in western India where in a population of 250,000 the Aroles[44,45] have reduced infant mortality from over 120 per 1000 live births to the low 20s and the birthrate from 40 to 23 per 1000. Village financed and controlled services are provided by mostly low-caste and illiterate women selected by the village. Preventive and simple curative care focuses on poor and low-caste groups who have been empowered also to improve general economic development.

SUMMARY

Experience around the world shows that health agencies can promote community-based surveillance for equity to focus low-cost interventions on priority needs. Social inequities which have seemed intractable can be resolved if care responds directly to demonstrated need. The concept of promoting equity as a basic principle of primary health care has an interesting psychological twist. The ethical imperative of equity can strengthen services when linked with the practical management tool of surveillance. Moral conviction in applying this social justice norm can facilitate action which is made

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TABLE 1 *Utilization of children's services according to caste and SES in Narangwal project (% of families)*

		No.	No use	Some use	Full use	Significance
Curative services	Low caste	476	12	21	67	NS
	High caste	801	13	23	64	
	Low SES	577	11	23	66	NS
	High SES	642	13	22	65	
Preventive and surveillance services	Low caste	476	16	22	62	P < 0.001
	High caste	801	23	33	44	
	Low SES	577	17	26	57	P < 0.001
	High SES	642	23	33	44	

* SES – Socioeconomic status based on land ownership

TABLE 2 *Utilization of family planning among high and low-caste women in Narangwal project*

	Caste	No.	Users	%	Significance
Pre-project users	Low	895	115	13	$x^2 = 20.3$
	High	1693	339	20	P < 0.0001
Non-users who became users during project	Low	486	189	38.9	$x^2 = 4.1$
	High	817	271	33.2	P = 0.04

efficient by the realism of statistically based methods of surveillance. If international agencies condition their aid on surveillance for equity their assistance will more likely go to those in greatest need. This is a more efficient and effective way of tracking their money than the previous tendency to set up vertical programmes which generally have poor sustainability. Surveillance helps mobilize political will and community participation by providing practical data for local, district and national decision-makers.

The many field demonstrations of successful surveillance for equity tend to have been brushed off by development experts who say they are difficult to replicate nationally. The Model County Project in China shows how a systematic extension process can test procedures in experimental areas and adapt them for general implementation. Surveillance can help bureaucracies maintain capacity for flexible and prompt response as decentralization promotes decision-making by local units which are held responsible for meeting equity targets. Surveillance for equity provides a mechanism to ensure such accountability.

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THE PRICE OF IMMUNIZATION AND THE VALUE OF INFORMATION

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Abstract

In the Republic of Mali, a mobile immunization team, serving two similar populations, achieved an immunization coverage rate which was one third greater in one population than they had achieved in the other. Furthermore, the teams achieved the higher coverage rate at approximately half the cost per completely immunized person (CIP) that it had expended for the lower coverage rate.

The two populations differed by virtue of their community-based information systems. One of them began operating such a system before the mobile team began their work; the other population did not get their information system into place until after the mobile team had completed the year's work. This report compares the two first-year results and shows that community-based information, used at the home and village level, can make immunization services less costly and of better quality. The authors also propose that community-based information services may easily repay their own costs by enabling communities and health personnel to lower costs and improve quality for several PHC interventions at once.

Background

Located in West Africa, Mali is a country of 8 million inhabitants. It is divided into Regions and Circles. Late in 1986, Save the Children initiated a Child Survival project in the main district of the circle of Kolondieba. Two years later, expansion began to the other 4 districts. The project's purpose is to educate families in behaviors which protect the lives and health of children and mothers from the most prevalent life threatening illnesses. To ensure equity of services to all community members, and to monitor the degree of attainment of each behavior, the project installed a Health Information System (HIS).

The Health Information System

The key instruments of the HIS are the home-based personal records of immunization and weight monitoring, the family enrollment forms on which each member of the community is registered, and the family health trainers' rosters of women and of children. The enrollment form contains data such as name, date of birth, gender, educational level, and immunization records. Data for women and children are tabulated in rosters. The rosters include immunization and other interventions data. They are used by the health extension workers and the nurses to plan and implement primary health care activities in the community.

Immunization Services

Immunization of the women and children of the Circle of Kolondieba was conducted by a mobile team. Before the team arrives in a village, the health center in Kolondieba town sends a message to the community leader who ensures that mothers with children under 3 assemble during the visit of the mobile team. In communities enrolled prior to the visit of the mobile team, the health extension worker identifies women and children eligible for immunization. He/She focuses his/her efforts on this target group. Through participative education and motivation, the health extension worker engages the eligible women to prompt each other to bring themselves and their children to the immunization sessions.

Methodology

Kadiana and Fakola are 2 districts of the circle of Kolondieba, each with about 20,000 inhabitants living in 32-34 villages. The immunization mobile team completed 4 visits to each of their villages. The population of Kadiana,

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however, was not enrolled for the HIS until after the fourth visit.

Coverage Rates

Using their rosters, health extension workers of both districts counted the number of children and women who are completely immunized. They likewise counted the number of children and women who were not yet completely immunized. The population of children under six years old and women of child bearing age is known for each district by reference to the enrollment. Consequently, the coverage rate of completely vaccinated women and children can be calculated by dividing the number fully vaccinated by the total number in each group. (Table 1)

TABLE 1. Immunization coverage data for the districts of Kebila and Fakola

	Kadiana	Fakola
Total Population	24,305	21,184
Total # of Children < 72 Months	4,898	4,368
Total # of Women of CBA*	3,505	3,217
Total # of Children Completely Vaccinated	3,321	3,809
Total # of Women CBA Completely Vaccinated	2,005	2,556
Total # Completely Vaccinated	5,326	6,365
Immunization coverage rate for children < 72 months	67.80%	87.20%
Immunization coverage rate for Women of CBA	57.20%	79.45%

* CBA: Child Bearing Age

Cost of the mobile team Per Day

Based on data from the records of the local health officer and SC's office in Kolondieba, the authors were able to calculate the daily cost of the mobile team. The computation included the salaries and benefits of the eight persons involved. Computation also included per diem, cost of the vaccines, supplies, equipment, transportation, and depreciation of the vehicle. To calculate the cost of the mobile team per day, total expenses was divided by the number of days that the mobile team spent in the district. The records of the health center in Kolondieba showed that the mobile team spent 97 days in Kadiana (Unenrolled population), and 61 days in Fakola (Enrolled population).

Cost Per 1000 CIP

To calculate the number of days needed to completely vaccinate 1000 women and children (1000 CIP), the authors divided the number of days the mobile team stayed in each district by the number of fully immunized women and children and multiplied the results by 1000. By then multiplying the number of days needed to completely immunize 1000 women and children by the cost per day, we computed the cost of achieving 1000 CIP in each of the 2 districts.

Cost of Enrollment

The district of Fakola was enrolled together with Kebila (another district of the Kolondieba circle) from October 1988 to April 1989. Since both districts were enrolled simultaneously, the authors computed the total cost and divided it among the 2 districts using a ratio that corresponds to their respective population.

The computation of the enrollment cost included:

1. Personnel
   * Management and support staff
   * Enrollment Aids/Supervisors/ Secretaries
2. Transportation
3. Supplies & Equipment

Management and support personnel are Save the Children staff and consultants that contributed a whole or a part of their time to the enrollment.

The enrollment process was composed of 6 phases: (1) Planning, (2) Preparation, (3) Training, (4) Enrollment, (5) Creation of Rosters, and (6) Updating. The number of person weeks per phase that each staff member contributed to the enrollment has been calculated. Enrollment Aids, supervisors, and secretaries are the personnel that were hired for the enrollment. Transportation includes the cost of fuel, maintenance, and depreciation of the mobylettes. Supplies and equipment include cost of items such as the printing of the enrollment forms, the paint and brushes for the house numbers, etc. Summary cost of enrollment is presented in Table 2.

Table 2: Total cost of family enrollment in Fakola

Category Description	Amount
PERSONNEL	
1. Save staff	1,969.94
2. Enrollment Aids and Secretaries	4,797.40
TRANSPORTATION	
1. Kolondieba Expenses	512.01
2. Mobylettes	715.15
3. Transport of Mobylettes	300.00
SUPPLIES AND EQUIPMENT	
1. Kolondieba Expenses	585.41
2. Bamako Expenses	5,005.95
TOTAL	13,885.86

To compute the cost of the enrollment in terms of 1000 CIP, the authors divided the total cost of the enrollment times 1000 by the number of fully immunized women and children.

The difference between the cost of immunization in the enrolled versus the unenrolled population per 1000 series completions represents the amount of the enrollment already paid for by the reduction in immunization cost. This could also be expressed in percentages by dividing that difference by the cost of the enrollment and multiplying the cost by 100.

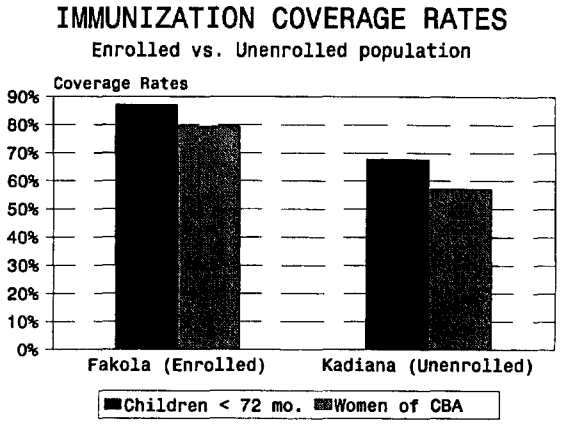
The authors also calculated the cost of immunization per capita if a certain coverage rate per 1000 CIP is achieved in both population. The cost of reaching the higher coverage rate, achieved in the enrolled population, in the unenrolled population was computed by dividing the higher coverage rate times the cost by the lower coverage rate. The results was divided by 1000 to calculate the cost per CIP in each population.

Results

The total population of Kadiana is 24,305 (source of data: Family enrollment - January 1990) and of Fakola 21,184 (source of data: Family enrollment - December 1988).

Coverage

Data retrieved from the rosters of women and children for Kadiana after the mobile team had completed its work showed that 5,326 or 63.38% of all eligible women and children were completely immunized. The number and percentage for Fakola were 6,365 and 83.92%, respectively. These data also show a coverage rate of 67.8% for children aged less than 72 months in Kadiana and 87.2% in Fakola. Coverage rate for women of childbearing age is 57.2% in Kadiana and 79.45% in Fakola. (Table 1 & Graph 1)



Mobile Team Costs Per Day

The total cost of the mobile team for both districts is $24,208.66. Since the mobile team spent 158 days to complete 4 rounds in each district, the cost of the mobile team per day is $153.22. In Kadiana, unenrolled population, the mobile team spent 97 days, with a cost of $14,862.34, and in Fakola, enrolled population, the team spent 61 days with a cost of $9,346.42. The exchange rate used for this analysis is 275 F.CFA for one U.S. dollar. This was the prevailing exchange rate at the time the data was collected.

Immunization Costs Per 1000 CIP

In Kadiana (unenrolled population) the mobile team spent 97 days to completely vaccinate 5,326 women and children. In other words, 1000 CIP required completions needed 18.2 days to be achieved. In Fakola (enrolled population) the team spent 9.6 days to achieve the same results. (Table 3)

By multiplying the number of days by the cost per day, we can compute the cost of achieving 1000 CIP as $2,788.61 in Kadiana, and $1,470.91 in Fakola (Graph 2).

We can also conclude that the mobile team cost in the enrolled population was lower by 47.25%.

$[1 - (2{,}788.61/1{,}470.91)] * 100 = 47.25\%$

Table 3: Cost of mobile team and family enrollment per 1000 series completion

	Kadiana	Fakola
Total number of days in the field	97	61
Days per 100 series completion	18.2	9.6
Mobile team cost per day in the field	153.22	153.22
Cost of mobile team for each district	14,862.34	9,346.42
Mobile team cost per 1000 series completion	2,788.60	1,470.91
Cost of Family Enrollment per 1000 series completion		2,181.60

Enrollment Costs Per 1000 CIP

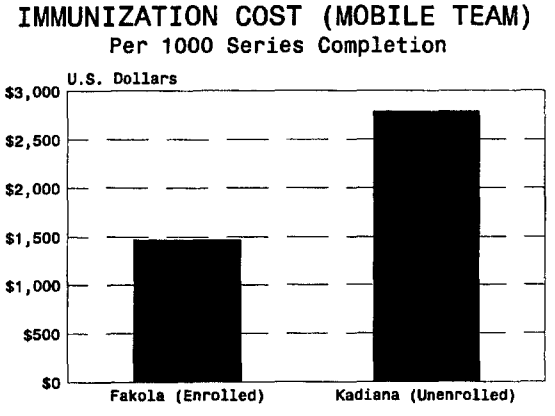
Enrollment expenses in Fakola totaled $13,885.86. Since 6,365 women and children were completely immunized, the cost of enrollment per 1000 CIP is $2,181.60.

Cost Per One CIP (Assuming Equal Coverage Rate)

In the enrolled population, a coverage rate of 83.92% (6,365 persons) was reached. To achieve the same rate in the unenrolled population, 7,050 persons will have to be completely immunized. To completely immunize this group, the number of days for the mobile team needs to increase by a factor of (7050:5326) or 1.32. Since the team spent 97 days in Kadiana (Unenrolled population), it would need 128.40 days to reach the same coverage rate achieved in 61 days in the enrolled population.

Knowing that the cost of immunization per day is $153.22, to achieve a coverage rate of 83.92%, Kadiana will cost $19,673.45 and Fakola will cost $13,235.78. Using the total number of eligible women and children as a denominator, the cost per capita will than be $2.34 in Kadiana, and $1.75 in Fakola; a reduction of 25.21% :

[1 - (1.75/2.34)] * 100 = 25.21%



Discussion

In summary, immunization cost $1,470.91 per 1000 CIP in an enrolled community and $2,788.61 per 1000 CIP in a non-enrolled community. This suggests that information systems can cut immunization costs by 47.25%. This result is also confirmed when the cost per one CIP is calculated assuming equal coverage rate in both population. The cost is then reduced by 25.21%.

The HIS is designed to satisfy many needs of health planners and decision makers, beginning at the family level and extending all the way to macroplanning. The findings of this paper demonstrate the importance of including the needs of information users at every level in designing such systems.

Another conclusion that could be drawn from this study is the benefit of community-based HIS in increasing the probability of a woman or child being immunized. By using the equation P (E) = m/N where P(E) is the probability of a person being immunized, m is the number of people actually immunized and N is the number of people eligible for immunization, we can conclude:

P(Enrolled) = 6,365/(4,368+3,217) = 0.84

P(Unenrolled) = 5,326/(4,898+3,505) = 0.63

We can conclude that the probability of being immunized in the enrolled population is higher by 33.33%.

By using the Attributable Fraction (AF), the authors were able to determine the percentage of the immunized population attributed to the enrollment.

$$AF = \frac{\text{(Rate for exposed) - (Rate for unexposed)}}{\text{Rate for exposed}}$$

AF = (87.20 - 67.80)/87.20 = 0.2224

In other words, the immunization of 22.24% of the eligible population is attributed to the Health information system.

In the unenrolled population, the coverage rates after 4 visits by the mobile team was lower by 22.25% for women and by 19.4% for children than the enrolled population. (Table 4) In real terms, the enrollment may have been responsible for protecting 716 more women and 847 more children than would have been protected without enrollment. It might be possible to guess roughly how many deaths may occur among the unprotected children and the infants born by the unprotected women.

Although the cost of an HIS is relatively high, these findings show that it can be recovered by the reduction in cost of the interventions. (Graph 3) The difference in cost of immunizing 1000 women and children between the enrolled and the unenrolled population is $1,317.70. This represents 60.40% of the cost of the enrollment that has been recovered by more efficient immunization alone during its first year of functioning. Subsequent years of use will recover more of the cost. Also, an in depth analysis of the cost of the other interventions in enrolled versus unenrolled populations and the continuous use of the HIS over time may demonstrate that the remaining 39.60% of its cost can also be recovered.

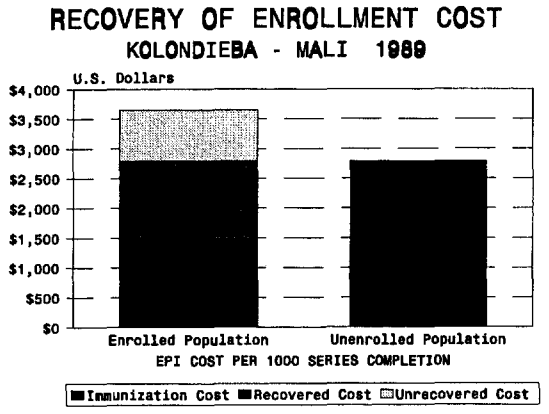


Table 4: Recovery of cost of family enrollment per 1000 series completion.

Indicator	Index
Cost of enrollment paid for by the reduction in immunization cost per 1000 series completion	1,872.34
Percentage increase in cost per 1000 series completion	47.38%
Difference in coverage rates for children < 72 mos.	19.40%
Difference in coverage rates for women of CBA	22.25%
Cost of FE recovered through the use of a HIS in conducting immunization campaign	85.82%
Cost of FE that need to be recovered by other interventions or through time	14.18%

In conclusion, the data strongly suggest that an information system which includes population enrollment and follow-up reduces the cost of immunization, increases the number of beneficiaries, and greatly improves coverage. Further analysis might show similar reductions in cost of other primary health care interventions. The decreased cost per intervention can then justify the cost of the information system.

DO WOMEN'S SAVINGS AND CREDIT PROGRAMS AFFECT FERTILITY? A CASE FROM SAVE THE CHILDREN/BANGLADESH

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May 27, 1994

Abstract

This study uses longitudinal data from the Bangladesh field office of Save the Children (US) to examine the relationship between participation in savings and credit programs and fertility. Results suggest that fertility rates for members are lower than for non-members though differences are largely attributable to region of residence: non-members in more conservative areas are only slightly more likely to have large families than members residing in those same areas. Nonetheless, members are significantly more likely than non-members to use a modern method of contraception, irrespective of social class or region of residence. These data link participation in savings and credit groups with increased use of contraception. Even so, future research will need to clarify the potentially complex relationship between group activity, the empowerment of women in Bangladesh, and fertility.

Background

Discrimination against women in Bangladesh, whether economic, social, or political, deprives them of the ability to lead healthy, satisfying lives. Purdah instition-alizes this discrimination by confining women's mobility and actions outside the home and severely limiting life chances. Women who observe purdah--either by their own choice or by requirement--are restricted from going to the market, the mosque, medical facilities, school past puberty, and fields, factories, and other places of employment, effectively excluding them from most forms of economic, religious, intellectual, and social life. In fact, it is often only through intermediaries--young children, husbands, fathers, and grown sons--that women have access to the world beyond the walls of their own home (Abdullah and Zeidenstein, 1982). Women's reliance upon others for daily tasks often translates into a lifetime of dependence. As one author has observed, (Cain, 1988), a woman is considered fortunate if she can successfully transfer her dependence from one category of male to another: first father, then husband, and finally son. The implications for women are clear: women who faithfully subscribe to purdah exert limited control over household resources and decision-making and, along with children--especially daughters--have restricted access to nutritious foods, appropriate medical attention, and social services (Miller, 1993).

Evidence from South Asia suggests that participation in women's groups enhances their material prospects (Dwyer and Bruce, 1988). Groups may also effect changes in women's outlook, increasing their freedom within the family unit and enabling them to mobilize community government (Dwyer and Bruce, 1988).

Introduction

In Bangladesh, Save the Children has attempted to address gender inequities through a number of programs, including women's savings and credit groups.

Program Description

Women's savings groups consist of 15 to 20 women who meet on a routine basis to save money, gain access to loans, and receive training in community development. Women who participate in groups save 2-5 taka/month, depending upon the amount agreed to by all group members. This money is pooled and used for emergency and non-productive credit. Grants to the Bangladesh field office of Save the Children form the working capital for most loans

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to group members. Group members themselves decide the order in which loans are given (individual loans are usually for $20-25). Extremely high repayment rates are attributable, in large part, to group pressure to pay back loans in a timely manner.

Women's savings group members elect leaders from among their own ranks. Savings group leaders are generally better educated than group members. Save the Children field-based staff, including Community Development Organizers and Village Development Trainers, supervise savings groups.

In addition to providing a means of saving money and accessing credit, women's savings groups are also a locus for other development work, including training in gender awareness, maternal and child health, income generation, and education.

Save the Children has made a deliberate effort to target asset-poor women, in part because they are generally not able to obtain capital or credit from commercial banks or at otherwise fair interest rates. A number of criteria have been used to classify and target asset-poor women, including the type of material they use to construct houses, the quantity of cultivable land which they own, their household assets, income, and self-sufficiency in food. Based upon these criteria, women are divided into four groups: A, B, C, and D. Members of group A are the most advantaged financially while members of group D are the most assetless.

Methods

Data from the Bangladesh field office of Save the Children were used to compare married women of reproductive age currently participating in savings groups with married women living in the same communities who do not participate. While savings groups are intended to reach the poor, some wealthier village women have joined the groups. Between 1987 and 1992, 25% of savings group members were from the two highest classes (A and B). Women's savings group non-members (controls) were somewhat more likely to be better off: 40% of non-members belonged to classes A and B. Women's savings group members and non-members live in four rural areas of Bangladesh where Save the Children currently works: Mirzapur, Rangunia, Ghior, and Nasirnagar. Mirzapur and Ghior are both near Dhaka and Rangunia is near Chittagong; travel to these large cities is frequent. On the other hand, Nasirnagar--located in the northeast corner of Bangladesh--is isolated. It is often regarded as more conservative than either Mirzapur or Ghior and considerably poorer than Mirzapur, Ghior, and Rangunia.

Table 1 (*note:* all tables appear at the end of the article) provides information on length of association with savings groups. As of the 31st of March, 1993, 93% of all women in the study had participated in savings groups for at least one year. More than 40% belonged to women's savings groups five or more years.

Data for this study were collected by "paid volunteers" (Save the Children employees given a nominal wage) who visited each household once per month. The total population served by paid workers during the period of study was approximately 54,000. In other areas where Save the Children works, women's savings group leaders collect limited data. Because the quality of data collected by women's savings group members varies, these data are not included in the present analysis.

A number of indicators were used to compare members, non-members, and their offspring. The intent was to assess the extent to which membership in savings groups impacted upon the use of contraception and fertility rates.

Except for contraceptive prevalence rates (which rely on the number of women enumerated as of January 1st), all rates were calculated based on the mid-year population for members and non-members. Between 1987 and 1992, the mid-year population for savings group members ranged from a low of 1,397 (1987) to 2,621 women (1992). Non-members were also the least numerous in 1987 (7,545) and the most numerous in 1992 (8,690). Selection criteria for membership in savings groups included social class (those belonging to the two most assetless classes), marital status (only married women participate), and age (women 15 years of age or older).

Table 2 provides information on the number of

live births by year for women's savings group members and non-members.

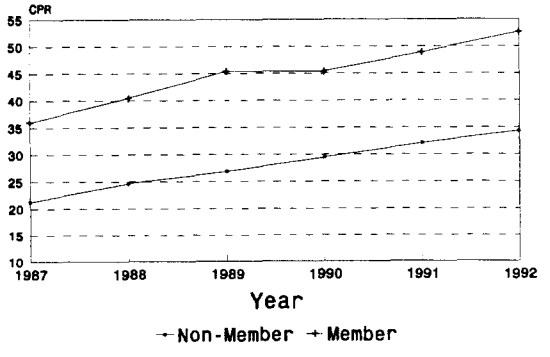
Social class and region of residence are thought to exert an influence on fertility behavior and health outcomes independent of membership in savings groups. Consequently, all analyses are stratified by class (classes A and B on the one hand and C and D on the other) and residence (Nasirnagar versus Mirzapur, Rangunia, and Ghior). As has already been mentioned, the populace in Nasirnagar is considered to be considerably poorer than in the other three regions and socially and religiously more conservative than in Mirzapur and Ghior.

Results

For all analyses related to women's use of contraception, those who were not sure if they were using a method at time of interview were grouped with non-users.

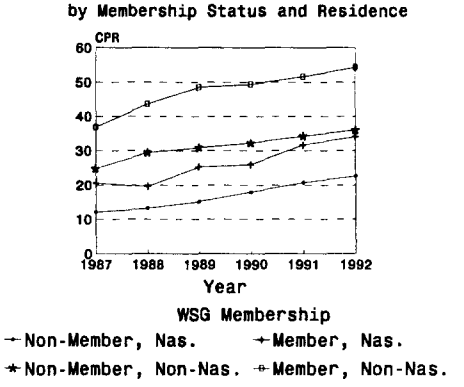
Figure 1 indicates that women's savings group members were more likely than non-members to adopt a modern method of contraception. The contraceptive acceptance rate of married members who were 15-44 years of age climbed from 36% in 1987 to 53% in 1992, an increase of almost 50%. Non-members' use of contraception grew at about the same rate; however, they were consistently less likely to use modern methods of contraception: only 34% did so in 1992. It is difficult to assess the extent to which group membership influences the use of contraceptives: savings group members were considerably more likely to be using a modern method in 1987 when data collection began but more than a third of all women participating in savings groups joined before that date.

Figure 1
Contraceptive Prevalence Rate



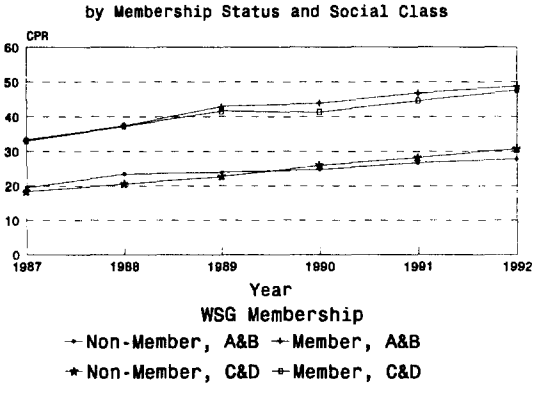
Members from non-Nasirnagar regions were the most likely to use contraceptives; more than half did so by 1991 (Figure 2). Non-members from Nasirnagar were the least apt to use a modern method: by 1991, only one in five were regularly using contraceptives.

Figure 2
Contraceptive Prevalence Rate
by Membership Status and Residence



Social class played no role whatsoever in explaining women's use of contraceptives. Usage rates for non-members from classes A and B were virtually identical to those of non-members from classes C and D (Figure 3).

Figure 3
Contraceptive Prevalence Rate
by Membership Status and Social Class

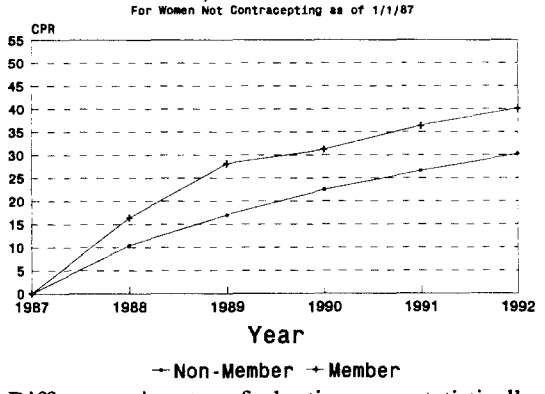


Likewise, members from classes A and B were no more likely than members from lower social classes to practice family planning. Nonetheless, differences between members and non-members were pronounced. Table 3 details the extent of these differences. According to data presented in table 3, members of women's savings groups were significantly more likely than non-members to use contraceptives (p value for the chi-square test < .001 for every year between 1987 and 1992).

Non-members and members were then stratified by region of residence and social class. Results, presented in table 4, suggest a marked difference between groups. For example, members living in Nasirnagar were considerably more likely than non-members in Nasirnagar to use a modern method of contraception. These differences were statistically significant at $p < .01$ for every year between 1987 and 1992. As has already been mentioned, social class had no measureable effect on the adoption of a family planning method. Even after controlling for social class, members were significantly more likely than non-members to use modern contraception. These differences were statistically significant for all classes and all years (table 4).

In an attempt to ascertain the true impact of savings group participation on the adoption of family planning techniques, all women not contracepting as of January 1, 1987 were followed to assess the extent to which non-members and members moved from one status (non-user) to another (user). Data presented in Figure 4 suggest that members' rate of adoption over time was greater than that of non-members.

Figure 4
Contraceptive Prevalence Rate
For Women Not Contracepting as of 1/1/87



Differences in rates of adoption were statistically significant (using chi-square tests, $p < .001$) for all years (table 5). Members from non-Nasirnagar areas who were not contracepting as of 1987 were the most likely to adopt a method; non-members in Nasirnagar were the least likely (Figure 5).

Social class did not affect the likelihood that women would adopt a method by 1992 (Figure 6).

Figure 5
CPR by Residence
For Women Not Contracepting as of 1/1/87

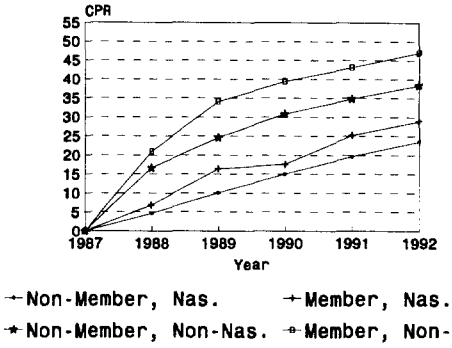
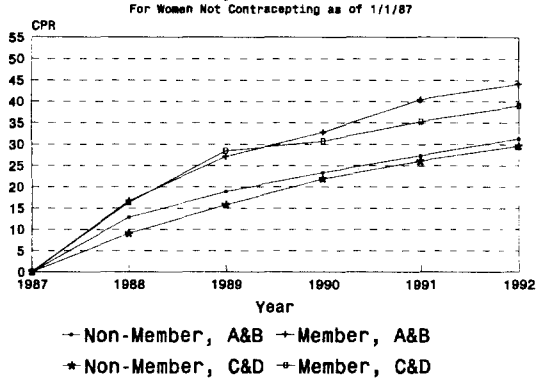


Figure 6
CPR by Social Class
For Women Not Contracepting as of 1/1/87

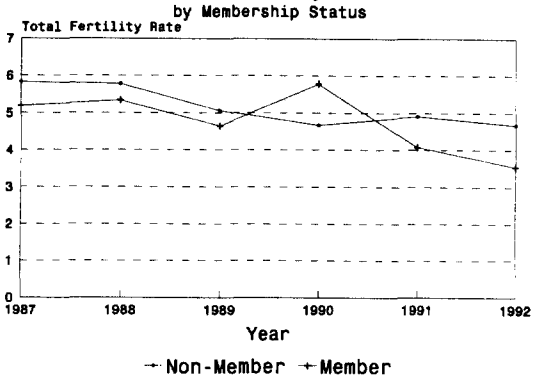


Chi-square tests for differences between members and non-members, stratified by region of residence and social class, are presented in table 6. These analyses only track women who were not using a contraceptive at one point in time. Women not using a contraceptive as of January 1, 1987, could have used one before then, raising the possibility that members' greater propensity to use contraceptives preceded their activity in savings groups.

Given these variations in the use of contraceptives, it is not surprising that total fertility rates for members and non-members were also different. The total fertility rate is the average number of children that would be born alive to a woman during her lifetime if she were to pass through her childbearing years conforming to the age-specific fertility rates of a given year (in this case, the years from 1987 to 1992)(Population Reference Bureau, 1985). Figure 7 indicates that with the exception of 1990, the total fertility rate for members was consistently lower than for non-members; by

1992, each savings group member had, on average, 3.5 children. Non-members had 4.7 children.

Figure 7
Total Fertility Rate
by Membership Status



Because the total number of births by year for some groups of women was quite small (e.g., women's savings group members from classes A and B), aggregate data for the entire period (1987-1992) were used in stratified analyses of fertility. Region of residence had a strong influence on fertility levels. Table 7 indicates that while the total fertility rate for non-members using aggregate date for the six year period ending in 1992 was 5.1, non-members living in Nasirnagar had a considerably higher fertility rate (6.1) than non-members in Mirzapur, Rangunia, and Ghior (4.2). This pattern was even more pronounced among members. Social class had a modest effect on members' and non-members' levels of fertility. Data presented in table 7 suggest that members from classes A and B had the lowest rates of fertility; non-members from classes A and B had rates comparable to members from classes C and D; and non-members from classes C and D had the highest overall rates.

Discussion

Women who belong to savings groups are much more likely than non-members to use contraceptives. Even after controlling for the effects of region of residence and social class--two factors thought to be highly associated with the adoption of modern contraception in Bangladesh--membership in women's savings groups plays an important role in distinguishing between those who use contraceptives and those who do not. In fact, differences between members and non-members were highly statistically significant for every year, independent of region of residence and social class. Even so, because there is no information on women's use of contraceptives prior to joining savings groups, it is not possible to assess the impact of group membership on fertility-regulating behavior.

While women's savings group members have lower levels of fertility than non-members, much of the variation can be accounted for by region of residence: women living in Mirzapur, Rangunia, and Ghior have much lower levels of fertility than women in Nasirnagar.

While reductions in levels of fertility may be attributable to participation in savings groups, other factors, including women's control of resources (often determined by birth order), position within the household, and exposure to development activities other than those offered by Save the Children, could also explain differences between groups. In the case of contraceptive usage rates, it is difficult to determine why women who participate in savings and credit groups are more likely to adopt a modern method of family planning. Data from this study suggest that members were more likely than non-members to use a method at the outset of data collection. However, rate of adoption for those not using a method in 1987 was greater for members than for non-members. A recent study (Schuler, Meekers, and Hashemi, 1992) on the fertility behavior of women participating in Grameen Bank and Bangladesh Rural Advancement Committee (BRAC) groups suggests that it is length of association with groups and not group membership *per se* which has a significant effect on current use of contraception.

These analyses account for the effects of social class and region of residence, allowing a more careful review of differences between members and non-members. However, it may be that regardless of social class or region of residence, women who join savings groups are qualitatively different--in their thinking and in their behavior--from those who do not. It is possible that self-selection for savings group membership contributes to differences in health outcomes. In-depth studies on savings group members and non-members, along with more detailed research

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on the quality of their participation, could provide important insights into the social process of change which precedes changes in health behaviors and outcomes. While this research is an important first step toward understanding the cross-sectoral impact of NGO-sponsored activities, further work will need to identify *how* women's participation in community activities influences their own well-being as well as that of their children.

TABLE 1

Length of Association with Women's Savings Groups as of March 31, 1993

Number of Years	Percent
< 1	7
1 <= x < 2	27
2 <= x < 3	11
3 <= x < 4	7
4 <= x < 5	7
5 <= x < 6	9
6 <= x < 7	9
7 <= x < 8	6
8 <= x < 9	10
> 9	9

TABLE 2

Live Births by Year - Women's Savings Group Non-members and Members

Year	Non-members	Members	Total
1987	1411	233	1644
1988	1438	284	1722
1989	1283	323	1606
1990	1178	364	1542
1991	1234	294	1528
1992	1177	269	1446

TABLE 3

Frequencies and Chi-squares for Contraceptive Usage for Women's Savings Group Non-members and Members

Year	Non-Members		Members		x^2
	Practicing	Not Practicing	Practicing	Not Practicing	
1987	11312	5026	372	682	109.4***
1988	1519	4891	577	879	154.1***
1989	1720	4896	806	1021	224.2***
1990	1889	4694	930	1155	182.6***
1991	2098	4648	1106	1207	210.6***
1992	2226	4498	1149	1069	248.2***

Note. *** $p < .001$. One degree of freedom for all x^2 tests.

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TABLE 4

Frequencies and Chi-squares for Contraceptive Usage for Non-members and Members, by Region of Residence and Social Class.

Group/Year	Non-members		Members		x^2
	Practicing	Not Practicing	Practicing	Not Practicing	
Non-Nasirnagar					
1987	891	2458	316	488	50.7***
1988	1067	2257	497	565	75.8***
1989	1171	2224	666	635	110.1***
1990	1252	2169	745	651	114.9***
1991	1337	2108	868	702	118.9***
1992	1410	2028	892	599	147.9***
Nasirnagar					
1987	412	2550	57	194	14.4***
1988	451	2635	80	316	8.5**
1989	386	2781	140	386	76.9***
1990	636	2526	185	504	15.3***
1991	766	2535	237	506	24.6***
1992	815	2471	258	469	34.7***
Classes A and B					
1987	523	1853	105	168	36.6***
1988	649	1755	152	205	36.6***
1989	701	1776	214	233	67.5***
1990	725	1691	243	242	73.4***
1991	792	1674	292	253	89.2***
1992	811	1618	292	222	99.3***
Classes C and D					
1987	789	3174	267	514	76.9***
1988	869	3137	242	675	9.4**
1989	1022	3117	592	788	165.8***
1990	1163	3005	688	912	120.9***
1991	1310	2970	813	955	129.8***
1992	1413	2882	859	845	159.0***

Note. $p < .01$. $p < .001$. One degree of freedom for all x^2 tests.

TABLE 5

Frequencies and Chi-squares for Contraceptive Usage for Women Not Contracepting as of January 1, 1987

Year	Non-members		Members		x^2
	Practicing	Not Practicing	Practicing	Not Practicing	
1987	0	0	0	0	
1988	481	4131	152	774	27.3***
1989	721	3526	327	838	72.0***
1990	878	3032	409	902	40.4***
1991	985	2721	525	915	48.8***
1992	1038	2385	554	826	42.8***

Note. *** $p < .001$. One degree of freedom for all x^2 tests. Totals for each year (rows) will fluctuate due to death and out migration. In-migrants post-1987 were not included in analysis.

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TABLE 6

Frequencies and Chi-squares for Contraceptive Usage for Women Not Contracepting as of January 1, 1987, by Region of Residence and Social Class

GroupYear	Non-members		Members		x^2
	Practicing	Not Practicing	Practicing	Not Practicing	
Non-Nasirnagar					
1987	0	0	0	0	
1988	373	1875	132	500	6.3*
1989	496	1521	263	511	24.9***
1990	573	1286	320	492	18.7***
1991	597	1118	390	514	17.5***
1992	599	961	403	454	17.0***
Nasirnagar					
1987	0	0	0	0	
1988	109	2255	20	274	2.7
1989	225	2005	64	327	13.4***
1990	308	1743	88	411	2.1
1991	390	1601	135	401	8.0**
1992	440	1423	151	372	6.1*
Classes A and B					
1987	0	0	0	0	
1988	222	1514	36	180	2.5
1989	307	1316	72	194	9.5**
1990	344	1124	94	193	11.1**
1991	383	1013	130	191	21.2***
1992	398	868	133	168	17.6***
Classes C and D					
1987	0	0	0	0	
1988	259	2617	116	594	32.7***
1989	415	2209	255	644	68.5***
1990	535	1907	314	710	29.9***
1991	603	1707	395	724	30.9***
1992	641	1516	421	658	28.2***

Note. *$p < .05$. ** $p < .01$. *** $p < .001$. One degree of freedom for all x^2 tests. Totals for eachyear (rows will fluctuate due to death and out migration. In-migrants post-1987 were not included in analyses.

TABLE 7

Total Fertiliy Rates (1987-1992) for Women's Savings Group Non-members and Members

	Nasirnagar	Non-Nasirnagar	Classes A & B	Classes C & D	Total
Non-members	6.1	4.2	4.6	5.3	5.1
Members	6.2	3.8	4.1	4.7	4.6

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Summary

***Background**: Measuring progress towards the Child Goals for the 1990s (CG90s) challenges "data poor" countries. EPI cluster surveys are well-suited to measure indicators for common events such as vaccine coverage where neither sub-group analysis nor explanation of findings is of prime concern. But sampling frame and sample size requirements limit the applicability of this technique for other questions in other settings. Sentinel Community Surveillance (SCS) is an alternative.*

***Methods**: SCS rests on purposive selection of communities which are representative of larger populations. Selection criteria are stated and representativeness is defended. All households in the selected communities are surveyed periodically. "Meso-analysis," the designing of additional survey questions and/or employing qualitative techniques in subsequent survey rounds, can refine explanatory hypotheses for observed prevalences. Although spatial sampling does not apply, temporal sampling requires confidence intervals or other significance tests. SCS has been applied in developing countries to monitor most CG90s.*

***Results**: The author presents examples of vaccine coverage and efficacy, ORT usage, salt iodination, vitamin A deficiency, breast-feeding practices and a meso-analysis of the association between ARI duration and tepid sponging. The village reports from the Iringa, Tanzania nutrition project stimulated village dialogue and response.*

***Conclusions**: Sentinel community surveillance is an alternative monitoring technique that: rapidly provides accurate, detailed, actionable data at low cost; melds qualitative explanatory ability with quantitative prevalence estimates; stimulates informed dialogue and builds capacity. Despite criticism from academics and researchers, it is a reasonable method in many settings. [eds.]*

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A MONITORING OPTION FOR DEVELOPMENT IN "DATA" POOR COUNTRIES

NEIL ANDERSSON

Monitoring and development traction

Even when community-based monitoring is widespread, as in the case of growth monitoring, the sheer volume of data obstructs their incorporation into a national picture[1]. That is why to monitor progress towards Universal Childhood Immunization (UCI), a simple cluster survey method was so useful. It served as a monitoring bridge to communities, to children who might be left out by the services.

The pressure and resources of UCI successfully focused attention on an achievable goal. Attention remained focused with the aid of periodic measurement of progress through the Expanded Programme of Immunization (EPI) coverage surveys, and holding up those "scorecards" to increase traction towards UCI. The scorecards worked. Much of the data was generated by a cluster survey method devised to be robust and reproducible. It provided comparable and actionable data from most countries at national level and, in a few cases, at subnational level. It did not require elaborate calculations, since only one thing was measured -- the proportion of children under five years who were vaccinated.

In many developing countries, existing information systems do not provide data that are sufficiently reliable or detailed for monitoring. Many of these data collection systems, being service-based (records of schools or health facilities) do not include the worst off -- who almost always contribute more to the illiteracy, disease, and death indicators[2].

In international poverty monitoring circles, as in those concerned with other aspects of monitoring development, discussion has turned around what data should be presented

[1] Pearson R. Thematic Evaluation of Growth Monitoring. Evaluation Office 1983.

[2] Taylor CE. Surveillance for equity in PHC: policy implications from international experience. *International Journal of Epidemiology* 1993; 21/6: 1043-9.

(indicators) and how they should be presented[3]. Little has been said about *where* those data should come from, or *who* will do it. Partly this ommission is justified; it recognizes the different circumstances and capacities in different countries.

But it also leaves some countries in a difficult position. The pressure to produce indicators, without guidance about where they come from, can lead to a *reality-indicator gap.* The indicator says one thing while the reality is another. It is not a question of honesty; it is a question of evidence, and habits about using evidence. The word "estimate" is used freely to describe an indicator when what is meant is "guess". Soon it becomes difficult to tell the difference. And estimated development progress, by axiom, comes to mean "guess".

Scorecards motivate by reflecting the state of play. To increase traction, indicators of development must reflect evidence. That is why monitoring UCI worked. With its robust simplicity, the EPI cluster technique reflected part of the reality at community level.

Multiple indicator surveys

Repeatable sample surveys provide an efficient means to get community level data on specific problems. They reduce the enormous costs of monitoring everything everywhere all the time. However, to monitor target-driven multisectoral development, very large sample sizes are needed for statistical confidence in the data. Measuring several different things, with different frequencies, and changing at different rhythms, require increases in sample size.

For a common occurrence (vaccination rates between 50% and 80%), 30 clusters of seven children per cluster give a good idea of the proportion vaccinated under the age of five years. When we need the age and sex distribution each subgroup holds only 20 children. If we want to know how many of these have DPT-1, DPT-2 or DPT-3, we are down to a "rate" based on the merest handful.

To generate reliable indicators on a relatively rare occurrence, like neonatal tetanus or measles morbidity and mortality, we need sample sizes many, many times larger. And to evaluate impact (reduction in measles) or change in coverage (increased use of ORT, increased breastfeeding), as required by the mid-decade goals, one has to take account of a double variability -- the variability of the baseline and the variability of the follow-up estimate. Assessment of changes -- comparison of indicators at different times -- requires bigger samples than the point estimate of an indicators at all different times -- requires bigger samples than the point estimate of an indicator.

There are also very few indicators of impact that change linearly because of a single intervention. Infant mortality falls because of breastfeeding, immunization, actions of the mother in the care of common illness and several other factors. If we are to maximize impact, we need to know what works best and where, and to invest in that.

Although scorecard indicators are usually expressed as hard numbers (for example, 80% vaccinated, or 20% reduction in IMR), it is often useful and sometimes indispensable to link quantitative and qualitative data. Since the 1940s, when the Indianapolis Group Fertility Survey set the model for WFS and DHS, the limits of quantitative data for programme management have been under discussion. Qualitative data are often necessary to shed light on *why* indicators change. The surveys carried out under DHS-1 and DHS-2 were criticized on this basis.

Monitoring also includes learning from the community -- including what they think should be done to reach the development targets. And what they consider the obstacles to reaching them. Small clusters of children, perhaps two or three households, do not permit linking quantitative and qualitative data.

An alternative for some countries

Sentinel Community Surveillance (SCS) was not originally designed to monitor development progress through following national level indicators. It was conceived as a capacity building *development process* that produces accurate detailed and actionable data rapidly and at low cost[4 5]. It focuses on the use of data on

[3] Unicef Task Force on Monitoring. Monitoring Child Goals in the 1990s. 10 May 1991. Also, Operationalization of the Mid-decade goals, 24 June 1993 CF/EXD/1993-008.

[4] see previous essay on *Impact, coverage and costs.*

[5] Andersson N, Martinez E, Cerrato F, Morales E and Ledogar RJ. The Use of Community-Based Data in Health Planning in Mexico and Central America. Health Policy and Planning, 1989, 4(3): 197-206.

impact in local and national planning, by stimulating informed dialogue about the causes and costs of impact[6]. Through this dialogue, SCS data increase the pressure to take more rational and informed decisions.

SCS is a concentration of resources in time and place; the sites are concentrations in place; the sites are concentrations in place, an intense look at a panel of mini-universes. Since SCS is a cyclical monitoring scheme, by returning to the same panel of communities after a given time interval, savings can be made from monitoring everything everywhere all the time, while estimating impact. The ability to repeat measurement in the same place makes impact estimation relatively straightforward[7].

Because of its logistical efficiency -- working a full day in each site, then traveling to another site the next day -- SCS usually yields bigger sample sizes than the same resources invested in random samples. This permits, once issues of population inference are settled, declarations of greater statistical confidence about impact and factors contributing to impact.

Typically, SCS uses very short focused questionnaires. An SCS interviewer might cover anything from 25 to 50 households per day, compared with three or four for a DHS interviewer. This increases the sample sizes possible when resources are limited.

SCS involves large contiguous parts of a community (not just seven households per cluster) to permit the analysis of local factors affecting impact and the link between quantitative and qualitative data (from observation, key informants or focus group discussions within the site). This is the SCS meso-analysis concept[8].

Because of a whole mini-universe of contiguous households make up the sample, it is also very easy to get data from the nearby health services or schools that serve the community. A panel of sentinel communities thus represents a panel of the interactions between communities and the services. We have data on both, and these data can easily be linked with reasons for non-attendance in the households. Medical care can be linked with household occurrence and outcome of disease. We can find out about costs to the services of a given activity, say, vaccination. We can find out from the households why they do not take advantage of this when it is available, how much time they lose waiting for attention, and how much it costs when their child gets ill though not being immunized[9].

An important component of the cross-design scheme (analysis of existing data, Rapid Anthropological Procedures, household surveys) known as Sentinel Community Surveillance is its epidemiological approach to household data. An attempt was made, at the same time as generating interpretable data on the situation of children, to strengthen the foundations of a sustainable, impact-based measurement scheme that could link qualitative and quantitative data[10].

Now, in designing a community-based sample surveillance scheme that overcomes the limitations of EPI-style cluster surveys and larger DHS-style random sample surveys, some of the same questions arise:

- How should the sample be chosen to optimize the balance between logistic and scientific considerations?
- How sure can we be that indicators obtained by a sample will be representative of the whole country?
- What effort and resources will it take to do it?

Purposive and random samples

For many developing countries, a random sample cannot even be contemplated for two simple reasons: sampling frame and size. To be

[6] Ruijter, Jose M. Sentinel Site Experience in Angola. *Convergence* Volume XXXIV, Number 4, 1991.

[7] Ledogar RJ & Andersson N. Impact Estimation Through Sentinel Community Surveillance, An affordable epidemiological approach. Third World Planning Review, August 1993.

[8] UNICEF/CIET. Informe del Primer Coloquio Internacional sobre Sitios Centinela. Acapulco, Mexico Noviembre 1992.

[9] Andersson N, Paredes S, Legorreta J, Ledogar RJ. Who Pays for Measles? The Economic Argument in Favour of Sustained Universal Child Immunization. Health Policy and Planning, December 1992.

[10] Andersson N. Impact, coverage and costs: an operational framework for monitoring child survival, emerging from two UNICEF projects in Central America. Guatemala: UNICEF, September 1985.

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defensible, an adequately sized random sample should be taken from a complete and up-to-date sampling frame that gives every household in the country an equal chance to enter the sample. In practice, this means a comprehensive list of everyone in this country. Many countries do not have such a sampling frame. Some have not had a census for a decade or longer. In some countries the census, if recent, is incomplete.

Once we are dealing with an incomplete sampling frame, its potential biases should be weighed up next to the potential biases should be weighed up next to the potential biases of observers influencing the selection. Observers can be trained and their opinions counterbalanced through team participation in the selection. But it may be very difficult to estimate the potential bias of an incomplete sampling frame.

An ACC publication puts the case for purposive sampling clearly:

It is recommended that the selection of sites be based on purposive selection and could be limited to as few as two for each domain i.e., the concept should be the use of sentinel sites rather than a random sample of adequate size to provide a valid estimate of the indices of the domain as a whole. The justification for this can be summed up in terms of the analogy with leading economic indicators, namely speed of reporting and analysis requiring a limited total number of sources, as well as emphasis on data quality. (emphasis in original)[11]

The advantage of a truly random sample is that it eliminates selection bias. The investigator is unable to bias the selection through his/her partial view of the overall population of interest. This advantage in the context of a two-stage random sample (where the investigator subdivides the population into a series of domains -- based on prior knowledge -- from which a random sample can be taken), boils down to the reliability of the investigator.

If prior knowledge is a scientific basis for subdivision of sites in a two-stage random sample, and the integrity of the investigator is not in doubt, why is it not a sufficient basis for selection of representative sites? Just as existing knowledge is applied to subdivide the country or region into strata or domains, in each this knowledge is applied to pick out the site most likely to represent the domain.

The personal knowledge of people who have worked for many years in the region is unlikely to be less informed and less up-to-date than any other sampling frame. But representativeness, estimated in this way, is in the eye of the beholder. Prior knowledge may be biased and, particularly if the experience of only one investigator with limited experience is taken into account, this may produce a mistaken estimate.

Sample Size and Cost of fieldwork

In order to reduce the random error in probability and purposive samples alike, samples size should be as large as possible. The problem of size in random samples can be explained by an oversimplifield example of the height of, say, one hundred children of different ages. If we take, a random sample of one child from the hundred, there is only a small chance of getting the correct average height. This is not to say the sample is biased. It is just wrong -- by chance. The sample is too small to give confidence in the estimated average height. To have more confidence in our estimate we need a bigger sample. If we wanted to look at several other related indicators (age, sex, weight), we would need a still bigger sample. And if we wanted to look at indicators that vary from time to time and place to place, like diarrhoea rates or ORT practices, and some like malnutrition that have grades of a response instead of yes/no it would have to be still bigger to comply with standard probability theory.

Suddenly we need to consider an otherwise achievable sample size (like the 30 cluster, 7 household EPI surveys) raised to the power of 10 or more. We are very quickly out of range of what is feasible.

The unsatisfactory resolution of this problem has been to fall short of the sample size required by rigorous sampling theory, to use a more practical size *and to emphasize that the selection is random and, therefore, not biased by the evaluator.*

With a random selection, we would certainly avoid selection bias by dishonest or poorly informed researchers. We would appear to conform to standard probability sampling theory and so would not be questioned by those

[11] UN Adminstrative Committee on Coordination, Subcommittee on Nutrition. Suggested Approaches for Nutrition Surveillance, April 1989.

who mistakenly believe that a random sample is by definition a representative sample.

There are short term advantages to this but in the case of at least one country that tried sawn-off part-random sampling, it can be short lived. It only takes one person to look in an elementary statistical text and to ask difficult questions about statistical power for the scorecard-the ability to say with confidence that progress was made -- to be discredited. It is impossible to defend an incomplete random sample.

A misconception about samples is that it is not valid to extrapolate from a non-random sample. *The interpretation depends on the representativeness, not on how sites were chosen.* Representativeness has to do with how closely sites reflect reality. This can be validated against other sources and the interpretations conditioned accordingly.

Safeguards for population inference

If we need to draw conclusions from indicators based on a sample survey, for national and international advocacy, some caution is necessary.

Just as a random selection of sites cannot be guaranteed to be representative -- there is a possibility that repeating the sample produces a different result -- so a purposive selection can fail to be representative. Indicators derived from aggregated data can then be wrong. In making a purposive selection, there are several way to reduce this potential error.

1. Perhaps the easiest safeguard is to consider, from the beginning, that the sites may not be representative. A summary indicators across all the sites may, for example overestimate ORT use by 10% or underestimate by 15%. But if, after two years, the use of ORT across all sites has increased by 30%, even if the original figure was a bit wrong, we have some of the data we need. ORT use increased by 30%. The first safeguard is thus to focus on changes, on the 30% *difference,* across "approximately" representative sites.

2. The likelihood of the sample being representative is higher with 30 carefully selected sites than, say, with 15 sites, simply because there is more chance to include and to balance different types of site. The largest *feasible* number is desirable.

3. Stratification increases the chance of the proportions being correct. For example, six sites from the cities, two from minor towns and 22 rural; or three from each province. This is very simple to the procedures used in multistage random sampling or in randomized controlled trials. The final confidence in the sample is directly proportional to the amount of effort and transparency with which this stratification is done.

4. The selection is not conceived as definitive; just as knowledge changes and populations shift, so does - representativeness. In Mexico, for example, the initial 40 sites were extended to 43 to take better account of the urban/rural balance. In Zimbabwe, 30 sites in the first cycle were extended to 40 in the second and third cycles. A preliminary selection provides for an early start and further knowledge accumulated in the measurement process and comparison with other experiences will permit the adjustment of the selection (usually by the inclusion of additional sites).

5. Criteria for justification of the selection are clearly specified. While the actual selection may invoke a wide variety of dimensions of previous knowledge, it should be justified in terms of three types of data that can generally be estimated from existing sources if sufficient effort is invested. Investing this effort to find data on 50 sites is a very different issue from validating an entire sampling frame -- population density, access to services (including health care) and, insofar as data are available, health status.

6. The selection should be done by a multi-disciplinary group, all of whom have experience of the area to be worked. In Central America, regional teams were used for this or, in Nicaragua where the scheme was decentralized to district level, district teams. In Zimbabwe, Liberia and Mozambique, national teams did the selection. The knowledge of different members of the team tend to balance out the unrepresentative aspects.

7. There is also the possibility of validation or comparison with other studies investigating fewer variables but using a different methodology. In Nicaragua, the representativeness of sentinel sectors was validated by a *post hoc* comparison of infant mortality estimated by the Brass technique in the first study cycle with the same sort of data derived from a previous study based on a probabilistic sample two years earlier. Retrospective estimations of IMR for urban and rural areas in each region in 1977-78 in the two studies revealed only decimal point differences.

In Zimbabwe, the initial selection was held up next to the intercensal survey and, when available, the census. They were able to compare proportions of households in different sectors (urban/rural and by provinces). In Guerrero, Mexico, validation using the census compared infant mortality, education status and access to water and sanitation. In that case, in fact, 15% of the SCS population had not been included in the census a month earlier. This provides a caution about expecting "gold standard" sampling frames, like a national census.

SCS and the 1995 WSC Goals

SCS has been used to monitor progress towards the World Summit goals in several countries. The process has been consolidated in Nicaragua, El Salvador, Guatemala, Honduras, Belize and Panama, where UNICEF and its partners have invested in capacity building over the last eight years. They are now able to produce indicators on most of the Goals relevant to Central American countries.

African experience is also growing. In Liberia, under very difficult working conditions, the application of community-based monitoring to inform the emerging country programme also generated data on no less than 13 major indicators of progress toward the Goals[12]. Rwanda has adapted dynamic monitoring as an integral part of the country programme[13]. Zimbabwe, while tracking the social dimensions of economic structural adjustment, obtained valuable data on education, access to health care, and malnutrition[14]. Mozambique, at the same time as training a large number of nationals, has laid the baseline nationally for 14 indicators in their first two SCS cycles[15].

Many of the WSC Goals that have been monitored using SCS are listed in Annex 4. Not all the WSC Goals can be monitored using SCS. Clustered or rare conditions like goiter, poliomyelitis, tetanus, Guinea Worm -- as they approach eradication -- require other monitoring techniques. SCS is not a standalone comprehensive system; it is a community based adjunct to existing systems and a capacity building tool to make better use of other monitoring schemes. A few of these areas bear more detailed description.

a) Increased immunization coverage

Coverage is relatively easy to measure, applying the questionnaire developed in the EPI coverage surveys to SCS. In addition, several countries have been able to get valuable information on the reasons for failure where vaccination coverage is not increased sufficiently. Ideally, vaccine coverage questions could be added to a cycle on health care and common childhood illnesses; this allows for a richer dialogue with the communities about the results, especially the illnesses avoided.

A detailed vaccination coverage survey in Liberia found, based on comparison of maternal response and Road-to-Health cards using serum antibody levels as a standard, that maternal response is a quite robust indicator of immunization status[16].

It is quite easy to estimate vaccine efficacy. Using simple questions about time of

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[12] UNICEF Evaluation Office. Evaluation of the Liberian Emergency Operation. 1993.

[13] Pearson R. Rwanda training workshop. Sentinel community surveillance-type survey on diarrhoea. Summary Report. Evaluation Office, October 1992.

[14] Several reports are available that document the Zimbabwean process, including *Zimbabwe: Monitoring the Human Face: The Social Dimensions of Structural Adjustments in Zimbabwe*. Evaluation Office 4-11 Jan. 1992. Also *Zimbabwe: Drought and Social Dimensinos of Adjustment in Zimbabwe*. Evaluation Office 28 March to 8 April 1992. UNICEF Harare, Zimbabwe *Final results of the 2nd Sentinel Site Survey* 16 February 1993.

[15] UNICEF Mozambique. Results of the First Round of Sentinel Community Surveillance. Maputo 1993

[16] UNICEF Liberia. The coverage and impact of vaccination in Monrovia. Draft August 1993.

vaccination and the time of illness, a vaccine failure index can be calculated. Dividing the difference in illness rates between vaccinated and unvaccinated, by the rate among the unvaccinated, is a robust indicator of vaccine efficacy. This was done in Somalia, after the 1992 famine and measles epidemic[17].

Among children receiving the vaccine in Liberia, by taking a drop of blood from a finger-prick, the extent to which it provides protection ("true coverage") has been tested -- for measles, polio, and pertussis vaccine. It is not difficult to obtain morbidity data on measles and pertussis through surveys.

b) Use of ORT in cases of diarrhoea

ORT impact, coverage and costs should be measured in community-based epidemiological studies, since not all cases attend health facilities. In SCS, ORT is linked with other crucial aspects of home management (food and fever control) and with prevention of diarrhoeas (water supply and use, sanitation).

Data on costs of diarrhoea can be used in social mobilization efforts to increase ORT use -- shorter episodes cost less. When these data are translated into programmes, they permit a dialogue much more interactive and empowering than "Use ORT, it's good for your child." SCS data, widely and appropriately communicated, can help mothers to see what they can gain or lose, and take decisions and action.

A special focus of ORT monitoring might be the causes of the apparent fall off in use over the last few years. Unless mothers are asked directly, this area will continue to be shrouded in speculation.

c) Iodization

In Zimbabwe, iodization has Ben monitored at commercial outlets in 40 sentinel communities, indicating the wide variation of salt iodization in the country. "Iodized" salt was found to be free of iodide and "normal" salt found to have extremely high levels. This set the stage for a multi-level monitoring approach to iodine deficiency.

LEVEL 1: SCS data provide a baseline to monitor availability of iodized salt at community levels. A unit of commercial salt is purchased in each site by the team supervisor, and analyzed later.

LEVEL 2: Legislation and regulation of imports. Monitoring though direct contact with producers.

LEVEL 3: Once all community outlets are found to dispense iodized salt, household level monitoring sentinel communities may be contemplated. This could be a complement to the extensive and successful school-based monitoring system, as developed in Ecuador. Completion to this level would comply with the 1995 Child Goals.

LEVEL 4: Identification of high endemicity areas for "hot spot" local eradication monitoring. This could link with the initiative to monitor goitre prevalence, Thyroid Stimulating Hormone and creatinine levels.

LEVEL 5: Maintenance surveillance: opportunistic monitoring through schools, linked to an education initiatives, is inexpensive.

d) Vitamin A deficiency

Since the main risk group are under five years of age, and they are often out of the main stream of health care coverage, household studies are a *sine qua non* to monitor Vitamin A deficiency. A three stage monitoring system was developed in Zimbabwe (possibly to be applied also in Mozambique and Madagascar), beginning with sentinel community surveillance.

LEVEL 1: An appropriate baseline strategy is to ask about two aspects in a household survey (i) night blindness and (ii) domestic production (and/or consumption) of Vitamin A rich foods. Some careful piloting of the concept of night blindness is desirable in each region. If there is no local understanding of the concept of night-blindness, it is unlikely to be a widespread problem. It also provides experience about how these questions should be raised in further more intensive monitoring.

LEVEL 2: Opportunistic monitoring, using EPI contacts, perhaps for one or two months, everywhere in the country, will permit mapping

[17] Centre for Public Health and Nutrition Surveillance, Somalia Nutrition and Health Assessment. *Somalia: Bakool region -- nutritional and health assessment* February 1993

of the night blindness areas. At the time of vaccination, the mother can be asked if there are any older children, their ages and sex, and if they suffer night blindness. Retraction of expansion of coverage will make these data less representative, so it will be important to maintain the reference grid provided by Level 1 monitoring through SCS.

LEVEL 3: In areas with a widespread night blindness problem, Local Eradication Monitoring, similar to that proposed for Guinea Worm, may be appropriate. This would be linked with a programme of interventions, including health promotion, gardens, etc..

e) Improving breast feeding

Breast feeding can only be monitored effectively through a community-based approach. In SCS, several questions are asked for each child on breastfeeding ("at what age was water introduced?" "at what age were other foods introduced?") permit interpretation of exclusive breastfeeding at four and six months, without asking directly about breast feeding. This obviates the need to have specially selected interviewers to discuss the intimate issue like breastfeeding.

The advantage is that these data can be related directly to common illnesses of the child -- duration of diarrhoea and ARIs. The local evidence of the protective effect can be used as fuel in promotion of breastfeeding.

Actionable impact data -- behind the indicators

Simply knowing the indicator is not enough to achieve progress. In order to do this, it is necessary to move *upstream*, to identify what leads to these avoidable deaths, to learn what produces the indicators. Getting beyond simple frequencies to the identification of *causality* is not only desirable. It is necessary and SCS experience has shown that it is possible. Annex 4 illustrates one case from Liberia, where other possible explanations of an impact are excluded one by one, leaving programme managers with actionable information.

There are a few things that, if done well and widely -- like vaccination, ORT, water supplies, sanitation, hygiene habits, antenatal care, etc. == will have a good impact. But a successful action in one place may not be the first or best way to optimize resources in another place. For almost the same resources as it takes to get a bald indicator -- for example, the rate of ORT use -- we can get locally specific hard data on some of the factors that lie behind ORT use, why people use it or why they do not. For virtually the same cost, we can also interact with mothers and communities to find out how they see it, what they think can be done and how they think it should be done.

In a community or household, several factors sustain high death rates, but in a complex situation-specific web of knowledge, attitudes and practices mediated by culture, education, environment and climate. Tow or more factors might interact synergistically, for example, investment in water and specific elements of knowledge of diarrhoea control, to produce a bigger impact than each of these factors on their own. Knowing about this helps for better use of resources.

Statistical handling of SCS data

Since there is no sampling within a sentinel site -- all households are covered -- SCS data are handled as mini-universes, each of which can be followed over time. in the analysis, "site" is a factor to be take into account, like age, sex or education. Sites can also be grouped by characteristics (geography, religion, prevailing opinions or price of basic grains) to provide a link between qualitative and quantitative data, between data from the household and data from the community or local environment. This advantage of SCS, dubbed "meso-analysis", is not possible with EPI- or DHS-style random cluster surveys.

An added advantage of covering the whole population in each site is that this helps "control" several environmental factors that might affect all children in a given community. Thus we can compare, for example, diarrhoea episodes managed with ORT, with children with diarrhoea who do not benefit in this way in the same site. The resulting calculation, called the risk difference, tells us how many children might be saved if they received ORT. Putting a cost on this allows analysis of the cost and benefit of the intervention[18].

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[18] Ledogar RJ, Andersson N and Paredes S. Who Pays for Health? The Household Economic Costs of Illness and Health Care Measured By Sentinel Community Surveillance. 1992 Summer Scientific Meeting in association with the Internatinoal

SCS cycles, since they involve going back every six months or so to the same community, make impact estimation very easy. We simply compare number of households using iodized salt last year with the number this year. If the proportion has increased across all the sites, this is hard evidence of progress.

It is a fairly widespread misconception that confidence intervals (or other significance tests) can only be applied in the context of a probabilistic sample. Random error is reduced by increased sample size, irrespective of how the sites are chosen. Random selection simultaneously contemplates several aspects of random error: spatial random error (knocking on the next door might produce a different result), temporal random error (interviewing tomorrow or yesterday may produce a different result in the same person, purely by chance).

Even if spatial random error is minimized by covering every household in purposely selected sites -- permitting us to comment upon occurrence in an unsampled domain -- the possibility of temporal random error persists. This will be limited by increased sample size and it can be evaluated formally in tests of significance. Probability theory is also applicable for the comparison of occurrence in two or more domains, such as the comparison of various sentinel sites with different levels of coverage[19].

Aspects of the philosophy and methodological issues of representativeness are dealt with in Annex 1.

SCS is not a quick fix

Sentinel community surveillance was conceived and designed to improve health through capacity building and dialogue around recent actionable data[20]. The capacity building process is not a one off training, but the establishment of a learning curve linked to practice. The practice begins to produce data early, and this can be useful for monitoring progress. But the learning process continues, and the investment must continue too (see below, Costs...).

In this sense, it is not like establishing a cold-chain, where one might train technicians in a few weeks and leave them to run it. In each SCS cycle, more indicators can be estimated, more detail sought on causality and capacities deepened. What begins as an externally guided process passes capacities to nationals at a central coordinating level, spreads out to a decentralized provincial level, then to district or municipality. Initial involvement of an individual national might be through being an interviewer, then data entry, then analysis. In decentralization of these capacities, it is necessary to invest to maintain quality. This costs.

Another problem is that data from SCS and routine sources might conflict. Any sample can be unrepresentative and produce misleading results. And routine data can sometimes produce biased indicators through incomplete coverage. Sometimes this conflict is resolved in favor of the sampling system, if it is believed that this is more consistent. Sometimes the difference between the sources can draw attention to an unrepresentative selection of sites. The selection can then be adjusted.

A third problem that requires special attention is the *test group bias* or *Hawthorne effect*. If a dynamic process like SCS is implemented in a handful of sites -- say, two percent of a country -- it is possible that these become increasingly less like the rest of the country and, consequently, less sentinel. A questionnaire tightly structured around a problem and its solutions, followed by discussion about which solution is preferable, will *hopefully* change something in the community. But if we manage to do this, in a well focused discussion about ORT and diarrhoea, it is unlikely it changes vaccination rates or iodization of salt. If the few minutes interaction does provide a spur for change in relation to ORT, the sites are probably still sentinel for iodization, Vitamin A, etc.

The way we avoid the Hawthorne effect in SCS is not by restricting knowledge of the objectives or the results of the survey. It is by spreading them more widely. A first principle of SCS is that it generates data to feed a communication strategy *that goes well beyond*

Epidemiologic Association, ADELF, and the Society for Social Medicine of Great Britain " Surveillance in Europe and the EC".

[19] Kuritz S, Landis FR and Koch GG. A General Overview of Mantel-Haenszel Methods: Applications and Recent Development; Annual Reviews Public Health. 1988; 9: 123-60. Also Mantel N and Haenszel Wm. Statistical Aspects of the Analysis of Data from Retrospective Studies of Disease. Journal of the National Cancer Institute. 1959; 22/4: 719-747.

[20] Eisner M. Central America tries out 'sentinel sites'. July 1989. UNICEF INTERCOM 56. pp 11 and 22.

cycle is applied over the entire empowerment area, not just the representative sites. If the communities between the sites are well appraised of the dynamic and outcome of the SCS cycle, they should not land up being too different from the sites.

In practice, a series of inefficiencies make the Hawthorne effect less of a problem than one might think. The participatory nature of designing the cycle leads to several imperfections, almost as a matter of definition. The questionnaires usually include too much, so it is not always easy to provoke creative associations among those interviewed (for example, asked about diarrhoea and household hygiene, they might wonder about a possible link).

Furthermore, SCS managers do not always diligently go back to the sentinel communities for the feedback. Or, for the sake of efficiency, they have feedback at district level and include non-sentinel communities.

We have found that these inefficiencies of implementation mean a changeover of sites, originally envisaged 50% every 3-4 years, is only necessary every 5-6 years.

SCS interpretation for status indicators

SCS is not a quick fix for monitoring development. It was designed to measure change, but it is an affordable adjunct that has produced usable national and sub-national indicators. However, care is required in analysis and interpretation (see Annex 2). Because SCS is almost invariably based on a purposive selection of sites, caution must be used until the selection has been validated, and the results expressed in a particular way.

The problem arises when we execute the survey and, because of increasing experience of the interviewers or for a variety or reasons, we get 100 - households in one site, 120 in the next and 200 in the next. If the situation was different in the three sites, these sizes of the individual sites would be **weights** if we simply added all sites together (internal weighting thus refers to the number of households contacted in each site). It is not difficult to avoid this problem.

We can check the heterogeneity of situations in the three sites. If they are quite different, it is best to express the results for the individual sites -- or for homogeneous groups of sites. Characterization of the differences between sites can be the most useful result of the study, providing much more information than simply the internally weighted average. We would be able to declare, for example, that in no site were less than 45% of children vaccinated and in no site were more than 67% vaccinated. We would also be able to characterize the differences between higher coverage and lower coverage sites.

If a summary indicator must be obtained and the sites are not faithful to the proportions in the whole population, a series of external weights can be calculated from the reference frame -- perhaps the latest census, large reference studies, or even the consensus opinion of what the weighting should be. These weights are applied (multiply by the weighted proportion, divide by the actual proportion). The resulting estimate is adjusted or weighted for representativeness.

Sub-national schemes

national indicators are useful for global advocacy, but these must be made up of data that come from aggregated sub-national data collection schemes. It is also at the subnational level that action must be taken to improve the development indicators. An absolutely pivotal aspect of any national monitoring scheme is thus how it breaks down into -- or adds up from -- sub-national schemes.

Over-interpretation is a common error of the partially trained, in any measurement process. If 30 sites are chosen to represent the diversity of conditions in a country, then that is how the resulting indicators should be interpreted. The fact that sites from all provinces are included does not mean that the provinces are "covered" in the sense that the selection from each province is representative of that province. Caution is thus required in disaggregating to provincial level. Only if there were sufficient sites selected, and carefully weighted, could two provinces be compared.

When confronting heterogeneous data in different sites, caution is required before generalizing from one site or subgroup to all other similar communities. For example, in one country, two or three sites of resettlement communities might be included in a national panel of sites to reflect resettlement areas in relation to other areas, such as urban, commercial farms or communal areas.

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This is not the same as saying that these two sites are truly representative of all resettlement areas; they may each represent the average conditions in resettlement areas, or they may reflect the best and the worst conditions found in resettlement areas. This is not a terrible problem when comparing the risk of people who live in resettlement areas with those who live in other areas.

It may be a problem, depending on how the sites were selected, if one wanted to make a statement about all resettlement areas. It is quite difficult that two sites be truly representative of the full diversity of resettlement conditions. A declaration that "91% of children in resettlement areas were vaccinated" overstates the way two or three sites represent the resettlement areas. This is not a legitimate interpretation of the finding that 91% of households in each of two sites reported vaccination. It would be better to say "a child in a resettlement site was 40% more likely to be vaccinated than a child in one of the nine urban sites."

A special concern about sub-national systems is illustrated by the Madagascar case, where two competing but potentially compatible demands are being made of the monitoring and evaluation function. The first demand is to monitor progress towards the mid-decade goals for children at a national level. The second is to provide a cross-cutting intersectoral support in the area-based initiative, aimed at poverty reduction and demonstration of how locally organized initiatives can work. These require comparable community-based measurement inside and outside the intervention areas.

Thus a two-tiered approach is required -- a national measurement grid to produce national indicators, and an operationally compatible local process to produce data of comparable content and quality in the area-based programme. One option is the development of a national SCS scheme supplemented by more locally intensive area-based SCS schemes[21].

Costs of implementing SCS

Any monitoring system, that seeks to go beyond simply repackaging data from sometime dubious sources, costs. The EPI cluster survey was a relatively inexpensive option, costing $40,000 to $80,000 per study. At the other extreme, the DHS and Westinghouse studies cost anything from $250,000 to one million dollars. The recent *Enquete be base* financed by UNICEF in Madagascar cost over $200,000. A survey scheme depending on outside expertise, as is the case, for example with DHS-type surveys (DHS-3 involves a contract of around US$60 million for 25 surveys), will always be expensive. If local people are trained, it is more sustainable.

Because of this capacity building, sentinel community surveillance is usually expensive to set up, but with low running costs once established. In Nicaragua, UNICEF invested heavily in the first few years (after 1985). By 1988-9, the largest region was able to conduct a cycle in 96 sites for which UNICEF only contributed the exercise books used for questionnaires. In Liberia, the first cycle cost $4,000 Up-Country and $3,000 in Monrovia, but these costs exclude UNICEF staff time. The second Liberian cycle cost much more; it included an international consultant and analysis of 2,000 blood samples (to estimate measles antibody levels).

In Zimbabwe, three cycles were completed in a little over one year, for a cost of $60,000 and the virtual full time work of a UNICEF L2 staff member. During this time, 12 counterparts were trained in all aspects of the method, and dozens of provincial level officials were trained and participated. The 1988 Zimbabwe-DHS study cost twice as much as the three SCS cycles, it took 18 months to produce results and left very few people trained.

In Mexico, each cycle costs around $2,000 excluding salaries. In the micro-regional Planning initiative based on the SCS methodology, these costs are weighed up next to the savings made by the community through use of the data. For example, each case of childhood diarrhoea costs the household $8. Prevention of cases through use of the data can thus be used to weigh up the cost and benefit of the SCS operation.

A tension between representative data and community participation

Monitoring can be a spur to development by the way it motivates people locally. They see what can be changed, how to change it, and progress can be made. An excellent example of this mechanism comes from Iringa, where quarterly

[21] Madagascar: bridging through the ICAAC Goals. Evaluation Office 27 August 1993.

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village reports provided the substrate for dialogue and development action. Among the many positive lessons from Iringa[22], two stand out for countries trying to develop community-based monitoring:

1. In addition to the quarterly village reports, complementary sample surveys conducted by well trained teams would allow a grid for balancing the uneven data from the very local village processes. This would have allow them to be aggregated to make a regional picture.

2. An attempt was made to measure impact. Most area-based programmes can and should do, but do not. However, monitoring data cannot be used uncritically for impact evaluation. A strong baseline is needed in the programme areas and a comparison baseline non-programme areas.

Part of the difficulty in community-based monitoring initiatives is the tension between two different objectives of monitoring -- monitoring to mobilize locally, and monitoring to generate data for planning and to mobilize nationally or internationally. In order to generate indicators for national and international use, the quality of data must be comparable and they must be aggregated to represent the national entity. Few countries, at least not those who have most to do for sustainable development, will be able to tool up national universal community-based monitoring. Data-poor countries are almost invariably also weak in data management capacities.

What is needed is a sample process, sufficiently representative and homogeneous in quality, to lay the baselines quickly and to measure progress in a sustainable way.

There has long been a debate about the appropriateness of different community-based monitoring schemes. The central concern is to find the balance between local ownership, including local participation in and use of the scheme, and the need to aggregate representative data.

A single scheme does not easily have both of these desirable characteristics. An exception is the setting where there is 100% access to basic services and where community resources and mobilization is such as to permit full participation in the development information scheme while, at the same time, state structures permit communication and integration between levels (household, community, district, region and national). This is a theoretical setting.

The practical question, therefore, is *how participatory* a scheme can be that also produces representative aggregatable data -- or *how representative* the data can be, coming from a participatory scheme. SCS provides a framework for each country to establish its own balance.

The problem with all sample community-based surveillance systems is knowing what happens to the people or communities not in the sample, and including them in whatever process is begun by the monitoring. In SCS, local mobilization is a two-stage process.

First, there is interaction with sentinel communities about what their problems are. This is developed into a formal study and analysed. Ideally, the results are discussed with the community, to include their interpretations and conclusions, as additional results that will be aggregated to make up a regional or national picture. The terms for communication more widely are also developed in sentinel communities. The second stage of the process is communication of the results to the whole region or country. Without this, there is no reason to expect widespread local mobilization. As for GMP[23], several countries have used the logistical advantages of SCS to extract data.

Conclusion: Evaluation <u>as</u> development

The pressure to make progress is such that we simply cannot afford the luxury of investing monitoring the *only* produces indicators for international advocacy. The monitoring and the data also have to work locally. We have to look for the multiplying effects.

One of the biggest opportunities in monitoring progress is capacity building. only a part of this has to do with economic sustainability -- capacities of questionnaire design, computer-based analysis or interpretation and presentation of data. Perhaps a more important part it the "community building"

[22] Pelletier DL. The uses and limitations of information in the Iringa Nutrition Program, Tanzania. Cornell Food and Nutrition Program, Working Paper 5, February 1991.

[23] Pearson R. GMP Review 1993

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skills, including dialogue around results, group liaison and general development management. Monitoring, and local mobilizing and the process and the product of monitoring, can be a way to *help achieve the development targets.*

With stronger national capacities and appropriate measurement processes, almost anything can be measured. Sentinel community surveillance brings the planners into dialogue with communities while producing data for local mobilization, national strategic planning and global monitoring.

In Nicaragua and Honduras, the first countries to start national SCS schemes, around 100 people in each country received exposure and 5-10 intensive training. in other Central American countries, fewer were exposed, but each has a handful of people well versed in the different processes involved. In Liberia around fifty people were trained, two of them UNICEF staff. In Somalia, 25 nationals were trained and three UNICEF staff/consultants. In Rwanda, the entire UNICEF office received some training, four of them to a substantive level, and 30 nationals. Training was also done in Malawi, Angola, Zimbabwe, Niger, Mozambique, Pakistan, Thailand, Mongolia and Mexico.

Monitoring can itself have an impact on development through the use of indicators in advocacy, from more informed policy decisions and more informed action. But it can also contribute simply from the mobilizing participatory process of exchanging opinions and obtaining answers. Basing development more soundly on impact assessment requires more than just feeding locally relevant data into the advocacy process. What will count is locally relevant data tied to local knowledge an framed in terms that permit intelligent decisions.

Information like *"a vaccinated child, in a community like this last year, had one tenth the risk of an unvaccinated child"* can help to establish confidence in decision-taking. When this information on risk reduction is transmitted, people perceive it as important to their own lives. They are given the locally relevant facts, and they see that they have a choice in how to act. The facts are clear, and the decisions are their own. When the same data are available to communities, to municipal authorities, to national planners, to educators and the media, pressure is built up behind the facts. It becomes increasingly difficult **not** to act.

An example of this comes from the Sierra Madre in Guerrero, Mexico, where an entire municipality mobilized to protect its water sources, motivated by the research finding that these sources put communities at diarrhoea risk. Within a few weeks of hearing the results of the research, communicated by radio, every single community had sent representatives through the difficult mountainous passes to collect chlorine; every well in the was protected as a result[24]. The data also provided the basis of a demand to the federal government for a latrization programme, that resulted in the construction of nearly one thousand latrines being built in the municipality.

This is the "pressure of fact" that UNICEF can help to build through community-based monitoring. There is a wholly different impetus to development articulated in this way, after careful local groundwork.

Impact is not just an imperative for national planners or international donors. Each household in every community wants to see impact and, when they see it, they derive new energy from the achievement. Monitoring ties this energy into development, gradually building the culture of decision-taking based increasingly on scientific measurement, and increasing access to that by families in the worst-off areas in the world. SCS is designed for measuring impact and, under some conditions, components of impact; it facilitates interaction with the communities, adding the qualitative dimension of what they think about it, what they are prepared to do about it.

After appropriate packaging, information from SCS can service households, communities, national planners -- as well as for international comparisons. The key is that the same data that are needed for local action can be aggregated for international indicators; advocacy is important, but the change this produces in behavior and its impact on children's well-being is absolutely vital.

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[24] see essay on *Microregional Planning* in this collection.

Annex 1
Representative samples

A crucial question about any sample is its ability to produce representative results, not only in relation to people who attend the services (health facilties or schools) but also to those who do not have effective access. This would be easy if cost was not a factor, but it is one.

In its colloquial use, the term "representative" conjures up imagery of a consitutuency being "spoken for" by someone capable of identifying their needs and pressuring to have these needs met. When referring to a sample from a population, "representative" means that the *statistic,* or estimate from the sample, is the same as the true value in the whole population from which the sample is drawn. Thus, when the percentage of children vaccinated in a sample is 78% and the real proportion vaccinated in the population is 78%, we can say the sample is representative in relation to vaccination status. But of course the real population value is unknown, so we have the difficulty of being sure that the sample is representative.

In formal statistical terms, the fundamental implication of representativeness of a probability sample is that, if it is repeated several times, the same results would be obtained. In other words, *because* the sample is representative, if followed by another representative sample, the results of the two samples will be the same. Repeated random samples of 99% of the population stand a very good chance of producing the same correct result; repeated random samples of 1% stand a much bigger chance of producing different results -- and of not being correct/representative.

Probability theory does not call for repeated samples but postulates that, depending on the sample size and under fixed conditions, the probability of its repetition producing the same result can be calculated. If the size is large enough to limit the possibility of random error (all the component elements have an equal chance of entering the sample), probability samples can eliminate one important type of systematic error -- bias due to the observer influencing the selection. Repeating the exercise should thus, according to this theory, produce the same results.

