Meeting the *Behavioural Data Collection Needs* of National HIV/AIDS and STD Programmes

A joint IMPACT/FHI/UNAIDS Workshop: Report and Conclusions

May 1998

UNAIDS

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MAY 1998

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1
Introduction

HIV continues to spread in most countries of the world.

Understanding of the virus is growing, but many behavioural aspects of the epidemic remain incompletely documented and poorly understood. Changes in HIV infection rates over time have been hard to interpret in many contexts because programmes frequently lack complementary information on changes in behaviour. National prevention programmes are sometimes designed with only limited understanding of the size of various populations vulnerable to HIV and the nature and determinants of risk among them. The impacts of prevention programmes on behaviour often remain uncertain because behavioural data is not collected or is seriously incomplete.

These gaps in knowledge are to an extent inherent in the nature of HIV. The virus is spread mainly by behaviours — sexual and drug taking — that are generally private, sometimes illegal, and often difficult to discuss openly. These behaviours are also very dynamic, sometimes altering radically in short periods of time as social and economic changes sweep through countries. But they *are* the engines driving the epidemic. Unless efforts are made to understand and quantify these behaviours more thoroughly, it will not be possible to gauge who in the population is at risk of infection or to measure changes in behaviour that may increase or reduce people's risk of and vulnerability to HIV. The result then, will be poor and inefficient use of available resources, producing responses with only limited effectiveness.

In recent years, many national AIDS programmes have, together with their national and international partners, begun to collect information on behaviour that puts people at risk of HIV infection. Several countries have found this information invaluable in persuading people to support action against AIDS. It has also been useful in devising and directing effective programmes aimed at cutting risk behaviour, and in demonstrating that people are indeed behaving more safely.

As experience with collecting information about behaviour has grown, it has become apparent that countries have different needs and that behavioural data can meet those needs in different ways, using a variety of methodologies and instruments.

This document aims to describe the contribution behavioural data can make to the planning, execution, and monitoring of HIV prevention activities. It considers

the available tools and recommends a minimum data collection package that varies according to the stage a country has reached in its HIV epidemic. The purpose of this document is to guide national programmes in setting up efficient behavioural assessment and monitoring programmes to assist them in programme design, direction, and evaluation.

Compiled by Family Health International and UNAIDS, this document draws on the experience of several organisations and countries in collecting behavioural data.

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Why track behaviour?

For the first decade or so of the HIV epidemic, many countries concentrated resources on tracking the spread of the virus itself. Industrialised countries focused on AIDS case reporting, while many developing nations, particularly those of sub-Saharan Africa, set up sentinel surveillance systems to detect the spread of HIV. After stripping personal identifiers from blood samples taken for other purposes — most commonly antenatal syphilis testing of pregnant women — sentinel surveillance systems test blood for HIV. This data is thought to give some indication of the levels of HIV infection in the general population.

However, because a person may be infected with HIV for a decade or more without showing any symptoms, HIV prevalence rates can reflect a combination of recent infections and infections that are many years old. Consequently, the prevalence rate is very slow to reflect changes in new infections. Prevalence that is stable or falling may mean that people are behaving more safely and fewer are becoming infected than in previous years. It may, however, simply reflect the fact that HIV-infected people are dropping out of the tested population because they have died, moved away, or are too sick to go to the health facility where they might be tested. It may mean that nearly everyone with risk behaviour is already infected, or that the group of people tested has changed over time. Indeed, the relationship between HIV incidence and prevalence is so complex that in some cases falling prevalence may mask a still rising incidence of HIV infections, especially among young people.

Clearly, then, HIV prevalence rates do not serve as a good indicator of changes in new infections or as a measure of the success of programmes designed to reduce new infections. What are the alternatives? HIV incidence is costly and problematic to measure, since it involves testing the same group of individuals repeatedly over time or using costly testing methods on large numbers of people to detect a small number of new infections. Other physical markers that track sexual risk behaviour more closely than HIV are curable sexually transmitted diseases (STDs). Bacterial STD prevalence rates more closely reflect incidence rates because they are usually treated with antibiotics upon detection. However, surveillance of STDs in most countries is of lower quality than HIV surveillance. It is also extremely incomplete in the many

countries where most surveillance data are collected in the public sector, while most treatment occurs in the private sector.

Although measuring changes in new HIV and STD infections is difficult, it *is* possible to track changes in the behaviours that lead to those infections. There are several reasons to do this, and they vary in importance according to how widespread HIV is in a country and which communities are affected.

2.1 Behavioural data serves as an early warning system for HIV and STDs

Behavioural risk is not distributed uniformly throughout a population. On average, some subpopulations or communities may have higher levels of risk behaviour than others. Which subpopulations or communities are particularly vulnerable can vary greatly from country to country and may need to be defined locally in terms of occupation, migration status, sexual orientation, geographic location, income level, or any number of other factors. Behavioural data can help identify those subpopulations or communities at risk locally and can suggest the pathways the virus might follow if nothing is done to brake its spread. It can also indicate the levels of risk behaviour in the general population and the behavioural "bridges" between the general population and more vulnerable subpopulations. If these "bridges" are strong, arresting HIV transmission in vulnerable subpopulations or communities early becomes an urgent and critical component of slowing the spread in the population as a whole.

This kind of behavioural information can act as a call to arms for many people — politicians, religious and community leaders, and people who may themselves be at risk — signalling that the threat of HIV is very real even in areas where it is not yet visible. Such data are a powerful tool in pressing for action.

2.2 Behavioural data informs effective programme design and direction

A country monitoring the HIV epidemic is doing so because it wants to slow the spread of the virus through effective prevention programmes. Effective prevention is prevention that enables people to adopt safer behaviours and protect themselves from the risk behaviour of their partners. But effective prevention requires more than just knowing who is at risk. It also requires understanding why they engage in risk behaviour, motivating them to reduce their risk, developing their prevention knowledge and skills, improving their access to the means of prevention in ways that are appropriate and accessible to them, and providing a supportive social and policy environment for behaviour change. These requirements create a strong need for qualitative data to illuminate and clarify the determinants of risk in specific subpopulations and situations. Unless the context and forms of risk behaviour are well understood in each specific vulnerable subpopulation or risk situation, it is not possible to provide and effectively support relevant safe alternative behaviours. Thus, behavioural research data can help communities and programme planners design initiatives carefully focused on breaking the links in the chain of transmission in a particular country, region, or group.

In addition, behavioural research data can quantitatively indicate who is most at risk of contracting or passing on HIV infection, and why. Such data can document levels of risk in specific communities that may be particularly vulnerable to rapid HIV spread or identify characteristics of individuals who may have higher risk, allowing prevention efforts to be prioritised and directed so as to have the greatest impact.

2.3 Tracking behaviour improves programme evaluation

A good behavioural data collection system can give a picture of changes in sexual and drug-taking behaviour over time, both in the general population and in vulnerable subpopulations. The system will record a reduction in risky sex just as it will record persistent risk behaviour or shifts in the pattern of risk. These changes can provide an indication of the success of the overall package of activities aimed at promoting safe behaviour and reducing the spread of HIV, both in the general population and in specific vulnerable subpopulations.

Showing that behaviour can and does change following national efforts to reduce risky sex and drug taking is essential to building support for ongoing prevention activities. However, while behavioural data can help evaluators document these changes, it is important to realise that it can *not* show a direct causal link between

an intervention and a particular level of behaviour change. Most people are exposed to many sources of information and make decisions based on many — and complex — criteria. Information or activities provided as part of a prevention programme will contribute to what people decide and how they behave, but there may be many other factors in the equation. Reported behavioural data alone rarely make it possible to isolate and attribute change to a single component of a programme.

2.4 Changes in behaviour help explain changes in HIV prevalence

As discussed earlier, changing behaviour and a consequent reduction in new HIV infections is just one possible reason for changes in HIV prevalence data. It is, of course, the most encouraging explanation to those trying to reduce the spread of the virus. But without collecting data that show trends in behaviour over time, program evaluators will not be able to ascertain whether behaviour change contributes to changes in HIV prevalence.

Focusing entirely on HIV prevalence without complementary behavioural data can also be misleading. When HIV prevalence stabilises — and even when it stabilises at very high levels — there is often a tendency to become complacent: the problem has peaked, it won't get any worse. This can be a dangerous fallacy. For example, prevalence among injecting drug users in Bangkok has been stable for almost a decade, but careful studies of cohorts of drug users have shown that they continue to become infected at a rate between 5 and 10 percent per year. Stable prevalence results because the number of newly infected drug users roughly equals the number dropping out due to death and to ceasing injection.

