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**AIDS TECHNICAL SUPPORT PROJECT (ATSP)
LESSONS LEARNED: SURVEILLANCE, DATA
FOR DECISION MAKING, AND POLICY**

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Acronyms

AIDS	Acquired immunodeficiency syndrome
AIDSCAP	AIDS Control and Prevention Project
ATSP	AIDS Technical Support Project
ANC	Antenatal Clinic
BBS	Behavioral Surveillance Survey
BCC	Behavior Change Communication
BUCEN	U S Bureau of the Census
FHI	Family Health International
GPA	Global Program on AIDS
HIV	Human immunodeficiency virus
IAVI	International AIDS Vaccine Initiative
NACP	National AIDS Control Program
NIAID	National Institute of Allergy and Infectious Diseases, NIH
NIH	National Institutes of Health
STD	Sexually transmitted disease
STI	Sexually transmitted infection
UNAIDS	Joint U N Programme on HIV/AIDS
USAID	U S Agency for International Development
WHO	World Health Organization

Introduction

The HIV/AIDS pandemic is now composed of distinct epidemics, each with its own features and forces. The HIV/AIDS epidemics within each region and country have become increasingly diverse and fragmented, and they have created a multifaceted and devastating pandemic, although together they continue to have a disproportionate impact on the developing world. This divergence is acknowledged by the U.S. Agency for International Development, which seeks to prevent the further spread of HIV/AIDS.

Throughout the world, progress in slowing the HIV/AIDS epidemic is threatened by social, cultural, economic, and regulatory barriers to prevention. USAID supports policy dialogue and reform at all levels to create a more favorable environment for prevention efforts.

One tool that is extremely useful for this type of policy dialogue is surveillance — both medical and behavioral/modeling. We currently lack the behavioral data necessary to fully understand changes in HIV seroprevalence (the infection rate in a given population). Improvements are needed in our ability to collect and analyze surveillance data, including epidemiological, behavioral, and socioeconomic data.

I. Expanding HIV/AIDS Surveillance

Understanding and predicting future trends in HIV/AIDS in developing countries will require more a systematic linkage between behavioral and medical research. This will be the only way to create an epidemiological surveillance database capable of providing much-needed insights into the dynamics of sexual behavior, HIV population profiles, and the role of prevention interventions. This database must include research into how the increasing pace of population uprooting and population movement in Africa is influencing patterns of vulnerability to infectious and social diseases in general and to HIV/AIDS in particular.

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A. BEHAVIORAL SURVEILLANCE

In routine practice, nonexperimental observational methods are commonly used in outcome evaluation. It is important to recognize, however, that a pre-post evaluation design may be useful for assessing a prevention program's proficiency in delivering services, although it is not very convincing for measuring program effectiveness. The inference of cause and effect from such a design is problematic because competing explanations for changes over time (e.g., in attitudes and behaviors) cannot be ruled out. In addition, quantitative estimates of expected

behavioral outcome require precise estimates of baseline levels and an understanding of how much change is meaningful in the selected intervention settings. Without this knowledge, the tasks of setting sensitive targets for expected levels of change in a pre-post design is difficult.

1. Behavioral Surveillance Survey (BSS)

In response to these limitations, AIDSCAP moved toward a behavioral surveillance approach, beginning in Bangkok in 1992 and later in India, Senegal, and Indonesia. Behavioral surveillance is a monitoring and evaluation system designed to track trends in knowledge, attitudes, and behaviors related to HIV prevention among various risk groups within the overall population, rather than measuring changes against predetermined targets. Such a system allows for monitoring of decreased risk in some groups and detection of emerging and/or increasing risk in others. It also helps program managers and stakeholders evaluate program success while at the same time reassessing programmatic needs in a changing environment.

The BSS offers a number of advantages and uses. For example, it

- provides more targeted information than systems that collect data on general populations only
- eliminates the need to collect data separately in a multitude of projects that reach the same target groups
- ensures comparability and a degree of standardization not necessarily present when data collection is implemented by a variety of different implementing agencies
- provides data at regular intervals to guide interventions during the project instead of only at the beginning and the end
- moves focus away from the measurement of unpredictable levels of change and more toward monitoring of trends in various target groups
- allows different target groups to be added or withdrawn from data collection, which ensures an element of flexibility.