Whether concerned with the colloquial or formal statistical implications of representativeness, in a "representative sample" there is an intuitive sense that the elements that make up the whole should be reflected, in appropriate proportions.

Within frequency probability sampling theory, given an adequate sampling frame, it is admissible and even recommendable to stratify (divide into categories or strata) the sampling frame in terms of prior knowledge of the categories likely to modify the effect to be measured. This is a way of further decreasing random error. For example, in a given country, some 30% of the population may be concentrated in the capital. There is a possibility that, if a random sample of the population were taken to determine the prevalence of a given condition, the entire random sample could land up being drawn from the capital -- by chance -- which is by no means representative of the poor rural conditions in the rest of the country.

Thus, consistent with standard sampling practice, one might divide the country by regional boundaries or geographic characteristics, and by urban/rural divisions, urban rich and urban poor, and so on, to be confident that these are appropriately reflected in the final sample. The subdivision should adhere strictly to the sampling frame, respecting the proportions reflected in that frame (for example, 20% urban poor, 10% urban middle and wealthy, and the rest rural poor). If the subdivision adheres strictly to these proportions, and a large enough sample is taken from each stratum, there is a good chance it is representative.

Since up-to-date sampling frames are not always available, it is possible for the investigator to weight these categories incorrectly, through ignorance or lack of detailed knowledge, to produce what is effectively a biased subdivision (10% urban poor, 20% urban middle class and the rest rural). A random sample within each category would add up to be unrepresentative of the population at large.

By virtue of the "prior knowledge" used to stratify the sample, it might be biased to an unquantified extent. When we do not have a reliable, up-to-date sampling frame (like a census), we may be obliged to "map" out the population using whatever knowledge is to hand. If we take a random sample from this, the only error we avoid - bias or ignorance of the selector - is hardly worth avoiding.

Even if a probabilistic sample could be justified by an up to date [sic] sample frame, there is one important practical consideration.

The indicators generated by monitoring progress will have to withstand comments from academics and researchers. Suggestions have been made that monitoring should be stalled to update the sampling frames. A battery of techniques have been suggested, including aerial photography and mini-censuses. But many of the poorest countries in the world are at war, making aerial photography an heroic option. Mini-censuses may themselves be biased. These suggestions tend to ignore the urgency of data requirements in these countries and the prevailing resource constraints.

Annex 2

Suggestions for interpretation and presentation of SCS generated indicators

1. Before expressing a prevalence figure, it should be examined in all sites individually. If the site-specific occurrence is very heterogeneous, a single summary should not be derived without weighting [sic]. In El Salvador, for example, the number of households to be covered in each site was preset to achieve a representative balance. In Zimbabwe, the actual sample obtained was compared with the data from the 1987 intercensal study; when they became available, data from the October 1992 census were used to validate the selection. These data could be used to construct weights.
2. If all sites are roughly the same, and broadly representative of the area, there is little problem in deriving a summary indicator. For example, in the huge urban slum of Cazenga in Angola (400,000 people), one in three children of school-going age did not go to school. In other situations, it may be useful to include an estimate of heterogeneity (Zelen's test is adequate).

3. If the sites are heterogeneous, a range might be useful, by groups of similar communities. In Monrovia, for example, 50% of people in the capital had access to safe water (up from 4% during the war, before the UNICEF programme), and 20% of up-country residents (where UNICEF's programme was slow to reach). The range of occurrence in the different groups is informative.

4. It may be useful to look more closely at the difference between the groups. Because we have a population base, we can express the risk as a difference. Thus, for example, the proportion of women reporting low birth weight (LBW) might be 50% higher among those without access to antenatal care. This is more interesting to planners than separate indicators of LBW and antenatal care. It tells them not only how coverage and how LBW are going, but what might be the gain per unit investment in coverage with prenatal care.

5. Essentially, goal monitoring is all about change. We want to know how things have improved over time, or the difference between communities benefiting from a certain action and those without coverage. If we can get these data accurately for a roughly representative panel of communities, we can follow the communities over time to derive estimates of impact in relation to costs

Annex 3

The SCS cyclical process

1. Identification of the pocket of problems and solutions to be researched, for example, diarrhoea, use of ORT, access to water and sanitation.

2. Downloading and analysis of the data from existing sources (routine data and previous studies), attempting to align the data in the three SCS analytical categories - impact coverage and costs.

3. Development of the instruments of the cycle, including clarification of objectives, questionnaire, meso-analysis schedule, data entry format, report outline to test how data will be used.

4. Pilot testing including data entry and analysis.

5. Fieldwork including household questionnaires, meso-analysis schedule (key informants, observation, focus group discussions).

6. Data entry and preliminary analysis.

7. Feedback and interaction with sentinel communities for interpretation and strategy development.

8. Definitive analysis identification of confounders and effect modifiers (see Annex 4).

9. Development of the communication strategy.

10. Selection of the next pocket of problems.

Annex 4

"Progress to Goals" Indicators from Sentinel Community Surveillance (SCS)

1, 2. IMR and U5MR The Brass indirect method, direct methods and longitudinal studies were used in 15+ countries, the community-based McCrae method in eight.

3. MMR Unsatisfactory attempts in several countries, including Mozambique. Best done using a universal reporting technique. Prenatal and perinatal causes of maternal mortality have been investigated in Mexico and Nicaragua.

4. Weight/height/age Anthropometry has been done in SCS in several countries including Honduras, Mexico, Somalia and Liberia. The advantage is to be able to look at the risk factors in the panel of communities.

5. Water and sanitation The Central American countries, Angola, Mozambique, Liberia, Zimbabwe and Rwanda all have SCS experience in WATSAN coverage surveys - linked to diarrhea and mediating factors like education.

6. Adult literacy Almost all of the 20 or so countries using SCS have data on maternal literacy. Several (for example, Mozambique, Mexico) have data on schooling of other adults.

7. Basic education Several countries (e.g., Zimbabwe, Liberia, Mozambique, Angola, Mexico) have detailed, gender-specific data on school attendance by school-aged children, its costs and reasons for non-attendance.

8. Family planning was touched upon in Honduras and Zimbabwe, but there is not extensive experience with this indicator in SCS. Birth intervals can be calculated in several countries.

9. Birth attendance Good SCS cycles have been done in Nicaragua and Mexico asking about births in the last two years to increase the numbers for risk analysis.

10. Birth weight A successful cycle was done in Nicaragua, where large numbers of women have institutional or attended deliveries. Problems when a small percentage of children are weighed at birth.

11. Vitamin A Sentinel surveys in Gorakhpur, Calcutta, Rajistan and Bhopal studied xerophthalmia between 1984 and 1988. In Mozambique, mothers of children under five were asked about night blindness.

12. Measles was studied comprehensively in Mexico and, to a lesser extent, in Liberia and other countries. Cause-specific mortality is easier to study after an epidemic. Measles-related deaths can be difficult to define.

13. Immunization There have been several advances in EPI coverage surveys. Immunosurveillance schemes have been implemented in Honduras, Panama, Mexico and Liberia. SCS coverage studies exist in 15-20 countries.

14. Diarrhea and ORT Almost all countries using SCS have been able to provide very useful data on ORS and other aspects of home management of diarrhea.

15. ARI Several countries have studied ARI, prevalence and actions in the household. Some have data on costs.

16. Exclusive breastfeeding Several SCS cycles have been done in Angola, one in Liberia and various in Mexico. One asks at what age liquids were introduced, and at what age food was introduced.

17. GMP Coverage with growth monitoring has been studied in Honduras and Liberia, and anthropometric studies have been done in several countries.

18. Iodization In Zimbabwe, salt was purchased in each of 40 sites and analyzed for iodine. This provided a map of community availability that could be used to monitor increasing availability over time.

Annex 5

Do-able impact evaluation

Behind the indicator

For almost the same cost as finding out the frequency of a condition (like ARI or diarrhea) and the practices of household management

(ORT, antibiotics), it is possible to look behind these indicators.

Table 1 illustrates this for tepid sponging and ARI. A child benefiting from tepid sponging to bring down his/her fever, has 55% better chance of a short duration ARI. Of course, there are many other things that can explain this effect, including indirect links through other factors. For example, the children with protracted episodes may be malnourished, or unvaccinated or cared for differently in other respects.

To exclude this possibility, we look at the effect of tepid sponging in the malnourished and the well nourished, the vaccinated and unvaccinated. If it is the same in groups or if the average effect (unbiased estimate) is the same as the principal one - relative risk 1.55 in this case - then the malnutrition or vaccination does not explain the effect of tepid sponging.

This also allows us to identify special subgroups. For example, there is apparently no benefit of tepid sponging among children who do not also benefit from ORT. The programme implication of this is obvious.

We can also get details on the cost of short duration episodes and/or protracted episodes. This gives fuel to encourage mothers to adopt this inexpensive practice.

Table 1

Tepid sponging in cases of ARI
Children aged 12-59 months, Monrovia 1993

	Tepid sponging yes	Tepid sponging no	
ARI 1-5 days	261	111	372
6-14 days	276	212	488
	537	323	860
	49%	*34%*	

Odds ratio 1.8 (95%Cl 1.36 - 2.4)

A child benefiting from tepid sponging is almost twice as likely to have an ARI of short duration.

Factors excluded by stratification

AGE	12-23m	24-35m	36-48m	Unbiased	95%Cl
	r3.4	r1.9	r1.35	R1.81	1.3-2.4
SEX	male	female		Unbiased	95%Cl
	r1.9	r1.7		R1.8	1.3-2.4
GIVE	less	same/more		Unbiased	95%Cl
FLUIDS	r1.1	r3.6		R1.8	1.3-2.4
MUAC	<12cm	12+ cm		Unbiased	95%Cl
	r3.2	r1.7		R1.8	1.3-2.4
MALNU-	normal	mild	severe	Unbiased	95%Cl
TRITION	r3.2	r2.5	r12.5	R1.8	1.3-2.4
MEASLES	yes	no		Unbiased	95%Cl
VACCN	r1.9	r1.8		R1.8	1.29-2.4
CARD	yes	no		Unbiased	95%Cl
	r2	r1.7		R1.8	1.3-2.4
MEASLES	yes	no		Unbiased	95%Cl
HISTORY	r1.9	r1.8		R1.8	1.3-2.4
SERO-	yes	no	unknown	Unbiased	95%Cl
CONVERT	r1.9	r1.8	r1.7	R1.8	1.29-2.4
SHARE	1-5	6 +		Unbiased	95%Cl
sleeping	r2.0	r1.1		R1.81	1.3-2.4
SIZE HH	1-5	6-10	11+	Unbiased	95%Cl
	r1.74	r1.8	r2.1	R1.80	1.3-2.4
NUMBER	1-2	3 +		Unbiased	95%Cl
children	r1.84	r1.4		R1.80	1.3-2.4
CAREER	Mother.	Grandma	Other	Unbiased	95%Cl
	r1.68		r6.2	R1.8	1.3-2.4
EDUCN.	none	<4yrs	5+ yrs	Unbiased	95%Cl
guardian	r2.0	r1.5	r1.7	R1.8	1.3-2.4
BREAST	<4mths	5-12m	12+ m	Unbiased	95%Cl
FEED	r3.4	r2.0	r1.7	R1.8	1.3-2.4
COST	Nothing	$1-10	$11+	Unbiased	95%Cl
EPISODE	r1.65	r1.2	r2.2	R1.8	1.3-2.4
Reside	<6mths	7-11mth	12+ mth	Unbiased	95%Cl
Monrovia	r2.4	r2.1	r1.7	R1.8	1.3-2.4

Mesoanalysis - grouping by site

In almost the same time as it took to find out whether the children in 18 sites in Monrovia had been vaccinated (coverage), guardians were asked if and when the children had suffered measles. It was possible thus to calculate, for each site, the efficacy of the vaccine and the vaccine failure.

Comparing sites where it "worked" with sites where it did not could provide insights into how to improve the EPI, despite the fact that impressively high levels of vaccination had been attained. The

individual factors could also be taken into account. A drop of blood was taken by finger prick from each child and the antibody levels analyzed. This gave additional information to programme managers about the true coverage of their programme.

Table 2

Measles vaccination and efficacy by site

Site	Vaccination coverage	Vaccine efficacy*	Vaccine failure**
2	74%	83%	7%
17	67%	76%	0%
5	67%	67%	10%
12	68%	66%	8%
9	81%	60%	11%
13	74%	53%	15%
15	66%	59%	11%
3	86%	43%	11%
4	72%	39%	13%
8	79%	30%	14%
11	66%	27%	15%
14	73%	11%	9%
6	73%	11%	11%
7	73%	3%	20%
10	79%	0	11%
18	77%	0	2%
1	84%	0	20%
16	69%	0	29%
Overall unweighted	73%	38%	13%

* excluding those who were vaccinated after suffering measles, or less than one month before, and children under 6 months

** suffered measles despite vaccination

Field Application: Description of and Experience with Community-Based Health Information Systems

Save the Children has experience in community-based health programs and health information systems in many countries where hundreds of communities are providing basic health care for their 1.7 million members. A typical country's program has one or more impact areas each managed by a Health Program Coordinator. Each impact area is comprised of several zones with a Supervisor supporting 10 or more extension workers, often called Resident Home Visitors. Each of these, in turn, covers about 100 families in their Neighborhood Service Area. Health program strategies in all settings are: (1) community-centered, (2) population-based and (3) complementary to the nation's formal health care system.

Community-centered

Save the Children health projects enable communities to organize and manage their primary health care. Individuals require the affirmation and support of family, neighbors, community authorities and community institutions to adopt and persist in new behavior. Furthermore, many behaviors (e.g., completely immunizing children by age one) require families to depend on their nation's formal health care system. Save the Children finds that communities can form local committees to promote health-protective behavior and access the governmental health care system.

Population-based

Save the Children health projects emphasize that every resident within the geographic limits of the catchment area is included. We assist communities to identify, count and follow-up all members. This is accomplished through: (1) enrolling every family, (2) creating separate rosters for the follow-up of children and women and (3) registering the births, deaths and migrations of community members.

The **enrollment**, accomplished through a census, assures inclusion of every community member and provides a profile of the population's age-sex structure. It also provides a defined population base for needs assessment in every sector of development.

Rosters, created from the enrollment, assure systematic follow-up and equitable care for all children and women - the health sector's priority groups. Through the rosters, every family with a young child and every woman of childbearing age is prompted to participate in health activities, and their practice of health protective behaviors is recorded.

Registration of births, deaths and migrations allows accountability to the community, to the project staff and to donors. When these vital events are counted and divided by the number of people (population base) among which they occurred, the resulting proportions are vital rates, specific to the population base. Changes in vital rates may be linked with changes in health practices. In such cases, the association between the practice of protective behaviors and health and survival can be measured.

Complementing the Nation's Formal Health Care System

All nations in which Save the Children works are signatories to the Alma-Ata Declaration. They have declared their commitment to the goal of health care for all their citizens by the year 2000, and have agreed to strive for this goal through the strategies of Primary Health Care. Save the Children enables communities served by the national Primary Health Care system to practice protective behaviors for which they possess the resources in their own homes and to utilize national health services that provide technical skills or material resources which individual families do not possess. Save the Children advocates for strengthened government programs where they are incomplete by: developing appropriate relationships and good communications through all levels of National Ministries of Health; sharing expertise and demonstrating effective health program design and implementation.

The Essential Health Information System

Although the broad strategies to achieve equity in health are similar, each health system reflects local health priorities, culture, ideas and preferences. Even amidst this diversity, however, certain health information system elements are essential. An understanding of the basic "generic" system will prove invaluable as the reader interprets our and others' field experiences and considers the applicability of such systems to other settings.

Information is essential for every step at every level in a health program. Planners need information to identify and prioritize health problems. Mothers need information about the next vaccination opportunity. Supervisors need information about the number of births in their community. Resident home visitors need information about whom to visit. On the other hand, information systems have been appropriately criticized if they demand marginally useful facts and require extraordinary effort. Information is like motor oil. Too little is disastrous; too much is inefficient and occasionally disastrous.

Save the Children's information system attempts to resolve the tension inherent in balancing efficiency and equity. In brief, the system serves six levels of information users (Table 1.) Each user is also an information provider to all levels.

Table 1. Levels of Health Information Users

1.	Families
2.	Resident Home Visitors (health workers/volunteers)
3.	Supervisors and Community Leaders
4.	Health Coordinators and District Health Officers
5.	Field Office Directors and Ministries of Health
6.	Home Office Staff and Donors

The flow and use of information throughout the system are accomplished with the help of several "instruments" (Table 2): cards, forms, rosters, registers and reports. The information may be transmitted and stored orally, in writing and/or electronically.

The instruments support and are guided by a series of "activities" (Table 3) which *in toto* describe the community-based health information system. The activities involve: characterizing the population; identifying risk groups; reaching each household with health information and/or services; assuring services of good quality; empowering each mother to act on her own and her children's behalf; maintaining an accurate characterization of a dynamic community and measuring program effects in terms of coverage, behavior change and vital rate change.

Information Users, Instruments, and Activities: All Together

Just as the health system responds to information gleaned from the whole community, so the health information system must be capable of providing this. **Family Enrollment Forms** are completed during a baseline census. Enumerators allot each mother and her children one form on which they note each family member's name, birth date, sex, relationship to head of household, vaccination status and optional socio-economic data such as education and occupation. The aggregated family enrollment forms provide an instantaneous glimpse of the age-sex composition of the community.

Table 2. Health Information Instruments *

1. Home-Based Records: *Immunization Card, Growth-Monitoring Card, Home Visit Card, Women's Health Card.*

2. Visitor-Based Reports: *Pregnancy/Birth Card, Death Report Form, Child Roster, and Women's Roster.*

3. Supervisor- and Community-Based Records: *Supervisor's Roster*

4. Impact-Area or District-based Records: *Family Enrollment Forms, Birth Registers, Death Registers, Migration Reports*, Reports from Visitors' Rosters and from *Supervisors' Rosters.*

5. Field Office- and Ministry of Health-based Records: Summary Reports of health outputs and population health status..

6. Reports generated at home-office for donors of health project outputs and population health status.

* *Those instruments in italics are discussed below.*

Certain segments of the population are biologically at high risk and thus targeted by Primary Health Care: women of child-bearing age and children under age five years. The Family Enrollment Forms guide the assembling of **Women's Rosters** and **Children's Rosters.** Resident Home Visitors use these notebooks to identify individuals at high risk and to track interventions on their behalf. For example, the Women's Roster includes identification number, name, birth date, birth spacing training and details for 3 successive pregnancies. The Child Roster includes identification number, mother's name, child's name, birth date, immunization dates, completed vaccination status and growth monitoring.

Community structure changes due to vital (i.e., *life*) events, and the one-time family enrollment will need revision. Resident Home Visitors can keep the information up-to-date by completing vital event cards. The **Death Report** Form includes identifying data, date of death, date of completion, cause of death and immunization status. The **Pregnancy/Birth Card** contains mother's identifying data, expected date of delivery, reminders for at least 3 prenatal visits, immunization reminders and outcome. The **Migration Reports** note the details of moves within the impact area or permanent migrations into or out of the area. The vital events noted from these reports require on-going updating of Family Enrollment Forms and Rosters.

The ultimate "health worker" resides in the household: the mother. She uses several health information systems instruments. She has a **Women's Card** to track her health history, especially the reproductive and family planning aspects. Each child has a **Vaccination Card** (often provided by the government) documenting all immunizations. Likewise each has a **Growth Card** or *Road to Health* Card on which are recorded the weights periodically taken during the first years of life. Often these two cards are combined into a single instrument. The **Home Visit Card**, one per family, records the date, training content and ancillary observations of each household visit by the Resident Home Visitor.

Just as Resident Home Visitors need to remind mothers to receive prenatal care and to obtain vaccinations for their children, so supervisors need to support the Resident Home Visitors in performing their activities. The **Supervisor's Roster** focuses the supervisor's attention to areas and individuals most in need of support. For each Resident Home Visitor it lists the number of: followed children; reported and

Table 3. Health Information Activities and Level

Organization:

1. Promote community demand for health information;
2. Map and house numbering;
3. Enroll each family;
4. Count the population from the enrollment forms; identify age-sex profile;
5. Create children and women rosters, copying their names from enrollment forms;
6. Create and distribute the Home-Based instruments.

Resident Home Visitors:

7. Visit homes regularly to promote health behaviors, to update rosters from Home-Based instruments, and to report pregnancies, births, deaths and migrations.

Supervisors:

8. Supervise resident home visitors and monitor project output through roster examination rosters; control information quality through supervised visits to samples of homes; report achievements and remaining work to families and resident home visitors;.
9. Collect reports of pregnancies, births, deaths, & migrations from resident home visitors;
10. Report results of supervision at regular intervals to Coordinators and District Health Officers;
11. Register reports of births and deaths: report vital events monthly to families, resident home visitors, and community leaders; analyzing birth and death rates by population group: report results of analysis at least annually to all levels.

Coordinator and Local Management:

12. Computerize data, if applicable, for more frequent, complete and detailed reporting;
13. Summarize monitoring and supervision reports at quarterly intervals and report to all levels with appropriate commentary concerning the programmatic implications of the findings.

expected births; reported and expected deaths; mothers trained and yet to be trained in oral rehydration therapy; children completely and not completely immunized; children weighed and not weighed; children gaining and not gaining and children visited and not visited.

Table 4[1] provides additional examples of the interplay between users, instruments, and activities. Note that more than one user can access the instrument at the same level (i.e., both the mother and the Resident Home Visitor use the Vaccination Card to decide who needs vaccinations). Also note that the frequency of each activity varies with its urgency and that

quality control checks are integrated for each example. What is lacking in this schema, however, are the explicit decisions the information demand. Table 5 details some of the decisions made from Village Health Promoters' (equivalent to Resident Home Visitors) rosters in SC's Malawi Child Survival Program.

Further Experience

The remainder of this chapter includes 5 reports of community-based health information systems (3 from Save the Children and 2 from other organizations). Rubardt and Marsh[2] report from Malawi on early experience implementing a manual HIS emphasizing: (a) the applicability of population-based health information skills far beyond the relatively small impact areas of Child Survival projects and (b) the challenge of linking information to action. Next, from Bangladesh, comes a report,[3] complete with illustrative forms, detailing the strategic decision to computerize only a sub-set of their population of 160,000. In the final case[4] from Save the Children, Kaye reports experience from Jakarta slums. She cautions against relying on volunteers in urban settings, suggesting a stream-lined health information system for constrained situations typical of many developing country settings.

An extensive case from the Andean Rural Health Care's Bolivian experience[5] details their use of a census-based, impact-oriented approach to child survival. Finally, from Haiti, Augustin et al[6] describe the effort of a consortium of local non-governmental organizations to provide maternal and child health care to 400,000 people. Because of mixed success, they proposed reducing community health worker workload by narrowing targeted individuals to high-risk pregnancies and their offspring.

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[1] Establishing such a system and training for this system are detailed elsewhere: (1) Daniel K. *Measuring Health - A practical guide to establishing a health information system.* Save the Children. 1990. and (2) *Reaching the unreached through HIS - a training manual for developing a health information system.* Save the Children. 1991.

[2] Rubardt M and Marsh D. *Malawi: Community-based Health Information System and Beyond.* Save the Children. 1995.

[3] Hossain A, Masud A, Ali L, de Souza A and Marsh D. *Health Information System: The Experience of Save the Children/Bangladesh Field Office.* Save the Children. 1995.

[4] Kaye K. *Urban Health from the Perspective of a NGO: Lessons Learned from a Case Study in Jakarta, Indonesia.* Save the Children. 1994.

[5] Perry H. *The application of a census-based, impact-oriented approach to community-oriented public health on the Northern Altiplano.* 1995.

[6] Augustin A, Wray J, Allman J, Boulos R, Rohde J. *Mobilizing Private Voluntary Organizations for Primary Health Care.* 1994.

Table 4. Community-Based Health Information System: Examples of Levels, Users, Uses, and Supervision *

Level	*User*	*Instrument*	*Question*	*Periodicity*	*Quality Control*
Household	Mother	Vaccination Card	Which child needs which vaccine, when?	Continuous	RHV tracks vaccine schedule of each child.
Household	Resident Home Visitor	Home Visit Card	What health promotion activities do I need to stress with this family today?	Quarterly	Supervisor notes proportion of children whose mothers have received ORT training on Supervisor's Roster.
Neighborhood Service Area	Resident Home Visitor	Death Report Form	Who died, when and of what?	Quarterly and as needed	Supervisor compares expected to reported deaths on Supervisor's Roster.
Neighborhood Service Area	Resident Home Visitor	Child Roster	Who are the children in my neighborhood service area?	Continuous and Quarterly	Supervisor compares reported visits to actual numbers of children under 5.
Community	Supervisor	Child Roster	What is the measles vaccine coverage in this zone?	Quarterly and Annually	Health Project Coordinator compares with coverage data from baseline family enrollment.
Impact Area	Health Project Coordinator	Death Registers & Birth Registers	What is the Infant Mortality Rate in the Impact Area?	Annually	Donors, home office and Ministry officials compare to baseline and official national statistics.

* Assumes a quarterly household visiting schedule. ORT = oral rehydration therapy, RHV = resident home visitor

Table 5. Chilipas (Mangochi District, Malawi) Impact Area Health Information System
Level: Village Health Promoter (VHP) Rosters

Information	*Information Source*	*Information Frequency*	*Decision*	*Information Flow*	*Flow Frequency*	*Supervision & Frequency*
<3 growth velocity static	village GM by VHP	monthly	home visit	monthly report	monthly	HSA, 2-3/month
<3 growth velocity faltering	village GM by VHP	monthly	refer to HC	monthly report	monthly	HSA, 2-3/month
<2 behind on immunizations	transferred from RTH from <5 outreach clinics	monthly	refer to HC or outreach	monthly report	monthly	HSA, 2-3/month
<5 died	common village knowledge	as needed	home visit for verbal autopsy; note in roster	death report and monthly report	monthly	HSA, 2-3/month
>5 years of age	from birth date at enrollment	monthly	cross out name	----------	----------	HSA, 2-3/month
birth	common village knowledge	as needed	home visit, enroll in roster	enroll in roster, birth report and monthly report	monthly	HSA, 2-3/month
mother lacks training in ORT, AIDS, etc.	roster	as needed	home visit to teach & mobilize for health ed.	# trained by content into monthly report	monthly	HSA, 2-3/month
WRA pregnant	common village knowledge	as needed	home visit to recommend ANC, enter EDC in roster	monthly report	monthly	HSA, 2-3/month
WRA behind on TTV	TTV card	as needed	home visit to recommend ANC	monthly report	monthly	HSA, 2-3/month

ANC=antenatal care, EDC=estimated date of confinement, GM=growth monitoring, HC=Health Centre, HSA=Health Surveillance Assistant, ORT=oral rehydration therapy, RTH="Road to Health" Card, TTV=tetanus toxoid vaccine, WRA=woman or reproductive age

MALAWI: COMMUNITY-BASED HEALTH INFORMATION SYSTEMS AND BEYOND

MARCIE RUBARDT* AND DAVID MARSH**

Summary

Save the Children's Child Survival Project in Mangochi district, Malawi, provides an informative case to review the implementation and implications of a community-based health information system. Like other SC systems, this depends on a baseline census, identifying high-risk groups and logging them on rosters to target interventions. The strategy to computerize tracking individuals (as opposed to the population) was carefully weighed and declined because of concerns that grass-roots ownership might have been compromised in this setting. The system has been in place for 6 months. Present challenges include continued in-service training in the mechanics, meaning, manipulation and use of the numbers. Supervision is assisted by comparing reported to expected values. Village Health Promoters, the household-level workers, make data-based decisions. Clarifying thresholds, interpretation plans and responses for higher level decision are under active review. Future directions include: (1) linking this community-based health information system to government's Health Centers through overlapping supervision of Promoters and training for the facility's In-charge in epidemiology and management and (2) linking all District facilities for health surveillance, supplemented by periodic probability surveys. In summary, a denominator-based and decision-based health information system is essential to achieve health equity for populations — small and large.

Save the Children provides maternal and child health services to 40,000 Yao people in the remote Chilipa Highlands of Malawi's Mangochi District. A recent Mid-Term evaluation of this 3 year USAID-sponsored Child Survival project has provided an opportunity to review (and preview) its health information system: past, present and future.

The Past

Consistent with other Save the Children health projects, preliminary discussions between Malawian Ministry of Health (MOH) officials and Save the Children experts agreed upon a geographical catchment area of an underserved, needy population in Malawi's southern region. Upon award of the grant, SC personnel performed a census enrolling all 40,000 inhabitants. The Mangochi team entered each member of each household into ProMIS, a software package developed by Save the Children to track health and demographic events in defined populations. This allowed precise characterization of the population, such as its age-sex composition and the immunization status of target groups (children under age five and women of child-bearing age). The census also sought the relationship of each person to the head of the household so as to identify households headed by females. The fear of stigmatization precluded valid identification of orphaned children, however. Each targeted individual was entered into one of two rosters ("women" or "child") for future monitoring of services (such as receipt of health education messages), and status (such as immunization coverage or growth velocity).

Thereafter followed a strategic debate concerning the future role of computerization. On one hand, ProMIS offered the ability to track individuals and to efficiently prepare reports of coverage for the entire impact area or sub-groups of interest. On the other hand, producing timely and accurate village-level reports and rosters seemed difficult without a manual system. Indeed, project staff felt that the manual tracking system was a key intervention to improve community health, in part, because it allowed health promoters to directly assess the status of their households. Alternatively, if the Village Health Promoters' (VHP) monthly rosters depend

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on a process that was both conceptually and physically distant, then immediacy and especially ownership would be compromised. Thus, why have both a manual and a computerized system? After consultations, the Program Manager concluded that the computerization of data relating to targeted groups and the whole population justified its cost. Information on target groups allowed for program monitoring. Census-based information allowed for: characterization of specific sub-groups; deriving new indicators and guiding future projects and research. On the other hand, a computerized individual-level tracking system was viewed as a duplication in the Mangochi context.

The Present

The existing manual system has been in place for several months. The data is flowing, its quality is improving, decisions are being made based on its analysis, and the first quarterly report has been produced. The four layers of data review with their approximate populations per person include: the Village Health Promoters (300), the Health Surveillance Assistants (1500), the health program supervisors and Program Manager (40,000). The Program Manager monitors quality through regular review of the reporting forms for internal consistency and through comparing reported and expected values for key rates, ratios and proportions. Improving quality has been an on-going process of feeding back corrected forms, reviewing the meaning of the numbers on the reports and training health workers to transform data into information (for example, calculating rates) using their own numbers in order to improve understanding of the relevance of the reports to their work. Not surprisingly, limited literacy and, until very recently, a political climate that discouraged critical thinking have slowed progress.

Village Health Promoters (VHPs) are volunteers nominated by Village Health Committees (VHCs). These women are the link between the household and the health services. Actions based on review of their two rosters include: (1) household visits encouraging individuals at risk to attend immunization, growth monitoring or prenatal care clinics; (2) petitions to VHC to mobilize recalcitrant defaulters; (3) health education sessions to meet women's needs and (4) monthly activity tallies to their supervisors, the Health Surveillance Assistants (HSAs). Rosters are updated by (1) distinguishing children after their fifth birthday or those who have expired or out-migrated; (2) adding newborns; (3) adding identified pregnancies; (4) recording dates of immunizations, antenatal care and health education discussion by topic, and (5) recording dates and velocity of child growth.

The HSAs are paid workers trained by SC according to MOH curricula (nationally they comprise an important peripheral health cadre). As their name implies, they also conduct surveillance for key morbidity and mortality events supplemented by the VHPs' observations. They assist the VHPs' completion of monthly tallies and aggregate their VHP supervisees' counts into a monthly two-page report form (attached). Of note, SC's monthly form is presently influencing the Ministry of Health's revision of its own monthly HSA form. Decisions made at this level include: training VHPs in additional, needed health education messages; on-the-job training in roster maintenance and reporting and identifying emerging health issues from surveillance data.

In turn, all monthly report forms are centrally computerized (using dBASE) and aggregated to yield indicators for the entire impact area with the option to track individual villages or HSAs. *In toto*, there are 145 results reported monthly — including counts and the corresponding percents. These provide data for tracking progress against the objectives outlined in the project's Detailed Implementation Plan. Since the system is new, its objectives to date have stressed the operational village-level field aspects of: data collection; tallying; interpretation and use of the data rather than just reporting upwards. Managers' use of the data thus far has primarily been to monitor progress and to target supervision needs. Use by management as well as by others in the District will expand as the reliability of the data improves.

The Future

This infant, modest, manual, community-based health information system faces an ambitious future in a variety of directions. First, on-going refinement of the existing system will lead to simplification as many redundant or non-

essential indicators can be omitted. Certain technical questions, such as case definitions for morbidity and mortality surveillance, will strengthen the validity of these activities. Comparing observed to expected numbers of vital events (births, child deaths, pregnancies) can estimate coverage and guide support. Lastly, many indicators can guide action, especially in this impoverished setting which is prone to drought and food shortages whose population is at extreme high risk for AIDS and susceptible to seasonal variations in malaria and enteric diseases. The challenge is to identify useful indicators pointing to such conditions, the thresholds calling for a "situation re-analysis," an interpretation plan and a likely response approach.

Other potential directions for this community-based health information system have implications for far larger populations. One involves District-wide surveillance; the other concerns strengthening District health services. The surveillance effort is a recently begun UNICEF supported activity which arose from successful 1994 drought surveillance in Mangochi District lead by SC. Present plans call for identifying and training information specialists at each of the District's 25 Health Centers who would, in turn, re-train and supervise the existing HSAs in both numerator-based (i.e., counts) and denominator-based (i.e., rates) data collection techniques. Measurement activities will include monthly activity reports (service-based) currently completed by health center staff, supplemented by quarterly and annual community-based surveys for key population parameters (such as nutritional status of vulnerable groups, contraceptive prevalence and vital rates). Mangochi District (population 700,000), then, could stand as a sentinel for the nation's health (population 10,000,000).

Strengthening District Health Services, also supported by USAID, remains at this writing in the conceptual stage. Nonetheless, SC is well poised to strengthen Malawi's existing health infrastructure. That is, our mission of equitably advocating for those in greatest need, our skills in health information theory and practice in constrained settings, our insistence on "catchment area" care for defined populations and our grass-roots, household-level experience all are critical elements to supplement a District's health system — the coverage of which drastically thins beyond the Health Center level. Thus, a critical strategy to improve the health of rural poor populations involves "basic epidemiology and management for the *in-charge*" at the peripheral MOH facility, whether in Malawi or elsewhere.

* * *

Community-based health information systems, with their epidemiological and ethical underpinnings, are essential to better serve the health needs of populations and individuals. This Malawi case demonstrates both the operational challenges and the wide applicability of this approach to small and large populations. Two generalizations bear repeating. Health services that fail to reach the household level will remain inequitable. The public trust requires health managers and epidemiologists to design and use information systems for decision making.

NAME OF REPORTER: _____ PROMOTER/SUPERVISOR/COORDINATOR

AREA/VILLAGE: _____ DISTRICT: _____ CODE: _____

MONTH/YEAR: _____

VILLAGE HEALTH PROMOTER'S/SUPERVISOR'S MONTHLY REPORT FORM

A. IMMUNIZATION **CHILDREN RECEIVED IMMUNIZATION THIS MONTH**
KATEMELA ***ANA OLANDILA KATEMELA MWEZI UNO***

FULLY IMMUNIZED <1 yr
ANA OMALIZA KATEMERA YENSE

<5 yrs

NOT FULLY IMMUNIZED < 5 yrs
ANA OSAMALIZA KATEMERA YENSE

TOTAL HOUSEHOLDS
No. YA MABINJA

TOTAL POPULATION
CHIWELENGELOI CHA'ANTHU

B. GROWTH MONITORING

No. OF CHILDREN IN ATTENDANC
No. YA AMENE ABWERA KU SIKELO

No. OF UNDERWEIGHT/FALTERING
No. YA OMWE SIKELO YATSIKA

TOTAL CHILDREN < 5
No. YA ANA OCOKEPERA ZAKA ZISANU

TOTAL WOMEN AGED 15-45
No. YA AZIMAI A ZAKA ZA PAKATI PA 15-45

No. OF CHILDREN WHO RECEIVED VIT A
No. YA ANA OMWE ALANDILA VIT A

HOME VISITS MADE TOP UNDERWEIGHT/FALTERING CHILDREN
MAULENDO OYENDELA ANA OTSIKA SIKELO

TOTAL DEATHS < 5 YRS/MALIRO A ZAKA ZOCHEPERA 5

C. DISEASE SURVEILLANCE

NAME OF DISEASE ZINA LA MATENDA	NO. OF WOMEN TRAINED AZIMAI OPHUNZISIDWA	CASES KUCHULUKA KWA ODWALA		CASES APPROPRIATELY TREATED KUCHULUKA KWA OCHILISIDWA MIKWANILA	DEATHS MALIRO	
		0-11 MONTHS	12 -59 MONTHS		0-11 MONTHS	12 -59 MONTHS
MALARIA MALUNGO						
DIARRHOEA KUTSEGULA						
ARI CHIBAYO						
MALNUTRITION KUCHEPA ZAKUDYA						
MEASLES CHIKUKU						
AIDS EZI						

Appropriate Treatment/Mankwala/Chithandizo choyenela
Kutsegula = ORS, Malungo = Fansidar japena Kupita kuchipatala, Chibayo/Chifuwa = Antibiotic (ngati ndi kupuma mowilikiza mob
Kunyentchels/kusoea zakudya = Kumuyendela kapena kupita naye kuchipatala

D. PREGNANCY/WAPAKATI

No. OF PREGNANT WOMEN RECORDED
No. YA AZIMAI A PAKATI

No. OF WOMEN ATTENDING ANC
No. YA OYENDA KU SIKELO YA PAKATI

No. OF WOMEN ATTENDING PPCARE
No. YA AZIMAYIOYENDA KU CHIPATALA ATABELEKA

IMMUNIZATION STATUS (ttv)
DONGOSOLO LA KATEMERA WA AZIMAI A PAKATI WA KAFUMBATA

No. OF DELIVERIES/*No. YA ANA OBADWA*
M *AMUNA* F *AKAZI*

Status of Pregnant Women/Katemela wa azimai apakati

1 st	2 nd	3 rd	4 th	5 th

Status of Delivered Mothers/Katemela wa azimai obeleka

0	1 st	2 nd	3 rd	4 th	5 th

OUTCOME/KUBADWA KWACHE

ALIVE WAMOYO	STILLBORN NTHAYO	PREMATURE OSKAWAI MATSIKU	MISCARRIAGE KUPITA PA CHABE	UNDERWEIGHT SIKELO YOKWANA	NEONATAL DEATH	MATERNAL DEATH WOMWALILA NDI OAKATI

PLACE OF DELIVERY
MALO OBADWIRA

HOME KUNYUMBA	other TTBA UTBA		
HOSP/CLINIC KUCHIPATALA			

NB: TBA = TRAINED TBA
UTBA = UNTRAINED TBA

E. CHILD SPACING

WOMEN TRAINED
AZIMAI AMENE APHUNZISIDWA

NEW ACCEPTORS
OYMBA LERO SIKELO YOLELA

TOTAL USING FP
OGWIRISA NTCHITO FP

No. OF CONDOMS DISTRIBUTED
No. YA MAKONDOMU OGAWIDWA

F. HEALTH COMMITTEE MEETING

ITEM DISCUSSED _____
ZOKAMBILANA _____

No. OF TIMES MET
No. YOKUMANA

G. DRUG REVOLVING FUND ***THUMBA LA MANKHWALA***

DRUG *MANKHWALA*	BEGINNING OF MONTH *KOYAMBIRA KWAMWEZI*	STOCK NOW *OTSALA PANOPA*	MONEY COLLECTED *NDALAMA*
ORS			
FANSIDAR			
BACTRIM			

MAPHUNZIRO A AZAMBA

No. OF TBAs
No. YA A AZAMBA

TRAINED
WOPHUNZIRA

UNTRAINED
OTSAWOPHUNZIRA

Summary

***Background**: Community-based health care interventions should identify and serve high-risk groups and track mortality among them.*
***Methods**: The Andean Rural Health Care (ARHC) provided Primary Health Care to a population of 27,800 in three Bolivian communities starting in 1983 in agreement with the Ministry of Health. After lengthy exploratory pilot stages, ARHC conducted censuses to enroll each family for quarterly or more frequent home visits according to risk. Community-based auxiliary nurses provided interventions (health promotion, growth monitoring, immunizations, vitamin A, and curative and antenatal care) and tracked vital events. The 17 steps of program planning, implementation and evaluation over a 7 year cycle are detailed. In 1993-4, follow-up household surveys were conducted.*
***Results**: The program had enrolled 94%, repeatedly monitored growth in 80%, and fully immunized 79% of children 12-23 months of age. Under five mortality in these communities (1992) was 110/1000 live births compared to 202/1000 in adjacent locations where health programs were just starting. The per capita recurring cost for local field expenses was US$ 8.57.*
***Conclusions**: A census-base aided ARHC to define communities' health problems, to identify individuals at risk, to achieve nearly complete house-hold level coverage and to measure mortality impact. A minimum two year exploratory phase prior to definitive program development is noted. While the costs were higher than in many developing countries, they exceed the Bolivian Ministry of Health's 1992 expenditures by only 30%. Plans to: (1) add family planning and tuberculosis services; (2) explore community financing and (3) expand within and outside of Bolivia are under review. [eds.]*

THE CENSUS-BASED, IMPACT-ORIENTED (CBIO) APPROACH TO CHILD SURVIVAL AND ITS APPLICATION BY ANDEAN RURAL HEALTH CARE IN BOLIVIA

HENRY B. PERRY, III*

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I. Introduction

In spite of the enormous advances in child survival technologies during the recent decade, there still remains a substantial gap in our understanding about how most effectively to apply these technologies in ordinary, typical field situations and how to assess progress. We are now moving from an era in which child survival efforts have focused on individual specific interventions, beginning with the "twin engines" of oral rehydration therapy (ORT) and immunizations, to a more comprehensive approach in which a broader array of child survival interventions are being utilized and common constraints to effective delivery of services are being given greater consideration.

Because of a lack of applied field research data, those responsible for international health policy have often had to infer a certain child survival impact on the basis of services, such as, the number of ORT packets distributed or the number of immunizations administered. As evaluation methods have improved, it has become more recently a common practice to assess "intermediate" outcome measures such as vaccination coverage or ORT knowledge/use among mothers of small children and presume that these measures are indirect indicators of impact on child mortality. While these approaches have led to important advances in child survival programming, one of the frontiers of improving child survival lies in improving an individual program's capacity to assess its overall impact on mortality rates of whole communities.

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It is becoming increasingly clear that there is much to be learned about how health programs can "package" and deliver a set of interventions most effectively so that child survival impact (that is, improvement in community-based rates of infant and child mortality) is actually achieved, documented, and maximized in typical field settings. The potential of this new knowledge for improving the impact of health programs in developing countries around the world using current knowledge and resources could be substantial. The International Centre for Diarrhoeal Research, Bangladesh, has expressed this same idea in its strategic plan for the year 2000:

> "There is growing recognition that finding cost-effective ways to deliver existing, proven, low-cost health and family planning technologies to the rural and urban poor could save as many lives as a new vaccine or drug" (ICCDR,B, 1994, p. iii).

To know that a specific intervention such as ORT or growth monitoring works under carefully controlled field conditions does not necessarily mean that when it is applied in diverse and more routine field conditions in combination with a series of other interventions that the efficacy of this particular intervention will remain the same (Gadomski et al, 1990). Strategies for reaching high-risk infants and children with essential services that reduce mortality is a key element of programming which has been too frequently ignored. As Gwatkin, Wilcox, and Wray (1980) observed,

> [u]nless services reach those in need, even the best-conceived primary health and nutrition programs can obviously have little impact on mortality. Thus ... the development of plans for getting services to the people [in real need] is as important as are decisions concerning which services should be offered.

Unfortunately, it is the case that when health services are provided upon "demand" (that is, when the individual or the individual's caretaker has to seek out health services), then often those most at risk of death do not obtain the needed services. This is because those who are disadvantaged in terms of education, economic resources, social status, or geographic location are often those who are at greatest risk of death and most unwilling or unable to seek out health services. Therefore, aggressive outreach services are an essential component of programming if a mortality impact in the population is to be achieved.

Finally, there is the need to be concerned with the assessment of the actual outcome of interest, that is, child survival. Have program efforts actually improved child survival? There is a multitude of reasons why mortality impact assessment has not received the same degree of emphasis in program evaluation as has assessment of coverage and/or quality, but the need for programs to be able to assess their own mortality impact is critical for local program evaluation as well as for formulation of child survival program policies (Ewbank and Gribble, 1993).

In reflecting on the lessons of the global smallpox eradication campaign of the 1960s and 1970s, one of the participants in that campaign made this observation:

> [m]ost of all, this lesson [of successful eradication of smallpox] teaches us to be aware of focusing entirely on processes, or on any other means to an end rather than on the end itself, which is reduction in morbidity and mortality (Hopkins, 1988, p. 1595).

There is a lesson here for the child survival movement.

What follows describes an approach to child survival programming developed by Andean Rural Health Care. This approach provides a methodology for identifying high-risk groups, for ensuring that basic services reach the high-risk groups, and for assessing overall mortality impact.

II. Development of the Census-Based, Impact-Oriented Approach at Andean Rural Health Care

Andean Rural Health Care (ARHC) is a non-governmental organization working with communities in Bolivia, South America, to improve child survival and community-based primary health care. At the time of initiation of field activities in the early 1980s, the field staff and technical advisors gave considerable attention to how mortality rates could be lowered and how such a mortality impact could actually be assessed. Thus, ARHC's initial project gave strong emphasis to the idea of a community-based health program with a focus on prevention of deaths.

It soon became obvious that if mortality impact was to be assessed, it would be necessary to

monitor mortality rates over time. In order to calculate mortality rates, it would be necessary to have a registration of deaths (the numerator) as well as census data with which to determine the population at risk of death (the denominator). Since, in Bolivia, neither an effective vital events registration system nor an up-to-date and accurate local census were in existence, the health program itself had to develop a mechanism for carrying out these tasks. We judged that we could carry out these tasks at the time of occasional household surveys.

By the early 1980s, only a few community health projects had been able to assess their overall mortality impact in the population being served by the project. It was at this time that the results of the Narangwal Project were about to be published (Kielman et al, 1983; Taylor et al, 1983). The results of the Berggrens' work in Haiti (Berggren et al, 1981) and the seminal monograph by Gwatkin et al (1980) also had recently appeared.

These evaluations all showed that mortality rates among infants and children could be lowered through community outreach efforts involving vaccinations, nutritional monitoring and supplemental feeding, oral rehydration therapy, and early antibiotic treatment of pneumonia. ARHC set out to replicate these findings in the Bolivian context.

It was ARHC's good fortune to have been able to recruit from the outset the seasoned advice and expertise of Dr. John Wyon and Drs. Warren and Gretchen Berggren, all of whom at that time were faculty members of the Harvard University School of Public Health. Although the Berggrens left Harvard and later joined the staff of Save the Children, Dr. Wyon continued his involvement as an advisor to ARHC and its fledgling program.

Prior to beginning his involvement with ARHC, Dr. John Wyon had directed from 1953-1960 a field project in India known as The Khanna Study (Wyon and Gordon, 1971). The Khanna Study was the first longitudinal field study of a family planning intervention ever carried out. This study provided family planning and also registered vital events in communities in Punjab through monthly home visits. This experience proved to be vital in the later evolution of ARHC's programs in Bolivia.

ARHC began its field activities on the Northern Altiplano of Bolivia, a highland plateau at an elevation of 12,500 feet above sea level which is inhabited by traditional native Americans known as the Aymara. Health services in the area were almost non-existent even as late as the early 1980s, and the local people were still more accustomed to traditional medical practices than to modern medicine and public health.

During the initial years of field operations in the Carabuco Health Area (from 1983 until 1987), the program field staff had to overcome many suspicions before a relationship of trust and confidence with the local communities could be developed. The Carabuco Health Area is composed of 9,500 people living in 31 communities. Many of these communities are more than a several-hours walk from the central health center constructed by the government on the outskirts of the small town of Carabuco. Although there had been some early attempts in 1983 and 1984 to conduct community censuses and to provide child survival services in the home, these activities had to be curtailed because of distrust on the part of influential local community leaders.

However, beginning in 1987 sufficient trust between the local communities and the health program staff had developed and it became possible to begin a census in cooperation with community members. As part of the census activities, all of the homes in the community were identified and assigned a number. This number was placed on the front of the house and also on a community map where the house was identified. A census form was completed which listed the current residents of the house. All of the family's health information, including growth and vaccination records, were placed into a family health folder which was identified and then filed by the number of the house and by the name of the community.

We had not anticipated beforehand the benefits beyond the capability of monitoring mortality rates which would result from census enumeration and home visitation. Nevertheless, the Carabuco Health Program field staff soon came to appreciate the value of this information for strengthening its delivery of child survival services. Prior to carrying out the initial community census, a small field staff had been visiting each of the 31 communities around Carabuco every three months or so to provide "traditional" child survival services in group sessions. These "traditional" child survival services included (1) notifying the community in advance of the field staff's upcoming visit, (2) providing educational talks, nutritional monitoring, immunizations, and Vitamin A capsules to mothers and/or their young children at the time they gathered at a central location in the community, and (3) treatment of sick children. Pregnant women and sick older persons in the community also received care at that time.

Once the censuses and household enumerations had been carried out, however, the field staff realized that they could determine by a relatively simple inspection of the family health folders which of those children who needed a child survival service had not come for the group session on that day. Thus, usually that afternoon (or in some cases the following day) after the family health folders had been reviewed, the staff would visit the home of the child in need of a service. In the beginning, this was usually a vaccination or a growth monitoring. In a relatively short period of time (usually a day or two for a village of 300-400 people), a staff of 3-4 health workers could achieve a high level of coverage of the basic child survival services which were needed at that particular point in time in that community. Having a record of all the children in the village, a map showing where exactly these children lived, and a health folder for each family showing each child's immunization and nutritional monitoring status made this all possible. In the late 1980s, the program's field staff was still based in the small town of Carabuco and only made quarterly visits to each village unless a medical emergency arose in the meantime.

The field staff found that the families, pleased to have the health workers come to their homes, welcomed this form of assistance. Over a period of several years, all of the 31 communities around Carabuco eventually requested to participate in the census and home visitation activity.

As a result of the success of this very significant initial step, the field staff made additional efforts at improving outreach. These were the initial steps toward what ARHC now refers to as routine systematic home visitation (RSHV). At the time of the quarterly visit to a village, the staff would not only visit those children who needed a vaccination or a growth monitoring, but they would, if time permitted, go to every home to update the census information - to record births, deaths, and migrations- and to register any newly detected pregnancies.

ARHC's initial experience in 1983 with a retrospective household survey led to an identification of the limitation of this approach for obtaining accurate mortality data. At that time, ARHC conducted a baseline survey of over 1,000 households on the Northern Altiplano. This survey included information about infant and child deaths during the previous year, but the number of deaths actually reported by parents was found to be markedly less than predicted on the basis of what were widely thought to be mortality levels of children on the Altiplano in Bolivia at that time. Eighteen percent of the children ever born to women participating in this survey were reported by their mothers at the time of the household interview to have died by the time of the study (Hornberger, 1985). At that time, most estimates of infant mortality rates on the Northern Altiplano were considerably greater than 18% of the live births. That is to say, the infant mortality rate alone (not including mortality after the first year of life) was thought to be much greater than 180 deaths per 1,000 live births. There were scientific assessments of the infant mortality rate on the Altiplano at that time which were much higher than 180, including as high as 275 (MPC, 1983; Rance et al, 1989). Others have also noted the limitations of traditional retrospective reporting systems such as civil registries of vital events and retrospective household surveys to detect infant and, in particular, neonatal deaths (Clairin, 1985; WHO, 1992).

Reflection on this experience led to the conclusion that families were not likely to report infant and child deaths in a retrospective fashion, perhaps partly because of guilt and perhaps partly because of difficulty in remembering. Thus, the concept arose of prospective home visitation to register vital events. This was precisely the same methodology which Dr. John Wyon had employed in The Khanna Study.

As the local ARHC staff became more experienced with home visitation, the staff began to see more clearly a number of additional advantages which had not been foreseen initially. Routine systematic home visitation to all the homes in a village (with more frequent visits to those at high-risk or in special need) dramatically reduced the social and geographic distance between the health program and the family. The family came to know the health workers and the health program. The health workers also came to know the families and their particular social and physical home environments. Furthermore, the health workers found that the home visit provided an ideal opportunity for health education tailored directly to the mother's needs and knowledge level. None of these benefits could be achieved at group meetings of mothers in which the mothers gathered together to receive child survival services and a health education "lecture" from a health worker.

The final step in the evolution of this transformation of health care delivery in Carabuco was the decentralization of the health staff. By 1990, the Carabuco Health Program staff had grown to 18 persons - 1 physician, 2 midlevel health staff, 13 auxiliary health nurses, 1 driver, and 1

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groundskeeper. Because of the considerable distance from the Carabuco Health Center to many of the outlying villages (in many cases more than several hours away), 11 small health posts were constructed throughout the program area to make services more readily accessible. Each auxiliary nurse previously based in Carabuco was relocated to a newly constructed post to provide a permanent, readily available source of health care for those living nearby. These auxiliary nurses then became even more community-based than they had been. In almost all cases, these auxiliary nurses had grown up in one of the communities where they were assigned, so they knew the area and the people well.

This process of decentralization was completed by the end of 1991. By then, each community-based auxiliary nurse was carrying out routine systematic home visitation, targeted home visits to high-risk children and their mothers, and home care of sick community members when they were unable to come to the local health post for care. Each community-based auxiliary nurse had a set of two or three communities for which he or she alone was responsible. The community-based health auxiliary served as a point of contact with the Carabuco Health Center and arranged for referral for more specialized services if the family was willing to obtain them.

All field staff at Carabuco gradually recognized the advantages of this census-based approach to delivery of health services. In fact, the enthusiasm for this approach was so contagious that the field staff in ARHC's other two sites in Bolivia adopted the same approach in Mallco Rancho (at 8,000 feet above sea level) and Villa Cochabamba/ Montero (at 500 feet above sea level).

The early experience with the application of this census-based approach using routine systematic home visitation to register vital events and to deliver essential services led to the realization that the leading causes of under-five deaths and the distribution of ages at death differed significantly in the three program areas. In Carabuco, the leading causes of death among under-fives were respiratory (both pneumonia and asphyxia), accounting for 43% of all childhood deaths. In the Mallco Rancho program area, pneumonia and asphyxia accounted for only 19% of the under-five deaths while diarrhea and/or malnutrition accounted for 38% of the deaths. In the lowland periurban low-income neighborhood of Villa Cochabamba/Montero, 55% of the under-five deaths were caused by diarrhea/ malnutrition (see Table 1). These differences are highly significant statistically ($p = 0.005$).

The distribution of ages at death for the three program areas differed notably. In Carabuco, over half (53%) of the under-five deaths were during the first three months of life. In Mallco Rancho, there was also a concentration of deaths in the first three months of life (42% of the under-five deaths), but with a greater percentage of deaths occurring from 3-21 months of age than in Carabuco. In Villa Cochabamba/Montero, there were two peak age groups at which deaths were concentrated: 3-6 months and 15-21 months of age. There were virtually no deaths in any of the program areas after 24 months of age. Thus, these data demonstrated that children 24-59 months of age were not a high-risk group to receive child survival services. When the data are collapsed into two categories (age at death under one year and age at death greater than one year) as shown also in Table 1 these differences among program sites in age at death are also statistically significant ($p = 0.020$).

The process of calculating age-specific mortality rates for each program area proved to be illuminating for the field staff. The results clearly identified infants and children under 24 months of age as being at greatest risk of death. The cause of death was nearly always preventable or treatable. Figure 1 shows the example for Carabuco of age-specific death rates by five year age groups, and Figure 2 shows the percentage of under-five deaths occurring there at each three month age interval. These data demonstrate that it is possible to identify with considerable precision which age groups are at greatest risk of death, even in small populations.

Andean Rural Health Care's early experience with what Dr. Wyon refers to as "community-oriented public health" stimulated the elaboration of a broader set of concepts which we now refer to as "the census-based, impact-oriented" (CBIO) approach.

III. Theory and Principles of the CBIO Approach

The CBIO approach, as developed by ARHC in Bolivia, benefited greatly from its collaboration with Dr. John Wyon. Dr. Wyon, now retired Senior Lecturer at the Harvard University School of Public Health, served as Field Director of The Khanna Study in the Punjab of India, a pioneering community-based longitudinal epidemiologic research project focusing on population dynamics (Wyon and Gordon, 1971). The CBIO approach has also been heavily influenced by the tradition of community-oriented primary care (COPC) established by Dr. Sidney Kark and his colleagues

Table 1. Differences in Cause of Death and Age at Death Among Under-Fives in Carabuco, Mallco Rancho, and Villa Cochabamba/Montero, Bolivia, 1990-2

	Carabuco (n=49)	Mallco Rancho (n=37)	Villa Cochabamba (n=20)
Cause of death			
respiratory problems (pneumonia or asphyxia)	43%	19%	10%
diarrhea/malnutrition	0%	32%	55%
other	57%	49%	35%
TOTAL	100%	100%	100%
Distribution of age at death			
under 12 months	76%	59%	45%
12-59 months	24%	41%	55%
TOTAL	100%	100%	100%

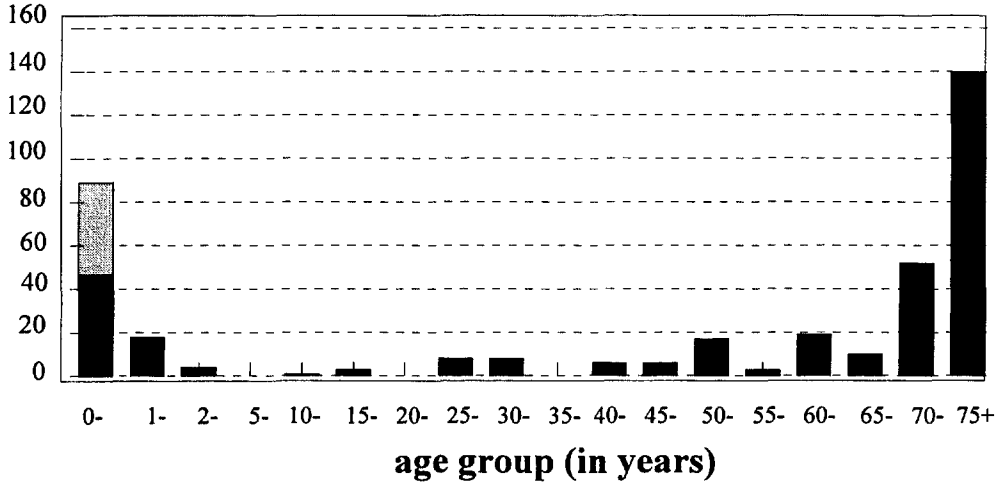
Source: Vital Events Registration Data for Carabuco (1990-2), Mallco Rancho (1991-2), and Villa Cochabamba/Montero (1992).

(Kark, 1974; Geiger, 1993). Many of the basic principles of the CBIO approach were applied during the 1970s by Drs. Warren and Gretchen Berggren (in collaboration with Dr. Wyon) in their work in conduction with the Hospital Albert Schweitzer in Haiti (Berggren et al, 1981). The Berggrens later applied these same concepts in various ways to Save the Children health projects around the world when Dr. Warren Berggren served as the organization's Director of Primary Care.

ARHC has taken as its overarching organizational goal the improvement of health in the specific communities where it has been asked to work. It has also taken as a central goal the actual demonstration of improved health as a result of the health services provided. Because in Bolivia mortality rates among infants and children have remained so high, ARHC began its work in 1983 with the goal of not only establishing primary health care programs which would be responsive to the community's perceived health needs but also focusing on the improvement of child survival in the community. The CBIO approach merges the basic principles of curative medical services which are directed to the health needs of defined communities with the basic principles of public health. These are combined into a unified and coordinated health program. While ARHC has applied the principles of the CBIO approach to the improvement of child survival in Bolivia, these principles could, in fact, be applied to many kinds of problems (even beyond health) affecting traditional communities. They could be applied in developed countries as well, with very different types of health problems and available resources. For instance, the principles could readily be applied by a Health Maintenance Organization (HMO) serving a population of clients who are not necessarily living in a contiguous set of houses as in a traditional community. Thus, the principles of the CBIO approach could be applied in theory, in any population of any size and with any configuration of resources and health problems. The application of these CBIO principles in other areas of community development beyond health represents an area for future conceptual development.

One of the strengths of the CBIO approach is that, in contrast to primary health care and other curative health services as they have been traditionally practiced at fixed service delivery points such as health centers, it incorporates an aggressive

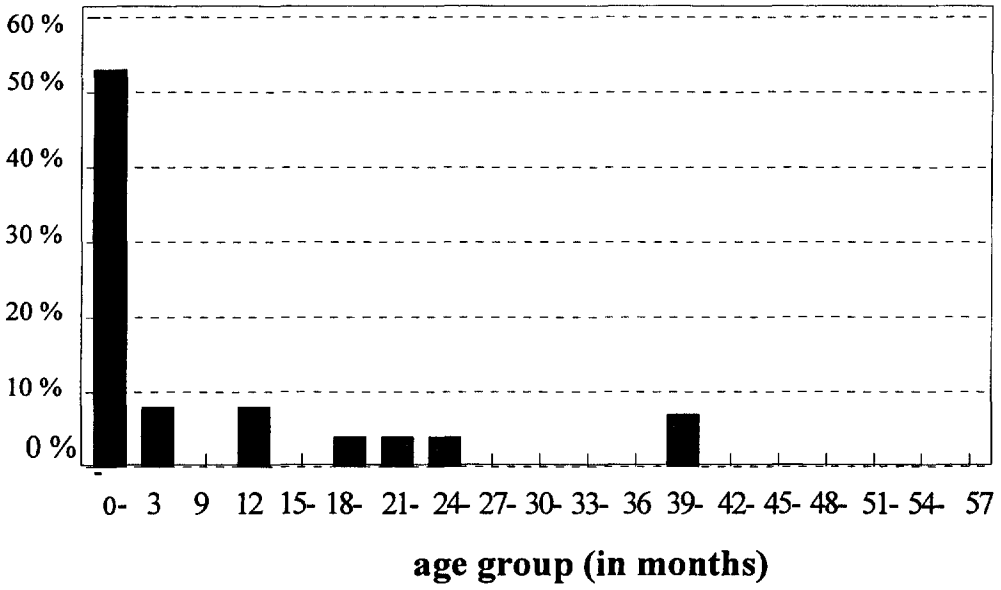
Figure 1.
AGE-SPECIFIC DEATH RATES
CARABUCO, BOLIVIA 1992



lower portion of first year deaths is
neonatal, upper portion is post-neonatal

Figure 2.
PERCENTAGE OF CHILDHOOD DEATHS IN
CARABUCO BY AGE AT DEATH

percentage of deaths registered, 1992



outreach component. This aggressive outreach component makes it possible to determine from an epidemiological perspective the major health problems in the population of any community (or communities) and the characteristics of those who are at greatest risk of these health problems. With this information, it becomes possible to focus program efforts on these particular health problems and those who are at greatest risk.

It is commonplace for traditional primary health care and other curative services in developing countries to be overwhelmed by persons coming to the health facility in search of treatment for acute medical conditions, often without any possibility of the program becoming proactive and focusing on prevention. The CBIO approach, on the other hand, attempts to respond to the acute health care needs of the population while at the same time placing a major emphasis on the prevention and early treatment of the most significant health problems of the community which can be addressed with the resources available.

The outreach component of the CBIO approach is vital in addressing one of the major problems of traditional curative and preventive health services - namely that a significant portion of the population, and particularly those at greatest risk of illness and death, never receive services that are based at fixed delivery sites. Access to basic services may be limited by socioeconomic, educational, or geographic barriers. Unless the portion of the population "at the margin" is somehow reached, the health of the overall population will improve far less than it might otherwise, if at all.

Four basic theoretical concepts underlying the CBIO approach are:

1. Health improvement arising as a result of health program activities is unlikely in a set of communities unless the program staff: know the most frequent, serious, preventable or readily treatable conditions in these communities; can identify those persons at greatest risk of developing these problems and can provide appropriate preventive or curative services to the targeted community members.
2. Rates of sickness and death in communities must be measured if health improvement is to be documented.
3. The calculation of these rates requires the capability of both identifying community members who have become sick or have died and of determining the composition of the population at risk by age, sex, and address.
4. Epidemiologic priorities and the characteristics of those at greatest risk of preventable or treatable health problems vary from one locale to another. Therefore, for greatest program effectiveness, diagnoses of the community's health problems and those at greatest risk must be made using information obtained from within the program area.

The CBIO approach is "community-oriented," meaning that the health activities which evolve from the approach are oriented to the needs of the community and involve the community as an active participant in the process of program development and service delivery. This CBIO approach takes as one of its basic tenets the task of defining health priorities not only from the epidemiological perspective, but also from the community's perspective. Therefore, the CBIO approach responds not only to the epidemiologic priorities but also to the health priorities as the people experience them and as they themselves define them. Part of the power of the CBIO approach is its capacity to provide a means for helping local program staff establish program priorities (especially among competing demands for curative and preventive/child survival services), to use program resources in a way which reflects program priorities, and to measure progress in health improvement over time.

IV. Application of CBIO Theory and Principles

A. Introduction

The application of CBIO theory and principles can be conceptualized in two stages: the Exploratory/Pilot Stage and the Definitive Program Operation Stage (see Table 2). During

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the Exploratory/Pilot Stage, initial program efforts take place without benefit of a Definitive Community Diagnosis. The exploratory efforts prepare the way for a pilot program which in turn leads to the capacity to make a Definitive Community Diagnosis.

Table 2. Stages in the Application of the Census-Based, Impact-Oriented Approach

I. Exploratory/Pilot Stage
  A. exploratory program planning
  B. pilot program implementation

II. Definitive Program Operation Stage
  A. definitive community diagnosis
  B. definitive program plan
  C. definitive program implementation
  D. evaluation and community rediagnosis

During the Definitive Program Operation Stage, a Definitive Community Diagnosis is made. The Definitive Program Plan and the Definitive Program Implementation are based on the Definitive Community Diagnosis. Following a period of program implementation, program evaluation takes place through reassessment of community perceptions of priorities and through redetermination of the epidemiologic priorities and high-risk groups. Thus, on the basis of a community rediagnosis, a new program plan is established and implementation activities are altered accordingly. Thus, this process repeats itself indefinitely.

Neither the practitioners of the CBIO approach nor the set of communities collaborating with them, acting separately or together, can respond to all of the communities' problems at once. Therefore, they aim to make a community diagnosis of the communities' problems and then set out to address first those problems which have been carefully selected as priorities. Following these principles, staff and community members together design methods to determine the current priority problems of the collaborating communities. These problems are of two types: those which the community recognizes as priority health problems and those which the program staff determines to be epidemiologic priorities. The epidemiologic priorities are the most frequent, serious, readily preventable or curable health problems affecting the community. Some health problems may be included on both lists of health priorities (community and epidemiologic).

Beginning at the time of the Pilot Program Operations and continuing on indefinitely, the staff members of the CBIO programs create and maintain effective contacts with all the households in each collaborating community, or with at least a randomly selected sample of them. This approach makes possible six crucial features of the CBIO approach. Staff members:

1. assess the communities' view of the nature and frequencies of their high priority problems;
2. identify the determinants of the most frequent, serious and preventable or easily curable problems affecting the community and as diagnosed by medical criteria;
3. identify the individuals and families most at risk of these high priority problems;
4. design interventions to address the priority problems at the least cost possible;
5. regularly assess the effectiveness of the programs as measured by changes in community-based rates of sickness, death and unwanted children; and,
6. periodically review and redesign programs with the collaborating communities to address current priorities.

B. Exploratory/Pilot Stage

During the Exploratory/Pilot Stage of program development, all of the necessary preliminary arrangements are made and pilot program functioning begins (see Table 3). This includes establishing the program's overall goals and objectives, clarifying anticipated sources of financial support, negotiating agreements with governmental authorities at the national, regional, and local levels, and reaching agreements with local community leaders. During this period of Exploratory Program Planning, core program leadership staff are assembled and trained.

During the period of Exploratory Program Planning, the program leadership gathers whatever information is readily available which can serve as a basis for writing the initial

program plan. This task calls upon a process referred to in the military as reconnaissance. Two types of reconnaissance are called for: "library" reconnaissance and field reconnaissance. "Library" reconnaissance is a review of all known documents that may be relevant to the initial formulation of the program. Field reconnaissance includes a first-hand review of the potential program sites along with initial discussions with community and governmental leaders to assess the relative advantages and disadvantages of program location. On the basis of this information, a written preliminary program design is developed. With this preliminary program design in hand, those field sites considered to be suitable are revisited to discuss the feasibility of the initial program formulation. The field site is then selected and, on the basis of additional field reconnaissance in the selected program site, the preliminary program design is modified accordingly.

Table 3. Steps in the Exploratory/Pilot Stage of Application of the Census-Based, Impact-Oriented (CBIO) Approach

I. Exploratory Program Planning
- A. develop overall program goals and objectives
- B. clarify anticipated sources of financial support
- C. negotiate agreements with governmental officials at the national, regional, and local levels
- D. recruit core program leadership
- E. establish working agreements with the communities and their leaders

II. Pilot Program Operations
- A. establish a tentative, preliminary "working" community diagnosis based on existing information and other readily obtainable information from within the community
- B. develop a preliminary work plan on the basis of the tentative diagnosis
- C. develop a preliminary pilot health information system
- D. recruit and train additional field staff
- E. try out on a pilot basis the preliminary work plan and the preliminary health information system

These initial steps provide the opportunity for the program leadership to apply reality checks on the accuracy of the data available to them up to that point and the feasibility of officials and local communities responding to requests for hosting the proposed program. At this point also, the program leadership can acquire some understanding of the qualities of locally available staff and the feasibility of basic aspects of the proposed field methods.

A prime goal of the Exploratory/Pilot Stage is to develop a relationship of trust between the health program and the community and also to establish the health program's initial priorities. This process continues in the Definitive Program Operation Stage.

In order to develop a relationship of trust between the health program staff and the community, the program staff must come to know the community. The community must also come to know the health program staff, their goals, and their proposed methods of operation. Through this joint learning process, the opportunity arises for a relationship of trust to emerge. It is this relationship of trust which is the fundamental building block upon which all later program developments depend.

The health program must define the exact geographic boundaries of dwellings of the community members and determine who resides within the program area and where. Keeping track of community members is a complicated task since the community's population changes from day-to-day as a result of births, deaths, in- or out-migrations, and relocation of individuals within the program area.

ARHC's Bolivian staff have dealt with these problems by working with local communities to establish village maps, locating each house in the community on such a map, and giving each house a number. The residents of each house are identified. This information is then updated every six months. It is this process which makes the CBIO approach "census-based."

The preliminary program design includes the following information:

1. the goals of the program (including the goal of improving child survival in defined communities) with justification for specific objectives based on existing information;

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2. the kinds of communities to be selected for the program and why;
3. the proposed program sites; and,
4. the methods proposed to deliver, manage, and evaluate the program in collaboration with the client communities.

After completing the field reconnaissance, the pilot program design is modified to become the initial (field checked) program design, complete with a realistic budget for the initial period of field work.

The initial program design will contain hypotheses, proposals, and methods which will make it possible to:

1. distinguish clearly residents from non-residents of the community;
2. identify every community member;
3. determine community views on health priorities;
4. record the incidence and cause of disease, death, birth, migration, and other relevant events and states;
5. arrive at agreement on what are most likely to be the most frequent, serious, readily preventable or curable problems in the community, based on findings from the library and field reconnaissance;
6. design specific programs to address the above problems;
7. agree on a term (such as one year) for the following: when the exploratory phase will end; when analysis of the available community-based data will be brought up-to-date; when the results will be assessed by community members and staff, and when the decision will be made on a revised community program design derived from the first community-based definitive diagnosis.

With the initial program design and the funded budget in hand, the program leadership is now ready to establish official relations with the government health authorities at the national and local levels and also with any other participating non-governmental organizations. Once this has been established, the tasks at hand become the following:

1. find and employ field staff likely to be good leaders for the next and subsequent stages of program development;
2. establish logistical support for the initial field operations;
3. select the specific site of initial program operations;
4. invite one carefully selected community to begin negotiations with the program leadership which would result in an agreement enabling initial program activities (this also includes building active roles for community members in both initial and subsequent stages of program operations);
5. design, implement, and improve methods to learn the views of the community members on health priorities;
6. design, test, and redesign data forms suitable for use both in the clinic and homes and for purposes of statistical analysis;
7. field test and improve specific programs designed to address hypothesized priority problems;
8. complete plans for the analysis of the data accumulated during the duration of the exploratory phase, and apply the results to the design of the program based on the first community diagnosis.

After completing this considerable set of initial tasks in the Exploratory/Pilot Stage, it is possible to move onto the second set of tasks in this stage, namely Pilot Program Implementation. At this point, the assembled core program leaders have made a preliminary diagnosis based on readily available information to justify the initial thrust of curative and preventive services. This is based on information obtained from written sources, from other agencies, and from local community sources.

Once this step has been completed, it is possible to develop a preliminary work plan which addresses the tentative program priorities established by the "working" diagnosis. In tandem with the creation of the preliminary work plan is the development of the trial health information system (HIS). HIS development

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requires clarification of what information is needed by whom, when and how this information is to be collected. In conjunction with these activities is the recruitment and training of additional field staff. Once these tasks have all been achieved, pilot testing of the preliminary work plan and HIS can take place.

Based on ARHC's experience in establishing five new health programs, it seems reasonable to allow for at least two years to complete the Exploratory/Pilot Stage,. However, if the implementing organization and its leaders are not experienced in program development (as was ARHC's case in establishing the Carabuco program), a much longer time period may be required.

C. Definitive Program Operations Stage

During the Definitive Program Operation Stage, an initial Definitive Community Diagnosis is completed and based on this diagnosis, the Definitive Program Plan is developed. Definitive Program Implementation then begins. At a later date, Evaluation and Community Rediagnosis take place (see Table 4). The Definitive Program Operation Stage lasts indefinitely as it continues to repeat Steps I-IV. The length of time required to pass through a complete cycle varies depending upon local circumstances, but a rough estimate would be an initial five-year cycle with cycles gradually diminishing to three-year periods.

Just as it is imperative for a physician treating a patient to make as accurate a diagnosis as possible, it is critical for evaluators to make as accurate a Definitive Community Diagnosis as possible. If not, the "treatment" which has been "prescribed" may not be effective. Thus, just as it is in the case of an individual patient, the investment of time and resources to make a diagnosis of the community's health problems is justifiable if the likelihood of actual health improvement is enhanced as a result of the diagnosis. That is to say, if the diagnostic evaluation is accurate and if it points to a "treatment" which is available and affordable, then the diagnostic evaluation is well worth the time and resources expended. This is especially true if it leads to a less expensive treatment than might have been the case without the diagnostic evaluation. While this may seem unlikely, it in fact occurred at ARHC's field locations as high-risk children have become more clearly identified.

Table 4. Steps in the Definitive Program Operation Stage of the Census-Based, Impact-Oriented (CBIO) Approach

I. Definitive Community Diagnosis
- A. establish relationship of trust between the program and the community
- B. "define the community" (see text for details)
- C. determine the most frequent preventable or treatable causes of sickness and death in the community (and their root causes)
- D. determine the health priorities as experienced by the community
- E. establish program priorities based on the epidemiologic and community priorities

II. Definitive Program Plan
- A. determine as precisely as possible the resources available for program operations
- B. develop program work plan based on program priorities and available resources

III. Definitive Program Implementation

IV. Evaluation and Community Rediagnosis

V. Return to Step II (develop a new Definitive Program Plan)

Like the situation of a physician's diagnosis of an individual patient's medical problem, a relationship of trust with open and frank communication between the health program and the community fosters the ability to make an accurate diagnosis.

Before the definitive community diagnosis can begin to be made, it is necessary to identify all of the people in the program area through the enumeration of households, preparation of community maps, and determination of household membership. Once these considerable tasks have been completed, it becomes possible to determine, through prospective home visitation, the most frequent, serious, readily preventable or treatable health problems which exist in the community and the characteristics of those who are at greatest risk of developing these problems.

ARHC refers to this prospective longitudinal home visitation approach as routine systematic home visitation (RSHV). RSHV includes the registration of vital events, pregnancies, and illnesses. At the time of a home visit, the staff obtain or update census information for the household. Information about illnesses and deaths in the household since the last visit is recorded. Thus, it becomes possible to measure morbidity and mortality rates. Mortality rates are usually calculated on an annual basis. In short, RSHV makes it possible to make an accurate epidemiological assessment of the health needs of the community.

The community's view of its health needs may differ substantially from the epidemiological priorities which have been determined through RSHV. In the application of the CBIO approach, it is important to determine what these community priorities are and how best to respond to them. It has been ARHC's experience that this can be effectively achieved through three different methods. First, what spontaneous needs for health services arise as the program is beginning? These are mostly needs for the acute care of illnesses, and most (but not all) can be met by establishing a community-based primary health care service. Secondly, what are the health priorities which the people themselves identify? This can be determined through community surveys or through RSHV. Finally, what do the community leaders consider the health priorities to be? This can be assessed by face to face meetings with community leaders.

Once the epidemiological priorities and the community's own health priorities have been determined, the health program leadership then has the responsibility of combining these into a coherent and realistic set of program priorities. The community's participation in this, as in all program activities, is essential. The establishment of program priorities is the final step of the Definitive Community Diagnosis. It is the systematic determination of the epidemiological and community-expressed priorities along with the planning and implementation of the program based on these priorities which gives the CBIO approach its "impact-oriented" focus.

As the Definitive Community Diagnosis is being completed, Definitive Program Planning begins. As part of the program planning process, the resources available for the program are specified (whether they are financial resources, community resources, facilities, supplies, transport etc.) Given the program's priorities as identified in the community diagnosis and given the resources which have been identified, a work plan is created which directs program resources toward the health program's priorities. An important element of the planning process is to ensure that those individuals identified as being at high-risk receive the services which are designed to prevent or treat the condition from which they are at risk of becoming seriously ill or dying.

Once the Definitive Community Diagnosis and Definitive Program Planning have been completed, it is possible for Definitive Program Implementation to begin. After a period of time (anywhere from 18 months to three years in ARHC's experience), an evaluation of program activities is carried out along with a community rediagnosis. Thus, program implementation efforts are assessed, particularly with respect to impact and coverage, and the epidemiologic priorities along with the community's own definition of its health priorities are redetermined. At this point, the process repeats itself and the Definitive Program Plan is developed again. The cycle then, in theory, repeats itself indefinitely.

As a practical matter, ARHC's field staff have not always carried out the phases of the CBIO approach in precisely the order called for in the above discussion. Those carrying out pioneering efforts in any area encounter unexpected circumstances which must be dealt with. Furthermore, field conditions are always changing, and directors of field programs must learn to become masters of making the best of difficult and unanticipated conditions. For these reasons, CBIO theory and principles have had to adapt to practical realities. Even so, the concepts of the CBIO approach the touchstone for ARHC's program directors as they face the difficult tasks of program development.

D. Special Considerations: Home Visitation

ARHC field staff have found that home visitation has become an essential element of program implementation. Routine systematic home visitation (RSHV) facilitates all stages and steps in the application of the CBIO approach (Perry and Sandavold, 1993). Through RSHV,

all of the homes in the program area are contacted, a census is taken or updated, and vital events are registered in a prospective fashion. Through RSHV, barriers to services are greatly reduced, be they geographic barriers, socioeconomic barriers, or barriers produced by a lack of trust. In the absence of RSHV, these barriers are more significant and they impede the flow of health services to the family as well as the willingness or ability of the family to seek out health services. In the absence of RSHV, a sound community diagnosis of the most frequent, serious, preventable or treatable conditions is not possible.

However, as a result of RSHV (or a variant thereof), the health staff has come to know the families and their social and physical environments. Likewise, the families have learned about the program and know the program staff. Presumably, the staff member visiting the home earns the trust of the families. Finally, RSHV gives a basis for determining the characteristics of persons who are at high risk and, equally important, exactly where such persons can be located.

One of the important lessons learned by ARHC's field staff is that a number of health services can be provided effectively in the home. Education is given directly to the family at the time of home visitation. Vaccinations and nutritional monitoring are carried out at the time of home visitation. Acute illnesses are treated if possible, and patients in need of additional services are referred for appropriate care. Home visitation provides an ideal setting for carrying out other health activities as well - such as diagnosing and treating tuberculosis or providing family planning education and/or family planning services (Perry et al, 1994).

High-risk individuals receive targeted follow-up home visitation. The frequency of follow-up home visits depends upon the particular situation. Severely ill or severely malnourished children, for instance, may be visited on a daily basis until the child's condition becomes more stable. Those children who are defined as being at high risk because they need a vaccination, on the other hand, may not be visited as promptly.

E. Special Considerations: Relations with the Ministry of Health

ARHC's community-based health programs have placed a heavy emphasis on child survival activities but at the same time they have provided primary health care services for the acute health needs of the entire population including referral to hospital services when needed and when acceptable to the patient. ARHC has integrated its program efforts with the Bolivian Ministry of Health. For all of its programs, ARHC has negotiated an agreement with the MOH giving ARHC authority to direct the MOH personnel assigned to the area, thereby merging all MOH staff into the ARHC program staff. In this way, a unified program of primary health care and child survival has emerged which has worked to the benefit of all parties concerned, especially the communities themselves.

V. Results of the Application of the CBIO Approach

How successful have ARHC's programs been in reaching the individuals in the populations for which the programs are responsible? Have interactions between the programs and the people led to improved health within the program areas? In what way is the integration of child survival and curative services complementary and in what way is it antagonistic? Are the costs of the CBIO approach feasible? These questions will be answered briefly here.

In the ensuing discussion, we will limit the findings to ARHC's three most developed programs: Carabuco, Mallco Rancho, and Villa Cochabamba/Montero. These are three very distinct programs in three separate regions of Bolivia. The Carabuco Health Program serves 9,500 Aymara Native American people of the highlands of Bolivia in an isolated rural area. The Mallco Rancho Health Program serves 5,800 Quechua Native American people of the highland valleys of Bolivia in a rural area near a large city, while the Villa Cochambamba/ Montero Health Program serves 12,500 people of mixed ancestry in a low-income periurban neighborhood of the city of Montero in the semitropical lowlands which border Brazil. Although the programs serve very different areas, the basic principles of the CBIO approach have been applied in a similar fashion in each area as described above. Most of the results presented here are based on household surveys carried out in Carabuco and Mallco Rancho in

the fall of 1993 and in Villa Cochabamba/ Montero in the Spring of 1994. The results of the household sample surveys presented here for the three program areas combined represent the results for each program weighted by the program's population (see the Appendix for further details).

