Monitoring Programme Outcome and Impact Indicators – the Role of Surveys and Surveillance

What questions do monitoring programme outcomes and impacts answer?

Programme outcomes and impact indicators are measures of a programme's intended effect on the population being targeted by the interventions. Promoting HIV risk avoidance or risk reduction practices is an important component of HIV prevention programmes for most-at-risk populations, and measuring change in this area is central to the task of monitoring and evaluating these programmes. Behavioural change that reduces a population's exposure to HIV infection may include having fewer high-risk sexual partners, using condoms in higher-risk sexual encounters, reducing injecting drug use, or adopting safer injection practices. Tracking changes in sexual and drug-injecting behaviour over time gives an indication of the success of a package of activities aimed at promoting safer behaviour and reducing the spread of HIV in most-at-risk populations.

HIV prevention programmes often put a great deal of effort into behaviour change communication programmes that aim to provide information about how HIV can be avoided and to dispel misconceptions about the disease and how it is transmitted. Monitoring levels of knowledge among most-at-risk populations can prove useful, particularly in those populations where knowledge of how HIV is transmitted and the ways to avoid it is not yet widespread or where misconceptions exist.

Programmes ultimately aim to decrease the number of new HIV infections. HIV prevalence among most-at-risk populations – an indirect measure of programme impact – is important for measuring the success of programmes that aim to reduce the spread of HIV in these populations. While HIV prevalence is a recommended indicator, it does have several limitations. HIV prevalence is a measure that can be slow to change in a more mature epidemic and may only reflect changes in incidence (new infections) after a lag of five years or more. (In contrast, in a relatively young and rapidly growing epidemic, incidence is almost immediately translated into prevalence). In addition, HIV prevalence loses some utility as a measure of the impact of prevention programmes when antiretroviral therapy becomes widely available (the number of PLHIV increases, which can mask changes in numbers of new infections). Despite these limitations, in the absence of measures of HIV incidence, HIV prevalence remains essential to our ability to track and monitor trends in the epidemic.

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When is it necessary to monitor programme outcome and impact indicators?

Behavioural surveys and epidemiological surveillance to assess knowledge and risk behaviour and provide information on the level of HIV infection in most-at-risk populations are both important components of situation analysis and problem identification. This information should be used to inform the national response and programme design at all levels and, thus, they are critical activities to conduct before designing programmes and allocating resources. By collecting this information before the implementation of programmes, these data can also serve as a baseline for M&E activities.

Once programmes are implemented, regular behavioural surveys are recommended, particularly when strong prevention programmes are put in place. The frequency of these surveys will depend on the amount of behavioural change that is expected to occur in the populations being monitored, the availability of resources, and the willingness to use the information generated to improve prevention efforts. Ideally, they should be conducted every one to two years.

The frequency of surveillance activities will depend on resources and surveillance methods. HIV sentinel surveillance (HSS) is generally conducted annually, while surveillance that is part of an integrated biological and behavioural surveillance system may be conducted less frequently, perhaps every one to two years.

Who should monitor outcome and impact indicators?

Behavioural and epidemiological surveillance may occur under the leadership of the national AIDS programme or a national epidemiological monitoring centre. In some countries with concentrated epidemics, surveillance may be conducted by NGOs and other civil society organizations and may not be coordinated by national or subnational governments. Because many programmes for most-at-risk-populations are often provided by NGOs, these organizations have an important contribution to make in planning these activities. They are also likely to want to use the data generated to improve their own prevention services and are, therefore, likely to have useful ideas about appropriate survey questions. Secondly, they are likely to have good access to communities that are otherwise difficult to reach.

Very often, a tension exists between national and local officials over the collection of behavioural or biological data and the scale to which the data can be applied. National officials required to report to their legislatures, for example, may wish to cite the national HIV prevalence rate. To this end, national officials may plan national surveys that are designed to estimate a national rate, with small samples from each locality aggregated for a sample size sufficient only to estimate national figures.