Behavioural data showing no change in high levels of risk activities, or continued risk in certain age groups or sections of the population, should ring alarm bells even when HIV prevalence seems stable. Several factors unrelated to intervention effects can contribute to observed stabilisation or decreases in HIV prevalence in a given setting. These include mortality (especially in mature epidemics), saturation effects in subpopulations at higher risk, differential migration patterns related to the epidemic, sampling bias, and errors in data collection and analysis.

2.5 Behavioural data can help explain variations in prevalence

Although comparisons across regions, cultures, and countries must be made with extreme caution, behavioural data can also help explain differences in levels of infection between one region and another. This is particularly true when indicators of risk behaviour are standardised across all studies and surveys, with the same wording and reference periods.

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Linking behavioural data with HIV serosurveillance

Because the relationship between HIV incidence and prevalence grows increasingly complex as the epidemic matures, UNAIDS and its partners are promoting the strengthening and development of existing sentinel surveillance systems into "second generation" surveillance systems, in which behavioural data collection becomes an integral component. Second generation systems focus more closely on the segments of the general population where most new infections are concentrated, in particular young people. HIV prevalence among the young serves as a proxy for incidence because young people have only been sexually active for a short time.

This gives national programmes a rough indicator of ongoing incidence to complement currently collected prevalence data. The addition of behavioural data collection to the second generation surveillance system then allows serosurveillance and behavioural data to be used and compared concurrently, enabling national programmes to better understand and explain the currently observed trends in the national HIV epidemic.

In any system collecting sensitive data, such as information on serostatus or information on sexual or drug-related risk behaviours, steps must be taken to minimise biases. For this reason, antenatal clinic serosurveillance is usually conducted using unlinked anonymous blood samples that have been routinely taken for other purposes, such as syphilis testing. This approach reduces the bias introduced when people are asked to give a blood sample for HIV testing and refuse. Similarly, if one selects a sample of young women to answer questions on sexual and drug-using behaviours, some of them are likely to decline to be interviewed. Should one ask for *both* a blood sample and an interview on risk behaviour, especially from women late in their pregnancies, the combined refusal rate could prove quite high. Furthermore, ethical and practical operational difficulties aside, asking women in the later stages of pregnancy about their sexual behaviour and condom use will not generally yield results in any way typical of the female population at large. Similarly, sexual behavioural trends from male STD clients are difficult to interpret because such clients are, by definition, engaging in some type of high-risk behaviour.

Thus, in order to minimise biases, avoid jeopardising the validity of the serological data, and gather less biased behavioural data on the population as a whole,

it is usually recommended that blood samples and risk-behaviour interviews be obtained from different individuals. But in order to establish a clear association between behaviour and HIV prevalence in the community, the data on HIV serostatus and behaviour have to be drawn from the *same source population*. These two needs are not incompatible. It is not necessary that blood and behavioural data be obtained from the same individuals, although this would have the strongest explanatory power, but only that the relationship between the population contributing the serological data and the population providing the behavioural data can be determined.

Determining these relationships requires carefully defining the population from which a key sentinel surveillance site (such as a large urban antenatal clinic) draws its attendees and collecting behavioural data from a random selection of households in the same catchment area. If this is done as part of national or regional behavioural surveys, it may mean deliberately oversampling in the catchment populations of key sentinel sites (that is, the population served by the particular site in question).

Because women attending antenatal clinics are not randomly chosen from the population, they may differ in significant ways from other members of the source population. For example, young women at antenatal clinics generally represent a portion of the total young female population that has become sexually active at an earlier age than average. In order to link the behavioural data with the HIV prevalence data, it is therefore recommended that a minimum set of sociodemographic questions be asked of all antenatal clinic attenders at sentinel sites. The questions should include age, parity, last birth interval, level of schooling, occupation, and length of time living in the area (as an indicator of migration). These indicators can then be compared with those collected from the population being asked about behaviour, allowing any systematic differences between the two groups to be identified and adjusted for in the analysis.

A more direct way of linking behaviour and serostatus is to undertake a population-based survey in which both HIV data and behavioural data are collected. However, success in this approach has been varied. Some countries successfully added testing for HIV serostatus to population-based behavioural surveys. Blood or saliva samples were taken and tested anonymously, after informed consent. (All participants were given the opportunity to be counseled and to choose to have their blood tested separately from the research project to learn their HIV status.) But in other countries, refusal rates for testing in such population-based surveys have been quite high, and the results are difficult to generalise. In addition, people not captured in a household survey (because they travel frequently, for example) may be disproportionately likely to be HIV infected.

4

What is needed to understand and track behaviour?

There are many ways of collecting data on behaviour.

This section describes the strengths and limitations of the methods most likely to be used in meeting the planning and evaluation needs of national programmes. Some of these methods may already be in use in a given country. Most countries will choose a mix of behavioural data collection methods, depending upon the particular stage of the epidemic, the response so far, and the political and social environment of the country.

Whatever methods are chosen, it is important that they be designed with the needs of the country in mind. Unless behavioural data are credible and relevant to actions that can be taken to prevent the further spread of HIV, they will be of little practical use. This means that the behavioural data collected must provide a firm understanding of the behavioural patterns and distribution of risk in the population, and the systems established to monitor behavioural risk must feed into the design, direction, and evaluation of prevention activities.

In deciding their country's data collection needs, programme managers should bear in mind that some populations and vulnerabilities are likely to strike more of a chord with policymakers and the general public than others. Often political support for prevention activities among more socially marginalised, but highly vulnerable, subpopulations is weak. Behavioural studies can help build support for such essential activities by demonstrating that risk behaviour and vulnerability in the general population or in politically important groups are closely related to risk in these other vulnerable populations. Sometimes such data can provide the critical additional leverage needed to encourage and strengthen support for urgently required prevention activities in vulnerable subpopulations.

4.1 The role of national programmes in behavioural data collection

Because effective programmes should operate from a realistic assessment of behavioural risk and track impact through changes in behaviour over time, national AIDS programme managers should take responsibility for coordinating the collection of data on sexual and drug-taking behaviours. They should further ensure that the data collected meet the information needs of their countries and programmes. However, the national AIDS programme need NOT be responsible for carrying out all the data collection itself. While this is possible in a few cases, more often national programmes have limited

capacity and personnel for behavioural studies and must take advantage of outside help or use existing resources to obtain behavioural data.

There may be ongoing programmes of health, fertility, or reproductive health surveys, for example, that could easily add a sexual behaviour module in future survey rounds. The international Demographic and Health Surveys programme is one example, but many countries carry out similar surveys nationally on a more regular basis. Often academics, NGOs, and private market research firms have carried out or regularly conduct behavioural studies in the course of their own research, prevention, and marketing activities. Where feasible and appropriate, these studies can provide inputs for a national behavioural data collection system or offer ideas for developing a new data collection system or improving an existing one. Similarly, national programmes can often use the behavioural research capacity inherent in the university, NGO, or private sector to conduct the actual data collection by providing resources or arranging support for the work from other sources.

Thus, the responsibility of programme managers in behavioural data collection should be primarily to determine behavioural data collection needs; plan and coordinate national, international, and bilateral agencies' activities and resources to meet those needs; and identify the most capable national institutions for implementing the recommended data collection approaches. This will help create strong interest among the selected national institutions and partners in collecting data of good quality and can lead to sustainable data collection systems for country programmes.

4.2 Key components of behavioural data collection systems

Development of any system of behavioural assessment should begin with a careful preliminary assessment of the behavioural situation, if this has not already been done. Such an assessment will have several components. These include a review of existing behavioural studies and data sources in the country, a rapid assessment of risk behaviours, mapping of where the risk is and who is at risk, and formative qualitative work to identify opportunities, barriers, and appropriate approaches to promoting behaviour change.

A review of existing data is the first step of the preliminary assessment. It should be conducted regularly so national programmes can expand their understanding of what is often a dynamic behavioural situation and can avoid duplication of efforts and waste of resources. In most countries, numerous universities, NGOs, and private firms have undertaken a number of smaller-scale behavioural studies. Often these organisations carry out focus group discussions and in-depth interviews, sometimes with a view to designing an intervention or launching a product, such as a new brand of condom. Such qualitative research can indicate what subpopulations are most at risk in a society and can point to particular attitudes or behaviours that need to change to make sex or drug taking safer. Some of these organisations, as well as various governmental agencies, may have also conducted quantitative behavioural studies, such as marketing surveys or reproductive health surveys. Before additional behavioural assessment or monitoring are undertaken, existing data should be reviewed thoroughly to learn what is already known, identify key areas of concern, locate gaps in existing knowledge, and determine which methods and approaches are likely to be effective in the local setting. Such reviews of existing data sources will assist national programmes in defining additional information needs for formulating relevant policies and programmes.