Depending on the size of the program area, the surveys either included all households having young children (in the case of Mallco Rancho) or a sample of such households. For the sample surveys, the cluster sample technique was used for the Carabuco surveys and a systematic sample of half of the households was used in Villa Cochabamba/Montero. The surveys were carried out as part of ongoing program evaluations. The individual program results are also included in the Appendix.

A. Enrollment of Children in the Health Program and Coverage of Services

Household surveys have revealed that 94% of the children 12-23 months of age in the three program areas had previously been identified by the health program and were enrolled in the program's health information system (see Table 5). These children all had a "Road to Health" Chart on which growth monitoring and vaccination information was placed.

For the three program areas combined, 79% of the children 12-23 months of age had completed their entire series of vaccinations (BCG, Polio3, and measles), as shown in Table 5. In terms of coverage of growth monitoring, Table 5 demonstrates that 80% of the children in these three program areas combined had had their growth assessed at least three times during the previous 12 months.

B. Mortality Impact

The mortality impact analysis which has been carried out so far is based on death data collected in Carabuco, Mallco Rancho, and Villa Cochabamba/Montero through 1992. On the basis of infant and childhood deaths registered through routine systematic home visitation in Carabuco from 1990-1992, in Mallco Rancho from 1991-1992, and in Villa Cochabamba/ Montero in 1992, and on the basis of grouped population data for children under five in these program locations, a probability of death before reaching the age of five was calculated for these children and compared to a national sample of children in the Bolivian National Demographic and Health (DHS) Survey (Sommerfelt et al, 1991). Mortality rates for ARHC's established program areas also are compared with those for children in Ancoraimes and Sipesipe where ARHC collected baseline mortality and census data in 1992 and 1993 when new field programs were being established. Each of these two new program sites was adjacent to one of ARHC's established program sites. The details of this analysis have been described elsewhere (Perry, 1993) and are available from the author on request. The national DHS data are based on a retrospective household survey, while data for both the established programs and the control

Table 5. Assessment of Outreach and Coverage of the Census-Based, Impact-Oriented (CBIO) Approach in ARHC's Three Established Program Areas in Bolivia, 1993-1994

percentage of children 12-23 months of age enrolled in the health information system (with a growth and vaccination chart)	94%
percentage of children 12-23 months of age with their entire series of vaccinations completed (documented receipt of BCG, polio3, DPT3, and measles)	79%
percentage of children 12-23 months of age with at least three growth monitorings during the previous 12 months	80%

note: the data shown here are combined from each of the surveys in ARHC's established program sites and weighted according to each program's population (see the Appendix for further details). A total of 882 children were assessed through these surveys.

sources:
(1) Carabuco: cluster sample survey of households with children under two (1993)
(2) Mallco Rancho: survey of all households with children under two (1993)
(3) Villa Cochabamba/Montero: survey of every other household with children under two (1994)

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areas were obtained through prospective home visitation.

This analysis indicates that when the children in ARHC's established program areas are compared to children in the control areas (where child survival activities were just beginning), the overall probability of death of children from birth to age five, as shown in Table 6, differs by 46%: the probability of death is 0.202 in the control locations and 0.110 in the established program locations.

When the children in ARHC's established program locations are compared with similar children participating in the national DHS survey, child survival differs by 32%; the probability of death for these control children is 0.161 compared to 0.110 in the established program areas (see Table 6 also). Although a preliminary analysis of the 1993 data has been carried out so far only for Carabuco and its adjacent "control" area in Ancoraimes, the substantial differences in under-five mortality appear to be persisting.

One caveat which should be mentioned is that during the first several years of vital events registration based on RSHV, it is quite possible that mortality rates may go up rather than down because of gradual improvements in the completeness of death registration, particularly of newborn children. This actually happened in Carabuco between 1989 and 1990. Consequently, confidence should not be placed in the results of the calculations of mortality rates until there is strong evidence that at least 95% of the deaths have been registered. This usually does not occur until vital events registration has been underway for several years. Thus, mortality impact calculations for a given program area may seriously underestimate program effectiveness if reliable baseline mortality data are not obtained before program interventions begin or if information cannot be obtained from a suitable comparison area.

It has been ARHC's experience that integrating a curative primary health care program with a child survival program has resulted in a synergistic positive interaction. The child survival effort has strengthened the curative primary care effort, and the curative primary care effort has strengthened the child survival effort.

Table 6. Results of Mortality Impact Analysis in ARHC's Three Established Program Areas

percent difference in probability of death from birth to age five (on the basis of current mortality rates) in ARHC's established program areas:

compared to children in adjacent "control" areas 46%

(0.110 for ARHC established programs vs. 0.202 for adjacent "control" areas)

compared with a national sample of children with similar socio-economic and geographic characteristics 31%

(0.110 for ARHC established programs vs. 0.161 for adjacent "control" areas)

mortality rates in established and control areas

		established	control
0 - 11 months	(*)	77.4	116.7
12 - 23 months	(**)	23.1	57.9
24 - 59 months	(**)	4.6	11.0

note: (*) the mortality rate shown here for 0-11 months is infant mortality rate (infant deaths per 1,000 live births)
(**) age specific mortality rate (deaths in age group per 1,000 persons in age group

source: vital events registration and census data for Carabuco, Mallco Rancho, Villa Cochabamba/Montero, Ancoraimes, and Sipesipe. Bolivia; Sommerfelt et al, 1991.

C. Interaction Between ARHC's CBIO-Child Survival Efforts and Its Other Primary Health Care Activities

The process of aggressive outreach for delivery of child survival services brings the health staff into contact with the entire community. Naturally, other people in the community in addition to young children have health problems and these people also seek assistance from the health workers. The capacity of child survival health workers to assist with the resolution of other health problems in the community as a whole strengthens the credibility of the child survival effort. As one of ARHC's program directors puts it, to have child survival activities without a community-based primary health care program for the entire community

would be like trying to applaud with only one hand.

The child survival effort in ARHC's three established program areas have constituted 65% of the overall program efforts, according to staff estimates. Thus, 35% of program efforts have gone into primary health care efforts which were not actual child survival interventions. Approximately 25% of the overall child survival effort itself has been devoted to the maintenance of the health information system and to home visitation (see Table 7)

D. Staffing Levels and Program Costs

On the basis of staffing levels in 1993, these three established programs, serving a total population of 27,800 persons, had 1 physician for each 4,633 persons, 1 midlevel health professional for each 5,520 persons, and 1 lower level health worker for each 1,396 persons (see Table 8). These norms are well within those established by the Bolivian Ministry of Health for minimal service delivery in underserved areas.

An analysis has been undertaken of the overall local cost of these three established programs in Carabuco, Mallco Rancho, and Villa Cochabamba/Montero, taking into consideration the value of the contributions made by the Ministry of Health, depreciation costs, costs of training, and other expenses. This analysis has shown that the per capita annual recurring cost for local field expenses (excluding expenses for the National Office in La Paz, Bolivia, and for the International Office at Lake Junaluska, NC, USA) amounted to $8.57 in 1992. While these costs are somewhat high compared to program expenditures in many developing countries, they are not unreasonable within the Bolivian context. If these costs could be reduced to $5-6 per capita, the programs should be sustainable on an ongoing basis through a combination of local financial contributions from the community for services received and from the Bolivian Ministry of Health for preventive and child survival services.

The Ministry of Health (MOH) itself spent an average of $6.59 per capita in 1987 (Martin et al, 1992). The local population has the capacity to contribute an average of $3 per capita per year for local health services and the MOH has a similar capacity.

Table 7. Comparison of Staff Effort Devoted to ARHC's Curative Health and Child Survival Services

	percentage of over-all health effort devoted to child interventions (*)	percentage of over-all child staff survival effort devoted to survival HIS and home visits (**)
Carabuco	80%	28%
Mallco Rancho	73%	20%
Villa Cochabamba/Montero	50%	25%
WEIGHTED TOTAL	65%	25%

notes: (*) a rough approximation is that at least one-half to two-thirds of child survival services are delivered in the home

(**)health program efforts not devoted to child interventions were devoted to other primary health care services

source: staff estimates, 1993

Table 8. Staffing Levels for ARHC's Three Established Programs, 1993

	numbers of staff				
category of provider	Carabuco	Mallco Rancho	Villa Cochabamba/ Montero	total	population per worker(*)
MDs	1.5	2.0	2.5	6.0	4,633
midlevel health staff	0.0	3.0	2.0	5.0	5,520
lower level health staff	10.0	3.0	7.0	20.0	1,396
support staff	2.0	1.0	1.0	4.0	6,950
administrative staff	2.5	3.0	2.5	8.0	3,475
all staff	16.0	12.0	15.0	43.0	647

note: (*) the total combined population of these three established program areas is 27,800

source: ARHC program records and census data

E. Simplified Assessment of Coverage of Child Survival Services

One of the advantages of a population-based health information system (HIS) is that it makes possible assessments of coverage by simply sampling records rather than carrying out household surveys. Of course, one must be confident that the records in the system accurately reflect the entire population. In the case of ARHC's health information system, the family's health information is contained in a family health folder which is filed by the number of the house and the name of the community. Vaccination coverage, for instance, can be assessed by simply taking a sample of family health records. This was done in Carabuco, for instance, in 1989, 1990, and 1992, and the results were almost identical to the results obtained from cluster sample household surveys conducted at the same time (see Table 9). Of course, independent household surveys are valuable to assure that the records in the HIS accurately reflect the population and also, of course, to collect additional information that may not be in the HIS.

VI. Discussion

The quality of the programs which ARHC has developed, as reflected in the coverage of services and mortality impact attained, appears to be well worth the modest extra added expense required by the CBIO approach. The resource requirements for implementing the CBIO approach, while somewhat greater than for more traditional approaches to primary care and child survival services, are nonetheless within the grasp of the limited resources available for many, if not most, developing countries today.

The findings from ARHC's three established program locations obtained by applying the CBIO approach have made it possible to distinguish very different groups of children according to their age at death and the medical cause of death. By focusing on those particular children at risk and the leading conditions responsible for death in that program location, the local staff can maximize the effectiveness of the resources available to reduce mortality. In Carabuco, for instance, the focus is now on respiratory problems in children under three months of age. There is now no compelling reason in Carabuco to continue growth monitoring of children beyond two years of age since there has not been for several years a death among a child 24-59 months of age which was related to infection or malnutrition.

Table 9. Comparison of Vaccination Coverage Levels Estimated by Household Surveys and by Sampling Family Health Records in Carabuco

year	percentage of children 12-23 months of age with complete vaccinations (*)	
	household survey results	review of health post records
1989	77%	64%
1990	86%	89%
1992	85%	89%

note: (*) complete vaccination refers to documented receipt of BCG, polio3, DPT3, and measles

source: cluster sample household surveys and reviews of samples of family health folders in Carabuco (a 10% systematic sample was taken in 1989 and a 20% sample in 1990 and 1992)

In Villa Cochabamba/Montero, on the other hand, the focus is now on the prevention of malnutrition and on the successful treatment of diarrhea among children under two years of age. Thus, this knowledge of risk factors is very helpful to programs in orienting their limited resources toward maximal impact rather than applying all known child survival interventions to all children under five.

ARHC's child survival programs are now, in 1995, approaching coverage levels of 90% and even greater. It is hard to envision that coverage levels of child survival services in local program population in the developing world could reach much beyond 90% unless similar levels were achieved throughout the country. This is because of the migratory patterns of low-income people. In Bolivia, for instance, mothers and their children migrate between the cities and the countryside, and there is a significant regional migration for seasonal farm workers as well.

One of the important lessons which ARHC field staff have learned in the application of the CBIO approach is the need to move slowly and gradually from a small pilot area to larger areas. Otherwise, staff would be overwhelmed with the volume of work to be carried out. Furthermore, the methods developed would likely not be suitable to application on a larger scale. Related to this is the obvious need to recruit village volunteers to assist with some of the work so that all of the essential tasks can be completed at a level of staffing that is appropriate for sustainability in the long run.

Because of the many advantages which the CBIO approach has provided for ARHC's field programs in Bolivia, there is a growing interest in the wider application of these concepts in other underserved areas. In an Expert Review Panel, convened by the PVO Child Survival Program of the U.S. Agency for International Development, the CBIO approach was reviewed in detail. The Panel recommended that this approach be applied on a broader basis in Bolivia and that it be tried on a provisional basis in other countries (Ofosu-Amaah, 1994). So far, this has not occurred, but ARHC is now eager either to apply the CBIO approach in new settings or to encourage other groups to field test the approach.

As ARHC now moves more vigorously into family planning and into tuberculosis diagnosis and treatment, the advantages of a strong home-based service delivery system have become even more obvious to field staff. The enthusiasm which ARHC's field staff have for the CBIO approach is one of its main selling points. It provides the health staff with a conceptual approach to designing and implementing field activities which results in a

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palpable sense of accomplishment- a sense of pride in a job well done and objective evidence that the aggressive outreach efforts have paid off.

A recent review of child survival efforts in Africa concluded that there is a need for mortality assessment of integrated programs that provide a package of child survival interventions. Another conclusion was that such assessments should be based on longitudinal prospective collection of vital statistics (Ewbank and Gribble, 1993, p.3). The CBIO approach represents one methodology by which health and family planning programs can integrate population-based child survival services with ongoing primary health care efforts for the entire community.

Although family planning was not permitted by the Bolivian government when ARHC began its programs, these restrictions have recently been lifted. Over the evolution of ARHC's programs, local interest in and demand for family planning services has increased notably as mothers have realized that more of their children than before are now surviving (Perry et al, 1994). The CBIO approach represents an ideal methodology for integrating child survival and family planning services since there is growing evidence that provision of family planning services in the home by women health workers can lead to very high contraceptive prevalence rates (CWFP, 1994).

Local health staff and their program directors may be reluctant to move from fixed delivery sites into aggressive community-based outreach activities because of the perceived additional effort and inconvenience involved. It has been ARHC's experience, however, that once the transition was made, these same staff members became vigorous proponents of the new approach.

VII. Conclusion

The CBIO approach provides a methodology for determining health priorities in an entire population and for developing a package of services which focuses upon health priorities identified by the community diagnosis. Through ongoing epidemiologic surveillance, made possible by routine systematic home visitation, child survival impact and mortality rates can be assessed.

The application of this approach by Andean Rural Health Care in its community health programs in Bolivia has led to strong progress in terms of both high coverage of child survival services and improvements in actual child survival. ARHC staff members have found this approach to be workable and highly motivating because it gives them the capability of using locally obtained information for planning program activities and for evaluating results.

The CBIO approach has the potential for helping child survival programs around the world to improve their effectiveness at a minimum extra cost. Experience in other settings outside of Bolivia in the application of this approach is now urgently needed.

The quality of the program which has emerged along with the coverage of services and mortality impact attained appears to be well worth the modest extra added expense. The resource requirements for implementing the CBIO approach, while somewhat greater than those for more traditional approaches to primary care and child survival services, are nonetheless within the grasp of the limited resources available for many, if not most, developing countries today.

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APPENDIX

I. Methodology for Weighting Program Results

Each of ARHC's three established programs have together a total program population or 27,800. Appendix Table 1 shows the overall populations of each specific program area and the relative percentages of the overall population in each program area.

In Appendix Table 2, the percentage of children enrolled in the program's HIS as determined by the presence of a growth

chart/immunization card for those children included in the household surveys. The overall percentage of children enrolled is determined by weighting the percentage of children in each specific program area by the population weight for that program. This is done by multiplying the percentage enrollment for the specific program area by the weight factor and dividing by 100. The result (shown in the third column) is in fact the percentage of the entire group of children surveyed (for all three program areas) who are enrolled in that specific program area. Thus, the sum of the column is the overall percentage of children enrolled.

This same methodology is used for Tables 3 and 4, to determine the vaccination coverage as well as the nutritional monitoring coverage for the entire combined program area.

Appendix Table 1. Population of ARHC's Three Established Programs and Calculation of Their Relative Population Weights

program area	total population	percent of total
Carabuco	9,500	34.2%
Mallco Rancho	5,800	20.8%
Villa Cochabamba/Montero	12,500	45.0%
TOTAL	27,800	100.0

source: program census data

Appendix Table 2. Percentage of Children 12-23 Months of Age Enrolled in the HIS and with Growth and Vaccination Charts

program area	percentage of population enrolled in each specific program (*)	population weight (**)	percentage of combined program population enrolled in specific program (***)
Carabuco	97.8 (179/183)	34.2	33.4%
Mallco Rancho	80.8 (76/94)	20.8	16.8%
Villa Cochabamba/ Montero	97.4 (151/155)	45.0	43.8%
	WEIGHTED TOTAL	100.0	94.0%

notes: (*) actual n's shown in parentheses
(**) derived from Appendix Table 1
(***) [(column 1 x column 2)/100

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Appendix Table 3. Coverage of the Complete Series of Vaccinations Among Children 12-23 Months of Age

program area	coverage in each specific program (%) (*)	population weight (**)	percentage of coverage in combined population attributed to specific program area (***)
Carabuco	84.9 (157/185)	34.2	29.0%
Mallco Rancho	74.5 (70/94)	20.8	15.5%
Villa Cochabamba/ Montero	76.8 (116/151)	45.0	34.6%
	WEIGHTED TOTAL	100.0	79.1%

notes: coverage is calculated by dividing the number of children 12-23 months of age with documented receipt of the complete series of vaccinations by the total number of children 12-23 months of age in the study x 100
(*) actual n's shown in parentheses
(**) derived from Appendix Table 1
(***) [(column 1 x column 2)/100]

Appendix Table 4. percentage of Children 12-23 Months of Age With at Least Three Growth Monitorings During the Previous 12 Months

program area	percentage in each program areas monitored three times (*)	population weight (**)	percentage of combined prgm population monitored in specific program (***)
Carabuco	85.4 (158/185)	34.2	29.2 %
Mallco Rancho	71.3 (67/94)	20.8	14.8 %
Villa Cochabamba/ Montero	80.6 (125/155)	45.0	36.3 %
	WEIGHTED TOTAL	100.0	80.3 %

notes: coverage is calculated by dividing the number of children 12 23 months of age with documented receipt of the complete series of vaccinations by the total number of children 12 -23 months of age in the study x 100
(*) actual n's shown in parentheses
(**) derived from Appendix Table 1
(***) [(column 1 x column 2) / 100]

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HEALTH INFORMATION SYSTEM: THE EXPERIENCE OF SAVE THE CHILDREN/BANGLADESH FIELD OFFICE

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Summary

The Health Information System (HIS) supports services to 160,000 people in the Bangladesh Field Office (BFO). Like the prototypical Save the Children HIS, it rests on three essential elements: a census, identification of risk groups, and longitudinal monitoring of vital events and health indices. The census enrolls families through Family Registration Forms, Monthly household level demographic surveillance updates catchment area population (Birth and Death Reporting Forms). Rosters of risk groups (0-2 Year Old Children and Fertile Couples) target and track health activities. Nine other forms help the Family Health Promoter organize and summarize her activities. Monthly Programme Monitoring Reports compare actual knowledge, practices, or coverage to targets by community allowing focused attention to lagging programs and populations. BFO distinguishes between service delivery and research in that only 30% of the total population (from 17 randomly selected "sentinel" communities) is computerized; the remaining 115 000 are tracked by a manual system. Computerization facilitates analyzing longitudinal trends in mortality and service coverage. This census-based system (whether manual or computerized) has served as a sampling frame for surveys directed at specific problems and for supervisory lot quality assurance surveys. In sum, BFO's HIS monitors programs and beneficiaries, raises community awareness and involvement and guides program planning and implementation

Save the Children (SC) technical advisors have emphasized the advantages of health information systems based on complete community censuses and periodic longitudinal monitoring of high risk groups.

Internationally, the number of persons enrolled in SC census-based programs currently totals approximately 496,000 (160,000 in Bangladesh; 140,000 in Mali; 48,000 in Nepal; 43,000 in Honduras; 40,000 in Haiti; 40,000 in Malawi and 25,000 in Burkina Faso). A computerized system tracks approximately 60% (295,000) of these individuals. In addition to these rural sites, SC also maintained a community-based system in Jakarta, Indonesia between 1986-1991 covering about 62,000 persons in three slum communities. The Bangladesh program is the largest, and it provides useful lessons.

Save the Children's HIS: 3 Essentials

The Bangladesh Field Office (BFO), is typical for SC in that its health information system has three basic components: (1) a census which enrolls all community residents; (2) identification of individuals in high risk groups (usually women of reproductive age and children younger than age five years) to target health interventions and (3) on-going, periodic monitoring of vital events in the community and specific health indices (e.g., immunization status, ORT training, use of contraception) among high risk groups. Data on health indices are recorded in outreach workers' rosters which facilitate planning and delivery of services either by household level workers, by community-based immunization programs, or by clinic-based providers. Data on vital events obtained through routine home visiting are used to update the census at least annually. Data on program rosters are updated monthly.

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Target groups for whom health data are periodically collected vary according to intervention. For example, programs to prevent or treat endemic diseases may longitudinally gather information on all community residents. The periodicity of monitoring depends on a combination of factors: distance between houses, resources available to the program (e.g., number of outreach workers, whether outreach workers are paid or serve as volunteers) and the nature of program interventions. Census-based systems need not be limited to the collection of health and demographic data. Indeed, the BFO collects information on socioeconomic factors that can affect health, such as family income, household assets, household construction, land holding, women's literacy, drinking water source, and sanitation (Table 1).

Table 1: Household Level Data

Homestead/Cultivable/Fallow Land holding
Fallow Land holding
Annual Income
Consumption Self-covered/Food Shortage
Savings/Debts
Drinking/Washing Water Source
Latrine Type
House Type/Separate Cow shed, Kitchen
Own TV, Cassette Player, Bedding, Bedstead
Lighting

In order to effectively manage its health and development programs, Save the Children has recognized the importance of quantitative indicators to demonstrate program impact. In response to the well recognized need to collect timely and valid data SC has developed a unique computer program, ProMIS, to assist in managing and analyzing data for defined populations. Since its development in 1986, PMIS and its updated version, ProMIS, have assisted program planning and implementation in many of Save the Children's programs throughout the world, including Bangladesh. An important feature of ProMIS is its ability to produce rosters (lists of individuals) that meet specific criteria. For example, ProMIS can generate a list of children under age 5 years and their vaccination history or a list of women between ages of 15 to 49 years and their pregnancy status outcome. These lists help target interventions to those in greatest need.

The Manual System

A manual health information system tracks household socio-economic variables and individual-level services for the entire population. For example, the **Family Registration Form** (attached) lists household members by name, age, marital status, occupation and education; identifies household by neighborhood (*para*) and village and designates head of household. For married women in the household, the enrollment form contains information regarding contraception, pregnancy outcome during the last two years, and details of any infant deaths.

Family health promoters (FHPs), visit approximately 350 families at least once a month throughout the entire program area (population 160,000). They update vital events (births, deaths, in/out migrations), immunization status, pregnancy follow up, contraceptive usage, and health related training on a monthly basis. They note information in a number of records and rosters.

For example, the FHPs record births on attached **Birth Registers** (manual system) or **Birth Reporting Form** (computerized system - see below) which summarizes the monthly birth experience, including: name of mother, last menstrual period, gravity, pregnancy monitoring, date of delivery, delivery attendant, delivery place, and delivery outcome. In each case the unique identifying number of both mother and infant are noted.

The rosters assist FHPs in training families and in helping them to access appropriate locally available services. The **List of 0-2 Years Children and Immunization Status** (attached) contains name, identification number, date of birth, immunizations and morbidity surveillance information for each worker's target children. The **List of Fertile Couple and Contraception Status** (attached) summarizes reproductive history, tracks monthly contraceptive use, guides follow up, targets family planning motivation, and identifies pregnancies for prenatal care.

Other forms help FHPs in their work. The **Village Workers Daily House Visit and List of Work Performed** (attached) sheet facilitates planning and self-monitoring. The **Date of Conducting Training Session/ Targeted Subject** (attached) allows workers to

target households in need of training in key health topics.

Forms not attached include: Death Register, Death Reporting Form, Monitoring Form for Training Programmes: Group/Family Training, TT List for 15-45 Years Women, List of 6 Months-6 Years Children & Distribution Status of Vitamin A Capsule, Pregnancy Monitoring, Individual and Family Migration Form, and Monthly Reporting Form. Table 2 summarizes individual level variables routinely longitudinally collected.

Table 2. Individual Level Data

Name
Sex
Date of Birth
Relationship to Head of Household
Marital Status
Years of Completed Education
Primary and Secondary Occupations
Date, Primary & Secondary Cause of Death
Migration Date and Type
Immunization Date and Type
Last Menstrual Period Date
Pregnancy Reporting Date and Outcome
Pregnancy Attendant
Place and Date of Delivery
Family Planning Method and Date Adopted
Weight and Date of Weight

The Computerization Debate

SC's health program in Bangladesh has implemented its community-based system in a manner which recognizes that the functions of facilitating service delivery and generating epidemiologically valid data for research on vital rates are independent activities.

Historically, The Bangladesh Field Office (BFO) has passed through two phases of computerizing its health information systems. First, the BFO computerized the baseline census, vital events and program update data on a population of approximately 75,000 individuals from 1986 to 1991 (the earlier "PMIS data set"). Second, starting in 1992 it has maintained computerized records for sentinel-site populations (the current "ProMIS data set").

Computerization facilitates analyzing longitudinal trends in mortality and service coverage but imposes an additional cost on the program. SC's BFO has recognized that it is not necessary to computerize vital events data for the entire program area in order to monitor trends in birth rates and infant and child mortality rates. A population base of at least 20,000 is generally sufficient to allow observation of trends in such rates without having these trends obscured by annual fluctuations. To follow trends in maternal mortality, however, a population base of at least 100,000 would be needed. The Bangladesh Field Office Health Program Directors chose to computerize the records of 45,000 persons (approximately 30% of the total program population), living in areas covered by 17 village health workers who were randomly chosen from the 104 serving the entire population. Each sub-population they cover is considered a sentinel population. Mindful of the "design effect" arising from a limited number of sentinel points, the total "computerized" population far exceeds the minimum (20,000) to achieve representativeness. Thus, the program monitors approximately one third of the total population for important community variables. Data from the 17 sentinel sites have been used for report production, program monitoring and research.

Meanwhile, the community-level manual system used throughout the impact area has stressed ease of use and sustainability. The computerization further allows managers to compare reports based on comprehensive manual reporting and computerized sentinel reporting.

Other Uses of HIS

Census-based systems and presentations of community-based data in quantitative formats do not preclude other approaches to data collection and presentation; rather they may even facilitate. A census-based information system can act as a sampling framework for surveys focused on specific problems. Qualitative studies are often conducted to better define the underlying reasons for important health problems to inform the design of health care interventions. For example, in areas where census-based data show that few couples practice family planning, in-depth interviews and focus group discussions can explore whether the low prevalence of contraception reflects lack of accessible services, traditional beliefs or other factors. In another operations research study, the BFO's ProMIS data set was used to analyze differential uptake

of immunizations in different places within the SC program area.

The data base is a source of information for other research as well. For example, one study examined the association between participation in Women Saving Groups and child health and fertility behavior. In addition, action research used the household and individual data base of the health information system to investigate adolescent health, birth practices, maternal mortality and maternal nutrition.

Recently, the BFO introduced participatory appraisal techniques into its program operation. Villagers produced maps of defined neighborhoods to identify households' demographic and health characteristics to target interventions and to allow self-monitoring. Linking the existing quantitative computerized system and this participatory more qualitative system is under active review.

Supervision for Quality Assurance

The FHPs also prepare monthly activity reports which are reviewed by their supervisors in the field. The quality of data must be good since decisions are based upon them. Likewise the reports must be timely. Each report is released within 6 weeks of the period in question. For example, the central office requires the aggregated data for January by 15 February. Data checking is completed by 1 March, and the report appears by 15 March.

The Bangladesh Field Office has built into its HIS a quality assurance component. The impact area supervisors review and analyze the data collected and recorded by their FHPs. The coverage and validity of the HIS data is monitored by spot checks to compare the data reported by the FHPs to the actual conditions in the households. Lot quality assessment techniques are also used for monitoring the quality of data. These are applied semi-annually when supervisors and staff re-visit 5% of the households in randomly selected clusters or lots. These data are then compared with the data as recorded in the FHPs rosters and registers. Fixing a minimum acceptable level for the assurance of the quality of the data, the supervisors discuss with the FHPs the actual findings at the households in terms of service coverage and accuracy in data collection and recording. The supervisors take corrective measures where necessary, having identified areas, workers and/or training where situations are weak or special attention is necessary.

Data for Decision-Making

Computerized presentation (as distinguished from computerized tracking of individuals) of the data informs health workers about important issues, such as coverage rates, particular interventions requiring special attention and FHPs' performance. The monthly and quarterly graphical presentation of the program status communicates at a glance outcomes and activities related to different interventions by time and place. These bar charts require less effort to interpret than large tables of figures. Staff at all levels can assess, target and monitor risk groups. Accompanying reports, also guided by input from the field, help management staff direct attention to problem areas.

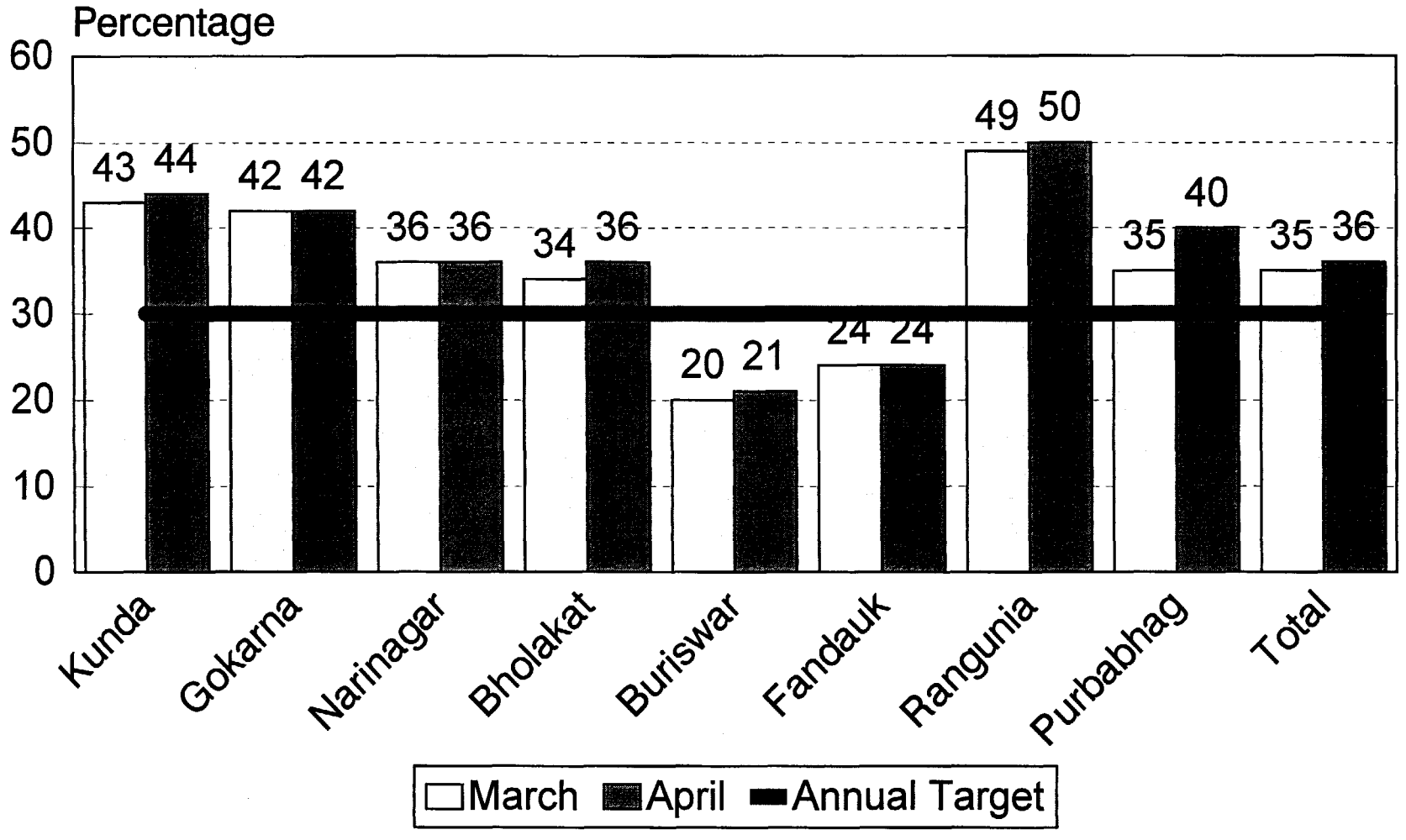
For example, the BFO Program Monitoring Report for April 1995 showed that the overall family planning usage rate was 36 percent. As can be seen in Figure 1, all unions except Buriswar and Fandauk had family planning usage rate surpassing the target of 30%. Based on these results, the BFO staff concluded that in Buriswar "there remains much scope of improvement in contraception usage where one third of the total target were not using contraceptives." On the other hand, in Purbabhag the rate rose to 40% from the March level of 35%. Although the number of diarrhea cases increased in the month of April (not shown), in most unions there was nearly 100% appropriate management of diarrhea (Figure 2). Management of acute respiratory infection was also generally good, but less so than diarrhea (Figure 3).

* * *

In conclusion, the SC-BFO's health information system monitors programs and beneficiaries, raises community awareness and involvement and guides program planning and implementation to positively impact the lives of Bangladeshis in their communities. Moreover, the computerized health information system (ProMIS) has allowed even greater analysis effects of its different programs.

Fig 1. Use of Family Planning Methods

Unionwise Coverage



Note: Decimals are rounded to the nearest one

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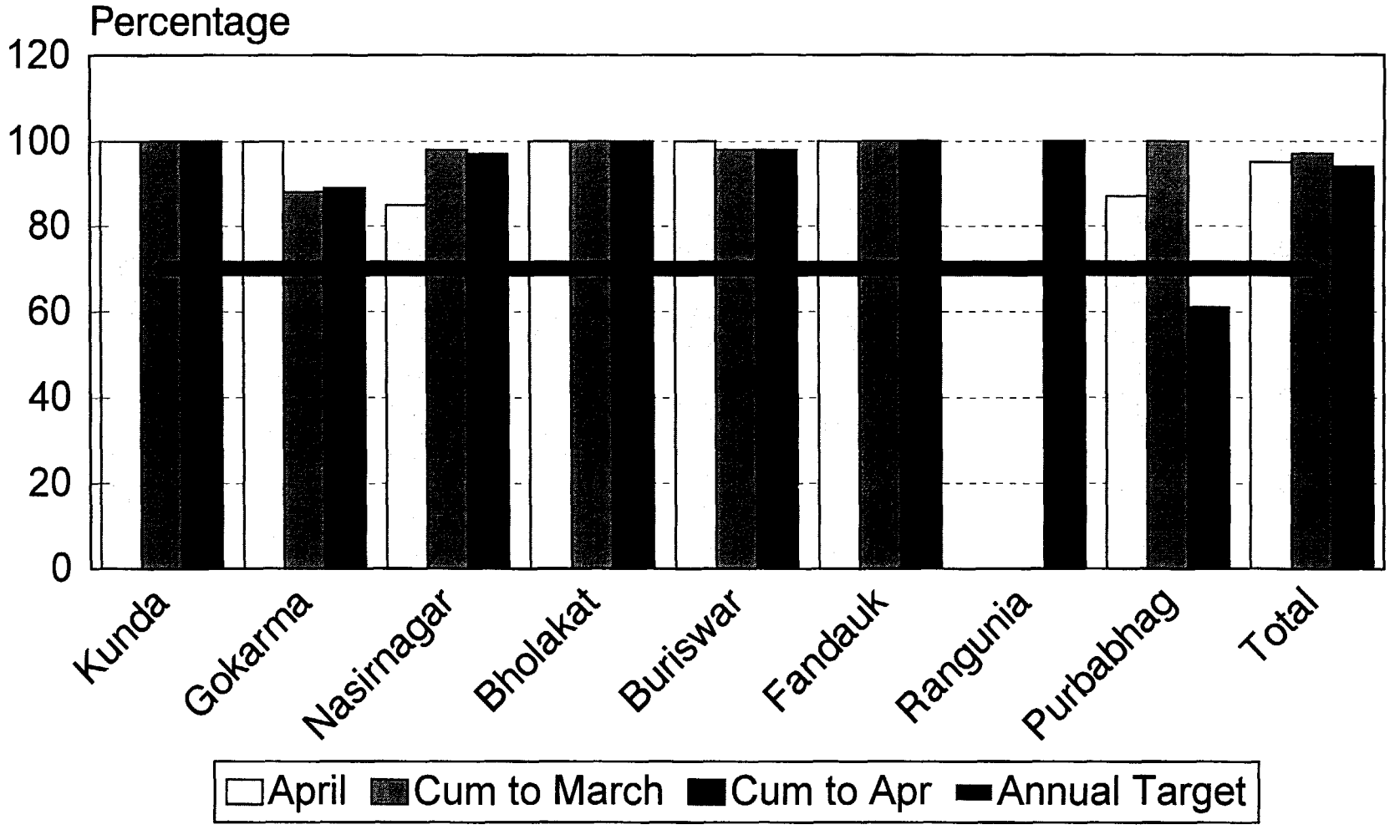
Fig 2. Management of Diarrhoea

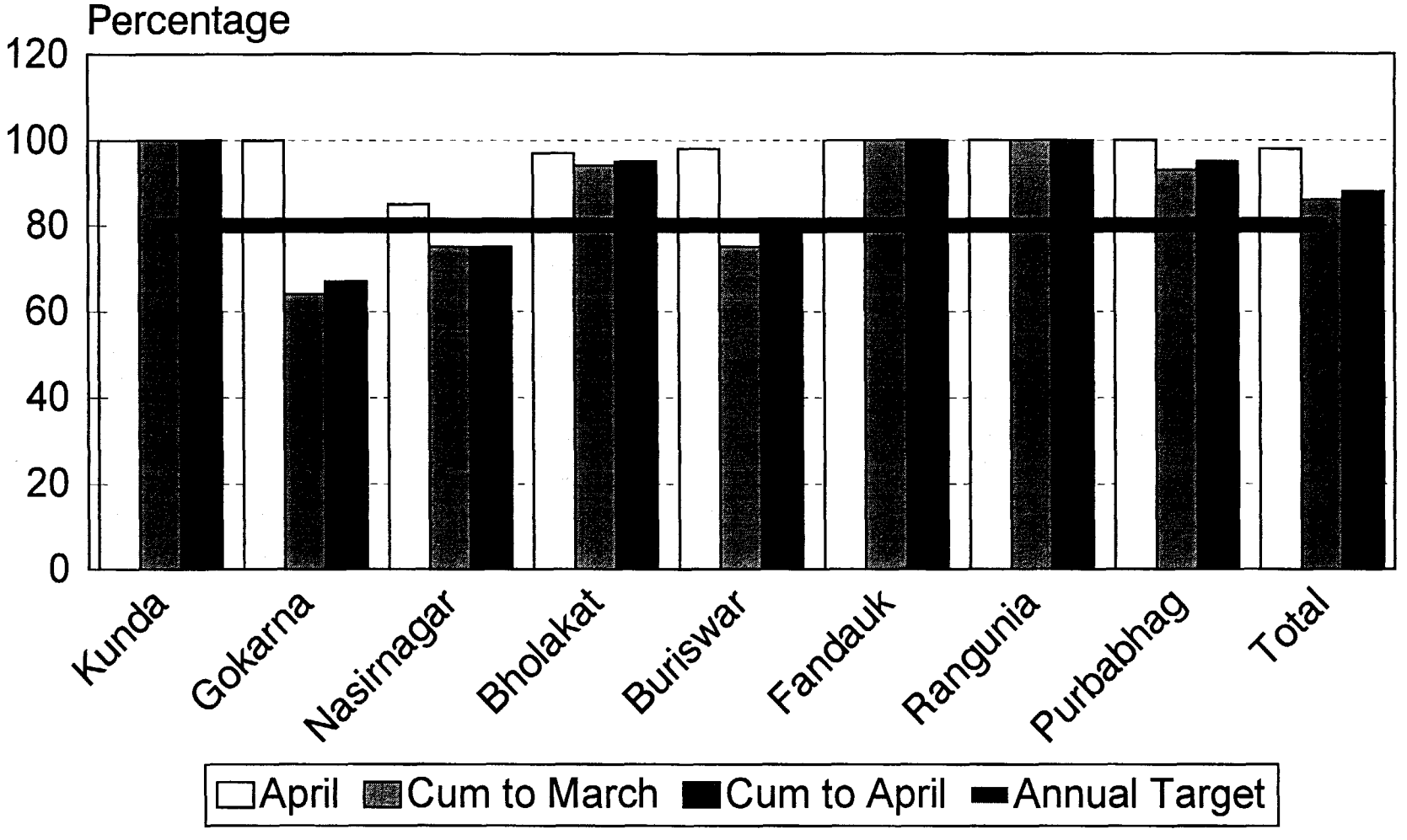
Unionwise Coverage



Note: Decimals are rounded to the nearest one

Fig 3. Management of ARI

Unionwise Coverage



Note: Decimals are rounded to the nearest one

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SAVE THE CHILDREN (USA)
FAMILY REGISTRATION FORM

Date of Registration: _____/_____/_____
Community Volunteer: _____

Target [ ] Non-Target [ ]
Program Area: Nasirnagar/Rangunia
Village: _____
House No.: _____

Sl. No.	Husband/ Father	Wife/ Mother	Cpl. No.	Name	Sex	Date of Birth	Relation to Household Head	Marital Status	Year: 1993				Year: ____				Year: ____				Remarks
									Occupation		Highest	In	Occupation		Highest	In	Occupation		Highest	In	
									Primary	Others	Class Passed	School Now?	Primary	Others	Class Passed	School Now?	Primary	Others	Class Passed	School Now?	
1																					
2																					
3																					
4																					
5																					
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For Ever Married Women Only:

SL. No.	Cpl. No.	Father's Residence				Use Family Planning Method		Pregnant Now?		What was the outcome of your last Pregnancy of past two years?						REMARKS
		Own Village	Own Union	Own Thana	Neighboour Thana	Yes	No	Yes	No	Misscarried (at how many months?	Child was born death (date)	Live Birth (Date)	If Child Died: Cause of Death/Symptoms	Date of Death	Age of Death (Month/Day)	

	Year: 1993				Year: ____				Year: ____			
Land Ownership	Own use	Rent out	Mortgage out	Total	Own use	Rent out	Mortgage out	Total	Own use	Rent out	Mortgage out	Total
Homestead												
Cultivable												
Pond												
Others												
Total Land:												
Does the family have a regular monthly cash income of Tk. 1000 or more?	[ ] yes [ ] no											
Did the family have any food deficit during the last one year?	[ ] yes [ ] no											
Ownership of household goods	[ ] Radio/Cassette/TV [ ] Winter Clothing/quilt [ ] cot/bed [ ] bicycle, boat/bullock [ ] Sari ___ per woman											
Wall type	[ ] brick [ ] bamboo [ ] CI Sheet [ ] Wood [ ] mud [ ] Straw [ ] Other ____											
Roof type	[ ] Brick [ ] CI sheet [ ] Tile [ ] Bamboo [ ] Straw [ ] Other ____											
Facilities	[ ] Separate cowshed [ ] Separate kitchen [ ] Electricity [ ] Latrine [ ] Tubewell											
Ownership of domestic animals/birds	[ ] Cow/buffal o [ ] goat/sheep [ ] horse/mule [ ] poultry birds [ ] other											

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SAVE THE CHILDREN (USA)

PRIMARY HEALTH CARE PROGRAM
BIRTH REGISTER

From _____ *Month,* _____*Year, To* _____ *Month,* _____ *Year*

Impact Area: _____
Village: _____
Para/Unit No.: _____
Name of Worker: _____

House-hold No.	Target OR Non-Target	Name of Mother	Sl. No. of Mother in family	Age of Mother at the time of delivery	Date of delivery	Outcome Delivery			Child				Birth Information			Was Pregnancy Monitored? From	
						Miscar-riage	Still Birth	Live Birth	Sex	Birth order	Name	Sl. # in Family Register	Who Delivered	Where	Was there any problem? If yes, what type of problem	Which month? How many times?	REMARKS

Save the Children (USA)
Birth Reporting Form

For the Month of: _____

Union Code [ ] [ ]

Village Code [ ] [ ]

House No.	SI. No.	Name of Mother	Date of Delivery	No. of Pregnancy	Delivered by (Code) (A)	Place of Birth (Code) (B)	Pregnancy Outcome (Code) (C)	Pregnancy Monitoring		1st Date of LMP	Name of Child	Sex (Code) (D)	SI. No. of Child
								Duration of Pregnancy at first monitoring	Number of Monitoring				

(A) Delivered by
1. MBBS/MA/MWV/NMW
2. Trained Traditional Birth Attendants
3. Village Health Practitioner
4. Untrained Birth Attendants
5. Close Relatives

(B) Place of Birth
1. Hospital/Clinic
2. Own House/Village
3. Other Village under SC area (village code)
4. Other Places

(C) Pregnancy outcome
1. Live birth
2. Still birth
3. Miscarriage/abortion

(D) Sex
Male = M
Female = F

Prepared by: _____
Date:

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SAVE THE CHILDREN (USA)

PRIMARY HEALTH CARE PROGRAM

LIST OF 0-2 YEARS CHILDREN AND IMMUNIZATION STATUS

January, _____ Year - December, _____ Year

Impact Area: _____
Worker: _____

House-hold No.	Name of Child	SI. No. in Family Regis-ter	Date of Birth	Sex	Target OR Non-Target	Children Suffered from Any Diseases? (Diarrhea, ARI, Measles/Fever)												Immunization Status & Date								Remarks
						Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	D 1	P 2	T 3	PO 1	LI 2	O 3	Measles	BCG	

SAVE THE CHILDREN (USA)

PRIMARY HEALTH CARE PROGRAM

LIST OF FERTILE COUPLE AND CONTRACEPTION STATUS

January, _____ Year - December, _____ Year

Impact Area: _____
Worker: _____

House-hold No.	Name of Female Partner	Sl. No. in Family Regis-ter	Age	Educa-tion passed which grade?	Target OR non-Target	Age at Marri-age	No. of Alive Children		No. of Dead Children		No. of abor-tions & Still born	Total No. of births	Menstrual Cycle and Contraceptive Status												Remarks
							Boy	Girl	Boy	Girl			Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	

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SAVE THE CHILDREN (USA)

VILLAGE WORKERS DAILY HOUSE VISIT
AND
LIST OF WORK PERFORMED

Name of Worker: _____
Unit/Para: _____
Village: _____

Date	Planned Activities	Target Household/ Which Household	Remark/ How much accomplished/ Any new information?

SAVE THE CHILDREN (USA)
DATE OF CONDUCTING TRAINING SESSION
TARGETED SUBJECT

House-hold No.	ORT Management	Family Planning	Weaning Food	Safe Potable Water	Infants food and Nutrition	Diet of Pregnant/ Lactating Mother	ARI	Sanitary Latrine	Immuniza-tion	Others

Summary

Background: *Partnerships between government and non-governmental organizations (NGOs) are necessary to provide health services to the poor, particularly in developing countries. NGOs have long provided substantial health care in Haiti. When the Ministry of Health requested NGOs to collaborate towards improved Primary Health Care (PHC) in 1982, the Association des Oeuvres Privees de Sante (AOPS) was born.*
Methods: *AOPS' strategies included: targeting children and mothers; registering total populations (usually 10,000 per NGO); providing services at centrally located rally posts; monitoring and evaluating, and training physicians in community medicine (so that they, in turn, would train community health workers (CHWs), manage the health team and provide services at the rally posts). CHWs conduct censuses, assess risk, assist service delivery and provide follow-up and home visits for health promotion and vital event surveillance.*
Results: *Between 1983-1988, 28 NGOs began PHC activities covering 400,000 people. All enrolled families through baseline censuses. Measles vaccination coverage increased from 0-1% of children to 5-56% in all but one site. Impact in childhood nutrition, family planning and oral rehydration usage was mixed. Of the 16 NGOs functioning for at least a year, only one ceased permanently. Remaining challenges involved physician turn-over, cost-recovery and CHW communication skills, compensation and transport.*
Conclusions: *The uneven success prompted a strategic review to decrease CHW workload, including: (1) focusing community-based surveillance to identify and follow pregnant women only and (2) identifying maternal characteristics associated with high risk of infant death. [eds.]*

MOBILIZING PRIVATE VOLUNTARY ORGANIZATIONS FOR PRIMARY HEALTH CARE IN HAITI[1]

ANTOINE AUGUSTIN, MD*, JOE WRAY, MD**, JAMES ALLMAN, PHD**, REGINALD BOULOS, MD*** AND JON ROHDE, MD****[2]

The thirty-eighth World Health Assembly, held in Geneva in May 1985, focused attention on the need for collaboration between non-governmental organizations (NGOs) and governments in implementing the global strategy for primary health care (PHC) and the achievement of the Alma-Ata Conference goal of Health for All by the Year 2000. The government of Haiti had in fact anticipated this when, in early 1982, the MSPP (Ministry of Health and Population) convened a meeting of NGOs delivering health care in Haiti, and explicitly solicited their participation and assistance in improving and extending PHC delivery in Haiti by focusing on a few priority interventions. Following that meeting, *L'Association des Oeuvres Privees de Sante,* (AOPS, The Association of Private Health Organizations) was established in order to organize and support the NGOs willing to undertake such efforts. Since early 1983, 80

[1] This report is based on a paper (Augustin A, Allman J, Lyman-Fenn T, Wray J. *Selective Health Surveillance at the Village Level: An Applied Demographic Approach to Assess the Effectiveness and Impact of Low Cost Primary Health Care in Rural Haiti)* presented at the Population Association of America Meetings, 28-30 March 1985, Boston, Massachusetts, USA.

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Activities reported here were supported in part by a Cooperative Agreement with USAID (#521-0169)

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NGOs have joined AOPS and 40 of these are committed to provide PHC services. Population-based community health outreach services are now reaching over 600,000 persons. An additional 400,000 persons are now covered on an outreach basis by programs which have not registered their target population.

This paper first describes the approach developed by AOPS in response to PHC service delivery needs in Haiti, in the context both of the situation in the government (public) sector and also that in the NGO (private) sector. We then present several assumptions that underlie the approach, review some prior experience in Haiti that contributed to the methodology, and then describe the implementation of the approach. Finally, a review of the results obtained is presented and problems encountered are discussed.

1. The Situation in Haiti

The Republic of Haiti shares the island of Hispaniola with the Dominican Republic. It has a population of 5.9 million people, with 74 percent living in rural areas. The Port-au-Prince metropolitan area has a population of 1 million people (Institut Haitien de Statistique, 1983). Table 1 gives an estimate of selected health and population parameters.

Of the estimated 100,000 deaths which occurred in Haiti in 1985, over 45,000 were in children under five. Of these, 27,000 children died before their first birthday. Table 2 provides estimates of the age distribution of deaths during the first five years of life in Haiti (Augustin, Clesca, Lerebours, 1985).

Diarrhea, the number one cause of death in infancy and childhood, is a disease endemic to this area. The reported occurrence of diarrhea among children under five "during the last two weeks," as shown in Table 4, ranges from 21% to 54% (Allman, 1985; Boulos, 1985; Augustin, 1985; Corail, 1985; Cayemittes and Ward, 1985; Lerebours, 1985).

2. PHC in the public sector

Haiti is one of the 134 countries that participated in the WHO/UNICEF Conference on Primary Health Care held at Alma-Ata in 1978. Long before that, however, the government of Haiti, with a variety of international donor assistance, had been struggling to improve health services delivery. Haiti's problems were typical of those in Third World countries: how to build the infrastructure required to shift from an urban-centered, cure-oriented system to a system that can make essential preventive and curative services accessible to its rural population. In spite of constant resource constraints as stringent as any in the Western Hemisphere, real progress has been made and some vertical programs have enjoyed considerable success. Nevertheless, as the Ministry of Health and Population moved to improve and extend PHC delivery in the early 1980s, in response to the Alma-Ata Conference, its efforts had to be carried out in the context of continuing serious resource constraints.

Two of the many previous attempts to improve PHC in Haiti are especially relevant here. The training of government-paid community "health agents," each of whom was to provide village-based curative and preventive services to approximately 300 registered families under the supervision of a fixed-facility-based government auxiliary nurse, was an important component of the USAID-supported Rural Health Services Delivery Project. A key concept in the utilization of the health agents was the provision of preventive services at "rally posts," convenient places of assembly where the agent would meet 20 to 30 mothers and their children at monthly intervals to carry out growth monitoring and nutrition education, immunization, family planning, etc. The rally post approach was based on a pilot project carried out in Petit-Goave, Haiti, in the late 1970s by the MCH division of the Haitian MOH, with technical assistance from Dr. Warren Berggren of the Department of Population Sciences, Harvard School of Public Health (Berggren et al, 1982). The project demonstrated that in addition to monitoring the growth of children at rally post gatherings, other PHC services, including immunization, family planning services, and nutrition and health education, could be provided effectively at these gatherings, with substantial improvement in population coverage and efficiency.

The second relevant event was the announcement in 1982 by the Minister of Health of the *Nouvelle Orientation de Sante,* a health policy calling for emphasis on six priority problem areas in PHC: for infants and children, diarrheal diseases, malnutrition and immunizeable disease; for adults, high fertility, tuberculosis and malaria (the latter also to apply to children) and a strategy for delivering these services that, among other things, called for increased participation of NGO health groups. This policy was endorsed by the Ministers of Health who have served since then and remains the focus of efforts to improve PHC in Haiti.

3. Health Care and the Private Sector in Haiti

For decades much of the health care available in Haiti, especially in rural areas, has been provided by NGOs, many of them supported by religious groups. More than 200 such programs have been identified.

Usually serving a small geographic area, they are typically hospital or clinic-based, heavily curative in orientation, operated by a small staff of physicians and/or nurses and, like the public sector, constrained by financial resources and limited in outreach. In 1982, these organizations operated 49 percent of the rural health facilities and accounted for an estimated 1.8 million out-patient visits (for an estimated population of 4 million persons), with expenditures of around six dollars per capita per year. Most of the visits were for curative treatment and service statistics revealed limited success in preventive services. For example, in the North Health District, with an estimated under-5 population of 120,000 in 1982, service statistics from private institutions revealed that well under 10 percent had received any immunizations, less than one percent of the under five children were being weighed monthly and ORT was rarely used. For an estimated 30,000 pregnant women, under 1000 prenatal visits were reported and less than 6 percent of eligible couples were using a modern method of contraception (Binette, 1982).

In this situation, many of the NGO physicians, nurses and program directors were painfully aware of the need for more effective efforts. Given their limited resources, however, and the constant demand for curative services at their facilities they simply saw no way to do things differently, in spite of continuing efforts to connect the public and private systems, dating back to the 1960s.

In addition, a few of the NGOs had made serious attempts at improved PHC outreach. Two of the largest private operations, the Hospital Albert Schweitzer, in the Artibonite Valley, and the Complexe Medico-Sociale of Cite Soleil (formerly Cite Simone), an urban slum near Port-au-Prince, have large, well-established programs. At the Schweitzer Hospital the program was initiated in the late 1960s by the Berggrens. Over the years it has evolved and expanded; today PHC services are delivered at rally post gatherings by community health workers who have been extensively trained and operate with almost no direct supervision, but refer cases to senior staff at fixed facilities when necessary. At present a total population of around 160,000 rural Haitians is served in this program in the Albert Schweitzer Hospital catchment area.

In Cite Soleil, the Complexe Medico-Sociale serves a slum population through a system that includes three large health centers, an 80-bed hospital, a 100-bed nutritional rehabilitation unit, as well as community, youth and vocational training centers. Over 100,000 persons are registered and PHC activities are fostered by paid community health workers who gather targeted populations for preventive services at the health centers and carry out follow-up activities in the defined populations for which they are responsible. Using this approach, impressive levels of coverage have been achieved. For example, a sample survey carried out in mid-1985 revealed that 95 percent of mothers knew about ORT and 78 percent of them reported having used ORT to treat the most recent episode of diarrhea in one of their children. Other achievements have not always been so dramatic but the directors of the Cite Soleil program, as well as many outside observers, are convinced that outreach activities, based on total population registration, have increased coverage and effectiveness tremendously.

4. The recent public-private link in Haiti

The explicit request for NGO health organization participation in improving and extending PHC services, made by the Minister of Health of Haiti in late 1982, occurred in the context of PHC efforts in the public and private sector as outlined above.

The response of the NGOs was generally positive, but there were both questions about how best to participate effectively and also doubts about the feasibility of attempting to take on more responsibility. After some discussion among the NGOs, it was agreed that an organization should be established to coordinate efforts and develop an approach to improve their performance in PHC delivery - and *L'Association des Oeuvres Privees de Sante* (AOPS) was born.

5. The AOPS Rationale

In planning a "package" of PHC activities that could be recommended to NGOs, the fundamental need was for an approach that offered a reasonable likelihood of success and was feasible to implement within the very real resource constraints of the NGOs. Some of the assumptions that governed planning of the AOPS are worth spelling out:

a. ***Focus on infants, children, and mothers.*** The PHC interventions stressed in the Nouvelle Orientation of Haiti's MSPP were oriented toward the needs of infants, children and mothers. The AOPS approach was planned with a similar focus because in Haiti (as indeed in most poor populations of the Third World - whether urban or rural) it makes eminent sense. Most of the gross excess of mortality in those populations is in fact occurring in young children and much of that mortality is potentially preventable by the application of a short list of relatively simple and inexpensive interventions - namely, those in the

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Nouvelle Orientation.

b. ***Total population registration***. As long ago as 1971 the value of a total population-based approach to health service delivery was noted, not only to provide baseline data for reliable evaluation of coverage and utilization of services, but also, and more importantly, as an effective screening tool for identifying sub-populations in need of special care and to make it possible to follow up non-participants (Wray, 1971). Subsequently, after review of health and nutrition interventions for which adequate data were available for impact evaluation, Gwatkin et al. (1980) noted that a consistent feature of effective projects was vigorous outreach, based on total population registration, and resulting in remarkably complete population coverage.

The feasibility and usefulness of such an approach in a country like Haiti had been demonstrated by the experience at Albert Schweitzer Hospital (Berggren et al, 1982), the MSPP (DSPP, 1982) and by the experience of the Complexe Medico-Sociale in Cite Soleil (Boulos et al., 1985). These programs, however, like many of those reviewed by Gwatkin et al., could mobilize resources far in excess of those available to most of the small AOPS member organizations. Thus AOPS had to devise approaches that could be carried out by small institutions.

c. ***The Rally Post approach***. The typical NGO health organization in Haiti has a staff that does not exceed one or two physicians or nurse practitioners, one or two auxiliary nurses and a record keeper. Often the physicians seconded by the MSPP are only one or two years out of medical school and are hospital and curative care oriented; the auxiliary nurses are likely to have had nine months of training at most; the programs are usually managed by a priest, a nun, or the pastor of a Protestant church, who have many other duties besides managing a health center (Augustin, 1985). It has been abundantly documented that a fixed facility health program has an extremely limited effect beyond a very short distance (King et al, 1956; Fredriksen, 1971; Rahaman et al, 1983). The question was how an NGO program with a small, busy staff could reach out to cover its population effectively.

It was clear that a substantially more efficient method of delivering preventive services was needed and, fortunately, a model for such a method was available in Haiti. As noted, the Berggrens had initiated the rally post scheme in Haiti in the late 1960s (Berggren et al., 1982). Subsequently the model had been refined by the MSPP of Haiti in another rural area, Petit-Goave, with technical assistance from the Berggrens. This "rally post" approach, modified later to be incorporated in the MSPP Rural Health Service Delivery project, appeared to provide major elements that could be replicated by the average NGO (Augustin, 1985).

d. ***Strong emphasis on monitoring and evaluation***. It has been noted that just as there is a well recognized obligation in the clinical care of patients (not always met, to be sure) to monitor their progress regularly to be sure that the response to therapy is satisfactory, so a similar obligation to monitor progress exists for those responsible for the care of populations (Wray, 1970). Monitoring should provide answers to two important questions: are the health care activities having the desired effect, and is the target population adequately covered? Other than in relatively generously funded experimental field studies - Narangwal, Danfa or INCAP, for example - this is almost never done. The obvious requirement for total population registration and follow-up and the equally obvious difficulties in doing so make it seem impossible, almost utopian even to suggest it, to most people responsible for the care of rural populations. The result is that the vast majority of PHC programs can only be evaluated by counting activities or making estimates, and often even that is not done.

In planning the AOPS approach, however, there was both the determination to provide services on the basis of total population registration and targeting of particularly vulnerable groups and also a commitment to develop a feasible method of evaluation that would allow each NGO health group to measure its own progress and effectiveness. Fortunately there were in Haiti, as discussed above, demonstrations of the feasibility of such an approach. These demonstrations also reveal that there are enormous difficulties, but the potential value, both for improving service delivery and also for evaluating impact, seemed to justify serious efforts to overcome the difficulties.

The key elements of the AOPS strategy, then, can be summarized as follows:

- Emphasize a limited set of priority interventions focused on the needs of mothers and children: ORT, promotion of breast feeding, growth monitoring, immunizations, prenatal care and family planning.

- Total population registration with identification and follow-up of priority groups: women in union and their children under five.

- An outreach approach, with services provided to groups by a community health team and village-based health workers, delivered to target populations from a defined area gathered at a convenient location - a "rally post."

- Ongoing monitoring of coverage and impact of selected interventions, particularly ORT, immunizations, growth monitoring and family planning.

e. ***The AOPS Service Delivery Model.*** The challenge faced by AOPS was to develop an approach that could be managed and implemented, with minimum disruption of ongoing activities, by the institution. The focus was on making the program fit the capabilities of the manager and the resources of the organizations, rather than vice versa - thus avoiding the pitfall of designing strategies that required large infusions of external resources or were beyond the capabilities of those who were supposed to execute them. With these caveats in mind a basic service delivery plan was devised that included the following steps:

1. The participating NGO health care group identifies a geographic area with a population of 10,000 in the health district it serves. The area is then divided into sectors containing approximately 1000 people each. One of the NGOs had the resources to plan a program for an area with 30,000 people.

2. At the same time, the NGO sends a physician for one month of full-time training in Cite Soleil, where the Complexe Medico Sociale is operating the most comprehensive population-based community health program in Haiti. The training covers the entire methodology of the PHC activities.

3. In each of the sectors of 1000 people, community councils or other community groups are contacted by NGO program administrators and apprised of the project. Specific project goals, priorities, and detailed modus operandi are explored before agreeing on a final implementation plan. The community groups then participate in the selection of community health workers who are expected to be literate, older, stable and respected individuals who have an independent source of income.

4. On completion of their training, the physicians return to their districts where they initiate the training of the 10 or more community health workers who have been selected. Training lasts one month and includes:

- Census taking and registration of the total target population.

- Promotion of the essential elements of primary health care including the use of oral rehydration, growth monitoring, immunization, family planning and pre-natal care.

- Rally post operations. These posts are places of assembly where village residents meet the community health team from the village health center. The posts are easily accessible to the villagers and are the principal site where preventive services are provided.

5. Once trained, the CHWs return to their communities and carry out the initial census/population registration in the area for which they are responsible.

6. On completion of the registration, the CHWs review the records for each family with the NGO program manager and record keeper and draw up, from these records, a list of priority individuals in each group to be served (children under three years of age, pregnant women and women eligible for family planning) who are to be assembled each month at the regular rally post gatherings.

7. When preparations for rally post activities are completed and schedules for each sub-district are established, each CHW notifies his target population of the date, time and location of the rally post gathering in their area.

8. At the scheduled time and place, the CHW meets the NGO center team - usually a physician, an auxiliary nurse, a record keeper and several community volunteers - to assist in carrying out the rally post PHC activities.

9. Between the regular rally post gatherings, the CHW carries out necessary follow-up activities as instructed by the team. These include home visits when indicated, recording vital events, identifying newly pregnant women, selling ORS packets, etc.

6. Resources for Implementation

AOPS and its member NGO organizations, as well as the MSPP which had called for NGO participation in the first place, were committed to

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genuine collaboration and from the beginning it was understood that AOPS as the coordinating organization, the NGO itself, and the Ministry would contribute resources.

AOPS, with financial support from USAID, was able to provide a variety of resources for program planning, start-up, monitoring and evaluation including:

- The development of the basic plan.
- The one month training program for the technical director.
- Technical assistance in initiating the program.
- Census/registration forms and other record forms.
- Assistance in data management, analysis of results and evaluation of progress.
- The sum of $10,000 - one dollar per person in the total population to be covered - for start-up costs, to be used for equipment, supplies, renovations, CHW training and other expenses, at the discretion of the NGO program manager.

The Ministry, acting in accord with the principle that the NGOs were a fully integrated part of the Haitian PHC delivery system, agreed to provide other resources, mainly for program implementation, as follows:

- Personnel - physicians and/or auxiliary nurses - may be seconded to the NGO.
- Cold chain equipment and vaccines.
- Essential drugs and contraceptives.
- Growth charts and, if necessary, scales.

The NGO, to be eligible for AOPS assistance, must be registered with the Ministry and also have its specific community health program approved by district health officials. Thus, each NGO program is integrated into Ministry's district level health plans. In addition, the Ministry requires the participating NGOs to:

- Emphasize the priority interventions, as described above.
- Take responsibility for all or part of basic health services for a defined population in a specific geographic area.
- Supervise other health personnel, especially community health workers and volunteers (e.g., midwives).
- Train and supervise their paramedical personnel according to Ministry norms.
- Develop new programs and facilities in areas of the country not adequately served by the Ministry.
- Provide regular reports of health data and service statistics, using Ministry norms (DSPP, 1983).

7. Program Implementation

Implementation of the AOPS approach began in early 1983 and service delivery by the first group of participating NGOs began in June, 1983. These NGOs were recruited in a phased manner - 3 to 4 every three months. Thus, AOPS staff responsible for training and start-up technical assistance were not overloaded and later groups could learn from the experience of their predecessors.

Between June 1983 and October 1985, NGOs were recruited and activities began in 28 locations as shown in Table 3.

8. Program Accomplishments

a. ***Data Collection and Registration***. As noted earlier, monitoring and evaluation were considered essential to the AOPS approach. In practice, there has been considerable variation among the participating NGOs, due in part to differences in resources available and also to the level of interest of program managers and health care providers.

At a minimum, in addition to population registration, each NGO program is expected to maintain an updated registry of children under five and pregnant women, and to assess target population coverage for immunization, growth monitoring, pre-natal care and family planning at regular intervals. Programs also maintain a register of users of modern methods of contraception from which a contraceptive prevalence rate can be calculated.

NGOs with greater capabilities and interest maintain a closely supervised vital events registry where all births and deaths are recorded. This allows documentation of the overall impact of the program. In addition, selected institutions have acquired the capability to conduct impact studies, particularly in the area of oral rehydration therapy, immunization against

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measles, pre-natal care, and growth monitoring.

All NGO programs utilize a system of data collection based on the family register sheet, based on the form used in the Khanna project (Wyon and Gordon, 1971). The original form was first introduced in Haiti at the Albert Schweitzer Hospital in 1967. It has since then been revised. It incorporates data on family composition, family size, immunization and pregnancy status. In addition, it contains an optional section for fertility history and records some socio-economic parameters.

While the form is used for the initial census carried out by CHWs, it is regularly updated to reflect the current health status of the registered family. This updating is facilitated by the use of follow-up sheets which are registers of all priority group members that a specific community health worker is expected to follow. Inspection of the follow-up sheet provides at a glance an idea of how a specific health sector is faring.

b. ***Services***. In 1982, there were only two population-based community health programs in the country, one at Albert Schweitzer Hospital, with a registered population of 160,000, and one in Cite Simone, a peri-urban slum, with a registered population of 80,000. Three years later, the number of persons enrolled in population-based programs had jumped to 610,000. An additional 400,000 persons were covered by extensive outreach service networks operated by scattered PVOs around the country.

The remainder of this section will focus on the performance of PVOs with population-based programs who are affiliated with AOPs.

- *Promotion of oral rehydration therapy*

Among 23 reporting institutions, 409 health workers received training in the promotion of ORT and have become distributors of ORS packets in their villages or neighborhood blocks.

Studies done at three different sites provide a basis for judging the effectiveness of the program at the level of private institutions, as may be seen in Table 5. The data are from one urban program and two rural programs. For the sake of comparison data from another rural area of the country are also provided.

- *Immunizations*

The combined target population for the 23 established programs for immunization is 72,000 children under five and 108,000 women of child bearing age. Only 15 of the NGOs have more than one year of service delivery. Coverage data for BCG, Measles, DPT and Polio vaccines after one year of service delivery are shown in Table 6.

- *Growth Monitoring*

Population-based growth monitoring programs are now targeted to all children under three in AOPS affiliated programs. Of these, an estimated 15 to 20 percent have never actually been weighed or had been weighed only once.

While nutritional status indicators are reported regularly by all institutions, they pertain only to children who participate in rally post activities, creating a selection bias.

Given this bias, a study carried out at one of the sites (Belle Anse, a small isolated coastal town) revealed increased growth velocities among participants in a growth monitoring program. Children with regular attendance had a significantly better weight gain than the children who were weighed only 2 or 3 times over a one year period. High attendees gained 98 percent of the weight expected during the observation period while low attendees gained only 93 percent ($p<0.05$ - Van Oyen, 1985).

In addition, it was shown that children with severe malnutrition had increased growth velocity compared to normal children as may be seen in Table 7.

- *Family planning*

Of the 16 institutions with more than 1 year of service delivery, 4 are run by Catholic groups and no serious efforts have been made by these institutions to increase availability of contraceptives. Of the remaining 12, baseline and current data on contraceptive use are presented in Table 6.

While oral contraceptive pills continue to be the most prevalent method, it is also associated with a high drop out rate. In Cite Simone, the continuation rate for oral contraceptives is 24 percent (Boulos 1985).

9. Problems of implementation

As the foregoing statistics reveal, some progress has been made in a few areas, less satisfactory results in others. Performance has varied widely among the NGO teams and, at each location, among the various interventions. As must be expected, a host of problems have arisen. What is most important is that there is generally a sense of accomplishment, enthusiasm for the AOPS approach and what it makes possible, and willingness not only to continue, but also

to expand activities. As Table 3 showed, two of the areas have extended their population coverage to 50,000. Ten more of the NGOs are committed to expand their activities to cover additional populations of 10 to 25,000.

Management problems that occur in any such efforts are common. Several are worth discussing here:

a. ***Sustainability of activities***. Of the sixteen NGOs that have been carrying out PHC activities for at least a year, only one has ceased altogether and four more have experienced temporary suspension of activities when staff were not available. Thus the overwhelming majority have shown to themselves that priority outreach activities can be carried out on a continuing basis.

b. ***Staff turnover***. Four of the NGO programs have had difficulties because of problems with physicians. In three programs, the "management," one of them a grass roots community organization, dismissed and replaced physicians whose performance was considered unsatisfactory.

c. ***Health team performance***. The small paid staff of one physician, two auxiliary nurses and a record keeper are expected to travel to at least two rally posts per week. Getting to these posts is often time consuming and may require long walks over rough terrain or horseback riding. During the three or four other working days the same staff mans the health center. There is thus competition for the available staff time between curative and outreach preventive activities. Tension has occurred between managers, staff and patients over conflicting demands, but generally, resolution of such problems has been accomplished.

d. ***Community health workers***. Some of the NGOs have found funds to pay their CHWs a small salary; others rely entirely on volunteers. The demands on the time of the CHWs are considerable whether they are paid or volunteer and many have difficulty in meeting them.

Regular contact with the NGO health team at the rally posts not only allows for supervision but also for observation and evaluation of the CHWs, especially of their success in bringing their target populations to the rally posts. Such observation, coupled with ongoing review of service statistics, shows that many of them are performing excellently; others are less energetic.

A comprehensive review of the performance of the CHWs revealed that they knew the tasks they were to perform and the content. The most serious shortcoming was found to be an inability to communicate that content to mothers. It was recognized that this had been overlooked in the training of the physicians who trained the CHWs and subsequent groups have been better prepared.

e. ***CHW motivation and compensation***. A great deal is expected of the CHWs and most of them consider themselves overworked. It has been observed that one of the more serious problems concerning compensation is in the programs where the CHWs are paid a regular salary. The amount seems very small compared with the work required of them. In the programs that rely on volunteers, there is also some talk of being paid, but the program managers, usually religious leaders, have so far been successful in maintaining morale without providing cash compensation.

f. ***Transportation***. For the NGO health team as well as the CHWs, the most significant constraint on their work is transport. For the CHWs in communities away from main roads, their census activities, rally posts and follow-up visits require prodigious amounts of walking - much of it uphill. Nine of the 23 presently active NGO program teams have a vehicle available at all times, two have part time access, and the remaining twelve have none. The latter must rely on public transportation where available or travel on foot or horseback.

g. ***Logistic support***. Aside from the initial registration forms provided by AOPS, most consumables are provided by the MSPP which, when the PHC activities were beginning in 1983, was in the throes of decentralization. NGOs were therefore instructed to obtain their supplies from District or Regional depots. In the early months there were frequent and sometimes serious shortages, but the MOH system is now functioning reasonably well, at least to the regional level, and the NGOs are obtaining supplies there and there are fewer complaints.

h. ***Financial support***. Aside from the start-up funds provided through AOPS, and the MOH supplies, each NGO is responsible for covering the costs of their programs. Since the health center team has to be paid anyway the additional costs are relatively limited. Many of the NGOs are operating a variety of programs - schools, development projects, churches, etc. - in addition to their PHC programs.

Thus, providing funds for health activities is merely part of a constant struggle to raise the necessary money. PHC activities are provided free of charge, but most programs charge a small fee for curative services at their clinic. To date, most of the programs are having financial problems, but somehow manage to continue, and each is on its own in solving its problems.

10. Discussion

As envisioned at the Alma Ata PHC Conference, primary health care incorporates a broad set of activities to be carried out primarily by community health workers, with appropriate support of the entire health system. In Haiti, the primary health care approach adopted by the Ministry of Health encompasses the phased implementation of selective priority health interventions. This phased implementation and the selection of key interventions were deemed to be the only viable avenue for a health system with limited resources (Lerebours, 1985).

The experience of Haitian NGOs appears to confirm that a limited approach emphasizing key interventions is a feasible route for NGOs to take, given their lack of resources, but even with this limited approach, there is evidence of significant strain in the implementation of interventions. This strain is well exemplified by the "skinny Hercules" metaphor. The seven labors of the "skinny Hercules," as seen by community health physicians, are perceived by health workers as a multitude of responsibilities they have to accept to be effective.

One question which arises with constant regularity is whether the continuous updating of a population-based registration system does not constitute an added, unnecessary load on the shoulders of community health workers. This question is asked most often by those who perceive the population-based approach as a tool primarily for research and evaluation. We have argued for the utilization of population-based epidemographic surveillance as a necessary part of health care service delivery (Wray, 1971; Augustin et al, 1985).

The caveat is that the surveillance system should be designed to monitor only a very limited set of parameters. Most parameters can be obtained through the operation of a pregnancy registration system. At any one time, only 2 percent of a given CHW target population is pregnant (20 women in a population of 1000). Keeping track of these women and the outcome of their pregnancies is not unduly onerous for the CHW. At the same time, this activity provides highly reliable prospective data on mortality patterns.

Our efforts at reducing the workload of CHWs are now focusing on the identification of maternal characteristics associated with a high risk of infant death. At Narangwal (Taylor et al, 1984), it was found that the 4 percent of children under 3 with severe malnutrition accounted for 43 percent of child deaths. We are documenting a similar experience in Haiti. Whether an effective approach to such high risk populations, and this includes not only children with severe malnutrition, but also children born with a low birth weight, among others, might be developed, is a challenge we seek to confront over the next four years.

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TABLE 1

Haiti: Selected Health and Demographic Indicators

Total population	5.9 million
Crude birth rate	36/1000
Crude death rate	17/1000
Net migration rate	5%
Population growth per year	1.75%
Infant mortality rate	110-124/1000
Still birth rate	20/1000
Life expectancy at birth	53 years
Percent all deaths:	
under 1 year	27%
under five years	45%
Percent children under five with severe malnutrition (weight for age < 60%)	4%
Maternal mortality rate	3.2/1000
Contraceptive prevalence	5.5% (rural)
Vaccination coverage (0-4 years)	
BCG	49%
DPT (3 doses)	11%
Polio (3 doses)	9%
Measles (1 dose)	7%

Sources: Institut Haitien de Statistiques et d'Informatique
Augustin, 1985
DSPP, 1982
Lerebours, 1985
AOPS, 1985

TABLE 2

Estimated number of deaths in infants and children in Haiti, 1985

Number dying through:

1st day	2,700
1st seven days	5,400
1st twenty-eight days	10,000
1st year	27,000
59 months	45,000

TABLE 3

DATE	INSTITUTION LOCATION	PROGRAM DURATION (in months)	POP. COVERED
June 1983	Montrouis	21	15146
	La Vallee	20	10685
	Las Cahobas	20	9516
	Mirebalais (ext)	20	23131
Sept. 1983	Gros Morne	17	9131
	Pont Sonde	16	8168
	Fonds Parisien	16	7270
Jan. 1984	Belle Anse	16	15294
	Taifer	14	8036
	Bonne Fin	12	1679
	Pignon	15	12616
	Thomassique	12	10355
April 1984	Thomazeau	14	10392
	Duplessis	12	10682
	Freres	11	10161
Aug. 1984	Mirebalais	9	48137
Jan. 1985	Marigot	3	10000*
	Cayes Jacmel	3	10000*
	La Mongtagne	3	10000*
	Chambellan	0	10000*
	Cazale	2	10000*
	Carrefour Poy	2	10000*
April 1985	Fonds des Negres	1	10000*
	St. Raphael Pignon	2	50000*
	Fermathe	1	10000*
	Quartier Morin	1	8725
July 1985	Cookson Hills	0	10000*
	Bethel	0	10000**
	Grande Colline	0	10000**
Oct. 1985	Thomazeua (extension)	0	25000**
	Las Cahobas (extension)	0	25000**
	Bethel (extension)	0	10000**
	Deluge, La Voute	0	10000**
	Freres (extension)	0	30000**
	Belle Anse (extension)	0	20000**
Jan. 1986	Gros Morne (extension)	0	25000**
	Marigot (extension)	0	25000**
	La Vallee (extension)	0	25000**
	La Montagne (extension)	0	25000**
April 1986	Fermathe (extension)	0	25000**
July 1986	Grande Colline (extension)	0	25000**

* Target for registration. Tabulation not completed.
** Target for planned registration.

TABLE 4

Children under five with diarrhea reported in the last two weeks

Site	Percentage
Peri-urban slum	50%
Rural coastal (PVO)	48%
Rural central highlands (PVO)	54.4% (children under 1)
Rural coastal (public)	20.83%
National	31.42%
Port-au-Prince	44.6%

Sources: Boulos et al., 1985
Corail, 1985
Augustin, 1985
Cayemittes and Ward, 1985
Lerebours, 1985
Allman, 1985

TABLE 5

Children under five with diarrhea reported in the last two weeks

Site	Percent of mothers using ORT for most recent episode	Percent of mothers who ever used ORT
Peri-urban slum	78%	95%
Rural coastal (PVO)	39%	35%
Rural central highlands (PVO)	35%	87%
Rural coastal (public)	%	45%
Port-au-Prince	N/A	80%

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TABLE 6

Percent coverage for immunizations and utilization of contraceptives before and one year after initiation of activities

	Immunizations								Family Planning	
	DTP		Polio		Measles		BCG			
	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Belle Anse	0	33	0	35	0	56	25	75	0	12
Fhase	9	65	9	65	0	37	29	88	N/A	3
GrosMorne	4	13	4	11	0	5	12	42	N/A	7
La Vallee	9	27	5	21	1	14	8	13	2	6
Mirebalais	1	38	1	36	0	42	N/A	N/A	1	11
Montrouis	0	12	0	10	0	0	0	46	N/A	N/A
Pignon	21	38	14	28	1	18	43	83	N/A	26
Pont Sonde	0	5	0	5	0	18	N/A	N/A	N/A	N/A
Taifer	0	7	0	7	0	N/A	0	N/A	0	1
Thomazeau	N/A	24	N/A	24	N/A	23	N/A	26	N/A	8

TABLE 7

Mean weight gain, expressed as percent of expected gain in children, by nutritional status Gomez classification at the first rally for children (n=294) with regular attendance (4 to 5 times for rallies)

Initial nutritional status		**As percent of expected gain**
Normal	(n = 87)	93
Grade I	(n = 105)	98
Grade II	(n = 78)	100
Grade III	(n = 24)	110

Source: Van Oyen, 1985

Summary

***Background**: Since 1986, Save the Children (SC) has worked with the Indonesian government to provide Primary Health Care to defined Jakarta slum communities. The population served increased over five years from 14,000 to 62,000. SC helped volunteers maintain a community-based health information system through quarterly household visits; organized community health planning workshops; provided nutrition education for mothers of malnourished children; involved such parents in income generating programs and distributed anti-dengue larvicide, all in collaboration with government.*
***Methods**: SC performed two surveys in 1991. We interviewed 690 mothers with 593 children under age three years from the enrolled families to determine health behavior, immunization coverage, child nutrition status, and diarrhea incidence. We also assessed enrollment completeness and characterized enrolled vs. non-enrolled families.*
***Results**: Families where SC worked longer were more likely to be registered (88% vs. 82% registered with 5 vs. 1 year SC presence, respectively). Those unregistered were more likely to be poor or recent in-migrants. Enrolled mothers were more likely than unenrolled mothers to have fully immunized children, to know about and use oral rehydration solution and to use family planning. Improved immunization status persisted after controlling for economic status. Twenty percent of migrations were not recorded in the information system.*
***Conclusions**: Service quality and coverage suffered with program expansion unmatched by staff increases. Voluntarism was constrained perhaps by urban cash demands. Supervision was likely compromised due to time for computerizing data. The community valued the program and petitioned for a paid government supervisor - offering to pay transportation. An efficient urban health information system might include: an initial census; periodic rapid surveys and twice yearly household visits to identify and track all pregnancies - all within the framework of existing government systems. [eds.]*

URBAN HEALTH FROM THE PERSPECTIVE OF A NGO: LESSONS LEARNED FROM A CASE STUDY IN JAKARTA, INDONESIA

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Like most American non-government organizations which work in the field of international health and development, Save the Children has based its programs mainly in rural areas. The American branch of the Save the Children Alliance was founded in the 1930's to improve the health and welfare of children living in the remote, poverty stricken hills of Appalachia, Kentucky. Today, Save the Children (SC) has as its mission the achievement of lasting improvement in the lives of disadvantaged children.

