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Working Group on Global HIV/AIDS and STI Surveillance

Guidelines for Second Generation HIV Surveillance

WHO

UNAIDS

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Second generation surveillance for HIV:

The next decade

Joint United Nations
Programme on HIV/AIDS
(UNAIDS)

World Health Organization
(WHO)

Global surveillance of HIV/AIDS and sexually transmitted infections (STIs) is a joint effort of the World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS). The UNAIDS/WHO Working Group on Global HIV/AIDS and STI Surveillance, initiated in November 1996, is the main coordination and implementation mechanism for UNAIDS and WHO to compile the best information available and to improve the quality of data needed for informed decision-making and planning at national, regional and global levels.

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Second generation surveillance for HIV

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The diversity of HIV epidemics around the world is becoming ever more apparent. Existing HIV surveillance systems are ill-equipped to capture this diversity, or to explain changes over time in mature epidemics. Efforts are now being made to build on existing systems, strengthening their explanatory power and making better use of the information they generate.

Strengthened systems, dubbed "second generation surveillance systems", aim to concentrate resources where they will yield information that is most useful in reducing the spread of HIV and in providing care for those affected. That means tailoring the surveillance system to the pattern of the epidemic in a country. It means concentrating data collection in populations most at risk of becoming newly infected with HIV—populations with high levels of risk behaviour or young people at the start of their sexual lives. It means comparing information on HIV prevalence and on the behaviours that spread it, to build up an informative picture of changes in the epidemic over time. It also means making best use of other sources of information—communicable disease surveillance, reproductive health surveys, etc.—to increase understanding of the HIV epidemic and the behaviours that spread it.

This document suggests classifying the epidemic into different states—low-level, concentrated and generalized—depending on the prevalence of the virus in various population sub-groups. The most efficient mix of data collection for surveillance will depend on the epidemic state in a country. The recommended choice of populations among whom data are collected will vary from epidemic to epidemic; so will the mix of behavioural and bio-medical surveillance.

Data use will also vary according to the epidemic state. Where HIV is uncommon, biomedical surveillance and especially behavioural data can provide early warning of a possible epidemic. Where it is concentrated in sub-populations with high-risk behaviour it can provide invaluable information for designing focused interventions. In generalized epidemics it can help indicate the success of the response and provide information essential for planning care and support. In all epidemic states, surveillance systems aim to provide information that will increase and improve the response to the HIV epidemic.

This document provides an overview of the principal issues which need to be considered in strengthening surveillance systems and increasing their utility. It suggests priority approaches for the various epidemic states. Technical guidelines are provided in separate documents.

Introduction

a summary

Goals of second generation surveillance systems

- *Better understanding of trends over time*
- *Better understanding of the behaviours driving the epidemic in a country*
- *Surveillance more focused on sub-populations at highest risk of infection*
- *Flexible surveillance that moves with the needs and state of the epidemic*
- *Better use of surveillance data to increase understanding and to plan prevention and care*

A decade has passed since the initial guidelines on HIV surveillance were drafted by WHO in 1989. As HIV continues to spread around the world, it has become increasingly apparent that the epidemic does not follow the same course in all societies. Rather it affects different geographical areas and population sub-groups in different ways at different times.

This complicates the task of monitoring its course, intervening to prevent the further spread of HIV, and planning to minimize its impact. It also makes a thorough understanding of the nature of each country's epidemic more vital than ever.

Such an understanding can only be achieved with more information about who is most at risk in a country, and which behaviours put them at risk. Solid behavioural data will identify sub-populations at risk and will help focus serosurveillance* resources where they will yield maximum information about the epidemic. Behavioural data also help explain trends in prevalence in mature epidemics. Second generation surveillance systems aim at monitoring trends in behaviour as well as HIV infection. They build on the lessons learned in the first decade of surveillance, strengthening and expanding existing systems to achieve the goals of second generation surveillance.

This document reviews the achievements of the first decade of surveillance for HIV. It describes the strengths and weaknesses of existing systems and outlines the basic principles of second generation surveillance systems. It then goes on to make recommendations for meeting the surveillance needs of countries in different epidemic states.

This document is intended to guide policy on strengthened surveillance for HIV. Technical guidelines for the various elements of surveillance—HIV and AIDS case reporting, field guidelines for serosurveillance for HIV, sexually transmitted infection (STI) surveillance, and behavioural data collection are being published separately as part of this series. Existing technical guidelines are listed in the *References*. Many of these documents are currently under revision. Finalized versions are posted on the web sites of the organizations involved as they become available, and web sites are also listed in the *References*.