If areas of limited behavioural knowledge are identified in the review of existing information, national programmes should undertake a rapid preliminary behavioural assessment aimed at filling the most immediate and urgent gaps in knowledge of risk behaviours in the population and in vulnerable subpopulations. This preliminary assessment, which will typically take approximately six months, has three primary purposes. First, it will assist national programmes in prioritising prevention efforts by further defining which risk behaviours are driving the epidemic locally and by determining the size of various at-risk populations. Second, it will contribute to effective prevention programme design by improving understanding of the factors influencing risk behaviour, identifying enablers and barriers for behaviour change, and determining acceptable and appropriate prevention approaches for the subpopulations determined to be most important epidemiologically and behaviourally. And third, it will inform the development of the behavioural tools and

instruments needed for longer-term tracking of behaviour in the country, which is important in identifying continuing prevention needs and evaluating the effectiveness of prevention programmes. This preliminary assessment will draw heavily upon a number of different qualitative approaches, including rapid assessment methodologies, geographic and social mapping of risk behaviours and at-risk populations, in-depth interviews, key informant interviews, and focus group discussions. These approaches will be outlined in more detail in the next section.

Behavioural data collection systems aimed at tracking changes in behaviour over time should have, at their core, two cross-sectional methods:

- one covering the general population (household-based), such as the survey described in *Evaluation of a National AIDS Programme: A Methods Package*. Geneva: WHO/GPA; 1994, and
- repeated behavioural surveys in selected population groups (non-household-based), such as described in *HIV Risk Behavioural Surveillance: Methodology and Issues in Monitoring HIV Risk Behaviours*. Workshop Summary. Bangkok: Family Health International; 1997.

Even once these systems are established, however, national programmes will continue to make use of qualitative approaches as necessary to obtain a deeper understanding of behavioural risk or to analyse the factors influencing the behaviour changes detected by these behavioural tracking systems.

Collection of useful behavioural data should always be complemented by other available information that can help verify observed behavioural trends and findings. This allows for "triangulation" to determine whether self-reported behavioural data and resulting biological and programmatic indicators are consistent with one another. For example, declines in reported STDs can be compared with reported reductions in risk behaviour, or reported levels of condom use can be validated against condom sales in the region or country.

4.3 Rapid assessments, mapping and qualitative studies

What are they?

Rapid assessments, mapping methodologies, and qualitative research approaches have been developed in a number of fields, but are equally applicable to the study of risk behaviour, especially for hard-to-reach populations about which national programmes currently know little.

Rapid assessments usually involve a group of researchers with a variety of skills (e.g., survey, focus group, and anthropological research) who work closely with members of the community being studied to develop a quick but comprehensive picture of the risk situation in that community and the factors driving it. This picture is formed using a combination of in-depth interviews, focus group discussions, observation of the community, and small rapid surveys (involving only a handful of relevant questions). The use of multiple approaches makes it possible to detect and resolve inconsistencies in information in the field, giving the research team and community a clearer understanding of the situation by the end of the study. Typically the entire study will involve one to two months of fieldwork, along with appropriate preparation and analysis time. The analysis should be shared with members of the community who provide their own feedback on its accuracy — an essential step in the process.

Mapping methodologies are used to quantify the number of risk settings of a particular type or the size of a given community with higher-risk behaviour. In mapping approaches, the research team identifies the type of settings where risk behaviour occurs or where community members congregate and then attempts to systematically map these settings using a combination of geographic mapping, "snowball" approaches, and other techniques. In geographic mapping, researchers exhaustively go through a given area and map the locations of organised settings such as commercial sex establishments, classifying them by type and conducting ethnographic research on the risk situation in those sites. Even a large city can typically be mapped in less than a month. In snowball approaches — often more appropriate for very hidden communities, such as men having sex with men in many countries — key informants help identify entry points, and networks of contacts are then followed in an attempt to map out the current situation. These approaches can

also be supplemented by capture-recapture techniques to estimate the size of specific populations with higher behavioural risk. These techniques will not yield data that is perfectly comparable over time because those sampled are not a random subset of the total population of interest and cannot therefore be considered representative of that population. However, particularly in hard-to-reach populations, imperfect information is better than no information.

Qualitative research methodologies, including focus group discussions, in-depth interviews, and key informant interviews, are intended to provide a deeper understanding of risk situations. In focus groups, six to ten members of the study community are brought together to discuss a limited set of topics in detail. The emphasis is on group interaction, with a facilitator encouraging active discussion among the group members. In in-depth interviews, respondents are allowed to respond to a detailed set of questions in an unstructured manner. In key informant interviews, specific individuals with a clear understanding of a local risk setting or situation, such as bartenders at night clubs, taxi drivers, or leaders in a vulnerable community, are asked to share their knowledge and experience. This information is then used to formulate more focused research to enhance understanding of the broader community.

What do they deliver, and what do they require?

These three approaches deliver two major benefits. First, they allow the risk situation in a given vulnerable population or community to be quantified in terms of number of settings or size of the population. This can be an essential component in prioritising prevention programmes and deciding where efforts should be focused.

Second, they provide a greater in-depth understanding of risk behaviours and the factors motivating them than can more structured research approaches. Without this type of information, the development of relevant prevention programmes is difficult, if not impossible. Qualitative approaches are particularly valuable for prevention programme designers because they allow respondents to express their own concerns, rather than just responding to the concerns assumed by the researchers. If such information is applied intelligently, it is likely to lead to more appropriate prevention programmes for particular communities. These same qualitative techniques should also be used to "field test" specific prevention alternatives with community members and to adapt them to match the community's needs more closely before implementing them on a wide scale.

These approaches to preliminary assessment require a research team skilled in the various techniques. Many people mistakenly believe that they can be applied by anyone with only minimal training. However, the reality is that the quality of the data collected is a function of the quality of the research team and the team's ability to control the imposition of its own biases on the findings. Thus, national programmes should recruit experienced social scientists to assist in the design of the research, training of field staff, and implementation of these approaches. These studies also require active involvement of the study community in the design and analysis of the research and in dissemination of its results. Community members know their own risk situation better than any outsider does. They are the true "experts" on risk in their own settings, and their opinions should be considered carefully in interpreting the findings.

Other points for consideration

As the first steps in an organised research agenda for informing national programmes, rapid assessments, mapping, and qualitative research can begin opening doors to affected communities. National programmes often have serious difficulties in reaching and working with populations such as sex workers, men who have sex with men, or other marginalised communities, yet these are often priority populations in prevention efforts. Because these approaches are strong on community involvement, they can help form links between the affected communities and the national programmes. Where the national programme lacks capacity or willingness to involve communities in research, it can often draw upon nongovernmental organisations or community-based organisations already working with these specific communities. This will begin the process of building the rapport and forming the teams that are needed to design and implement relevant and appropriate prevention programmes for those communities.

One serious concern in applying these approaches is that there is tremendous potential for harm to the communities studied, especially if they are already marginalised or stigmatised. While maps of commercial

sex establishments are of value for targeting and implementing prevention efforts, they can also be used by authorities to undertake enforcement actions against these sites. It only takes one incident of this type to permanently sour relations between the national programme and the affected community, making it difficult or impossible to mount much-needed prevention programmes. Thus, absolute confidentiality of all potentially damaging findings must be maintained, and each member of the study team must agree on the need for this confidentiality.

One of the real strengths of qualitative approaches (key informant interviews, in-depth interviews, and focus group discussions) is that they allow new ideas to arise. Because the guidelines formulated for these interviews are typically broad, there is considerable latitude in how the respondents or focus group participants respond. In such a setting, it is much more likely that participants' real concerns will be expressed. Using this information in the design of prevention programmes improves their relevance.