In the 1970's and early 1980's, the organization's development philosophy was one of community-based, integrated RURAL development: the goal was to improve living conditions for children through the multisectoral development of their communities (i.e., through strategies that integrated efforts to strengthen health and education services and agriculture, and to increase economic opportunities). In the late 1980's, there was a shift toward a more intensive focus upon disadvantaged women and children. This transition coincided with accelerating rates of urbanization in developing countries and rising levels of poverty in American cities, two trends which contribute to the feminization of poverty.

Today, SC's Inner City Program figures prominently in the agency's domestic portfolio. In the international department, there are three active urban projects: one program in Amman, Jordan covers three squatter settlements which have a population of 15,000 Palestinian refugees; another in Manila, Philippines, covers a population of 7,300; and a third, in Jakarta, Indonesia, covers a population

of 14,000. All of the international urban programs are community-based and rely upon community health workers; in two of the programs, partnerships with the local health department were developed to increase the department's ability to support community-based workers. A fourth urban program is now being planned for marginal areas of Bogata, Columbia: it will focus upon prevention of teen pregnancy.

The current program in Jakarta builds upon lessons learned from two much larger Child Survival projects which SC had implemented in that city between 1986 and 1991. As these lessons led to a greater awareness within the agency that uniquely urban development problems sometimes require approaches different from those used in rural areas, the remainder of this section will be devoted to a case study of SC's earlier Jakarta programs.

Indonesia's pattern of urbanization resembles that seen elsewhere in the developing world: between 1980 and 1985, the nation's annual urban growth rate was 5.5%, more than five times that in rural areas. The proportion of Indonesians living in cities is expected to increase from 26% at present to over 36% in 1995, with much of this resulting from continued high rates of rural-to-urban migration. The level of urban poverty first exceeded that of rural poverty in 1981, and the incidence of poverty is declining more slowly in urban areas than in rural: according to the Indonesia Central Bureau of Statistics, 23% of urban residents live in poverty. With a population of 7.9 million in 1985, Jakarta accounted for 19% of the total Indonesia urban population. By the year 2000, Jakarta's population is expected to reach 15.7 million.(1,2)

The government of Indonesia demonstrated its commitment to primary health care by establishing local health posts, posyandus, first in rural areas and more recently in cities. The purpose of the posyandu is to bring "an integrated package of MCH, FP, nutrition, immunization and diarrhoeal disease control into a service point at the village/hamlet level."(3) Using its extremely limited resources, the district health department (puskesmas) implements posyandus by providing personnel to deliver immunizations, prenatal care and family planning; establishing monitoring systems for children attending the clinics; and training community volunteers (kaders) to conduct growth monitoring sessions, record immunization and growth monitoring data, and promote posyandu attendance. The Indonesian government plans to increase the number of posyandus, particularly in the most populous provinces: this case study was designed in part to determine whether services offered through posyandus are accessed by the entire community or specific groups, and to measure the health impact of those services.

Support of posyandu activities was integral to SC's work in Jakarta: in 1986, the Indonesia Field Office received funding from USAID's Child Survival I grant to start a health program in the slum area of Duri Utara; receipt of additional funding in 1989 from the Child Survival V grant allowed expansion of this program to the adjacent slum area of Duri Selatan and to nearby Jelambar Baru, bringing the total population covered by the project to 62,000.

SC health staff organized health planning workshops for community residents; helped kaders maintain a community-based health information system; organized nutrition education sessions for mothers with malnourished children; involved some parents of malnourished children in income generating programs; distributed a larvicide to prevent dengue; and attempted to upgrade posyandu activities through better management and coordination with the puskesmas. These health activities were complemented by two much smaller projects initiated by the agency: credit unions and day care centers.

After program expansion, it became difficult for the SC health team to adequately supervise kaders: home visits, necessary for the maintenance of health and vital events information in the community-based system, occurred irregularly, and interactions between kaders and mothers were not as effective as desired. Time lost by kaders in duplicating on government health records the same information collected in SC's Health Information System made it even more difficult to improve the quality of health interventions.

The following lessons learned were derived from an August 1991 survey of 690 mothers and 593 children (aged younger than three years) who lived in the communities of Duri Utara and Jelambar Baru. At the time of this survey, SC had been operating in Duri Utara slightly over five years and in Jelambar Baru less than one year. Interviewers who conducted the survey were either members of the SCF health team or community health workers (kaders). Because the community-based health information system which SCF had implemented in the project area theoretically enumerated all community residents, it served as our sampling frame; through a separate survey, the completeness of enrollment in this community-based system was assessed and socioeconomic characteristics of

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unenrolled residents were compared to those enrolled.

In our analysis of survey findings, health indices and behaviors were usually considered dependent variables, determined by socioeconomic status. Health behaviors included use of ORT, breastfeeding, contraception, and choice of site of delivery. Health indices included immunization and nutrition status, and incidence of diarrhea. One additional health behavior, choice of primary care provider (i.e., posyandu vs. private medical doctor) was sometimes considered as an independent variable (on which indices of health status and other behaviors depend) and sometimes as a dependent variable (in itself determined by socioeconomic status).

Among the conclusions drawn from our study, those that appeared most generalizable to other urban settings were as follow:

1. An understanding of the socioeconomic heterogeneity which often exists in even the poorest urban communities should inform the design of programs to deliver services as well as the analysis of service impact.

Like many urban slums, Duri Utara and Jelambar Baru are ethnically and economically heterogeneous: in both, relatively affluent Chinese comprise 25% of the population and ethnic Indonesians the remainder; it should be emphasized that those labeled "affluent" in this study would not be considered so by western standards. Patterns of using health services differ according to socioeconomic status: wealthier residents tend to obtain primary health care from private providers, while local government clinics (posyandus and clinics based at sub-district health departments) provide care for poorer residents. Certain health practices (use of ORT, immunization status) were better among those who obtained routine care at government clinics; these better practices may, however, be outweighed by the lower prevalence of malnutrition and lower incidence of diarrhea observed among wealthier residents.

Although the higher socioeconomic status of those who seek care from private providers may help counterbalance any of their poorer health practices, those who do not avail themselves of preventive health care place both themselves and others at greater risk of morbidity and mortality. Finding some poorer health practices among more affluent residents indicates that, in this setting, standards of preventive care in the for-profit sector may be worse than those in the public sector and warns against strengthening the private sector solely on the basis of concerns about quality.(4,5)

Efforts to reach ALL segments of the community with information about the importance and availability of preventive health care are clearly warranted: these efforts are most likely to be successful if outreach workers are of the same ethnicity and socioeconomic status as their target group.

It could be argued that improving the protective health behaviors of more affluent residents would most effectively be accomplished by improving the standard of care offered by private providers (for example, through training programs, increased regulation by the municipal health department, and financial incentives). The expense of seeking care from private medical doctors, however, may seriously reduce the living standard of the "affluent" in these communities. Moreover, encouraging use of the posyandu by wealthier residents offers an opportunity to build greater community cohesion. It also holds promise for creating a new population of posyandu users who are more able to DEMAND effective services at the local clinic (e.g., the monthly presence of an immunization team from the sub-district health department) and who could subsidize (through the institution of a sliding fee scale) services for the poorest members of the community. Thus, in some cities, NGOs may function most effectively by better equipping the public sector to meet current and potentially increased demand.

A high proportion (75%) of all residents in these communities practice contraception, regardless of socioeconomic status or type of primary health care service used. It would be worthwhile to investigate which aspects of the government's family planning promotion campaign were responsible for achieving such universally high levels.

2. The purpose of a community-based health information system should be clearly specified. The costs of implementing in an urban area a system which can achieve this purpose must be balanced against the benefits which the system is expected to bring to community residents and public and/or private health care providers.

Even though the two communities described here had a relatively LOW proportion of recent in-migrants--fewer than 10% of survey respondents had moved into the project area within the last two years and approximately 75% had lived there longer than

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five years--data contained in the agency's health information system (HIS) were not as complete or accurate as expected.

One goal of a community-based HIS is the promotion of equity in the use of health services: such a system is meant to identify and reach out to groups who are often neglected. The achievement of this goal requires that ALL community residents be registered in the system. Here, completeness of HIS data was assessed through a household survey, during which those found to be unenrolled in the HIS were asked to complete a study questionnaire: the proportion of families who were unenrolled was 12% in the community where Save the Children had operated longest and 18% in the community where program activities had started more recently. Those who had not been enrolled were more likely to be poor and recent in-migrants, high risk groups which proponents of community-based information systems hope most to capture.

The extent to which health benefits were associated with enrollment was unclear. Though enrolled mothers were more likely than unenrolled mothers to know and to use ORT, to have their 12 to 36 month old children fully immunized and to use family planning, all differences except for that in immunization levels disappeared when we controlled for economic status: the persistence of a difference in immunization status may reflect higher levels of government clinic use among poor enrolled mothers than among poor unenrolled mothers.

Inaccuracy of data contained in the HIS was suggested by the finding that approximately 20% of family migrations (either out- migrations or re-locations within the project area) had not been recorded in the HIS records. This type of inaccuracy most likely resulted from lapses by kaders in their schedule of home visiting and from inadequate supervision by SC project staff. Rapid expansion of population coverage without a proportional increase in the number of health staff made it difficult to maintain the schedule of home visiting which had been established at the start of the program (at least four times per year) and which was necessary to ensure the system's ability to generate epidemiologically sound data: supervisors made few efforts to verify information reported by kaders by visiting homes themselves and paid little attention to the quality of interactions between kaders and mothers (i.e., in terms of mothers' comprehension of health messages communicated by kaders). Computerization of manual records did nothing to improve the quality of information in the system: the time needed to transfer data between manual and computerized systems may in fact have further reduced the staff's ability to supervise kaders.

Rapid program expansion was not the only reason for a disintegration in supervision: political factors and some lack of focus within the program on how best to strengthen the posyandu system also contributed. SC had no control over the appointment of kaders: mid-program, a change in local political leadership resulted in the appointment of a new group of kaders: home visiting schedules were further interrupted as this new group was trained. While an acknowledged goal of SC's health program was to strengthen the government's primary health care system, the maintenance by the agency of a recording system that paralleled the government's added to the confusion: SC's information was (at least in theory) derived from home visits while information contained in government records was (in practice) derived from clinic visits; because kaders were encouraged to update government records using data from SC's system, they had less time to devote to home visits and health counseling activities, even during clinic.

Proponents of community-based health information systems view them as tools to achieve community empowerment as well as greater equity: as community residents learn to collect and interpret health data, they are better able to assess and address their own health needs. In this program, however, over-worked project health staff tended to emphasize the system's potential for generating vital events rates which could be used to monitor program impact; while health information was occasionally channeled back into the community through meetings with community leaders, little attempt was made to determine whether such forums truly represented all groups in the community (e.g., mothers, new in-migrants, Chinese residents, the very poor) or whether they increased community demand for services. There was also little effort on the part of health program staff to work systematically with kaders or other community members to improve their ability to interpret health data.

At the end of the program, however, there was evidence that some aspect of SC's program DID in fact increase community awareness of the importance of primary and preventive health care: community leaders supported the agency's efforts to create within the sub-district health department a position which would provide supervisory support to kaders; even more impressive was the willingness of these community leaders to designate part of their community endowment fund to pay the transportation expenses of such a supervisor, in order

to facilitate his ability to work with kaders in the field.

The problems that plagued this program's HIS were similar to those encountered in the maintenance of other impact-oriented, data driven demographic surveillance systems.(6) Any NGO which intends to implement a community-based HIS in an urban setting would do well to consider the following questions.

Will the program rely on community volunteers or paid staff to collect data? Scarce resources and concerns about program sustainability often mandate reliance upon volunteers. If this is the case, it is appropriate to question whether the generation of epidemiologically sound data should be a primary goal of the HIS: program impact might best be measured through periodic, rigorously conducted surveys rather than through data collected in the HIS. Although the urban poor may be better educated than their rural counterparts, the time which they have available for volunteer activities is probably more limited: the demands of a cash economy and the absence of traditional support from an extended family are especially likely to preclude participation of the poorest members of the community in volunteer activities (thereby making it less likely that the poorest households will be visited). It is difficult to perceive how volunteers could visit homes frequently enough to maintain reliable information about vital events; moreover, only intensive training could enable this level of worker to distinguish between such events as stillbirths and early neonatal deaths and to identify common causes of morbidity and mortality. What will it cost to provide such supervision and training? At the end of the program, will it be possible to transfer these responsibilities to local health authorities or to a community organization?

While an HIS run by community volunteers may not generate flawless epidemiologic data, it can still empower community residents and promote equity: NGO health staff will need to identify or assemble community groups who are interested in health issues, and train these groups in interpreting health data and in communicating with decision-makers in their communities and in local government. How can we design an HIS which will achieve greater equity and community empowerment, yet which is simple and inexpensive enough to be maintained by community residents working in partnership with local public health authorities? Certainly it seems logical for any health program activities to be preceded by collection of data needed to plan services: 1) a community census which provides information about population age groups and some socioeconomic risk factors and 2) rapid surveys to obtain information about prevalent health problems (and the community's perception of these problems). The frequency with which ALL families need to be visited after the initial census is determined by the rigor desired in the reporting of vital events. The identification of specific target groups who will be monitored longitudinally and the frequency with which such groups will be monitored is determined by the type of services promoted by the program. For example, if the program includes services to improve maternal and neonatal health, a community-based system could be used to identify all pregnant women, refer them for prenatal and obstetric care, record birth outcomes, and encourage initiation of appropriate neonatal care (including breastfeeding and immunizations); in order to identify all pregnant women in the community at some point during their pregnancy, volunteers would need to visit the homes of all women of reproductive age at least two times a year.

How can a community-based HIS best complement the efforts of public and private service providers? If the HIS is to be considered useful by service providers, information collected in the community-based system must be related to service statistics maintained by the providers: for example, data collected in the community may provide denominators to allow calculation of service coverage. Achieving greater equity in use of health care services rests on the assumption that there are services in or near the community that can meet the increased demand which presumably will result from HIS activities: it may be necessary for NGO health staff to work with public or private health care providers to improve the capacity and quality of their services.

Should the NGO establish a community-based system independently or work within a government framework? SC's Jakarta experience suggests that the establishment of an HIS which parallels the government system is counterproductive. Most costs of maintaining any HIS will eventually be borne by some level of government. Thus, NGO staff should understand the existing government recording system and assess health department interest in a community based approach. If the health department has already established a framework for a community-based system, the NGO should work as much as possible within that framework, training existing government personnel as supervisors of community HIS workers and assisting in the achievement of greater efficiency.

3. Poor urban residents have greater access to facilities which can provide advanced care than do most rural residents. Such access affects mortality rates and the overall spectrum of causes of mortality: thus, morbidity may be a better index than mortality of health conditions in slums. There is potential for expanding the role of institution-based providers in meeting the primary health care needs of the urban poor.

Despite the concentration of tertiary care centers in cities, the urban poor in developing countries were generally thought to have little access to hospitals; whatever access they did have was perceived as having no impact on overall community health.(7) In these Jakarta communities, on the other hand, we observed that utilization of hospital services was higher than expected, at least for curative care. Delivery in hospital was common, especially among more affluent women: even among poorer women, the proportion of deliveries attended by traditional birth attendants was much lower than the 65% observed nationally.(1) Moreover, numbers of infant and child deaths in the two communities were lower than expected on the basis of national mortality rates, suggesting that in case of serious illness, access to hospitalization may avert death. (Regarding analysis of mortality, however, we recognize that the sample covered in this survey was much too small to allow the calculation of reliable rates and that under-reporting of neonatal deaths almost certainly occurred.)

We cannot assume that access to hospital services is similar in other slums: trends toward long term residence--as observed in Duri Utara and Jelambar Baru--permit the evolution of greater community organization (8) and may also change patterns of service utilization among the urban poor. In any given slum, patterns of hospital use should be clarified: an assumption that the urban poor will not seek care at hospitals should not preclude the possibility of working with institution-based personnel to expand access to comprehensive health care (including curative as well as preventive services).

The proximity of hospital-based obstetric care offers an option which usually does not exist in rural areas: early referral of complications. Certainly hospital delivery of uncomplicated births is not necessarily desirable: it could severely strain limited facilities. Information about appropriate indications for seeking hospital care, however, should be included in all urban prenatal care programs; arrangements should be made with hospital-based providers to ensure availability of appropriate emergency services (e.g., establishment of criteria for charity care, development of sliding fee scales). On the community side, NGOs could work with credit unions or savings groups to develop insurance funds for hospitalization. Institution-based personnel could also assist in reversing the trend toward bottle feeding which is observed most strikingly among wealthier women in these communities (who are those most likely to deliver in hospital); Unicef's "Baby Friendly Hospital Initiative" provides a model for this type of activity.

4. Since malnutrition and diseases related to water and sanitation have a multifactoral etiology, solutions must likewise integrate interventions from several development sectors. Interventions which lie entirely within the health sector (e.g., ORT) can avert individual deaths and identify those in need of more intensive care (e.g., through growth monitoring), but usually fail to address underlying causes. Even interventions targeted toward individuals will be futile if communities lack resources to treat and monitor those whose health indices identify them as high risk. Thus, within the health sector, it is necessary to establish a "health infrastructure which can regularly reach the groups at risk" (9); without such an infrastructure, the most effective selective interventions cannot achieve lasting community benefit.

As expected, data on children's nutritional status and incidence of diarrhea supported the close relationship between health and economic and environmental factors. The prevalence of malnutrition among all children is high: 44% are mildly malnourished (weight-for-age between 75% and 89% of median); 22% are moderately malnourished (between 60% and 74% of median); and 3% are severely malnourished (less than 60% of median). Levels of moderate and severe malnutrition were highest among children from the poorest families (although comparison between classes was somewhat tenuous because affluent children were less likely to have participated in growth monitoring). Community-wide incidence of diarrhea was also high: 28% of mothers reported that at least one of their under-three year old children had diarrhea in the last month, and 7% reported that at least one of their children in this age range had been hospitalized for diarrhea in the last year. Poorer mothers were significantly more likely to report diarrhea. Poorer families were also more likely to

purchase water from vendors rather than to obtain it from an indoor tap or hydrant, and a trend toward higher incidence of diarrhea among those who had to buy water persisted even after control for economic status.

These findings are consistent with those reported elsewhere: as the urban poor must depend almost entirely on cash income to meet their food needs and as opportunities for steady work may be scarce, it is not surprising that levels of malnutrition in some developing country slums actually exceed those in poor rural areas (10); the use of contaminated water and expenditure of an often exorbitant proportion of limited household income on water from vendors contribute to high rates of infant and child mortality among the urban poor.(11)

The persistence of malnutrition among children who had taken part in an extensive growth monitoring program shows that a selective intervention unaccompanied by adequate follow up is likely to fail. Follow up can only occur in the presence of a health infrastructure capable of delivering comprehensive care: such infrastructure permits uninterrupted delivery of selective technologies and adequate follow up (with curative care, if necessary) of those identified as high risk.(9) By establishing local health clinics, the Indonesian government has taken an important step toward creating this type of infrastructure; now, to realize the potential of these clinics, it is necessary to strengthen delivery of preventive services at the posyandus and to institute on-site curative care or effective referral.

The clear association between health status, and economic and environmental factors indicates that even a comprehensive health care system needs to be part of a multisectoral approach. Nutritional rehabilitation of children detected as being severely malnourished during growth monitoring sessions does not address what is usually the root cause of the problem: absolute poverty. This case study offered some evidence, however, that increasing opportunities for income generation was by itself an inadequate solution: children of poor mothers who were involved in income generating activities were more likely to be malnourished than were children of women who did not work for cash income; it will be important to make some form of child care accessible to working mothers.

Findings from the case study also underscored the importance of cooperation between municipal health and water and sanitation departments: in some cities, NGOs could perform a valuable service by facilitating such cooperation. Further qualitative studies are needed to determine whether water sold by vendors is contaminated at the time of purchase or whether unsanitary conditions within households that must purchase water (the poorest in these communities) are more likely to be responsible for high rates of diarrhea. If water is in fact contaminated at time of sale, the public health and sanitation departments could cooperate to develop a licensing system for vendors.

5. The development of convincing and practical health education messages as well as effective, integrated interventions should be informed by qualitative as well as quantitative data.

It would be impossible to derive from further quantitative studies the type of information needed for the development of practical interventions. By exploring mothers' reasons for not having their children immunized and providers' reasons for not administering immunizations to mildly sick children, the Expanded Program on Immunization Urban REACH Program showed how qualitative data could inform the development of strategies to promote immunization.(12) Strategies to improve nutrition and reduce the incidence of water-borne diseases should be informed by qualitative answers to the following types of questions: in communities where many mothers must work in factories, how relevant is advice to breastfeed exclusively? how extensive and enforceable are laws that require employers to give mothers time off to nurse their children? how is water used in the household? what handwashing practices are prevalent? is water bought from vendors reserved for special uses and supplemented by more contaminated water?

Save the Children's health program in Jakarta now covers a population of approximately 14,000 in the four poorest neighborhoods of Jelambar Baru: at least 10% of the households in this area are headed by women, and there is a large population of commercial sex workers.

Health and development activities are concentrated much more intensively on the following target groups: new migrants, women factory workers, commercial sex workers, women who are head of their household, pregnant women and families in which one or more children are severely malnourished or delayed in their immunizations. The health information system has been simplified to reflect this sharper focus: regular home visits are made only to members of targeted groups; communication between community volunteers and commercial sex and factory workers, however,

usually takes place in the setting of a health center rather than in an individual home.

Kaders are now expected to function more as case managers. A revolving loan mechanism, the Kader Productivity Fund, has been established to provide some financial incentive for the performance of health promotion activities and the delivery of certain services (e.g., nutritional rehabilitation of severely malnourished children).

Experience from the Child Survival programs emphasized the need to institutionalize responsibility for the training and supervision of kaders. Consequently, Save the Children has encouraged the subdistrict health department (puskesmas) to designate one of its clerical level workers as Health Coordinator, with responsibility for kader recruitment and performance. The Health Coordinator Training Module which is being developed by SC will be piloted in those puskesmas which serve the agency's program area; if Health Coordinators prove to be effective, the module can be used more widely to train this level of government health worker. The willingness of local political leaders to allocate a portion of their community savings to cover transportation costs for the Health Coordinator suggests a higher community prioritization of primary health care needs and may herald greater cooperation between health department and community.

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Supporting Field Methods: Tools to Support, Explain and Guide Community-Based Health Information System

A variety of supportive field methods guide a community-based information systems. These "action research" tools lie squarely in the common ground between program management and field research. We believe that public health managers must have both an interest in and an aptitude for applied research to identify and solve problems efficiently. Optimizing program impact requires an inquiring mind. The following methods aid this spirit of inquiry.

Some techniques describe attributes of the target population and thus are useful for a baseline needs assessment or an evaluation. Others deal more with program implementation either in its supervision or in providing information and resources for various interventions. Some methods are strictly quantitative based on probability samples and derive variable prevalences with statistically rigorous confidence intervals. Other qualitative techniques, almost devoid of numbers, seek to uncover explanatory clues to describe some of these prevalences. Still others are a combination. The papers we have selected (Table) are representative of the kinds of methods that Primary Health Care teams will want to consider to strengthen their programs.

A logical starting place is "The KPC Survey: a Tool for Child Survival Project Assessment."[1] These notes describe the pedigree, rationale, and usage of the commonly used "knowledge, practices, and coverage survey" developed by the Johns Hopkins University's Child Survival Support Program. Survey teams interview a probability sample of 300 mothers of children under age 24 months, asking such questions as: "What are the signs of respiratory infection that would cause you to take your child to a health facility?" (knowledge); "After delivery, when did you breast-feed for the first time?" (practice); "Do you have an immunization card for your child?. Record dates for all the immunizations." (coverage). This highly quantitative method provides health teams and communities with precise prevalences of key indicators which will guide them as they prioritize problems, design responses, and measure results in a "before-after" manner. Since the questions are specific for common Primary Health Care interventions, they can be used to compare across populations or even regions.

KPC surveys neither measure attitudes, nor do they seek to explain the resulting prevalence distributions. For example, the survey will not explain why 90% of breastfed 2 month olds have already received other foods -- against standard public health teaching.[2] Understanding this phenomenon will require detailed information not available from a brief questionnaire. Qualitative methods are a logical choice for generating possible, even probable, explanations. Dearden[3] defends both qualitative and quantitative methods, each in the context of the question asked. He then details three commonly used tools: focus group, key informant interview and participatory rural appraisal. Focus groups are semi-structured discussions with small, socially homogeneous groups around limited, related topics wherein a facilitator seeks to elicit ranges of local perceptions related to a health phenomenon. For example, questions exploring feeding the newborn in the first day of life might be: what is meant by "feeding"?; when is the first feeding?; what is this feeding?; what other things might go in the baby's mouth?; who gives it?; why?; what about colostrum? and so on. Key informant interviews, not surprisingly, involve discussions with individuals who have special information, such as village head men (about local customs), traditional birth attendants (about delivery practices), or the District Health Officer (about government - PVO relationships). Participatory rural appraisal has dual goals: obtaining information (appraisal) and community development ("participatory"). Community members actively contribute to problem identification, data gathering and interpretation and response. Clearly each of these qualitative approaches is vulnerable to bias and non-representativeness because of the types and size of samples involved. On the other hand, these approaches are offset by the detail, breadth and potential explanatory power of the information.

"Positive deviance" is a highly participatory blend of approaches.[4] It involves a quantitative

needs assessment, a follow-up qualitative "explanation-for-action phase," and an intervention designed by the community incorporating the information they have gleaned. The conceptual crux involves finding and learning from "positive deviants," that is, families at apparent risk who, in fact, have healthy children. The method is designed to empower communities to sustain their concern for, measurement of and response to their collective health. This "deviant" approach was recently used in Malawi to explore reasons for volunteers' variable performance: villages with well-functioning village health committees and women's literacy programs (but with weaker volunteer programs) were compared with villages with stronger volunteer programs despite less apparent social infrastructure.

Our list is brief but not free of controversy. Verbal autopsy, for example, although useful in some settings to identify some causes of child death,[5] is not unreservedly recommended until further research discovers the best set of field questions.[6] Verbal autopsy involves interviewing a knowledgeable, bereaved family member about the details of their child's death in order to identify clinical clues which will permit assigning a reasonable estimation of cause of death. Presently verbal autopsy is most valid for those few syndromes which are distinct, recognizable and recallable, such as tetanus, measles and pertussis. Particular difficulties involve distinguishing ARI from malaria deaths and identifying deaths due to AIDS. The UNICEF/WHO memorandum interestingly stresses the potential value of facility-based statistics to approximate indirectly both the overall level and the pattern of child mortality in catchment areas. Whether field- or facility-based, health systems utilization information derived from a mortality review may be useful regardless of the cause of death or its diagnostic certainty. For example, timeliness and patterns of seeking care in conjunction with quality and costs of care and referral inform curative program responses to ill health.

Measuring changes in maternal mortality through community surveillance is almost impossible because the events are so rare and most populations under demographic surveillance are relatively small. Thus, we chose to include a paper[7] focusing on process or intermediate variables because the approach is both reasonable and applicable to other questions. The intended audience is the evaluator but program designers and implementors will benefit from considering their 4-stage model: (1) outline a causal pathway through which an intervention hypothetically will work; (2) determine how the pathway will be affected by events outside the program beyond its control; (3) develop indicators for each step and (4) chose the best combination of indicators that together support the success of the intervention. A related paper[8] of interest, not included, addresses performing a rapid appraisal of maternal health. These authors note that 40% of pregnancies have complications and that 9-15% of pregnancies have serious complications requiring referral. These common events can serve as proxies for the much rarer maternal mortality (0.1-0.5 % of pregnancies, for example).

Restated, an alternative strategy to measuring less common mortality is surveillance for more common morbidity. This is well suited for programs which aim to eradicate diseases such as measles, neonatal tetanus or polio. Often such surveillance combines total and cause-specific mortality and cause-specific morbidity. The Introduction to Surveillance for Morbidity and Mortality[9] outlines the principles and types of surveillance for Primary Health Care settings. Clear, universally applied case definitions are foundational. Of note, Save the Children and other private voluntary organizations are exploring strategies of community-based surveillance for identifying and following pregnant women and their babies as alternatives to continuous universal household coverage in some settings. Finally, health surveillance activities are of particular interest to government counterparts. Save the Children has taken the lead in developing a district-wide surveillance system for assessing food sufficiency in a vulnerable area of Malawi. Other health events will likely to be added to this basic system.

The final two papers, directly from Save the Children's experience, help program managers maintain satisfactory data coverage, quality and timeliness. Kaye and Galvao[10] provide helpful supervisory techniques such as: enrollment

validation surveys to measure coverage, tables comparing observed and expected vital events to highlight variance, and linking pregnancy and birth tallies to identify possible data gaps. The case of interpreting infant mortality details the many threats to validity that the program manager confronts during the analysis and interpretation of key vital indicators. Lot quality assessment[11] is presented as a useful technique to identify quickly community health workers who need further support in maintaining complete and up-to-date health information records.

* * *

A final observation. In the brief time devoted to preparing these few pages, a stream of valuable reports were "discovered." Some were new while others were not. Continually revising the content soon became unfeasible. Each of us must read the literature and/or remain in contact with people who do.

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Table. Methods to Support Community-Based Health Information Systems: Papers*

Author	Title	Content	Phase	Qual	Quant
Newberry	KPC Survey...	Theory of KPC surveys: what they do and don't do	N, E		x
Dearden	Strengthening health services through...	Brief guide to FGD, KII, and PRA with indications of qualitative vs quantitative	N, E	x	
Sternin	Positive deviance...	PD as an empowering technique for sustainable change	N, I	x	
Gray	Verbal autopsy...	State-of-the-art VA	N, E		x
WHO/ UNICEF	Measurement of overall and cause-specific child...	Indirect techniques to measure total child mortality with cautions against VA; facility-based data stressed	N, E		x
Ward et al.	A strategy... to reduce maternal mortality...	Theory of developing proximate indicators for reducing maternal mortality	N, E		x
Claquin et al.	Surveillance of morbidity and mortality	Rationale & types of surveillance in Primary Health Care	I, E		x
Kaye and Galvao	Management tools for improving quality...	Supervising the completeness & timeliness of records and their interpretation	I		x
Galvao and Kaye	Using lot quality assessment...	Supervising the accuracy and timeliness of community health workers' rosters	I		x

*E=evaluation; FGD= focus group discussion; I=implementation; KII=key informant interview; KPC=knowledge, practices, coverage; N=needs assessment; PD=positive deviance; PRA=participatory rural appraisal; Qual=qualitative; Quant=quantitative; VA=verbal autopsy

Summary

Background: *Various Assessment tools appraise project performance, including: facility surveys, ethnographic surveys; disease surveillance; longitudinal community-based information systems and knowledge, practices and coverage (KPC) surveys. KPC surveys can be a valid, representative, economic tool to assess key health variables among target populations. KPC survey methods have been rigorously designed and tested by technical experts from universities, WHO, UNICEF, CDC and USAID in collaboration with colleagues managing health programs in developing countries. The resulting questions, questionnaire and analysis plan encourages comparison between and among countries while not inhibiting local modification. KPC surveys neither measure attitudes nor seek to explain causation — questions better addressed through qualitative or analytic studies.*

The KPC Methods: *Sampling methods are modified from WHO's 30-cluster sampling techniques. Forty to forty-five questions measure (1) mother's knowledge and practices regarding her health and the health of her children less than age two years in up to nine program content areas and (2) immunization coverage. Questionnaires must be translated to and back-translated from the local language. Analysis involves computing frequencies of all variables and selected cross-tabulations. Hand tabulation of 300 questionnaires require approximately 160 person-hours of effort vs. about 40 hours for computerized data entry analysis with Epi Info. Hand-tabulation allows more participation by project staff while computerized analysis allows for more complex analysis with precise graphical output. Combined approaches may be best.*

Conclusion: *A key health program goal is reduce child mortality, but observing changes in vital rates is expensive and may not guide program management. Simple analysis of the intermediate variables explored in KPC surveys provides detailed proximate information on program effect. [eds].*

THE KPC SURVEY: TOOL FOR CHILD SURVIVAL PROJECT ASSESSMENT

DAVID NEWBERRY*

The KPC Survey

Various assessment tools may be used to appraise project progress toward objectives and collect data useful for making management decisions about service activities. Such tools include, but are not limited to, knowledge, practice and coverage surveys (KPC surveys), facilities surveys, ethnographic surveys, disease surveillance activities, and longitudinal community-based information systems.

Well-designed KPC surveys reduce the need to study an entire population to obtain valid representative data. PVOs face many problems in the design and conduct of surveys, including dispersed population, difficult access, and logistical and time constraints. One method for overcoming some of these difficulties is a carefully designed sampling technique. Sampling reduces the number of individuals who need to be interviewed, and if done properly, produces a high response rate that provides quality data for well-informed decision-making. There are many methods available for selecting a sample; the method chosen depends on the nature of the issues under investigation.

The World Health Organization has used the 30 cluster sampling technique to detect the rate of disease occurrence, assess health conditions at the community level and identify high risk factors. This method considers a sampling unit to be a "cluster" of persons rather than an individual. The "cluster" units are drawn from a sampling frame of all eligible communities in the survey area. The total population of all the communities in the survey area is divided by 30 to obtain the sampling interval needed to select 30 clusters. A randomly-selected household in each cluster marks the beginning of that sampling unit, and interviews continue until all required interviews are completed.

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Background and Design Criteria for the KPC Survey Questionnaire

The Knowledge, Practice and Coverage (KPC) Survey was developed by the PVO Child Survival Support Program (CSSP) to assist private voluntary organizations (PVOs) in monitoring and evaluating USAID centrally-funded Child Survival projects. The survey was adapted for use by PVO Child Survival grantees after four years of study and pretesting. During field and headquarters workshops, PVO staff shared with CSSP staff their problems with data collection. Next, CSSP technical staff worked with an epidemiologist, experienced in rapid surveys for management purposes, to design a standardized rapid survey method that would yield practical information on topics such as immunization coverage, use of oral rehydration therapy, and infant and child feeding practices. CSSP staff reviewed how each PVO project used its survey data to develop a Detailed Implementation Plan for its Child Survival Project. CSSP technical staff studied the survey quality (reliability and validity of data) of 45 PVO projects.

There were several design criteria. It was essential that the survey yield information useful for Child Survival project management. Thus, the questions had to focus on technical interventions which addressed those health problems that contributed most to infant and child mortality. Questions could not elicit information on general social or demographic conditions or on conditions which would not be expected to change much within the three year cycle of the Child Survival grant. Each question had to focus on some change in specific health knowledge and behavior which could be expected to occur within the family during the grant, and which could significantly affect infant and child mortality.

It was important that survey questions be technically sound, up-to-date, and yield information comparable where possible with national data reported by the country to the World Health Organization (WHO) or UNICEF. Discussions with technical specialists from universities, WHO, PAHO, UNICEF, U.S. Centers for Disease Control (CDC), and USAID contractors led to a consensus on the most technically relevant questions for nine modules: 1) immunization; 2) case management of diarrheal diseases; 3) breastfeeding and child nutrition; 4) vitamin A capsule supplementation; 5) case management of acute respiratory infections; 6) pregnancy care; 7) family planning practice; 8) growth monitoring; and, 9) mothers' information on literacy and income generation.

It was also important that surveys be practical to administer under the difficult conditions in which many projects are operating. Therefore it was decided that the final questionnaire should include no more than 40 to 45 questions and that the interview should take about 20 minutes to complete. The generic questionnaire is **not** meant to be used in its entirety; each project selects questions which are relevant to local health problems and reflect the project's own goals, objectives and interventions. Questions on nutrition may be adapted to the local setting, and questions that are not a part of the generic questionnaire may be added. However, survey specialists do not recommend that PVOs add many new questions.

Before requiring that the KPC Survey be used in all baseline and final assessment of PVO Child Survival projects, USAID formed a Rapid KPC Survey Task Force to evaluate the first set of completed baseline surveys and to set survey goals for the future. The group served as an advisory body and was composed of public health professionals and survey specialists from universities and private consulting firms. In addition, Task Force members assessed how PVO projects had used survey data in designing their DIPs.

It was decided that the KPC survey could provide only limited information about attitudes (e.g., attitudes toward feeding during illness). For this purpose, CSSP recommends that PVOs use qualitative or ethnographic assessments, such as focus groups or key informant interviews. It is important for PVOs to understand that the survey, as such, is not designed to measure the "whys" -- that is, the reasons for delays in achieving objectives. The survey does identify problems that qualitative research tools can better answer.

Objectives of the KPC Survey and Population Covered by Survey

The methodology chosen for this type of rapid survey is the World Health Organization (WHO) 30 cluster sampling technique. The survey establishes baseline and final estimates of child survival knowledge, practices and coverage levels as they relate to a project's primary health care interventions. The KPC survey is a simple and quick methodology that can be administered by trained PVO projects at low cost

without or with limited outside technical assistance.

The study population consists of mothers (or primary caretakers) of children less than 24 months of age living in the PVO project area. By restricting the sample to mothers of children younger than 24 months, final surveys can detect the project's ability to reach children born during the three years of the project, and establish whether the project was successful in communicating to new mothers certain action messages about key Child Survival interventions. Another reason for focusing on mothers of children in this age group is that these are the children most likely to die from the preventable diseases prevalent in developing countries.

The survey objectives are to provide the PVO project manager with information about:

- the coverage rates of BCG, DPT3, OPV3, and measles vaccines among children aged 12 to 23 months;
- actual practices of mothers regarding breastfeeding, introduction of foods (by nutrient types), home treatment of diarrheal disease, immunizations, medical care for a child's acute respiratory infection, pregnancy care, and family planning;
- knowledge of mothers of children less than two years of age about the purpose of tetanus toxoid immunizations, timing of measles immunizations, timing of introduction of foods, expected weight gain during pregnancy, and recognition of signs of ARI which require referral; and,
- the literacy level of mothers who are to receive health messages (which enables health project managers to design more effective health education messages).

Another objective of this survey is to empower local field staff in this rapid assessment technique. Data analysis and the compilation of a preliminary report are considered integral components of the survey, and are conducted as much as possible by the local staff

Survey Process

Translation of Survey Questionnaires and Supervision of Interviews

Once the questionnaire is final, the instrument must be translated into the local language using a vocabulary that can be understood by mothers. After translation into the local language, the questions should be translated back into the original language by another person to establish the accuracy of the translation. If necessary, the questionnaire can be translated into non-written languages.
Interviewers and supervisors are assigned to cover all selected communities in the 30 cluster sample. The supervisors are responsible for identifying communities and choosing the correct starting point within each cluster. Each day, supervisors observe at least one complete interview by each interviewer; they also audit each questionnaire for completeness shortly after the interview so that the mother can be revisited in the case of missing or contradictory information.

Manual and Computerized Tabulation and Analysis of Data

Manual Tabulation of KPC Survey Data

In conducting KPC surveys, PVO project staff have discovered that manual tabulation of data helps sustain Child Survival interventions by empowering project staff and community residents. Manual tabulation requires team effort, with participation of about a dozen project staff, local collaborators, or Ministry of Health personnel. Through hand tabulation, project staff see survey results come to life and understand fully that the final frequency data reflect conditions in their own communities. Project staff become more able to use the data in management, as all levels of project staff participate in and contribute to the analysis and discussion/recommendation sessions.

Training and Tabulation

Tabulators require a short course of training from the survey trainer in tabulation techniques. Manual tabulation is learned quickly because it is, in essence, counting. When all counting is complete, tabulators end up with a numerator and a denominator from which they can calculate a percentage. Once percentages are calculated for mothers' answers, the tabulators are able to translate the numbers into a

written statement, on the bottom of the tabulation form. Usually a trial run with a few questionnaires is advisable to work out any misunderstanding of the tabulation process.

Process

Manual tabulation can be done in any location, no matter how remote the project area. Save the Children/Nepal works in districts high in the Himalayas and in the southern jungle: neither area has electricity and both are a day's journey from the capital city. At one Save the Children Child Survival site, a team of sixteen project staff completed tabulation in two days, working from early morning until nightfall under the supervision of the survey trainer and the manager of the Child Survival project. Tabulation of the responses to questions takes one day. The second day is spent cross-tabulating question responses with age; calculating Child Survival indicators and, if necessary, re-tabulating questions where errors were made.

The resources needed for this process are:

- persons to tabulate (tabulators)
- working space
- blank frequency tables
- pencils
- erasers
- calculators
- lanterns or candles for work in the evening

As is evident, fewer resources are needed for manual tabulation of data than for computerized tabulation: there is no need for computers, software, electricity, and more highly trained data entry people.

Hand tabulation yields a set of forms which present the frequency of mothers' responses for each question; age distributions for mothers and infants; and coverage data for immunization and vitamin A. Data analysis takes one entire day.

In analysis sessions, each tabulation table is reviewed, implications are discussed, and recommendations for follow-up are proposed.

After two recent baseline surveys, managers of Save the Children/Nepal and World Vision/Indonesia projects gathered project staff and government counterparts, all of whom had participated in the household interviews, for the analysis session.

The analysis process should be thorough; careful review and discussion of the implication of each piece of data will result in a useful project management plan. If everyone participates, this can be a very exciting process. For example, the SC/Nepal analysis session included representatives from each SC program sector (i.e., Women in Development, Agriculture, Micro-enterprise, Non-formal education) and ideas for linkages between sectors were born.

In Nepal and Indonesia, project managers chose not to transport the questionnaires to the capital city for computer tabulation because they wished to keep the data at the project site and no project staff were computer literate.

Computerized Tabulation of KPC Survey Data: Use of Epi Info

What is Epi Info?

Epi Info is an all-in-one package that can meet practically every project survey analysis need. It allows users to develop questionnaires, enter survey data and analyze the data, graph and print survey results, and import survey results from other surveys for analysis.

Epi Info's word processing function allows the user to design a questionnaire or import one which has been saved in an ASCII format as well as to edit an imported questionnaire.

The data entry function allows data from completed interview forms to be entered into the Epi Info computerized questionnaire. To assist with data entry, Epi Info has an additional function that allows the user to develop such data entry instructions as automatic coding, skip patterns, and minimum and maximum ranges.

The Analysis function uses simple commands to analyze the data. It is possible to quickly produce frequency distributions, cross-tabulations, and more sophisticated statistical analyses. Epi Info also allows the user to produce bar and pie charts, print the results of analysis, and import data from a spreadsheet (such as Lotus) or DBase file for analysis.

Other Epi Info functions allow the following: exporting of Epi Info data for use in other software programs; merging records from different Epi Info

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data files; and making statistical calculations such as sample sizes for studies and surveys.

Note:
Epi Info, Version 5, requires an IBM-compatible microcomputer running PC-DOS or MS-DOS operating system (version 2.1 or higher), 512 K bytes of random-access memory (RAM), and at least one floppy drive.

How has it been used?

WHO, CDC, UNICEF, and most other international health organizations use Epi Info for microcomputer handling and analysis of epidemiologic data from questionnaires. The Epi Info software is also used to help set up study designs. Users can develop a questionnaire, revise it, and transfer it into a screen record into which an entire survey can be entered over a very short period. The survey findings can be analyzed and printed in a few minutes, while sophisticated cross-tabulation and regression analysis may be generated over a longer time. Results can then be processed into text and written as reports.

Many PVO Child Survival projects have used Epi-Info to tabulate and analyze the results of Rapid Knowledge, Practice and Coverage (KPC) surveys. Survey trainers who help Child Survival project staff carry out a Rapid KPC Survey usually train project staff to tabulate and analyze the survey manually. (This permits field staff taking part in the survey to take "ownership" of the data analysis and results). If, however, projects have access to computers and electricity, and have management or computer staff trained in Epi Info, the survey trainer also can assist projects to tabulate and analyze the survey using Epi Info.

The Rapid KPC Survey process requires tabulation and analysis immediately after conducting interviews to allow rapid feedback to communities. Initial tabulation and analysis may need to take place in areas where electricity and computers are not available. Projects can then tabulate by computer later if more sophisticated analysis is desired.

Data Entry and Analysis

Data entry with Epi Info usually requires two persons per computer. One person reads the responses recorded on a single survey questionnaire time while the other team member enters the response on to a computerized version of the survey questionnaire. When the responses from all questionnaires have been entered into the computer, tabulation is complete and project staff can then analyze the data.

Once data entry is complete, the computer teams can run the Epi Info ANALYSIS program and have the computer calculate the frequencies of responses to the survey questions and cross-tabulate responses with other parameters such as age. These results (frequency distributions and cross-tabulations) can appear on the computer screen or be routed to a text computer file or a printer. Text computer files can be edited in word-processing software programs such as WordPerfect, and tables and graphs can be inserted into survey reports written in these programs.

A two-person team usually needs about two days to enter the responses from 300 KPC Survey questionnaires and print the frequency distributions and key cross-tabulations (four or five). If a project has more than one computer and more than one trained data entry/analysis team, then this process can be completed in one day.

Advantages and Disadvantages

Advantages
The main advantage of computer tabulation with Epi Info is that it requires less effort (number of person hours) than manual tabulation. Two to three trained persons can enter survey data for 300 questionnaires and produce frequency distributions for each survey question in a two-day period (approximately 40 person hours of effort). In contrast, manual tabulation of 300 survey questionnaires (of about 45 questions each) requires about 160 person hours of effort: for example, 10 hours for a group of 16-20 persons working in teams of two.

Another major advantage, is that Epi Info allows more flexible and sophisticated analysis and reporting of data. For example, manual tabulation requires project staff to decide ahead of time what frequency distributions and cross-tabulations will be needed. With Epi Info, printing of frequency-response and cross-tabulation tables is done after data entry (computer tabulation), allowing users more flexibility in deciding which tabulation tables to print. Also, Epi Info users can produce tables, graphs and charts directly and quickly from survey data entered into the computer. Additionally, sharing the data is easy, as it requires only the shipment of a diskette rather than a packet of about 150 manual tables.

Epi Info is inexpensive, is used and available worldwide and is easy to learn compared with other statistical/survey software programs. Therefore, if project staff are proficient with computers and have access to computers and a suitable power source, survey trainers and project managers may consider tabulating and analyzing the results of Rapid KPC Surveys using Epi Info.

Disadvantages

If data are tabulated only by computer, there is less participation by project staff and others who took part in the Rapid KPC Survey and consequently a lower sense of community ownership of the data. Manual tabulation usually requires participation of many more of the persons who were involved in the survey process and elicits their insights as they write comments on the tabulation forms. Manual tabulation also focuses on tabulating responses to individual questions rather than entire questionnaires and thus gives manual tabulators a deeper understanding of the results for specific questions.

Another disadvantage of computer tabulation (versus manual tabulation) is that it requires that users have more training and a solid background in computers to do all the functions required for tabulating surveys, such as: developing or adapting a survey questionnaire, adapting data entry to reflect the "jumps" on the survey questionnaire, printing frequency tables, "cross-tables", graphs and charts. Persons who perform manual tabulation can be trained on the job and require only basic arithmetic skills (add, subtract, multiply, divide). Therefore, the "person hours" needed for computer tabulation are of a higher skill level than the "person hours" needed for manual tabulation.

The last major disadvantage for computer tabulation, especially for programs working in remote areas, is that it depends on access to electricity, computers and printers.

The final interpretation of the results is the most difficult and most productive part of the whole survey. The local field staff should recognize their own achievements as well as constraints to project implementation. They should identify areas for improvement and needs for further team training.

Where to get more info on Epi Info

Copies of the software and manual are available directly from:

USD, Incorporated
2075A West Park Place
Stone Mountain, Georgia 30087
USA
(011-1) 404-469-4098

The cost per copy (including the manual) is US$50 if ordering from within the US and US$65 if ordering from outside the US. Ordering can be done by telephone using a credit card (VISA). Ordering by mail can be done with a check that must be drawn from a US Bank.

Technical support for Epi Info is available by phone, fax, or mail from:

Orkand Corporation
Attention: Carol Worsham
2635 Century Parkway, Suite 200
Atlanta, Georgia 30345
USA
phone: (011-1) 404-728-0545
fax: (011-1) 404-315-6440

Technical support includes on-line help for beginners to advanced users: from developing questionnaires to help importing data from other database programs. Technical support also includes a three-day beginner training course; this course is offered in Atlanta, however, the Orkand Corporation also is willing to conduct the training anywhere around the world.

The cost for the three-day course varies depending on the number of participants:

6-9 participants = $325/each + trainer travel and per diem (if applicable)
10-13 participants = $300/each + trainer(s) travel and per diem (if applicable)
14-17 participants = $275/each + trainer(s) travel and per diem (if applicable)
18-21 participants = $250/each + trainer(s) travel and per diem (if applicable)
22-25 participants = $200/each + trainer(s) travel and per diem (if applicable)

Interpretation of the Data for Project Action

Once the interviews have been completed, the data entered and the results analyzed, work to interpret and use the data begins. The field team should be assembled to discuss the survey results, to draw conclusions from the results and determine whether

project strategies need to be modified. Then the conclusions must be shared with all field staff, the MOH, and the community.

The final interpretation of the results is the most difficult and productive part of the whole survey. The local staff should recognize their own achievements as well as constraints to project implementation. They should identify areas for improvement and needs for further team training.

A project manager may need help in understanding what statistical tests mean. For example, a result significant at .1 means that if you repeated the survey 100 times, subsequent findings would lie within a range 10% greater or 10% less than the calculated percentage 95 out of 100 times. For example, if the survey found 50% of the mothers interviewed reported their children had diarrhea during the previous two weeks, the actual rate of diarrhea would be between 40% (50% - 10%) and 60% (50% + 10%).

Levels of knowledge and practice obtained through the 30 cluster survey method can be compared to national and international survey findings to estimate trends in mortality or morbidity. However, unless the sample size is increased, it is unlikely that the sample size will be sufficiently large to permit conclusions to be drawn about the statistical significance of changes from baseline to final survey.

Feedback to the community follows tabulation, analysis, and report writing. Project managers set a date for the feedback session and give community members about four days notice. Letters of invitation are distributed to local government agencies, community leaders and groups, school teachers, and other NGOs working in the area. The community feedback session allows project staff to review project goals and objectives with the community and report on survey findings; if well-facilitated, the meeting provides a forum where community members can present their ideas. The community feedback session is usually well attended. If the Child Survival impact area is very large, several feedback sessions may have to be scheduled in order to reach the entire population.

A total of 18 people (17 men, 1 woman) participated in a recent feedback session in a Save the Children project in Nepal: the group included a district public health official, health post staff, the Vice Chairmen of different wards, school teachers, community leaders and Save the Children/US Nuwakot field staff. Survey findings were presented by the Project Coordinator and the Deputy Public Health Coordinator. The summary of results highlighted important findings from each of the intervention modules on the questionnaire. All who attended participated actively in the discussion with many questions and comments. For example, the Vice Chairman raised questions about the side effects of Depo-provera injection and the information needs of Depo users. Participants were concerned about the percentage of children who had diarrhoea in the last two weeks: levels of use of Jeevan Jal (ORT) were not considered satisfactory; the group suggested increased promotion of Jeevan Jal in non-formal education classes.

In summary, the importance of the Rapid KPC Survey in Child Survival project planning, implementation and management cannot be emphasized enough. All KPC surveys yield findings that provide great benefit to PVO and MOH staff members, as well as to community members and families. The survey team of interviewers and supervisors plays an important role in survey analysis, interpretation and strategy modification. A key to long term success of the survey program will be continued training of individuals and organizations (including staff at headquarters offices), and individuals from in-country Ministries of Health, universities, and private consultants.

Summary

Qualitative research attempts to understand phenomena or processes using a range of flexible tools, such as observation, open-ended questions and discussions. The researcher is involved, to varying degrees, in the lives of those they study. Qualitative methods are best suited for: (1) exploring a question; (2) seeking in depth understanding (e.g.,, attitudes or program internal dynamics), especially if study subject participation is desired or (3) interpreting the results of quantitative surveys. Resources permitting, combining quantitative and qualitative methods offers both numerical measures of occurrence and/or association as well as likely explanations for the numbers. Three fundamental methods are detailed step by step with field illustrations from developing countries: focus group discussions, key informant interviews and participatory rapid appraisal.

STRENGTHENING HEALTH SERVICES THROUGH QUALITATIVE EVALUATIONS: PRACTICAL TOOLS FOR THE FIELD

KIRK DEARDEN, DR.P.H., M.P.H.*

Why Use Qualitative Methods?

Every day we evaluate--either formally or informally. However, despite the frequency with which we evaluate, we are not all good evaluators. We may not have the information we need to properly evaluate or we may not be acquainted with the tools we need to carry out effective evaluations (Rugh, 1986). Yet for those of us who are involved in program development and implementation, our understanding of programs very much depends upon effectively collecting and analyzing quantitative and qualitative data. For example, we would certainly want to know if our program has had an impact and how much of an impact. We would also like to know what changes programming might need, based on experience in the field. Sometimes, programs adversely affect groups we work with. What negative effects, have our programs had on others' lives? Quantitative and qualitative research tools can be used to answer these questions.

The purpose of this chapter is to acquaint the reader with several of the qualitative techniques available to health care professionals. A second purpose is to provide a framework for deciding when to use which methods. Steps to conducting effective qualitative research and evaluation and examples from the field round out the discussion. For those interested in pursuing a given method in greater detail, references and resources are listed at the end.

What is Qualitative Research?

Qualitative research is an attempt to understand phenomena or processes using a range of tools. Researchers are involved--to varying degrees--in the lives of those they study. Data may come from observation, open-ended questions, and discussions. Methods and approaches are both flexible and "organic"--changing according to the collective information gathered and based upon the needs of the researcher and those participating in the study.

How Does "Research" Differ from "Evaluation"?

These terms are often used interchangeably. In fact, research and evaluation are very different. Evaluations are meant to assess program progress and impact. Has the program accomplished what it was meant to? How has the program affected program participants? others? Research, on the other hand, is meant to look at broader issues, issues which may or may not include a focus on programs. In the context of development work, research should inform about the development process. How does training for traditional birth attendants affect neo-natal mortality rates (i.e., is there a change

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and why the change?) How does women's access to credit impact upon fertility? Why? These are questions which extend well beyond the need to assess program progress and impact.

This chapter reviews three qualitative approaches to evaluating programs: focus groups, key informant interviews, and Participatory Rural Appraisal techniques.

Focus groups capitalize on group dynamics to understand an issue. In focus groups, a skilled moderator fosters discussion among a small group of individuals (usually six to eight people) about a particular topic. Notetakers take notes (as their title suggests; in many cases, they may also tape discussions) and make observations about interaction (verbal and non-verbal) among group members. The composition of any one focus group is generally limited to those of the same sex, those at the same point in the life-cycle, and those with similar levels of socioeconomic status. Even so, multiple focus groups should be conducted so that comparisons can be made, for example, women's experiences to men's, the experiences of those who have participated in an NGO-sponsored program to those who have not, the experiences of the young and the old, and the well-to-do and the poor (Academy for Educational Development, 1988).

Key informant interviews are discussions with a select number of individuals who are particularly knowledgeable about a given subject. For example, women who have made frequent visits to the government health post might be asked about their experiences with health care providers. Community health workers could be questioned about women's receptiveness to ORT. A limited number of women might be asked in detail about their treatment of children's diarrhea. Opinion leaders (village chiefs, union leaders, presidents of associations, leaders of women's groups, and others) should also be considered important key informants. Key informant interviews are characterized by extensive probing and open-ended questions. They are conducted one-on-one between the respondent and a highly skilled interviewer (Academy for Educational Development, 1988; Patton, 1980).

Participatory Rural Appraisal (PRA) techniques are a family of easy-to-use tools which rely on the active participation of community members in monitoring and evaluating their own development. PRA methods are closely related to a host of other rapid assessment techniques including Rapid Rural Appraisal (RRA) and Rapid Assessment Procedures (RAP). While much of the PRA methodology comes from agricultural development work, PRA has also been used successfully in other disciplines, including health. The most frequently used PRA methods include mapping, transect diagrams, timelines, wealth ranking, informal censuses, and genealogies (Program for International Development and National Environment Secretariat, 1989).

Guidelines for application

Given the availability of these and other techniques--both quantitative and qualitative--how should one select an appropriate method for research? program evaluation? Table 1 -- adapted from the work of the Academy for Educational Development (1988) and Patton (1980)--provides a useful guideline. Criteria for selecting quantitative or qualitative methods can be loosely categorized as relating to the purpose of the investigation, the intended audience, and other factors affecting choice of methods, including cost and time.

Which qualitative methods are best suited to evaluating health programs? Of course, this depends upon the objectives of the project and the purpose of the evaluation. What is it that we hope to accomplish as a result of this evaluation? Table 2--adapted from the work of AED (1988), provides criteria for how to select from among qualitative methods.

One of the dangers associated with the blind use of these tables is that the range of research and evaluation methodologies may not be explored. For years, social scientists have been debating the merits of their particular approach to research (whether it be "quantitative" or "qualitative" without recognizing that there can be a great deal of complementarity between the two approaches. Quantitative and qualitative methods are different, however, they are not diametrically opposed to each other and they should not be used in isolation. In fact, evaluations are most

convincing when staff combine an array of techniques (Pedersen, 1992).

Selecting Methods: Practical Experiences from the Field

In January of 1994, Save the Children staff in Haiti participated in a workshop on qualitative techniques. Most staff were already familiar with *quantitative* techniques but needed to know when to use quantitative techniques, when to use qualitative techniques, and when to use both.

After an introduction to various research and evaluation tools, staff members were divided into two groups. Groups were given a range of situations requiring a decision about which methods should be used. Groups were then joined, and a spokesperson from each group described which method their group would use and why. The scenarios--along with possible answers--appear below.

Q. The government reports that 45% of women 15-49 years old use a modern method of family planning. You are the new program director for the country and, based on conversations you've already had with men and women where you work, you have reason to suspect that the contraceptive prevalence rate is much lower. Which method would you use to determine the validity of the government's report?

A. Because you are interested in level of occurrence (of adoption of family planning) use a survey (one type of quantitative data collection). The word "percentage" provides a clue--you will need numeric data on every individual. Alternatively, data could be collected for a sample of individuals.

Q. In an attempt to decrease the incidence of diarrhea in the region, pumps are installed in every village. Anecdotal evidence suggests that only a few women in each village regularly use wells. Which method would you use to get a rough idea of how extensively pumps are being used? What method would you employ to better understand *why* pumps aren't being used?

A. There are several approaches to collecting this information. One possibility is to conduct a structured survey. A survey would give detailed information on what percentage of households got water from pumps. Likewise, structured interviews could help your project get a better handle on the prevalence of diarrhea. Since you are interested in getting a *rough* idea about pump usage, a more cost-effective approach would be to have 2 or 3 individuals from a handful of communities map out their villages (using PRA techniques) and identify households which are currently using pumps. This might be a good opportunity to conduct an informal "focus group" on reasons for use/non-use. Alternatively, more formal focus group discussions could be held--but perhaps at the risk of a more open response. Again, a combination of methods would be most appropriate.

Q. You are the new program director for an NGO which has a two-pronged approach to development work: small loans to villagers to increase their income and nutrition education to improve health status. You have heard that women and men who have access to credit have successfully used credit to increase their income, but you would like to know if income has actually increased and whether or not women's increased income (as opposed to men's) is more likely to be spent on nutritious foods and health care needs in general. Would you use quantitative or qualitative methods? Why?

A. If you are interested in determining how much increase in income, use quantitative surveys. Information on income is, by nature, quantitative (and very difficult to collect!). A survey can also be used to assess the extent to which increased income is spent on children. Focus groups could be used to evaluate changes in income expenditure, but they would not be the best means of identifying the exact change in every individual's spending

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habits. Income is a sensitive issue--one that won't be talked about much at the group level--another reason not to use focus groups. However, focus groups could be used to explore broad differences in how women and men spend money. Interaction of respondents in a focus group setting would stimulate a richer understanding of why women spend more money on children (if this is the case). If these questions were asked at the individual level, they could be very awkward.

Q. In an attempt to increase the nutritional levels of household members, you have decided to start an in-kind loan (potato seedlings) in Bolivia. Your objective is to make sure that only the poorest of the poor get loans but you don't have the time or money to conduct a survey of every household. What method should you use and why?

A. Participatory Rural appraisal techniques. Use them to map out households in the community. Then a select group of individuals could rank the wealth of each household by putting beans, stones, chips of pottery, or other readily available items next to each household on the map. If the credit program is about to begin, these wealth rankings could be used to target the poorest of the poor. If the project is well underway, wealth ranking could be compared to lists of individuals who have access to credit to assess the extent to which the poorest of the poor really do have access to credit.

Steps to Conducting Successful Focus Groups

This section--based on the work of AED (1988 provides *basic* guidelines for carrying out focus groups. More detailed information can be found in references cited at the end of the chapter (see, for example, AED, 1988; and Folch-Lyon and Trost, 1981). While focus groups are relatively easy to use and a basic understanding of how to use these methods can be gleaned from manuals, there is no substitute for solid training, practice, and keen observation.

Steps:

1. Establish the purpose of conducting focus groups. Are focus groups meant to:
   - Generate ideas (e.g., about program directions)?
   - Stimulate thinking on a specific topic (e.g., how to make health programs more gender sensitive)?
   - Understand attitudes and behaviors (relating to fertility control, for example)?
   - Elicit responses to on-going or future projects?
2. Determine the number of groups needed
   - Usually at least two groups are needed for each variable considered relevant to the topic (e.g., males/females, program participants/non-participants)
   - Conduct groups in each geographic region where a meaningful difference is felt to exist (e.g., are some regions more liberal/conservative than others?)
3. Determine focus group composition
   - It is generally best to conduct focus groups among relatively homogenous groups (those of the same sex, the same stage in the life cycle--e.g., women of reproductive age, and experience with a given development program)
4. Establish the length of time needed for each focus group
   - Limit sessions to no more than one hour and a half!
5. Develop a topic guide (a broad outline of issues to be addressed plus probes to get at each issue)
   - Avoid covering too many issues
   - Pick questions directly relevant to the matter at hand
   - Sequence topics such that they move from the general to the specific
   - Avoid opening the session with sensitive issues (e.g., family planning, female circumcision) or topics that might put focus group participants on the defensive
   - Adapt the content of the topic guide to the needs of each focus group (e.g., men/women, program participants/non-participants)
   - Select open-ended non-biasing questions (e.g., "what were your

reactions when you first attended a women's health group meeting" rather than "did you like the women's health group meeting" or "what did you like about the meeting").

6. Determine focus group size (usually 6-8 people)

7. Determine focus group setting
   - This should be a private, comfortable, non-threatening environment (e.g., schools or government buildings may encourage participants to respond "correctly" rather than honestly)

8. Determine group seating arrangements
   - Avoid designating "status" in seating arrangements
   - Make it possible for the moderator to have good eye contact with all respondents
   - Seat respondents at approximately equal distances from the moderator and clearly in sight of all other participants

9. Select a moderator who:
   - Puts people at ease
   - Is accepting and non-judgmental
   - Is good at interpersonal communication (listening is especially important)
   - Is aware of non-verbal language
   - Is preferably of the same sex

10. Brief the moderator about the project, the participants, the topic guide, and the objectives of focus group discussions
    - Alternatively, the moderator and notetaker could be involved in the design and execution of focus groups from the outset

11. During focus groups, **probe, probe, probe**!
    - Don't be satisfied with "easy" answers (e.g., what specifically does respondent mean by not being able to participate in health training sessions because they "take up too much time"?)

12. Use a range of techniques to elicit discussion and arrive at deeper meaning
    - Study opposites (e.g., have group members <u>describe</u> in detail the characteristics of those who use/don't use family planning)
    - Use role-playing, visual stimuli, and hypothetical situations (geared to the experiences of focus group participants) to elicit responses
    - Use "top-of-mind" associations (e.g., "what's the first thing that comes to your mind when I say 'family planning'?)
    - Question the meaning of the obvious (e.g., "what does 'better living conditions' for women and children really mean?")
    - Use a "benefit chain" to uncover deeper meaning (e.g., "what is the benefit of having a wider variety of foods to eat?" (healthier children) "what is the benefit of healthier children?" (more quality time for work and school) "what are the advantages of having more quality time for work and school?" (children will not lead lives in difficulty), etc.
    - Diplomatically point out (and explore) contradictions in what participants say
    - Have participants describe best-of-all-possible-world scenarios to uncover their thoughts on the ideal immunization program, the ideal contraceptive, the ideal food/liquid for children with diarrhea

13. Frequently evaluate moderator's (and notetaker's) work
    - Do group members feel comfortable (e.g., does moderator establish "rapport")?
    - Is there real interaction among group members (as opposed to a series of individual interviews)?
    - Do group members talk among themselves as well as with the moderator?
    - Are moderator's questions unbiased?
    - Does the moderator allow discussions to evolve or does he or she blindly follow the topic guide, creating an artificial discussion?
    - Does the moderator encourage honest disagreement between group members (assuming there is disagreement) rather than forcing a consensus?

14. Analyze results
    - Use notes and cassette tapes to:
    - Sum up different positions represented during focus group discussions (avoid tallying results)

- Assess the extent to which each position was held by group members
- Pull out verbatim phrases which best represent each position
- Identify and interpret constants and differences that emerged for each topic
- Think about the objectives of focus group discussions and link them with results: what key decisions/actions flow from these?

15. Disseminate findings--preferably in a brief, easy-to-read format

16. Remember:
    a. What was not said in focus group discussions is often as important as what was said (which topics were noticeably avoided? why?)
    b. Who said what is often very important
    c. How much was said about a topic is revealing
    d. The order in which things were said *may* be key to understanding the issue
    e. The manner in which things were said is frequently very important

Steps to Conducting Successful Key Informant Interviews

Patton (1980) indicates that "the purpose of [qualitative] interviewing is to find out what is in and on someone else's mind. The purpose of open-ended interviewing is not to put things in someone's mind...but rather to access the perspective of the person being interviewed. We interview people to find out from them those things we cannot directly observe." (p. 196). Key informants are individuals who provide information that the observer (for example, a program staff member or a researcher) cannot access in any other way. Alternatively, key informants may also be a source of explanation for events the observer has actually witnessed (Patton, 1980). By "key informant" we mean any individual who is particularly knowledgeable and articulate about a given subject (Patton, 1980). Technical expertise in a given field is not a pre-requisite for serving as a key informant.

Key informant interviews are but one type of one-on-one interview. Patton (1980) delineates three broad approaches to qualitative interviewing: the informal conversational interview, the general interview guide approach, and the standardized open-ended interview.

The informal conversational interview "relies entirely on the spontaneous generation of questions in the natural flow of an interaction, typically an interview that occurs as part of ongoing participant observation." Because development workers are unlikely to conduct "formal" participant observation on an on-going basis, the informal conversational interview is not well suited to their work.

The standardized open-ended interview consists of a series of carefully worded open-ended questions which are administered in a uniform fashion to all respondents. Given its close relationship to the structured survey, the standardized open-ended interview may be most effective when combined with close-ended interviews.

The third approach to qualitative interviewing--using a general interview guide--holds considerable promise for health care professionals and development workers. The interviewer outlines a series of issues to be explored during the course of conversation. The wording and order of questions are not pre-determined. Rather, the interviewer uses the guide as a checklist to make sure that most or all topics are addressed (Patton, 1980). Interviews may take place over a number of days, weeks, or months, depending upon the degree of depth desired.

Steps:

Qualitative research techniques are considerably more organic than quantitative methodologies. Consequently, there is a danger to prescribing a single set of guidelines, especially for key informant interviews when "process" needs to be fluid. Even so, there are several key components of effective interviews.

1. *Decide upon objectives for the interview*

   What specifically would I like to better understand as a result of interviews (e.g., a better feel for mother's

understanding of the etiology of diarrhea, patient-practitioner relations in a variety of settings, obstacles to allopathic health-seeking behavior)?

2. *Develop an interview guide*

An interview guide is meant to guide discussion such that the same *type* of information is obtained from more than one key informant. The interview guide--if done well--will help define the most salient issues and address those issues in a limited amount of time (Patton, 1980).

3. *Practice wording questions on your own*

While the structure of a key informant interview is not predetermined, mastering the ability to answer questions can only come through practice. Practicing how questions might be worded and modifying questions based on work in the field are two key components to generating substantive discussion.

4. *Gain and maintain the confidence of the key informant*

Key informants are more likely to share their knowledge if they can trust the interviewer. This involves assurances from the interviewer that data will be treated confidentially. In addition, trust is developed through the establishment of "rapport". Does the key informant feel comfortable with the interviewer? Is the key informant likely to share information--even sensitive information--with the interviewer?

What can the interviewer do to put the key informant at ease? The first step toward gaining the confidence of the key informant is to take a genuine interest in the respondent and what he or she values most. In a qualitative study in Bangladesh on the barriers to health-seeking behavior for Acute Respiratory Infections (Zeitlyn and Dearden, 1993), interviewers began visits to mothers' homes by taking sick children on their laps, then asking questions about the children's names, ages, and interests. Physically handling sick children allowed interviewers to observe symptoms first hand and establish a bond of trust among themselves through mutual interest in the child.

A second step is to avoid asking questions about threatening or sensitive issues, especially at the outset of the interview. It is better to begin discussions with a set of broad "icebreaker" questions that demonstrate interest in the individual and allow for the respondent to participate comfortably in the conversation. Questions about non-controversial behaviors, activities, and experiences (in the present) are the most likely to generate response (Patton, 1980).

During the discussion, the interviewer should remain as neutral as possible. If the key informant feels that the interviewer holds a strong position, he or she may be less likely to speak out. Concomitantly, respecting respondent's opinions and knowledge helps ensure that he or she will continue to provide information.

5. *Choose language and dress carefully*

Language should reflect local dialect and terminology, where possible (take care not to insult those interviewed by trying to imitate them). Dress should be modest. Ostentatious clothing or other clothing which clearly identifies the interviewer as "wealthier" should be avoided.

6. *Ask questions that will elucidate and illuminate*

Initially, it is best to have the respondent describe behaviors, activities and experiences--probes can then be used to elicit greater detail, including information about the respondent's interpretations, opinions, and feelings of events just described (Patton, 1980).

Avoid close-ended (yes/no or multiple choice) questions. Rather than asking whether a respondent eats a given food during pregnancy, ask what foods she eats while pregnant. Checklists can be used for coding purposes. Close-ended or short answer questions (including information on social class and demographics) up front can discourage the key informant from responding at length later on.

7. *Avoid biased or "loaded" questions*

These questions put the respondent on the defensive. Rather than asking why the respondent didn't take her child to the health clinic during an episode of ARI, ask her to describe the sequence of events surrounding the identification of ARI and the decision-making process regarding treatment.

8. *Ask singular questions*

Multiple questions (that is, questions with more than one idea) confuse the respondent (Patton, 1980). For example, "What are your impressions of doctors' pay and doctors' services at the clinic?" is really a question with two parts.

9. *Avoid the overuse of "why" questions*

As Patton (1980) suggests, "'Why' questions presume cause-effect relationships, an ordered world, perfect knowledge, and rationality". Further, because responses to "why" questions could potentially cover a broad range of issues, it is next to impossible to know whether the respondent has exhausted all of the reasons for subscribing to a given idea or behavior. Rather than asking why a mother chooses a traditional healer over an allopathic health care worker for the treatment of her daughter's diarrhea, the interviewer could ask the mother what it is about the traditional healer that led her to use his services? Other equally important considerations in a mother's choice of healers might include time, money, belief systems, mobility, and other factors. Asking a mother why she chose a traditional healer could elicit any one of a number of responses. More specific questions about the nature of the healer, time, finances, and beliefs will help ensure that detailed information about a range of factors can be collected.

10. *Allow the key informant to respond fully*

Don't cut the respondent off. Likewise, allow ample time between questions: rushing from one question to the next is not only unnatural, but it prevents the key informant from adding additional thoughts. It is often helpful to allow the respondent to ask additional questions or make further comments at the conclusion of an interview. Alternatively, the interviewer must not lose control of the interview. The interviewer can politely interrupt the key informant if the discussion is providing little substantive information.

11. *Probe*

Many of the probing techniques already described for focus group discussions can also be applied to key informant interviews. For example, diplomatic questioning about the meaning of the obvious or benefit chains can be used in key informant interviews. Likewise, follow-on questions can be employed to gain deeper understanding. Often, these follow-on questions can take the form of repeating the responses of the key informant. "You mentioned that people in this village are reluctant to use tap water for drinking because it is considered too 'cold'. Could you tell me a little more about that?"

12. *Take notes and tape record the interview if possible*

It will be difficult to record verbatim everything the key informant says. A tape recorder can capture information transmitted verbally, allowing the interviewer to focus on questioning, listening, and observing verbal and non-verbal behavior. If a tape recorder is

used, the key informant must be made aware of its presence and purpose.

13. *After the interview is complete, review notes to make sure they are legible and in logical order*

Write down or record observations about the interview itself (who participated, when, where, important phrases from or observations about the interview) during the interview as brief field notes. That same day, write down expanded notes about the interview. These should be typed up and can be analyzed using one of several computer software programs (e.g., GOFER, ANTHROPAC, ETHNOGRAPH) (Patton, 1980; Scrimshaw and Hurtado, 1987). If observations are not recorded the same day, many of the results of the interview are lost.

14. *Analyze results*

- Review the original focus of the study.
- Organize and transcribe the data (transcribe the data as is--don't modify the data to make sentences grammatically correct, for example).
- Begin content analysis. Write notes in the margins of one of the copies of the transcripts. These notes can provide standardized key topics or subjects addressed during the interview. Alternatively, GOFER or ETHNOGRAPH can be used to identify key terms and subject matter in the text.
- If case studies are to be used, write a case record. A case record pulls together all of the information collected into a single package. Write the narrative, which is a "readable, descriptive picture of a person or program" (Patton, 1980, p. 304).
- For further analysis of results, use any of a range of techniques described by Patton (1980) or others (Scrimshaw and Hurtado, 1987).
- It is important to point out that unlike the analysis of quantitative data (which occurs once information has been collected), the analysis of qualitative data (and indeed, the formulation of "data collection instruments"), is an on-going process.

15. *Write up report and disseminate findings*

Steps to Conducting Successful Participatory Rural Appraisal

Participatory Rural Appraisal is "a semi-structured process of learning from, with, and by rural people about rural conditions" (Chambers, 1992). Increasingly, PRA techniques are also being used in urban settings. PRA can improve our understanding of behaviors within complex personal and social realities (Scrimshaw and Gleason, 1992). It can also be used for a variety of other program needs, including exploratory research and program planning, monitoring, and evaluation. PRA data generation techniques are especially suited to programs which are by nature participatory (Cernea, 1992).

How does PRA differ from Rapid Assessment Procedures (RAP)?

Rapid Assessment Procedures are used to better understand why things happen: why women breastfeed (or fail to breastfeed) or why some women seek allopathic treatment for their children's ARI while others do not. Unlike PRA, the RAP research process is not controlled by villagers themselves but by a multi-disciplinary group of culturally knowledgeable researchers. Using Rapid Assessment Procedures, information which is fairly rich in detail can be collected quickly; however, community participation is sacrificed. Conversely, in PRA, the goals of the investigation are chosen jointly by villagers and outsiders.

A Few Key Principles

PRA methods, like key informant interviews, are organic, diverse, and iterative. As a

consequence, there is no "recipe" for conducting successful PRA exercises. There are, however, a broad set of principles governing the effective use of these methodologies.

1. In PRA, the role of teacher and learner are reversed (Chambers, 1992).
2. Villagers control the generation of information and its interpretation (Chambers, 1992). PRA is *not* extractive.
3. Participatory Rural Appraisal is *not* research done in a hurry.
4. PRA is flexible and relaxed.
5. PRA rests on "optimal ignorance" (not trying to find out more than is needed) and "appropriate imprecision" (not trying to measure what does not need to be measured or not measuring more accurately than is necessary for practical purposes (Chambers, 1992).

Components

Determine the purpose of PRA; Is it meant to:

- explore ideas, including ideas for future programming?
- get feedback from the community about programs in progress? programs to be implemented?
- gain greater knowledge about beliefs, practices, and existing knowledge?
- provide an overview of community structure?

Decide upon specific methods to be used

There are a range of PRA techniques and more are being created and modified every day. Some that might be useful include:

- **pie charts** or wheels which can be divided into domains. For example, Mascarenhas (1991) looked at trends in maternal and child health by asking a woman from a middle class household to provide details about family planning, food habits, immunization practices, birth attendant, method and place of birth, rest and health care and personal hygiene for mother and/or child. Each of these domains was represented by one slice of the pie and generations were represented by place on the wheel (center, mid-point, and periphery). Thus, the woman's grandmother's food habits were listed at the center of the circle, her mother's food habits next, then her food habits at the outer edge. This allowed for an easy comparison across time of food habits during childbearing and lactation.

- **free-listing/pile sorting** can be used to "elicit information from subjects on the range of women's illnesses [and other illnesses] and associated symptoms" (Kanani, RAP). Once a list of illnesses is collected and written down/pictured on separate cards, women (or men) can sort and pile cards according to similarities and differences between the diseases.

- **maps** to identify water sources/water quality (have villagers draw maps with locally available materials--their knowledge and perceptions of resources will be very enlightening) and existing health facilities and health services (including coverage areas for Community Health Workers and Traditional Birth Attendants).

  maps can also be used to locate pregnant women, malnourished children, the handicapped, widows, households with no adults who are literate, households with children less than one year old, and households where children are not attending school

  maps can be used in conjunction with genealogies/informal censuses to identify village inhabitants. In small villages this can be done very quickly with just a few individuals. It is important that this data be cross-checked. For example, interviewing a small group of older men might yield slightly different results from interviewing young women.

  maps can also be used in conjunction with wealth ranking. In wealth ranking,

a few villagers are asked to draw households on maps, then represent the relative wealth of each household with locally available materials (shells, rocks, pottery shards, etc.). Wealth ranking can be used for program planning as well (as a means to identify the poorest of the poor, for example, if this is the target group).

- **timelines** can be used to assess changes over time in the composition of diets, the quantity of food consumed, agricultural output, etc.

- **informal discussions**--at water pumps, at the market, at the village square, and other places where people congregate--to learn about why pumps, tubewells, and latrines are/aren't used, to discuss strategies for improving their use, etc.

More detailed information about these methods is available from a variety of sources, including Scrimshaw and Gleason (1992), RRA Notes (a publication distributed free of charge by the International Institute for Environment and Development), and Theis and Grady (1991).

- Refine and limit the list of objectives to be accomplished through PRA
- Select participants (or types of participants, e.g., women with at least one child, middle-aged men with no history of contraceptive usage, etc.) based upon careful criteria for inclusion
- Select an adequate location for exercises (comfortable and "natural" settings are best) and a time that is suitable to villagers
- Train staff in the use of PRA techniques
- Establish rapport

Chambers (1992) suggests that outsiders (i.e., program staff and others) be relaxed and re-oriented. They should avoid wagging the finger, holding the stick, sitting on the chair behind the table...dominating and overwhelming thought and speech...demanding information and answers...believing that we know and they are ignorant, [and] that they are the problem and we are the solution" (p. 298). Icebreakers and equalizing exercises (e.g., simple everyday tasks such as basket weaving, transplanting rice, constructing houses) are also an important component of establishing rapport.

- Take care not to raise villagers' expectations (Mascarenhas, 1992)
- Be creative

John Hatch (referenced in Rhoades, 1992) suggests that the investigator team approach farmers (or others more directly connected with health care systems) about exchanging labor for information (be sure to keep notes of the day's experience, then be systematic in writing up notes). Spending at least a full day working with farmers and others can help provide an insider's perspective on the lives of villagers. In addition, willingness to learn from villagers not only puts them at ease, but allows them to become teachers, rather than learners.

- Use triangulation (the cross-checking of information using several methods of data collection, see Chambers, 1992)
- Allow villagers to analyze and feed back results to program staff. It is absolutely essential that villagers themselves "own" the process of analysis and feedback. Staff may want to further analyze results. If so, any write-up of results should be brief and easily understandable.

Questions staff should address in their analysis might include: What was said/not said during PRA exercises? Who was seen/not seen? What other sources of error are there? How might they affect the results obtained? Fostering critical self-awareness among staff is absolutely essential for PRA exercises (Chambers, 1992)

What are the Limitations Associated with Qualitative Methods?

There are a number of potential dangers associated with the improper or isolated use of qualitative methods. These include:

an inability to capture dynamics over time

this is especially problematic when qualitative research is rapid or occurs at only one point in time

inaccurate information

opting for appropriate imprecision and optimal ignorance can have very definite consequences for the validity of information obtained (Cernea, 1992)

unrepresentativeness
who is and who is not selected for focus groups? key informant interviews? PRA exercises?

irresponsibility or amateurism in approaching qualitative methods (Cernea, 1992)

lack of focus

oversimplification of social reality (Pedersen, 1992)

many thoughts, processes, and actions are simply too difficult to represent verbally and in a short period of time; care should be taken such that what is said is not simply taken at face value

taking the "group response" as the average response or as the meaningful response

this is especially problematic in focus group discussions and PRA exercises where a few individuals dominate the conversation: their response (or even the majority of individuals in the group) is <u>not</u> necessarily the group response. What other voices were/weren't heard? What is the <u>variety</u> of response rather than the average response?

"audience effects" on the individual

how does being in a group moderate response? (Stycos, 1981)

subjectivity

what biases do outsiders bring with them about health? social relations? etc.

over-reliance on qualitative methods to "neutralize" the ideology and value systems of researchers and informants (Pedersen, 1992)

can't (and shouldn't!) be quantified

the number of individuals in a focus group who responded a certain way to a given question should <u>not</u> be counted

findings may not be generalizable

Finally, these "rapid" approaches to program planning and research are not a substitute for long-term basic research methods and procedures (Cernea, 1992).

Even so, there are a number of very appealing strengths associated with qualitative research. These include, among others, greater community participation and ownership of data and lower costs. Most importantly, qualitative research allows us the chance to "peer into" the lives of those we work with most closely. These insights provide a unique opportunity to better understand how development can be a collaborative process.

Case Study: Focus Group Discussions in Mali

In April, 1994, staff from Save the Children's Mali field office conducted 12 focus groups as a way to better understand women's contribution to development in rural areas (Save the Children, 1994). Staff were also interested in identifying programmatic changes necessary for the full inclusion of women in the development process. Prior to conducting focus groups, staff (all of whom were Malian nationals) received training in focus group techniques. Most had no previous experience with focus groups. Most of the first day was spent training staff and allowing them the opportunity to practice their skills. Here are some of the lessons staff learned:

Allow plenty of time to set up focus groups.

> Save the Children teams arrived the night before and met with the village chief, elders, and community members. Based on criteria established by Save the Children, community members themselves selected who would participate in discussions the following day. Staff members also spent the night in villages (living at the same level as the villagers) to gain a broader perspective of community life.

Respect the concerns of village elders and other local leaders. If they are not to be included in focus group discussions (often it is best not to include them), arrange separate meetings with them.