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Local officials, on the other hand, are most interested in the rate within their province, where they are responsible for the implementation of prevention programmes. In general, in concentrated epidemics, the information needs of local officials may be more important than those at the national level. It is useful to consider the administrative level at which programmes are typically planned and implemented and then collect data at that level.

What methods are available for behavioural and epidemiological surveillance?

When assessing the effectiveness of an intervention, surveys of the population using the service of interest may be sufficient. However, for understanding changes in knowledge, behaviour and HIV status in populations targeted by HIV prevention programmes, surveys must also include people theoretically targeted by an intervention but who do not avail themselves of the service. This section will review some of the methods for monitoring indicators of knowledge, behaviour and HIV prevalence in these populations.

Surveys are used to assess the perceptions, behaviours, knowledge, attitudes and, increasingly, infection status, of most-at-risk populations. Good surveys utilize well-tested and validated instruments administered to representative populations of interest. A sample may be chosen to represent different subpopulations within a most-at-risk population. For example, a sample obtained at bars, clubs or cruising areas where men are seeking other male partners will only be representative of men who go to these and similar venues. Such limited representation is acceptable if it is understood and conclusions are limited to the represented population. The sampling design and instrument used with a given population should be used as the basis of all future surveys assessing similar information, to assure some level of consistency and ability to monitor trends.

Sampling methods for surveying most-at-risk populations

Household surveys are not adequate for tracking risk behaviours that are not widespread in the general population but which may contribute disproportionately to the spread of HIV, such as injecting drug use, male to male sex, or selling sex. To obtain data from individuals with these high-risk behaviours, special surveys of these populations must be conducted. Household surveys also do not reach individuals who are mobile and who tend to spend extended periods of time away from home, such as the military, migrant workers, long-distance truck drivers or other frequent travellers. These populations may be at higher risk of HIV infection, often because they are clients of sex workers or have multiple sexual partners. These are often referred to as 'bridge groups' because they may then transmit HIV to their wives or girlfriends, members of the general population who themselves do not engage in high-risk behaviour. Despite the aforementioned limitations in reaching these populations, household surveys are useful for obtaining information about more common and less stigmatized behaviours, such as men having sex with a sex worker. The following is a brief review of sampling methods for hidden and hard-to-reach populations. For a complete review, see guidelines on behavioural surveillance surveys by FHI.

Venue-based methods

Synopsis: Estimate risk behaviour and other characteristics of groups (e.g. IDUs, FSWs, MSM) attending venues such as bars, brothels, cruising areas, truck stops and shooting galleries.

Main Features: All known venues that risk groups frequent are mapped, and the times of operation recorded. There are a number of rapid assessment techniques to assist in mapping and finding hidden populations, such as International Rapid Assessment, Response and Evaluation (I-RARE). Mapping provides a time-location sampling frame where venues open longer have a higher probability of being sampled. A random sample is taken from the list with the probability of a venue being sampled proportional to the length of time it is open. Venues are then visited during the selected time segment and interviews are conducted.

Assumptions: This assumes that all venues frequented by members of a particular risk group are mapped and that members of a risk group can be identified and recruited at a venue. These methods can be time-consuming and labour-intensive and tend to find only visible members of a population. For example, IDUs or non-gay-identified men typically avoid public gathering sites that could potentially identify them as group members.

Network-based methods

Synopsis: Estimate the characteristics of members of a risk group who belong to the same networks.

Main Features: Members of the risk group are identified through methods such as snowball sampling, random walk, chain referral or respondent-driven sampling (RDS). In snowball sampling, random walk and chain referral sampling, informants in a high-risk population identify other members of their group for sampling. These individuals then identify others, creating a chain of informants. These three methods are essentially convenience methods and have biases associated with the need for the investigators to find referred group members. RDS takes 'snowball sampling' and combines it with a statistical model that assigns weights to create, in theory, a probability sample.