One of the limitations of qualitative approaches is that they are *not representative* of the study population as a whole. Because of the intensive manpower requirements of conducting, transcribing, and analysing large numbers of in-depth interviews or focus group discussions, it is not possible to collect a large enough sample to represent an entire community. Further, the nonstructured nature of the responses often makes it difficult to quantify the findings into convenient categories. In addition, key informants, respondents for in-depth interviews, and focus group participants are generally not chosen to be truly representative, but to be "good examples" of members of a given community. Thus, any attempt to generalise the findings to the community at large without a quantitative follow-up (as discussed in the next two sections) may run the risk of reaching incorrect conclusions.

4.4 Behavioural surveys in the general population

What are they?

Behavioural surveys in the general population are cross-sectional household surveys in randomly selected samples of a population. They can be regional or community-based, and can address either the 15 to 49 age group or focus on youth ages 15 to 24. The interviewing is always done within the household. Population-based surveys should be repeated at regular intervals of several years to gain a picture of trends in behaviour over time.

What do they deliver, and what do they require?

Household surveys can provide a credible picture of the extent of risk behaviour in the general population and of the links between the general population and groups with higher-risk behaviour, such as sex workers or drug injectors. Understanding the magnitude of these links is essential to planning an effective national programme and directing resources. Should the links into the general population be limited, prevention resources can be concentrated largely in more vulnerable populations, with general population efforts being developed more gradually. Should these links be extensive, however, the potential for rapid HIV spread throughout the society is high, and resources should be mobilised to obtain broad population coverage in prevention programmes while still working intensively and extensively with vulnerable populations.

Household-based surveys are often logistically complex. However, many countries have experience with such surveys through national censuses and economic or health surveys. Sample frames and sampling expertise are often available through national statistical offices, local universities, or private firms. Indeed, existing survey programmes in these other areas may provide an opportunity to collect behavioural data relevant to HIV without setting up a separate survey structure.

Because participants in household surveys are randomly selected from the general population, selection bias is minimised provided that non-response is kept at a minimum. Sample sizes may be large, allowing frequencies of risk behaviour to be calculated for different age groups with small confidence intervals. In addition, standard procedures for sampling are easily replicated when the surveys are repeated.

In linking HIV sentinel data from key sites with behavioural data, it may be useful to oversample in areas surrounding key sentinel sites, provided the sampling area is defined in such a way as to select from the same source population that visits the sentinel site. Such oversampling can help ensure that sufficient behavioural data is collected in these areas to allow for informed interpretation of observed changes in HIV seroprevalence.

If the household-based survey includes data on HIV serostatus, it can establish links between risk behaviour and HIV infection at the individual level. It can also be invaluable in calibrating the results of sentinel serosurveillance among pregnant women (see also *Second Generation Surveillance for HIV. The Next Decade and Beyond.* Geneva: UNAIDS and WHO; 1998). Including data on HIV serostatus, however, considerably increases both the logistical complexity and the expense of a household-based survey. In some places the collection of HIV data — even if it is done using nonintrusive techniques such as saliva testing — may also increase refusals to participate in the survey. Thus, it is unlikely that such serostatus surveys can be tacked on to existing data collection efforts in reproductive health or other fields without substantially biasing the results. Such an exercise should be seen more as a research tool than a surveillance method.

Other points for consideration

Because they provide credible information on the general population, population-based surveys are an important advocacy tool. In several countries, national or regional surveys of sexual behaviour have set alarm bells ringing in the corridors of power and have prompted the establishment or strengthening of prevention activities countrywide (Table 1).

If household-based surveys collect internationally standardised indicators of risk behaviour, the information can be used to make intercountry comparisons. This must be done cautiously, however, because reporting bias may differ from country to country.

Household-based surveys are not good for tracking rare events or behaviours that are infrequent in the population. To get a statistically significant measure of change in behaviours not widely prevalent in some settings, such as injecting drug use or homosexuality, sample sizes in a household survey would have to be larger than is logistically or financially feasible.

Also, household-based surveys commonly underrepresent persons who are more difficult to contact at home. Individuals living in institutional settings, such as university students and military recruits, or mobile groups, such as males working away from home (e.g., miners, agricultural workers, or long-distance truck drivers), are usually not included in household-based general-population samples.

Experience has shown that national AIDS programmes encountered many difficulties when they tried to carry out population surveys themselves. Some national programmes had shortcomings in carrying out data management and analysis in a timely fashion. In some countries, the reports of behavioural survey data were not discussed, and their conclusions were not taken into account in the planning or redesign of prevention activities. In others, inadequate attention was paid to ensuring that neighbours or other family members could not inadvertently overhear respondents' answers to sensitive questions, producing seriously biased results. In addition, some people are reluctant to discuss sensitive matters such as sex and drug use with people they perceive as figures of authority in the state or community.

Finally, surveys of this type cannot provide the in-depth understanding of the factors influencing risk behaviour that is necessary for the design of prevention programs. While repeated household surveys can demonstrate trends in risk behaviour, they usually cannot explain those trends. Such explanations normally require qualitative follow-up of interesting findings using in-depth interviews, focus group discussions, anthropological observation, and other qualitative tools.

4.5 Repeated behavioural surveys in selected population groups

What are they?

Repeated behavioural surveys in selected population groups also use cross-sectional designs to collect behavioural data at regular intervals (annually or biannually). Sampling approaches should be consistent and repeatable, so that trends in the selected subpopulations can be measured over time. To improve the quality of the results, probability sampling is emphasised whenever possible.

Most often targeted behavioural surveys in subpopulations aim to collect data on groups whose behaviour may put them at high risk of HIV infection but who are not easily captured using household survey approaches. In such cases, behavioural surveys may more appropriately include specific population subgroups whose profile matches the behavioural characteristics of groups targeted for interventions.

These survey systems can be set up for many different population subgroups. Experiences with FHI's

Table 1: HOUSEHOLD SURVEYS SUPPORTED BY WHO/GPA AND UNAIDS IN THE DEVELOPING WORLD

COUNTRY	TYPE OF SURVEY	COVERAGE	PERIOD OF FIELDWORK
Benin	PI	1 city	1997
Botswana	KABP	national	1994
Brazil	PR	1 city	1990
Burundi	KABP, PI	national	1989, 1993
Cameroon	KABP, PI	1 province, 1 city	1993, 1996
Chile	PI	national	1995
Central African Republic	KABP	national	1989
Costa Rica	PI	national	1996
Côte d'Ivoire	PR	national	1989
Cuba	PI	national	1995
Djibouti	PI	national	1994
Ethiopia	PI	5 cities	1993
Guinea Bissau	KABP/PR	national	1990
Hong Kong	PR	national	1992
India	PI	5 states	1995
Jamaica	PI	national	1994
Kenya	KABP, PI	national, 1 city	1990,1996
Lesotho	KABP/PR	national	1989
Mauritius	KABP	national	1989
Mexico	PI	1 city	1995
Niger	KABP/PR	national	1993
Philippines	KABP, PI	1 city	1990,1996
Senegal	PI	1 city	1997
Singapore	PR	national	1990
Sri Lanka	KABP, PI	national, 1 city	1989,1993
Sudan	PI	4 cities	1995
Tanzania	PR, PI	national, 1 city	1990, 1993
Thailand	PR	national	1990
Uganda	KABP, PR;PI	national, 5 districts	1991, 1994
Zambia	KABP, PI	1 city, 1 city	1990, 1996
Zimbabwe	PI	national	1995

KABP=Knowledge, attitudes, behaviour, practices; PR=Partner relations; PI= Prevention indicators; /=Combined questionnaire

behavioural survey methodology indicate a considerable level of similarity in chosen sample groups, with most countries opting for a variety of groups spanning a range of socioeconomic and occupational characteristics (see Table 2). The choice of groups will vary according to the risk situation in each country and the needs of the various organisations, communities, and individuals who may use the results. Thus, those who will use the results should be encouraged to actively participate in choosing the populations to be surveyed.

What do they deliver, and what do they require?

Behavioural surveys in selected population groups provide information on the behaviour of people who may be at high risk of HIV infection but who may not be captured in sufficient numbers and with the necessary frequency in general population surveys. These people often drive the growth of the epidemic in the early stages and may provide a conduit for HIV into the broader population. Thus, reducing the level of risk behaviours among these people is absolutely essential to effective national prevention efforts.