Listen carefully. Listening is a key ingredient to successful focus groups.

> Because Save the Children staff are often involved in community education, it is easy to educate villagers about the benefits of immunization rather than listening to why villagers are reluctant to have children immunized. As Patton (1980) notes: "the purpose of interviewing is to find out what is in and on someone else's mind...not to put things in someone's mind. (p. 196).

Probe! Unless probing is used extensively, focus group content is shallow.

> For example, what does it mean when people say that because of education, men and women can "walk easier together"?

If one of the major purposes of focus group discussions is to avoid bias (i.e., produce valid answers), discussions should be led by individuals who are not affiliated with the program. If staff instruction and learning are key concerns, using them to conduct focus groups can be an enriching experience for the staff and for the program.

> In Mali, because Save the Children staff conducted focus groups, it was difficult to frame discussions as anything more than "needs assessments". One solution is to train villagers from other areas to conduct focus groups. This would have the added advantage of bringing discussions back to the level of villagers themselves.

The mastery of focus group techniques is a gradual process.

If possible, take focus group discussion notes in the local language.

Initially, considerable lead time may be needed for the development and translation of focus group guidelines. Ideally, these guidelines should be developed by staff members themselves.

Scenarios which use local terminology and real-life situations are especially helpful in generating group discussion.

Feeding back results from focus group discussions in plenary gives villagers the opportunity to "keep" and "analyze" their own data. These sessions may also foster even greater input from villagers--especially if focus group members held widely differing positions about a given topic.

> In Mali, focus groups were held separately and simultaneously for men and women. Once focus groups were complete, the two groups met together and were informed of the content of each other's discussion *(don't analyze results in front of villagers!)*. Men and women were then given the opportunity to comment and react in plenary. These results were at least as interesting as those obtained during separate discussions.

Be open to the possibility of other formats for focus group discussions: they may provide villagers with a more "real world" setting.

> What would a natural focus group look like in a given setting? Would it take place under a mango tree? at the pump? or sitting with a group of women on a mat shelling peanuts?

Adapted from Save the Children Federation (US), Mali Field Office (1994). Using qualitative methods in gender research and program planning: Results from Mali (Woman/Child Impact Program Occasional Paper No. 2). Westport, CT: Save the Children.

Case Study: Participatory Rural Appraisal in Bolivia

The Bolivia Field Office of Save the Children has used participatory evaluation and research tools on an on-going basis to develop,

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implement, and evaluate programs. Women's groups--the primary focus of the field office's work--use "autodiagnosis" to explore experiences, attitudes, and practices related to maternal and neo-natal health.

Lessons learned:

- There are no right answers--only what the women themselves believe and understand. Allowing women from the community the opportunity to identify and prioritize health problems allows Save the Children to build programs on program participants' perceptions of key health issues.
- Participatory techniques can be used to raise awareness about a given health problem and increase the community's confidence in their ability to gather information from neighbors about maternal and neo-natal health.
- Open-ended, non-biasing questions ("How do you feel when you're pregnant?", "How do you feel toward the newborn?") encourage women to speak freely about problems and needs.
- Role play can be used effectively to learn what group members know and do about maternal and neo-natal health problems during pregnancy, labor, delivery, and post-partum.
- Pictorial dictionaries of terms can be developed to assess women's knowledge of childbearing and childbirth. Drawings help stimulate responses to problems that otherwise might not be raised.

  One example is eclampsia. After drawing a woman experiencing eclampsia, women are asked whether it occurs in the community, how often, its local term, how it is treated, and what happens if it is not treated.
- Dividing women into smaller groups (i.e., 8-10 women per group) allows them to more fully discuss their own health problems, assess the extent to which other women (that is, those not participating in health groups) experience these problems, then prioritize those which need the greatest attention.
- Women within groups help each other in designing easy-to-use pictorial guides to assess the frequency of health problems which community women experience in childbearing. Interviews with community women are very open-ended allowing respondents to relate difficulties they have faced in childbearing.
- Results from interviews are presented in plenary during women's health group meetings. "Health flags" are used to represent quantitative results: a small cut-out doll is placed in the red column of the flag to represent a woman who has experienced difficulty. Based on these results and discussions with health group members, problems are prioritized.

Adapted from Sanchez, E., Howard-Grabman, L., and Bartlett, A. (1991, June). Researching women's health problems using epidemiological and participatory methods to plan the Inquisivi MotherCare project. Paper presented at the annual meeting of the National Council for International Health, Washington, D.C.

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Table 1

Questions for Deciding Upon an Appropriate Methodology

Is descriptive information needed about the quality of program activities and outcomes (as opposed to levels or quantities of program activities and outcomes)?	Is it important to know level of occurrence?
Is depth of understanding needed?	Is breadth of information needed (less detailed information about a larger population)?
Is active participation of the community needed? Is open exchange of ideas desired?	Is the objective to describe (especially trends and actions)?
Will results of the evaluation be used primarily by community members and project staff?	Are results of the evaluation intended for audiences outside of the project (e.g., donors/academic audiences)?
Is the study exploratory in nature/meant to generate ideas?	Is the study meant to be "definitive"?
Is the study meant to discover attitudes, motivations, or behaviors?	Is it important that distance be maintained between "investigator" and "informant"?
Is guidance needed on a community's (potential) reaction to a project?	Does the program emphasize individualized outcomes? Is it important to be able to ascribe change to every individual participating in the program?
Might the program affect participants in unexpected ways?	Is it essential that project inputs and outcomes be monitored in a routine fashion?
Is detailed information needed about a few particularly successful cases? unusual failures?	Will the results of the study be used to raise the visibility of the program or agency as a whole?
Is it important to understand the internal dynamics of programs (including strengths, weaknesses, and processes)?	Is "proof" needed (e.g., program impact must be demonstrated to donors)?
Will the evaluation be used to help staff "think on their feet" and use that thinking to improve programs?	
Is it difficult to obtain a valid and reliable standardized instrument which can measure program outcome (e.g., women's level of empowerment)?	
Is additional information needed to interpret results from quantitative studies?	
Are quantitative methods considered to be too costly and time consuming?	
↓	↓
Use Qualitative Methods	Use Quantitative Methods

Table 2

Selecting an Appropriate Qualitative Methodology

Use Focus Groups when...	Use Participatory Rapid Appraisal when...	Use Key Informant Interviews when...
Broad information from an array of individuals with exposure to programs is desired (e.g., groups of comparison might be program participants vs. non-participants, young vs. old, male vs. female, positive experience with development programs vs. negative experience)	Broad information from an array of individuals is desired. PRA methods depend upon information provided by small groups of individuals from various segments of society (e.g., village chiefs, traditional birth attendants, husbands, wives) to draw conclusions about communities as a whole.	Detailed information from a limited number of individuals is needed
The topic is such that most respondents can say all that is relevant or all that they know in a short amount of time	A part of individuals' vast knowledge (of birthing practices, disease etiology) is needed quickly	The topic is such that a greater depth of response per individual is desirable (e.g., complex subject matter and very knowledgeable respondents)
Interaction of respondents may stimulate a richer response or new and valuable thoughts (e.g., testing ideas about how to "market" contraceptives)	Interaction is needed to "complete the picture" (e.g., to gain a fuller understanding of how childbearing and delivery have changed over the years)	Group interaction is likely to be limited or nonproductive
Group/peer pressure will be valuable in challenging the thinking of respondents and illuminating conflicting opinions	Group interaction is needed to cross-check data (e.g., completing and verifying censuses)	Group/peer pressure would inhibit responses or cloud the meaning of results (some focus group members might inhibit others, leading to the erroneous conclusion that the dominant view expressed is the "normative" view of the group)
Subject matter is not so sensitive that respondents will temper responses or withhold information	Subject matter is not so sensitive that respondents will temper responses or withhold information	Subject matter is so sensitive that respondents would be unwilling to talk openly in a group (e.g., abortion, female circumcision, use of contraception)
A single subject area is being examined in-depth	Community-level data are collected at one point in time but provide a broad picture of change over time	It is necessary to understand how attitudes and behaviors are linked on an individual basis over time
An acceptable number of "respondents" can be assembled in one location relatively easily	An acceptable number of "respondents" can be assembled in one location relatively easily	"Respondents" are geographically dispersed or not easily assembled for other reasons
Quick turnaround of results is critical; funds are limited	Extremely quick turnaround of results is critical	Quick turnaround is not critical; budget will permit higher cost
Only modest feedback to community is desired	The ultimate objective of evaluation and research is to empower communities to monitor themselves, to prioritize problems and to develop solutions to those problems	Only modest feedback to community is desired
It is not essential that community members understand data or results	Data to be collected can be represented visually and understood by community members themselves (e.g., they can draw maps of villages in the sand then rank household wealth with locally available items)	It is not essential that community members understand data or results

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Summary

***Background**: Strategies to enhance development program sustainability include both focusing on problems identified by communities and incorporating indigenous solutions. Positive deviance (PD) studies are qualitative, participatory inquiries to identify actionable explanations for observed patterns of disease. Community prerequisites for a PD study are: awareness of a problem; commitment its solution through collaboration with an NGO and an understanding of sustainability. A Poverty Alleviation and Nutrition Program (PANP) in Thanh Hoa Province, Viet Nam illustrates the method.*
***Methods**: All village children less than 36 months were initially weighed to assess the extent of child malnutrition and to identify families for the PD study. Community participants identified from these results three poor families with a well-nourished child and 3 well-off families with a moderately or severely malnourished child. Participants then identified three sets of behavior for good health: good child care behavior, good food behavior, and good health behavior, each with 6-12 questions. They then visited the six households to observe and inquire about 28 variables. Analysis resulted in a "model family chart" to guide sustainable nutrition rehabilitation of previously identified malnourished children.*
***Results**: All well-nourished children were fully immunized, well spaced, and received three meals a day with snacks. All PD mothers were still breast feeding children over age one year. All PD grandmothers knew about proper weaning foods and good hygiene. Specific "successful" menus and other good behavior tips were incorporated into 2 week nutritional rehabilitation workshops.*
***Conclusions**: PD studies identify and benefit from the use of community role-models, a familiar and logical strategy which holds promise as a sustainable development technique. [eds.]*

POSITIVE DEVIANCE AS THE FOUNDATION FOR SUSTAINABLE DEVELOPMENT

MONIQUE STERNIN,* 1994

I. INTRODUCTION: BACKGROUND AND OVERALL STRATEGIES OF THE POVERTY ALLEVIATION AND NUTRITION PROGRAM (PANP)

Strategies

Community development initiatives Phase One involved establishing a four-commune pilot site with a population of 20,000 people in Thanh Hoa, one of the poorest provinces in Vietnam. The selected communes became a "social laboratory" through which a wide range of community development initiatives could be tested. Over a three-year period of continuous testing and evaluation, a Poverty Alleviation and Nutrition Program (PANP) was realized. The model was predicated on the belief that in order for development gains to be sustainable, strategies and solutions to community problems must be identified within the community by the commune members themselves. Translating this process into action enables the PANP to focus on community resources, as well as its needs. This practice contrasts with the more traditional development approach, providing standardized programs to communities based solely on identified needs.

Other strategies include:

- fostering commune ownership of program through use of community-identified solutions to problems and community management of program (monitoring and evaluation)

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- utilizing mechanisms which promote behavioral change in the target population (i.e., caretakers of malnourished children) to ensure sustainability
- emphasizing human development/transfer of skills, with participatory trainings scheduled over time, allowing participants to learn step by step, skill by skill through actual implementation
- providing a time-framed collaboration: collaboration with the communes is limited to 2 to 3 years only and is fixed at the onset of the collaboration, thus highlighting the need for the commune to develop their own human resources to ensure continuation of program after phase-over.

Positive Deviance

The methodology used to identify and exploit community resources is a "positive deviance" study. A positive deviance study identifies people within a community who have unique behavioral practices which set them apart from others within the same community. For example, in the four pilot communes a positive deviance study was undertaken by the community to determine how a number of very poor families were able to have adequately nourished children while their neighbors of the same economic status did not. It was discovered that poor families who had adequately nourished children (the positive deviants) fed their children more frequently and added small shrimps, crabs and vegetable greens to their children's diet.

Positive deviant studies have been conducted successfully in 14 communes (total population: 80,000 people) in two districts in Thanh Hoa province.

Implementation

A Nutrition Education Rehabilitation Program (NERP) was developed to promote this demonstrated successful formula already utilized in the commune. The benefits of utilizing these nutritious, readily available and accessible food supplements, shrimps, crabs and greens, became the central message of the nutrition program. Parents of malnourished children were able to enhance their children's nutritional status within the context of their existing poverty. A community-implemented positive deviance study therefore becomes the foundation for the PANP implementation.

Human Resources

One of the key components of the PANP model has been the establishment of a group of Health Volunteers in each commune. Through a training-practice-review approach utilized by Save the Children, commune and hamlet leaders, health staff and health volunteers gain a comprehensive set of skills, enabling them to implement and independently manage the PANP model after the joint two-year implementation plan.

Health Volunteers are the catalyst through which women, children and men are empowered to improve the health of the community and subsequently, significantly impact the quality of their lives. This process establishes a structure through which community development can be initiated and subsequent gains in standards of living achieved.

In addition, a Management Steering Committee is established to oversee the overall program implementation (monitoring and evaluation) and report of the district authorities. They are the village leaders, hamlet leaders, Women's Union and Farmer's Union heads, and head of the commune health center.

II. Introduction of the Positive Deviance Concept in the Commune

Prerequisites for positive deviance study

- Villagers aware of serious nutrition problem in the commune
- Commune leadership commitment to solving the problem
- Commune leaders willing to collaborate with NGO
- Villagers' understanding of the concept of sustainability in context of human, material and financial resources

Community training for Positive Deviance Study

The commune steering committee, hamlet leaders and health volunteers participate in a training in which the Nutrition Education and

Rehabilitation Program (NERP) is introduced. Analyzing the results from the first Growth Monitoring Promotion (GMP) session weighing all children under 3, participants are challenged to sustainably eliminate 2nd and 3rd degree malnutrition in their community. The 2 goals of the program are stated as such:

1. to rehabilitate together all 2nd and 3rd degree malnourished children

2. to enable the caretakers of these children to continue rehabilitation and/or maintain it on their own at home, in the context of their poverty

On exploring the two goals, participants become aware that the first goal, rehabilitating children, is easy enough; all it takes is for someone to provide adequate food to the child and treat his illnesses with appropriate medicine. Regarding the second goal, participants are asked how caretakers could continue rehabilitation and/or sustain the enhanced nutritional status of their children on their own after participation in the NERP.

The answer, they soon realize, must be found in the village, and the few poor families with well nourished children may provide the key to solving the problem.

Selection of Families for Positive Deviance Study

The first GMP session not only gives the villagers the scientific tool to assess the magnitude of the nutritional problem affecting the population under 3, but also the opportunity to choose more accurately children and their families for the Positive Deviance study.

During the training, participants select 6 families from the GMP list for the study, based on the following criteria:

- 3 poor or very poor families with a well nourished child (normal nutritional status) between the ages of 1 to 3
- 3 relatively well-off families with a severely malnourished child (2nd or 3rd degree) between the ages of 1 and 3

Content of Positive Deviance Study/Family Visits

Participants identify and define the three necessary conditions for a child to be in good health as care, food and health, which are translated into the 3 axioms of the Positive Deviant study in the following terms:

1. "Good Child Care" behavior
2. "Good Food" behavior
3. "Good Health Care" behavior

Visiting the six selected families enables the participants to find out what caring behaviors, what foods and what health seeking behavior have enabled three families to have healthy children despite their poverty. Visiting the three families who are relatively well off but have malnourished children and using the same approach (observation and questions) provides an insight about what causes malnutrition. Besides providing a new conceptual framework and development tool, the Positive Deviance study, through the comparison of the two different sets of families, enables the participants in the training to specifically define the key components in the 3 categories.

Techniques for Positive Deviance Study

One home visit to each family is planned and the interview questions carefully drafted (see questionnaire, appendix 1). A list of items for observation is made and includes family members' physical appearance and behavior, child behavior, state of house and kitchen, if any, garden, animals, etc. Villagers participate as observers while the trainer carries out the same interview with each family.

III. Positive Deviance Findings Utilized in Program Design and Implementation to Ensure Behavior Change

1. The Model Family Chart

After all 6 families have been interviewed, participants reconvene to analyze the results of their study and define what are "Good Child Care," "Good Food," and "Good Health Care." They make a Model Family Chart for their commune, writing in the specific findings in the 3 categories.

2. Inputs into the NERP Program Design

Results from the Positive Deviants study are immediately utilized for NERP program design and implementation.

- Good Food

  a) NERP Daily Menu: based on the Model Family "Good Food" findings, participants are asked to create a model NERP menu using a food square (see appendix 2). Hence, the specific food that the Positive Deviant families feed their children becomes a critical component in the daily menu of the extra meal provided through the NERP.

  In addition to the Positive Deviants food, Save the Children subsidizes additional food (rice, eggs, tofu or fish, and fat) purchased locally to speed up the rehabilitation of the child. This combined menu (Model NERP Menu plus SC contribution) is used throughout the 2 weeks of the NERP session except for the 6th day of each week.

  b) Caretaker's Daily Food Contribution: to promote behavior change in the way caretakers feed their malnourished children, they are required to bring the specific food that the positive deviant study revealed was fed to adequately nourished children in their commune. This parent/caretaker daily contribution is considered the "price of admission" to the 12-day long NERP session, held every month.

  c) The Sixth Day Menu: on the 6th day of the two-week NERP session, a special Menu is offered to the children consisting only of the caretaker's daily contribution plus rice. The purpose of this change in Menu is to emphasize what food the family can feed the child adequately on their own at home. Families are encouraged to try it the next day (day 7 - off) at home before coming back for another 6 days of practicing rehabilitating their children at the NERP center (usually the health or another volunteer's home).

- Good Child Care

  a) Educational messages on hygiene, frequency of feeding, breastfeeding, etc. for caretakers of malnourished children during NERP sessions.

  b) Program implementation (feeding the child, processing food, cleaning the child's face and hands before and after eating, cleaning hands before handling food, etc.) at the NERP sessions.

  c) Targeting the appropriate child's caretakers as participants in the NERP program: not mothers exclusively, but whoever looks after the child (grandparent, father, older siblings, etc.).

- Good Health

  a) Individual child nutritional status monitoring promotion with regular GMP sessions.

  b) Education of caretakers at NERP sessions on the sick child (knowledge of danger signs, management and prevention for ARI and diarrheal diseases).

  c) Immunization promotion.

  d) Treatment of the sick child by commune health staff.

  e) Deworming and distribution of Vitamin A.

IV. EXAMPLES OF FINDINGS

- *Good Food*

All "Positive Deviant/Model" mothers were still breastfeeding their children over one year of age.

In the first four communes, children were being given river/rice paddy shrimps and small crabs, in addition to greens (cassava leaves). For other communes, the "good food" was identified as roasted peanuts, mustard greens and salt (mountain areas) or sea fish, fish sauce and sweet potato leaves (see food square examples). Children were fed 3 meals per day and, in addition to meals, were given snacks in the form of sweet potatoes or puffed rice throughout the day.

- *Good Child Care*

The secondary caretakers (grandmothers) displayed a solid knowledge of weaning foods and good hygiene. The children were well kept and lively.

- *Good Health Care*

Children were well spaced and all immunized. Mothers knew what to do if the child had diarrhea. Mothers understood the importance of breastfeeding and were supported by grandmothers in this view.

V. LESSONS LEARNED

Positive Deviance Concept

Over the past 3 years the teaching of the concept of positive deviance and training in positive deviance studies have been greatly improved. Firstly, the term has been changed to a less scientific and more accessible term - the "model family." Finding role models in a community is a very logical and familiar undertaking that community people understand easily. In Vietnam, a child's health is not only the responsibility of the mother, but of the entire family, and since women work up to 12 hours a day in the field, childcare is not limited to the mother, particularly for children over one year of age. Thus, targeting the mother exclusively was not reflecting the reality of the caretaking situation.

Training of Trainers in Positive Deviance Study

Special care must be put into the training of trainers, especially if they are health professionals. They tend to know the answers to all health problems and want to impose their knowledge on the villagers. With this approach, trainers need to relinquish their power, and be willing to learn from people who are less educated than themselves.

The addition of the Model Family Chart has also helped in conceptualizing an experience and enabling the learners to translate the experience into actions. It also fixes the knowledge acquired through the Positive Deviance Study and is a constant reminder to the villagers of "the power within," which is the cornerstone for the sustainability of the overall Poverty Alleviation Nutrition Program.

Appendix 1

Training for Family Visits

Interviews with families: Questions for the Trainer to ask at each family visit to the mother of the child or other primary caretakers.

Notes to trainer:

- Ask the following or similar questions in each section listed below at each family visit.
- Write out answers to each question.
- Encourage participants to ask questions.

Questions about **GOOD FOODS**:

1. How old is your child?
2. Are you breastfeeding at the moment? If no, how old was the child when you stopped breastfeeding?
3. Why did you stop breastfeeding your child at that time?
4. How old was the child when you started giving him/her supplementary food?
5. What were the supplementary foods you used?
6. What do you feed your child each day?
7. Where do you get these foods from?
8. How many times a day do you feed your child (including snacking)?
9. How many meals a day do you feed your child?
10. How many meals a day do you feed your family?
11. What did you feed your child this morning?
12. What are you going to feed your child later today?

Questions about **GOOD CHILD CARE**:

1. Who looks after the child now?
2. Who feeds him every day now?
3. How often do you give a bath/wash your child?
4. Who looked after your child when he was 3 months old? 6 months? 12 months? 24 months? (according to age of child)

5. Whom does the child spend the most time with in the family?
6. Does this person play a lot and teach things to the child?

Questions about **GOOD HEALTH CARE**:

1. Did you go to the health clinic for a checkup before your delivery?
2. Where did you give birth to your child?
3. Did you have any problems delivering the child? If at home, did you have anyone to help?
4. Was your child born on time or premature?
5. Has the child been vaccinated?
6. How often has your child been sick since he was born? What was the problem?
7. What do you do if one of your children is sick?
8. When do you take your child to the health center?
9. What do you do when the child or any other children has diarrhea, colds and fever or other illness?
10. Do you know what to do to prevent your child from having diarrhea?

Appendix 2

Extra Meal Menu
Food Square (Individual Portion)
Children's Menu in "Positive Deviant" Families

Coastal Area

MOTHER'S MILK	RICE/SWEET POTATOES
SEA FISH/SHRIMP PASTE AND FISH SAUCE	SWEET POTATO LEAVES

Lowland Area

MOTHER'S MILK	SWEET POTATOES
RIVER SHRIMP AND SALT	SWEET POTATO LEAVES

When sea is rough and sea fish unavailable, children are fed shrimp paste.

Extra Meal Menu
Food Squares (Individual Portion)
Children's Menu in "Positive Deviant" Families
Tan Dan Commune

Mountain Area

MOTHER'S MILK	SWEET POTATOES
ROASTED MASHED PEANUT AND SALT	GREEN LEAFY VEGETABLE

Coastal Area

MOTHER'S MILK	SWEET POTATOES
SHRIMPS OR CRABS	GREEN LEAFY VEGETABLE

Lowland Area

MOTHER'S MILK	RICE AND SWEET POTATOES
ROASTED MASHED PEANUT AND SALT	SWEET POTATO LEAVES

Extra Meal Menu
Food Square (Individual Portion)
Thuc Don NERP

Coastal Area

MOTHER'S MILK	RICE/SWEET POTATOES
SEA SHRIMP/DRIED SEA FISH AND FISH SAUCE	VEGETABLES

Lowland Area

MOTHER'S MILK	RICE
RIVER SHRIMP	SPINACH/ MUSTARD GREENS

Summary

Information on causes of death is used for the following: to establish public health priorities; study age and sex patterns of disease; monitor trends in mortality from specific diseases and to evaluate the impact on mortality of preventive or therapeutic measures. Vital registration and death certification in developing countries is incomplete and where available is often limited to a single underlying cause of death. Children dying in developing countries often die from multiple infections, undernutrition and/or the delayed effects of diseases such as measles.

"Verbal autopsies" (VA) are interviews with bereaved family members months to years after a death to determine approximate causes of death among children in developing countries. The author reviews the technical aspects of interview and questionnaire design and the experience validating VA. He then assesses the applicability of VA in terms of the following: clinical and epidemiological characteristics; interview questions for diagnosis (algorithms); medical conditions likely to cause confusion; validity evidence and field experience for diseases of public health importance (i.e., neonatal tetanus, perinatal deaths, measles, diarrhea, acute lower respiratory infection, pertussis, malaria, meningitis, malnutrition, tuberculosis, AIDS, accidents and violence).

VA seems to perform best for identifying diarrhea, measles, neonatal tetanus, pertussis, meningitis, and injuries. Unfortunately, few diseases are unmistakably distinct, recognizable and recallable. However, in the absence of better alternatives for the foreseeable future, VA should continue to supplement surveillance and survey activities. Research into the best combinations of questions will improve VA accuracy and strengthen comparisons between investigations. [eds.]

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VERBAL AUTOPSY: USING INTERVIEWS TO DETERMINE CAUSES OF DEATH IN CHILDREN

DR. RONALD H. GRAY[1]

"The death rate is a fact, anything beyond this is an inference."
– William Farr

INTRODUCTION

Information on causes of death is used to establish public health priorities, study age and sex patterns of disease, monitor trends in mortality from specific diseases, and to evaluate the impact on mortality of preventive or therapeutic measures. The objective of this article is to review methods for data collection and reliability of cause of death information.

It has long been recognized that registration data on cause of death are flawed and provide only an imperfect record due to errors in physician diagnosis or certification of death, coding errors, and inconsistencies due to revisions of the International Classification of Diseases (1977, Sirken *et al*, 1987; Goodman *et al*, 1987; Moriyama, 1989). To evaluate the accuracy of cause of death data, several studies have compared the underlying causes recorded on death certificates with findings at autopsy (Kircher *et al*, 1985; Battle *et al*, 1987; McFarlane *et al*, 1987; Anderson *et al*, 1989), or with diagnoses made by an independent

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physician's review of clinical records (Gau and Diehl, 1982; Benavides *et al*, 1989). All such studies have shown substantial disagreement between the underlying causes on the death certificate and the reference autopsy or panel review diagnosis. The disagreement tends to be greatest for those diseases that are most difficult to diagnose clinically and for deaths in the elderly, who often have multiple illnesses. Also, discrepancies are generally greater for deaths which occur in smaller hospitals or at home (Battle *et al*, 1987; McFarlane *et al*, 1987). The error rates have changed over time for some diseases such as pulmonary tuberculosis, whereas errors in diagnosis of conditions such as myocardial infarction appear to have remained relatively constant (Stehbens 1987, Anderson *et al*, 1989). Thus, even in countries with established vital registration systems, there are significant errors in cause of death statistics and some authors argue that we "must come to understand and accept a realistic degree of necessary fallibility" (McFarlane *et al*, 1989).

Vital registration in many developing countries is incomplete and many deaths go unrecorded. Among registered deaths, information on causes of death is often defective, as indicated by the high proportion ascribed to unknown causes or to nonspecific symptoms such as "fever" or "senility" (WHO, 1977; WHO, 1980). Unsatisfactory death certification is to be expected in situations where many deaths occur outside of hospitals, often without medical attention. Even when a patient has received medical attention, death certification is often of poor quality due to inadequate facilities for accurate diagnoses or pressures on health personnel time. A further difficulty arises with childhood deaths. In developing countries, children often die from multiple infections and undernutrition or from the delayed effects of diseases such as measles. Thus, the convention of ascribing a single underlying cause of death fails to fully capture the synergistic interaction between acute and chronic disease and nutritional insufficiency (Mosley and Chen, 1984).

To overcome these difficulties, investigators have often used information derived from interviews with relatives of the deceased person and attempted to reconstruct events prior to death in order to reach a medically accepted diagnosis. Such interview based diagnoses, or "verbal autopsies," can provide important information, but there has been no critical review of methods and experience with these procedures. This paper draws on the published and unpublished literature, and particularly the results of a workshop held at the John Hopkins University, School of Hygiene and Public Health (Gray *et al*, 1990a). The focus is on deaths during infancy or childhood. We review the theoretical basis for verbal autopsies and methods for data collection, the diagnosis of specific diseases and experiences in field studies. Although this report draws upon information on morbidity, it does not attempt to review the literature on health interview surveys which has been considered elsewhere (Ross and Vaughan, 1986; Kroeger, 1983 and 1985).

Verbal Autopsy Methods

Certain diseases have characteristic symptoms and signs that in association form a relatively distinct clinical syndrome. Such diagnostic syndromes are frequently used in medicine, particularly when there are no definitive confirmatory investigations available. The objective of a verbal autopsy interview is to identify well defined medical syndromes using information about the terminal illness elicited from close relatives of the deceased person. The approach is most useful when the characteristic symptoms and signs of the disease are sufficiently distinctive to differentiate the disease of interest from other conditions with which it might be confused. The postmortem interview attempts to replicate a conventional medical history used to establish a differential diagnosis (i.e., a list of conditions consistent with a patient's symptoms and signs). However, unlike a physician's diagnosis, the verbal autopsy can not [sic] establish a definitive diagnosis because confirmatory information derived from physical examination medical investigations, laboratory tests or autopsy is not usually available. There is, therefore, inevitable uncertainty in the accuracy of verbal autopsy diagnosis.

There are only a limited number of diseases which present sufficiently distinct syndromes that are potentially suitable for verbal autopsy diagnosis. In children, these conditions include acute conditions such as neonatal tetanus, prematurity/low birth weight and birth injury, measles, diarrhea/dysentery, acute lower respiratory infection (ALRI), pertussis,

meningitis, and injury, and certain conditions such as tuberculosis (TB), nutritional deficiency, and AIDS (Gray et al, 1990a). Not all these conditions can be diagnosed with equal accuracy, and the main focus of research has been on diseases which constitute common causes of morbidity and mortality amenable to prevention or treatment. In adults, causes of maternal health have been assessed by verbal autopsy (WHO, 1987; Koenig *et al*, 1988; Fauveau, 1989), but there is relatively little information on causes of nonmaternal adult deaths (Hayes *et al*, 1989).

Data Collection

Reporting of deaths has been based on longitudinal population surveillance or on retrospective information derived from interviews in population surveys. Surveillance studies have the advantage of more timely and complete reporting of deaths and utilize a cadre of more experienced field workers. They have the disadvantage of higher costs which may limit population size, and thus the number of events, and they require a long duration for data collection. The majority of surveillance studies cover populations in excess of 20,000 persons, with home visits at regular intervals ranging from two weeks up to six months. The duration of data collection has varied from 3-10 years. In contrast, surveys are more economic and expeditious, but have the disadvantage of a longer average interval between death and interview which could introduce recall errors, and may lack personnel experienced in the use of verbal autopsy (Gray *et al*, 1990a).

Some surveillance studies use medically trained personnel such as physicians or nurses, whereas others use trained lay interviewers who are regularly supervised by professional staff. Surveys generally require the same set of interviewers to administer both the regular survey questions and the verbal autopsy, although some investigators feel that it might be preferable to have a separate staff of specialized verbal autopsy interviewers in order to improve data quality and minimize omission of events (Gray *et al*, 1990a).

Verbal Autopsy Interviews, Classification and Coding of Causes of Death

The structure of questionnaires used for verbal autopsy interviews has varied considerably between studies (Zimicki 1986, Garenne and Fontaine 1986, Gray *et al* 1990a). Most employ an open ended question regarding the respondent's perception of the circumstances surrounding the death, views on the probable cause of death, and information on use of medical services. It is important to elicit information on "how" the death occurred rather than "why," because the latter question is often interpreted in terms of a metaphysical explanation. Open-ended questions can provide important information on the sequence and timing of events and use of health care. They also help establish rapport with the bereaved respondent, and can be sensitive to local interpretation or terminology for diseases (Zimicki 1986, Garenne and Fontaine 1986, Gray *et al*, 1990a; Bang *et al*, 1990). However unstructured interviews may be difficult to interpret, and if used alone, key information may be omitted. Also, open-ended questions are vulnerable to interviewer bias and to culturally specific interpretation of illness, which may differ from Western Medical notions of disease.

Most studies also use structured questionnaires, with either a comprehensive list of specific questions regarding symptoms and signs or a short series of "filter" screening questions that direct the interviewer to disease-specific modules containing more detailed questions (Gray et al, 1990a). An example of a screening questionnaire is given in Table 1. The screening questions should be very sensitive (i.e., detect all cases of the index disease), and the supplementary questions should be highly specific so as to reduce the number of false-positive diagnoses by excluding other conditions that might be confused with the index disease.

To achieve high specificity, it is important to obtain information on the presence of cardinal symptoms and signs, the timing of onset, and the duration and persistence of symptomatology relative to the timing of death. Also, some estimate of severity is needed for certain symptoms; for example, with diarrhea it is useful to know the number of stools on the worst day of illness. This can entail lengthy interviews and many investigators have used separate instruments for neonates (with a focus on events surrounding birth), as well as questionnaires for older infants and children. However, a single questionnaire for all infant and childhood deaths is usually adequate (Gray

TABLE 1. EXAMPLE OF FILTER SCREENING QUESTIONS

1.	Frequent loose on liquid stools	⇒	diarrhea module
2.	Blood in stools	⇒	diarrhea module
3.	Cough	⇒	ALRI module
4.	Difficulty breathing	⇒	ALRI module
5.	Generalized skin rash	⇒	measles module
6.	Convulsions/spasms		
	in a neonate	⇒	tetanus module
	in an older child	⇒	meningitis module
7.	Stillbirth or deaths		
	<1 week of life	⇒	perinatal module
8.	Injury	⇒	injury module

et al, 1990a).

The questions should use lay terminology and, as much as possible, utilize local terms for common well-recognized diseases. However, such local disease terminology may be less specific than the required medical diagnoses. In the Filipino dialect of Cebuano, for example, the word "tipdas" implies all illnesses with a rash, including but not exclusive to measles. Similarly, in Bangla the term "alga", [sic] which implies infantile convulsions and cyanosis (turning blue), includes neonatal tetanus as well as other causes of convulsions in the newborn (Zimicki 1986). Also, the local cultural taxonomy of illness may not conform to recognized biomedical classification. An example is the term "empacho", [sic] which issued in Mexico and Central America to describe a disuse related to diarrhea, but which has no biomedical equivalent (Kendall et al, 1984). Thus, local names for a disease may be insufficient for reliable diagnosis. Some investigators have trained interviewers to demonstrate signs such as rapid breathing in order to avoid miscommunication (Bang et al, 1990).

Supplemental information from a variety of sources can be of value. Medical records, death certificates, child health cards, immunization records, prescriptions or medicine containers can provide important information and should be used when available. In addition, knowledge of local disease patterns can be helpful. For example, if there is an epidemic of disease such as measles, the presence of a rash-related illness prior to death makes the diagnosis of measles more plausible. Similarly, if there is seasonal variation in disease, a death during the season of peak transmission is more likely to be due to the specific disease (e.g., malaria), than a death during the season of low transmission (Gray et al, 1990a).

The optimal interval between death and interview has not been established. Although some investigators have interviewed relatives "as soon as possible" after death, others feel that it is preferable to wait 2-3 months until the phase of acute grief is over (Garenne and Fontaine, 1986). In surveys, interviews are usually conducted 2-9 months after the event (Gray et al 1990a).

The diagnosis and classification of cause of death often requires medical judgment. Some investigators have used disease-specific algorithms based on the presence and timing of symptoms or signs and the age of the decedent. However, many studies base diagnoses on a review of questionnaires by physicians (Gray et al, 1990a; Fauveau et al, 1990). It is conventional to ascribe immediate underlying and contributory causes of death on the basis of the temporal ordering of illnesses and knowledge about the relationship between illnesses. For example, in a case of measles with pneumonia, it is likely that the measles is the underlying cause of pneumonia. Other classification schemes such as primary and secondary diagnosis have also been used (Garenne and Fontaine, 1986; Gray et al, 1990a), but these may be biased by selection of a particular disease of interest as the underlying condition. It is, therefore, preferable to record multiple causes of death to avoid such

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bias and to facilitate analysis of disease interactions. The medical definition of syndromes is often based on the presence of specified major criteria which are pathognomonic for the disease, and minor criteria which are symptoms or conditions frequently associated with the disease. Thus, some investigators grade diagnostic accuracy by the degree of relative certainty and classify diagnoses as "definite, possible, or probable" based on the extent to which predefined criteria are met.

The International Classification of Diseases (ICD) (1977) provides a comprehensive coding system using three- or four-digit categories and WHO has produced simplified coding schemes for lay reporting of illness and death (WHO, 1978). However, these coding systems are more complex than usually required and shorter code lists for specific diseases of interest are used in most studies. Considerable training is required for coders, particularly if they are required to distinguish between underlying and immediate or contributory causes of death.

Validation of Verbal Autopsy

Few investigators have attempted to formally validate interview diagnoses of illness or cause of death by comparison with physician diagnoses, confirmatory investigations or laboratory tests (Kalter et al, 1990a and b; Alonso et al, 1987; Greenwood et al, 1987b; Leeuwenburg et al, 1984a and b). The objective of validation is to determine the sensitivity and specificity of the interview or "test" diagnoses relative to a reference or "true" diagnosis based on medical assessment. Sensitivity is measured as the proportion of "true" cases of disease correctly identified. Thus, a sensitive test will detect the majority of "true" cases and a specific test will exclude the majority of non-cases (Barker and Rose, 1979; Swets, 1988).

Frequently there is a trade-off between these two measures, whereby a highly sensitive test may be relatively nonspecific and vice versa. The choice of the best "test" diagnosis will vary depending on the ultimate goal, but in general one strives for a balance of sensitivity and specificity. Another measure of the utility of a test diagnosis is the positive predictive value, which is the proportion of all positive cases detected by the test that are in fact true positives according to the reference diagnosis. However, the positive predictive value varies with the population prevalence of the index disease and is thus much more difficult to generalize (Barker and Rose, 1979).

Accuracy of diagnosis can also be indirectly inferred by comparison of disease patterns derived from interview diagnoses with the known epidemiology of the disease (e.g., variation by age, sex or season). This provides "epidemiologic plausibility." Also, changes in disease patterns following interventions such as immunization can provide indirect evidence for the accuracy of interview diagnoses. Such indirect evaluation of "epidemiologic plausibility" may be flawed because of biased reporting due to transfer diagnoses from the target disease to another condition, or because of the persistence of diagnostic habits that lead to continued reporting of the target disease despite a reduction in its incidence (Zimicki, 1986; Gray et al, 1990a). This diagnostic bias should not, however, affect results from randomized trials.

Interview Diagnosis of Specific Diseases

The following review will examine verbal autopsy diagnoses for childhood conditions of public health importance. For each disease we review the main clinical and epidemiologic characteristics, the questions used in verbal autopsy diagnoses, conditions that might be confused with the index disease, and evidence for the accuracy of verbal autopsy diagnoses, as well as experience with field studies. Not all questions have equal weight in achieving a diagnosis, so those questions that are most informative (i.e., major criteria) have been highlighted in bold.

Neonatal Tetanus

Neonatal tetanus is considered to be a major cause of death in developing countries, although reliable data are not generally available. Neonatal tetanus mortality rates estimated from WHO surveys range from 1 to 67 per 1,000 live births and the proportion of neonatal deaths attributed to tetanus ranges from 7 to 70% in developing countries (Stanfield and Galazka, 1984; Galazka and Stroh, 1986). The disease is due to contamination of the umbilical cord stump by Clostridium tetani spores as a result of poor cord care or application of substances such

as cow dung or ghee (Islam et al 1982; Foster, 1984; Stanfield and Galazka 1984; Woodruff et al, 1984; Traverso et al, 1989). Neurotoxin released by the organism causes severe muscle spasms, convulsions and death. The disease can be prevented by improved cord care practices and by maternal immunization with two doses of tetanus toxoid vaccine. The disease symptoms usually commence 2 to 14 days after birth and death occurs between the 3rd and 30th day (although most deaths occur between the 6th and 8th day). While the definitive diagnosis is based on the clinical features of the disease and isolation of the causative organism, the clinical presentation is sufficiently distinctive to permit diagnosis by maternal interview. Usually the presentation is of a child who suckled normally and cried normally for at least two days after birth, then ceased to suckle or cry within 3 to 28 days and developed generalized rigidity and/or convulsions leading up to death. Often there is clenching of the jaw (trismus), and tightness and retraction of the mouth (risus sardonicus). However, in societies where infants are not fed early breast milk (colostrum) during the first few days of life, cessation of swallowing would be a more useful sign than cessation of suckling (Zimick, 1986; WHO, 1982).

The differential diagnosis of neonatal tetanus requires exclusion of brain damage due to congenital defects or birth trauma and asphyxia, which usually present within the first day of postnatal life as poor feeding, weak crying, flaccidity, coma or seizures. It is more difficult to differentiate tetanus from neonatal meningitis associated with septicemia or metabolic disorders (Galazka and Stroh, 1986).

WHO (1984b) has conducted numerous clinical studies and mortality surveys using an algorithm for tetanus diagnosis based on the questions in Table 2. The validity of verbal autopsy diagnoses of neonatal tetanus is difficult to assess directly. In larger clinical series, cessation of suckling is reported in 69-100% of clinical cases, rigidity or spasms in 97-100% and trismus/risus sardonicus in 71-100% of cases. Fever or umbilical sepsis is reported in 20-50% (Galazka and Stroh, 1986). One study in the Philippines found a sensitivity of 94-100% using a modification of the WHO algorithm, but the specificity could not be adequately assessed (Kalter et al, 1990a). In a Bangladesh study, the WHO algorithm was compared to all possible cases of tetanus identified by open-ended interviews with mothers of deceased children. The WHO algorithm had low sensitivity because many women did not breastfeed for some days after birth, so the question on cessation of feeding had little predictive value in this context (Zimicki, 1986). However, the absence of clinically confirmed diagnoses makes this Bangladesh study difficult to interpret.

TABLE 2. ALGORITHM FOR NEONATAL TETANUS

1. Did the Infant **die between the 3rd and 30th** day of life?
2. Was the infant **able to suckle (and/or cry)** after birth?
3. Did the infant **stop suckling (and or crying)** when it became ill?
4. Did the **illness start between 2-28 days** after birth?
5. Did the infant's **body become rigid?**
6. Did the infant have **convulsions?**
7. Did the mother receive two tetanus toxoid immunizations during this pregnancy or her last pregnancy?
8. What was done to cut the cord and dress the stump?

Affirmative answers to questions 1-6 are diagnostic of neonatal tetanus.

There is evidence of epidemiologic plausibility for the verbal autopsy diagnosis in the age distribution of putative tetanus deaths as compared to other perinatal deaths, and in urban/rural or seasonal differentials of estimated disease incidence. Also, verbal autopsies used in the evaluation of preventive programs of maternal tetanus toxoid vaccination or traditional birth attendant (TBA) training in cord care have shown substantial declines in neonatal tetanus deaths as compared to control populations with no interventions (Stanfield and Galazka, 1984; Foster, 1984). However, in one Bangladesh study where an unstructured interview was used, neonatal deaths classified as tetanus increased after an immunization program; probably because field workers who had been sensitized by the vaccination project overdiagnosed the disease by ascribing to tetanus all deaths reported as "alqa," the local term for convulsive illness (Zimicki, 1986). This clearly indicates the need for careful definition and structured questions. In summary, the WHO algorithm for

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neonatal tetanus appears to be sensitive but it is difficult to determine its specificity and it is likely that some nontetanus deaths are misclassified as tetanus.

Perinatal Deaths

The majority of births and perinatal deaths in developing countries occur without medical supervision and are not recorded in vital registration. Surveys may also underestimate perinatal mortality because of failure of maternal recall, or because interviews only ask questions about live births, and thus omit stillbirths. Also, some early neonatal deaths are probably misclassified as stillbirths (WHO, 1984). Nevertheless, a number of investigations suggest that perinatal mortality is a major and relatively poorly-understood public health problem in the developing world.

Hospital-based studies in developing countries suggest that 55-75% of perinatal deaths are associated with prematurity and low birth weight and, as expected, mortality risk varies inversely with birth weight and length of gestation (Kramer, 1987; Gray et al, 1990b; Haas et al, 1987). However, it is difficult to diagnose low birth weight or premature delivery by verbal autopsy methods. To be reliable, birth weight should be measured by an accurate scale within 24-48 hours of birth, but this information is seldom available since the majority of deliveries occur at home and TBAs seldom measure birth weight. Recent Egyptian studies of color-coded scales used by TBAs suggest that this simplified technology can be highly sensitive (100%) and specific (94%), but unfortunately such scales are not in widespread use (Ritenbaugh et al, 1989). Studies of proxy measures for low birth weight such as mid-upper arm circumference have found sensitivities between 71-97% and specificity above 80%, but the cut-off criteria have varied from 9.0-10.0 mm for arm circumference (WHO, 1987; Sauer Born et al, 1990). Estimates of gestational age are particularly problematic in cultures where women do not know the dates of their last menstrual period, and specialized neonatal examinations to determine infant maturity cannot be conducted in most field settings (Ferraz and Gray, 1990; Gray et al, 1990b). In summary, objective measures of prematurity/low birth weight are currently not available for the overwhelming majority of births in developing countries.

Birth trauma or asphyxia due to complications of delivery and/or poor obstetrical care are also thought to be major problems in less developed countries, but little information is available outside of hospital deliveries Also, it may be difficult to differentiate between deaths due to these conditions and deaths due to prematurity/low birth weight (WHO, 1984a).

There are no well established questions that have been used to diagnose perinatal causes of death and the items suggested in Table 3 are derived from a number of reports.

Prospective studies have used structured maternal interviews and open-ended interviews to determine causes of perinatal death in India, Bangladesh and Kenya. The findings are summarized in Table 4. About one-third or more of perinatal deaths were ascribed to low birth weight in the three South Asian studies, compared to one quarter in the Kenyan study. In all four studies, over one-third of deaths were attributed to birth trauma/asphyxia and in approximately one-fifth of cases no specific cause could be identified. The findings were generally consistent between studies and suggest that verbal autopsies can be used to identify major perinatal conditions.

Measles

Measles usually occurs in children over the age of five months and is a major cause of death during childhood in developing countries, with case-fatality rates varying from 1% to 24% (Aaby et al, 1987). The majority of measles deaths are associated with complications such as ALRI or diarrhea. Also, following acute measles, there is an increased risk of subsequent mortality for 9-12 months due to postmeasles pneumonia, diarrhea and nutritional deficiencies (Foster, 1984; Aaby et al 1987). Although there is debate over the duration of such postmeasles mortality, frequently deaths within one to three months of an acute episode are attributed to measles. The risks of mortality are higher for younger children, and among children who are secondary cases (i.e., children who acquire the disease from other cases within a household). Overcrowding and prior nutritional deficiency may also increase the mortality risk, although the latter issue is debated (Aaby et al, 1983; Aaby et

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TABLE 3. PERINATAL DEATHS

Identification of Perinatal Death:

1. Did the baby show **any sign of life after birth** (i.e., breathing, crying)?
2. Did the baby **die within one week of birth?**

Low birth weight/prematurity:

3. **How big was the infant at birth?**
   Normal size _____, Small _____, **Very Small** _____
4. Was the duration of pregnancy normal _____, or **shorter than normal** (< 8 months)_____?

Birth trauma/asphyxia:

5. Was the **delivery prolonged** (>12 hours)?
   Or complicated (specify.....)
6. Were there bruises or marks of injury on the baby's body? (specify.....)
7. Was this a multiple pregnancy?
8. **Did the baby fail to breathe, cry, or suckle normally during the first day after birth?**
9. Did the baby have **spasms or convulsions within the first three days of life?**
10. Was the baby **floppy or unconscious during the first 3 days of life?**

Congenital defects:

11. Did the baby have any **abnormalities of the head, body or limbs?** (specify.....)

Questions 1 and 2 establish a perinatal death. Questions 3 and/or 4 suggest low birth weight and/or prematurity. Questions 5-10 suggest birth trauma/asphyxia, and 8-10 differentiate perinatal problems from neonatal tetanus. Question 11 attempts to identify congenital defects.

TABLE 4. PERCENT OF PERINATAL DEATHS ATTRIBUTED TO PREMATURITY/LOW BIRTH WEIGHT AND BIRTH TRAUMA/ASPHYXIA IN COMMUNITY STUDIES

Study Size and Author	Number of Deaths	Low Birth Weight/ Prematurity %	Birth Trauma/ Asphyxia %	Birth Defects %	Infection %	Unknown/ Ill Defined %
INDIA* Kielman et al[21] (1983)	124	32.2	37.1	6.5	5.6	18.6
INDIA Shah et al[52] (1984)	172	33.1	34.0	2.3	4.1	26.5
BANGLADESH Faveau et al[53] (1990)	492	37.8	36.4	2.4	4.1	20.0
KENYA Norbeck et al[54] (1984)	221	24.9	38.5	8.1	7.2	21.3

* Deaths in the first week of life.

al, 1984 and Aaby et al, 1990; Foster, 1984; Garenne et al, 1990). Vaccination programs can substantially reduce the risk of death from measles.

Measles is often recognized by the mother and frequently there are local terms for the disease that may be useful in diagnosis. However, such local terminology may be applied to other rash-like illnesses and, by itself, is too nonspecific for a diagnosis. The occurrence of a measles epidemic, or of other cases in the household, also helps to establish measles as a probable cause. A history of measles vaccination makes the diagnosis less likely, but does not exclude the disease because vaccine failures are known to occur.

WHO (1984b) program and other investigations have used verbal autopsy methods to diagnose deaths associated with measles. The most common questions are listed in Table 5.

TABLE 5. DIAGNOSTIC ALGORITHM FOR MEASLES

1. Was the child 5 or more months old?
2. Did the child have **fever?**
3. Was there a **blotchy rash lasting 3 or more days?**
4. Was there **peeling or darkening of the skin among children who survived for 5 or more days?**
5. Was there cough, runny nose or red eyes (conjunctivitis)?
6. Was there other cases of measles in the household or a measles epidemic?
7. Did the above conditions occur within 1-3 months prior to death?

Affirmative responses to questions 1-4 are diagnostic for measles. Questions 5-7 are supportive.

Several studies have shown that verbal autopsy diagnosis of measles is highly reliable. A study of 48 measles-associated deaths in the Philippines compared maternal interviews with physician diagnoses. The verbal autopsy diagnosis was found to be 98% sensitive and 90% specific (Kalter et al 1990). A similar study of children who survived acute measles found a sensitivity and specificity of 94% (Kalter et al, 1990). In a Kenyan study, serological tests for measles antibodies were compared with maternal interview diagnoses for 556 children; the sensitivity was 96% but the specificity was only 54% for all "possible, probable and definite clinical cases." If only "definite" cases are considered (i.e. those meeting all criteria in Table 5), the specificity was 85% (Leeuwenburg et al, 1984a). However, a seroepidemiologic study of 600 unvaccinated children in Mozambique found that a maternal history gave only 50% sensitivity and 83% specificity (Cutts et al, 1990). Several studies using verbal autopsies have shown declines in measles deaths following immunization programs, which adds epidemiologic plausibility to the verbal autopsy diagnosis (John et al, 1980; Kasongo Project Team, 1981; Hull et al, 1983; Clemens et al, 1988; Aaby et al, 1990; Holt et al, 1990; Keenig et al, 1990).

Diarrhea

Acute or chronic diarrheas and dysentery are known to be associated with a substantial proportion of child deaths in developing countries (Feachem, 1986; Mata, 1983; Black, 1984a). Although caused by numerous pathogens, these diseases have a common pathway of transmission through the ingestion of contaminated food or water due to inadequate sanitation and water supplies, unhygienic food preparation or storage, and poor personal hygiene (i.e., lack of hand washing) (Mata, 1983; Black 1984a). The age-specific incidence of diarrhea and diarrheal deaths varies, depending on feeding practices in different societies. Breastfeeding is highly protective against diarrhea and the peak period of risk for the disease is during the introduction of supplementary foods or weaning (Mata, 1983; Feachem & Koblinsky, 1984; Black, 1984a; Khin-Maung-U et al, 1985; Clemens, 1990). Poor nutrition is associated with increased diarrheal case-fatality and with longer duration of diarrhea, and conversely, recurrent or prolonged episodes of diarrhea undermine nutritional status (Black et al, 1984b; Mata, 1983). Children who die of diarrhea frequently have other concomitant acute or chronic illnesses (Butler, 1987). Oral rehydration therapy (ORT) can markedly reduce case fatality from dehydrating diarrhea and has become a widespread treatment for this condition. Dysentery, however, requires antibiotic treatment as well as rehydration (Mata, 1983; Black, 1984a; WHO, 1989).

Most studies of diarrheal morbidity or mortality define an episode of diarrhea as a history of more than three to four loose or liquid stools per day, and define dysentery as frequent liquid stools containing blood. Open-ended questions on the presence of "diarrhea" may be unreliable because of the subjective nature of maternal assessment and because of cultural variation in the use of local terms (Black, 1984a; Kendall et al, 1984). Since diarrheal deaths are generally associated with dehydration, interviews usually ask questions about signs of dehydration such as thirst, sunken eyes, dry mouth, etc. (Black, 1984; WHO, 1989). A suggested list of questions is given in Table 6. A Philippines study compared verbal autopsy diagnoses of diarrhea associated deaths with confirmed clinical diagnoses in 43 children who died as a result of diarrhea alone and in 92 children who died of diarrhea plus other associated illnesses (Kalter et al, 1990a). Among the children in whom diarrhea was the sole cause of death, a history of loose or liquid stools ascertained by verbal autopsy had a sensitivity of 84% and specificity of 79%. The addition of further questions indicating severe diarrhea (≥ 6 stools per day, thirst or sunken eyes) decreased the sensitivity to 68%, but increased the specificity to 92%. In the 92 children who died of diarrhea and another concomitant disease, the history of loose/liquid stools had a sensitivity of 78% and a specificity of 79%; with questions on more severe diarrhea, the sensitivity was reduced 57% but the specificity increased to 92%. A related study of children who survived a diarrheal episode showed high sensitivity (95%) and specificity (80%) for interview-based diagnoses. The diagnosis of moderate or severe dehydration was unsatisfactory in both fatal and non-fatal cases (Kalter et al 1990a and b). However, it is difficult to assess the degree of fluid loss without weighing the child before and after rehydration, and even physicians underestimate the severity of moderate dehydration when using clinical judgment (MacKenzie et al, 1989).

A study in Bangladesh compared maternal histories of diarrhea with observation of stool consistency in living children and found an 80% agreement (Black, 1982). However, in a Kenyan study, maternal reports of "diarrhea" (without specifying the number or consistency of stools) were found to over-report 15-40% of episodes when compared to visual inspection of stool specimens by investigators (Leeuwenburg et al, 1984b). This highlights the need for detailed information concerning the characteristics and frequency of stools rather than subjective maternal assessment of "diarrhea." A Gambian investigation of children with marasmus and chronic diarrhea showed that maternal interviews on admission correctly identified 75% of cases; and one month after discharge, maternal interviews agreed with the clinical diagnosis in 91% of cases (Alonso et al, 1987). However, the postdischarge interview may have been affected by communication with the physician during hospitalization.

TABLE 6. DIAGNOSTIC ALGORITHM FOR DIARRHEA/DYSENTERY

1. Was there a history of **3-4 or more loose or liquid stools per day?**
2. How many stools were there on the worst day?
3. Was there **blood in liquid stools?**
4. Did the child have any of the following: **dry mouth, thirst, dry wrinkled skin, sunken eyes, lack of urine, depressed fontanelle in infants?**
5. Did the illness persist until time of death?

Question 1 indicates diarrhea and question 2 grades the severity. Question 3 indicates dysentery, and question 4 identifies dehydration.

Field studies using maternal interviews have shown age, sex and seasonal patterns of diarrhea consistent with those observed in clinical studies (Mata, 1983; Leeuwenburg et al, 1984b; Black, 1984a). Also, ORT programs have demonstrated declines in diarrheal mortality based on verbal autopsy, which is consistent with observations from clinical trials (Oberle et al, 1980; Kielman et al, 1985; El-Rafie et al, 1990). This suggests epidemiologic plausibility for interview-based diagnoses.

In summary, verbal autopsy diagnoses of diarrhea appear to be reliable if adequate information is obtained on stool frequency and consistency. However, maternal recognition or recall of the severity of dehydration may be problematic.

Acute Lower Respiratory Infections

Acute lower respiratory infection (ALRI) is a major cause of morbidity and mortality among children in developing countries. Mortality is higher for infants (10 to 30 per 1000) than for toddlers (1.6 to 4 per 1000) (Chretien et al, 1984; Foster, 1984; Victoria et al, 1989), and mortality is particularly high among premature infants or malnourished children. Case-fatality rates are also increased in populations living at high altitudes or in overcrowded conditions. ALRI is due to infection of the lung or lower respiratory tract by bacteria (mainly *Streptococcus pneumoniae* or *Hemophilus inflouenzae*) and viruses (mainly respiratory syncytial virus) (Foster, 1984; Berman, 1990). Treatment varies antibiotic therapy can reduce mortality from bacterial, but not viral, ALRI respiratory distress can be treated by oxygen plus bronchodilator drugs (WHO, 1990). Vaccines provide some protection from pneumococcal and H. influenza infections, but are not yet in widespread use (Foster, 1984; Riley, 1986; Berman, 1990).

The diagnosis of ALRI is difficult because the symptoms and signs of respiratory infection vary with age of the child and the severity of illness. Ideally, definitive clinical diagnosis ideally should be based on X-ray findings, culture of the causative organisms, or specialized tests such as pulse oximetry that measure blood oxygen levels. Without such investigations, there is uncertainty in physician diagnoses due to interobserver variation in the detection of respiratory signs during auscultation of the chest (Steinhoff, 1990; Berman, 1990; Redd, 1990).

WHO has developed simplified diagnostic algorithms to facilitate case management of sick children with ALRI (WHO, 1990). Severe pneumonia is defined by cough and chest in drawing, rapid breathing (>50 per minute), and inability to drink. Pneumonia is defined as cough and rapid breathing but no chest indrawing. However, these guidelines for clinical management are difficult to use as criteria for verbal autopsy and there is still no well-defined algorithm for postmortem diagnosis. The most frequently used verbal autopsy criteria are cough for three or more days, accompanied by dyspnea (defined as difficulty breathing and/or rapid respiration for more than one day before death). It is important to differentiate between respiratory failure at the time of death, which is a common mode of dying, and persistent respiratory distress for some days preceding death, which is more likely to be due to ALRI. Fever may not be present, particularly in young children (Gray et al, 1990a; Berman, 1990).

The algorithm in Table 7 is in part based on clinical judgment and has not been fully evaluated.

TABLE 7. DIAGNOSTIC ALGORITHM FOR ALRI

1. Did the child have a **cough for more than 3-4 days?**
2. Did the child have **difficulty breathing (dyspnea)** as indicated by the following: chest indrawing, nasal flaring, grunting or wheezing, cyanosis (blue color of lips)?
3. Did the difficult breathing last for **more than one day?**
4. Did the child have **rapid breathing?**

Affirmative answers to questions 1-4 indicates ALRI. The persistence of cough and difficult breathing differentiates ALRI from terminal respiratory distress

A validation study of 100 ALRI-associated deaths found that the verbal autopsy diagnosis was problematic (Kalter et al, 1990a). The presence of cough and dyspnea without qualifying the duration of symptoms had high sensitivity (86%) but low specificity (47%), whereas a history of cough lasting four or more days and dyspnoea for one or more days had a sensitivity of 59% and specificity of 77%. The main difficulty was that many children who died had a cough and signs of terminal respiratory distress which can only be differentiated from ALRI by questions regarding duration of symptoms. We know of no other study to validate the verbal autopsy diagnosis of ALRI. However, field trials of pneumococcal vaccine and studies of antibiotic treatment which used verbal autopsy diagnoses have shown declines in ALRI associated mortality, which suggests that the diagnosis is sufficiently accurate to detect the impact of interventions. (Riley, 1986; Black 1990; Bang et al, 1990).

There have been several investigations of the accuracy of physician diagnoses in

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children with non-fatal ALRI. Studies which compare physician's findings in sick children with X-ray confirmation of ALRI or pulse oximetry measurements suggest that the clinical diagnosis may be unreliable. For example, in studies of very young infants, a rapid respiratory rate (>60 per minute) had sensitivities ranging from 40-61% and specificities ranging from 55%-61%. Similarly, chest retractions had a sensitivity range of 66-94% and a specificity range of 28-54% (Berman, 1990). In older children rapid respiration (>50 per minute) had higher sensitivity (66-75%) and specificity (67-98%). However, these investigations were conducted in groups of sick children who were selected as having suspected pneumonia (Redd, 1990). Community studies in the Gambia suggest that for infants, fever, failure to breastfeed and vomiting were predictive of radiologically diagnosed ALRI; whereas for children aged 1-4 years, fever and a respiratory rate >60/minute were most useful signs (Campbell et al, 1989).

Maternal, interview-based diagnoses of non-fatal ALRI have been evaluated in a number of investigations. One British study interviewed mothers whose children had physician-diagnosed ALRI during infancy and found that only 17% of mothers remembered the illness when questioned at the child's first birthday (Watkins et al, 1982). In the Gambia, clinical diagnoses were compared with maternal interviews conducted at the time of hospitalization and were found to agree in 84%of cases (Alonso et al., 1987). In the Philippines, interviews with mothers of children with ALRI who had been discharged from hospital were compared to physician's diagnosis (Kalter et al, 1990b). A combination of cough, fever and dyspnea gave a sensitivity of 68% and a specificity of 84% for the maternal interview diagnoses. Another study in Burkina Faso also found that ALRI diagnoses by field worker interviews underestimated ALRI incidence when compared to physician diagnoses (Lang et al, 1986).

In summary efforts to validate ALRI diagnoses based on verbal autopsy interview, physician's clinical findings or interviews with mothers of surviving children have shown that there is misclassification of children with ALRI which mandates caution in interpretation of studies of ALRI mortality and morbidity.

Pertussis

Pertussis or whooping cough, caused by *Bordetella pertussis*, is widespread in developing countries and is believed to cause around 4% of deaths in children and adolescents. Case-fatality rates vary from 1 to 7% (Foster, 1984; Muller et al, 1984). The organism causes a chronic paroxysmal cough, often lasting more than one month, reduces nutrient intake, and often leads to severe malnutrition. Most deaths from pertussis occur within three months of infection. Mortality is highest during infancy and among malnourished children. The risks of the disease and death vary with population density. In crowded situations such as urban areas the disease is endemic and infection frequently occurs during infancy, whereas in less dense populations transmission occurs in older children and tends to follow an epidemic outbreak pattern. The disease can be prevented by vaccination (Morley, 1973; Foster, 1984).

The definitive diagnosis is based on culture of the organism or serological tests, but a presumptive clinical diagnosis can be made on a history of paroxysmal coughing which persists for two or more weeks, with choking and/or vomiting after the paroxysms. There may also be a characteristic "whooping" sound during inspiration and children frequently have conjunctival hemorrhages. The algorithm in Table 8 is based on WHO studies in Kenya (WHO, 1984b; Muller et al, 1984).

TABLE 8. ALGORITHM FOR PERTUSSIS

1. Did the child have **severe paroxysms of coughing lasting 14 or more days?**
2. Was there **choking and/or vomiting after the bout of coughing?**
3. Was there a "whooping" sound during inspiration?
4. Was there redness of the eyes (conjunctival hemorrhages) and/or swelling of eyelids (periorbital edema)?
5. Was the child in contact with other cases of whooping cough?

Affirmative responses to question 1 and 2 identify pertussis. Questions 3-5 are supportive.

There has been no direct validation of the above questions for use in verbal autopsy, but several

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studies of sick children have validated these criteria for the diagnosis of morbidity. Voorhoeve et al (1978) compared probable or definite diagnoses of pertussis based on laboratory findings with diagnoses based on maternal history alone. They found confirmatory laboratory evidence for pertussis in over 80% of suspected cases during an epidemic, but only in 40% of sporadic cases seen during non-epidemic periods. A clinical study in the U.S. found that a history of prolonged cough (14 days) had a sensitivity of 98% and a specificity of 63%; additional criteria for paroxysmal coughing decreased the sensitivity to 52%, but increased the specificity to 83% (Peter et al, 1988). Several vaccine trials using interview based diagnoses have shown declines in pertussis morbidity and mortality (Morley, 1973; Muller 1984; Foster, 1984). It is therefore likely that the algorithm for pertussis is satisfactory in field settings.

Malaria

Malaria is widespread throughout the moist tropics and endemic malaria is a particularly important public health problem in West Africa, where over 90% of the population is infected by end of the first year of life (WHO 1979; Bradley and Keymer, 1984). Because of the complex epidemiology of malaria, it is difficult to estimate its impact on mortality. Studies in the Gambia suggest that acute malaria is responsible for around 4% of infant deaths and 25% of deaths among children aged 1 to 4 years. Mortality rates were estimated at 6.3 per 1,000 for infants and 10.7 per 1,000 for children, and the mean duration of acute illness prior to death was less than three days (Greenwood et al, 1987b). Both acute and chronic malaria can contribute to mortality from other diseases by undermining health (e.g., anemia) and nutrition. Thus studies of mortality following malaria control programs have demonstrated declines in death rates beyond that expected from declines in acute malaria deaths alone (Gray, 1974; Bradley and Keymer, 1984; Greenwood et al, 1988). In addition, maternal malaria infection during pregnancy results in reduced birth weight which can also contribute to subsequent infant deaths (McGregor, 1983). Stable endemic malaria is predominantly a disease of infancy and childhood because infected survivors develop immunity to the parasite, whereas in relatively nonimmune populations epidemic malaria can cause heavy mortality in all age groups. Malaria can be prevented by mosquito control measures, long-term prophylactic drug use, or drug treatment of acute illness (Bradley and Keymer, 1984).

The clinical diagnosis of malaria can be difficult and a definitive diagnosis depends on demonstration of a high density of parasites in the blood. In Gambian studies, a presumptive diagnosis was made on the basis of a history of high fever in a previously well child, without significant other concomitant respiratory or gastrointestinal illness (Greenwood et al, 1987b). If malaria transmission is seasonal or epidemic, then afebrile illness during periods of peak transmission is more likely to be due to malaria. It is difficult to assess the validity of such presumptive diagnoses, in part because many children in endemic malarious areas have parasitemia without fever, and because children who have already received antimalarial drugs may have no parasitemia. Morbidity surveys in the Gambia found that 65% of children with fever had malaria parasites in their blood, but 30% of febrile children also had parasitemia (Greenwood et al, 1987b). Similarly, a study of illness in Congolese school children showed that 46% of children with fever had evidence of malaria parasites, but among children suspected of malaria the diagnosis could only be confirmed by blood smear in 20% of the cases (Trape et al, 1987). Physician diagnoses without laboratory confirmation are also problematic; a study of 104,281 patients in Zimbabwe showed that the percent of clinically suspected cases of febrile malaria confirmed by laboratory tests varied from under 5% in the season of low transmission to over 30% in the season of peak transmission (Taylor and Taputaira, 1988). Thus, fever as a criteria for malaria diagnosis is insensitive and nonspecific. One investigation of 16 seriously ill Gambian children with clinically diagnosed malaria found that open ended interviews with mothers gave a presumptive diagnosis of malaria in 75% of cases on admission to hospital and in 90% of cases one month after discharge (Alonso et al, 1987). Despite these problems with diagnosis, it is noteworthy that a randomized trial of chemoprophylaxis showed substantial declines in malaria mortality using verbal autopsy diagnosis (Greenwood et al, 1988). Since this was a randomized study with blind observation, it is unlikely that diagnostic bias

affected the outcome. In summary, more information is needed to assess the accuracy of diagnosis of malaria deaths by verbal autopsy methods. This should be a priority area for research.

Meningitis

Cerebrospinal meningitis occurs throughout the world and is a major public health problem in tropical Africa, where annual epidemics occur during the dry season in a "meningitis belt" of Sahelian countries extending from Sudan to Mali (Greenwood et al, 1984; Tikhomirov, 1987). Meningitis was responsible for approximately 9% of deaths in Gambian children under age 7 years (Greenwood et al, 1987a). The disease is characterized by high fever of sudden onset, severe headaches, and stiff neck, and may progress to delirium, coma and convulsions. Infants often have a bulging fontanel. Diagnosis is confirmed by examination of the cerebrospinal fluid (Robinson, 1985).

Criteria for the verbal autopsy diagnosis of meningitis have not been well established, but studies in Senegal and Nigeria used an algorithm based on fever, headache, neck extension (often with flexed arms and legs), and **swollen fontanelle in infants** (Bradley and Gilles, 1984; Garenne and Fontaine, 1986). Additional signs included convulsions and photophobia. Since most deaths occur during epidemics, the presence of other cases provides supporting evidence. No validation studies for the interview-based diagnosis of meningitis are available.

Chronic Illnesses: Malnutrition, Tuberculosis and AIDS

Many children suffer from chronic ill/health as a consequence of nutritional deficiencies, recurrent acute infections and chronic infections with diseases such as tuberculosis (Mosley and Chen, 1984). Pediatric AIDS is also a growing a [sic] public health problem, particularly in Africa. It is difficult, however, to distinguish these chronic conditions from one another and to determine their contribution to death using verbal autopsy methods.

Anthropometric studies have shown that protein-calorie malnutrition increases the risk of death from a number of infectious diseases (Chen et al, 1980; Briend et al, 1987; Martorell and Ho, 1984). However, only a minority of undernourished children manifest overt clinical syndromes of malnutrition such as marasmus or kwashiorkor which might be diagnosed by verbal autopsy, and in the majority of cases anthropometry is required to detect less severe malnutrition. Unfortunately, anthropometric information derived from growth monitoring charts is seldom available for deceased children and even the recognition of clinical malnutrition may be subject to errors in maternal perception or recall.

Vitamin A deficiency can lead to blindness and has been associated with an increased risk of morbidity and mortality from a variety of infections (Feachem, 1987; Sommer et al, 1983; Sommer et al, 1986). Also, Vitamin A supplementation in deficient populations or in sick children has been associated with reduced mortality (Sommer et al, 1986; Barclay et al, 1987). Vitamin A deficiency is thought to be common in many developing countries as indicated by the prevalence of corneal damage due to xerophthalmia or its precursor of night blindness (Sommer et al, 1981). Thus, a history of these visual problems may provide an indicator of Vitamin A deficiency prior to death.

Tuberculosis (TB) is widespread in the developing world and its prevalence is particularly high in Africa and South Asia (Styblo and Rouillon, 1981). Due to the lack of reliable data, it is difficult to estimate the mortality attributable to tuberculosis, although in general incidence and mortality rates are high during infancy and early childhood (Clemens et al, 1983; Curtis et al, 1984). BCG vaccination shortly after birth offers some protection from the disease and TB is responsive to antibiotic therapy. Pulmonary tuberculosis is the most frequent form of infection, but disseminated infection of the lymph nodes, bones, intestinal tract and brain also occur, particularly in children. Most cases present with chronic cough, low grade fever and weight loss, but may also have hemoptysis (blood in the sputum), joint swelling due to bone infection, abdominal swelling due to intestinal infection, and enlarged lymph nodes in the neck, axillae or groin (Robinson, 1985). These protean manifestations make diagnosis difficult in the absence of X-Ray investigations, bacteriologic or serological tests.

Perinatal transmission of human immunodeficiency virus (HIV) from infected

mothers to children or from contaminated needles or blood transfusion is an increasing problem in sub-Saharan Africa (Quinn et al, 1986; Mann et al, 1986; Mok et al, 1987; Poulsen et al, 1989). Mortality among infected children is high and in a Zambian study 44% of seropositive children had died by the end of the second year of life (Hira et al, 1989). The immunodeficiency due to HIV infection increases the risk of acquiring other acute infections such as TB, and these conditions in turn undermine nutritional status. Thus, children with AIDS often have multiple infections and the clinical diagnosis of pediatric AIDS is difficult in the absence of confirmatory serological tests (Rubenstein, 1986; Mann et al, 1986; Hira et al, 1989). Also, the interpretation of positive HIV tests in infants is complicated by the passive transmission of maternal antibodies (Mok et al, 1987). A provisional WHO case definition for pediatric AIDS consists of three major signs: weight loss or slow growth, chronic diarrhea and prolonged fever with minor signs including chronic cough, a variety of infections and dermatitis (Quinn et al, 1986). The major features of the disease also vary somewhat with age (Rubenstein, 1986; Hira et al, 1989). Thus, it is difficult to distinguish AIDS and AIDS-related conditions from other chronic or recurrent illnesses, and the WHO diagnostic case definition has limited sensitivity and specificity in sub-Saharan Africa (Mann et al, 1986).

In summary, there is as yet no satisfactory algorithm for the verbal autopsy diagnosis of chronic malnutrition, TB or AIDS. The questions listed in Table 9 may be helpful in diagnosis, and draw upon several studies, but have not been adequately evaluated. For each question, the possible associated diseases are given in parentheses.

TABLE 9. ALGORITHMS FOR CHRONIC CONDITIONS

1. Has the child had **weight loss or slow growth?** [malnutrition, TB, AIDS]
2. Was there **chronic cough > 1 month?** [TB; AIDS]
3. Was there **prolonged fever > 1 month?** [TB; AIDS]
4. Was there **prolonged diarrhea > 1 month?** [malnutrition, AIDS]
5. Was there **blood in the sputum?** [TB]
6. Was there a generalized skin rash? [AIDS]
7. Was there repeated common infections? [malnutrition, AIDS]
8. Was there generalized enlargement of lymph nodes? [TB, AIDS]
9. Did the child have **scarring of the cornea or blindness?** [vitamin A deficiency]
10. Did the child experience difficulty locating food or toys after dark, compared to the other children of the same age (night blindness)? [vitamin A deficiency]

Accidents and Violence

Injuries are potentially important but often overlooked causes of death, particularly during childhood and adolescence (Smith and Barss, 1990). Death rates from injury in the 0-14 age group are similar in developed and developing countries (around 1 per 1,000). In Bangladesh, mortality from injury (primarily due to drowning) was 7.6 per 1,000 in the 0-5 age group (Chen, 1986) and in Sri Lanka there were over 1,000 deaths from pesticide poisoning (Jeyaratam et al, 1982). It is relatively easy to obtain information on deaths due to injury using verbal autopsy methods, by asking descriptive questions on how the injury occurred (external cause, e.g. car accident) and on the nature and location of the injury (e.g. fractured skull). However, there may be underreporting of causes such as homicide (particularly infanticide) and suicide, and there may be imprecise descriptions of the nature and location of injury. Confirmation of deaths due to injury may also be obtained from medical or legal records.

WHO (1978) has classified the external causes of injury into nine categories, shown in Table 10. The use of verbal autopsy methods and this classification of causes of injury has not been validated for childhood deaths. However, in an Egyptian study of deaths among women aged 15-49 years, 92.8% of injury related deaths reported by interview were confirmed by physician certified death certificates. Also, there was 74.2% agreement on the specific cause of injury (Grubb et al, 1988).

Summary and Conclusions

It is unlikely that reliable information on causes of death will be available for major populations in developing countries until there is widespread registration of deaths, adequate

TABLE 10. EXTERNAL CAUSE OF INJURY

1. Bites or stings of venomous animals
2. Accidental burns
3. Accidental drowning
4. Accidental poisoning (excluding food poisoning)
5. Transport (traffic) accidents, classified by type e.g., motor vehicle, etc.)
6. Other accidents
7. Suicide, self-inflicted injury
8. Homicide, assault
9. Violence of unknown cause
10. For 5-9 obtain descriptive information on the nature and location of the injury.

medical service coverage and proper completion of death certification. In the interim, researchers and policy makers will depend upon information derived from secondary sources such as interviews with relatives of the deceased. Such verbal autopsy diagnoses will always be subject to error because few diseases present as unmistakably distinct syndromes with symptoms and signs that can be readily perceived and recalled by the relatives. Moreover, the absence of clinical information will, of necessity, result in less precise presumptive diagnoses rather than definitive clinical diagnoses. Nevertheless, verbal autopsies can provide data of value to public health, particularly data needed for allocation of health priorities and for evaluation of intervention programs. Therefore, it is likely that verbal autopsies will be more widely used in surveillance and survey studies, and that greater standardization of interview methods and wording of specific questions can provide more consistency between investigations.

The objective of this paper has been to review current experience and to suggest approaches to standardization. The review suggests that verbal autopsies may provide relatively reliable diagnoses for diseases such as diarrhea, measles, neonatal tetanus, pertussis and meningitis and for injuries. However, diagnosis is more problematic for other acute conditions such as ALRI and malaria, or chronic conditions such as TB, AIDS and malnutrition. There clearly needs to be more research to validate verbal autopsy diagnoses against standard clinical diagnoses so as to determine the most sensitive and specific questions for interviews and to determine the effects of cross-cultural variation on the interpretation of questions and on the quality of diagnosis.

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MEASUREMENT OF OVERALL AND CAUSE-SPECIFIC MORTALITY IN INFANTS AND CHILDREN: MEMORANDUM FROM A WHO/UNICEF MEETING

Summary

A joint WHO/UNICEF informal consultation on the "Measurement of overall and cause-specific mortality in infants and children" was held in Geneva on 15-17 December 1992. The participants included physicians, demographers, statisticians and programme personnel from different regions. The recommendations were aimed at helping countries and international organizations to produce more frequent and more reliable data on overall child mortality and to estimate broad patterns of child mortality by cause of death, especially for ranking the major causes of death and monitoring progress towards the achievement of mortality reduction goals of the World Summit for Children.

The verbal autopsy method was reviewed to assess its potential for use in different situations-surveys, longitudinal surveillance, health services and civil registration--and its capacity to provide national estimates of causes of death. Documented national and international experiences and validation studies were examined together with other methods already being used. The potential of the preceding birth technique and other indirect methods to estimate mortality in childhood -- for use by countries and programmes more frequently and with as much disaggregation as possible--was evaluated.

Introduction

The collection of up-to-date information on overall and cause-specific mortality in children is becoming more and more important because of its usefulness to a wide variety of decision makers. At the provincial, district and local levels this information is needed for programme management and evaluation; at the national level, for soliciting extra-budgetary funds and for resource allocation among programmes and population subgroups; and at the international level, for advocacy, resource allocation among programmes and population subgroups; and at the international level, for advocacy, resource mobilization and distribution. The World Summit for Children (New York, 1990) called for "each country to establish appropriate mechanisms for the regular and timely collection, analysis and publication of data required to monitor relevant indicators relating to the well-being of children which record the progress being made towards the goals set forth in the global plan of action and corresponding national plans. These indicators cover a wide range of health-related topics." The World Summit for Children agreed upon five targets related to the reduction of mortality.

- Between 1990 and the year 2000, reduction of infant and under-five mortality rate by one-third or, respectively, to 50 or 70 per 1000 births, whichever is less.
- Elimination of neonatal tetanus by 1995.
- Reduction by 95% in measles deaths and reduction by 90% of measles cases (compared to pre immunization levels) by 1995, as a major step to the global eradication of measles in the longer run.
- Reduction by 50% in the deaths due to diarrhea incidence rate in children under the age of five years.
- Reduction by one third in the deaths due to acute respiratory infections in children under five years.

Current data availability

Despite the growing need for information on mortality, for many countries, there is very little information on infant and child mortality rates, and much of the health information from countries with poor statistical infrastructure is out of date, and of poor quality. For example, only 66 out of 101 countries with populations of at least one million had national level data

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on infant and child mortality rates for 1980 to the present.[a] Information on cause-specific mortality for this age group is even more scarce. The WHO Regions that particularly include Africa, SouthEast Asia, the Eastern Mediterranean and the Western Pacific.

Given the need regularly to monitor both overall and cause-specific mortality, and the dearth of available information in many countries, it is clearly necessary to develop strategies for monitoring mortality which can be implemented either continuously or on a frequent basis. This needs to be considered within the context of ostringent financial and human resources and logistical constraints.

Measurement of Overall Mortality

There are two low-cost methods of monitoring overall infant and child mortality, which could enable countries to monitor mortality more frequently. There are the preceding birth technique (PBT) used at the time of immunization, and in maternity clinics and antenatal clinics, and rapid household surveys which require a small number of questions to gather the essential information on mortality levels and trends.

Preceding birth technique (PBT)

The PBT[b] is a simple and inexpensive way of taking advantage of the contact women have with the health services around the time of birth, either at the time of immunization or in antenatal or maternity clinics, in order to monitor mortality among infants and children. The woman is asked three simple questions: whether she has been pregnant before; if so, what was the outcome of her last pregnancy; and if she has had a previous live birth, whether live-born child is still alive. These data are aggregated at regular intervals, usually when there are data for about 1000 mothers. The proportion of previous births which are still alive turns out to be very close to the probability that a live-born would survive until age two, referring a time centered around two-thirds of the average birth interval before the delivery of the current birth. Thus, if the average birth interval is 30 months, the PBT applied at the time of delivery provides an estimate of what the probability of surviving until age two was approximately 20 months ago.

The PBT is appealing for a number of reasons. In many cases, the information is already being collected by the health services, especially during the course of antenatal visits or delivery, although it may not be currently analyzed to obtain estimates of mortality. If these data are not already being collected routinely, they are relatively easy to add to a routine reporting system in which data are continuously collected. The data collected by the PBT is of direct relevance to health managers as they refer directly to mortality trends among health service users. The information is also of direct relevance to the antenatal or delivery care of the mother because the death of a preceding child, especially during delivery or shortly thereafter, is a risk factor for the current pregnancy.

The PBT is best suited for local or district levels. It could be used for evaluating mortality trends and differentials among health service users at the local or district levels and be the basis for local and community policy decisions and actions. It could also be an important tool for improving the quality and use of health service data, and for targeting families at high risk. However, caution is urged when interpreting the data.

Extrapolating from health service users to the community at large is considered appropriate only if the coverage is very high. In addition, changes in observed mortality rates over time should be carefully investigated as they may reflect a change in the composition of health services users as much as a real change in mortality rates in the general population.

There are a number of factors to consider in determining the suitability of the PBT for a particular health service setting. Although the collection of information about the survival of preceding births could be performed during antenatal clinics and delivery clinics may obtain better information

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[a] Child mortality since 1960s. *A data base for developing countries* (ST/ESA/SER. A/128). New York, United Nations, 1992.

[b] **David P, Hill A.** *Measuring childhood mortality for programme needs.* Unpublished document. WHO/ESM/UNICEF/CONS/WP/4, 1992.

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from the individual mother, because the information could be perceived as being useful for her health care. In addition, obtaining the information might be a greater burden for the immunization worker than for an antenatal clinic worker or maternity clinic worker, since the questions used by the PBT are somewhat out of context in the immunization overage is generally greater than the coverage for antenatal care or delivery care. Therefore a larger proportion of women will be reached through the immunization approach.