Assumptions: All network-based methods assume that informants will be representative of the target population, but those interviewed may in fact be a biased sample. RDS has features that help overcome some of the limitations of the convenience methods in creating a representative sample. Additional assumptions with RDS are that all members of the risk group are connected with the risk group by at least one reciprocal social tie, that people will visit the office for an interview, and that people will not pretend to be a member of the risk-group to receive an incentive.

Institution-based methods

Synopsis: Estimate the characteristics of a group identified through institutions.

Main Features: Members of the risk group are identified in institutional settings such as STI and TB clinics, needle exchange programmes, prisons and methadone clinics.

Assumptions: Populations are likely to be representative only of those group members that seek services or who have had the misfortune of being caught, in the case of prisons. Nonetheless, a large number of group members may be encountered and much can be learned about programmes not based in these institutions. Such samples, which by nature are convenience samples, can be calibrated against a more complete sample in an ad-hoc survey, provided that the institution-based sample is truly collected systematically in a stable population.

Methods of sero-surveillance among most-at-risk populations

Sero-surveillance provides the foundation for measuring the impact (or grand effect) of all programmes aimed at reducing the spread of HIV in a population. The mix of populations included in a surveillance system generally depends on the epidemic stage and on the populations most-at-risk of HIV. Where HIV is concentrated in populations practising higher risk behaviour, these populations should receive priority for inclusion in the surveillance system. As discussed previously, however, HIV prevalence as a measure of programme impact does have limitations. Unless there is a stable population trend in HIV over time, it is not possible to make incidence estimates from prevalence data – and getting stable populations is very difficult with most-at-risk populations. Improvements in current surveillance systems are needed if HIV prevalence is to be a valid measure of programme impact.

To better understand trends in HIV prevalence, UNAIDS and its partners promote second generation surveillance where behavioural data are integrated into sero-surveillance systems (see UNAIDS 2000). Second generation surveillance systems also focus more closely on those segments of the population where new infections are occurring, such as the most-at-risk populations discussed in this guide. Biological and behavioural data can be collected in the same population but through separate data collection exercises or can be combined into one data collection activity. The following summarizes the two main approaches to monitoring HIV prevalence in most-at-risk populations:

HIV sentinel surveillance systems (HSS)

Synopsis: Populations at risk of HIV infection are tested for HIV on a regular basis, usually annually.

Main Features: Populations tested may include STI clinic populations, IDUs, FSWs, military conscripts, pregnant women, etc. Among clinic populations, this can be conducted as anonymous, unlinked testing, where remnant blood specimens from routine testing (e.g., syphilis) are tested for HIV antibodies after all identifying information has been removed. Non-clinic populations of identifiable risk group members (e.g. IDUs) should be surveyed using probability sampling methods. Behavioural surveys would theoretically draw from these same populations but would not necessarily include the same individuals. Unlinked anonymous testing is only carried out in clinics where HIV Counselling and Testing (CT) are readily accessible, preferably in the clinic itself, or within a clinic a short distance away. Then only time that this is not true, is when HIV prevalence data are required for advocacy to increase CT availability in an area. Unlinked anonymous testing remains an important tool for measuring HIV prevalence. Unlinked anonymous testing is the only means by which unbiased data for prevalence estimates can be accrued. Most other available methods are subject to participants' refusals, which in areas with high levels of stigma, can lead to unusable data due to high refusal rates.

Assumptions: This assumes that the same populations will be surveyed at each point in time. Most HSS systems collect information and usually include age, gender, and risk group – as defined by where they were interviewed – and little else. This information is often insufficient to evaluate the success or failure of a programme.

Integrated Behavioural Biological Surveillance Systems (iBBS)

Synopsis: These are behavioural surveys that also include HIV testing.

Main Features: Biological specimens and behavioural information are collected concurrently. These surveys use the types of sampling methods discussed previously. Similar to HSS, iBBS should be implemented periodically with similar methods in similar populations. (See FHI, 2000.)