Table 2: EXAMPLES OF BEHAVIOURAL SURVEYS IN SELECTED POPULATION GROUPS

	CAMBODIA	INDIA (TAMIL NADU)	INDONESIA	SENEGAL	THAILAND
FEMALE	Sex workers Beer vendors Working women	Sex workers Factory workers University students	Brothel-based sex workers Non-brothel-based sex workers Factory workers High school students	Registered sex workers University students Secondary school students Domestic housekeepers Women in income-generating groups Office workers	Direct sex workers Indirect sex workers Factory workers Vocational students
MALE	Military/police Motorcycle drivers Vocational students	Truckers/helpers Factory workers University students STD clinic attenders	Truck drivers Sailors/seaport labourers Factory workers High school students	University students Secondary school students Truck drivers Apprentices in the informal sector Workers	Army conscripts Factory workers Vocational students

Accordingly, many countries choose to target their initial prevention initiatives at those with higher levels of risk behaviour. This is particularly valuable early in the HIV epidemic because if these individuals adopt safer behaviours, the virus may spread more slowly into the general population. By tracking trends in these groups, the repeated behavioural survey approach can indicate whether behaviour has indeed changed following the introduction of prevention efforts and whether those changes are sustained. These systems can also highlight ongoing risk behaviours that need to be addressed in future prevention efforts.

The key requirements for successful surveys in selected population groups are definable and accessible populations and workable sampling frames. Both are easier to achieve in some vulnerable communities than in others. Brothel-based sex workers, for example, are easier to enumerate than drug injectors or non-brothel-based sex workers. Men who have sex with men will be easier to sample in areas where organised social settings, such as gay bars, exist than in places where male-male sex most often happens outside of socially well-defined homosexual contexts.

In addition, members of these groups need to be accessible in large enough numbers to allow identification of behavioural trends. In countries where these behaviours can lead to social ostracism and even imprisonment, it may be difficult and in some cases ethically unacceptable to fulfill this criterion.

Other points for consideration

The repeat cross-sectional methodology of target-group-based behavioural surveys provides programmes with short-term indications of progress. This is in contrast to epidemiological data such as HIV prevalence trends, where the impact of a prevention programme is not evident for several years and which are influenced by many other factors unrelated to interventions.

Surveys in selected population groups concentrate resources on measuring behaviour among those who are most likely to be driving the epidemic and/or whose behaviour may change more rapidly than that of the general population. This can help keep the focus on where HIV transmission is occurring rapidly and build support for prevention efforts among these populations. Both results are particularly important in the early stages of the epidemic, when resources are scarce and reducing risk behaviour among groups exhibiting high HIV transmission has the greatest impact on the course of the epidemic.

Because this survey approach reaches people outside of the household, they may be able to speak more freely about their sexual and other risk behaviours. To date however, there is little evidence to suggest that the results of well-designed and well-administered household surveys are less valid than those of surveys conducted in other venues. This is clearly a topic for further research.

Survey systems in selected population groups often concentrate attention on behaviours that many prefer to ignore or on groups that are frequently marginalised. As a consequence, behavioural information on selected

subpopulations produce problematic reactions from policymakers in some countries. Surveys among youth, for example, are often disregarded, as community leaders in many societies are extremely reluctant to admit the extent of sexual activity among young people. Surveys among sex workers may be used to advocate for increased enforcement efforts against them, which make sex workers inaccessible for prevention efforts but do nothing to reduce the demand for their services. Thus, if these systems are to be used to mobilise further action, it is essential that key stakeholders, including policymakers, be involved in their development. Furthermore, it is important that results be disseminated in ways that are sensitive to the concerns of stakeholders but do not exacerbate the marginalisation of the surveyed populations.

Many population groups, such as sex workers or factory workers, experience turnover or rapid in- and out-migration. Since the purpose of behavioural surveillance is to track behavioural trends for population subgroups, such rapid turnover is of minor consequence for sampling purposes. However, since knowledge of rapid turnover is important for interpreting behavioural surveillance data and for programme implementation, questions on background characteristics and length of contact with the sample site/location should be included in the questionnaire.

Repeated surveys among hard-to-reach populations with higher levels of HIV risk are new to most countries. They require skill, sensitivity, and the backing of the communities involved, all of which may take time to develop. These skills and community involvement must then be maintained over time, requiring careful selection of a sustainable community or institutional base. Nonetheless, the value of the information they provide makes such efforts worthwhile. The resulting increased capacity of research institutions will also serve data collection activities for the country at a whole.

As with general population surveys, repeated behavioural surveys in specific populations should be complemented by qualitative follow-up to interpret their findings in a meaningful way that can inform programme design and direction.

5

Do people tell the truth about their sexual and drug-taking behaviour?

One reason more behavioural data has not been collected in the past is that many people are deeply skeptical about the validity of self-reported data on sexual behaviour. "Everybody lies about their sex lives," the reasoning goes, "so why bother asking?" The same was said of asking about contraceptive use just 20 years ago, but fertility and reproductive health surveys are now routinely conducted on every continent. The likelihood that people will lie about their sexual behaviour appears to increase as more stigma is attached to this behaviour. Extramarital sex for women carries more stigma in most societies than extramarital sex for men, for example, which accounts for greater underreporting of this behaviour by women than by men.

Growing experience in collecting data on sexual behaviour indicates that people do not always lie. They are, however, more likely to tell the truth in some situations than in others. The extent to which people answer questions about sex openly and truthfully depends on the setting of the question. Are privacy and confidentiality assured? Is the interviewer sympathetic and of the same sex and age bracket as the respondent? Are questions nonjudgmental? The long list of factors potentially biasing response is well known in the social sciences. Questions on sexual behaviour are simply at the most sensitive end of the spectrum of behavioural data collection.

Obviously it is not possible to validate data on sexual practices through direct observation. It is, however, possible to triangulate them with data from other sources to see whether the picture presented is consistent and credible. For example, process evaluation data on condom sales, the intensity of peer education, or the quality and coverage of media campaigns can be combined with an analysis of behavioural outcome data to provide an understanding of the process through which interventions achieve effects. In addition, results from behavioural surveys should be analysed together with findings from qualitative evaluation research (e.g., focus group discussions, key informant interviews, and rapid ethnographic studies) carried out in subsamples of surveyed target populations.

Moreover, those tracking the HIV epidemic may be less concerned with the exact level of risk behaviour in a population than with trends in those behaviours. Behaviour trends are of great interest in explaining

changes in HIV prevalence. Even where there is misreporting, repeated behavioural surveys will show changes in trends over time, provided that the magnitude or direction of misreporting does not change significantly.

There is now enough experience in collecting data on sexual behaviour to suggest that it can be successful in most circumstances, providing certain basic criteria are met. Questionnaires must be carefully designed and tested to balance the needs of the local community with the interests of regional and international standardisation. Interviewers must be carefully selected, well trained, and prepared to communicate with respondents in a way that builds trust and avoids judgement. Interviews should take place in private, and respondents must be sure that the information they give will remain confidential.

Finally, when assessing behavioural change it is important to realise that prevention programmes have to be implemented for sufficient amounts of time and on a large enough scale to have an impact on personal behaviour, social norms, communities, and on the epidemic.

6

Recommended mix of data collection methods

As is now clear, different data collection methods deliver different products with varying levels of cost and complexity. To use its resources most efficiently, a national programme must make choices about what mix of methods to adopt, with what frequency, and on what scale. These choices will reflect the stage of the epidemic in a country as well as the political and social environment, the existing capacity for research, and the available resources.

Family Health International, UNAIDS, and their partner organisations have made recommendations for a minimum package of behavioural data collection for each major stage of the epidemic. These recommendations are part of the UNAIDS/WHO guidelines for second generation surveillance systems and are based on the assumption that HIV serosurveillance is in place or is being developed in line with those guidelines.

Obviously, many countries will already have put in place some or all of the data collection mechanisms recommended. Tables 4 to 6, which summarise the minimum package for each stage of the epidemic, can serve as a checklist for countries planning to strengthen their behavioural data collection efforts.

6.1 Stages of the HIV epidemic

The HIV epidemic has developed differently in different parts of the world. It was originally categorised by major transmission modes into "Pattern One" countries, where the virus was concentrated mostly in homosexual male and drug injecting communities, and "Pattern Two" countries, where HIV spread mostly between men and women during sexual intercourse. Recent shifts in patterns of infection in some countries now suggest another classification that allows for the movement of countries or regions between categories. UNAIDS and its partners have developed a classification that groups HIV epidemics into three types: low-level, concentrated, and generalised (Table 3). Countries will have different information needs in each epidemic stage, and these needs may shift if the epidemic develops and moves from one type to another.