The next steps in developing PBT will be to test it further in various countries in antenatal and maternity clinics, an at the time of immunization, to determine the comparative advantage of each of these settings. Attention should be paid to how the different settings influence the results and to the ease with which women answer the questions in each of the different settings, keeping in mind that asking women about the death of an infant or child should be treated with care and sensitivity. The purpose for which these data are being collected and its links to action needs to be clearly identified, both on the individual level (what follow-up actions should be taken when a death is identified) and the aggressive level (how will these data be used at various levels in the health system).

Household surveys

Infant and child mortality can be estimated using household surveys by the Brass technique or the preceding birth technique, both of which require asking mothers a small number of questions regarding the survival of previous births. The Brass technique computes the ratio of children ever born, while the preceding birth technique computes the proportion of surviving preceding births to all preceding births. Both methods are relatively inexpensive and could be used in stand-alone surveys or as additional questions in other household surveys or as additional questions in other household surveys, e.g., for disease control programmes. Neither method requires inquiries into dates or births or dates of death of previous children. They are relatively easy to administer and can be used in areas where dates are difficult to obtain. The PBT has the advantage of providing time trends. The sample size required to obtain a precise recent estimate of mortality is larger than the sample size usually required to estimate a time trend using the Brass technique. Therefore, when there are resource constraints most programmes would probably be willing to forego a precise recent estimate of mortality, and be satisfied with measuring a trend over time using the Brass questions. However, whichever survey method is used, careful implementation of the survey is important in order to obtain accurate results. This includes careful design and pre-testing of the questionnaire, as well as good training and supervision of field staff. Adequate attention must also be given to survey coordination and to local sensitivities. Demographic expertise is necessary for interpreting the results.

In addition to surveys, additional analysis of census data, using age-standardized proportions dead, would be a practical and inexpensive way of obtaining local area estimates of child mortality. Health authorities should encourage the statistical authorities to include indirect questions on child mortality in censuses and general household surveys. In Africa, a number of recent censuses have omitted indirect mortality questions, thus limiting the opportunity to use census data for monitoring mortality. Countries seeking to improve their vital registration systems could improve their measurement of mortality by arranging to ask questions concerning past child mortality at the time a woman is registering a birth.

Measurement of cause-specific mortality

Measurement of cause-specific mortality is needed for several purposes: (i) to establish the relative public health importance of the different causes of death; (ii) to evaluate trends over time, especially as a method of evaluating the probable impact of intervention programmes; (iii) to investigate the circumstance surrounding the deaths of children from specific causes and to devise effective actions to decrease mortality; (iv) to investigate the reasons for differing rates of infant and child mortality between geographic areas; and (v) to evaluate the effectiveness of specific health interventions in controlled settings.

A promising method for measuring cause-specific mortality where vital

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registration systems are weak is the verbal-autopsy method.[c] This approach has been used in research studies, usually in situations where deaths have been identified by a demographic surveillance system. Specially trained investigators interview the bereaved family, usually within six months of the death. Recently, brief verbal autopsies have been attempted in cross-sectional national household interview surveys, such as, the Demographic and Health Surveys (DHS) programme. These surveys use pre-coded questions and rely on computers to code the information.

Use of verbal autopsy to measure mortality from specific diseases

Verbal autopsy is not equally suitable for all diseases in all settings. The ideal situation for any specific cause of death to be measured by verbal autopsy would be that it has a clear an unambiguous clinical syndrome consisting of a set of signs and symptoms, which are always present in the terminal illness of children dying from this specific cause but are not present in the same combination in any other fatal illnesses. These signs and symptoms should be clearly recognized by the respondents, even if they do not interpret them within the standard medical classification of illness.

During the consultation, evidence on the accuracy of verbal autopsies for identifying specific causes of death was reviewed. Validation studies have been done in various settings, with different patterns of disease prevalence-in Bangladesh, Egypt, Gambia, India, Kenya, Mozambique, Namibia and Philippines. The studies did not all use the same basic questionnaire, study design or algorithms for determining the cause of death (or cause of severe illness). However, despite these differences, some patterns emerged. Table 1 summarizes the sensitivity and specificity of verbal autopsies for detecting major causes of childhood deaths; only studies based on children who have died are included.

Neonatal tetanus was found to have high levels of sensitivity and specificity (sensitivity from 0.90 upwards, and specificity 0.79 to 0.98); verbal autopsy would seem to be a useful instrument for identifying neonatal tetanus as a cause of death and for measuring mortality. However, deaths from neonatal tetanus are known to be underreported owing to underreporting of neonatal deaths in general, yet a large proportion of the deaths under 5 year-olds occurs during the neonatal period. Therefore, no matter what system is used to identify deaths for further investigation, special attention should be paid to improving the identification of neonatal deaths. In addition, as the rates of neonatal tetanus decline sample sizes required for measuring its prevalence with precision increase. Thus, in many instances, it may be impractical to identify enough deaths to be able to measure the proportion of children dying from neonatal tetanus with adequate precision.

There has been little validation of the use of verbal autopsy for neonatal deaths other than for identifying neonatal tetanus. However, based on the few validation studies, and other related work, it appears that it would be almost impossible to distinguish between sepsis and pneumonia in the newborn based on verbal autopsy. More research was called for in using verbal autopsy for children who die during the first weeks of life.

For *measles*, sensitivity (0.67 to 0.98) and specificity (0.85 to 0.99) were considered to be high. Thus, the verbal autopsy would seem to be a good method for identifying measles as a cause of death, although the epidemic nature of measles must be kept in mind. During any short time period, whether or not there are deaths from measles depends largely on whether there has been an outbreak of measles during the period under study. Therefore, for measuring measles mortality, it is necessary to examine mortality during outbreaks or to monitor long-term trends.

The sensitivity and specificity for *diarrhoea* presented a mixed picture. Sensitivity ranged from 0.36 to 0.90 while specificity ranged from 0.61 to 0.97. Several of the verbal autopsies used in validation studies contained a number of questions about the frequency and consistency of the stools during the illness preceding the death.

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[c] **Ross DA.** *Monitoring cause-specific infant and child mortality rates in areas where death certification systems are weak.* Unpublished document WHO/ESM/UNICEF/CONS/WP/2, 1992.

Sensitivity and specificity varied depending on which criterion was used for the classification of a diarrhoea-associated death and there was a clear relationship between sensitivity and specificity depending on the strictness of the criterion. Overall, the levels of sensitivity and specificity for deaths associated with diarrhoea were moderate and not high enough to recommend that verbal autopsies be undertaken on a regular basis in every country to monitor mortality from diarrhoea.

The sensitivity and specificity for *acute respiratory infections* (ARI) were lower than for diarrhoea. Apart from one extremely low value of sensitivity found in Kenya, sensitivity ranged from 0.56 to 0.72 while specificity ranged from 0.60 to 0.91. There is a good deal of overlap between the symptoms of ARI and malaria, and it was concluded that the specificity and sensitivity of the verbal autopsy for classifying ARI would depend not only on the questions asked and the algorithms used, but also on the prevalence of other diseases with overlapping symptoms.

The sensitivity of verbal autopsies for *malaria* in the studies reviewed was low, ranging from 0.45 to 0.72 although the specificity was considered to be moderately high, ranging from 0.85 to 0.89. The difficulty of assigning malaria as the cause of death based on medical records contributed to the poor results in validation studies. One problem, when assigning causes based on medical records, is that of distinguishing between children who die from malaria and those who die with parasitaemia but not from malaria. In highly endemic areas, if all children who died with evidence of parasitaemia are classified as dying from malaria, this misclassification will result in an overestimate of malaria as a cause of death based on medial records, and consequently the verbal autopsy instrument would appear to have lower sensitivity than it would have for "true" malaria deaths. The nonspecific nature of many of the symptoms and signs of malaria and their overlap with symptoms and signs of other causes of death (such as ARI and measles) make it very difficult to distinguish malaria from other causes of death based on an interview with the child's next of kin or carer.

The sensitivity and specificity of verbal autopsies, especially when there are overlapping symptoms from diseases such as ARI, diarrhoea and malaria might be improved by focusing more on the symptoms of severe disease than on the clinical presentation for case detection of clinical disease. This approach seems promising in light of the results for cerebral malaria from Namibia, where sensitivity and specificity for cerebral malaria (a severe form of malaria) were much higher than those found for all forms of malaria. In the case of the study in Namibia, most malaria deaths were caused by cerebral malaria, and therefore cerebral malaria could be used in place of malaria without loss of accuracy. However, it was recognized that there are areas of in which a high proportion of malaria-related deaths are caused by severe anaemia, a complication of malaria, rather than by cerebral malaria. Thus the substitution of cerebral malaria for malaria would not be appropriate in all settings.

The sensitivity and specificity of the verbal autopsy diagnosis of *malnutrition* compared to anthropometric measures on admission to hospital, were considered to be satisfactory in the three studies that were presented. Sensitivity ranged from 0.71 to 0.89 while specificity ranged from 0.76 upwards.

The structure of a verbal autopsy interview

There are two major issues concerning the structure of the verbal autopsy instrument which have important impacts on the way the interview is conducted, and in the interpretation of the response.

(1) Whether multiple causes of death are permitted or only a single cause of death is allowed. This is an important issue since many deaths have more than one cause. For most purposes, multiple causes of death should be permitted, and the causes of death should not be ranked into hierarchical categories such as primary or secondary causes.

(2) The choice between using physicians to code open-ended history questions based on their clinical experiences and judgment, versus using a combination of pre-coded questions about the symptoms and signs of disease preceding death, with a fixed algorithm for each specific disease. This latter method does not require coding by physicians.

The decision on whether or not to include open-ended questions will depend on circumstances in which the verbal autopsy is

Table 1: Sensitivity and specificity of verbal autopsies for detecting major causes of childhood death, based on validation studies.

CAUSE OF DEATH AND COUNTRY	SENSITIVITY	SPECIFICITY	COMMENTS
Neonatal tetanus			
Philippines (1)*	94-100	--	
Kenya (2)	90	79	
Bangladesh (5)	97	98	
Measles			
Philippines (1)	98	90	Age 120 days, rash and fever 3 days
Philippines (1)	98	93	Age >120 days, fever 3 days, rash anywhere except only on extremities
Philippines (1)	83	99	Age.> 120 days, fever 3 days, rash anywhere except only on extremities, plus progressive rash
Kenya (2)	90	96	
Namibia (3)	71	85	Age > 120 days, rash
Namibia (3)	67	90	Age > 120 days, rash, fever > 3 days
Diarrhoea			
Kenya (2)	36	96	
Philippines (1)	60	85	.6 liquid stools per day
Philippines (1)	78	79	Frequent loose or liquid stools
Namibia (3)	56	90	>6 liquid stools per day
Namibia(3)	89	61	Loose or liquid stools
India(4)	90	78	Gastroenteritis
Bangladesh (5)	77	97	>6 liquid stools
Acute respiratory Infections			
Philippines(1)	66	60	Cough and dyspnoea>1 day
Philippines(1)	59	77	Cough > 4 days and dyspnoea >1 day
Kenya(2)	28	91	
Namibia (3)	72	64	Cough with dyspnoea or tachypnoea
India (4)	56	81	
Bangladesh (5)	58	82	Cough or difficult breathing or fast breathing
Malaria			
Kenya (2)	89	96	Te diagnosis based on medical records included all malaria parasitaemia
Namibia (3)	45	87	Fever and convulsions or loss of consciousness for all malaria parasitaemia
Naamibia(3)	72	85	Fever and convulsions or loss of consciousness for all malaria parasitaemia
Malnutrition			
Kenya (2)	89	96	
Namibia (3)	73	76	
India (4)	71	100	
Accidents			
Kenya (2)	78	100	
India (4)	100	100	
Sepsis			
Kenya (2)	61	81	Neonates

[a] The number in parentheses are references, as follows:

1. **Kalter HD et al.** Validation of post-mortem interviews to ascertain selected causes of death in children. *International journal of epidemiology*, 1990, **19**:380-386.
2. **Snow R. et al.** Childhood deaths in Africa: uses and limitation of verbal autopsies. *Lancet*, 1992, **340:** 350-355.
3. **Mobley C et al.** *Validation of verbal autopsy method for causes of childhood mortality in the Namibia.* (Unpublished, December 1992).
4. **Sachdev HPS et al.** *Validation of verbal autopsy technique.* (Unpublished, December 1992).
5. **Osinski P,** personal communication, 1992.

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being undertaken. If the questions are being asked as part of a large-scale survey with lay interviewers, it may be more difficult to take an unstructured history approach than in a clinical setting, where trained practitioners conduct the interviews.

Open-ended questions have the advantage of providing information on the perceptions of the mother or carer, the time sequence, and the severity and duration of various symptoms, and help to establish a rapport with the mother or carer in a very sensitive area. Open-ended questions, together with physician coding, can make use of all information provided in the open history as well as an "expert judgment. However, this is time-consuming and subjective, making it difficult to compare studies from different settings and among different countries.

On the other hand, the combination of pre-coded questions and structured algorithms has the advantage of providing information on symptoms that were absent as well as those that were present. Since results are more objective, they are easier to interpret and compare across studies, countries and time. A pre-coded questionnaire requires less training and knowledge of concepts and terms for local illnesses on the part of the interviewers, since they will need to ask only direct questions and record pre-coded answers. It is also relatively easy to reanalyse causes of death using different algorithms if necessary at a later date. Even with the structured algorithm approach, open-ended questions at the beginning of the verbal autopsy interview are important for establishing the rapport necessary to proceed with a structured interview about the sensitive subject of death. Therefore, the use of a standardized pre-coded questionnaire and redefined diagnostic algorithms is to be preferred for international comparisons and for studies of changes in cause-specific mortality over time, where standardization of interviewing and coding practices would be otherwise difficult to achieve.

Settings in which verbal autopsy can be used

To date, most of the work, with verbal autopsy has been in research settings, in which *demographic surveillance systems* have been functioning for many years. These settings have the advantage of collecting data on a regular basis and providing very good mechanisms for identifying deaths. Their disadvantages are that the results come from a relatively small area and are not necessarily representative of the country as a whole, and that prolonged observation may result in unmeasurable conditioning effects. They are also very expensive to establish and maintain, and are beyond the resources of most developing countries.

An alternative would be to use *household surveys* to identify infant and child deaths from which to estimate mortality. This has been done on an experimental basis by the Demographic and Health Surveys (DHS) programme, as well as by WHO's diarrhoeal disease control programme in collaboration with the London School of Hygiene and Tropical Medicine. More work in this area is required.

Next steps in the work on verbal autopsies

The use of verbal autopsies either within surveys or with deaths identified through routine reporting systems is not yet at the stage of development where it can be advocated for monitoring national levels and trends in cause-specific infant and child mortality rates by all or even most countries. Nevertheless, the infant and child verbal-autopsy method appears encouraging enough to advocate its further development and application within research settings as specified below, and to encourage its use within carefully designed and conducted settings of surveys, surveillance, and routine reporting systems.

The following plan of action for improving the verbal-autopsy methodology was proposed:

(1) To further study the sample sizes necessary to detect changes in cause-specific infant and child mortality using verbal autopsies, given the likely operating characteristics of the instrument, in terms of sensitivity, specificity, and predictive values.

(2) To agree on a draft "best judgment" verbal-autopsy questionnaire and to validate this questionnaire in different geographical areas. These validation studies should shed light on a number of important issues including:

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— the effect of different recall periods of up to five years on validity/performance of the verbal-autopsy instrument;
— The relative validity of verbal-autopsy questionnaires with and without an open-ended history section and coding by physicians;
— The relative validity of verbal autopsy modules or questionnaires with and without a focused ethnographic study to help with the design of the locally applied version of the questions.

(3) Based on the results of the validation studies, to draft to two standardized verbal-autopsy modules to use in different settings: a long version of up to 50 questions and a short version with as few as 10 questions.

Recommendations

Measuring infant and child mortality from all causes

(1) Countries should be encouraged to monitor overall infant and child mortality more frequently.

(2) The preceding birth technique (PBT) should be used in antenatal clinics, maternity clinics, and at the time of immunization to monitor infant and child mortality because of its low cost, simplicity, operational links to health actions, as well as its capacity to provide a more recent estimate of mortality than can be obtained with other methods.

(3) For making national estimated of infant and child mortality that are representative of the population, countries should continue to use censuses, household sample surveys, and registration systems.

Measuring cause of death in infants and children

(1) The use of verbal autopsies, whether in surveys or for deaths identified through routine reporting systems, is not yet at the stage of development where it can be recommended for monitoring national levels and trends of cause-specific mortality for all or even most countries.

(2) The verbal-autopsy method should be further developed and validated.

(3) The reporting systems of the health facility should be used and strengthened.

These recommendations are being followed up. Investigations into the required sample sizes to detect change has begun. A long version of the "best judgment" verbal-autopsy questionnaire has been drafted and a number of validation studies will be started.

This Memorandum is based on the report of a WHO/UNICEF Informal Consultation which was held in Geneva on 15-17 December 1992. The participants were: Dr R. Bairagi, Dhaka, Bangladesh; Dr R.E. Black (*Chairperson*), Baltimore, MD, USA; Dr J. Blacker, London, England; Dr T. Boerma, Columbia, MD, USA; Dr U. D'Alessandro, Banjul, Gambia; Dr P.H. David, London, England; Dr A. de Francisco, Dhaka, Bangladesh; Dr A. Hill, Boston, MA, USA; Dr. K. Hill, Baltimore, MD, USA; Dr H. Martinez, Mexico City, Mexico; Dr F. Midhet, Cambridge, MA, USA; Dr B. Pelto, Nyon, Switzerland; Dr D. Ross, London, England; Dr H.P.S. Sachdev, New Delhi, India; Dr Siswanto Agus Wilopo, Yogyakarta, Indonesia; Dr G. Stroh, Atlanta, GA, USA; and Dr M. Strong, Dhaka, Bangladesh. *UNICEF*: Ms B. Carlson (*Rapporteur*), Dr J. Gulaid, Dr G. Jones, and Dr V. Orinda. *WHO*: Dr J.-C. Alary, Ms M. Anker (*Rapporteur*), Dr M.A. Belsey, Dr Binh Khanh Nguyen, Dr J.A. Cattani, Dr C.J. Clements, Mr H. Dixon, Dr O. Fontaine, Dr O. Frank, Dr F. Gasse, Dr M. Gersenovic, Dr M. F. Gomes, Dr S. Gove, Dr H.R. Hapsara, Dr. J.-P. Jardel, Dr R. Kim-Farley, Dr S. Orzeszyna, Dr P. Phillips-Howard, Dr S. Sapirie, Dr P. Sato, Dr P.M. Shah, Dr E. A. Sherwin, Dr S. Siméant, and Dr R. Waldman (*Chairperson*).

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A STRATEGY FOR THE EVALUATION OF ACTIVITIES TO REDUCE MATERNAL MORTALITY IN DEVELOPING COUNTRIES

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Summary

The expense and effort involved in collecting the data necessary for calculating material mortality rates and ratios often discourages efforts to evaluate projects. The use of a set of carefully selected process indicators is presented as a practical alternative. The evaluation strategy proposed is based upon a recently published conceptual framework of maternal mortality. The strategy includes four stages: (1) outlining the causal pathway through which an intervention is hypothesized to work; (2) determining how the pathway will be affected by external factors; (3) developing indicators at each step of the pathway; and (4) selecting a combination of indicators that together will provide sufficient evidence that the intervention was successful. This process is illustrated for three program interventions: providing safe abortion services, increasing knowledge of obstetric complications, and improving quality of medical care.

The Safe Motherhood Initiative (SMI) was launched in 1987 in Nairobi, Kenya, at the first International Safe Motherhood Conference. This was a response to a growing recognition articulated in the Lancet article "Where is the 'M' in "MCH?" (Rosenfield and Maine 1985) that maternal health and maternal mortality were being virtually ignored by many maternal and child health programs in developing countries. Since that conference, maternal mortality has received increasing attention in the field of international health, and most of the major donor agencies are actively promoting programs to prevent maternal mortality.

As more organizations design and implement field projects to reduce maternal mortality, increased attention will need to be directed at how these programs can be monitored and evaluated. Because the SMI is still relatively young, there are no widely accepted principles or strategies for the evaluation of programs, nor is there explicit consensus on the specific indicators that are best suited to evaluating the success of such programs. Furthermore, although we can learn from the experience in other health areas, maternal mortality is sufficiently different from other international health problems to require a different approach. The relatively rarity of maternal deaths compared to other health events, the unpredictability of obstetric complications, and the wide variety of measures being tested necessitate the development of evaluation strategies that address the specific needs of the programs attempting to reduce maternal mortality.[1] Simply adopting the evaluation strategies used in family planning and child survival programs will be misleading and potentially counterproductive.

Our overall purpose in this article is to begin a discussion that we hope will culminate in a set of widely accepted strategies for the development of evaluation indicators for maternal mortality programs. The focus here is on the evaluation of interventions specifically designed to reduce maternal mortality. We will first discuss some of the reasons why final outcome measures cannot be relied upon for evaluation. We next summarize the model of the determinants of maternal mortality upon which the evaluation strategy is based. The evaluation strategy is then outlined. The fourth section provides examples of how this strategy can be used to evaluate program interventions, and summarizes the types of programs to which this approach is applicable. Finally, we discuss the implications of this strategy for program planning and research design, as well as for monitoring and evaluation.

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THE NEED FOR ALTERNATIVE MEASURES OF PROGRAM SUCCESS

The experience of other, more mature, international health initiatives (such as family planning and child survival) has clearly shown the value of process and outcome evaluation. The importance of process and outcome indicators for programs that attempt to reduce maternal mortality is even greater than for family planning and child survival programs. Even though maternal mortality is much more common in developing countries than in developed countries, it is still a much rarer event than either births or infant and child deaths. Therefore efforts to measure changes in maternal mortality over time are more time-consuming, more expensive, and more difficult than efforts to measure changes in birthrates or infant-child mortality.

Government vital registration systems are far from adequate in most developing countries. Population surveys of maternal mortality are expensive because of the large sample sizes required. Both vital registrations and population surveys undercount maternal deaths (Benedetti et al. 1985; World Health Organization 1987). Furthermore, unless the sample is very large, the numbers of death will be too small to provide estimates stable enough to measure trends over time.

Although demographic surveillance, the continuos monitoring of all demographic events, can provide reliable information on maternal mortality, the human and material inputs required are substantial and beyond the scope of most projects. Furthermore, given the small number of maternal deaths in a population, extremely large numbers of women must be followed. For instance, in the largest demographic surveillance effort, in the Matlab region of Bangladesh, where maternal mortality is fairly high (400 per 100,000 live births), 21,000 women of reproductive age were followed for 3 years. In that period only 40 maternal deaths were recorded. (Faveau et al. 1991). In less extensive efforts the numbers of deaths recorded will be too small to show whether program effort has made an impact.

During the last few years, important progress has been made in developing methods of providing indirect estimates of maternal mortality, such as the "sisterhood method" developed at the London School of Hygiene and Tropical Medicine. The "sisterhood method" uses data from household surveys in which adults are asked about their sisters (how many survived; how many died of pregnancy-related causes, etc.). The data are then used to construct indicators such as the maternal mortality rate and ratio. However, such methods will not be useful to evaluating most programs. For instance, the sisterhood method provides an estimate of mortality for a 10-to-12 year period (Graham, Brass, and Snow 1989). Therefore, if one used this method at the start of a project that began in 1991, it would provide an estimate of maternal mortality for 1981-90. Then one would have to wait at least 10 years to get an estimate of mortality after the program was implemented (i.e. 1991-2000). Although surveys using the sisterhood method are less expensive than traditional methods they can still be costly, even when carried out in conjunction with other research (by including questions regarding maternal deaths in surveys conducted for other purposes), because sample sizes must often be increased markedly.

Although it is realistic to expect further refinements of indirect methods in the coming years, at present most programs for the reduction of maternal mortality still need to rely on process measures, as gathering data on impact (that is, maternal mortality ratios[2] and rates) will not be feasible or cost-effective.

The evaluation strategy proposed here rests on the premise that it is possible to evaluate efforts to reduce maternal mortality without collecting the data needed to calculate maternal mortality ratio and rates. We do not deny that for certain purposes such data are necessary. However, we contend that for most projects it is neither feasible nor desirable to collect the data necessary to calculate these ratios and rates.

This statement is not as radical as it may sound at first. In the field of family planning, process indicators (number of contraceptives distributed, number of users, couple of years of protections, etc.) have long been considered valuable indicators of program success. The experience in the population field has been that research into fertility rates is not always necessary, nor is it advisable for the purpose of program evaluation. A similar situation is occurring with respect to child survival interventions, which are typically, evaluated through process indicators such as

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immunization coverage and use of oral rehydration solution. In these areas of research, process indicators are commonly used for evaluation purposes, although infant mortality and fertility are easier to measure than maternal mortality.

A MODEL OF THE DETERMINANTS OF MATERNAL MORTALITY

The evaluation strategy proposed here is based on an analytical framework of the determinants of maternal mortality published elsewhere (McCarthy and Maine 1992; see Figure 1). Only the key features of the model are summarized here, with emphasis on the implications of the model for evaluating interventions designed to reduce maternal mortality.

The first contribution of this model to program design and evaluation is to ensure that program planners and researchers recognize the full range of factors likely to influence maternal death. Second, we hope to encourage careful consideration of how any proposed interventions are likely to influence health and survival and of how other factors might intervene, either to help the intervention achieve its objective or to impede the process. Third, if one accepts the logic of the model, it is also clear that any intervention intended to prevent maternal deaths must ultimately operate to affect one of the three outcomes. Interventions must:

-reduce the likelihood that a woman will become pregnant; or
-reduce the likelihood that a pregnant woman will experience a serious complication of pregnancy or childbirth; or-reduce the likelihood of death among women who experience complications.

To evaluate the effectiveness of an intervention, it is first necessary to ask the question, "How is the intervention intended to affect the outcomes associated with maternal mortality?" An understanding of the process through which the project activity is hypothesized to prevent maternal deaths is vital to its evaluation.

THE EVALUATION STRATEGY

The evaluation strategy we propose includes four interrelated activities or stages in the development indicators with which to evaluate each intervention. An intervention here is a discrete project activity such as midwifery training or increasing knowledge of obstetric complications. The first stage of the evaluation process involves outlining a causal pathway through which the intervention is hypothesized to function. Because factors other than the intervention itself can have an effect on outcomes, the second stage consists of determining how each step in the pathway will be affected by external factors or other program components. Developing appropriate indicators for each step in the pathway and deciding what data sources to use for collecting the information on each indicator is the third stage. Although stage three is a routine component of evaluation, generally covered in evaluation texts, we have included it here for the sake of completeness. The fourth and final stage entails determining which combination of indicators will best provide a plausible assessment of the overall success of an intervention. At this stage it is also necessary to analyze which external factors need to be monitored in order to be able to ascertain and explain success or failure. Below we discuss each of the stages in this process in greater detail then provide three examples of how this process can be used to develop evaluation indicators for specific interventions.

STAGE 1: OUTLINE THE CASUAL PATHWAYS THROUGH WHICH AN INTERVENTION IS HYPOTHESIZED TO FUNCTION

The first stage in the process of developing evaluation indicators is to outline the causal pathway through which the intervention is hypothesized to function. As in the more general pathways in Figure 1, each step in the process that will lead to a reduction in pregnancies, complications, or deaths is identified.

This stage involves explicitly acknowledging the assumptions upon which the intervention rests. Program planners and evaluators need to assess whether the assumptions at each step are tenable. The causal pathways through which program interventions are hypothesized to work can be illustrated for virtually any intervention. However, the causal relationships being hypothesized are not equally plausible for all intervention strategies. For

instance, although a specific process can be illustrated for an intervention such as prenatal nutrition education, the evidence for a relationship between nutritional supplementation and reduction in complications, is not very strong, whereas the evidence for a relationship between an intervention such as improving quality of emergency obstetric care and reduction in maternal deaths is well established (Maine 1991).

The steps identified in the "causal pathway" should be supported by the best evidence available from existing studies and by knowledge of the area in which the intervention will take place. However, it is possible that in the course of implementing the intervention it is found that the pathway is wrong or that other variables must be added. The pathway should then be modified accordingly, and stages two through four repeated.

STAGE 2: DETERMINE HOW EACH STEP IN THE PATHWAY WILL BE AFFECTED BY OTHER FACTORS

Focusing on specific interventions and how they work does not reduce the need to consider the entire process that may affect maternal outcomes. As the model in Figure 1 illustrates, there are a number of social, economic, and behavioral factors that contribute to maternal mortality. It is important to consider the potential effects of factors external to the intervention being conducted, both for planning and for evaluation purposes.

The second stage of the evaluation strategy involves identifying which external factors or other intervention activities will affect the pathway and deterring which points in the pathway may be affected. For instance, one of the frequently proposed interventions for the SMI is improving the system of referring women to a place where they can receive treatment for obstetric complications. The success of this intervention could be influenced by a number of external factors, including the quality of care available, the availability of transport, and the distance to a referral center. These factors and their potential effects are analyzed at this second stage in the strategy.

It is important to examine how external factors will effect the indicators and what data can be collected to attempt to control for confounding variables. In most cases it will not be possible to control for all of the possible events or changes that could affect the success of the intervention.

In many cases it will be possible to use existing data from national-level studies. This is true whether one is using process measures or outcome indicators. Where the evaluation is being conducted in the context of operations research, good research design may improve the ability to control for the effects of external factors.

STAGE 3: DEVELOPING INDICATORS FOR EACH STEP IN THE CAUSAL PATHWAY

The third stage involves the development of indicators for each step in the pathway. The pathways illustrate what it is the program planners want to happen as a result of the intervention. At this stage in the strategy we develop indicators that assess whether each step actually occurs. Although in planning an evaluation the researchers would include all the process indicators related to whether the activities proposed actually take place (e.g., number of information sessions held, number of information sessions held, number of people trained, etc.), these have been omitted here for the sake of brevity and because their selection is generally more straightforward.

Selection of the appropriate indicators and methods must take into account many considerations, including availability and quality of data and resources to be expended. There may be a variety of potential data sources for each indicator; however, in the examples below we limit ourselves to some of the least costly data sources. For instance, in many cases information could undoubtedly be collected by active surveillance of the population of interest. However, this method is extremely expensive and should not be advocated for widespread use. This article does not detail all of the strengths and limitations of each data source, it merely provides examples of some of the appropriate and practical sources that could be used.

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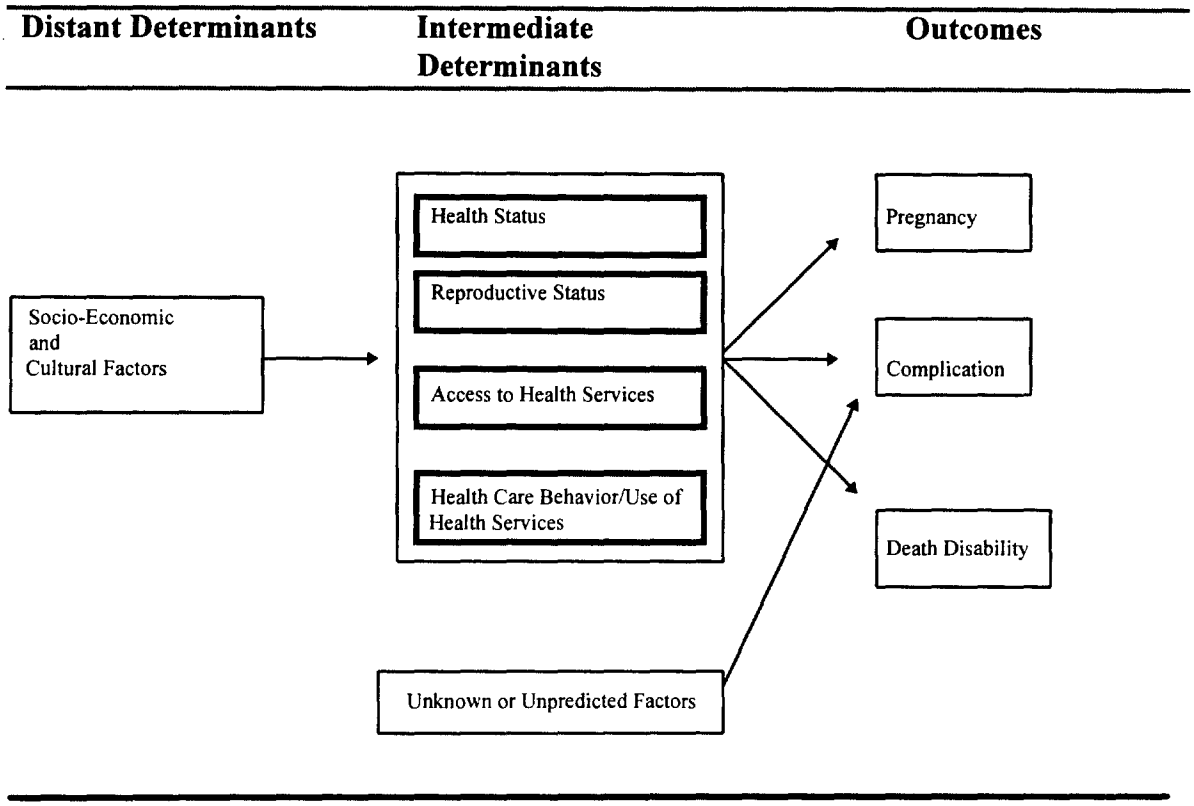

Figure 1: A Framework for Analyzing the Determinants of Maternal Mortality and Morbidity

STAGE 4: DECIDE ON THE MOST APPROPRIATE COMBINATION OF INDICATORS

No single process or outcome indicator can provide convincing evidence of the success of the intervention being evaluated, nor are we suggesting that they be used in isolation. Rather, we are suggesting that in order to ascertain whether the intervention has been successful, it is necessary to take a series of indicators into account. Thus, the final stage in the evaluation strategy is to determine which series of indicators relating to various steps in a pathway will provide the most logical, economical, and valid assessment of the effectiveness of the intervention. The validity of the assertions concerning the effectiveness of the program rests on choosing appropriate indicators. These must be indicators that, taken together, provide sufficient evidence to show that the intervention was useful.

EXAMPLES OF HOW THIS STRATEGY CAN BE USED TO EVALUATE SPECIFIC PROGRAM COMPONENTS

As discussed above, strategies to reduce maternal mortality must either prevent pregnancies, reduce the number of complications, or improve the outcome for women who experience complications. Below we illustrate how this evaluation strategy may be used by providing an example of one intervention to reduce the incidence of complications (the provision of safe abortion services). We then provide examples of two interventions designed to improve outcomes for women who experience complications (increasing knowledge of obstetric complications and improving quality of services).[3] Although an important strategy for reducing maternal mortality is to reduce the likelihood that a woman will become pregnant, we do not discuss the evaluation of family planning services here because a broad body of literature on the subject

already exists (Lapham and Simmons 1987; Seidman and Horn 1991).

EXAMPLE 1: REDUCE THE INCIDENCE OF COMPLICATIONS BY PROVIDING SAFE ABORTIONS (FIGURE 2)

Although the provision of safe abortions has not been one of the most frequently proposed interventions in the SMI, the causal relationship between complicated abortions and maternal deaths is well documented. Obstetric complications resulting from unsafe abortion practices are a major cause of maternal mortality in developing countries (World Health Organization 1991).[4]

Stage One. The mechanism through which the provision of safe abortion services is expected to reduce the incidence of complications is illustrated in Figure 2. This intervention would function by first increasing the availability of safe abortion services (step 1). This would increase the use of safe abortion services (step 2) and reduce the number of abortions conducted by untrained persons under aseptic conditions (step 3). A decline in the need for recourse to unsafe services would reduce the number of abortion-related complications (step 4). If we accept the logic of the framework in Figure 1, a reduction in the number of complications would result in a reduced number of deaths (step 5).

Stage Two. At this stage, we can identify external factors that may affect the intervention. For instance, there are several factors that could intervene between steps 1 and 2. Although availability may increase, accessibility may remain a problem; cost of services, distance from services, or social pressures might preclude their use. As shown below, these factors must also be monitored in order to determine if the intervention is successful and why.

Stage Three. This stage in the strategy involves developing indicators for each step in the causal pathway. The indicators for this first example are listed at the bottom of Figure 2. At the first step in the pathway, it is of interest to assess whether the availability of services has improved. The process indicator is simply "existence of safe abortion services." Health facility data regarding whether services are functioning (days of the week open, etc.) could be used.

At the second step in the pathway it is necessary to determine whether women are using the abortion services. This information could be easily obtained from the service statistics. Although it is likely that an increase in use of safe abortion services would lead to a reduction in unsafe abortions, it is not inevitable. It could be that the safe services are being used by women who would otherwise have carried their pregnancies to term. Thus, an external factor that could be assessed here is whether the women obtaining abortions had previously had unsafe abortions or would have used an unsafe practitioner had the improved services not been available.

Unfortunately, it is extremely difficult to obtain reliable information on the incidence of unsafe abortions (step 3). Nevertheless, if step 3 is successful it should necessarily lead to a reduction in complications (step 4). Thus we can assume that if step 4 occurred, then step 3 was successful.

At step 4 one would assess the reduction in abortion-related complications. Although ideally one would obtain information on the incidence of such complications in the population in practice this would not be feasible. Health service data are probably the only alternative, though they reflect only a small and unknown proportion of complications. If we use health service data it is necessary to know if anything other than program has affected the number of the complicated cases seen at the health services. Thus it would also be necessary to monitor other factors such as cost of treatment and quality of treatment services to determine whether they have remained constant.

Another factor of interest is whether knowledge of the availability of abortion services increases. Recent research suggests that in order to circumvent bureaucratic or legal obstacles, some women knowingly attempt abortions, then go to a health facility for treatment (World Health Organization 1991). This practice might increase if it were to become known that abortion services (and therefore treatment) were available, but the increase would not necessarily reflect a rise in the overall number of women obtaining unsafe abortions, merely an increase in the proportion who arrive at the health facility. As there would be less delay in seeking treatment, there might also be an improvement in the abortion-related case

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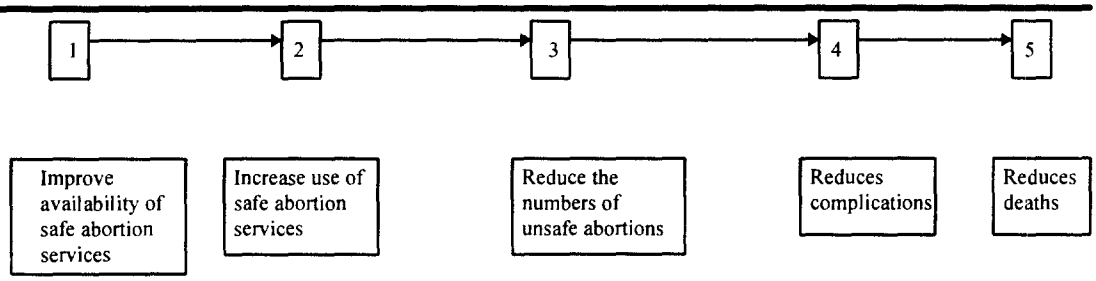
fatality rate, the outcome indicator at step 5.

Stage Four. The final stage in the evaluation strategy is to decide on the most appropriate *combination* of indicators. In this example the principal problem is that the data regarding a reduction in abortion-related complications is extremely difficult to obtain on a population basis and susceptible to bias in health facility data. Although we are advocating the use of this facility-based data, it should be used only in combination with the other indicators and careful monitoring of external factors, and it should be used to make only limited statements.

For instance, it would not be appropriate to rely solely on the process indicators at step 4, saying that abortion-related complications at the health facility declined and concluding that the intervention was successful. There are too many external factors that could have affected this statistic. However, it is somewhat more plausible to conclude that abortion-related deaths declined if safe abortions services were provided, use of these services increased, number of abortion-related case fatality rates did not change. This could be further substantiated if we can also say that costs, accessibility, and quality remained constant for both abortion and treatment services. It would become still more plausible if we could also say that that a proportion of the women using the safe abortion services report that they would have otherwise used (or had in the past used) an unsafe abortion practitioner.

As this example illustrates, none of these indicators taken alone would reflect the success of the intervention. However, by combining them and controlling for external factors, one can ascertain whether the intervention is successful with a reasonable degree of certainty



STEP	EVALUATION INDICATORS	DATA SOURCES
1	Existence of safe abortion services	Service statistics
2	Increases in numbers of women using safe abortion services	Health facility data
4	Reduction in number of abortion-related complications	Health facility data

Figure 2: Reduce the Incidence of Complications by Providing Safe Abortions

EXAMPLE 2: REDUCE DEATHS FROM COMPLICATIONS BY INCREASING KNOWLEDGE OF OBSTETRIC COMPLICATIONS AND DEMAND FOR SERVICES

Health information campaigns and health education activities designed to increase knowledge of obstetric complications and of where to obtain treatment are increasingly being proposed as a means of improving the use of health facilities and therefore of decreasing maternal mortality.

Stage One. The pathway through which this intervention is hypothesized to operate is illustrated in the top line of Figure 3. The first step in the process is to increase knowledge of obstetric complications and how treatment can be obtained (1). When a complication occurs, recognition of the complication and its seriousness should occur more rapidly (2). The pathway shows that this should lead to an earlier departure for a health facility (3). The fourth

step in the pathway is arrival at the emergency obstetric care facility and the final step is a reduction in maternal mortality.

Stage Two. A number of factors external to this specific intervention can affect the process at various steps. For instance, at step 4 the availability of transportation and distance to be traveled will affect the time between departure from home and arrival at the facility. Evaluation indicators at this step will reflect availability of transport as well as the success of this intervention in encouraging more timely arrival at the facility.

Stage Three. The evaluation questions, indicators, and potential data sources for this intervention are listed below the pathway. The first process indicator is the number of people reached by the community education activities. The information should be obtainable from program statistics.

Increased knowledge of obstetric complications (1) could be assessed through knowledge, attitude, and practice (KAP) surveys (both prior to and after interventions). These could be full-blown KAP surveys or mini surveys containing only a few key questions. Another option would be to explore knowledge and attitudes through focus groups initially and then conduct pre- and posttests of knowledge among the people who are exposed to the educational intervention. Although this method would not yield quantitative measurements of increase in knowledge among the general population, it could, at less expense, provide insight into whether the intervention is functioning and why (Ward, Bertrand, and Brown 1991).

Another issue is whether complications are being recognized earlier (step 2). One indicator of the time at which complications are recognized is the time from onset of a complication to its perception as a problem. Differentiating between when a complication actually began and when it was perceived as a problem is more difficult for some complications than for others. However, obtaining rough estimates (e.g., of time labor began) is possible (Martey, Dian, Twum, Browne, and Opoku 1991). Valuable information could be gleaned by interviewing women with complications, or their families. As this may not be feasible to do with a large sample, conducting case studies might be appropriate. This information could also be collected routinely from intake interviews conducted at the health facility

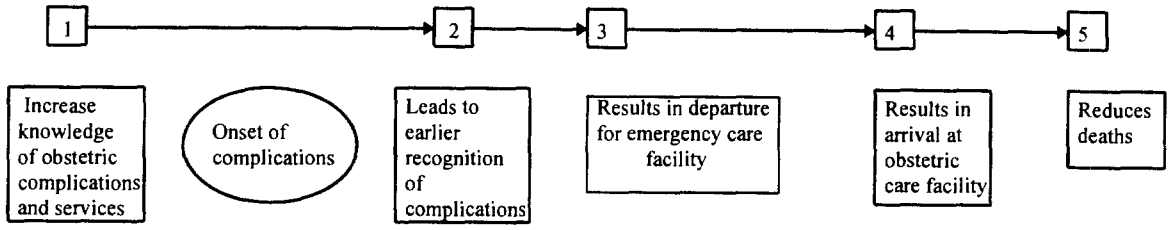
The next step in the pathway is departure for the health facility (3). This step will be affected less by the intervention than by such external factors as availability of transport and of fees for the hospital. It is also very difficult to distinguish between recognition and departure, thus, although external factors (e.g. availability of transport) should be monitored at this step, there are no indicators identified. It will not be possible to statistically control for such external factors. Rather, the project evaluators should ensure that ongoing monitoring data includes collection of information on the availability of transport and other potentially confounding factors.

The lack of indicators at step 3 is not a problem, as it is a prerequisite for the next step in the pathway, arrival at the health facility. The first indicator of interest at step 4 is whether the number of women arriving at the health facility with complications increases. In areas where hospital use for complicated cases is less than universal (most developing countries), the number of women arriving at health facilities should increase as a result of educational activities. This indicator can be best expressed as the proportion of expected complications for the area. A rough estimate of the expected number of complications can be calculated (population of area served X CBR X .15=expected complications).

The second indicator at step 4 is the time from onset of problem to arrival at health facility. This information can be obtained from intake interviews at the hospital or from case studies on a limited sample. An indirect measure of the time between onset of the condition and arrival at the facility is the women's condition on arrival at the health facility. If problems are being perceived sooner, women should arrive in better condition. This information can be obtained from health facility records. However, it should also be noted that there are a number of other factors related to the general environment or to other program components (e.g., transportation, seasonal variations in road conditions, etc.) that could also affect condition on arrival and should be monitored.

The final step, 5 is the last in the process leading to the final outcome (survival). One indicator at this point is the proportion of cases from the area where health information was provided that result in death (case fatality rate) at the hospital.

Stage Four Once again, we are not advocating the use of any single indicator such as condition on arrival or hospital case fatality rates. Rather, we suggest that by looking at a series of indicators it is possible to assert plausibly that the intervention was effective.



STEP	EVALUATION INDICATORS	DATA SOURCES
1	Number of people reached with information	Program statistics
1	Improved knowledge and attitudes of populations	Pre-and post-KAP surveys or min-surveys Focus groups and pre-and post-tests
2	Reduction in time from onset to perception of problem	Intake interviews Case studies
4	Increase in number of women who arrive at health facility	Health facility data
4	Reduction in time from onset of problem to arrival at health facility	Intake interviews
4	Proportion of expected complications arriving at facilities	Health facility data
4	Improved condition on arrival	Health facility data
4	Reduction in case fatality rate	Health facility data

Figure 3: Reduce Deaths from Complications by Increasing Knowledge of Obstetric Complications and Services Available

EXAMPLE 3: REDUCE DEATHS FROM COMPLICATIONS BY IMPROVING THE QUALITY OF EMERGENCY CARE (FIGURE 4)

Improving the quality of emergency care (care that "cures" the complication) can entail retraining or reallocating hospital staff, improving the availability of medical supplies, revising patient admission procedures, and various other activities. All are directed toward improvement of the quality of care provided to patients. Figure 4 shows the mechanism through which this intervention is hypothesized to function.

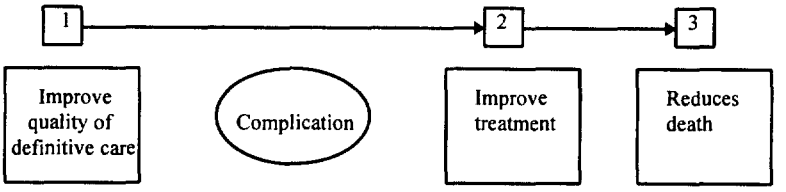
To develop a set of indicators for this intervention one follows the four stages in the strategy described above. (We will not repeat the discussion here.) The indicators developed in this manner are listed at the bottom of Figure 4. As can be seen in the figure, there are only three indicators for this intervention: quality of services, waiting time at the facility, and case fatality rates.

As this pathway subsumes a number of more specific activities, we have summarized the first indicators as "improvement in quality of services" This could reflect improvement in a variety of different things (e.g., staff performance, availability of essential supplies, etc.) At the second step in the process, an indicator that reflects whether the intervention is functioning is reduction in the time spent waiting for definitive emergency care. Research in several sites in West Africa has suggested that time from arrival to treatment (or death) is an appropriate proxy measure for general functioning of obstetric services (Prevention of Maternal Mortality Network 1992). This indicator reflects a number of factors that cause delays, including accessibility of staff, shortage of supplies or blood. and management problems. The final indicator, case fatality rate, should improve if the intervention is successful. For this intervention it is also necessary to monitor the number of women with complications coming to the hospital and their condition upon arrival.

We have included this example in summary form primarily to illustrate that the closer the intervention is to the final outcome (mortality), the fewer assumptions must be made. This is clear from a comparison of Figure 3 (which has 5 steps) and Figure 4 (which has only 3 steps). Similarly, the number of indicators and external factors that must be monitored are much fewer for the shorter pathway.

IMPLICATIONS FOR THE DESIGN AND EVALUATION OF PROGRAMS TO REDUCE MATERNAL MORTALITY

A wide range of interventions have the potential to reduce maternal mortality, and a variety of indicators can be used to measure success. Therefore program planners and researchers need to be



STEP	EVALUATION INDICATORS	DATA SOURCES
1	Improvement in availability of services	Inventory of essential services at health facilities
2	Reduction in time from arrival to definitive care at facility	Health facility data
3	Proportion of expected complications treated at facility	Health facility data
4	Reduction in case fatality rates	Health facility data

Figure 4: Reduce Deaths From Complications by Improving Quality of Emergency Care

especially careful in selecting both specific interventions and evaluation strategies. In this final section of the article we discuss some of the implications of adopting the evaluation strategy proposed here.

Explicitly outlining causal pathways can provide a greater understanding of the assumptions on which the program design is based. One of the implications of this is that interventions in which the causal relationship at each step are not plausible but well documented (e.g. improved emergency care leading to improved outcome for the patient) can be more safely evaluated with process measures. For instance, if one documents that more women with complications came to the hospital and that delays in reaching the hospital decreased at the same time that quality of care remained stable and hospital deaths declined, it is possible to assert that fewer women died of maternal complications. The same is not true for all interventions. The causal pathway for interventions directed at the more distant determinants of maternal mortality in Figure 1 (e.g. education or socioeconomic status) would be extremely long and complex. It would not be feasible to evaluate them in this way.

Outlining causal pathways and identifying how specific steps in the pathways are affected by external factors can clarify the relationship between interventions and external factors. However, this does not obviate the need for research designs that examine issues such as the relative effectiveness of separate interventions, potentially synergistic effects between program components, and the influence of external factors (economic, political, and social) on programs.

This article has discussed how evaluations can be conducted without maternal mortality ratios and rates. However, the strategy described here will also be useful for projects that do not intend to collect information on these statistics. Many of these projects will involve several interventions and it will be necessary to ascertain which program components are successful. This strategy can be used to select the appropriate process indicators necessary to determine how interventions work, as well as the relative influence of separate program components.

There would be some obvious advantages to using already accepted and more widely recognized measures such as population-based indicators. Assertions concerning program success would carry more weight if we could demonstrate declines in maternal mortality ratios and rates. In some places program administrators and policy-makers may have difficulty accepting process indicators as hallmarks of process success. They will have to carefully educated to understand both the need for alternative measures of success and the validity of the assumptions on which the selection of indicators rests. We recognize that this will be no easy task, but unless this takes place there will be continuing pressure to use largely incorrect estimates of maternal mortality and to conduct expensive and potentially futile research.

The material presented in this article is, we hope a "first generation" effort, one that will be followed by increasingly refined strategies and guidelines for the evaluation of programs to reduce maternal mortality.

NOTES

1. A maternal death is defined as the death of a woman while pregnant or within 42 days of

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termination of pregnancy, irrespective of the duration and the site of the pregnancy, from any cause related to or aggravated by pregnancy or its management, but not from accidental or incidental causes (ICD-9).

2. The maternal mortality ratio is the number of maternal deaths per 1000,00 live births. This is frequently called the maternal mortality "rate." but it is not a rate because the numerator (maternal deaths) is not included in the denominator (live births) and because there is no element of time. The true maternal mortality rate is the number of maternal deaths per 100,000 women of reproductive age (usually 15-49) per year. The maternal mortality ratio expresses the risk among women who have become pregnant. The maternal mortality expresses the effect of maternal mortality on the women in the population because it incorporates both the risk associated with pregnancy and the rate at which women in the population become pregnant (and are thus exposed to the risks).

3. The five major complications that lead to maternal death are hemorrhage, obstructed labor, infection, toxemia, and abortion-related complications. In this article we do not discuss how each intervention will reduce deaths from specific complications. Some, but not all, of the interventions used as examples express several of the major complications.

4. The provision of early treatment for abortion-related complications is another intervention that may reduce deaths from complications due to the abortion. That intervention is included under the category of improving treatment of complications..

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Summary

Background: *The main purpose of the Primary Health Care Management Advancement Programme (PHC MAP) is to help PHC management teams collect, process and analyze useful management information. The 9 MAP modules are: information needs, community needs, work planning, surveillance, monitoring indicators, service quality, management quality, cost analysis and sustainability.*
Review: *The chapter defines surveillance and reviews the characteristics of a good system, noting its applicability to assessing both health needs and program effectiveness. Surveillance includes quantitative counts and rates as well as qualitative investigations, such as verbal autopsy to learn likely causes of death. Four systems (routine reporting, sentinel reporting, surveys/special studies and case/outbreak investigations) are compared. Finally, the introduction orients the reader to using the remainder of the booklet to strengthen or design a surveillance system.*
Conclusions: *Surveillance of health outcomes, morbidity and/or mortality helps to identify risk groups, confirm current disease priorities, evaluate interventions' effectiveness and monitor trends to guide planning. Although surveillance systems are never perfect, well-designed systems provide PHC managers valuable data. [eds.]*

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SURVEILLANCE OF MORBIDITY AND MORTALITY*

PIERRE CLAQUIN, JACK REYNOLDS AND DAVID MARSH

What is surveillance?

Surveillance of morbidity and mortality is the collection and analysis of selected health and vital events to:

- identify, investigate, and control outbreaks or epidemics
- identify specific population groups at high-risk of illness and death from priority diseases
- confirm current priorities among disease control activities
- evaluate the impact of preventive and curative control activities on the incidence and prevalence of priority diseases in the community
- monitor disease trends so as to adjust plans to meet current needs

A more formal definition comes from the Centers for Disease Control (CDC), which defines epidemiological surveillance as "the ongoing and systematic collection, analysis and interpretation of health data in the process of describing and monitoring a health event. This information is used for planning, implementing, and evaluating public health interventions and programs. Surveillance data are used to both determine the **need** for public health action and to assess the **effectiveness** of programs.[1]

In the PHC MAP framework, morbidity and mortality surveillance data are used largely for monitoring and evaluation to determine whether the programme is having an **impact on health**. As such, it is an important tool that you can use

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to see if you are reaching your health goals. But surveillance data can also be used to assess health needs and to set health goals in planning. Whereas Module 2 concentrates on assessing health coverage, Module 4 is the one that concentrates on assessing health status.

In this module, surveillance is presented largely as a technique for monitoring and evaluating morbidity and mortality. And two levels of analysis are included. The first is **quantitative** surveillance of the **number of cases** of a given disease or death. The **second** is qualitative investigation of the **causes** of a disease or death.

	Morbidity	**Mortality**
Incidence	morbidity reports	mortality reports
Cause	case, outbreak investigation (diseases)	case, outbreak investigation (autopsies)

Managers need to have accurate information on the number of cases and the percentage of their target groups that are affected by a specific disease, and that are dying from specific diseases. They need this information to be able to evaluate the impact of their PHC strategy on health and to determine if core PHC services are effective.

Sometimes they also need to know what has caused a particular death or the outbreak of a particular disease. This information may be essential to make sure that the assumed causes are confirmed, and to adjust the programme to prevent such events from happening again.

Surveillance does not have to be complex to be useful. In fact, a common problem with many surveillance systems is that they are too complex and too large. By trying to collect comprehensive information on all diseases, there is little time left for analysis of the data and for taking action to reduce the number of cases of disease. For this reason, we strongly recommend that you collect only as much data as you can use and that you concentrate on the most important health problems.

Principles of Surveillance

The following list will give you an idea of what makes up a good surveillance system. According to CDC guidelines, an effective surveillance system:

- addresses health events which are of considerable public importance, i.e., cause a substantial amount of morbidity and/or mortality and are amenable to practical control or prevention;
- identifies and correctly classifies a large proportion of target health events;
- correctly reflects the distribution of events over time, place, and person;
- consists of components which include clear definitions of health events under surveillance, a clear and logical path for data flow, adequate knowledge of the population under surveillance and defined and appropriate methods for collection, analysis interpretation and feedback of information;
- gives rise to meaningful and effective public health action based on the data processed in the system;
- is uncomplicated;
- is adaptable and responsive to new demands;
- engenders a high level of participation;
- provides information rapidly enough to allow effective action to be taken;
- requires minimal resources appropriate to the circumstances.[2]

Surveillance systems are often national or regional in scope. They are designed to collect data on specific diseases, such as AIDS, for use in national policy-making. The systems we are suggesting in this module use the same methods, but are designed to be used at local levels, to help PHC managers monitor morbidity and mortality in their own programme area. As such,

they can reflect the health priorities and concerns of local communities.

An example

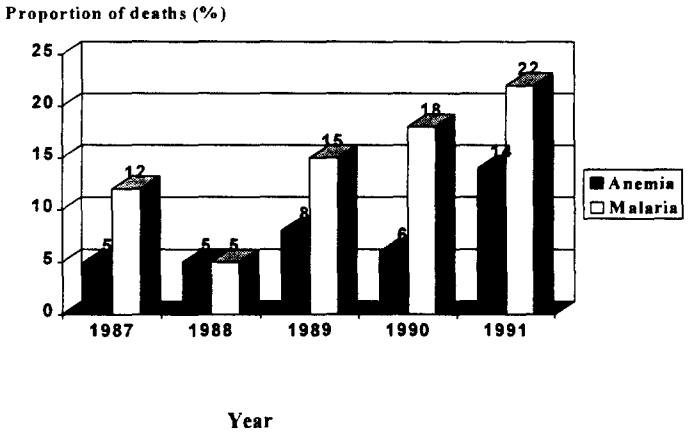
The University Medical Centre in Lome, Togo, has been monitoring data on paediatric deaths for nearly a decade. It is one of the few sites in Togo that has enough data to evaluate changes in infant mortality over time. Table 1 shows the ten leading causes of death among children less than five years of age in 1989. Malaria tops the list, accounting for one out of five deaths, followed by anaemia (13%) and malnutrition (12%).

This type of data has been collected every year since 1985. Figure 1 shows the data on malaria and anaemia deaths for the five-year period 1985-1989. The data clearly show an upward trend in the proportion of deaths due to these two diseases. The anaemia deaths, were associated with malaria.[3]

TABLE 1: Leading causes of death of children under age 5, Togo, 1989

Cause	No. deaths	Percentage
Malaria	199	22
Anaemia	117	13
Malnutrition	113	12
ALRI	85	9
Meningitis	66	7
Diarrhoeal diseases	58	6
Coma, NOS	42	5
Tetanus	20	2
FUO	19	2

Figure 1: Proportion of paediatric deaths from malaria and anaemia, Togo, 1985-1989



Limitations of Surveillance

Surveillance is a labour-intensive activity. It requires much effort to collect the needed data, especially if it is not already being collected as part of a routine recording and reporting system. Tabulation and analysis of the data is also time-consuming. For these reasons, most systems are limited to a few key indicators.

It can take several years of data collection before trends can be identified, particularly for diseases, such as dengue, that break out every five years or so. You may be able to use retrospective data

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to look at past trends, but this is often difficult. This is because the indicators you want may not have been collected, are slightly different than what you need, or are not reported consistently. It can be difficult to assess impact if your target population is small, or if you cannot set up control groups to compare disease patterns between programme and non-programme areas. You need a large population to compute rates, especially mortality rates, and it may be difficult to identify all of the deaths that occur in your area.

Reporting of surveillance data is often incomplete, especially from remote areas. Some programmes are fortunate to get 50% reporting, and even those reports may be incomplete or include errors which go undetected, if they are not checked carefully.

Despite these limitations, surveillance can be an important tool for PHC managers. It can help identify changes in diseases and injuries that require immediate action. And by investigating causation, a manager can often identify programmatic changes that could help prevent a problem from recurring.

Surveillance Methods

This module describes, and recommends, four surveillance methods. There are actually six principal methods, but two of them, vital registration systems and censuses, are not often feasible in developing countries. The six methods are summarized below.

Surveillance Methods	Description
Routine reporting systems	Information is routinely collected and reported by PHC staff
Sentinel reporting systems	A small number of reporting units (usually health centres or hospitals) carefully collect and report requested data
Surveys and special studies	Sample surveys are conducted periodically to estimate the level of a disease or condition in a given area
Case/outbreak investigations	Special investigations are undertaken to determine the cause of a disease or death and to recommend action to prevent its recurrence
Vital registration systems	Public and private health providers report births, deaths and other selected data to a central system
Census	A count of all of a population, often including questions about health habits, diseases, etc.

The first three of these methods are used largely to gather quantitative information about the incidence of diseases and deaths. The fourth is used to investigate the causes of diseases and deaths.

1. Routine reporting systems

In routine reporting, health staff, and sometimes, non-health people, collect information about the **number of cases** of reportable diseases and of selected deaths that occur in their area. Data are collected as a part of the routine screening and diagnosis process during home visits or during visits to health facilities, health centres and hospitals. Thus, the reports are based on direct contacts with the individual who is sick, dying, or has died. In some cases the information is provided second-hand from a relative, often the mother, friend or neighbour.

Routine data is usually recorded in family or individual folders and then transferred to summary tally sheets for reporting of the aggregated data. At the end of each month the information is compiled and sent to a supervisor for further compiling and analysis.

Most routine reporting revolves around health centres and hospitals. They obtain information from staff within the facility and from reports prepared by CHW's and other outreach workers. In some cases, community members help collect data from households.

Advantages. Routine systems have the advantage of taking data from an ongoing system. Thus, they are inexpensive and efficient ways to collect information. A new system, with additional staff to operate it, does not have to be set up. The data cover all health activities from routine well-baby clinics to surgery. The

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recording and reporting systems have been standardised, which means that the same type of data is collected, and the same reporting periods are used. This is a great advantage for making comparisons among areas.

Disadvantages. These systems almost always provide an incomplete picture of the total number of cases that occur. Some of the reasons for incomplete reporting are:

- Not all cases come to the health facility for treatment. Some people go to private providers for treatment, others to facilities outside the area, still others do not seek treatment at all. Distance, transportation costs, hours of operation, loss of income, cultural taboos, and many other reasons tend to limit the use of health facilities.

- Not all cases are identified by outreach workers. CHW's may visit a household only once every 3-6 months, and are likely to miss many cases that are not picked up by the health facilities. When they do visit, they may neglect to ask about health problems that happened months ago, and the mother may not consider them important enough to report on.

- Some diseases, such as neonatal tetanus, are more commonly treated at hospitals than health centres, and therefore go undetected by the health centre and CHW.

- Complete and accurate reporting are always a problem in PHC. Some CHW's are illiterate, others concentrate on the most pressing concerns; some nurses and doctors skip over some items because they are too busy, they don't believe the item is important, or they didn't ask. Even when reporting is fairly regular and complete, there may be inconsistencies among health workers if they don't use the same procedures, definitions and guidelines.

Nevertheless, routine reporting is the most common method used in surveillance. And because it is so inexpensive, it is likely to be attractive to many PHC managers.

2. Sentinel reporting systems

In sentinel systems, a small number of health units in a programme area is selected to report cases of diseases and deaths that are seen and diagnosed at their facility. They may also be asked to report additional information, such as the age and immunization status of the children treated at the facility. Staff at sentinel sites are given special training and supervision to ensure that reporting is complete and accurate.

The sites chosen are not necessarily chosen because they are representative of a given area. They may be chosen because they are likely to see cases of certain diseases, or because their caseload are high enough that rare events are likely to be identified. Other criteria that are important are reliability of data collection, timeliness of reporting, willingness of the staff to participate, high-quality laboratory or diagnostic capabilities.

Hospitals are often included as sentinel sites, since they are likely to have much higher caseloads than health centres, they are more likely to see serious diseases, infant and maternal deaths are more likely to occur there, and they are more likely to have staff trained in diagnosis and data processing.

Advantages. Sentinel sites may provide a more consistent picture of illness in a given area than routine reporting. Data collected from these sites may also show whether routine reporting is accurate or not. In addition, being chosen to participate in surveillance tends to motivate the staff to do the best they can to report accurately and on time.

Disadvantages. A major disadvantage of sentinel systems is that they are not representative of the entire population at risk. The data they generate may not be sufficient volume to generate rates and ratios, which are important for assessing changes in health status. Another disadvantage is that populations served by the sentinel facility may change, making the study of trends invalid.

Nevertheless, the sentinel system has a major advantage in the quality of the data produced. They are also relatively inexpensive to set up and operate, especially in contrast to a

"universal" system where all potential facilities would be required to report.

3. Surveys and special studies

Sample surveys, such as those described in Module 2, are often used for surveillance. They usually provide a broad estimate of the incidence or prevalence of a disease. They can also be used to estimate mortality rates, although the sample sizes required to do this are very large. Surveys can also be used to evaluate the reliability of the routine or sentinel systems. For example, a morbidity and mortality survey in a high-risk, underserved population may be a more accurate and practical method for measuring disease patterns that tend not to be seen at health facilities.

The surveys usually have to be repeated periodically, at least annually, to develop trend data. Although this can be expensive, the rapid surveys described in Module 2 are an affordable option. They also relieve the health staff of the burden of continual reporting.

4. Case and outbreak investigations

These investigations are attempts to identify the causes of a death or disease. They are not alternatives to routine and sentinel systems, but are used as the next step in epidemiological investigation. In general, a "case" investigation is an investigation of a **single case** of a disease or death; an "outbreak" investigation is an investigation of **many cases.** However, when the occurrence of a particular disease is very low, polio for example, even one case can be considered an "outbreak."

Purposes. The usual purposes of these investigations are to:

- confirm diagnoses and determine the causes (main/leading and associated)
- confirm the existence of an outbreak (an increase in the number of expected cases/deaths)
- identify the most appropriate control measures
- identify where and to whom to apply these measures
- determine why the outbreak occurred
- determine what can be done to prevent similar outbreaks in the future

These investigations are conducted systematically, usually following a written protocol and a logical cause-effect chain of events to identify the underlying cause of the problem. An example of a protocol for a neonatal tetanus investigation is found in Appendix C.

Advantages. These investigations have a programmatic as well as medical objective. They can identify errors that should be corrected (e.g., using contaminated needles) and procedures that could be changed to prevent problems from occurring the first place (e.g. increase home visits to monitor high-risk infants). The investigations can provide staff with a chance to learn more about the conditions and causes of diseases and deaths. They can use this information to improve internal procedures, and also to help community members understand what they can do to prevent unnecessary health problems.

Verbal autopsy. A special technique for case investigations of deaths, the "verbal autopsy," is featured in this module. A PHC health worker, who needs to be trained in the technique, conducts an in-depth investigation of the death through interviews with the mother and anyone else who was a witness to the death and the circumstances leading up to it. See Appendix E.1 for the instrument that is used.

The decision to conduct a case/outbreak investigation may be triggered by a standard protocol, such as investigate every case of polio, neonatal tetanus, and hepatitis; or, investigate every neonatal and maternal death. In many cases the decision may depend on the circumstances. If a strange or unexpected event occurs, this might be enough reason to investigate it, especially if it could be a threat to health.

In summary, each of these methods has its advantages and limitations. You may want to try a combination of systems, relying on your existing reporting system for as much data as is

reasonable, setting up a small sentinel system to continuously gather additional data on a few important health problems, and adding mortality and morbidity questions to an annual community survey to assess changes in health needs as well as coverage.

Also, don't expect too much of your surveillance system. Surveillance usually monitors outcome data-impacts and effects. A good system might identify changes in outcomes, but it will not necessarily explain what caused the changes. You may need to use other modules in the PHC MAP series to look more closely at programme inputs, processes, and immediate outputs to find the cause of the problem — or of a success.

How to use this module

Who and when
This module is designed to provide PHC managers, whether working in government or private organizations, with simple and inexpensive tools for setting up and operating a local surveillance system.

PHC managers are not likely to design or operate the system themselves. Staff with a background in planning, evaluation, MIS, as well as epidemiology and any similar discipline, can easily learn how to use the tools in this module to set up a system.

PHC consultants, especially those who are interested in data for decision-making, should also find the module helpful.

How the module is organized

The module can be easily adapted to meet local needs. The procedures that are described in the next section are general and flexible. The programmes that already have a surveillance system will find that the module can help them simplify their system. Those who do not have a system already should find that they can start small, designing a highly focused system of a few indicators at first, and expanding it later if it proves to be worthwhile.

This User's guide has two main sections, in addition to the Introduction and Quick Start. Procedures (or steps) come next, describing a simple, but systematic process you can go through to determine the kind of surveillance you need and how to set up a system that meets your needs. The appendices contain useful guidelines, worksheets, and tools that you can use in designing your surveillance system.

There is a computer file that comes with this guide that includes a number of "templates" in *Lotus 1-2-3* and *Quattro Pro*, or pre-designed tables that you can use to tabulate your data. Each template includes pre-designed graphs that you can display just by pressing one or more keys on your computer's keyboard.
A Facilitator's guide has also been developed to help you set up a workload to train staff to use the module.

How to Begin

If you haven't tried the Quick start section, you may want to do so, just to see how easy it is to set up a simple, but useful surveillance system. Then go the next section and read through the Procedures. This should give you a better idea of what a surveillance system involves and the kind of system you want for your programme.

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[1] Guidelines for evaluation surveillance systems. CDC Morbidity and monitoring weekly report supplement. Vol. 37, No. S-5, May 6, 1988

[2] Ibid

[3] Vernon, A. *Cause of death from hospital date in developing countries: A review based on the CCCD experience with hospital-based mortality surveillance systems in Sub-Sarahan Aftica.* Draft discussion paper, 9 May, 1992.

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Summary

***Background**: Complete community enrollment facilitates: community empowerment to recognize and respond to its health needs, equitable distribution of health services, and reliable epidemiological data. A less costly alternative may be to keep a sentinel "sub-community" under rigorous surveillance and to use a minimal health information system elsewhere. This might be limited to identifying all pregnancies through bi-annual home visits and tracking their outcomes. In either system, reliable data and analyses are needed. Save the Children has found the following tools useful.*

***Review**: Data quality can be increased by the following: (1) Enrollment Validation Surveys measure the completeness and accuracy of official enrollment and the characteristics of non-enrolled vs. enrolled families. (questionnaire attached); (2) Lot Quality Assurance Sampling is an efficient method to assess community health workers' performance in maintaining up to date health records (questionnaire attached); (3) Expected Vital Events Tables can provide rough projections against which observations can be compared; (4) Pregnancy-Birth Linkages can identify under-reported pregnancies, live births, or stillbirths and, (5) Home Record-CHW Roster-Clinic Record Cross Checks can highlight out-of-date home held records.*

Data interpretation can be likewise improved. "How to evaluate infant mortality rates generated in a health information system" is an instructive example which stresses the skills of recognizing when summary indicators are likely to be invalid, comparing reported with expected vital events, and evaluating causes of under-reporting of births and deaths and the misclassification of neonatal deaths.

***Conclusions**: Health information systems provide information for decision making. Whether large or small, they need continual supervision and support to allow valid responses. [eds.]*

MANAGEMENT TOOLS FOR IMPROVING THE QUALITY OF HEALTH INFORMATION IN SYSTEMS BASED ON FULL ENROLLMENT AND SENTINEL SURVEILLANCE

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August 9, 1993

Save the Children has built into many of its primary health care programs a population based health information system which requires complete enrollment of all community residents and periodic updating of health data for targeted populations (e.g., women of reproductive age and children younger than five years). The rationale of such full enrollment systems is 1) to enable community residents to assess and address their own health needs; 2) to promote protective health behaviors and use of preventive health services in an equitable way (i.e., in a way which ensures that no segment of the population will be "left out"); and 3) to collect reliable epidemiological data. Thus, activities which are necessarily entailed in such a system are 1) training community residents to analyze and interpret health data; 2) enumerating the entire population and periodically monitoring targeted groups; and 3) assuring the quality of data collected.

As Save the Children and other PVOs are beginning to realize, however, the amount of supervision required to maintain the quality of health data may be considerable and costly. Moreover, the unpaid volunteers who are usually trained to collect

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data may not be able to visit homes as frequently as planned. As PVOs move towards coverage of larger populations in their programs, the wisdom of instituting community-based systems capable of generating epidemiologically sound data for the entire population becomes more and more questionable.

A logical alternative is the demarcation of a portion of the program area as a sentinel surveillance area: in this limited area, health data will continue to be gathered with enough rigor to allow valid epidemiologic analysis of longitudinal trends. In the rest of the program area, a scaled-down version of the population-based HIS may be maintained: this "streamlined" HIS may continue to have as its objectives the equitable promotion of preventive health care and the empowerment of community residents--but NOT the collection of data for use in longitudinal epidemiologic studies. One version of such a streamlined HIS would require a complete community census at the start of the project (to allow for planning of services), and then bi-annual identification of all pregnant women in the community and follow up of birth outcomes. By focusing on pregnant women, the system could support three important health activities: promotion of prenatal care (including tetanus immunization); provision of information about safe delivery and options in case of complications; and (as birth outcomes were followed in subsequent bi-annual visits) promotion of appropriate early child care (e.g., exclusive breast feeding, immunizations).

In any system designed to generate data which are epidemiologically useful--whether based on enrollment of the entire program population or of a sentinel population--it is obviously important that data collected be of high quality. Save the Children has found the following supervisory tools useful for ensuring data quality. We conclude with a detailed example illustrating the use of selected tools to solve a problem: "an unbelievable IMR."

1. Periodic surveys to determine whether a significant proportion of families might not have been registered in the system. Health, Population and Nutrition Unit, Save the Children

Within the territory of each community health worker, the program supervisor randomly visits some households. At each household, the head-of-household or mother is asked whether his/her family has ever been enrolled and is shown the enrollment form which an outreach worker would have used during the registration interview; some very simple socioeconomic data about the family (e.g., ethnicity, rough estimate of income) are also noted at this time. The family's report about its enrollment status is compared to the CHWs' records, and the proportion of unregistered families is noted. The collection of simple socioeconomic data at the time of the survey allows the supervisor to determine whether certain groups (e.g., new in-migrants, the very poor) have been selectively omitted. An example of the type of "enrollment questionnaire" which Save the Children has used in the field is given in Appendix 1.

2. Lot Quality Assurance (LQA) techniques to determine whether data collected by individual community health workers are acceptable.

LQA is a technique for stratified random sampling which was originally developed by industry and which has been adapted to assess the quality of health care interventions.(1,2) Save the Children has found the method to be rapid, efficient and easily learned.

When Save the Children used this technique to assess the quality of data in its HIS, it defined "lots" as the health records for all the households covered by each CHW. Random samples were drawn from each lot, with the size of the sample determined by the proportion of data which had to be correctly entered on each record (compared to the actual home situation) in order for that record to be considered "acceptable" (in our case, 85%) and by the answers to two questions: a) Do you think there is a large difference in the proportion of UTD records between CHWs? (yes) and b) Do you wish to focus your efforts on finding the CHWs who need help? (yes)

A standard table has been developed to facilitate determination of sample size once the answers to these three questions are known; it is included in the article by Wolff and Black. This table also determines how many of the selected items in each sample must be "acceptable" if we are to be satisfied with the lot: in our case, it indicated the minimum number of sampled records which each CHW had to have correct (or at least 85% correct) in order to be considered as performing adequately.

Finally, we visited the designated number of randomly selected households in each CHW's territory and used a questionnaire to assess the quality of information for each household. (This questionnaire is included as Appendix 2.) We were then able to identify those CHWs who were not performing adequately and offer further supervision.

3. Tables showing vital event rates (e.g., crude birth rate and IMR) which can be expected in small areas based on national rates

Under-reporting of vital events is often a problem. Even though great fluctuation can normally be expected in rates reported for small areas at different points in time, we think that supervisors should inform CHWs of the numbers of births or deaths which would be expected in their communities if national rates prevailed; usually the areas in which PVOs work are the most disadvantaged of national regions, so the actual numbers of births and deaths are likely to exceed numbers based on national rates. For example, given:

(1) 1991 national crude birth rate: 33 births per 1000 people,

(2) 1991 infant mortality rate: 90 infant deaths per 1000 live births, and

(3) a total impact area population of 14,000 divided into 3 villages, then

a "small area supervisor's table" could be:

Expected Vital Events Over One Year (or 6 Months)

a Village	b Pop'n	c Live Births = (b)(33/1000)	d Infant Deaths = (c)(90/1000)
1	3000	99 (50)	9 (4-5)
2	5000	165 (83)	15 (7-8)
3	6000	198 (99)	18 (9)
total	*14000*	*462 (231)*	*42 (21)*

4. Periodic comparison of birth reports and pregnancy registers

Live births are frequently under-counted. One reason for this is the CHW's tendency to classify an infant who dies very shortly after birth as a stillbirth; (sometimes, however, the opposite occurs and the CHW will classify a stillbirth as a death of a liveborn infant). The definition and correct reporting of stillbirths should be clarified for CHWs. Periodic comparison of numbers of reported births (live and still) to numbers of pregnancies may help determine whether or not pregnancies are under-reported.

5. Periodic comparison of home-held records to CHW rosters and clinic records

Home-held records include children's immunization and growth cards and, in some programs, records of what CHWs have taught families (e.g., records of ORT training) and maternal health cards. Such records act as learning aids for families but can also assist supervisors: supervisors should verify whether information on home records is consistent with CHW rosters.

Case: "An Unbelievable IMR"

It is early 1990. After managing a child survival program which has included promotion of tetanus immunization and breast feeding and the establishment of an HIS, a Health Program Coordinator wants to determine whether there has been an improvement in infant mortality in his impact area. He finds to his dismay that the 1986 Baseline Survey did not report infant deaths and was conducted on a sample of residents who were not representative of the general population. Instead, he decides to compare the 1989 infant mortality rate generated by his impact area's HIS to the national rate published in Unicef's 1991 *State of the World's Children*. He expects that even after two years of health interventions, his project's rate will still be higher than the national rate. His impact area is very poor and started out with health indices which were much worse than those elsewhere in the country.

He finds that there were 290 births in 1989 and 14 deaths among infants under age one year, yielding an infant mortality rate of 48 deaths per 1000 live births (= 14/290 x 1000). He is shocked to see that his rate is much lower than Unicef's national rate, 73 deaths per 1000 live births. Based on the recorded number of births in his area, if the national infant death rate had prevailed, he would have seen 21 infant deaths in 1989 (= 21/290 x 1000).

Since he doubts that his Child Survival interventions could have made this great a change in such a short time, he begins to suspect that something might be going awry in the Health Information System. What could cause an Infant Mortality Rate to be falsely low? The denominator--the number of births--could be falsely HIGH. More obviously, the numerator--the number of infant deaths--could be falsely LOW. Or both! The Health Program Coordinator decides to do a little more investigation.

Using information collected on the family enrollment cards, he determines the midyear 1989 population in his impact area: 16,500. Based on the number of live births recorded in his area in 1989 (290), the crude birth rate would be 18 births per 1000 population (= 290/16500 x 1000). The Health Coordinator is appalled to see that this is far lower

than the national crude birth rate, 28 births per 1000 population. He knows that family planning has not yet won much acceptance in his area. If national crude birth rates had prevailed in the area, he would have seen 462 births in 1989 (28/1000 x 16500).

It appears, therefore, that births were under-reported in his impact area last year. This falsely low number of births should have artificially driven UP the infant mortality rate in his area. Our Health Program Coordinator might not have been so surprised by this under-reporting of births if he had constructed a population pyramid based on the numbers of individuals recorded in the family enrollment: he would then have seen that the proportion of under-one year olds (1%) was much lower than the 3-5% expected. (It is important to bear in mind when calculating crude birth and death rates that such relatively small errors in the denominator--the general population--will not affect the rates nearly so much as errors in the numerator--numbers of births and deaths.)

The Coordinator would also have noticed something wrong if he had compared the number of pregnancies recorded in his impact area's pregnancy register against the number of live births: he would have seen that the number of pregnancies greatly exceeded the number of births (though the number of pregnancies was still not high enough to yield the number of live births that could be expected--another case of under-reporting).

It is clear to the Coordinator that in the face of a falsely low infant mortality rate, this under-reporting of births suggests an even greater under-reporting of infant deaths. With an expected number of live births equal to 462, he would have expected to see 34 infant deaths (34/462 x 1000 = 74) if national rates had prevailed in his area, 2.5 times what was reported.

He begins to investigate possible reasons for such under-reporting at the community level. To his chagrin, he discovers that community health workers are NOT doing home visits every three months, as they were originally instructed. Moreover, when they do visit a home where an infant death has occurred, they feel uncomfortable inquiring and recording information about it; they also tend not to inquire about the status and outcome of pregnancies. In the process of perusing the pregnancy register, our health program coordinator notes a startling fact: 10% of the pregnancies are reported as ending in stillbirths. This seemed unusually high. He asks some community health workers how they define stillbirth and learns that they include infants who die very shortly after birth in this category: the failure to include these liveborn infants in the calculation of infant death rates leads to a false lowering of the rate.

The Health Program Coordinator begins to develop a plan of action for addressing this problem. This includes:

1. explaining to village health workers that home visits are the bedrock of our HIS: without reliable information on vital events and health status and practices among members of a household, Save the Children (and the community) will have no way of knowing whether or not anyone has benefited from health interventions;

2. developing an on-going system for feeding back information on community health status to those who collect the raw data--thereby allowing them to assess the completeness of their data collection as well as the success of interventions;

3. improving the ability of community health workers to inquire about and record information on infant death and pregnancy;

4. clarifying the definition of stillbirth and emphasizing that stillbirths should not be included in the calculation of infant and neonatal mortality rates, but that infants who are liveborn and die shortly after birth certainly ARE included in the calculation of these rates;

5. ensuring that the pregnancy register is kept up-to-date and includes a column for recording the outcomes of all pregnancies--miscarriages, abortions and stillbirths as well as live births;

6. instituting quality assurance checks on HIS data using Lot Quality Assessment techniques; periodic comparison of birth and pregnancy registers; and periodic surveys to check household enrollment.

The Health Coordinator develops following tool to help CHW supervisors based on national rates of expected numbers of births and deaths. He knows that much year-to-year fluctuation may be observed in infant mortality rates for small populations. Nevertheless, he decides that such small area rates can guide supervisors in assessing the completeness of vital event reporting.

The total impact area population of 16,500 is divided between 5 communities as shown below. The 1989 national crude birth rate is 28 births per 1000 people, and the 1989 infant mortality rate is 73

infant deaths per 1000 live births.

Expected Vital Events: 5 Communities

#	Pop'n	*12 month period* Births	Infant Deaths	*6 month period* Births	Infant Deaths
1	3300	92	7	46	3-4
2	3600	101	7	51	3-4
3	3000	84	6	42	3
4	2000	56	4	28	2
5	4600	129	9	65	4-5
ttl	*16500*	*462*	*33*	*232*	*15-18*

The Health Program Coordinator is concerned not only about the completeness of recording vital events but also about the quality of information about those events. He realizes that the calculation of neonatal mortality rates requires knowledge of the AGE at death and that recognition of the most important causes of infant mortality requires specification of cause of death. Consequently, he sets aside part of the general death registry to be a special infant death registry: he instructs community health workers that the age of infants who die before their first birthday should be recorded in days if they are younger than one month and otherwise in months.