Assumptions: It is assumed that the inclusion of HIV testing does not cause respondents to refuse to participate. Non-response to both the survey questionnaire and the HIV testing should be tracked however to assess whether any bias is being introduced. Integrated surveys are more complex than behavioural surveys but have the benefit of costing less than two separate surveys and offer the potential to analyse behaviours and infection rates together more readily.

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Greater validity of surveillance data should lead to sounder decision-making for the allocation of resources. To ensure maximum utility of these data, surveillance systems should be evaluated following every round so that lessons learned, gaps in the data and obstacles encountered can be studied, and alterations to the system can be made as needed.

Recommended outcome and impact indicators

Once the most relevant most-at-risk populations are identified and defined, indicators for these populations can be identified. These indicators should represent those behaviours believed to be most implicated in the transmission of HIV and which are expected to be changed as a result of HIV prevention programmes. In low-level and concentrated epidemics, the focus is on high-risk partnerships such as sex with a sex worker, unprotected sex with IDUs, unprotected anal sex among MSM, and using non-sterile injecting equipment. In addition to behavioural indicators, it may also be useful to monitor levels of knowledge about HIV prevention within these populations. The indicators presented below have been adopted from UNGASS. Detailed descriptions of these indicators are available in the Appendix. They represent the minimum set of indicators for programmes targeting most-at-risk populations. Programmes may wish to monitor other outcome indicators and are encouraged to do so.

2007 UNGASS outcome and impact indicators*

Outcome: Knowledge
- Percentage of [most-at-risk populations] who both correctly identify ways of preventing the sexual transmission of HIV and who reject major misconceptions about HIV transmission

Outcome: Behaviour
- Percentage of female and male sex workers reporting the use of a condom with their most recent client
- Percentage of men reporting the use of a condom the last time they had anal sex with a male partner
- Percentage of injecting drug users reporting the use of a condom the last time they had sexual intercourse
- Percentage of injecting drug users reporting the use of sterile injecting equipment the last time they injected

Impact
- Percentage of [most-at-risk populations] who are HIV infected

* Please refer to the UNAIDS website (www.UNAIDS.org) for updates of this list of UNGASS indicators for most-at-risk populations.

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Some programmes may also opt to track STI prevalence as an impact indicator, particularly for high-risk men who are likely to be clients of sex workers. Where HIV prevention programmes aim to expand access to and quality of STI services (i.e. for FSWs and MSM), it can be difficult to interpret changing levels of STI prevalence as an increase may reflect increased use of services or better diagnosis rather than an increase in risk behaviour. However, in populations where access to STI services remains relatively constant, STI prevalence can be a useful proxy for sexual risk behaviour and as an early warning sign for increasing HIV incidence.

How to select the most appropriate methods

The selection of the most appropriate sampling methods for surveys of most-at-risk populations will depend on characteristics of the population, such as whether the population is hidden or visible, whether members of the population congregate in sites that can be identified, how closely their social networks are, and how dispersed they are geographically. In addition, how the survey data are to be used and the availability of resources should also be considered.

What are the specific challenges related to most-at-risk populations?

The issue of how to sample 'hard-to-reach' populations, such as FSWs, IDUs, and MSM, and in particular, mobile and migrating populations, is one of the most difficult challenges for those involved in behavioural surveys and surveillance activities. Although it can be difficult to implement random sampling with these 'moving targets', sound, systematic sampling approaches should be employed and can be effectively implemented in many settings. Such approaches, if used consistently from one round to the next, increase the likelihood of obtaining reliable estimates of indicators within these populations.

Providing monetary incentives may increase study participation in some communities, however, large monetary incentives should be strictly avoided as they can be coercive. Providing monetary incentives also presents additional challenges. As the number of studies offering financial incentives increases in a community, study participants may expect higher remuneration in order to participate. Additionally, the participants in one study may also be participants in other studies. This may contaminate the findings of one study with those of another.