** In this document, serosurveillance refers to surveillance for HIV antibodies in all body fluids, not just blood.*

I. The first decade: Lessons learned

The approaches taken to HIV surveillance in the first decade have demonstrated many strengths upon which second generation systems should build as they try better to meet the needs of an epidemic that does not follow a single, inevitable path, but that unfolds in different ways in different countries. Past efforts at surveillance have also shown gaps in understanding the course of the epidemic and its relationship to changes in the behaviours that spread it. Second generation systems hope to fill some of these gaps.

a summary

Strengths and weaknesses of existing systems

1. Strengths

- *Surveillance helps generate a public response to HIV*
- *It helps target prevention activities and plan responses*
- *It monitors the success of the national response*

2. Weaknesses

- *Current systems rarely track the risk behaviours that provide warning signs for the spread of HIV*
- *Useful information from other sources is often ignored*
- *Surveillance resources are often targeted in the general population where little infection exists, while at-risk sub-populations are neglected*
- *Systems have difficulty explaining changes in levels of HIV infection in mature epidemics or in countries where therapy exists*

1. Strengths

Surveillance can generate a public response to HIV

Surveillance data have been crucial in many countries for generating a public response to HIV. This is especially important given the long years before large numbers of AIDS cases begin to appear, during which the epidemic remains invisible. In some countries the publication of credible information about levels of infection in various population sub-groups prompted political, religious and community leaders to act to prevent further spread even before the HIV epidemic turned into a more visible AIDS epidemic.

Two very different countries, Switzerland and Senegal, illustrate this point. In both countries, national leaders seized the initiative and began prevention campaigns soon after HIV infection was first reported and risk behaviour was confirmed. This early intervention has helped promote safe behaviour before the virus could become well established, contributing to keeping the epidemic low in both countries.

Behavioural data that pinpoint risk behaviour in the general population can be a valuable complement to HIV prevalence data in motivating action, as the case of Thailand has shown (see below).

Surveillance data help target prevention activities

One of the most important uses of surveillance data is to direct efforts to slow the spread of HIV. Surveillance data can demonstrate who is infected and who is at risk of infection, identifying sub-groups in need of active prevention programmes.

Perhaps the most useful data in targeting prevention activities are behavioural data. There are several examples of countries that have successfully used behavioural data to focus their prevention activities. In Thailand, for instance, the publication of behavioural surveys showing that a quarter of all men visited sex workers, coupled with the publication of information about high levels of HIV infection among sex workers, led to a successful national prevention campaign promoting 100 percent condom use with sex workers.

Despite such demonstrable successes, behavioural data collection has often not been integrated into regular surveillance systems.

Surveillance helps in planning to reduce the impact of HIV and AIDS

Since HIV infection typically takes many years to develop into symptomatic illness, the impact of the epidemic is not seen for some time after HIV infection levels begin to rise.

Surveillance data provide the inputs for models from which national estimates of infection, and projections of the illness and death that inevitably follow, are derived. National estimates and projections have proven extremely useful in raising awareness about the epidemic. They are also extremely valuable for planning to mitigate the impact of the epidemic, for example by redirecting resources to areas most affected, and strengthening social and orphan support systems.

Surveillance helps monitor the success of the national response

Surveillance systems by definition monitor trends over time. Serosurveillance monitors trends in infection, while behavioural surveillance monitors trends in the behaviours that lead to infection.

Taken together, data generated by these two branches of surveillance have been able to give an indication of the impact of national efforts to reduce HIV infection and increase safe behaviour. In Uganda, for example, later age at first sex and rising condom use recorded in repeated behavioural studies were reflected in lower infection rates in young women. The publication of this information, demonstrating the success of prevention initiatives among adolescents, provided important public support for continued efforts in this sometimes controversial area.

2. Weaknesses

Current systems provide poor early warning

In the early years of HIV and AIDS surveillance, systems tracking the epidemic have focused largely on tracking the spread of the virus itself through sentinel surveillance, or have relied on AIDS case surveillance. While these aspects of surveillance remain essential, they record infections that have already taken place and so miss the opportunity to give early warning of potential for infection.

Early warning systems are based mainly on data which record risk, rather than actual HIV infection. Risk data such as recording unprotected sex with multiple partners or sharing of unclean injecting equipment may come from different

sources: behavioural surveys or other biological markers (e.g., STI for unprotected sex). In the Russian Federation, for example, little behavioural data has yet been collected in the general population. However a dramatic rise in syphilis infection—from fewer than 10 cases per 100,000 people in 1988 to over 260 cases a decade later, has caused alarm about the potential for the spread of HIV.

Current systems do not make best use of available information from other sources

Until recently, HIV sentinel surveillance and AIDS reporting have been the main sources of information about the epidemic. Data from other sources—including STI information, behavioural studies and mortality data—have not been systematically included in the HIV surveillance systems. The results of syphilis testing among pregnant women, for example, are rarely compiled and used as indicators of risk behaviour by HIV surveillance systems. Regular surveys of reproductive health such as the Demographic and Health Surveys (DHS) contain data that can be used to track changes in sexual behaviour and condom use. But again, these rich sources are rarely used systematically by AIDS programmes to complement their surveillance systems.