He also instructs them to record information about cause of death: with help from some people with medical training, he develops a list of symptoms that community health workers can use to elicit from parents various common causes of death; he also instructs community health worker supervisors to visit homes where infant or child deaths have occurred to verify the cause of death given by parents and compare this cause to that recorded by local authorities (if such registries are available). For special studies on cause of death, he seeks advice on constructing verbal autopsy questionnaires.

The results of his investigation make the Health Program Coordinator realize that the Health Information System is not something that can be initiated and then left to run on its own: it requires constant maintenance, best delivered in the form of information validation and feedback.

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Appendix 1

QUESTIONNAIRE TO DETERMINE ENROLLMENT STATUS

name of person interviewed: _____

area:_____ village:_____ house no._____

name of interviewer:_____ date of interview:_____

1. IS THE FAMILY ENROLLED? yes____ no____

2. IF NOT: A. WHEN DID THE FAMILY COME INTO THE IMPACT AREA? date:____

B. SOCIOECONOMIC STATUS

latrine yes____ no____

housing walls
poles and mud____
mud____
sun-dried bricks____
burnt bricks_____

possessions
cattle____
radio____
bicycle____
motorbike____

source of income
farming____
seasonal labor____
other____

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Appendix 2

QUESTIONNAIRE TO ASSESS QUALITY OF HEALTH RECORD

*CHILD'S NAME*_____ *ID NO:*_____

*NAME OF PERSON INTERVIEWED*_____

*AREA:*_____ *VILLAGE:*_____ *HOUSE NO.*_____

*NAME OF INTERVIEWER:*_____ *DATE:*_____

1) IS THE FAMILY STILL THERE? *YES*____ *NO*____

2a) ARE ALL THE CHILDREN U5 LIVING AT PRESENT IN THE HOUSEHOLD RECORDED ON THE ROSTER? *YES*____ *NO*____

b) NUMBER OF BIRTHS SINCE ESTABLISHMENT OF ROSTER: _____
NUMBER OF BIRTHS NOT RECORDED ON ROSTER: _____
DATE THE UNRECORDED BIRTH TOOK PLACE _____

c) NUMBER OF IN-MIGRATIONS OF CHILDREN U5 SINCE ESTABLISHMENT OF ROSTER _____
NUMBER OF IN-MIGRATIONS NOT RECORDED ON ROSTER _____
DATE THE UNRECORDED IN-MIGRATION TOOK PLACE _____

3a) *ARE THERE ANY U5 CHILDREN RECORDED FOR THAT HOUSEHOLD IN OUR ROSTER THAT, IN FACT, ARE NOT THERE?*
*YES*____ *NO*____

b) *NUMBER OF U5 DEATHS RECORDED ON ROSTER* _____
NUMBER OF U5 DEATHS NOT RECORDED ON ROSTER _____
DATE THE UNRECORDED EVENT TOOK PLACE: _____

c) *NUMBER OF U5 OUTMIGRATIONS RECORDED ON ROSTER* _____
NUMBER OF U5 OUTMIGRATIONS NOT RECORDED ON ROSTER _____
DATE THE UNRECORDED EVENT TOOK PLACE: _____

4) FOR THE CHILD SELECTED FROM YOUR LIST, CHECK THE FOLLOWING:

a) IMMUNIZATIONS

DOES THE CHILD HAVE AN IMMUNIZATION CARD? *YES*____ *NO*___

ARE ALL THE IMMUNIZATIONS RECORDED ON THE CARD ALSO RECORDED ON THE ROSTER? *YES*____ *NO*___

IF NOT RECORDED ON ROSTER, DATE EVENT OCCURRED: _____

ARE ALL THE IMMUNIZATIONS RECORDED ON THE ROSTER ALSO RECORDED ON THE CARD? *YES*____ *NO*___

b) PARENT TRAINED IN ORT

WAS THE PARENT TRAINED IN ORT? *YES*____ *NO*___

DOES THE ROSTER SHOW THAT PARENT WAS TRAINED IN ORT? *YES*____ *NO*___

IF NOT RECORDED ON ROSTER, DATE EVENT OCCURRED: _____

DOES THE PARENT'S RESPONSE AGREE WITH THE ROSTER? *YES*____ *NO*___

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USING LOT QUALITY ASSESSMENT TECHNIQUES TO EVALUATE QUALITY OF DATA IN A COMMUNITY-BASED HEALTH INFORMATION SYSTEM

LOREN GALVAO, M.D., M.P.H. AND KATHERINE KAYE, M.D., M.P.H.

Summary

We report here on the application of Lot Quality Assessment (LQA) techniques by managers of a Save the Children Child Survival project in Mbalachanda, Malawi to evaluate data contained in a community-based health information system. By defining "lots" as the health records for all household with children under 5 years old which were listed on the rosters of village health promoters supervised by a given community health supervisor, and by establishing criteria for "acceptability" of samples drawn from these lots, we were able to identify and offer additional supervision to health workers (supervisors as well as village health promoters) who were not performing adequately. As *LQA sampling procedures require that only a small sample be drawn from each lot, the assessment could be conducted easily and quickly. Health workers were found to have the greatest need for help in updating demographic data and information about home-based oral rehydration therapy (ORT) training sessions, and the least for help in recording children's immunization status. We conclude that LQA can be a useful supervisory tool for health program managers.*

Introduction

LQA, a technique for stratified random sampling originally developed by industry, has been adapted in the health care field to evaluate the quality of health care interventions.[1 2] Unlike other techniques for rapid evaluation (e.g., cluster sampling techniques), LQA's main usefulness is not for evaluating coverage but rather for quickly determining where problems lie and identifying workers who need further supervision.

Save the Children (SC)/US has implemented community-based, integrated rural development projects in Malawi since 1983. In the area of Mbalachanda, the agency has since 1986 operated a USAID-funded Child Survival Project. Currently, this program covers a population of approximately 28 100. Primary health care activities are planned and implemented using data from a population-based health information system (HIS). The HIS requires complete enrollment of all community residents and periodic updating by Village Health Promoters (VHPs) of health data for the targeted population (children younger than five years): as data in rosters maintained by VHPs are used for service delivery, programme evaluation and epidemiologic studies, it is important that they be of high quality. VHPs are supervised by Community Health Supervisors (CHSs); on average, one CHS supervises six to eight VHPs.

In Mbalachanda, LQA was used to determine whether or not VHP rosters were up-to-date and accurate, and to identify VHPs and CHSs needing further supervision. This pilot test allowed us to learn whether LQA might be a useful supervisory tool for health programme managers in other primary care programs.

Methods

This assessment took place in March of 1992. A one-day "trainer of trainers" session was conducted for the Mbalachanda Health Program Manager and the Health Program Supervisor; they were trained in each step of the LQA technique by a public health coordinator/physician from Save the Children's U.S. office. CHSs conducted the household interviews: their 1-day training session, which included pretesting of the questionnaire, was conducted at Mbalachanda programme area. The evaluation team spent 2 days in the villages: approximately 80 % of this time was spent on the LQA; the remainder was devoted to a survey designed to assess the completeness of family enrollment.

Definition of "Lots"

In the LQA method, small samples or "lots" are judged acceptable or unacceptable according to previously set criteria. In Mbalachanda, lots were defined as the health records for all households with children younger than 5 years which were listed on the rosters of VHPs under the supervision of a given CHS. These records are listed in VHP rosters. Thus, the 14 lots sampled here consisted of the VHP rosters which fell under the

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supervision of each of 14 CHSs.

Sampling Procedure

A random sample was drawn from each lot, with the size of the sample determined by the answers to three questions: 1) what proportion of data on each record had to be correctly entered in order for that record to be considered 'acceptable'? (we selected 85%); 2) did we think there was a large difference in the proportion of up-to-date records between CHSs? (yes); and 3) did we wish to focus our efforts on finding CHWs who needed help? (yes).

A standardized table has been developed to facilitate determination of sample size once the answers to these three questions are known: in our case, 19 records were drawn from each of the 14 lots.

The standardized table is also used to determine how many of the selected items in each sample must be acceptable if we are to be satisfied with the lot: in our case, it indicated that the minimum number of sampled records which each CHS had to have correct (or at least 85% correct) in order to be considered as performing adequately was 17.

Assessment of Data "Acceptability"

Each interviewer visited 19 households selected randomly from the rosters in each CHS's territory and used a questionnaire to assess the quality of data recorded for each household. Questions were designed to ascertain the following: whether the family was still present; whether all children younger than 5 years who lived in the household were in fact recorded on the VHP roster; whether there had been any unrecorded births, deaths and/or in- or out-migrations; whether information on the children's immunization card matched that recorded in the roster; and whether information given by the parents about training in ORT agreed with that recorded in the roster.

Family Enrollment Survey

Because the rosters of the VHPs provided the sampling frame, the LQA could not be used to evaluate the completeness of family enrollment. Although the questionnaire used to ascertain data acceptability inquired whether a family listed on the roster was still present, it could not be used to determine whether a household was missing from the VHP roster.

A special survey was therefore designed to determine the proportion of families living in the program area who had not been enumerated during enrollment: the evaluation team checked whether families living in the 10 houses to the right of the nineteenth household visited for the LQA were listed on enrollment forms.

Analysis

Because of overseas travel time constraints, the results of the LQA were hand-tabulated at SC Headquarters. Results from LQAs subsequently conducted at other field offices have quickly and easily been tabulated in the field. Data about each of the three questionnaire topics (demographics, immunization and ORT training) were analyzed separately.

Results

Fifty per cent of CHSs had 85% or more of the demographic data in their rosters correctly updated. Thirteen out of 14 CHSs (93%) had 85% or more of the immunization data in their rosters correctly updated. Only five out of 14 CSHs (36%) had acceptably updated information about ORT training. Of the 149 households surveyed for family enrollment, 143 (96%) were enrolled.

Those CHSs who had fewer than 17 acceptable records for any of the three topics have received additional supervision, as have their VHPs. A repeat LQA will determine whether improvement in the skills of gathering data and maintaining records has been sustained.

The ease with which Mbalachanda health staff learned and implemented LQA techniques suggests that these techniques can serve as supervisory tools for management and health personnel in non-government agencies as well as in ministries of health and local health departments.(1)

In another instance where LQA was used to assess quality of health system information (1), census maps rather than health worker rosters provided the sampling frame: use of such maps obviates the need for a survey to check household enrollment status.

Although LQA is a sensitive test for poor performance, it is not very specific.[3] Programme managers must consider whether costs of providing increased supervision to health workers who in fact may *not* be performing so poorly outweigh the benefits. In our case, where the health information system was critical to achievement of objectives set in a Child Survival Programme, investment in increased supervision was warranted. Costs of supervision may be minimized if instruments used to evaluate worker performance yield information which will allow supervision to be focused on specific tasks.

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Other Health Information Systems: Facility- and Service-Based

Throughout this volume, we have defended community-based health information systems. Our determined endorsement of this approach stems from both the desirability of health services and supporting information systems that target defined populations and the limitations of information systems that are not population-based. The objectives of this chapter are two-fold, each illustrated with domestic and international examples. First we demonstrate the short-comings of facility-based programs and information systems. Second, despite these limitations, we present examples of certain situations suited to either a facility-based or service-based approach.

Perils of Facility-Based Information

In this volume's first paper[1], Fredericksen referred to his early experience in India demonstrating the "centripetal" nature of facility-based data. That is, utilization dropped off steeply with increasing distance from the health center. Not only is facility attendance incomplete, but also those who attend are often systematically different from those who do not. Kloos[2] studied facility utilization in Ethiopia. He noted that transportation was often far more expensive than treatment and that the resulting "distance decay" varied by health condition: steepest for diarrhea, most gradual for venereal disease and suspected tuberculosis. The latter diseases include those which have potential social stigmata, run indolent courses, are curable, usually require accessing the health system for cure, and affect adults.
An accompanying paper[3] underscores a new dimension to the danger of relying on management targets and facility-based information to draw conclusions about the health of populations. Lever[3] cross-checked an "Asian facility's" antenatal care coverage indicator of 70% by performing a community survey. He found that the real coverage was 20% and that no one who lived further than 1.5 kilometers from the health center attended it. He hypothesized that management by targets produced a "collusion between the supervisor and the supervisee...and discouraged any questioning of the accuracy of the records." He used five measures (availability, accessibility, utilization, adequate utilization, and effective utilization) to precisely evaluate coverage. While utilization (percent of "pregnant women who actually used the antenatal service at least once") was only 20%, the adequate utilization (percent of "pregnant women who attended for antenatal care at least the desired number of three times") was only 1%, and the effective utilization (percent of adequate utilization with good quality of care) was 0%!

Visaria et al[4] noted a similar phenomenon in Gujarat, India (1989-90) when they compared estimates of contraceptive prevalence based on family planning program service statistics and an independent survey of a random sample of married women in reproductive ages. Re-surveys of a sample of identified acceptors of contraception in 24 villages revealed that the use of modern contraceptive methods was much lower than indicated by service statistics. Depending upon the village, 15-39% of recorded acceptors were, in fact, known non-acceptors. The authors concluded that this discrepancy arose due to government pressure to promote reversible methods of contraception. The authors uncovered at least part of a likely explanation for why the reported rise in the practice of family planning in India had not been matched by a fall in the birth rate.

In both this and the preceding example, the desire to appear to meet program objectives probably explained the difference in findings between probability surveys and factitious service series. Certainly data falsification is not unique to facility-based information systems. However, data tampering may be more likely when the data collection is concentrated in the hands of fewer, mid- to high-level individuals (who are themselves judged by these numbers) rather than the more numerous grass-roots workers typical of community-based systems.

The limitations of facility-based data are not confined to developing settings. For over twenty years school-based health clinics in St. Paul (Minnesota), USA were believed to reduce adolescent pregnancy and birth rates. Due to the reported success of this program, there was a rapid growth of school-based clinics nation-

wide. However, Kirby et al[5] questioned the validity of the findings observing three limitations: 1) comparisons over time were based on a single baseline year and not upon multiple baseline years; (2) birth estimates were based only on those students continually attending school; (3) the reported birthrate figures were not tested for statistical significance. In response, the authors confidentially matched the names of female students from school records with mothers' names on Department of Health birth records to calculate birthrates for each of the high schools with clinics between the 1971 and 1986. The results showed that birthrates fluctuated dramatically from one year to next, and that school-wide birthrates were not significantly lower in the years immediately following the opening of a clinic than in the years preceding it. Thus facility- and population-based rates differ. While the former has a role answering questions about individuals attending a facility, the more interesting and important questions involve the larger population from which the attendees come. These questions need population-based data.

From these examples one sees that facility-based health information systems risk dramatically incomplete and inaccurate coverage. They lack information about those geographically or otherwise inaccessible. Put another way, the profile of attendees is unrepresentative of any community, except the attendees. Finally, facility-based data may be more vulnerable to corruption.

Roles for Facility-Based Information

Having cautioned about the pitfalls of center-based information, we wish to acknowledge and, indeed, support the notion that facility-based information systems and services are, indeed, appropriate for certain questions in certain settings, as the following examples demonstrate.

The Navajo Area Indian Health Service, a branch of the United States Public Health Service, has an extensive, computerized, facility-based "Resource and Patient Management System" to track individuals' clinical, demographic, and service payment parameters (Timothy Fleming, personal communication, 1995). This Indian Reservation is a large (approximately 200,000 people on 65,000 km^2), sparsely populated defined area served by out-patient clinics and primary and secondary in-patient facilities each linked to the information system. Here a facility-based system is defensible for several reasons: (1) the sparse population renders household level information extremely expensive; (2) the population enrolled actually exceeds the total Reservation population; (3) the "facility" is a network of more than 20 busy facilities sharing a common data base; and (4) transportation is readily available. Note, however, that even these conditions do not assure complete coverage.

In the developing world, facility-based information also suffices in certain instances. Consider several examples from Pakistan. The first example concerns a very local problem in the Tharparkar Desert of eastern Sindh Province. Here snake-bite is a threat recognized by the public and the health system. People who are bitten know that life-saving anti-venin is available at the Islamkot Basic Health Unit. Moreover, this life-threatening condition runs a slow enough course to allow even the remote victims to reach care. Facility-based snake-bite statistics, thus, probably closely represent the population's experience.

The second case concerns control of tuberculosis (TB), a major public health threat. Pakistan has Provincial TB control officers, clinics and sanitoria which adhere to the World Health Organization's strategy for TB control: case holding and treating until cured those *presenting* with TB, rather than mass *screening* for case detection. The reasoning is sound. Patients ill with TB will access the health system where multi-drug short-course chemotherapy can cure most, thereby protecting them and the public. On the other hand, population-based mass screening will be infrequent enough to miss many cases; moreover, those so identified will be less likely to adhere to rigorous treatment (unless on directly observed therapy) protocols and more likely to become resistant carriers since they did not "feel sick" in the first place. Thus, although facility-based information will be limited to those accessing the health system, this is the targeted group. Here facility-based services and information for disease control of a national problem are justified on epidemiological grounds.

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The third example involves burns in Karachi, Pakistan's largest city (estimated population: 10,000,000). Marsh et al[6] reviewed the experience of the city's two burn units which, by law, must admit all cases. Even allowing for patients who died in transit, those who reached burn units and died there accounted for an annual cause-specific mortality of 10/100,000, 35 times the rate of Japan, for example. They observed that even massive thermal injury was consistent with a 24-48 hour survival in the absence of associated injury, such as smoke inhalation. In each of these 3 situations, minimal levels of serious health problems could be assessed through facility-based information since: (a) the health system had life-saving treatment to offer, (b) the natural history of the condition allowed enough time to access it, and (c) only a few, recognized facilities in the health system were able to provide care.

A fourth report[7] from Pakistan illustrates another legitimate use of facility-based data. The authors conducted round-the-clock surveillance at Karachi's largest government casualty ward to describe the characteristics of road traffic accidents and to assess official statistics which were felt to be unusually favorable by developing world standards. Road traffic accident victims, as in the case of burns, must also be brought to government facilities for medico-legal investigation for possible wrong-doing. We found that the official police statistics from this facility during the same 21 day surveillance included only 34% of the cases we logged. The official statistics were incorrect. So, facility-based data are ideally suited to answer a facility-based question, such as how accurate are hospital-based police statistics. Interestingly, although we used a facility-based inquiry to assess a facility-based information system, the findings were relevant to a much larger community.

Facility-based information proved foundational for the surveillance experience of the Africa Child Survival Initiative Combating Childhood Communicable Diseases (ACSI-CCCD).[8] Universal, sentinel, or single site surveillance targeted three major areas: morbidity and mortality, quality of care, and overall child mortality. Some of the lessons learned bear repeating as they are also pertinent to community-based health information systems: (a) "surveillance systems are likely to be sustained only where they provide data that are useful for the planning and management of programs ('data for decision-making');" (b) "efforts are needed to assure the quality of data" (i.e., case definitions, simplification, and supervision); and (c) "there is a clear need for increased use of data at the local level." Note that these reports from 13 African countries deal with describing and tracking the health of large populations. Their purpose was not to track individuals. Facility-based data can provide valuable estimates of population parameters, but they are incomplete guides to providing services to defined populations. Such studies do serve equity only indirectly in that they describe levels, trends, and risk groups for ill health. Directly achieving equity, however, requires universal coverage that only a community-based information system can provide. Facility-based statistics, of course, are perfectly suited to describing facility-based questions and parameters.

Service-Based Health Information

Facilities are structures, like hospitals or clinics; on the other hand, services are activities, like family planning or immunizations. There is considerable, but incomplete, overlap as services can target populations, those attending a facility, or both. Not surprisingly, "inputs" such as logistics and supervision, and "processes" such as quality of care provided to beneficiaries, feature prominently in service-based information systems since these programs cannot directly measure changes in population outcome, such as health status, knowledge, and practice, without supplemental studies as we have shown above.

The first example, also from the ACSI-CCCD experience, is a hybrid examining several services at given facilities. Bryce et al's[9] "facility-based assessment" (FBA) assessed the quality of child survival services, including vaccination; treatment of diarrhea, fever, or respiratory infection; and prenatal care. In 13 African countries, samples of health facilities, stratified by training history, type and location, were generally obtained. FBA involved: direct observation of clinical encounters, interviews with health personnel, checklists for assessing facilities and supplies and reviews of clinical records. The data obtained identified training

needs and logistic problems. Remaining challenges included simplifying the approach, perhaps through the lot quality assurance method and regularizing such review.

Askew et al[10] examined family planning services in Burkina Faso in response to the Ministry of Health's commitment to expand and improve the program. They performed a situation analysis to assess the program's "sub-systems" (logistics, equipment, record keeping, IEC and services provided) as well as quality of care. They assessed all 21 urban public clinics and all clinics (n=32) from a random sample of 10 of 28 rural provinces. using inventories of equipment and services, clinical encounter observations, and interviews. The findings guided operational improvements, standards of practice and a five-year family planning plan.

A domestic example of the applicability of service-based health information comes from the initiative, "All Kids Count." Based on the rationale that immunizations protect the health of individuals and the public, in 1991 the Robert Wood Johnson Foundation initiated support for a series of demonstration projects throughout the US.[11] These sought to establish community-level immunization tracking systems to improve and sustain immunization coverage for preschool children. The US state of Arkansas, while not one of the "All Kids Count" projects, has developed a monitoring system linking immunizations administered at public clinics (85-90% of total) with birth certificates (personal communication, 1995). At the local level, reminder postcards supplied by the state, are sent to parents of incompletely immunized children. Because (1) immunizations are required for public school entry (and the vast majority of American children attend public schools) and (2) often immunizations are provided by public clinics, service-based (school and/or clinic-based) coverage statistics closely approximate population coverage.

Service-based health information is often facility-based since this is where services are concentrated. Yet they need not be. For example, the quality of care of community-based family planning distributors or community health workers' growth monitoring skills are service-based parameters which are also community-based. Service-based statistics adequately describe services, but they suffer from the same limitations of facility-based statistics in accurately describing defined populations unless they are also community-based.

* * *

Health information systems are as varied as the health systems they support. Each has important limitations and specific indications (Table). Client information from facilities or services that are not community-based is unrepresentative of the larger population. Moreover, services cannot be provided to those who do not present because their identity is unknown. On the other hand, certain health events are amenable to valid measurement from facilities. Fundamentally, however, equity in health, particularly for less mobile dependents, such as women and children, is best achieved through a community-based system.

Table. Health Information Systems: Limitations and Indications

	Facility-Based	Service-Based	Community-Based
Limitations	Incomplete population data Biased population data Vulnerable to fraud?	Same as facility-based (if services are facility-based)	Cost
Indications	Approximates population data for certain serious, treatable conditions Facility performance	Closely approximates population data for certain readily available, especially mandated interventions (i.e., immunizations) when linked to population data Service performance	Serves equity (universal coverage & care according to need) Guides care for defined populations

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MANAGEMENT BY TARGETS: IS COVERAGE AN ADEQUATE MEASURE FOR HEALTH CARE?

PETER LEVER*

Summary

Health service coverage is usually expressed as the proportion of the target population in need of a service that has actually used the service, but the quality of care that the user receives is rarely taken into account. A case study is presented in which an antenatal care service that apparently had a good level of coverage was shown not to perform well in reality. Firstly, the data on which the coverage figures had been calculated were proved to be false and secondly, the quality of the service was below acceptable levels. Some of the reasons for this situation are identified and possible solutions are discussed, including a revision of the rigid target system, improvements in training and community participation and an increase in resources.

Antenatal care coverage

Antenatal care is considered to be an important part of the work of health workers, particularly in rural areas in developing countries. The aim is to maintain and improve the health of the mother and the fetus, so that both arrive at labour in a good state of health (Chamberlain 1978). This is especially important in the poorer countries where maternal mortality is high. About 500,000 women die each year from causes related to pregnancy, and almost 99% of these deaths occur in the developing world (Herz and Measham 1987).

Antenatal care is seen as a way to reduce such high levels of maternal morbidity and mortality. As it is difficult to measure the quality and impact of antenatal care, the achievement of the service is commonly expressed as coverage, calculated as follows:

$$\frac{\text{Number of first antenatal contacts}}{\text{Number of expected births}} \times 100$$

(WHO 1981).

If this antenatal care coverage is high, many health service managers will be satisfied and believe that the service for which they are responsible is performing well. However, a service that is performing well on paper may not reflect the reality. Two additional aspects have to be taken into account when reviewing coverage data:

- Are the coverage data true?
- What is the quality of the service provided?

The following case study demonstrates that a service which appeared to be performing well was not doing so in reality. Possible reasons for this failure are discussed.

A case study from Asia

In an Asian country a small study was carried out to investigate the antenatal care coverage of a rural health centre that provided health care for a population of about 5000 in three villages. The study included an analysis of the case registers in the health centre and a house-to-house survey in the three villages.

All women who had delivered a baby in the 12 months preceding the study were interviewed on their utilization of antenatal care, and the services that they had received. The data obtained from the register were cross-checked with those obtained from the household survey.

Five measures of coverage were used in the analysis (adapted from Tanahashi 1978):

1. *Availability coverage*: determined by the number of pregnant women that the service could cope with, based on the availability of personnel and the time that the clinic gave to antenatal care.

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2. *Accessibility coverage*: based on the number of pregnant women who could reach the service, as determined by distance.

3. *Utilization coverage*: based on the number of pregnant women who actually used the antenatal service at least once.

4. *Adequate utilization coverage*: based on the number of pregnant women who attended for antenatal care at least the desired number of three times.

5. *Effective utilization coverage*: based on the number of pregnant women who, in addition to 4 above, received a good quality of antenatal care.

In total, 138 women who had been pregnant during the preceding study were identified and interviewed. Questions were asked about the frequency of their visits to the antenatal clinic, about vaccinations with the tetanus toxoid, about clinical examinations and about hemoglobin and urine examinations.

The household data were cross-checked with those in the antenatal care registers at the health centre, where it was found that 97 women were registered but only 27 women who had been for antenatal care were identified by the household survey. By following up a random sample from the register it was found that most of the register data were incorrect and/or false.

The performance of the two female staff was evaluated using an adapted checklist and by observation (Kumar et al. 1981). The service was provided weekly in the health centre, and monthly in an out-station in one of the villages. Staffing of the centre was adequate, and the availability coverage was calculated as 73%. For accessibility coverage for antenatal care, based on the distance a pregnant woman had to go to reach the service, it was found that all the women who had actually used the service lived within a distance of 1.5 km of the centre or its outstation, and that 57% of the population lived within this distance. The utilization coverage was calculated as 20% (the women who came at least once), the adequate utilization coverage as 1% (the women who came at least three times), and the estimate for effective coverage (the women who received a good quality of antenatal care as well) was 0%. Even though the findings based on a small sample that quantity and quality of antenatal care was obviously very far from acceptable.

Why was the coverage falsely reported?

How is it possible that a service which seems to be well organized and performing well on paper does so badly in reality? An antenatal care service was available in terms of personnel and health facilities, and was accessible within 1.5 km for 57% of the local population. The health centre reports stated that over 70% of the pregnant women had attended the clinic at least once for antenatal care. When such statistics are viewed from the district or higher administrative levels, the situation appears satisfactory and may even show an improvement over previous years. However, the register data must have been wrong. Why?

The management of health care in this particular country depends heavily on the use of 'targets', which are explicit objectives that are used to evaluate the performance of the health care system. They should, therefore, provide a useful management tool. Targets are set at national level and the next lower tier is assigned a 'share' of the total national target. This process continues, through the successive levels of government, until at district level the health managers assign targets to each health centre. Achieving these targets becomes the prime concern of health workers and their managers and those who do so are more likely to be promoted.

The health centre targets seem to be achievable since it appears that staff would have sufficient time to attend to the majority of antenatal cases. However, only a minority of pregnant women see any value in antenatal care, and even they are dissatisfied with the quality of the available services. In these circumstances, the targets cannot be achieved and so false entries are made in the registers. There are strong reasons why these false records should be accepted by the supervisors at the district level. If they were challenged by the supervisors they would not be able to meet their own targets and this, in turn, would cause difficulties for them. Management by targets, therefore, encourages collusion between the supervisor and the supervisee (at

whatever level in the system), and discourages any questioning of the accuracy of the records.

Why was the quality of antenatal care so poor?

Whilst the pressure from the use of targets gives a partial explanation of why coverage was overestimated, the use of targets does not explain why the quality of care was so poor. There were no time constraints on the staff, but there was a lack of equipment: because of this deficit, staff could not weigh the pregnant women or examine their blood or urine. However, even when there were plentiful supplies of needles and syringes, for example, the nurses chose the use the same needle repeatedly and did not use aseptic techniques.

Did the nurses know how to conduct proper antenatal examinations? One of them had recently completed a six-month course which would have qualified her to become a supervisor, and so it seems possible that the training was inadequate in achieving the necessary motivation. However, an important factor contributing to the poor quality of care could have been the low expectations of the health service personnel by the local people whom they served. The ethos within the health service did not regard the quality of care received by the client to be a high priority — especially compared with the overriding importance of targets. At the same time, the society as a whole did not appear to expect quality from government health services. Whilst it can be argued that these situations do not constitute positive support for poor quality, they do amount to an absence of factors that stimulate high quality.

What can be done to improve the situation?

It is clear that there were many reasons why the registers were false and why the quality of care was poor, which means that no single solution is likely to bring about radical change. It may help if the basic training is improved, but this is unlikely to lead to any major improvements by itself. Another possibility would be to improve motivation through better in-service training. However, this would be useless if it is only focused on the acquisition of skills, since there is no evidence that the staff lacked the necessary sills but rather that they did not put them into practice. Both managers and health centre staff would have to explore what they really want to achieve, and identify the problems that would have to be overcome. The danger is that such training might revert to a discussion of the existing targets, which have been shown to be so misleading and unhelpful.

More radically, the system for setting the targets should be reviewed and decentralized. A district could be allowed to set its own targets in close consultation with the health workers who will have to realize these targets. Only in such a way can the target system be expected to be useful and of assistance to the managers of the health service. Evaluative mechanisms would still be necessary to check the value of coverage data sent in by the health workers.

The study revealed that the community was not involved at all in the planning of services, which is by no means exceptional in antenatal care. Health centre management or village health committees might be expected to monitor the coverage and quality of health care. Such a committee should be able to exert some control over the health centre and its staff and over-reporting of activities would probably be discovered and not tolerated.

Many countries are using coverage figures (especially antenatal coverage) to show how their primary health services have improved over the last few years. While coverage can be a useful indicator, health workers must retain enough independence to ask two questions:

- are the coverage rates accurate?
- what is the quality of the care given?

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Biography

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Summary

The Africa Child Survival Initiative Combatting Childhood Communicable Diseases relied heavily on facility-based epidemiologic surveillance of targeted diseases (EPI preventable diseases, diarrhea, and malaria). The monograph discusses the role of surveillance in health information systems; its attributes (simplicity, flexibility, acceptability, sensitivity, predictive value positive, representativeness, and timeliness); management issues (equipment, costs, personnel); classification (case definitions, clinical Vs. laboratory confirmation, primary Vs. secondary cause of death); quantification (coverage, complete and timely reporting, estimating denominators); the role of computers; and the relative advantages of 3 types of surveillance (universal, sentinel, and single site). Single site surveillance (i.e., malaria surveillance at Mama Yemo Hospital, Kinshasa, Zaire) was often the best source of consistent data for preceding years. Sentinel hospital surveillance (i.e., pediatric admissions and death in 5 hospitals in Liberia) using Epi Info rapidly provided information useful to program and facility managers. Universal surveillance (i.e., hospital admission and death reporting in Togo) sought 8 variables for each admission at 30 hospitals; although the 646 deaths among 22,821 admissions captured only an estimated 10% of total mortality, the coverage was geographically extensive and the data were consistent with information from special studies. Key lessons learned included: the critical importance (but incompleteness) of epidemiologic surveillance, the need for investment and support, strategies to enhance data quality, and the need for data-based decisions especially at the local level. [eds.]

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THE ASCI-CCCD EXPERIENCE WITH ROUTINE EPIDEMIOLOGIC SURVEILLANCE: A REVIEW BASED ON IMPLEMENTATION EXPERIENCE WITH 13 AFRICAN COUNTRIES

BURUNDI, CAR, CONGO, COTE D'IVOIRE, GUINEA, LESOTHO, LIBERIA, MALAWI, NIGERIA, RWANDA, SWAZILAND, TOGO, ZAIRE

COMPILED FROM ACSI-CCCD PROJECT RECORDS BY ANDREW VERNON, MD, MHS
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EXECUTIVE SUMMARY

This document reviews the experience of the CCCD project with routine epidemiologic surveillance in 13 Sub-Saharan African countries, from 1981 until 1993. Historical aspects of epidemiologic surveillance in Sub-Saharan Africa are briefly reviewed. Key attributes and issues confronting surveillance systems are discussed. The three types of facility-based reporting systems (single site [SS],sentinel [S], and universal [U]) are described. The structure of the CCCD approach to surveillance within the context of development of overall health information systems is presented.

Examples are cited from the CCCD experience to illustrate surveillance efforts in all three types of facility-based systems. These include:

-malaria surveillance in central hospitals in Lome and Kinshasa [SS]
-poliomyelitis surveillance in Kinshasa [SS]
-mortality surveillance in the central morgue in Kinshasa [SS]
-surveillance of diarrhea case management in Zaire, Malawi, and Swaziland [S]

-national sentinel surveillance in Zaire [S]
-sentinel surveillance of measles in Kinshasa [S]
-sentinel hospital surveillance in Liberia [S]
-antimalarial sensitivity surveillance in Guinea, Nigeria, Togo, and Zaire [S]
-preceding birth technique mortality surveillance in large maternities (S)
-universal ambulatory and hospital reporting in Togo (U)
-experience with multiple interlocking systems in Nigeria and Burundi (U)

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B. Types of Health Information Needed.

In relation to CCCD objectives and targets, a variety of sources and means of gathering data were obvious objects for surveillance activities. The use of traditional facility-based morbidity and mortality data were readily engaged by project staff and consultants. More challenging were the needs to monitor the quality of care provided in facilities as well as the overall child mortality. The information needs in these two domains were generally met by special surveys, rather than by routine epidemiologic surveillance. Strategies to obtain quality-of-care data on a routine basis were successfully implemented briefly in Rwanda, as part of a national health-worker supervision project. The issue of quality of care remains challenging even in the setting of developed nations. To respond to the need for data on quality of case management and prevention services in the CCCD project, one particular methodology — the facility — based assessment-was added to those already in place.[27] To date, this has been a special survey activity rather than a part of "routine" surveillance; efforts are underway to standardize many aspects of the method and to promulgate its use in support of several specific World Health Organization programs, such as those addressing diarrheal and respiratory diseases (CDR) and AIDS (GPA).
The need for reliable mortality data in Sub-Saharan Africa remains a challenge for the decade of the 1990's. Few, if any, countries of Sub-Saharan Africa were able to establish valid and reliable systems of vital registration during the 1980's.[28] The paucity of reliable information on levels of infant and child mortality in Sub-Saharan Africa will continue to pose difficulties for programs in child survival.

One item of service delivery (or "process") information was gathered by all CCCD countries with as much or greater care than was given to the gathering of routine surveillance data — records of numbers of vaccinations administered. Administrative data on vaccinations administered was adopted in most, but not all, CCCD countries as the standard basis for estimation of vaccination coverage; a few countries continued to rely upon special coverage surveys for this purpose. Extensive discussion of coverage measurement is provided by another document in this series, and it is thus not considered in detail here.[29] However, the link between vaccination coverage data and EPI morbidity data was more than theoretical: in many CCCD countries, childhood vaccines were available only through the CCCD project, and often the vaccine depots required receipt of vaccination and surveillance reports before the next lot of vaccines was released to district officers.

Finally, the challenge of behavioral surveillance was engaged by CCCD with only limited success. Selected maternal behaviors, such as diarrhea and fever case management practices, were addressed by questions added to vaccination coverage surveys or by special program-specific surveys.[30] In general, however, CCCD was not notably successful in introducing and utilizing standardized methods for the collection of data on behavioral risk factors, which could be easily used for tracking trends over time and assessing program progress. Efforts were underway near the close of the CCCD project to develop locally sustainable methods for behavioral surveillance in Nigeria, using as a model the Behavioral Risk Factor Surveillance System of the United States.[31]

C. Classification and Quantification

Surveillance systems confront issues in both classification and quantification. Classification issues are those related to correct diagnosis of each case (or non-case). Quantification issues are those related to the difference between the actual numbers of persons or events occurring in the population, and the number of persons or events counted or estimated by the system. Problems in either area affect the usefulness of data derived from the system.

1. Classification. Several types of classification issues are pertinent to surveillance in the developing world, and three are discussed below. First, all surveillance systems should address the definition of a case. [32] Some systems leave the determination of what constitutes a case to the reporting source, usually a physician or laboratory; others prescribe specific case definitions to be used by those reporting.[33] In most developing nations this issue is complicated by the general lack of laboratory support, resulting in the necessity of diagnosis on clinical criteria alone. Standardized clinical case definitions for many of the major pediatric health problems in the developing world (selected vaccine preventable and diarrheal disease, malaria, acute lower respiratory infection and disease due to infection with the human immunodeficiency virus) have been proposed by the World health Organization.[34] The sensitivity and predictive value positive of these clinical definitions vary; they appear high for measles and poliomyelitis, moderate for dysentery and ALRI, and low for malaria, pertussis, and HIV disease.[35] Although a substantial base of information for the development of standardized case definitions exists, few CCCD nations have yet adopted or widely disseminated standardized case definitions (in fact, the United States did not propose such standards until 1990).[36]

A second classification issue involves the use of laboratory tests in assisting diagnosis of disease. All nations have been eager to acquire and utilize laboratory technology, but the ability of most CCCD nations to support this technology over long periods has been limited. In particular, adequate attention is irregularly given to the important problem of quality control. Two issues are involved: the technology for making certain laboratory diagnoses may not exist at all (e.g. the capacity to perform blood cultures for the diagnosis of septicemia), and good quality control (i.e. to ensure that the results of laboratory tests are reliable where they are available) may be lacking. This latter issue can be quite important, as is shown by the example of Kinshasa's Mama Yemo Hospital below. Third, a problem which is not unique to CCCD or developing nations generally, but which must be resolved, is the issue of primary cause of death. Even in circumstances where the clinical and laboratory data are of adequate quantity and validity, it is often difficult to determine what should be defined as the primary versus secondary causes of death. For example, what is the primary cause of death for a malnourished child of an impoverished illiterate mother who dies of pneumonia complicating measles; or, what is the primary cause of death for a similar child who dies of a febrile illness with severe anemia and dehydration? This is a classic problem.[37] It has received substantial attention in the developed world where detailed procedures exist to guide vital registration personnel in their determinations of underlying cause of death.[38] Few such guidelines exist that are appropriate for developing countries,[39] and the need for such guidelines is apparent.

2. Quantification. Many of the quantification issues can be exemplified by considering the case of hospital-based surveillance systems. Under CCCD, hospitals were one of the major sites at which epidemiologic surveillance was carried out. Hospital-based surveillance systems (HBSS) are by definition limited in coverage, since in most developing countries, only a part of the total population utilize hospitals. A large portion of the non-using population does not reside near enough to hospitals to seek care in the event of acute illness. Use varies according to several factors, including the number of hospitals and their distribution in the country, adequacy of transportation infrastructure, patterns of population density, the perceived efficacy and cost of care, and the severity of the illness. One consequence of differential use is that hospital-based do not represent (or represent inaccurately) that segment of the population lacking full access to hospital care. The degree of misrepresentation also varies for particular causes of death. The most often cited example of this problem is that of neonatal tetanus (NNT). NNT is known to be a serious problem for rural and poorly educated populations with limited access to health and hospital care. As a consequence, cases of NNT have a reduced probability of being detected by hospital-based surveillance, in comparison to many other diseases. This assertion is supported by recent estimates: of the 160,000 cases of NNT estimated to occur annually in the Africa region of the World Health Organization (46 countries), only 3% are reported officially.[40] Thus, health problems of the poorest and most distant segments of the population are likely to be

under-represented in hospital-based surveillance in resource-poor nations. Some hospital-based surveillance systems have recruited only the better-managed and more technically able hospitals. Such systems are often dominated by one, or a few, central facilities, and fail to represent the nation's hospitals as a whole.

A second quantification issue concerns completeness of reporting. Several aspects are relevant. First, all facilities must report in a timely manner if tabulation is to be meaningful. At the beginning of CCCD, few countries in Africa regularly published data on completeness of reporting; throughout the project efforts were made to monitor the proportion of facilities reporting in many CCCD countries.[41] Second, reporting from individual facilities should include all cases. However, especially in the large urban hospitals which often dominated CCCD-country surveillance data, cases and deaths occurred in multiple sites within the facility, but were not always counted at all sites. For example, in many hospitals in CCCD countries, either there was no central site for registration of all deaths, or that site was distant from the pediatric ward and its register did not allow ready extraction of pediatric deaths. Child deaths occurred in the emergency room, in the delivery suite, in the nursery, in the pediatrics ward, in the neonatal intensive care unit, in the pediatric intensive care unit, in the operating suite, or in other specialized units such as ORT units. Reporting from the pediatric ward alone sometimes missed deaths occurring in these other areas, and thus underestimated pediatric mortality. If all deaths are to be included in a surveillance system, then considerable time, personnel effort, and internal reorganization may be required to assure that reporting to a central registry is timely and complete, or that each site is visited in each reporting period to register all deaths.[42]

A last example of quantification problems concerns denominators for population rates. Cases or deaths in hospital are numerators only. One reasonable denominator might be the number of persons at risk for being hospitalized in that facility; however, most health facilities have difficulty in estimating their catchment populations. A second approach to this issue assumes that reported cases represent a minimal estimate of the number of cases occurring; population data are used as denominators to calculate a minimal population rate. As noted above, however, the frequent absence of valid and current census data — especially data appropriate to the regional, district, or city/town level — renders difficult the estimation of such disease rates. A second approach expresses the cases or deaths as a proportion of total admissions or of total deaths that occur over the same period of time. This approach seeks to address the concern that rises or falls in cases or deaths might be due to changes in rates of admission to the hospital for the cause of interest. It is not a fully satisfactory solution, however, since extraneous factors may alter this proportion (e.g. increases or decreases in admissions for diseases other than the one of interest, due to changes in disease patterns or to changes in the availability of care).

D. Information management and the PC revolution.

The 1980's witnessed the wide dissemination of the personal computer for all types of information management. Prior to the 1980's, the surveillance systems in most CCCD countries were pencil and paper systems, with very little automated data management and analysis. The first CCCD epidemiologists went to the field with early models of Kaypro® portable computers, and the precursor softwares to the first version of CDC's surveillance and epidemiologic analysis software, Epi Info.[43] By the end of the CCCD project, Epi Info had undergone 4 major revisions, and personal computing in surveillance offices of some CCCD countries (e.g. Zaire, Nigeria) had advanced to include computers based on the 486 chip, with Bernoulli boxes for storage of large data sets, the advanced data analysis capacities of Epi Info's version 5.01b and the surveillance data mapping capability of Epi Map Software.[44] In addition, diverse softwares for data management, word processing, graphics production, and desk-top publishing of reports were in routine use. In the majority of countries, however, surveillance data were handled through computer systems relying either on EPI Info or upon simple spreadsheets and database software.

The revolution in the way in which surveillance data were handled had both positive and negative effects. The major positive impact was

upon the extent and speed with which information derived from surveillance data became available to program managers and decision makers. Annual reports filled with surveillance and administratively-derived project data were available within 4-8 months of the end of the year and data were available for planning purposes even sooner. However, these machines and softwares sometimes increased the "distance" between the data sources (health workers and health facilities, generally) and those responsible for collating, analyzing and disseminating these data (the central office personnel), by focusing attention on software, analysis strategies, and graphics rather than upon field visits, verification of findings, and direct communication with field workers. This particularly posed a problem in those CCCD countries whose communication and transportation infrastructures were quite limited.

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X. Lessons for the Future

Nine principal lessons for the future with respect to epidemiologic surveillance systems in countries of Sub-Saharan Africa emerge from this review; these are summarized in Table 9.

First, routine epidemiologic surveillance provides information needed to support targeted public health and child survival programs. The examples provided above have illustrated the utility of information provided by such systems in directing public health actions. This link between surveillance and programs requires continued emphasis. At different stages of development, health programs require data for policy development, for monitoring and evaluation of program activities, and for assessment of program impact. Surveillance will continue to form an important support for targeted public health programs throughout the developing world.

Second, routine epidemiologic surveillance systems must be supplemented by or extended to include the collection of management and health service information, special surveys, applied research activities, outbreak investigations, and program monitoring and evaluation activities. Surveillance is best achieved when the variety of sources and means of gathering information are integrated to provide overall knowledge of the health situation. The effort to control measles in Kinshasa exemplifies this integrated use of data. Such integration may be best achieved in many setting by the establishment of a single site with responsibility and authority for health information management, such as that in Burundi described above. Whether this site actually receives all reports, and distributes data to interested offices, or whether interested offices manage their own data systems and provide a data copy to this site, will depend upon local needs. Integration, however, is likely to better serve the needs of health planners and decision makers by making information more readily available, and may help to foster collaborative efforts between programs.

Third, surveillance systems require investment and support — equipment, supplies, personnel, training, supervision — if they are to function successfully. This is illustrated by the experience of CCCD in Togo. Planning for personnel development, in-service training, supervision, and supplies and equipment, are required. Few countries in Sub-Saharan Africa have a distinct budget line item for such systems. Recently, the World Declaration on the Survival, Protection, and Development of Children, to which all CCCD countries except Liberia are signatories, called for each country to establish mechanisms for "the regular and timely collection, analysis, and publication of data required to monitor relevant social indicators relating to the well-being of children, "[92] including morbidity and mortality rates. Efforts are underway in multiple for to develop means to assist countries in responding to this need. The inputs required include equipment and supplies, as well as training and supervision.

Fourth, surveillance systems are likely to be sustained only where they provide data that are useful in the planning and management of programs ("data for decision making"). As a matter of efficiency, surveillance efforts will be focused upon those programs and problems which can demonstrate that the cost of data gathering is justified by the utility of the data gathered. Efforts to strengthen the surveillance and health information infrastructure are likely to be successful only to the extent that they serve to strengthen the relationship between data

	TABLE 9: Lessons for the Future
I.	Routine epidemiologic surveillance provides and important segment of information needed to support targeted public health and child survival programs.
II	Routine epidemiologic surveillance systems must be supplemented by or extended to include management and health service information, special surveys, applied research activities, outbreak investigations, and program monitoring and evaluation activities.
III	Health information systems generally, and surveillance systems specifically, require investment and support--equipment, supplies, personnel, training, supervision--if they are to function successfully.
IV	Surveillance Systems are likely to be sustained only where they provide data that are useful in the planning and management of programs ("data for decision making").
V	Efforts are needed to assure the quality of data which are collected, reported, analyzed and communicated.
VI	There is a clear need for increased use of data the local (district or facility) level. This implies both increased capacity development and increased authority for decision-making at this level
VII	Increasingly, training in rational data management (including attention to data quality and data preservation) will be needed by health personnel in African Ministries of Health.
VIII	Non-traditional applications of surveillance and use of non-traditional methods in surveillance will become increasingly important in the coming decade, as the challenges confronting programs shift from technical to behavioral.
IX	Systems of vital registration and mortality surveillance will require increased attention in the next decade. Particularly evident is the need for inexpensive methods which can provide data over extended periods, allowing improved assessment of trends.

collection and analysis , and use of data for planning and decision making.[93] This will be the case both at local and at higher levels. Surveillance data will increasingly form the basis for actions taken by program management. Part of this issue involves the communication of such data to those who are in a position to take action based upon them. The impact of surveillance data concerning chloroquine resistance in malaria exemplifies this point. Basing its decision upon both in-vivo and morbidity/mortality surveillance data. Malawi recently became the first country in Sub-Saharan Africa to designate a drug other than chloroquine (pyrimethamine-sulfadoxine) as its recommended choice for initial therapy of mild/moderate malaria in children.

Fifth, efforts are needed to assure the quality of data which are collected, reported, analyzed and communicated, and which serve as the basis for decisions. Pertinent concerns include the development and use of standardized case definitions, the simplification of the process of data collection, and development of supervisory systems to ensure timely and complete reporting, as well as the development of public health laboratory capacity and appropriate methods for laboratory quality control. The experience with the diagnosis of malaria at Mama Yemo Hospital in Kinshasa is illustrative of the issues that must be addressed.

Sixth, there is a clear need for increased use of data at the local (city, district, or facility) level. This implies both increased capacity development and increased authority for decision-making at this level. The CCCD experience with measles surveillance in Kinshasa exemplifies this point. Data gathered at the local level were analyzed there, and decisions about vaccine policy were based upon information derived from them. Similarly, the national system in Togo now permits analysis of hospital-specific data and will (in theory) allow local decisions to be made based upon local data.

Seventh, increasingly, training in areas relevant to surveillance will be needed by staff in African Ministries of Health. Personnel with skills in epidemiology, data management, training and communication will be needed. There is an

urgent need for the development of explicit long-term training strategies in these domains. Relatively modest attention has yet been provided to development of standards for data management and analysis in the environment of Sub-Saharan African Ministries of Health, and assistance in this domain is likely to be needed in the coming decade. As the quantity of data increases, attention to data security will be more urgently needed. Softwares and other tools appropriate to the developing country environment are also needed; these may differ greatly or little from the best available tools used in the context of more developed nations' surveillance activities, depending upon the specific programs involved.

Eighth, newer applications of epidemiologic surveillance and use of newer methods will be increasingly important in the coming years. The AIDS pandemic has clearly established the need for behavioral surveillance in Sub-Saharan Africa. Similarly, the expense associated with special surveys of case management suggests that simpler, less costly means of surveillance of the quality of services will be needed. Qualitative methods employed by social and behavioral scientists, such as focus groups and key informant interviews, will be of increasing use to surveillance epidemiologists in the next decade, as key challenges become behavioral rather than technical.

Ninth, systems of vital registration and mortality surveillance will require increased attention in the next decade. Particularly evident is the need for inexpensive methods which can provide data over extended periods, allowing improved assessment of trends. Already the challenge of monitoring progress towards the Child Summit goals of infant and child mortality reduction has focused attention upon this issue.

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[31] Siegel PZ, Brackbill RM, Frazier EL, et al. Behavior Risk Factor Surveillance, 1986-1990. In CDC Surveillance Summaries, December 1991, MMWR 1991; 40 (No. SS-4):1 - 24.

[32] CDC: Guidelines for Evaluating Surveillance Systems. MMWR 1988; 37 (suppl. no S-5); 1-18.

[33] CDC: Case Definitions for Public Health Surveillance, MMWR, 1990; 39:(No. RR-13): 1-43.

[34] See, for example, (1) WHO: "Provisional case definitions proposed by WHO for EPI target diseases," unpublished document, 1990; (2) WHO: WHO Expert Committee on Malaria, Eighteenth report. WHO Technical Report Series No. 735. Geneva, 1986; (3) WHO: A manual for the treatment of diarrhea. WHO/CDD/SER/80.2, Revision 2, 1990; (4) WHO: "Proposed clinical case definition for AIDS." Weekly Epidemiological Record, 1986; 61: 69-70; (5) WHO: Acute respiratory infections in children: case management in small hospitals in developing countries. WHO/ARI/90.5, 1990.

[35] For a robust discussion of this issue, see RH Gray [Johns Hopkins School of Hygiene and Public Health, Baltimore MD, USA], Interview Based Diagnosis of Causes of Death in Childhood, unpublished document, August 20, 1990. In December 1992 a joint WHO-UNICEF meeting considered this issue, and a summary of the meeting's recommendations is available from WHO in Geneva.

[36] CDC: Case Definitions for Public Health Surveillance, MMWR, 1990; 39: (No. RR-13): 1-43[.]

[37] WH Mosley, LC Chen. An Analytic Framework for the Study of Child Survival in Developing Countries, in WH Mosley and LC Chen (eds.), Child Survival: Strategies for Research, Population and Development Review, 10 (Supplement), 1984[.]

[38] See International Classification of Disease, 9th edition, volume I, p. 701ff[.]

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[39] M. Garenne, O. Fontaine. Assessing Probable Causes of Death Using a Standardized Questionnaire: a Study in Rural Senegal. Presented at IUSPP Seminar on Comparative Studies of Mortality and Morbidity, Siena Italy, 7-12 July 1986[.]

[40] Gasse F, Neonatal Tetanus Elimination Initiative, NNT Elimination Consensus Group Meeting, Expanded Programme on Immunization, World Health Organization, September 1990.

[41] Some countries, such as Nigeria, reported regularly on this proportion (expressed as "number of reports expected divided by number of reports received") in their feedback bulletins. Other countries published and commented on it regularly in their annual reports (e.g. Togo, Zaire). Attention to this issue was frequently made a part of supervisory visits by project staff to peripheral facilities.

[42] Related to this problem is the challenge of assuring that surveillance occurs at all times — at night, on weekends, and on holidays, or at other times of incomplete staff coverage. Similarly challenging from this perspective is the tendency, in many CCCD countries, for parents to remove ill family from the hospital when it appears that patient is likely to die.

[43] Dean AD, Dean JA, Burton JH, Dicker RC. Epi Info, Version 5: a word processing, database, and statistics program for epidemiology on microcomputers. Centers for Disease Control, Atlanta GA, USA, 1990.

[44] Dean AD, Dean JA, Burton JH, Dicker RC. Epi Map, Version 1. Center for Disease Control,, Atlanta GA, USA, 1992.

[92] Paragraph 34, section 5, of the World Declaration on the Survival, Protection, and Development of Children, Agreed to a t the World Summit for Children on 30 September 1990 in New York, as cited in UNICEF: First Call for Children. United Nations Children's Fund, New York, 1991.

[93] Arising from the recognition of the importance of this linkage, USAID, CDC, and Harvard University School of Public Health have collaborated in the development of a new assistance project named "Data for Decision Making," which will work with ministry of Health Partners in a dozen developing nations, including Cameroon and possibly Burundi and Nigeria.

Computers and Health Information: Proceeding with Optimistic Caution

Computers escort the information age. The plummeting costs of electronic computing and data storage capacity; the miniaturization of essential "appliances" (i.e., computer, CD-ROM, printer); the availability of powerful, user-friendly software and the globalization of information and communications networks have stimulated demands for more and faster information. Not all problems benefit from such computer power, especially in settings of budgetary constraint, tenuous electrical supply, scant technical support, and extraordinary training demands. On the other hand, even amidst such circumstances, health programs have much to gain by the judicious use of computers.

Microcomputers have been used for at least a decade in the health sectors of developing countries. The South-East Asia Regional Office (SEARO) of the World Health Organization (WHO) first systematically used them to analyze immunization-related data in 1986. Foremost among their observations was the effectiveness of computerized information systems in enhancing the access to and use of immunization data for program planning and evaluation. In fact, the demonstrated utility of easily accessible coverage data encouraged the collection and analysis of other health data. SEARO concluded that the installation of a computerized information system can serve to augment and improve a country's existing information system.[1]

Disease Surveillance

In the United States, the Centers for Disease Control (CDC) in Atlanta has strengthened epidemiological surveillance by electronically receiving data by modem from state health departments. These data improve the individual states', the country's and even the region's ability to monitor reportable diseases, to identify changing epidemiological patterns and to identify and characterize unanticipated health threats.[2] The core data are limited, reported as often as weekly, analyzed immediately (automatically in many cases), interpreted by experts and fed back to a variety of users including the media.

Paralleling the CDC's domestic epidemiological surveillance activities has been the heightened recognition that developing countries have similar needs. The Field Epidemiology Training Program,[3] a CDC-sponsored "learning by doing" curriculum, has enhanced the epidemiological skills of many third world public health professionals to respond to health problems in their own settings. In a related effort, the CDC is developing *Data for Decision Making*[4] modules and courses in such areas as applied program management, public health surveillance and decision making in public health to train decision makers in the effective use of data in identifying and setting priorities, in making data-based recommendations and plans for solving those problems, and in implementing and evaluating the plans.

Converging with this domestic and international experience were both the "computer revolution" and the recognition that biostatistical and epidemiological computer programs were unwieldy for basic analysis by non-academicians. The CDC in collaboration with WHO responded by developing Epi Info,[5] a versatile, "easier-to-use," public domain epidemiological software package. As the best public health software buy (US $50) currently available, it combines numerous programs: word processing and questionnaire design; data entry and checking; sample size and hosts of other common calculations; statistical analysis; basic graphing and charting and file merge, import and export functions. Read more about it in the KPC article in the *Methods* chapter.

In Frerichs' accompanying article,[6] he recommends both Epi Info and spreadsheets for surveillance in developing countries. As an example of converting data into information, he presents a detailed spreadsheet approach (with formulas) to analyzing excess cases of malaria.

Management

Computers have a clear role in health program management. The power of spreadsheets to organize and analyze financial data is well known. Less apparent may be the 16 other roles

for spreadsheets in management as identified by the Aga Khan Foundation's Management Advancement Program[7] (MAP). Indeed, the MAP series stresses throughout, the use of spreadsheets and Epi Info for better management of health programs' inputs, processes, outputs, and effects and impacts.

As suggested by Frerichs,[6] interpreting data can be as challenging as gathering them. By way of response, Cibulskis et al.,[8] in their attached report, present the theory and practice of a "knowledge-based system" for monitoring immunization coverage in Papua New Guinea. "Knowledge-based" refers to the software's ability to interpret data based on programmed decision rules culled from knowledgeable experts. In other words, rather than scanning hundreds of tabulated figures or (the preferred, but still tedious) bar charts, the health manager need only seek items "flagged" according to pre-determined criteria. For example: "IF average immunization rates decline by 20 percent in a quarter AND full reports have been submitted THEN there is a general decline in immunization." Moreover, the program can be designed to suggest responses to certain conditions: IF there is a general decline in immunization THEN consider checking vaccine supply, staffing, transport and/or clinic programming." Computers should be used to analyze and guide as well as to rapidly, but often incompletely, process large data sets.

Information

Like mortally overfeeding a pet goldfish, a glut of information can suffocate a health program manager, especially if he or she responsibly seeks to stay "net-worked" and up-to-date. In the recent past, critical technical information was not generally available. This is changing dramatically with the computer revolution and the "information highway." No longer is the advantage to those who access information. Rather, it is to those who select, assess, organize and use it.

Computerization assists these tasks in many ways. Most obvious is the ability to store vast amounts of information in tiny disks and drives. Yet, without proper organization, this electronic storage is little more than a miniaturized mountain of paper. Relational databases (dBASE, FoxPro, and others) can organize documents by multiple themes or key-words unlike the familiar paper file folders where each paper copy occupies a single space. Indeed, specialized databases (i.e., Papers) are specifically designed for such tasks. They have added time-saving features, such as bibliography print-outs in a variety of standard formats. Propriety information services (Med-line, POPLINE) combined database technology with the information storage capacity of CD-ROM (computerized disc - read only memory) discs. Subscribers can quickly search for relevant current and past citations with abstracts from the world's peer-reviewed literature and reports. The coming global networking of computers, improved scanning technology and movement towards publishing in both paper and electronic formats will shortly make original documents (not just their abstracts) readily available to anyone with electricity. Computers are increasingly powerful in *accessing*, *selecting* and *organizing* information. But *assessing* the quality and usefulness of information still relies on the conceptual skills of critical reading, yet to be computerized. And *using* information depends additionally on attitudes, politics and other factors that may be beyond the scope of computer assistance.

Research

Computers have a clear role in research. Study questions often arise from operational management problems that may only come to light through rigorous computer-assisted program supervision or monitoring. Refinement of a study question greatly benefits from a computer-assisted literature review to ascertain the current state of knowledge in a field. Questionnaire design, sample size calculation, data cleaning, analysis and displaying results are greatly assisted by computer power. Indeed, the ability of graphics software (e.g., Harvard Graphics or Powerpoint) to communicate research findings attractively and convincingly assists influencing policy. A particularly effective communication tool combines the power of graphics and spreadsheets (e.g., Excel) to simulate various scenarios, as in "sensitivity analysis" which measures the effects of ranges of likely values for independent variables of interest. Such models are useful as well as

intrinsically interesting (occasionally amusing or frightening) planning tools.

Demographic Surveillance

Demographic surveillance is usually a research strategy to track populations. The well-known "population laboratories" of Narangwal, Khanna, and especially Matlab and the Gambia, for example, have shed much light on the levels, trends and distributions of ill health and the impact of health interventions. Current demographic surveillance for research is certainly computerized.

However, demographic surveillance has another role: undergirding health programs' pursuit of equity. As has been repeatedly stressed in this volume, unless a population-based approach includes the counting and following of each target member in a community, universal coverage and care according to need (i.e., equity) will not be attained. This need not be computerized as long as there are suitable procedures for assessing risk, organizing extension workers' interventions and assessing program coverage and effects. Indeed, some would argue that computers detrimentally distance the health team, and especially the community, from analyzing health activities and effects.

ProMIS

On the other hand, computerized population tracking presents opportunities. In response, Save the Children has designed a public domain health information software package, ProMIS (Program Management Information System). This population-based tool manages census data and monitors indicators and is well-suited for most settings *with a fully functioning manual family enrollment system.*

Core data collected during family enrollment includes location identification number; full name; date of birth; sex and relationship in the family. We enter vital events (births, deaths, and migrations) to track population movements. ProMIS can produce longitudinal descriptive statistics, such as crude and age-specific natality and mortality rates. In addition to the demographic core, ProMIS stores other information specific to individuals in the population in various modules, such as: child immunization; growth promotion; pregnancy monitoring and cause of death. As for the demographic data, ProMIS also prepares statistical reports based on these health indicators, such as rates of immunization, cause-specific mortality and malnutrition. Moreover, through an accompanying feature, users can define their own modules to track additional variables of interest. Programs have often added family planning-, vitamin A- and/or ARI-related indicators. Planning for educational and micro-enterprise indicators is ongoing.

An additional key feature of ProMIS is its ability to produce rosters of individuals meeting user-specified criteria. For example, ProMIS will generate a list of children under age five years with their vaccination status or a list of women of child-bearing age and their pregnancy outcome histories. These lists are central to direct care to those at greatest risk.

Additional ProMIS features include: (1) the latest in user interface technology (pull-down menus and on-screen windows); (2) data storage in "dBASE-type" files familiar to many; (3) data exporting utility to common statistical software packages (i.e., SPSS, Epi Info, etc.) for more detailed analysis; (4) language independence with French, Spanish, and English language files built-in and (5) error-checking utility. ProMIS will run on an IBM compatible 286 (or faster) computer. A programmer is not required.

We include a paper detailing some of the outputs of ProMIS for monitoring communities and individuals. The program and manual are available at cost ($35.00) from Save the Children, 54 Wilton Road, Westport, Connecticut, USA 06880.

Conclusion

Computers can play central roles in many aspects of community-based health programs: disease-surveillance, management, information sciences, research, policy guidance and demographic surveillance for equity. Managers must weigh their pros and cons. As the information age permeates the global village, the pros will loom ever larger.

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Cibulskis R., Crouch-Chivers P., Posonai E., Moni C. and Thomason J., A Knowledge-Based System for Monitoring Immunization Coverage in Papua, New Guinea, *International Journal of Health Planning and Management* 1993; 8: 59-69, copyright (c) 1993 by John Wiley & Sons, Ltd. Reprinted with permission by John Wiley & Sons. Ltd..

A KNOWLEDGE-BASED SYSTEM FOR MONITORING IMMUNIZATION COVERAGE IN PAPUA, NEW GUINEA

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SUMMARY

Microcomputers have great potential to improve health service management in developing countries. In addition to their commonly recognized abilities to process numerical information, they can also provide assistance in interpreting it. They can highlight problems that require attention, suggest possible reasons why problems occur and suggest appropriate managerial responses. Computer programs which perform these more advanced functions are often known as knowledge-based systems (KBSs) since they incorporate the knowledge of experts in the area addressed by the system. Such systems are increasingly being used to support decision making in commerce and public administration and offer great potential to the health sector. This article presents preliminary results of work to develop a KBS to help mid-level managers monitor and evaluate health service provision in Papua New Guinea. It considers issues in the design and development of KBS and discusses their future potential.

INTRODUCTION

Accurate, relevant and up-to-date information is essential to health service managers if they are to recognize weaknesses in health service provision and take actions that will improve service delivery. Accordingly, the development of effective information systems is a necessary precursor to managerial improvement.

A variety of measures have been taken to strengthen health information systems. One strategy that has become popular is to employ microcomputers to process routinely collected data. Often this is done only a small scale (Wilson *et al.*, 1988), but there are examples where microcomputers form an integral part of national information systems development, such as in Papua New Guinea (Newbrander and Thomason 1988, 1988 Campos-Outcalt and Vickers, 1988) and the Philippines (Robey and Lee, 1990). By speeding up data processing, microcomputers enable routinely collected information to be readily available to health managers. The intention is that managers will use it to measure progress in delivery health services, identify problems and decide upon actions which might alleviate problems. In practice, however, information is seldom used as an effective management tool. Frequently, the sheer volume of information is too much to digest or managers do not have the expertise to interpret it adequately (Bowen and Payling, 1987; de Kadt, 1989).

This article describes an innovative approach that may encourage more appropriate use of information. It reports on initial work to develop computer software that will not only process data but also help managers to interpret and act upon it. The software uses data generated by the provincial health information system of Papua New Guinea. It is referred to as a knowledge-based system (KBS) because it incorporates the knowledge of people who are experienced in health service management and using health information. Although the KBS is only at a preliminary stage of development, the results obtained thus far are encouraging and though to be sufficiently important to be of widespread interest to all those concerned with the development of effective health information systems, especially in the developing world.

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THE NEED FOR A KNOWLEDGE-BASED SYSTEM

Papua New Guinea has undertaken a nationwide programme to computerize its provincial health information system (Newbrander et al., 1988). The computerized information system enables indicators of health service provision to be generated on a monthly basis for use in monitoring and evaluation by provincial health managers. The indicators cover a range of health service programme areas such as immunization, maternal health care, nutrition, disease surveillance, and inpatients (Campos-Outcalt and Vickers, 1988).

The presence of microcomputers has improved the availability of information and led to its increased use in decision-making (Newbrander et al., 1988). However, the benefits are not realized equally in all provinces. Provincial managers are not always sure how to analyze data or how to respond to problems identified. In addition, the computerized system generates a large number of different reports which are beyond the capability of many provincial managers to deal with effectively. There is a need for constant training and support in data analysis and the use of information for management purposes (Campos-Outcalt, 1991).

The Department of Health in Papua New Guinea provides such training and support as part of its management support programme, but cannot do so on a continual basis. It is necessary, therefore, to consider alternative ways of augmenting the support that can be offered. Recent progress in the development of KBSs suggests that microcomputers themselves can be of greater assistance in this area. Computers can be programmed to inspect data in an information system and draw attention to particular problems such as low coverage rates, or outbreaks of diseases. Once a problem is identified, computers can be also programmed to suggest possible reasons why the situation has arisen and what actions can be taken to alleviate problems. The computer is able to do this by working to a fixed set of instructions, which have been predefined by a team of "knowledgeable people."

Initial work to develop a KBS has concentrated on immunization services, as this is a well-defined programme area which is important not only in Papua New Guinea but in many countries throughout the world. Immunization data in the provincial health information system are derived from records of contact between clients and health workers. Vaccinations administered at a clinic or health facility are recorded on tally sheets and submitted to a provincial office on a monthly basis. Here they are inspected for completeness and entered on a computer. The computer then calculates approximate coverage rates based on an estimated target population for each health facility.

In the existing system the results are presented in the form of a table, which shows the vaccinations administered by each health facility. The table will contain information on six doses given to children under one: BCG, first and third doses of triple antigen (TAI and TA3), first and third doses of oral polio vaccine (OPVI and OPV3) and measles vaccine. Since there are usually 25 or more health facilities in a province, a table of results can contain 150 or more figures for inspection. It is also possible to obtain line graphs showing the cumulative uptake of immunization in comparison with a target population. There are four graphs for each facility (BCG, TA, OPV, measles), which results in at least 100 graphs for inspection.

It is impractical to review such an amount of data thoroughly on a regular basis, particularly when a similar amount exists for other health services activities. Moreover, it is not always clear what health service managers should be looking for in a set of figures or graphs. Our aim has been to define how data within the provincial health information system should be used, and incorporate these principles into computer software that can implemented within the existing information system of Papua New Guinea. The software is intended to provide guidance in using routinely collected information and to help provincial managers monitor health services more efficiently and effectively.

DEVELOPING A KNOWLEDGE-BASED SYSTEM

Development of a KBS differs from conventional software development (Edwards, 1991). In conventional data-processing systems, the tasks to be performed by the computer are usually well understood and can be readily expressed in a specification to which programmers can work. In contrast, the tasks

undertaken by KBSs are generally more complex and involve judgments based on human experience. Much time in system development is spent acquiring knowledge on how tasks should be performed and ensuring that the knowledge is represented faithfully when translated to the computer. To date, the software-development process has entailed repetition of three basic steps: knowledge acquisition, knowledge representation and execution.

Knowledge acquisition

Knowledge acquisition has taken place through detailed interviews with key informants and through reference to written materials (policy documents, training manuals).Key informants have been staff working in the National Department of Health who are both knowledgeable about provincial management functions and experienced in using health information. Interviews were initially informal, to map out a general framework for analyzing problems, but became increasingly more structured as more specific knowledge was required. Interviews were supplemented by brain-storming sessions to further elicit knowledge and resolve conflict of opinion.

Knowledge representation

This entails representing the knowledge of key informants in a series of rules which will help to solve problems. The rules follow a standard format:

IF *a certain condition is true* **THEN** *a certain conclusion applies*

For example:

IF *average immunization rates decline by 20 percent in a quarter* **AND** *full reports have been submitted* **THEN** *there is a general decline in immunization* **IF** *there is a general decline in immunization* **THEN** *consider checking vaccine supply, staffing, transport, clinic programming*

In formulating rules, it is often necessary to specify thresholds for recognizing certain problems, e.g. a decrease in immunization rates of 20 per cent represents a decline. In the absence of any general theory concerning the interpretation of immunization rates, the thresholds have been determined by consultation with key informants and empirical testing of their utility. The rules developed also need to be prioritized so that the system will highlight the most important problems occurring at any one time. Again, prioritization has been undertaken according to the judgment of key informants.

Execution

This entails implementing rules on a computer through a programming language or expert system shell. Crystal 4, a shell which has already been used to develop a KBS for analyzing performance indicators in the British National Health Service (Bowen and Powling, 1987; Bowen, 1988), has been employed. The shell is easy to use, links with databases in the Paua New Guinea information system and enables prototypes to be produced very rapidly. Once produced, prototypes can be verified and the process of knowledge acquisition can recommence.

OPERATION AND DESIGN OF THE KNOWLEDGE-BASED SYSTEM

Health service managers need to be able to answer three types of questions when inspecting immunization results:

1. Which health facilities are doing well and which are facing problems?
2. What are the important features of immunization uptake at a health facility?
3. How could the results have arisen and what can be done about them?

The KBS helps managers to answer these questions in three stages of data analysis.

Which health facilities are doing well and which are facing problems?

For any reporting period chosen, the KBS will present a list of health facilities in a province with their accompanying immunization uptake rates (see Figure 1). To help identify health facilities doing well and those facing problems, health centres are ordered according to their overall performance. In addition, a general increase or decrease in immunization rates since the last reporting period is highlighted (INCREASE or DECREASE). Increases and decreases in individual doses are also shown by arrows.

Immunisation Coverage up to Quarter 4, 1991

Rank	Health Centre	BCG%	3RD TA%	3RD OPV%	MEA%	Recent Change
1	TARI HOSPITAL	300 +	148	148	117 -	
2	WABIA SC	78 -	142	139	131	
3	SUMBURA SC	95	144 +	142 +	72	INCREASE
4	MENDI HOSPITAL	117	115	124 +	79	
5	ERAVE HC	135	73	93 +	106	
6	HANGAPO SC	63	80	85	94 -	
7	DET HC	112	76	77	94	
8	PAJAKA SC	85	61 -	89	97	
9	KAROBA HC	117	74	78	89	
10	IMBONGU SC	75	83 +	85 +	51	INCREASE
11	KOPIAGO HC	73 -	68 -	69 -	63 -	DECREASE
12	POMBOREAL SC	42	96 +	87 +	15	INCREASE
13	SUMI SC	77	75	54	68	
14	KAGUA HC	39 -	64	70	63	
15	IALIBU HOSPITAL	82	68 -	67 -	58	DECREASE

* Select a Health Centre for more Detailed Analysis *

Figure 1: List of health centres ranked from best to worst.

Such a display can also be produced by conventional data-processing systems. It is only 'knowledge-based' in the criteria chosen to detect changes and rank health centres. An overall increase or decrease of 20 percent from the previous reporting period or a change of 25 percent in individual doses will be highlighted. Ranking of health centres is based on the average immunization rate for OPV3, TA3 and measles. BCG, which ideally is given at birth, is excluded from the calculation because deliveries will often be conducted at a different health facility to subsequent immunizations. It may not, therefore accurately reflect a health centre's performance in routine immunization.

The display enables managers to focus immediately on those health centres requiring attention. Any health centre can then be examined in more detail by moving a highlighted bar to the centre in question.

What are the important features of immunization uptake at a health facility?

If a health centre has been selected for more detailed analysis, the program presents a bar chart of immunization rates broken down by quarter. It then displays a list of major findings that appear within the data, which are presented in order of importance (see Figure 2). In total, the system will search for 12 major categories of problem (see Table 1). Most combinations of conclusion can apply to a health centre, though some are mutually exclusive.

The criteria used to detect a problem and generate comments are very simple. For example, a high drop-out rate between first and third doses of OPV will be indicated if third-does OPV is 25 percent less than first-dose OPV and the absolute value of the first dose is greater than 30 percent (the latter condition is used to avoid this conclusion being drawn when coverage rates are very low).

It would be possible to use more rigorous criteria to detect problems. For example, a decline in immunization rates from one quarter to the next could be detected using formal statistical methods. However, we have deliberately avoided this approach as we wish to keep the system as simple as possible. Firstly, the use of more elaborate criteria would make the working of the system less visible to those contributing to its design. Secondly, it would involve more complex programming, which would make maintenance of the system much more difficult when it is implemented. In any case, given the imprecise nature of the data entering the system, rigorous statistical criteria are not necessarily more valid than any other. Although the criteria we have chosen are simple, they are to be effective in pointing out major problems occurring at a health centre.

Once the screen in Figure 2 has been inspected, a menu allows the user to return to the list of health centres to select another health centre for examination. Alternatively, the user can explore a finding in more detail and ask for explanation and suggestions for action.

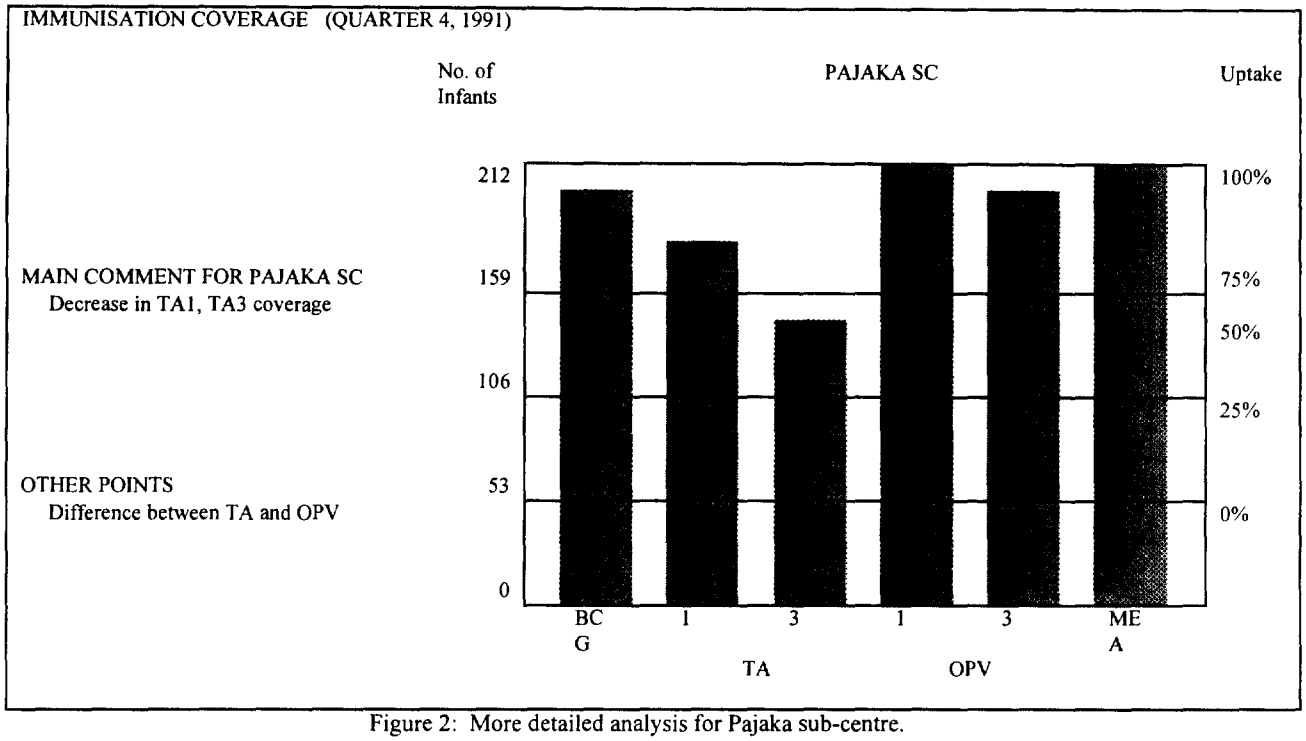

Figure 2: More detailed analysis for Pajaka sub-centre.

Table 1. Problems identified and categories of action suggested

Problems identified	Categories of action suggested							
	1 Positive feedback	2 Vaccine supply	3 Equipment/ staff	4 Staff training	5 Clinic program	6 Education communication	7a Denomin-ators	7b Reporting
1. (a) Total program failure (uptake rates = 0)		**	**					
(b) As above with reports missing		**	**					**
2. (a) General programme failure (uptakes <50%)		**	**				**	
(b) As above with reports missing		**	**		**			**
3. General decrease in coverage		**	**		**			**
4. General increase in coverage	**							
5. All uptake rates exceeding 100%	**						**	
All uptake rates good (80%+)	**						**	
All uptake rates >50% and < 100%	**	**	**	**	**	**	**	
All rates good, some exceeding 100 %	**						**	
Some uptake rates exceeding 100%$	**	**	**	**	**	**	**	
Uptake rates erratic (< 50% and 100%)		**						**
6. Reports missing								**
7. Uptake of measles vaccine low		**				**		
8. Decrease in single rates		**					**	
9. Increase in single rates	**							
10. Difference between TA and OPV		**		**				**
11. High drop-out rates				**		**		
12. BCG less than other rates		**		**			**	**

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EXPLANATION

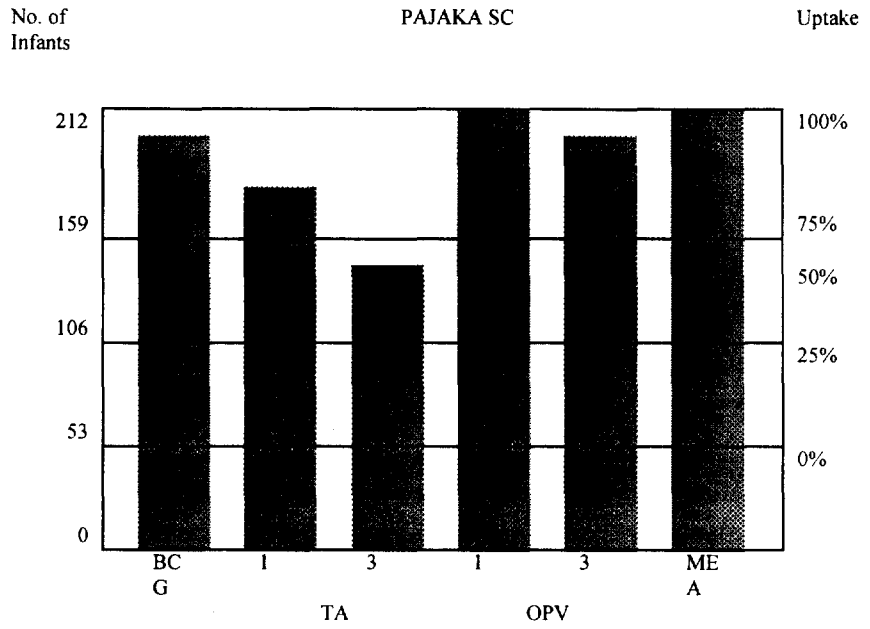
Decrease in TA1, TA3 coverage

There has been a decrease in some coverage rates. This could be due to:

(1) Shortages of vaccine
(2) Under-reporting of vaccinations given

Consider:

(1) Ensuring adequate supply of vaccine
(2) Checking vaccinations are reported correctly



* Press any Key to Continue *

Figure 3. Explanation of the finding "Decrease in TA1, TA3 coverage' and suggestions for action.

How could the results have arisen and what can be done about them?

If further explanation has been requested, the program briefly explains why a particular result could have arisen and suggests what management response may be appropriate (see Figure 3). Management responses have been grouped into seven major areas.

1. *Positive feedback*-encouragement of any good results
2. *Vaccine supply*-improving the ordaining and distribution of vaccines
3. *Infrastructure*-ensuring adequate staff and equipment such as transport, refrigerators, syringes, etc.
4. *Training and supervision*-ensuring that patients are treated courteously, data recording is carried out correctly, that immunization policy such as immunizing every opportunity is understood.
5. *Clinical programming*-ensuring that clinics are sited appropriately and are conducted regularly.
6. *Education and communication*-providing health education, motivating the community to use services and involving community health workers in their delivery.
7. *Information system*-ensuring that reports are submitted and that catchment populations of health centres are estimated accurately.

Table 1 above shows the relation between the problem identified by the system and the management responses suggested. At present, each problem identified by the system is considered individually. Thus, for any problem selected, a set of actions will be suggested without taking into account any other problems that might be occurring at the health centre. The intention is that users of the system will be more readily able to associate a particular finding with its consequent actions.

Sometimes the actions suggested for a problem are quite specific. On other occasions a whole range of actions may be indicated. This does not necessarily imply that a problem is more severe. Rather, it indicates that the reason for a problem is not clear and that a number of strategies may need to be explored.