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Another Relevant Study

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B. BIOMEDICAL SURVEILLANCE

As epidemics of HIV and other sexually transmitted infections (STIs) continue to evolve around the world, there is a growing need to understand more clearly the dynamics of transmission, the impact of the epidemics, and the interventions designed to curtail them. We must recognize the gaps in our knowledge, reexamine our data needs, enhance our ability to interpret this information, and identify the most cost-effective methodologies for gathering this data.

1. HIV Sentinel Surveillance

Every country must have an effective and efficient system of HIV surveillance in place. The overall aim of these systems is to provide data to guide and target intervention activities. The specific objectives are to

- establish the presence or absence of infection, particularly in countries or regions where the epidemic has not yet commenced
- measure the current level of infection in the population and identify variations by age, sex, and risk factors
- monitor the progress of the epidemic
- measure trends in prevalence or incidence by age and sex
- make projections of future numbers of infections and AIDS cases
- measure the health burden of the epidemic in terms of morbidity and mortality
- assess the impact of HIV control measures on the epidemic

In the early stages of an epidemic, it is most important to monitor for infection among subgroups of the population that are most at risk. This might include sex workers, their clients, STI patients, or injecting drug users. Monitoring can be carried out by sentinel surveillance for groups who are seen routinely at clinic-based sites, particularly STI patients and sometimes sex workers or drug

users. For other groups, special ad hoc surveys may be needed at periodic intervals.

In areas where the epidemic is well-established, sentinel surveillance of groups more representative of the general population have been promoted as the main tool for HIV surveillance. Antenatal clinic (ANC) attendees have been used as the primary sentinel group for this purpose.

Data by age is extremely important. As the epidemic progresses, monitoring the epidemic among the youngest age groups is perhaps the closest most countries can get to measuring incidence. Further recommendations now include the addition of a minimum amount of demographic data at a sample of sites, e.g., education, duration of stay in the catchment area, occupation of spouse.

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2. HIV/AIDS Surveillance Data Base

The HIV/AIDS Surveillance Data Base maintained by the U.S. Bureau of the Census is a unique compilation of HIV prevalence studies conducted in countries in Africa, Asia, and Latin America. There have been only a handful of national HIV seroprevalence studies conducted worldwide, and these have never been repeated to monitor trends. This is because these studies are generally too expensive. It is possible, however, to create a picture of the pattern of the HIV epidemic in a country by pulling together the sentinel surveillance, cohort studies, and cross-sectional surveys of the general population or of specific subgroups.

The HIV/AIDS Surveillance Data Base has become a key element in USAID's worldwide leadership in providing model, large-scale prevention and control programs to developing countries. As a pioneer in HIV/AIDS prevention programs in the developing world, USAID has assisted in monitoring the course

of the pandemic and modeling its future demographic and economic impact as a means of defining the most effective interventions available.

The HIV/AIDS Surveillance Data Base is utilized in its entirety by the Joint U N Programme on HIV/AIDS (UNAIDS) and was formerly used by the World Health Organization's Global Program on AIDS (WHO/GPA). UNAIDS and WHO/GPA have a high level of respect for the quality of the data and are highly dependent on it for their programming activities. The data base has been helpful to a variety of U.S. and multilateral agencies, including USAID offices and the regional bureaus. The data base also is a resource to the HIV/AIDS research community

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3. STI Surveillance

Controlling sexually transmitted infections is a key component of HIV prevention and control Intervention programs that include condom promotion and behavior change would be helpful in reducing both STIs and HIV In addition, early detection and treatment of STIs would reduce the incidence and duration of STIs and, as a result, would help reduce the incidence of HIV infection

Information obtained through STI surveillance is essential for targeting disease control efforts and analyzing the impact of ongoing efforts However, STI surveillance poses some unique challenges For example, gonorrhea and chlamydia share similar symptoms, asymptomatic infection is common, and symptoms may be non-specific. Therefore, accurate diagnosis of STIs is difficult without the use of laboratory testing Multiple reporting can be a problem when patients go from facility to facility in search of care for the same episode of STI Finally, those people who seek private sources of treatment often are excluded from the official surveillance figures.

Presently, it seems more realistic to establish sentinel systems for syndromes and work toward making these systems optimally functional Monitoring STIs in target populations may be a rapid and simple way to track the combined effects of partner change, STI treatment, and condom use in large populations Reporting

forms should include demographic data for each STI case, including occupation, if possible, and behavioral risk factors involved. The advent of DNA amplification techniques on easily obtained biologic specimens makes population-based surveys possible for some STIs.