Low-level epidemics are epidemics with an HIV prevalence assumed to be less than five percent in all known subpopulations presumed to practice higher-risk behaviours. Countries in the low-level stage of the epidemic might initially focus their surveillance efforts on populations with higher levels of HIV-transmitting behaviours, such as sex workers, truckers, migrant workers, military personnel, men who have sex with men, and drug injectors. The aim will be to monitor the trends

Table 3. STAGES of HIV EPIDEMICS

Type	Defining characteristics
LOW-LEVEL:	HIV prevalence has not exceeded five percent in any defined group.
CONCENTRATED:	HIV infection continues to be concentrated in highly vulnerable groups and has been recorded at over five percent prevalence in at least one of those groups. In pregnant women, however, prevalence is below one percent.
GENERALISED:	HIV prevalence is higher than one percent in pregnant women.

and levels of infection within these groups and also to map the dynamics of infection and sexual mixing patterns that are construed as high-risk or low-risk in nature.

Concentrated epidemics are epidemics with an HIV prevalence that has surpassed five percent in one or more subpopulations presumed to practice higher-risk behaviours but remains less than one percent among pregnant women.

Generalised epidemics are epidemics in which HIV has spread far beyond the subpopulations with higher-risk behaviours, which are now heavily infected. Prevalence among pregnant women is above one percent. In such epidemics infection levels in rural population may be fast mirroring those in urban areas. Most countries in sub-Saharan Africa have an established epidemic that goes beyond just populations practising high-risk behaviours. The generalised nature of the epidemic in this region calls for surveillance systems that give a cross-sectional profile of the infection in the general population.

6.2 Behavioural data collection in a low-level epidemic

In low-level epidemics, the risk of HIV infection is likely to be concentrated among those with higher levels of risk behaviour in a country. Depending on the country, these might include sex workers and their clients, drug injectors, men who have sex with men, or other populations. In this type of epidemic, it is recommended that HIV prevalence studies also focus on those with higher-risk behaviours. Risk behaviour may exist in the general population, however, and the links between higher- and-lower risk populations need to be investigated.

Many countries with low-level epidemics have not felt the need to invest resources in collecting behavioural data, assuming that if the virus is largely absent, risk behaviour must be limited. However, it is exactly at this point of the epidemic that behavioural data can act most effectively as a warning system. Where behavioural data and other indicators such as STD or hepatitis B prevalence show that people are having unprotected sex with multiple partners or are sharing injecting equipment, it may simply be a matter of time before HIV follows.

Collecting information on behaviour at this stage spotlights potential flash points for HIV infection. It can raise awareness among the public and among policymakers of the dangers posed by not doing anything to keep the virus confined at low levels, and it can help suggest what must be done, and for whom.

Preliminary assessment: identifying risk behaviours

This first step in the preliminary assessment might be described as the "homework" stage of data collection. It provides a preliminary picture of what is already known about risk behaviour in a country. This involves gathering all existing studies, published and unpublished, trawling through press reports and other sources of anecdotal information, and speaking to people likely to have information on sexual and drug-taking behaviour. In most countries, such research will provide enough information to identify the behaviours more likely to spread HIV and to characterise the individuals or groups that are more likely to engage in those behaviours. There are very few countries where all high-risk behaviours are equally represented; therefore, behavioural data collection should focus on those more likely to be driving the epidemic in a given country.

In many countries this information on risk behaviour will already be available as part of the analysis of epidemiological data on HIV/AIDS reporting or of a situation assessment carried out as part of a strategic planning exercise. Occasionally, this review will point to gaps in existing information about the epidemic that must be filled with basic anthropological research. Where no information exists and risk behaviours must be identified from scratch, the research may take up to three months.

Preliminary assessment: quantifying populations with higher risk

Behavioural data collection in a low-level epidemic will focus on populations with higher levels of risk behaviour. These populations must be quantified if representative data are to be collected. This generally involves a mapping of sites where the behaviours take place, such as brothels, shooting galleries, gay bars, and cruising areas, together with an estimate of the number of individuals associated with each site.

Preliminary assessment: examining links with the general population

The data needed to plan effective HIV prevention programmes in a low-level epidemic will depend on how much individuals and communities with higher levels of risk interact with those with lower risk. Qualitative research — in-depth and key informant interviewing and perhaps focus group discussions — among people with higher risk can help identify interactions with the general population. In using the term "general population" we recognise that it is a composite of many subpopulations and that people at higher risk are part of the overall general population. Accordingly, where these links are widespread, the behavioural data collection system must include general population surveys. This is most often the case where commercial sex is common, but the need may also arise where men frequently have sex with both men and women or where drug injectors are sexually active with people who do not use drugs.

Qualitative research can be as costly and time-consuming as a quantitative survey. Sample sizes are therefore small, and results may not be representative of the total source population. However, this type of research provides essential input for the design of survey questionnaires that will yield relevant, informative, and actionable data from a larger population sample. It may also provide information that will inform the sampling process. Therefore, qualitative research is an essential requirement for the design of appropriate prevention programmes.

Behavioural monitoring: populations with higher-risk behaviours

Once the populations with higher levels of risk behaviour have been identified and quantified, behaviour can be surveyed and risk quantified. Using random probability sampling or other sampling methods and a sampling frame constructed during the mapping process, a behavioural survey provides information that is representative or close to representative for the group in question. It acts as a baseline and can be repeated using identical sampling methods to measure change over time. The sample size will vary depending upon the population size and the frequency of the behaviours to be measured. Generally, sample sizes will fall between 250 and 400 respondents.

It is assumed that the data provided by baseline surveys will be used to design and promote programmes that aim to reduce risk behaviour. The frequency of subsequent survey rounds is recommended to be at least every other year but will at this stage depend on the nature of the programmes intended to benefit the survey population. The first round of data collection will always be the most costly and time consuming, as it involves training and concentrated work on a sampling frame. Collecting and analyzing the data for single round of a behavioural survey in selected population groups may take between three and six months, depending on the number of target populations and survey areas.

Some groups with higher levels of risk behaviour may be impossible to sample in a systematic and replicable way, or in numbers great enough to provide significant results. For these groups, ad hoc surveys linked to prevention programmes are recommended. Programmes aimed at changing behaviour in such groups should in any case have a component built in to monitor change over time; these evaluation techniques can be a useful addition to a broader behavioural data collection system.

Data on HIV prevalence in these groups should be collected on a voluntary basis with informed consent as part of service provision.

Behavioural monitoring: general population

The qualitative research will reveal links between populations with higher levels of risk behaviour and the general population. If they appear widespread, then a household-based survey of the general population is needed to determine what proportion of the population is at risk of acquiring HIV infection through contact with subpopulations more likely to be infected.

It is worth noting that this contact may shift over time in response to the epidemic itself. General

Table 4: BEHAVIOURAL DATA NEEDS AND METHODS IN A LOW-LEVEL EPIDEMIC

DATA NEEDS	METHOD	QUESTIONS ANSWERED	FREQUENCY	DURATION*
Preliminary assessment	Review existing data	What is already known? What are the gaps in current knowledge?	One time	
	Rapid assessment of risk behaviours	Which high-risk behaviours are driving the epidemic in this country?	One time	3 months
	Mapping of at-risk populations	Where do people engage in risk behaviour? How many people are associated with each site?	One time	1 month
	Qualitative research	What particular behaviours must change? Is there resistance to change? What are links with general population? What type of intervention is most appropriate?	One time	2 months
Behavioural monitoring	Repeated surveys in **populations with high-risk behaviour**	How widespread is risk in defined high-risk-behaviour groups? How widespread are safer behaviours? How common are links with general population? How has behaviour changed over time? And since before the intervention?	Annually/ biannually	3-6 months
	Where qualitative research points to links between high- and low-risk groups: Repeated surveys in **the general population**	What proportion of the general population is a sexual partner of someone with high-risk behaviour? Which behaviours put them at risk?	Every 4-5 years	6-9 months

*DURATION: includes all research or survey stages from preparatory work to the production of findings.

population data may therefore provoke a revision of groups included in targeted survey systems. For example, men in general population surveys in Thailand reported a reduction in brothel-based sex but an increase in commercial sex with hostesses in restaurants and bars. Such a shift may require a remapping of the populations with higher levels of risk behaviour and construction of a new sampling frame for targeted behavioural surveys.