As with all other data collection exercises among most-at-risk populations, ethical research practices must be adhered to, including respect for privacy, confidentiality, anonymity, and the principle of 'do no harm'. In collecting data from most-at-risk adolescents under the legal age of majority, particular attention will need to be paid to any national and global ethical issues (see Ethical Approaches to Gathering Information from Children and Adolescents in International Settings: Guidelines and Resources, Population Council, 2005).

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Whichever method is chosen for monitoring indicators in most-at-risk populations, instruments should be standardized by both population and geography. Steps to assess group membership of all respondents should be consistent across surveys, particularly when incentives are being offered to participants. Interviewers must be well trained, empathic and non-judgemental. Members of the population often make the best interviewers, though in smaller geographic areas interviewers should be chosen from outside the community to assure confidentiality. There may also be risks to members of at-risk populations themselves, as well as ethical issues concerning their employment. This can be seen, for example, when hiring former IDUs and asking them to return to the streets where drugs will be available and where they will experience situations that may have previously prompted them to relapse. Additionally, there is real danger to the lives and well-being of research staff involved in collecting information about illegal behaviours in certain settings. A number of innovative and unobtrusive measures can and have been used to try to obtain outcome and impact measures without placing staff at risk through direct interaction or observation (see Des Jarlais et al., and others).

How can the results of biological and behavioural surveillance be used?

Surveillance data are useful as part of problem identification and provide essential information to inform the national and subnational response. They also indicate whether collective efforts are being implemented on a large enough scale to have an impact on the epidemic and can indicate the success of a package of HIV prevention interventions (see Figure 14). However, to assess and substantiate the linkages between programme interventions and outcomes, integrated analyses are needed. Integrated analysis of biological and behavioural data are used at both ends of the public health questions approach framework presented in Chapter 1. Integrated analysis of behavioural and epidemiological data and the combination of these with programme-level data for evaluation are discussed in detail in the following chapter.

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Figure 14. The Use Of HIV Prevalence Estimates In Female Sex Workers And Men Likely To Be Their Clients To Track Trends In The Epidemic In These Most-At-Risk Populations.
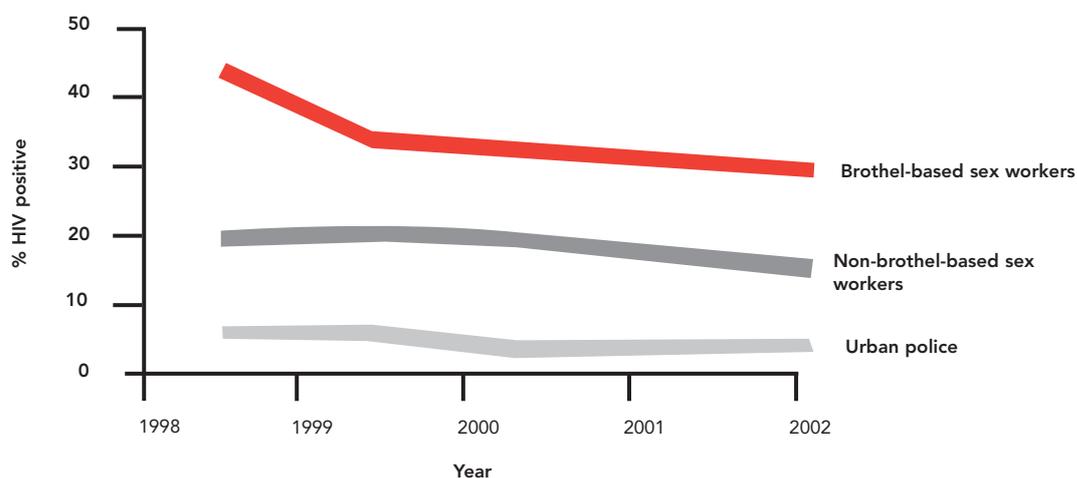
Source: Cambodia Surveillance Unit, National Center for HIV/AIDS, Dermatology and STDs (NCHADS),2004

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