Ultimately a single set of actions for a health centre, based on the particular combination of problems detected, may be more helpful. This will require a second level of interpretation which takes into account the likelihood of specific problems

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occurring and the need for certain actions (e.g. **IF** *there has been a decrease in rates* for OPV **AND** OPV rates are lower than TA **THEN** *a supply problem is highly indicated*). Such analysis could provide much greater power to the system.

THE POTENTIAL AND LIMITATIONS OF KNOWLEDGE-BASED SYSTEMS

Our work has shown that it is possible to develop a KBS that will help to interpret data generated by a routine health information system. Such systems could have wide applications. Not only could they be of direct assistance to managers in identifying and solving problems, but they could also promote improved feedback of information, which can in turn encourage better delivery of services. Such tools could also have an educational application, helping to impart expertise in the interpretation of information. they may thus have a significant role to play in strengthening the monitoring and evaluation of health services.

Development of a KBS requires a *body of knowledge* concerning the tasks to be performed by the system. There are currently few guidelines on how routinely collected health information should be analyzed or interpreted. Consequently, this knowledge has been derived from personnel working in the Department of Health, Papua, New Guinea. Using this strategy, it has been possible to develop a system which is understood by those contributing expertise and reflects their concern. There is no reason why a similar approach should not be used to develop KBSs elsewhere, provided the necessary expertise exists. A commitment from senior personnel and an investment of time is required, however, particularly on the part of key informants contributing to system design. This time is not wasted as it focuses attention on how information can be used in the decision-making process. All too often information system development is concerned solely with data collection. By considering the end of the information in terms of managerial response, it is possible to define more precisely the purpose of collecting information and provide solid guidelines on how it should be used. The lessons learnt can be of value in their own right, providing a solid foundation for establishing training programmes aimed at mid-level managers. The process also brings out weaknesses in existing information systems and can suggest modifications which will improve their design.

Development of a KBS also requires a *capacity* to translate knowledge into a form that can be executed on a computer. A specialized expert system shell, Crystal, was used because of the speed with which it is possible to develop prototype software. Expertise in using shells is not common in developing countries and this may limit the potential for developing a KBS. However, it is quite possible to incorporate some expertise into information systems using conventional data-processing software, such as dBase. Indeed, there is some advantage in considering conventional software for implementation of such products. This would increase the chances of obtaining support for maintaining and updating the KBS, which is an essential consideration for any computerized information system.

The utility of any KBS will ultimately depend on the *type* and *quality* of the data entering the system. For example, when considering immunization, it would also be valuable to have information on the functioning of the cold chain. In the absence of such information, it is quite possible to place too much reliance on coverage rates and obtain an incomplete pictures of immunization services. While this is a legitimate concern, and reinforces the need for care in interpreting results, it should not prevent appropriate use of data that is readily available.

Our work has only considered a single programme area, immunization, and has treated this in isolation of other health service activities. Interpretation of immunization results could be made more exact if data on other services were considered. For example, if a decline in the immunization coincided with a decline in antenatal and outpatient attendance, then a general problem in delivering services would be indicated rather than one restricted to immunization, such as vaccine supply. As the range of information considered by the system expands, its complexity will increase and the number of outputs that can be generated from the system will multiply. It will become increasingly necessary to be selective about what the KBS should achieve and avoid developing a system that is too complex to use and maintain. It will also be necessary to test such systems in the workplace and obtain feedback on their ease of use and the overall utility of any product. Development of a KBS is therefore not a rapid process at present. However, as experience is gained, it should be possible to accelerate the process and adapt the findings for use in other health care situations.

CONCLUSION

Our work has shown that it is possible to incorporate a degree of expertise into routine data processing systems. It can be encoded using simple rules that will help to identify problems and actions alleviate them. Although

our system is quite simple in design, it appears effective in operation. The ease with which it was developed suggests that such systems could have wide application in the future. The concept of KBSs is quite recent and the idea of building such a system for use in developing countries may seem ambitious. However, computer are now commonplace in many developing countries. In situations where health workers are both overstretched and undertrained, there is considerable justification for investigating how computers can provide greater help to health workers in performing tasks.

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Summary

Surveillance attempts to monitor and control selected untoward health events. Surveillance programs have four components: (1) a sensor to measure parameters of a population's health; (2) an expected or threshold level of these parameters; (3) a monitor to compare the measured to the expected values and (4) a controller to institute corrective action to lower the level of disease. Surveillance systems must be simple and useful. They should collect only essential data; feed back results to "sensors" and initiate timely control action. Data are the raw numbers from the sensor; information is the results of data analysis and monitoring (i.e., percents, rates, excess cases); knowledge is this information once absorbed by the controller and action is the controller's knowledge-based response. Microcomputers greatly aid surveillance, especially with software such as Epi Info and spreadsheet and graphics programs. Examples of spread sheets with formulae to calculate excess cases are included. Sample surveys often must supplement surveillance to help explain findings or to eliminate facility-based measurement bias. Developing countries should first focus on communicable diseases because control activities are better understood than for other adverse health events. [eds.]

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EPIDEMIOLOGIC SURVEILLANCE IN DEVELOPING COUNTRIES

RALPH R. FRERICHS*

INTRODUCTION

Developing countries are different from technologically-developed countries in many ways. Most people are poorer, less educated, more likely to die at a young age, and less knowledgeable about factors that cause, prevent, or cure disease. Biological and physical hazards are more common, which results in greater incidence, disability, and death. Although disease is common, both the people and the government have much fewer resources for prevention or medical care. Many efficacious drugs are too expensive and not readily available for those in greatest need. Salaries are so low that government physicians or nurses must work after-hours in private clinics to feed, clothe, and educate their families. The establishment and maintenance of an epidemiological surveillance system in such an environment requires a different orientation from that found in wealthier nations. The scarcity of resources is a dominant concern. Salaried time spent gathering data is lost to service activities, such as treating gastrointestinal problems or preventing childhood diseases. As a result, components in a surveillance system must be justified, as are purchases of examination tables or radiographic equipment. A costly, extensive surveillance system may cause more harm than good.

In this article, I will define epidemiologic surveillance. I also will describe the various components of a surveillance program, show how microcomputers and existing software can be used to increase effectiveness, and illustrate how rapid microcomputer-assisted surveys can be used to supplement existing efforts.

EPIDEMIOLOGIC SURVEILLANCE

The word "surveillance" evokes images of mystery, police, saboteurs, and intrigue. The word was adopted by the English from a French term during the Napoleonic Wars (10). The original meaning was to watch over people who supposedly had subversive or criminal tendencies so as to prevent future problems. In contrast epidemiologists use the word in a way that is now common to public health. Epidemiologists follow disease causes or deaths with the intention of preventing future harm. Thus, surveillance is "the continued scrutiny of all aspects of occurrence and

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spread of disease that are pertinent to effective control" (11).

An expanded definition, which has been adopted by many health professionals in the United States, was published in 1986 by the Centers for Diseases Control (CDC) (37):

> [Epidemiologic surveillance is] the on-going systematic collection, analysis, and interpretation of health data essential to the planning, implementation, and evaluation of public health practice, closely integrated with timely dissemination of these data to those who need to know. The final link in the surveillance chain is the application of these data to prevention and control. A surveillance system includes a functional capacity for data collection, analysis, and dissemination to linked public health programs.

Again, the definition emphasizes the use of systematically collected data for control of disease.

Two terms that are related to surveillance are "monitoring" and "register" (or "registry"). Monitoring and surveillance are sometimes, but not always, used synonymously (10, 30, 37). Epidemiologic surveillance is a monitoring process. Both surveillance and monitoring feature continuous scrutiny and detection of change from expected levels. A surveillance system, however, goes one step further. Because surveillance also includes feedback and control, it is actually a monitoring and control process, rather than just a monitoring process. A register is similar to a surveillance program; both feature continuous gathering of data on all disease cases in a geographically-defined area. The primary focus of a register, however, is to list cases in need of long-term treatment (e.g. tuberculosis and leprosy registers), to describe patterns and time-trends of population-based incidence or mortality rates (e.g. diabetes registers) or to provide cases or deaths for etiologic studies (e.g. cancer registers).

Monitoring and Control Process

Perhaps the best way to explain a monitoring and control process is with the analogy of a building thermostat. Assume the thermostat regulates the heating and air-conditioning system. A person sets a temperature gauge to a comfortable level. The building temperature is continuously sensed by a thermometer in the thermostat. The actual temperature is compared with the desired, previously set level. If the observed temperature differs from the expected temperature, the thermostat sends a signal to activate the heater or air conditioner. Either one remains on until the temperature returns to the desired level. The thermostat then sends a signal to turn off the heater or air conditioner. The process of scrutiny and control continues until either the thermostat is turned off or the system breaks down.

An epidemiologic surveillance program is similar to the temperature-regulating system. Rather than sensing temperature, the surveillance program scrutinizes the occurrence of disease in specified populations. As shown in Figure 1. such a program typically has four components: sensor, monitor, level of expectation, and controller. The sensor identifies the state of health in the population under observation and sends a reference signal, which describes the state of health. The monitor receives the reference signal and compares it with the expected level. Usually, the expectations are set based on national or local policies or standards. If the measured level of disease differs from expectation, the monitor sends an error signal to the controller. The controller, who is a person or agency with some ability to take corrective actions, acts to reduce the level of disease in the population. The effectiveness of this action is measured by the sensor, which again sends a reference signal to the monitor. If the disease incidence falls below the expected level, no further action is required. If the controller has not been successful, however, the error signal again points to the unacceptable level of disease and the process continues.

SENSOR

The sensor may take several forms. In some surveillance programs, the sensor is local physicians who are required by law to report the occurrence of notifiable diseases. In other programs, it may be health workers at a hospital or clinic. If blood is routinely screened for evidence of genetic disorders or antibodies for various infectious diseases, then the laboratory is the sensor. Teachers or school nurses may represent a sensor if they routinely report

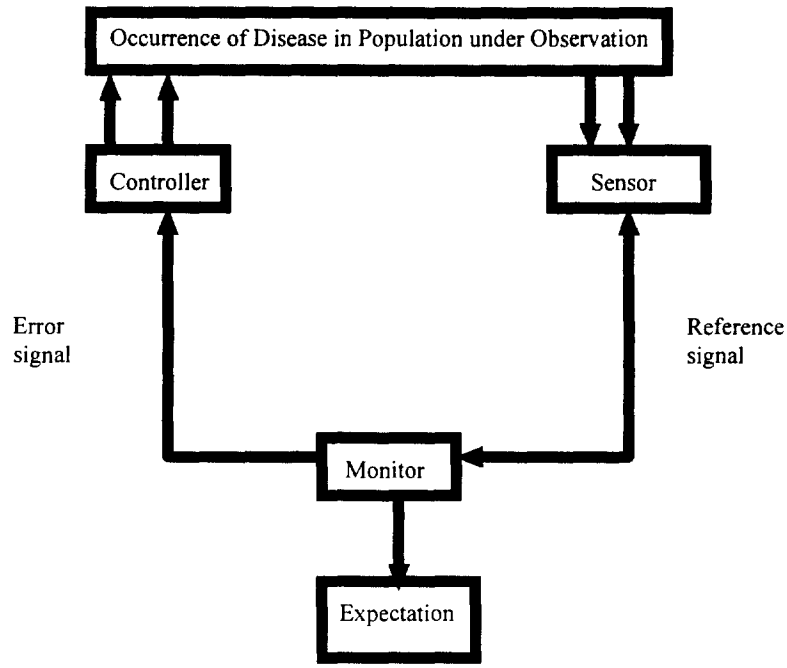

Figure 1 Components of an epidemiologic surveillance system

illness-associated absenteeism. Similarly, industries that routinely report absenteeism to government health agencies may be a sensor. A sensor also may be an annual interview or examination for members of the military.

MONITOR AND EXPECTATION

The monitor is usually an epidemiologist who reviews the information sent in from the field to decide if there is an acute outbreak or if the disease has reached epidemic levels. The epidemiologist compares the disease occurrence with a prior expectation and responds accordingly. For every disease, there is a threshold level of concern that might not be stated explicitly, but is there nevertheless. If a disease is uncommon, such as human rabies, or is subject to international health regulations, such as cholera, yellow fever, and plague, then the threshold to initiate action may be a single case. For more common diseases, such as malaria, influenza, and measles, the threshold may be many cases.

The level of expectation depends to a large extent on the feasibility of control and the resources of the control agency. For example, Walsh & Warren (40) note that the feasibility for malaria control in most countries is high because inexpensive drugs are available for prevention and treatment, and spraying programs work well to reduce the level of the vector. If a country has little money for control programs, the threshold may be set very high, so that only the occurrence of large epidemics will stimulate action.

CONTROLLER

The controller is the person or organization that initiates prevention or control activities. At the regional level, the controller may be a local health officer. At the national level, it may be the chief medical officer in a department of disease control. Some countries provide direct funds to epidemiology units for disease control. Most developing countries, however, maintain a tight rein on funding; the authority to allocate resources is vested in administrators, rather than epidemiologists. In such instances, the epidemiologist must explain the surveillance findings and present recommendations for action to the

administrator both in a timely manner and in terms that can be understood easily.

Total Count Versus Sampling

Most surveillance programs attempt to identify all cases, deaths, or injuries in a population for the disease of interest. This type of data gathering works well in developed countries that have sufficient resources and health professionals who comply with reporting requirements. Because surveillance diseases often are rare events in wealthy countries, no single practitioner is burdened excessively by the time-demands of reporting. When the disease is more common, however, even wealthy countries revert to sampling. For example the United States maintains an active surveillance program of pneumonia-influenza deaths. The deaths, however, are tallied each week for a sample of 121 cities, rather than a total count of the country (5).

Samples also commonly used in developing countries. As has been noted by the Expanded Program on Immunization (EPI) of the World Health Organization (WHO) reporting systems that require total counts are notoriously incomplete for most diseases (9). Based on EPI's experience, routine reporting is reasonably complete only when a disease is recognized as a high priority problem and when cases are less common. Thus, sampling is often the only way to obtain timely, accurate, information. For example, in Myanmar (formerly Burma), hospitals are the major sources of surveillance data for several diseases. Rather than a total count of all patients, the Department of Health only requires a 10% systematic sample of hospital patients discharged alive or dead (26). Surveillance data on nutritional status in Ethiopian refugee camps are provided solely by periodic cluster surveys (42).

When routine reporting systems are not functioning properly, EPI recommends that disease-specific data be obtained in surveys of sentinel sites, such as cooperative hospitals and clinics (9). Only a few sites are selected for sentinel reporting; selection is limited to those sites that have a capable and interested staff. For common diseases, such as measles and pertussis, the EPI program recommends the use of outpatient departments of pediatric hospitals of general health centers; for less frequent diseases, such as neonatal tetanus, diphtheria, and poliomyelitis, they recommend infectious disease hospitals or rehabilitation centers. Not all researchers agree, however, that sentinel sites are effective at surveillance. Walsh (39) has presented several caveats for those researchers who plan to use sentinel surveillance, the most important of which is that the selected sites should be representative of all sites in the country.

Later in this review, I will discuss the advantage for developing countries of using occasional sample surveys to supplement a total count surveillance program. Periodic surveys are especially useful for common diseases, injuries, or other health conditions for which the burden of reporting is excessive.

Diseases Included in Surveillance Programs

Many different diseases and health conditions are included in surveillance systems. The CDC has 98 on-going systems for surveillance (3). Although many of the diseases are communicable, the list is varied and includes such conditions as ectopic pregnancies, abortions, and occupational injuries. Similar diversity was apparent in a recent text on surveillance programs, primarily in economically more developed countries (10).

For developing countries, the list of disorders is much shorter and is usually limited to infectious diseases and, possibly, nutritional disorders. Most countries attempt to gather surveillance data on cholera, yellow fever, and plague, the three diseases subject to International Health Regulations. Other conditions typically included are those under active surveillance by WHO, such as AIDS, dracunculiasis (guinea worm,), poliomyelitis, influenza, and malaria. Also included are those conditions that are required to be reported at the national level by most countries, such as various forms of encephalitis and hepatitis, measles, typhoid, and paratyphoid, tuberculosis, leprosy, diphtheria, pertussis, human rabies, and tetanus. Other problems occasionally reported are accidents, low weight-for-age or weight-for-height, dog bites, and snake bites.

Reporting and Feedback

In the ideal, a surveillance program receives data on a regular basis from health

professionals in the field and provides them with prompt feedback on the tabulated findings. For surveillance systems that rely on multiple reporting sites, the process of reporting and feedback is shown in Figure 2. Data are systematically collected from sensors, which include hospitals, clinics, private practitioners, school nurses, and company physicians. All data are sent to a central site for processing, and evaluation of disease changes over time. The information is then shared with program managers and other officials who are responsible for disease control and distributed back in summary form to the persons who initially provided the data.

The method of reporting can be either active or passive. In active surveillance, health department personnel contact sources in the field at regular intervals and requests specific data on disease of interest. An active approach requires considerable time and effort by health department workers and is not often used in developing countries. In passive surveillance, the more common method, physicians and others in the public and private sectors complete a form for all reportable diseases. The form may be sent to the health department on a regular basis or when a disease case has been observed. Rather than relying on the salaried time of health department personnel, passive surveillance transfers part of the data acquisition cost to field professionals. Unfortunately, as noted by Evans (8), "time and lack of interest [by field personnel] greatly limit this [passive] system to a small percentage of reportable diseases." Thus, although the cost is low, so is the quality of the data

Feedback is an extremely important component of a surveillance program. As EPI has stated, "without feedback, health workers soon realize that it makes no difference what they report or whether they report" (9). Information has value only if it is used for decision-making. If field personnel do not understand or see the results of the decision-making process, they will be less willing to contribute to future surveillance efforts.

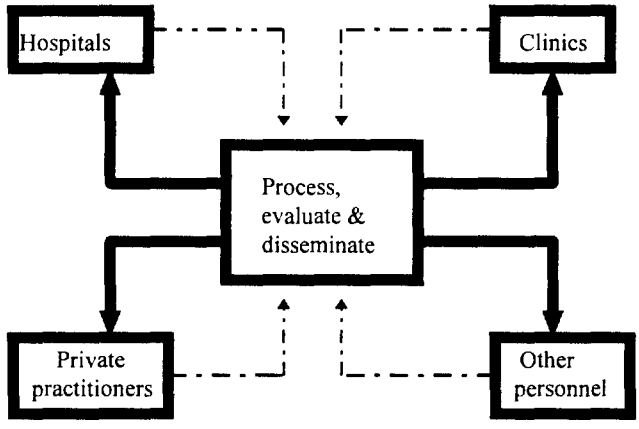

Figure 2 Reporting, processing, and feedback of surveillance data.

Epidemiologic Surveillance and Health Information Systems

When a government assumes responsibility for health care, epidemiologic surveillance activities are usually included as part of the health information system. Field personnel are expected to complete reporting forms for the health information system on a regular basis and send the forms to the next highest official. At the community level, the person who delivers services also gathers data. These data are explicitly used for planning, surveillance, management, evaluation, and education. However, the implicit assumption is that the data will be used to improve health status and bring the population closer to "Health for All," the goal espoused by member nations of WHO. If health information

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systems did not exist, physicians and others would still deliver services and provide advice on prevention and control of various diseases. Additional knowledge should not hinder delivery; it should improve effectiveness without raising cost.

When too much time is spent gathering data, the efficiency with which a program is managed may worsen. Each health worker only has a finite amount of available time. The relationship between data-gathering time and management efficiency is shown in Figure 3. When a health worker spends little time gathering data, more time is available for the delivery of services, but not in the most efficient manner. As more data are gathered, managerial functions, such as scheduling patients, maintaining equipment, ordering supplies, arranging counseling sessions, and scheduling immunization and well-baby clinics, are improved. However, the gains in efficiency often are offset by the loss of service time. This point is labeled "threshold" in Figure 3. Once health workers have moved to the right of this threshold, too much time is spent gathering data and not enough time is spent delivering services or planning prevention or control programs. In the post-threshold situation on the right side of Figure 3, health workers become discouraged by excessive demands on their time and, as a result, no longer provide truthful information. Program administrators become overwhelmed with the volume of data and fail to review adequately the information. Finally, government health officials become cynical about quality and refuse to use the data. The cost in salary-time remains the same, but the effectiveness of the health care system is diminished.

An example of how data gathering demands can overwhelm a health care system is taken from Myanmar in 1985 (12). Peripheral-level health workers were expected to complete more than 30 sets of forms either on a daily or monthly basis. At the rural health center level, the local staff had to submit a set of forms with 1160 variables every month. Of these variables 72% were requested by the Division of Disease Control, the unit responsible for epidemiologic surveillance. At the next administrative level, Township Medical Officers each month had to process and review these variables, plus 786 more variables on township-level activities, for a total of 1946 variables. The surveillance needs of the Division of Disease Control accounted for nearly 1000 of the variables sent forward by the Township Medical Officer. By the time the information was received at the national level, processed, and analyzed, and included in a detailed report, three years would pass. The information was then too dated to be used for decision-making. Although the surveillance report represented the time and effort of countless health workers, no one trusted the data.

When either too much information is requested or the local health worker does not understand the need for information, reporting quality and completeness decline. For example, in ten developing countries the estimated completeness of existing surveillance program for poliomyelitis was 1-26%, with an average of 7-8% complete (41). Nearly 93% of poliomyelitis cases were typically unreported. In Myanmar, the best reporting system was a set of monthly forms with a 10% systematic sample of discharges from the nation's 614 hospitals (12). Unfortunately, even with this system that relied on government-funded physicians, only 38% of the hospitals submitted a complete set of 12 monthly reports.

Data, Information, Knowledge, and Action

Surveillance programs by definition are action oriented. They are intended to serve as an early warning system for both raging epidemics and small outbreaks. It is easy, however, for surveillance efforts to become too complicated and loose [sic] their focus on action. Realizing the danger of too much data, EPI has stated that disease-specific reporting forms should be simplified to include only the number of cases and be limited to those diseases for which control programs exist or for which control programs exist or for which control efforts would be initiated (9). A similar caveat is given by Walsh (39), who states that "data should be collected to provide information that is essential for making decisions."

The link between data and action is not always evident. As seen in Figure 4, the flow of information starts with data, a set of discrete observations or facts on cases, deaths, and people. When processed and analyzed by

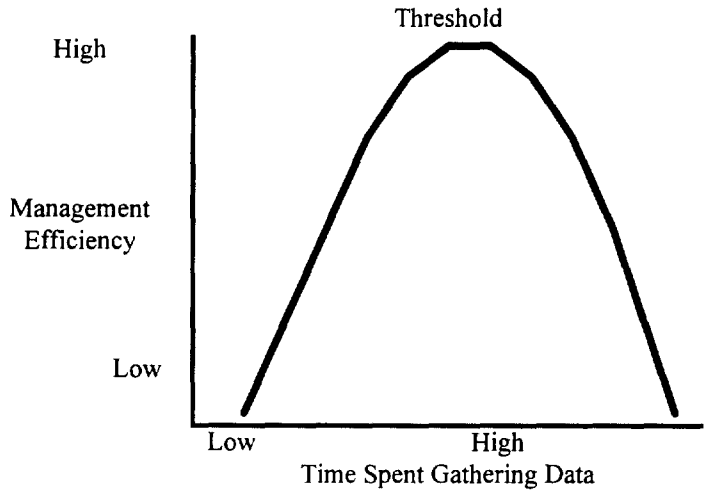

Figure 3 Effect of data gathering time on management efficiency.

epidemiologists or statisticians, these data are converted to percentages (or proportions), incidence or mortality rates, prevalence or risk ratios, or indices, such as potential years of life lost (32) or days of health life lost (24). Nothing more happens, however, unless an administrator or program manager learns of the information and absorbs it as knowledge. Action only follows if the administrator has the will and political power to act.

If the data are to result in action, various requirements must be met. First, the epidemiologist can help determine a minimum data set essential for decision-making, but cannot control the quality or timeliness of data gathering. This requires highly motivated health workers and good supervisors. Once the data are collected, the epidemiologist must turn them into information that communicators clearly to the administrator. In much of the developing world, however, surveillance data are presented in complicated tables that are hard to read and do not point to any specific action. Thus, the administrator will often move on to other matters and either delay a decision or allocate the same resources as in the past. Such decisions are especially harmful if diseases are flourishing at epidemic levels.

Graphs are the best way to present surveillance information. At minimum, every health region should have on their wall a graph showing the time trends for each disease in the surveillance system. If the disease is common, there also should be a line to distinguish epidemic levels from nonepidemic levels. Such information can easily be understood by health workers and administrators.

Action requires more than local health workers and an epidemiologist. Resources are usually scarce and there are many demands for program funds that must be satisfied by the administrator. The epidemiologist can do much, however, to guide program managers and administrators. Tugwell and colleagues have provided a framework to guide the decision-making process, which assumes that the goal is to reduce the burden that illness places on people at the community level (38).

USE OF MICROCOMPUTERS FOR SURVEILLANCE

Although much can be done in developing countries with minimal data sets, committed personnel, and active supervision, additional advances in surveillance programs can be brought about by the use of microcomputers. In the past decade, microcomputers have become increasingly important in developing countries. These small, inexpensive computers have the potential to revolutionize surveillance activities, as they have done for the epidemiological research. In 1984, Frerichs & Miller (19) brought a microcomputer to Bangladesh and proved that health

professionals who had never before used a computer could be taught in a short time to use this technology for epidemiologic research, data management, graphical presentations, and statistical analyses. In 1985, Gould and Frerichs (25) reported that the Bangladesh investigators were continuing to use the computer for both education applications and many research-oriented tasks.

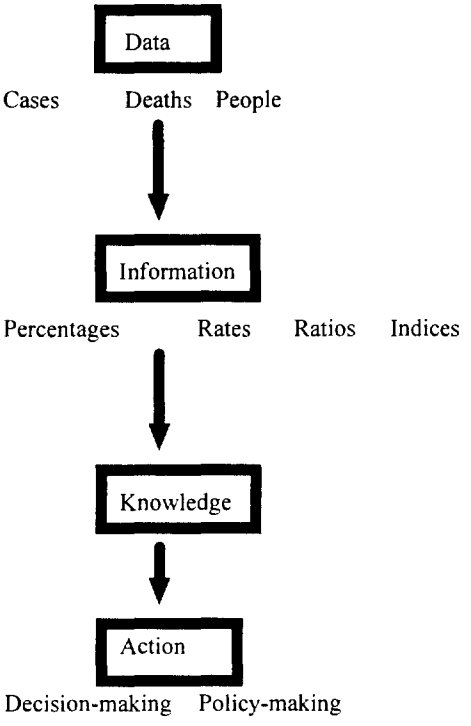

Figure 4 Link between data, information, knowledge, and action

Also, during the mid-1980s, Bertrand and colleagues were using microcomputers in Africa and South America for population-based surveys (1) and for management and planning purposes (2). They included an extensive surveillance program in the Sahel region of Africa to provide early warning of famine for relief projects (W. Bertrand, personal communication). Frerichs & Selwyn (20) recently have summarized many ways microcomputers serve the field of epidemiology, including data processing and analysis, program management, graphical presentations, and computer-assisted surveys.

Thacker & Berkelman (37) commented that the use of computers has increased the timeliness of data collection and analysis and has decreased the reliance of epidemiologists on programmers and statisticians for analysis and interpretation of findings. User-friendly software has allowed the epidemiologist to manipulate and analyze data for biologically-rather than statistically-significant relationships. Once, surveillance activities were hampered by lack of software; this problem no longer exists. Many types of database management programs are readily available from software vendors, along with teaching guides and reference manuals. Most of these programs, however, are costly and limited to data management. An exception is *Epi Info*.

Epi Info

Dean and colleagues at CDC have developed *Epi Info*, a multipurpose, public-domain program for word processing, database management, and statistical analysis (7). The price is minimal and includes the cost of printing the manual and preparing the computer disks for distribution. The program is used by epidemiologists around the world, including many who have been trained at CDC or by CDC personnel. The most recent version of the software was sponsored by both CDC and the Global Program on AIDS of WHO (see Ref. A). In the United States, the *Epi Info* program is of central importance to surveillance activities. Approximately 30 states use *Epi Info* to maintain, edit, and process data files containing disease reports. Every week, all 50 states send their local computer files to CDC to be merged in a standard format into a single national data file. *Epi Info* provides the standard format for the surveillance program.

For developing countries, the most recent version of the program assists with several important operations in disease surveillance. First, data from case records are entered into the computer and edited for minor errors, including duplicate entries. Second, the program processes the data and produces periodic tabulations of disease totals or disease cases. Third, frequency distributions and listings of any specified disease are produced by such variables as month, town, or city, age, and sex. Fourth, the data are converted into a standard format for submission or transmission to the national reporting office. To customize

the program for individual countries, CDC recommends contacting WHO representatives.

Spreadsheet Software

Among the most useful software for surveillance activities are spreadsheet programs, which resemble an accountant's ledger book with a large grid comprised of many rows and columns. The individual cells in the spreadsheet contain data, text, or formulas that relate the contents of one cell to others. The program allows health professionals to do a wide variety of functions without the assistance of professional programmers: data entry, editing, analysis; modeling, problem solving, and decision and analysis; preparing tables for annual reports; and generating many types of graphs. The following example will illustrate how a spreadsheet program can be used for surveillance purposes (see Ref. B).

Malaria has long been a problem in Southeast Asia. Cullen et al (6) have described an early warning system being used for malaria control in Northern Thailand for nearly a decade. The system is supposed to identify epidemic levels of the disease early enough so that remedial actions can prevent further spread. Following the scheme shown previously in Figure 1, the sensor is the local reporting of malaria cases (persons who are slide-positive for *Plasmodium falciparum* or *vivax*). The reference signal is the data flow from the field to the centralized processing unit at the district level. The monitor compares the observed number of malaria cases with the expected number based on nonepidemic monthly levels. Thus, the monitor attempts to determine if there are excess cases attributed to an epidemic. When the excess cases are detected, a reference signal is sent to the controller. The controller uses the information to initiate control measures, including the use of antimalarial drugs and vector control procedures.

A typical procedure for deriving excess cases is shown in Figure 5 with fourfold table common to epidemiology. The population in a given area is viewed during two time periods, when malaria is and is not at epidemic levels. During the epidemic period, persons living in the area who get malaria are listed in cell A while those who avoid the disease are in cell B. During the nonepidemic period the same two groups are cited in cells C and D. Thus, the total population in the area during the epidemic and nonepidemic periods is A + B and C + D, respectively. All persons in cell A had malaria. If the disease had not been epidemic, some of the persons in cell A might still have contracted malaria. These are expected or background cases. The expected cases, A_0, are derived by multiplying the malaria incidence rate during the nonepidemic period times the number of persons living in the region during the epidemic period. The excess cases, A_1, are the observed cases in cell A minus the expected cases, A_0. The excess cases represent the best estimate of cases attributed to the epidemic. By recognizing these excess cases at an early stage of the epidemic, the program manager can initiate control procedures to limit the size and duration of the epidemic.

Unfortunately, the calculation of excess cases used in actual surveillance programs is more complicated than the above-mentioned malaria example. Usually there is considerable variation from month to month in the occurrence of malaria. If the surveillance system is not very specific and identifies every increase as an epidemic, then control procedures will be initiated too frequently. That is, a nonepidemic rise will be falsely labeled as an epidemic (a false-positive epidemic). Conversely, if the surveillance program is too insensitive, then an actual epidemic will not be detected early enough (a false-negative epidemic). Cullen et al (6) also presented several, more realistic methods for determining excess malaria cases. One was favored, however, and is included here to illustrate the use of spreadsheet software (see Ref. B).

EXCESS CASES

Record keeping has been excellent in the Li District of northern Thailand for many years, which has provided Cullen et al with accurate data on the number of malaria cases. The monthly cases for nine years (1973-1981) are listed in Table 1 and shown in Figure 6. Although there was regular seasonal variation in malaria from 1973-1976, the peaks and valleys apparent in Figure 6 did not represent epidemic years. The data show that there were epidemics in 1977, 1978, and possibly 1981,

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with many more cases than expected. To derive the expected cases during 1977-1981, Cullen et al used monthly data from 1973-1976, the nonepidemic years. For each month, they determined the mean and the standard deviation of cases that occurred during the four year period. Taking January as an example (see Table 1), there were 10 cases in 1973, 8 in 1974, 21 in 1975, and 24 in 1976. The mean for the four years was 15.8 cases (i.e. 63/4) with a sample standard deviation (SD) of 7.9 cases. Assuming case incidence is normally distributed, 95% of the cases per month during nonepidemic years would be expected to occur within plus or minus 1.96 SD of the mean (rounded to 2 by Cullen et al). This implies that 97.5% of the monthly malaria figures during nonepidemic months would fall below the mean plus 2 SD. Thus, the mean plus 2 SD is the upper limit of monthly expected cases, which accounts for normal variation from one month to the next. Cases above this expected limit are termed excess cases.

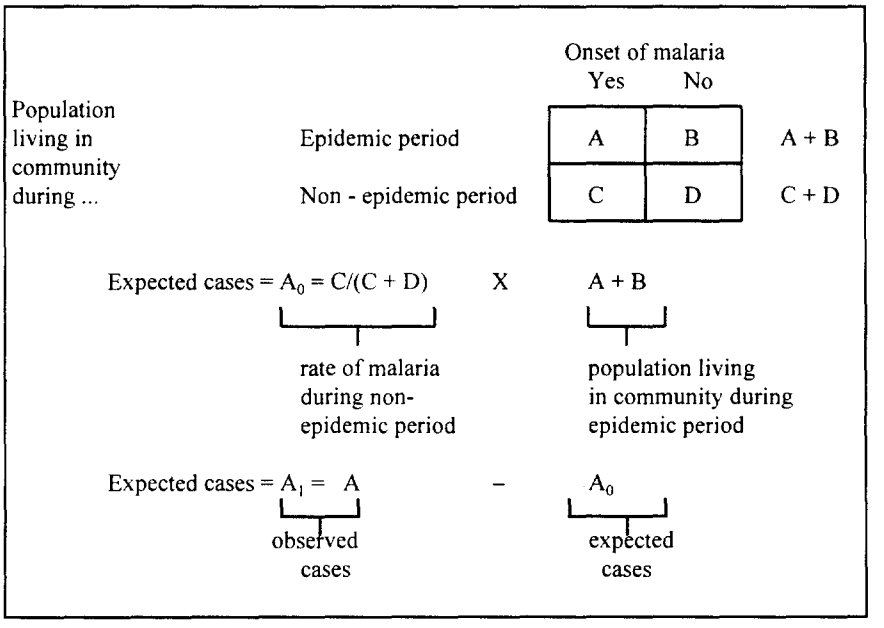

Figure 5 Determination of excess cases attributed to an epidemic.

EARLY WARNING Using the spreadsheet program, the expected and excess cases are derived for Li District data for the years 1973-1981 (see Figures A-D in the Appendix.) Starting in January 1977, there were several months when observed malaria cases exceeded expectation. As shown in Figure 7 there were 16 excess cases in January 1977, followed by both small and large increases in 1977-1978 and in 1981. Because the intention of a surveillance system is to provide early warning of an epidemic, a graph limited to excess cases provides a clearer reference signal for the controllers. Figure 7 shows such a graph, which includes an arrow pointing to the start of the epidemic. Figures 6 and 7 are the two graphs that would routinely be used by the malaria surveillance system.

In using this approach (although not with a spreadsheet program), Cullen et al pointed out that remedial actions could have been introduced in the first few months of 1977, rather than two years later in February 1979, as actually occurred (6). If the spreadsheet program had been available in Thailand and used to produce monthly tables and graphs, it might have been much easier to convince the local district administrator that action was needed. The ease and timeliness of producing these graphs points to the value of.

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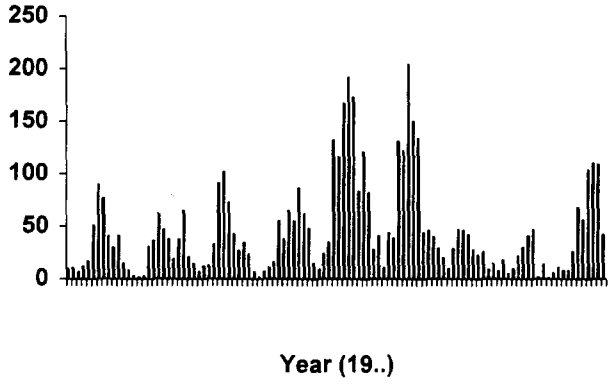

Figure 6 Slide positive malaria cases, Li District, northern Thailand, 1973-1981.

Table 1 Number of malaria cases per month for the years 1973-81 in Li district of northern Thailand (6)

Year	Jan.	Feb.	Mar.	Apr.	May	June	July	Aug.	Sep.	Oct.	Nov.	Dec.	Total
1973	10	11	7	12	17	51	90	77	41	30	41	15	402
1974	8	3	2	3	31	37	62	47	38	19	38	65	353
1975	21	15	7	12	13	33	91	102	73	43	27	35	472
1976	24	7	2	7	11	16	55	38	65	55	86	62	428
1977	48	15	9	24	35	132	116	167	192	173	83	121	1115
1978	82	28	41	11	44	39	131	122	204	150	134	44	1030
1979	46	40	29	20	10	29	47	46	42	28	23	26	386
	9	15	8	18	5	10	22	30	41	47	2	14	221
1980	1	6	11	8	8	26	68	56	104	110	109	42	549
1981													
Mean[a]	15.8	9.0	4.5	8.5	18.0	34.3	74.5	66.0	54.3	36.8	48.0	44.3	413.8
SD[b]	7.9	5.2	2.9	4.4	9.0	14.4	18.7	29.2	17.4	15.6	26.0	23.7	49.7
Mean + 2SD[c]	31.6	19.3	10.3	17.2	36.0	63.1	111.9	124.4	89.0	68.0	100.1	91.7	513.2

[a]Mean calculated for 1973-1978 (see text)
[b]Sample standard deviation for 1973-1978
[c]Mean plus two times the sample standard deviation for 1973-1978.

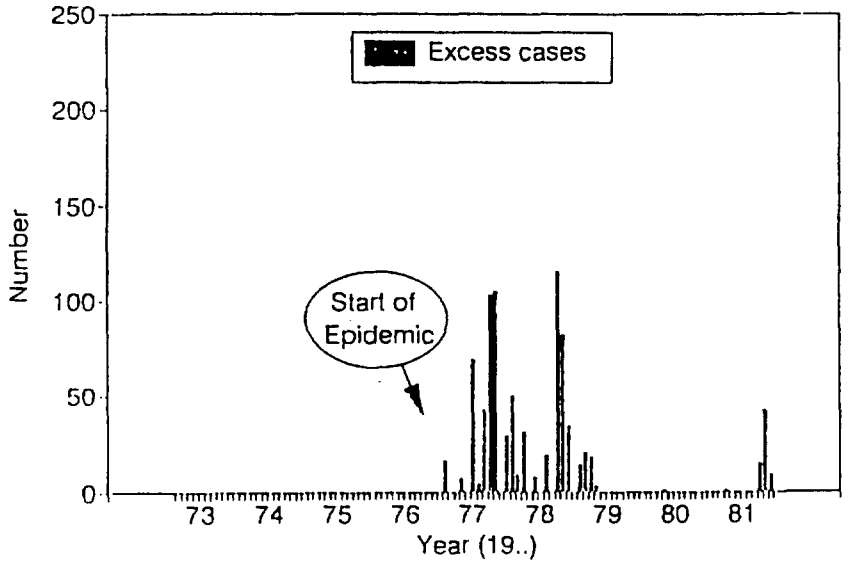

Figure 7 Excess malaria cases, Li District, northern Thailand, 1973-1981.

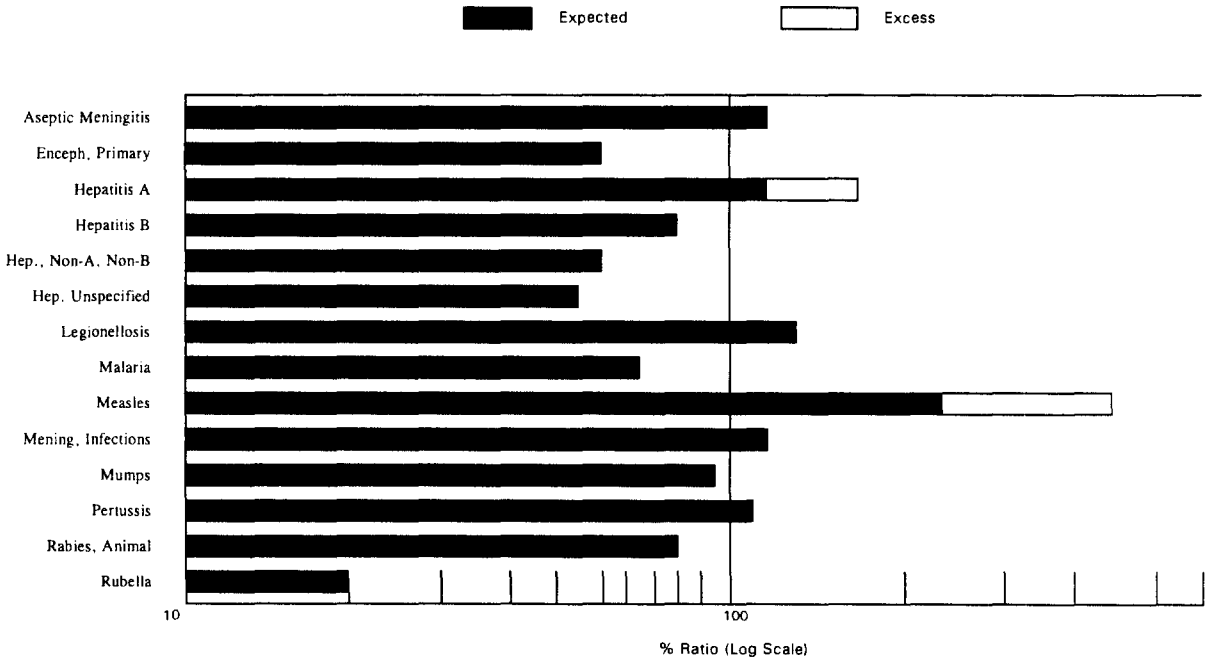

Figure 8 Expected and excess cases of notifiable diseases.

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microcomputers for surveillance efforts

Graphics Software

Graphics programs are another useful category of software for surveillance activities. Besides conventional line and bar graphs, which are featured in most spreadsheets programs, this software is used to display a wide variety of two- and three-dimensional graphs. The CDC uses many graphs in the *Morbidity and Mortality Weekly Report* to notify local officials of pending health problems. Being a large agency in a wealthy country, they have computer programmers on their staff to develop specially-designed maps, graphs, and tables. Their output is generated by large computer and special graphics plotters and laser printers, none of which are available in most developing countries. Although the specific hardware and software CDC uses to display information are not readily available, commercial graphics software can often provide an acceptable substitute. Figure 8 shows a horizontal bar graph produced by one such program (see Ref. C) that is similar to the CDC surveillance graph for notifiable diseases (4). Each week, a ratio is derived of observed cases during the past four weeks to a historical average of comparable four-week periods during the prior five years. If the ratio is within normal limits, the horizontal bar for the ratio is black. If the disease has become epidemic with many excess cases, a hatched-line pattern is used to show the excess. This graph and the publication in which it appears would represent the error signal of a notifiable disease surveillance program

A related software is the mapping program, which is used to construct and print maps of disease patterns for a given geographic area. Computer maps are a modern version of pin maps. Pins with colored heads are typically tacked in a map board to show where disease cases occurred. Different colored heads on the pins are used to designate different diseases or different groups, such as young children or males and females. Most surveillance in the developing world rely on both bar or line graphs and some form of pin map to show their findings. The former shows the trends over time for an entire region; the latter shows the location of the individual cases. With graphics and mapping software, both figures could quickly be generated every week and shared with local decision-makers.

SAMPLE SURVEYS TO SUPPLEMENT SURVEILLANCE

Sample surveys can provide important data to supplement information derived from a surveillance system. Even when surveillance is effective, however, more information may be needed to plan and implement control efforts or to evaluate their impact on the population once the control program is in place. Surveys can provide this kind of information. Surveys may also be vital in countries that derive their surveillance data from weekly hospital or clinic reports, rather than from a population sample. Such surveillance systems typically under-report disease cases by excluding persons who do not come to the facilities for medical assistance. Finally, surveys may provide the only source of factual information in the economically poorest countries; surveillance programs in these countries are often so inadequate that they are rarely used for decision-making. Here the governments may find that it is easier and less costly to hire and train a small survey team than to rely on a large surveillance system that cannot be effectively managed.

Large population-based surveys have been performed in many developing countries (28,33). Examples include an extensive survey by Frerichs et al in a rural region of Bolivia (15-18), serological surveys for HIV infection in Rwanda (34), and more recently a series of demographic and health surveys being done at the national level in many developing countries by the Institute for Resource Development (27). Although these surveys do not represent surveillance efforts, they do provide useful supplementary information. Unfortunately, these large surveys of several thousand persons are costly and often require a year or more before a final report appears with the study findings.

Small, two-stage cluster surveys have been widely used by various groups in WHO to gather data on immunization coverage, diarrhea and diarrhea control procedures, neonatal tetanus, lameness (poliomyelitis), and related activities (29). These surveys fill the

information void left by limited or inadequate surveillance systems; they provide population-based data and are typically completed in a few months. The completion time was reduced even more by Frerichs and colleagues who used portable, battery-powered microcomputers to complete WHO-style surveys in a few weeks (13, 14, 21-23). Typically, they would take 3-4 days to conduct the interviews or examinations, and use a portable microcomputer to enter and edit data every afternoon or evening. On the fifth day, they present their findings in graphs and simple tables to the local medical officer and interested community members. During the following 4-5 days, they use the microcomputers and commercial software to complete the analysis, prepare tables and graphs, and produce a final written report. This form of sampling, termed "rapid survey methodology," provides yet another information source for administrators in developing countries who are faced with the time-delays and poor data quality of many surveillance programs.

UTILITY OF SURVEILLANCE PROGRAMS

For infectious disease, the early warning provided by surveillance systems allows program administrators time to start various control activities. These activities may include isolating infective cases, immunizing children, spraying pesticides, chlorinating wells, restricting food-handlers, and eliminating open sources of open water. The desired action, however, is less clear for many of the noncommunicable disease surveillance programs typically found in more developed countries.

Surveillance programs are rarely evaluated, even those programs that focus on infectious diseases. In their extensive review of surveillance in the United States, Thacker & Berkelman (37) point out that there have been no published studies on the impact of surveillance data on policies and interventions, and very few studies that relate the cost of acquiring surveillance information to any tangible benefits.

For developing countries, the need seems more apparent. However, information on the cost and usefulness of surveillance efforts is equally scarce. Smith (36) expressed this concern for surveillance programs in developing countries: "More work is . . . needed to critically evaluate the usefulness of already existing surveillance systems. If they are found not to provide useful data, then serious consideration should be given to using available resources in other ways, such as the development of sentinel sites or periodic surveys." A related concern was voiced at a recent national epidemiology conference in Chile, which concluded that the main problem with their current epidemiologic surveillance program is that it does not lead to decision-making, or else that decisions are taken too late to have an impact on the disease (31).

In the past decade, the United States Agency for International Development funded a series of methodologic studies on rapid epidemiologic assessment (REA) in developing countries. The specific intention was to develop REA methods for health planning and decision-making and to develop or validate more efficient or innovative epidemiologic methods for making timely decisions about health problems and program for health care or disease control (35).

Surveillance systems are expensive to set up and maintain. As a result, they should be evaluated along with other programs to determine if they are fulfilling their goals. This evaluation should relate the cost of the program to the effectiveness or usefulness. For most workers, timely feedback is proof enough that the system is working and that their contributions are valued. With proper graphs, they can anticipate epidemics and perceive the effects of control strategies. For administrators, program managers, and political leaders the best indication of usefulness is that epidemics are noted early and kept under control. This control is the promise of epidemiologic surveillance. However, we need to evaluate this promise.

CONCLUSION

Epidemics can devastate a population. Death and disability can drain the vitality of a community. Economic havoc follows despair as productivity decreases and even food and shelter become scarce. Surveillance systems are designed to prevent disease and empower the people by providing

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early warning of an epidemic. The resultant extra time can be spent battling the disease while it is still at a manageable level.

A surveillance system will be effective only if the effective only if the quality of data is high, information is processed and analyzed rapidly, and the findings are clearly understood by those in power. In many developing countries, data collection and analysis are so difficult that only the most essential information should be collected: a listing of cases and deaths by cause, time of onset, and geographic area where the cases occurred. If resources are available, other related information should be considered, such as age, sex, characteristics of the agent, and circumstances leading to the disease onset. In many instances, however, the value of this additional information will not justify the added cost. When more extensive information is sought, it should be acquired in periodic community-based surveys.

Inexpensive microcomputers are being used by many national or district health departments throughout the third world. By using current computer hardware and software, surveillance data can be quickly processed and analyzed, and findings can be rapidly converted into simple, easy to understand tables and graphs. If surveillance data are believable and presented in a timely manner, administrators and program managers will be more inclined to use them to serve the community.

Appendix

Table 1 is entered into the spreadsheet program as numbers, text and formulas as shown in Figure A (see Ref. A). Rows 1 through 13 contain only text and numbers; rows 14 through 16 contain text and formulas. Figure B shows the same spreadsheet, but with formulae rather than calculations as shown in Figure A. The width of columns B through E was expanded to show the formulae. Elsewhere in the same spreadsheet, four long rows are created with the year in the top row, the observed malaria cases per month in the second row, the expected monthly cases in the third row, and the excess cases in the third row (see Figure C). Excess cases are defined as 0 if the observed cases are less than the expected cases and observed cases minus expected cases if the observed cases are greater than the expected cases. The formulae for deriving the excess cases are shown in Figure D. In words the formulae read, if observed minus expected is less than 0, enter 0, otherwise enter observed minus expected.

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A

1 Table 1. Number of Malaria cases per month for the years 1973-81 in Li district of northern Thailand

Year	Jan.	Feb.	Mar.	Apr.	May	June	July	Aug.	Sept.	Oct.
1973	10	11	7	12	17	51	90	77	41	30
1974	8	3	2	3	31	37	62	47	38	19
1975	21	15	7	12	13	33	91	102	73	43
1976	24	7	2	7	11	16	55	38	65	55
1977	48	15	9	24	35	132	116	167	192	173
1978	82	28	41	11	44	39	131	122	204	150
1979	46	40	29	20	10	29	47	46	42	28
1980	9	15	8	18	5	10	22	30	41	47
1981	1	6	11	8	8	26	68	56	104	110
Mean	15.8	9.0	4.5	8.5	18.0	34.3	74.5	66.0	54.3	36.8
SD	7.9	5.2	2.9	4.4	9.0	14.4	18.7	29.2	17.4	15.6
Mean + SD	31.6	19.3	10.3	17.2	36.0	63.1	111.9	124.4	89.0	68.0

Figure A Image on computer monitor of spreadsheet entries.

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	A				D
1	Table 3. Number of Malaria cases per month for the years 1973-81 in Li district of northern Thailand				
	Year	Jan.	Feb.	Mar.	Apr.
	1973	10	11	7	12
	1974	8	3	2	3
	1975	21	15	7	12
	1976	24	7	2	7
	1977	48	15	9	24
	1978	82	28	41	11
	1979	46	40	29	20
	1980	9	15	8	18
	1981	1	6	11	8
	Mean	@AVG(B4..B7)	@AVG(C4..C7)	@AVG(D4..D7)	@AVG(E4..E7)
	SD	@STDS(B4..B7)	@STDS(C4..C7)	@STDS(D4..D7)	@STDS(E4..E7)
	Mean + SD	+B14+2*B15	+C14+2*C15	+D14+2*D15	+E14+2*E15

Figure B Image on computer monitor of spreadsheet formulas

						1973							
Observed	10	11	7	12	17	51	90	77	41	30	41	15	continued but
Expected	31.6	19.3	10.3	17.2	36.0	63.1	112.0	124.0	89.0	68..0	100.0	91.7	shown on
Excess	0	0	0	0	0	0	0	0	0	0	0	0	next line
						1974							
	8	3	2	3	31	37	67	47	38	19	38	65	continued but
	31.6	19.3	10.3	17.2	36.0	63.1	112.0	124.0	89.0	68.0	100	91.7	shown on
	0	0	0	0	0	0	0	0	0	0	0	0	next line
						1975							
	21	15	7	12	13	33	91	102	73	43	27	35	continued but
	31.6	19.3	10.3	17.2	36.0	63.1	112.0	124.0	89.0	68.0	100.0	91.7	shown on
	0	0	0	0	0	0	0	0	0	0	0	0	next line
						1976							
	24	7	2	7	11	16	55	38	65	55	86	62	continued but
	31.6	19.3	10.3	17.2	36.0	63.1	112.0	124.0	89.0	68.0	100.0	91.7	shown on
	0	0	0	0	0	0	0	0	0	0	0	0	next line
						1977							
	48	15	9	24	35	132	116	167	192	173	83	121	continued but
	31.6	19.3	10.3	17.2	36.0	63.1	112.0	124.0	89.0	68.0	100.0	91.7	shown on
	16.4	0	0	6.78	0	68.9	4.10	42.6	103.0	105.0	0	29.3	next line
						1978							
	82	28	41	11	44	39	131	122	204	150	134	44	continued but
	31.6	19.3	10.3	17.2	36.0	63.1	112.0	124.0	89.0	68.0	100.0	91.7	shown on
	50.4	8.67	30.7	0	7.96	0	19.1	0	115.0	82.0	33.9	0	next line
						1979							
	46	40	29	20	10	29	47	46	42	28	23	26	continued but
	31.6	19.3	10.3	17.2	36.0	63.1	112.0	124.0	89.0	68.0	100.0	91.7	shown on
	14.4	20.7	18.7	2.78	0	0	0	0	0	0	0	0	next line
						1980							
	9	15	8	18	5	10	22	30	41	47	2	14	continued but
	31.6	19.3	10.3	17.2	36.0	63.1	112.0	124.0	89.0	68.0	100.0	91.7	shown on
	0	0	0	.782	0	0	0	0	0	0	0	0	next line
						1981							
	1	6	11	8	8	26	68	56	104	110	109	42	
	31.6	19.3	10.3	17.2	36.0	63.1	112.0	124.0	89.0	68.0	100.0	91.7	
	0	0	.726	0	0	0	0	0	15.0	42.0	8.92	0	

Figure C Spreadsheet entries for observed, expected, and excess cases (entered but not shown as four long rows).

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File	Edit	Style	Print	Database	Tools	Options	Window

	P			
1			Jan.	Feb.
	Observed		10	11
	Expected		31.6	19.3
	Excess	@IF((Q2-Q3)<0,0,Q2-Q3)	@IF((R2-R3)<0,0,R2-R3)	

Figure D Spreadsheet formulas for observed, expected and excess cases

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ProMIS: SOFTWARE FOR ACCOUNTABILITY

KEN HERMAN* AND DAVID MARSH**

Summary

Save the Children developed the ProMIS software program to assist monitoring the health of individuals and communities. Producing community-level reports and individual-level rosters with only a few key-strokes is among its most powerful features. We include a "hard-copy demonstration" of a Household Status Report, a community's Child Immunization Roster, a community's Immunization Coverage Rate Report, an area's Demographic Report, and an area's Death and Birth Rates Report as well as how to update an individual's vital status. ProMIS serves accountability and equity in health by highlighting individuals, communities and activities which need more resources.

Save the Children developed the ProMIS software program to assist monitoring the health of individuals and communities. A more detailed description of the program can be found in the introduction to this chapter. This paper demonstrates the types of reports and rosters that ProMIS can generate.

We considered including a ProMIS "demo" disc. However, the ProMIS program uses the computer's built-in clock to maintain accurate ages of enrollees in real time. Thus, everyone entered into ProMIS ages (along with the rest of us). Since we cannot continue to update a demonstration population with newborns, we would soon have no one under one year of age; many of the resulting ProMIS outputs would cease to be meaningful (although they would be accurate for this lop-sided population). Consequently, we opted to include only "hard copy" examples of these outputs. Even some of these are "dated" as you will see. We also include the basic commands, however, to show how easily ProMIS produces critical information to assess the status of individuals and populations.

* * *

A Household Status Report

1. Run ProMIS: type **run**
2. Access and open the *Reports* menu
3. Select the *Household* option
4. Specify the household in the *Report Specification Window*

Save the Children Federation — 6/20/90 — Page Number 1
Impact Area: 1 Mbalachanda — Sub-Area: 2 Mbalachanda
Village: 1 Yoramn Ng'Ambi — House: 2 — Group: 1

Household Status Report

#	First Name	Last Name	S	DOB	Age
1	Feathersona	Shalita	F	12/24/59	30
	Index Mother	Resident			
2	Jamilla	Shalita	M	6/11/50	39
	Spouse	Resident			
3	Trell	Boykin	M	5/23/55	
			Event	Date	
			Out-Migrate	03/26/90	
4	Willice	Shalita	M	11/01/79	10
	Child	Resident			
5	Gatris	Shalita	M	03/03/82	8
	Child	Moved-out			
			Event	Date	
			Moved Out	03/26/90	
			In-Migrate	02/21/89	
			Out-Migrate	4/14/88	
6	Habia	Shalita	F	02/14/85	
	Child	Dead			
			Event	Date	
			Died	05/02/90	

Figure 1. Sample Household Status Report produced for a single Group.

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** *Epidemiologist, Health, Population, Nutrition Unit, Save The Children.*

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The Household Report (Figure 1) is arranged by group and includes information for each person. The # indicates the person's line (individual) number on the Summary Screen. Also included are first name, last name, sex, date of birth and age. Age, which is as of the date on which the report was printed (June 20, 1990), is only shown for individuals with the status of Resident. Each vital event (birth, move, in-migration, out-migration, or death) and the date on which the event occurred are included for the individual with whom it is associated. For example, individual #5 was born in 1982. He migrated out of the impact area in 1988, migrated back in to the area in 1989, and moved out of the house (but remained in the area) in 1990. Since he is still a resident of the impact area, his age is reported. On the other hand, individual #3 was born in 1955 and out-migrated in 1990. Since he was no longer a resident, his age was not reported. Likewise individual #6 died at age 5 years (May, 1990). Since she was no longer a resident at the date of the report, her age was also not calculated.

* * *

A Child Immunization Roster

1. Access and open the *Roster* menu on top menu bar
2. Select the *Child Immunization* option
3. Specify the impact area and community in the *Report Specification Window*

Save the Children Federation/USA 07/13/93
Group continued from other page. Page Number : 2
Département : 01 Dori
Village : 01 Dantchadi

Child Immunization Output

Line	Name	Sex	Age	BCG	DPT1	DPT2	DPT3	OPV1	OPV2	OPV3	Measles	Fièvre Jaune
031*10* 5	Hadjatou Boureima	F	27	05/30/91	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /
032*02* 3	Mamoudou Amadou	M	24	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /
034*04* 4	Hadjatou Boureima	F	32	02/22/91	02/22/91	05/30/91	/ /	02/22/91	05/30/91	/ /	/ /	/ /
034*05* 4	Fatimata Moussa	F	30	02/22/91	02/22/91	05/30/91	/ /	02/22/91	05/30/91	/ /	/ /	/ /
034*06* 3	Hamadou abdouramane	M	27	05/30/91	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /
036*01* 3	Hamadou Boureima	M	48	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /
037*01* 6	Moussa Hama	M	28	05/30/91	05/30/91	/ /	/ /	05/30/91	/ /	/ /	/ /	/ /
037*04* 3	Aissatou Boureima	F	42	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /
037*05* 4	Aissatou Boubacar	F	22	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /
037*06* 3	Aminata Amadou	F	45	11/10/89	11/10/89	01/20/90	05/27/90	11/10/89	01/20/90	05/07/90	/ /	/ /
039*03* 3	amadou Hamadou	M	43	05/07/90	05/07/90	11/26/90	02/22/91	05/07/90	11/26/90	02/22/91	11/26/90	11/26/90
039*05* 2	Aissatou Boureima	F	45	05/27/90	01/20/90	05/07/90	11/27/90	01/20/90	05/07/90	11/27/90	/ /	/ /
040*01* 6	Djeneba Welinde	F	23	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /
041*02* 4	Amadou Mamoudou Dit	M	23	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /
042*01* 7	Mariama Mamoudou	F	26	05/30/91	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /
043*02* 3	Fatimata Hamadou	F	33	02/22/91	02/22/91	05/30/91	/ /	02/22/91	05/30/91	/ /	05/30/91	05/30/91
044*01* 5	Abdoulaye Hama	M	27	05/30/91	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /
045*01* 6	Haoua Abdoulaye	F	27	05/30/91	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /
045*05* 6	Hadjatou Hama	F	41	11/27/90	11/27/90	02/22/91	05/30/91	11/27/90	02/22/91	05/30/91	11/27/90	11/27/90
046*02* 3	Hadjatou Amadou	F	26	05/30/91	/ /	/ /	/ /	/ /	/ /	/ /	/ /	11/27/90
052*02* 8	Hadjatou Hamidou	F	23	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /
054*02* 5	Hadjatou Amadou	F	24	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /
054*03* 7	Mariama Hamidou	F	24	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /
055*01* 7	Mairama Moussa	F	46	11/27/90	11/27/90	02/22/91	/ /	11/27/90	02/22/91	/ /	02/22/91	02/22/91
056*01* 4	Boureima Alou	M	31	02/22/91	02/22/91	05/30/91	/ /	02/22/91	05/30/91	/ /	/ /	/ /
058*02* 3	Fadima Hama	F	23	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /
059*03* 6	Moussa Amadou	M	39	11/27/90	11/27/90	02/22/91	05/30/91	11/27/90	02/22/91	05/30/91	11/27/90	11/27/90
060*07* 3	Hamadou Boubacar	M	42	11/27/90	11/27/90	02/22/91	/ /	11/27/90	02/22/91	/ /	/ /	/ /
061*04* 4	Mamoudou Amadou	M	25	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /
061*05* 3	Fadima Hama	F	32	02/22/91	02/22/91	05/30/91	/ /	02/22/91	05/30/91	/ /	/ /	/ /
061*06* 3	Fadima Boubacar	F	35	11/27/90	11/27/90	/ /	/ /	11/27/90	/ /	/ /	/ /	/ /
061*07* 3	Fadima Mamoudou	F	48	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /
062*02* 4	Hama Hamidou	M	28	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /	/ /
067*01* 7	Mamoudou Hamidou	M	32	02/22/91	02/22/91	05/30/91	/ /	02/22/91	05/30/91	/ /	/ /	/ /
Percentage Immunized				% 61.8	% 44.1	% 38.2	% 14.7	% 44.1	% 38.2	% 14.7	% 14.7	% 17.6

Figure 2. Sample Child Immunization Output.

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This roster (Figure 2) allows the assessment of *individuals'* immunization status. It lists the household numbers, line numbers, names, sex and ages in months of each child from the community. Beside the name of each child is a column for each immunization. If the child has been immunized, the date of immunization will appear here. The last row of the report lists the percentage of children in the community that have been immunized for each immunization. Note that these immunization coverages do not take into account the children's ages. For age-specific, immunization-specific coverages, see the Immunization Coverage
Rate Report (below).

The odd age distribution of this village's children (i.e. no one under age 22 months) reflects the fact the report was generated from a database which had not been updated in about 2 years. Indeed, 10 of the 13 who had had no immunizations were 23-24
fact the report was generated from a database which had not been updated in about 2 years. Indeed, 10 of the 13 who had had no immunizations were 23-24 months of age, which would have been appropriate two years ago when they were newborns (except for BCG). Obviously field programs continually update their programs to guide their activities. The home office (where this example was prepared), however, has a collection of "aging" data sets.

* * *

An Immunization Coverage Rate Report

1. Access and open *Reports* menu on top menu bar
2. Select the *Immunization Coverage Rates* option
3. Select impact area and community in the *Report Specification Window*
4. Select output to screen

Immunization Coverage Rate
24/05/94

Antigen	0 - 11 #	0 - 11 %	12 - 23 #	12 - 23 %	24 - 59 #	24 - 59 %
Total Number	13		33		97	
BCG	6	46.2	23	69.7	72	74.2
DPT1	6	46.2	24	72.7	70	72.2
DPT2	2	15.4	22	66.7	67	69.1
DPT3	2	15.4	21	63.6	66	68.0
OPV1	6	46.2	23	69.7	69	71.1
OPV2	2	15.4	22	66.7	68	70.1
OPV3	2	15.4	20	60.6	66	68.0
Measles	0	0.0	14	42.4	65	67.0
Fully Immun.	0	0.0	12	36.4	65	67.0
No Immun.	7	53.8	9	27.3	25	25.8

Figure 3. Sample of Immunization Coverage Rates Report

The Immunization Coverage Rate Report (Figure 3) includes age-specific coverage from birth to 11 months, 12-23 months, 24-59 months, and total coverage by each immunization. It also provides age-specific rates for complete and for no immunizations. For example, this community of 143 children has 67% fully immunized and 26% with no immunizations, leaving 7% with partial coverage. Fifty-four percent of infants have had no immunizations at all, a major challenge for the program.

Depending on the area specified in the Report Specification Window, the geographic area can be as large as the whole impact area or as small as a sub-household group. The rate report describes the specified community as a whole and does not allow assessing the status of individuals (for which the roster is needed [Figure 2].)

An Area's Demographic Report

1. Access and open the *Reports* menu
2. Select the *Demographic - All* option
3. Select whole impact area in the *Report Specification Window*

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Impact Area: ALL
Sub-Area: ALL
Village: ALL
Demographic Report - Total Population

Age Range in: From	Years Upto	Females	Males	Total	% of Totals
0	4	1205	1400	2605	3.0
5	9	2923	3533	6456	7.5
10	14	2155	1999	4154	5.0
15	19	2289	2275	4564	5.4
20	24	3867	4024	7891	9.3
25	29	4274	4161	8435	10.0
30	34	3966	4128	8094	9.9
35	39	3854	3041	6895	8.1
40	44	3765	3821	7586	8.9
45	49	2625	2924	5549	6.5
50	54	2865	2880	5745	6.8
55	59	2895	2720	5615	6.6
60	64	1411	1296	2707	3.1
65	69	1871	2050	3921	4.6
70	74	1240	1233	2473	2.9
75	999	1021	1002	2023	2.4
Total		42226	42487	84713	100

Figure 4. Sample Demographic Report - Total Population.

The Demographic Report for the total population (Figure 4) includes the areas included and the age ranges with the corresponding numbers of males and females with totals and total percents for each range. If community sub-totals were selected, a separate report would be produced for each.

One can select Demographic Reports for children under age 5 years in which the standard age range is 6 months. One can also choose a user-defined Demographic Report in which one chooses non-standard age intervals of interest (i.e., 0-4 years [child], 5-14 years [school-age], 15-59 years [adult], and 60+ [elder]).

An area's *Death and Birth Rates Report*

1. Access and open the *Reports* menu
2. Select the *Rates* option
3. Specify whole impact area in the *Report Specification Window*

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Impact Area: 1 ALL
Sub-Area: 1 ALL
Village: ALL

Death and Birth Rates Date Range: 08/01/89 - 08/01/90

Total Mid-Year Population	3076
Total Mid-Year 1-4 Population	401
Total Number of Live Births	141
Total Number of Deaths	50
Total Number of Deaths of Under 1's	21
Total Number of 1-4 Deaths	6
Infant Mortality Rate 148.9	
Child Mortality Rate 42.6	
Under 5 Mortality Rate	191.5
Crude Death Rate	16.3
Crude Birth Rate	45.8

Figure 5. Sample Rates Report.

The Death and Birth Rates Report gives numerators, denominators and rates for natality and mortality. The derived mid-year populations (total and for children 1-4 years of age) for a specified area in a designated year are the averages of the populations on the report date and one year prior to the report date. Numbers of live births, total deaths, deaths to infants and deaths to children 1-4 years of age are shown as well as the derived: (1) *infant mortality rate* and *under five mortality rate* (infant deaths per 1000 live births per year); (2) the *child mortality rate* (1-4 year old deaths per 1000 live birhts per year); (3) *crude death rate* (total deaths per 1000 total population per year) and (4) *crude birth rate* (total live births per 1000 total population per year).

Updating an individual who has out-migrated

1. Access and open the *Group* menu
2. Select the *Add/Update* Option
3. Specify impact area, community, house, household group
4. Select individual
5 Access and open the *Individual* menu
6. Access and open the *Out-Migrate* program
7. Enter and confirm date of out-migration
8. Quit ProMIS: Access and open *Edit* Menu on top menu bar and select *Quit*

Reports and rosters may be produced in a variety of ways: to the screen; to a printer or to a file for later viewing, printing or analysis. Some reports may take several hours to complete (e.g., immunization coverage in an impact area) because they must calculate information on tens of thousands of individuals. Be sure to run these at a time when you will not be needing the computer for a while. The Processing Report Window indicates how much of the report of roster has been completed.

The figures shown above are examples only. Additional reports and rosters (not shown) include: Growth Promotion Statistics Report by geographical area; Growth Promotion Roster to identify individuals; Cause-Specific Death Rates Reports (for ages under 5 years and 5 and above years) by geographical area; Cause of Death Rosters to identify individuals; Pregnancy History (including family planning) Roster; Pregnancy Maintenance Roster and Women's Tetanus Roster — all to identify individuals.

* * *

The rosters and reports from ProMIS serve equity in health by identifying individuals, communities, and activities in need of more resources. They serve accountability by conveniently providing key indicators by which managers, donors, governments, communities and peers can measure program's effects. ProMIS is a tool to strengthen population-based health and health information systems.

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Conclusions and Next Steps

Save the Children has made a lasting contribution to community-based health information systems. The institution neither "invented" the notion nor pushed it to the frontiers of science. However, we have staked our reputation on it. And we will continue to espouse it as the "worst [system], except for all the others." This aphorism, borrowed from Winston Churchill's defense of democracy as a form of government, is fitting. Indeed, a community-based health information system is admittedly a political venture based on those democratic principles which are increasingly valued and widely, perhaps universally, applicable.

Summary

This Compendium has taken us through the recent **history** of community-based health information systems. We saw that such information systems pre-dated the codification of Primary Health Care at the 1978 Alma-Ata Declaration, but then, so did primary health care systems themselves. Nonetheless, the history of inclusive information systems is naturally intertwined with inclusive health systems. Indeed, one is hard-pressed to speak of one without the other. One cannot claim to have a population-based health system without the "proof." The information system provides this proof (and much more).

The **rationale** for such information systems borrows heavily from Primary Health Care's (PHC) justification. Community-based health information systems serve *equity*: care according to need and universal coverage. This is distinguished from care for those who can afford it. It is not even *equal* care for all. Rather it is *some* care for everyone and *more* care for those in special need. Medicine teaches that everyone faces certain health threats, but epidemiology teaches that risk is unevenly distributed. Equity has a sound ethical and epidemiological basis. Both PHC and community-based health information systems embrace other related concepts, each of which supports equity: accessibility, affordabilty, acceptability, participation, and quality. One cannot envision an equitable system that lacked one of these attributes.

The applied **experience** of Save the Children and other private voluntary organizations with community-based health information systems gets beyond PHC jargon. Field implementation imperfectly reflects blue-prints, ideal as they are. Field lessons reveal that information systems may be: slow to "get up and running;" overloaded with too many numbers; underutilized for decision-making; susceptible to errors; and/or distracting. On the other hand, they do guide house-hold interventions to those most in need (the pregnant, the malnourished, the measles-susceptible, for example). They inform managers about allocating resources. They show health teams where they have been, where they are, and where they are headed.

Perhaps most importantly, they force communities and community-member-grass-roots health workers to "confront the fundamentals: *vital events*" (Donna Sillan, personal communication, 1995). The actual numbers may be less valuable than reflecting on who is dying or giving birth and why? While the former is of keen interest to managers and scientists, but the latter may yield "development." Problem identification, naming, and discussion are prerequisites for response. Settings where Save the Children works are often characterized by helplessness and hopelessness due to poverty, violence, suffering and social systems that discourage debate and action. Just as a community's response to information (at a *meso*-level) can propel its empowerment, so a community health worker's response to information (at a *micro*-level to make decisions on behalf of her beneficiaries) can drive her empowerment. Health information begets health education.

Community health workers have been an integral component of Save the Children's health information systems. CHWs have been successful in outreach activities because the communities value the friendship, trust, and respect they bring to their task, and the CHWs share in the mutual responsibility for behavioral change and desire for community improvement. The CHWs are readily available and responsive

to their communities and have the ability to address economic, social, cultural and development conditions often outside of the responsibility, expertise and interest of most health professionals.

CHWs serve as a link between individuals, families and communities on one hand and primary health care providers on the other. The information system is dependent on their creativity and motivation to reach out and transmit public health messages to their communities and then to communicate relevant information back to the medical establishment providing a feedback system for joint action and decision making. The CHWs serve as a bridge in an information system that enables communities to identify their own needs and to implement their own solutions while enabling the medical establishment and formally trained workers to provide appropriate levels of care.

To be sustainable, the CHW program must receive ongoing and adequate supervision. Quality of services and information must be assured, and on-the-job training must be provided to CHWs to monitor appropriateness and relevance of health messages. Save the Children's experience has demonstrated that the CHW's work and information exchange role is most successful when a multi-level system of supervision is established. This system includes political support and supervision (via a civic official), technical support (via the Ministry of Health), managerial support (via accountability to community-based committees and organizations) and financial support (via communities). Since these community-based workers are for the most part unpaid, a supervision system must reward their motivation, reinforce their sense of commitment and provide non-material incentives to be sustainable.

We believe that community-based health information systems are the *sine qua non* for (probably) all equitable health systems and services. As necessary as they are, they are not sufficient, however. Other **methods** must supplement to validate, detail, and explain the numbers. A strange phenomenon can occur in the field: the numbers can become the focus of a program. Field managers must force themselves to ask questions. Are these data *accurate*? Are they *complete*? *Why* are there differences in accuracy and completeness by community? *Why* are there differences in vaccine coverage? *Why* are diarrhea episodes clustered in time and place? *Why* are women no longer attending health promotion sessions? The numbers will not answer such questions. Indeed, the numbers will not even *ask* the questions. Thoughtful workers and managers must bring prepared minds to the tables and bar charts. Interpreting the distribution of the numbers may require expert opinion (often available within the team) and possibly additional "studies" such as focus group discussions or lot quality assurance sampling.

Computerization is a lively topic in the field. Among Save the Children's programs, Malawi declined to use computers to track individuals while Bangladesh opted to computerize a large sentinel sample of individuals. Both settings use computers, however, to manage and analyze census data and to analyze and display reports. Setting up an information system is complex, especially in the constrained settings typical of where private voluntary organizations work. A computerized system is an additional layer of complexity which projects on brief three year time-tables may be slow to consider. Increased computerization is inevitable, however, in light of recent history. We believe that our software, ProMIS, is well suited to address the everyday needs of most population-based health programs, both the needs of managers to review community-level indicators and the needs of workers to prioritize their interventions.

True to democratic principles, not all health systems and information systems need look alike. Indeed, we have much to learn from **alternative systems**. Much of what we have already learned reinforces our notion that population-based systems excel in guiding services at the individual level. Alternative systems can provide useful proxies for population-based indicators; however, there is no substitute for actual counts of numerators and denominators if they are affordable. Indeed, the affordability question looms large in any debate comparing systems. To date this has been insufficiently addressed although we have the encouraging report from the Mali immunization experience. Nonetheless, the preconditions of the debate must be clear as these will weigh in the balance. That is, if epidemiological and/or

ethical reasons demand that services be provided to all, then one is more prepared to support the cost of an information system that guides such an undertaking. On the other hand, severely constrained budgets are often played out in systems that serve neither health nor equity.

In summary, community-based health information systems grew from a need to achieve equity in health in a participatory, accountable way. Save the Children seeks social justice by providing services to those most underserved and by empowering the powerless all while demonstrating responsible stewardship before beneficiaries, intervention team, government colleagues, and donors. Our planning cycle of community diagnosis, risk group identification, response implementation, and monitoring rely on community-based health information systems. Problem identification is guided by local ecology, community perceptions, and baseline census supplemented by other surveys. Risk group identification directly depends on the baseline census and longitudinally tracking vital events and identifying pregnancies. Program implementation rests on specifying individuals and individual groups for services as well as supporting individual workers and program components as needed through analyzing the appropriate aggregations and break-downs of information. Program monitoring includes much of the implementation activities as well as reviewing population-level indicators to measure outcomes, coverage, and impact. The central role of a community-based information system at each step is apparent.

Open Questions

This Compendium is hardly the final word on this vast and important topic. Rather it is a private voluntary organizations' attempt to signal the concept afresh in an increasingly favorable democratic global context which ironically includes worsening health conditions for huge regions and populations. Save the Children has taken its stand in favor of health information systems which track individuals because we believe in equity. We are anxious to consider new evidence. Radically different systems or slightly modified systems may reach similar ends. We urge others to compile the next Compendium, particularly if it will address some of the following questions.

- How much equity can be achieved without a community-based health information system?

This is a fundamental question. Are there communities or settings where facility-based or service-based or "other-based" health systems and information systems will achieve equity in health? Put another way, must we have household level services? We have shown that non-population-based systems can work for providing reliable estimates of certain disease burdens. But this answers a different question.

- How much can we stream-line community-based health information system?

Invariably, start-up experience with household-level information systems is overloaded with information. Even when managers know to expect and to avoid this, it happens anyway. How can we reward managers who achieve the same results with fewer numbers and sanction (gently) those who do not? The stakes are not trivial. Too much information deflects resources. It distracts and possibly demoralizes workers. One recent suggestion is to eliminate columns for the date of each child's individual immunization on house-hold level workers' rosters, substituting a single column for completed immunization (D. Sillan, personal communication, 1995). Should one want the details, he could look in the local immunizer's roster. How many other columns can we eliminate?

- How can we focus, expand, and refine the target group?

Epidemiology, economics, and ethics compel us to define target groups that validly reflect the distribution of risk in a community. We commonly do not progress far beyond the census-based age-sex determinants: children under five years and women of reproductive age. Vitamin A distribution includes those in the 6th year. Promoting child nutrition may be best focused on those under 3 years. Beyond these are strategies to limit target groups to pregnant women and their offspring. While this has the appeal of decreasing initial work-load, the ultimate target group could potentially become as large as the traditional targeting strategy. Alternatively the age parameter could become

more precise while considering additional factors as well, such as extreme poverty, previous child death, orphanhood, and the like. Village health committees could guide identifying households in need for additional services.

- How can we bring population-based health information systems "to scale"?

To date, population-based health information systems have served tens of thousands. Numerous projects have demonstrated the strengths and weaknesses of such systems for decades. "Save the Children has achieved coverage but not scale" (G. Pillai, personal communication, 1995) Why have governments not followed? What is lacking: information, policy, funding, and/or compatibility? Save the Children's Malawi example is an early attempt to apply denominator-based information to the District level. This was the fruit of an earlier collaboration on an issue of mutual concern: predicting food shortages. We must seek and capitalize upon other such issues to "capture the imagination" of government with our approach.

- What are the essential components of an adequate CHW supervision and motivation system?

Many population-based health information systems and community health workers rely on a overstretched formal health sector to provide supervision, motivation, training and services. Yet, health information with corresponding action is essential to the overall development of individuals, families and communities. What integrated systems approaches have been utilized supporting community health workers to provide outreach and to collect and utilize information for decision making? What is the state of best practices for supervision systems that build upon governmental and civic group infrastructure to motivate and reward community health workers who provide an essential information service?

- What time-frame and scope maximize the cost-effectiveness of community-based health information systems?

The intensity of effort for a complete census and enrollment is certainly more cost-effective in a longer-term program than in a shorter one. Indeed, short-term projects often frustrate community-based information efforts because they are expensive "up front" just when data quality is the poorest. Indeed, the first year is often devoted to "de-bugging" the system. We are encouraged by any plans to lengthen funded duration of child survival projects. A four, or better yet, eight year project would allow for a smoothly running system and some relevant action research.

Is there a limit to the size of an impact area's population above which disaggregation is more economical? Perhaps the question is better cast in terms of existing health infrastructure. For example, can community-based health information systems serve the catchment area of the lowest level government health facility? Again, even this entails parameters of population size and geography.

- What are the next steps for ProMIS?

The computer software, ProMIS, facilitates community-based data management and analysis. While extensively tested and revised through Save the Children's child survival projects, it has not yet endured the scrutiny of a larger audience. We welcome a critical review. Measuring its success will largely be reflected by its use, yet we hope for detailed feedback from non-users and users alike to learn what the next generation might look like. The debate about computerization is not settled. Home offices and even field offices obviously will be computerized. When will hand-held computers become accessories for household level workers?

- What is the relationship between community-based health information systems and research?

We have justified in part population-based information systems because they support research. At the same time we have shown that information is not always complete or correct, as shown by special studies. Moreover, some of the objectives of a community-based health system are achieved by its information system somewhat irrespective of its accuracy. Where does research fit here? One dictum might be that until the information has reached the validity threshold for decision-making, then research should not be contemplated. Another might be that information systems without paid household

level workers are unlikely to achieve sufficient validity for research. Information collecting is resource intensive.

- How do we invert the data collection/data response ratio?

Vast effort is spent in collecting, aggregating, analyzing, and displaying data. Far less effort is devoted to interpreting the data and to making data-driven decisions. Note that analysis refers to transforming counts into rates, ratios or proportions, for example; it does not refer to explaining the result. Perhaps data analysts are exhausted by the time the bar charts are produced. Perhaps pre-implementation targets are felt to be sufficient for the life of a project. Perhaps teams are unaware that thresholds, interpretations plans, and response strategies are best thought out in advance and periodically reviewed.

- What can the developing world's experience in community-based health information systems teach "the north"?

Many so-called developed countries have stark health inequities, both hidden and high-lighted (depending on one's perspective) by the average general prosperity. Some of these health systems are under active, critical review. These very countries have the resources to support population-based information systems. An HIS in an urban ghetto, for example, seems eminently cost-effective given the population density. Moreover, modern political trends ("democratization" or "reducing 'big government' ") often include devolving responsibility back to local communities. Both the technical and ethical lessons from the south have widespread applicability.

Final Thoughts

Community-based health information systems assist communities to recognize and address their health needs in an accountable fashion. Undergirded by sound epidemiological principles, these systems guide cost-effective services, empower the poor, seek equity and measure impact. Communities and public health managers together decide what data to collect and how to analyze them. The aphorism, "knowledge is power," has special significance for those unaccustomed to either information or power. Information in the hands of poor people, especially information that describes these very people, as in a community-based HIS, reaps good effects. Since community members are the first users of these data, the information itself is a strong motivator for positive behavioral change. Identifying "unreached" individuals is the *sine qua non* for explaining their marginalization and for proposing solutions.

Ministries of Health, north and south, need help to serve the health of the public. Private voluntary and non-governmental organizations, international organizations, universities and funding agencies must continue to examine, refine and document workable health information systems since these are an essential strategy for achieving health for all.

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