Household-based population surveys are a great asset in building support for HIV prevention activities among policymakers and the general public, especially when they demonstrate that behaviour has changed following past prevention efforts. It is therefore recommended that, where there are clear links between the general population and those with higher-risk behaviour, general population surveys be carried out every four to five years. It may be possible to reduce the cost of these surveys drastically by adding appropriate questions on sexual behaviour to existing household survey rounds, but the particular sensitivities of the topic must be considered. For example, interviewers in general health survey rounds may need extra training before asking questions about sexual behaviour.

6.3 Behavioural data collection in a concentrated epidemic

In a concentrated epidemic, the virus may remain confined to circles of people with higher-risk behaviour because there are few links between those populations and the general population. It may remain concentrated because there is very little risk behaviour in the general population. Or links and generalised risk behaviour may exist, but HIV may not have infected enough individuals to result in explosive growth. In that case, it may be just a matter of time before the epidemic becomes generalised. Determining which of these situations is the case and designing and measuring the success of the appropriate interventions are the key purposes of behavioural data collection in a concentrated epidemic.

At the concentrated stage of the epidemic, it is recommended that countries continue serosurveillance among the groups in which infection is concentrated and begin monitoring HIV in the general population, especially in young people. Behavioural data collection will increase the usefulness of this serological data.

Preliminary assessment in populations with higher risk

Because concentrated epidemics affect more people and present a greater risk to a country than low-level epidemics, there is an even greater likelihood that the data required for preliminary assessment of risk behaviour in the country will already be available. If it is not, the same steps outlined for countries with low-level epidemics should be followed.

Behavioural monitoring: populations with higher-risk behaviours

In a low-level epidemic, the frequency of behavioural surveys in populations with higher-risk behaviours will depend on the prevention activities carried out in that community (and may be guided by changes observed in serosurveillance). In a concentrated epidemic, by contrast, behavioural data should be collected much more systematically. Surveys in selected population groups with higher-risk behaviour should be designed to collect representative data annually or biannually depending on available resources.

The qualitative research performed in the preliminary assessment stage may identify definable groups that overlap extensively with both the general population and populations with higher-risk behaviours. If so, programme planners may consider adding these groups to those included in the targeted behavioural survey system.

Behavioural monitoring: general population

General population surveys are recommended in all concentrated epidemics. As in low-grade epidemics, they should aim to identify what proportion of the population has sex with members of identified groups with higher-risk behaviour and which risk behaviours are most likely to lead to HIV infection.

In concentrated epidemics, household-based surveys can help explain increases in HIV prevalence seen in sentinel serosurveillance. Designers of these surveys should bear in mind the location and population served by sentinel sites and should sample in geographical areas with key HIV sentinel sites. In order to monitor trends over time, it is recommended that general population surveys be repeated every four to five years.

Table 5. BEHAVIOURAL DATA NEEDS AND METHODS IN A CONCENTRATED EPIDEMIC

DATA NEEDS	METHOD	QUESTIONS ANSWERED	FREQUENCY	DURATION*
Preliminary assessment (if not yet done or if it needs to be broadened geographically or in other groups)	Review existing data	What is already known? What are the gaps in current knowledge?	One time	
	Rapid assessment of risk behaviours	Which high-risk behaviours are driving the epidemic in this country?	One time	3 months
	Mapping of at risk populations	Where do people engage in risk behaviour? How many people are associated with each site?	Repeated if survey data shows population or behavioural shift	1 month
	Qualitative research	What particular behaviours must change? Is there resistance to change? What are links with general population?	One time	2 months
Behavioural monitoring	Repeated surveys in **populations with high-risk behaviour**	How widespread is risk in high-risk-behaviour groups? How common are links with the general population? How do these behaviours change over time?	Annually/ biannually	3-6 months
and				
Explaining trends in HIV prevalence	Repeated surveys in **the general population** Sampling with emphasis on geographical areas with key HIV sentinel sites	What proportion of the general population has sex with someone with risk behaviour? Which behaviours put them at risk?	Every 4-5 years	6-9 months
	Repeated surveys in **young people** Sampling with emphasis on geographical areas with key HIV sentinel sites	What are the risk behaviours among young people? At what age do they begin? How do they change over time? Do trends in self-reported risk behaviour correlate with observed changes in HIV prevalence (e.g., explaining transition to generalised epidemic)?	Every 2-3 years	3-6 months

*DURATION: includes all research or survey stages from preparatory work to the production of findings.

Behavioural monitoring: young people

Young people are particularly vulnerable and are the key to the future course of the HIV epidemic. They are an essential focus for prevention messages in every sexual health programme. Since most new infections are in young people, modest changes in behaviour in this age group may have a significant impact on the epidemic. It is recommended that their knowledge, attitudes, and sexual behaviour be monitored once there is a concentrated epidemic.

In general, it is recommended that young people's behaviour be studied in household-based surveys, supplemented by surveys in particular groups of young people (homeless youth, young drug injectors) who may not be found in a typical household survey.

The exact age groupings will vary according to the local situation. In countries where the mean age at first sex is in the early 20s, resources should be concentrated in the 20- to 24-year-old-group. Countries where a large proportion of the population is sexually active by age 15 may consider including 12- or 13-year-olds. A rise in age of sexual inception is an important response to HIV prevention messages, so it may be necessary to track behaviour in both teenagers and people in their early 20s. It is recommended that surveys be repeated in these groups every two to three years, with sample sizes between 400 and 500 in each age and sex group (males and females younger than 20, and 20 to 24 years).

6.4 Behavioural data collection in a generalised epidemic

Groups with particularly high levels of risk behaviour may continue to drive new infections in a generalised epidemic, but the pattern of HIV spread goes far beyond higher-risk individuals and their immediate partners. By the time an epidemic becomes generalised, it is usually clear what the major risk behaviours are. Systematic and repeated behavioural data collection in the general population is essential for explaining changes in prevalence and tracking changes in behaviour over time. It must also focus on identifying the risk behaviours that have been neglected or have failed to respond to prevention efforts. New qualitative research may choose to explore the social, economic, and cultural context that determines who continues to be vulnerable to HIV infection and why.

Behavioural monitoring: populations with higher-risk behaviours

While it is important in a generalised epidemic to expand prevention efforts to those with somewhat lower risk of transmitting the virus, national programmes should not lose sight of groups that are driving the epidemic. Population groups practising high levels of risk behaviour still have a great impact on the spread of HIV infection in generalised epidemics. That is why it is essential to maintain a focus on interventions with those groups and, as a logical consequence, to monitor their behavioural trends.

In every generalised epidemic to date, the overwhelming risk factor for HIV infection has been unprotected sex with a partner of the opposite sex. While other groups, such as drug injectors or men who have sex with men, may also be at elevated risk, they have not historically contributed greatly to generalised epidemics. In this context, it is recommended that surveys concentrate their resources on tracking the behaviour of sex workers and any subgroups of the general population (for example, seasonal migrant workers) that interact extensively with sex workers but that may be missed in household surveys. Targeted surveys in these groups should be carried out every year or every other year, depending on available resources.

Behavioural monitoring: general population

Regular surveys of behaviour in the general population are critical in explaining the progress of HIV infection at the generalised stage of the epidemic. They are also a suitable tool for judging the overall success of the national response in supporting the adoption of safer behaviours. Because behaviours at the general population level tend to change more slowly, it is recommended that these surveys be carried out every four to five years.

Sampling for the general population survey should be coordinated with the key sites in the sentinel HIV serosurveillance system. This will make it possible to analyse behavioural trend data in conjunction with HIV prevalence data in antenatal clinic attenders from the same catchment area. Analysis of these data by age group (if possible by single year of age in the younger age groups) will enable evaluators to make a better informed interpretation of observed changes in HIV prevalence.