There are few STI surveillance systems in Africa, although Cameroon, Senegal, Zambia, and Zimbabwe have sentinel surveillance systems. Recent data from the Zambian system suggests a decrease in new cases of STIs and increased geographic coverage, but it is not clear if this reflects a genuine decline in STIs, declining attendance at the clinic under the National STI Control Programme, or even a decline in reporting. For example, private practitioners and hospitals do not report to the Zambian National STI Control Programme. (Interestingly, the total number of annual cases of chancroid and syphilis, which together had a much lower incidence than gonorrhea, have now surpassed the annual number of cases gonorrhea at the University Teaching Hospital, Lusaka.)

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4. HIVNET (Protocols and Study Outlines, 1997)

The National Institute of Allergy and Infectious Diseases (NIAID) and other elements of the U.S. National Institutes of Health (NIH) run a number of HIVNET sites and other projects in developing countries to carry out HIV prevention research. These activities provide opportunities for interaction and collaboration between NIH and USAID that can complement, leverage, and improve the HIV/AIDS programs of both agencies.

The HIVNET International sites generally involve subcontracts with U.S. academic institutions and their overseas partners to carry out HIV prevention research in behavioral research, STDs, tuberculosis, topical microbicides, and

vaccine studies in defined populations. The HIVNET International sites are linked with the domestic HIVNET sites run by NIAID, and there are shared data monitoring and laboratory references contracts.

Coordination between NIAID and USAID at the central and country level will provide USAID with early information on promising intervention modalities (such as the recent success of vaginal washing in reducing neonatal sepsis in Malawi). Interaction between USAID and HIVNET sites at the local level will also assist the HIVNET sites in their interactions with local communities, specifically in educating the public, asking the most important prevention research questions, and designing appropriate intervention studies.

NIAID-USAID interaction also can provide a bridge among national academic and research institutions, NGOs/PVOs, and the community. Another potential area of cooperation is in the translation of research advances into public health and clinical practice through the expedited development, patenting, and licensing of diagnostic, prevention, and treatment products appropriate for resource-poor settings.

II. Data For Decision Making

Effective and timely policy development and program planning and management depend upon adequate and reliable data and analysis. Modeling the future course of the HIV/AIDS pandemic and of its projected socioeconomic impact have been important tools for both policy and programmatic purposes. Modeling has received extensive attention during the 1990s, and, on occasion, the technical aspects of individual models have overshadowed the reasons for and the end results of modeling exercises.

Models are tools for data analysis and the results should be interpreted in ways that assist program planners and policymakers in making reasonable and informed decisions that can help control HIV/AIDS.

A. MODELING: IWGAIDS, DEMPROJ, EPIMODEL, SIMULAIDS

Despite the expenditure of considerable resources, 1wgAIDS has not proven to be an effective tool for modeling. Results have been problematic, in part because of the extensive data requirements and in part because of its complex interactions. However, 1wgAIDS has been successfully used in some instances.

In Kenya, the application of the 1wgAIDS model was used in a population project design phase. The findings of the application of data that were representative of East African countries showed that significant changes will have to occur as a result of combined interventions if the increase in HIV prevalence is to be stopped during the next ten years.

The application also showed that targeting can increase the effectiveness of programs by as much as five times. In particular, programs should be designed to target high-risk populations, adolescents, and family planning clients.

Two other programs have been far more useful: Epimodel and Demproj. These have been used in a variety of settings in all three developing country regions (Africa, Asia, and Latin America and the Caribbean). Both programs have been used to prepare AIDS Impact Model (AIM) presentations for a variety of audiences. There are anecdotal reports that some of those presentations have had policy impacts. Nonetheless, Epimodel projections remain to be validated against actual conditions, and many AIM presentations have lacked a contextual framework for follow-up.

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B. MEASURING THE POTENTIAL IMPACT OF HIV/AIDS INTERVENTIONS

Given the difficulties and high costs associated with direct measurement of the impact of HIV prevention programs through large-scale incidence studies, more emphasis has been placed on developing other methods of assessing impacts. These methods involve the use of multiple techniques for examining the relationship between available biological, behavioral, and socio-demographic data. The focus is on establishing linkages between outcome data from program

interventions and patterns of HIV prevalence and incidence, as well as estimating cost-effectiveness

These methods fall under several categories, including

- application of models to estimate the number of HIV infections that were likely to have been averted as a result of prevention activities
- application and validation of models to estimate HIV incidence rates and prevalence in selected populations
- application of methodologies for linking behavioral and biological data
- expansion of effectiveness analysis to cost-effectiveness analysis

For example, the newly developed AVERT Model is being used to estimate the impact of sub-population-specific behavior changes observed in AIDSCAP projects on the number of primary HIV transmissions averted. These estimates provide a better understanding of the effect of current HIV prevention strategies and are also useful to program managers and other stakeholders in their efforts to set priorities for future HIV programming.