Because general population data are important to understanding a generalised epidemic, it is recommended

Table 6: BEHAVIOURAL DATA NEEDS AND METHODS IN A GENERALISED EPIDEMIC

DATA NEEDS	METHOD	QUESTIONS ANSWERED	FREQUENCY	DURATION*
Preparation for behavioural surveys in selected population groups	Mapping of at-risk populations	Where do people engage in risk behaviour? How many people are associated with each site?	Repeated if indications of behavioural shift	1 month
Behavioural monitoring	Repeated surveys in **populations with high-risk behaviour** with emphasis on sex workers and their clients	How widespread is risk in high-risk-behaviour groups? How common are links with the general population? How do these behaviours change over time?	Annually/ biannually	3-6 months
	Repeated surveys in **the general population**	What puts people in the general population at risk of HIV infection? Has risk behaviour changed over time? Which behaviours have not changed?	Every 4-5 years	6-9 months
	Repeated surveys in **young people**	What are the risk behaviours among young people? At what age do they occur? How do they change over time?	Every 2-3 years	3-6 months
Explaining trends in HIV prevalence	Sampling geographical areas with key sentinel serosurveillance sites, with wide geographic/ethnic range	e.g., Are observed declines in HIV prevalence a result of behaviour change?	Linked to household-based surveys	
	In selected sites, household surveys with data on HIV serostatus	Serological confirmation of self-reported trends in risk behaviour by age group and sex.		
Contextual analysis, explaining continuing risk behaviour at community level	A range of methods, largely qualitative	What are the social, economic, or cultural factors supporting risk behaviour? How might these be changed to make sex safer? How can communities contribute to alter these determinants?	One time. Selected communities	

*DURATION: includes all research or survey stages from preparatory work to the production of findings.

that (in some instances where it might be feasible) household surveys collect data on HIV serostatus as well as behaviour. Saliva or blood specimens may be collected in households when interviews are conducted or separately in ad hoc clinics in association with clinical examination and treatment for specific diseases, including STDs. Informed consent and pre- and post-test counseling are prerequisites for this type of survey. Ethical guidance ensuring confidentiality and informed consent is needed.

Behavioural monitoring: young people

In generalised epidemics, the importance of behavioural patterns adopted in youth is greater than ever in determining the course of the HIV epidemic. As an epidemic matures and prevalence rises, most people exposed to HIV through their own or a partner's risk behaviour will already be infected. New infections are therefore concentrated in young people who have only recently become sexually active.

The positive side of this equation is that young people are more likely to adopt safe behaviour from the start of their sexual lives than are older people with already entrenched habits. In some countries, the only groups reporting substantial changes in behaviour in response to the epidemic are young people. And in those countries, youth are also the group in which HIV prevalence is falling most markedly.

In general, young people's behaviour should be studied in a household-based survey, supplemented by surveys in those (homeless youth, young drug injectors) who are less likely to be reached in a household survey. These young people often are at elevated risk compared to those living in household settings.

Surveys in young people should be repeated every two to three years, with sample sizes between 400 and 500 in each age and sex group (males and females younger than 20, and 20 to 24 years of age).

7

What next?

Behavioural data are of little value unless they are used for the benefit of the people from whom they were collected. The various reasons for tracking behaviour were discussed at the beginning of this document. This section describes the particular uses of the data once they have been collected and analysed.

Encouraging policymakers to support and promote HIV prevention

Public health officials need no convincing about the importance of dedicating time and resources to prevent further spread of HIV. The same cannot always be said for policymakers in other sectors, who are confronted with pressing priorities of their own.

In the early phases of the epidemic, well-designed, credible behavioural data can warn of the possibility of rapid HIV spread and encourage policymakers to act to prevent that spread. But this can happen only if the data are presented in language that policymakers can understand and in ways to which they can respond. The best ways to present behavioural data will vary according to the target audience: a ministry of education may be interested in knowledge and attitudes among youth, while a ministry of labour may want to know how widespread risk behaviour is in the urban adult population. The finance ministry might be startled by the implications of financing health care if 10 percent of those reporting risk behaviour were to become infected with HIV.

A comprehensive approach to promoting HIV prevention requires data on both the general population and groups at high risk for infecting themselves and others. Behavioural data on a mix of these groups improves understanding of who is at high risk and how (or if) risk patterns are changing. In other words, general population data provide information about unknown levels of risk in the overall population, whereas data on groups with high levels of risk behaviour provide more immediate information on the subpopulations that have the biggest impact on the epidemic.

Demonstrating that behaviours do change following prevention activities, both in groups with higher levels of risk behaviour and in the general population, is one of the most effective ways of increasing support for prevention activities. Behavioural data showing changes over time should be presented simply and rapidly to policymakers who have the power to influence funding levels and programme direction.

Making the public aware of the threat posed by HIV

Many generalised epidemics have reached their current stage because people in the general population did not know or did not want to believe that they were at risk of HIV infection. Behavioural surveys in the general population as well as in selected population groups can illustrate the extent of continuing risk behaviour. Presented to the respective target audiences through the media or other avenues, the findings of such surveys will increase awareness of the risk of unprotected sex with any partner.

It is also important for people to be aware of trends in behaviour over time. Knowledge that others are adopting safer behaviours can help reinforce behaviour change, especially among young people who respond to peer pressure. Thus, the targeted dissemination of relevant behavioural data to communities can enhance the effectiveness of prevention efforts over time.

Seeking support from non-government sources

Behavioural data can demonstrate success in prevention efforts and highlight continuing needs. Presented appropriately to private firms, development organisations, and international funders, these data can be used to mobilise additional resources for activities that are not being adequately covered in government spending plans.

Improving prevention programmes

As the picture of risk behaviour develops over time, it will indicate which behaviours have changed following prevention programmes and which remain entrenched. This information can and should be used to improve prevention programmes. Prevention packages that appear to be associated with behaviour change in certain subpopulations may be continued and expanded. Evidence of behaviours that remain unchanged despite efforts to promote safer alternatives indicates the need for a new approach — perhaps one that pays closer attention to the social or economic context that determines why people behave in that way.

8

Sustaining behavioural data collection over time

While cross-sectional behavioural data are clearly useful in determining who is at risk of infection and why, data showing trends over time are needed to explain changes in the epidemic and demonstrate the success of national programmes in reducing risk behaviour. Behavioural data collection systems should therefore be constructed to provide information over the long term. In order to ensure sustainability, there is a need to rely on local expertise to carry out these surveys. When needed, special training should be targeted to host country institutions, such as government ministries, university departments, private companies, or NGOs, that are likely candidates for implementing and maintaining the recommended behavioural data collection systems. This process of institutionalisation of local skills in data collection is crucial to ensure better quality as well as sustainability of programme monitoring and evaluation activities.

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Annex

Elements of Survey Costs

Survey design

- sample sizes per group and per region
- number of selected target populations
- number of sample clusters (dispersion versus concentration)
- travel time within and between survey areas

Length of the preparatory phase

- availability of sampling frame (How up-to-date is the sampling frame? Do maps exist? Are there current estimates of population/subpopulations?)
- whether translation of questionnaires is done and into how many languages
- pretesting and printing of questionnaires
- development of guides for supervisors and interviewers
- recruitment and training of field staff
- set up of data management specifications

Length of field work

- number of interviews
- number of interviewers
- number of interviews per day (mainly determined by the length of the questionnaire/interview time)
- number of clusters
- number of callbacks
- travel time

Data entry and data analysis, production of final report

- computer equipment
- number of entry clerks
- printing and dissemination of final report
- office supplies

Personnel

- salary levels (type of personnel required)
- per diem or living allowance levels

Transportation

- number of drivers
- vehicles and other modes of transport
- petrol
- maintenance

In most surveys, personnel and transportation are the most expensive items.

A general population household survey in sub-Saharan Africa may cost on average between 40,000 US$ and 60,000 US$, depending on the domains involved (two urban areas or one urban and one rural area). The recommendation generally is not to carry out national surveys.

The cost of repeated surveys in populations with high-risk behaviour will depend heavily on the number of target populations and survey areas. For example, a single round of behavioural surveys in three selected population

groups, conducted in two different geographical areas, may cost between 25,000 US$ and 35,000 US$ in countries in sub-Saharan Africa.

Additional information on surveys

National Demographic and Health Surveys (DHS-II and III) surveys with a module on AIDS and a subsample of men have been conducted in many countries, such as Burkina Faso, Malawi, Senegal, Tanzania, Benin, Central African Republic, Chad, Eritrea, Kenya, Mali, Niger, Uganda, and Zambia.

A list of countries with such surveys is available on Internet at the DHS+ website address:

http://www.macroint.com/dhs

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The UNAIDS/WHO Epidemiological Fact Sheets are designed to collate the most recent country-specific data on HIV/AIDS prevalence together with information on behaviours. More than 140 countries have provided information from serosurveillance, behavioural surveys, and other studies. Please contact:

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http://www.who.ch/emc/diseases/hiv

Acknowledgements

This document is a summary of different regional workshops held in 1997 in Nairobi, Kenya; Bangkok, Thailand; Berlin, Germany; and Oxford, UK. The results of these workshops provided the basis for discussing and preparing this document. The following participants are greatly acknowledged for their valuable contributions: Karen Stanecki, Ties Boerma, Ann Blanc, Lisanne Brown, Joseph Amon, Robert Magnani.