Another example is the development of a method to estimate age-specific HIV incidence rates using population-based seroprevalence data. Input parameters required for the model include age-specific HIV prevalence and estimates of age-specific mortality rates for HIV-negative and HIV-positive subjects. This model proved to be successful in approximating observed incidence rates, particularly in countries where prevalence data are available and where HIV prevalence has stabilized, which is when the underlying assumptions in the model are best met.

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C. COST ANALYSIS AND COST-EFFECTIVENESS ANALYSIS

Costing of HIV/AIDS interventions has been limited. Peer education, workplace, and STD interventions in Thailand and Kenya were analyzed by AIDSCAP. The financial operations of several businesses in Africa were reviewed within the context of preparation of the *PSAP* kit. UNAIDS is field testing a cost-effectiveness methodology, with results expected by the end of 1997. However, both rapid and more rigorous cost and cost-effectiveness analyses are needed to assist policymakers, program managers, and donor agencies in making decisions about the allocation of resources.

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III. Policy and Advocacy

A. METHODOLOGIES

Policies provide a framework within which organizational decisions can be made. Policies represent a broad statement of intent. Policies are made by governmental bodies, businesses, NGOs, religious groups, and other organizations.

There are two broad approaches to policy development:

- Policy outcomes result from a specific process, which is usually lengthy and complex. A key goal of this approach is often capacity-building of local groups of technical specialists and advocates to effectively engage in policy development.
- Broad policy guidelines are identified by a pre-selected group of “experts,” which makes recommendations to decision-making authorities. Usually, such recommendations occur during one-time events and do not include mechanisms for follow-up and sustained advocacy with policymakers.

Ideally, these two approaches are merged: a long-term policy development process is coupled with the generation of specific policy recommendations. This is most likely to occur by building the capacity of local organizations to engage in policy development and advocacy and by regularly updating international recommendations and guidelines to match changes arising from the epidemic.

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B. NATIONAL INSTITUTIONS

1. National AIDS Control Programs

Many national AIDS control programs (NACPs) remain bureaucratically and politically weak. There remains a need for a global analysis of these institutions and their strengths and weaknesses. Similarly, an overview should be undertaken of the approaches embodied in national AIDS policies and the effectiveness of efforts to implement those policies. Several country studies exist which provide a retrospective review of policy responses to the epidemic and provide guidance on framing future policy development strategies.

In general, most NACPs lack bureaucratic decision-making experience, have minimal budgets, and have had their roles preempted by expatriate state and funding decisions made by international donors.

2. NGOs and Religious Organizations

National HIV/AIDS networks exist in many countries, but most have not been described in writing. South Africa offers the most extensive exception. Some religious denominations have adopted both prevention and care policies on HIV/AIDS, others have resisted dealing with aspects of prevention. In most cases, there is little accessible literature on religious organizations' responses to HIV/AIDS.

Two lessons emerge:

- Strong, well-coordinated, and active NGO networks are capable of contributing to and influencing the direction and speed of national government policy development.

- The tendency of many AIDS programs staff members and activities to dismiss the potential contributions of religious authorities has been largely counterproductive and counterintuitive to the realities of effective policy development. Increasingly, religious hierarchies have recognized the seriousness of HIV/AIDS and have offered a variety of positive responses. Likewise, religious-based medical and health programs have gathered extensive experience on issues related to the care of those with HIV/AIDS.

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C. THE PRIVATE SECTOR

Guidelines have been published to assist formal sector businesses in adopting prevention programs in the workplace, and several studies have been published that review the likely impact of AIDS on business operations and profitability. The newsletter, *AIDS Analysis Africa*, provides the most regular discussion of these issues.

Overall, the commercial private sector has been slow to respond to the epidemic. In many cases, business people does not consider prevention an issue for the workplace. However, companies can be engaged if they are presented with data, analysis, and examples that fit their frames of reference.

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