Current systems may ignore at-risk sub-populations

In many countries, surveillance systems have centred on the general population. Blood taken from groups thought to be broadly representative of the general population, such as blood donors or pregnant women, has been tested, and where negligible levels of infection have been found it has been assumed that the epidemic is still at an early stage or that no epidemic exists.

In truth, however, HIV may already be at epidemic levels in sub-populations not reflected in the groups tested. Unless a specific effort is made to search out sub-populations at high risk of infection, (sex workers and their clients, drug injectors, STI patients, or men who have sex with men, for example) the epidemic may spread significantly before it is detected. One of the difficulties in reaching these sub-populations is that most are marginalized by society at large, and are poorly served by the institutions that could provide sentinel sites for HIV surveillance. In many developing countries, HIV epidemics remain concentrated in sub-populations at risk; trends in infection in these populations will not be captured by sentinel surveillance systems designed to track infection in the general population. In low-level epidemics, even sentinel systems in high-risk populations may show no clear trends in HIV infection.

Current systems cannot explain changes in mature epidemics

In the early years of an HIV epidemic, rising prevalence is almost always driven by a rise in new infections. But as time goes on and the virus establishes itself more firmly in populations vulnerable to infection, the equation starts to change. In mature epidemics, HIV prevalence generally begins to level off or to fall. This is often presented as good news: prevalence is stabilizing, the worst is over. The truth, however, may be far more complex.

Stable prevalence implies that there is one new infection for every person who drops out of the group being tested for HIV. So stabilizing prevalence may reflect changes in the rate at which people drop out of tested groups, because they have died or because they are too sick to come to a testing site, for example. People may also drop out of testing because they are abstaining from sex or consistently using condoms and so are no longer at risk of pregnancy or STI that would bring them to a sentinel clinic. HIV may also have an impact on inclusion in sentinel populations. It is known, for example, that HIV-infected women are less likely to become pregnant than HIV-negative women, and that their relative infertility increases with the duration of their infection.

Stabilizing HIV prevalence recorded in sentinel surveillance may result from:

- Stabilizing new infections;
- Rising death;
- Lower likelihood of being tested in a sentinel site through infertility or behavioural change;
- Changes in the age structure of infection, especially relative to the age structure of the sentinel population;
- Changes over time in the population being tested in sentinel sites;
- Changes over time in the survival time of people infected.

Simply recording changes in HIV prevalence does not contribute to an understanding of which of these factors may be responsible for the change. Well-designed behavioural surveillance is needed to help explain changing trends in prevalence. Where possible, surveillance systems may need to focus their attention on new infections, where many of the factors listed above do not come into play.

Current systems are confused by therapy, where it exists

In industrialized countries, surveillance systems have concentrated more on AIDS case surveillance than on HIV sentinel surveillance. When HIV infection led inevitably to AIDS in a relatively predictable time frame, this system gave a reliable, if belated, profile of infection. In addition, since most people with an AIDS-defining illness in industrialized countries come into contact with the health systems at some point, this system captured a high proportion of overall cases. However, with the advent of therapies that slow the progression from HIV to AIDS, the interpretation of AIDS prevalence data and its relationship to trends in HIV infection has changed. It is not yet known whether, in an age of therapy, there will be any predictable pattern in progression to AIDS or in survival with AIDS that would help in interpreting AIDS prevalence data.

In these situations, countries are increasingly introducing HIV surveillance and HIV case reporting. HIV case reports are even harder to interpret than AIDS case reports, since it is not possible to know how representative those who are tested are of the whole population. Even trends over time are hard to interpret, since changes in access to testing, access to therapy, perceived effectiveness of therapy, reporting regulations and other factors may affect people's willingness to be tested for HIV.

Current systems rarely change with the epidemic

When it first became clear that HIV was a global phenomenon, it was assumed that the epidemic would follow roughly the same course in all countries. Later, epidemics were described in two general types: *Pattern One,* driven by homosexual men and/or injecting drug users, and *Pattern Two,* largely heterosexual epidemics.

But HIV is too complex to fit into these neat categories. In some countries, the virus has remained contained in small, well-defined sub-populations. In others, it has spread from those sub-populations to a larger population of sexually active adults who would not consider themselves at high risk of infection. In still others, there are several simultaneous but relatively discrete epidemics in different sub-populations, as well as in the wider population with less obvious risk behaviour.

A country's surveillance needs will vary according to its epidemic state. Although it is by no means inevitable, an epidemic can shift rapidly between one state and another, and the surveillance system should be flexible enough to shift with it. For example, if an epidemic is thought to be concentrated in men who have sex with men but a growing number of reported HIV and AIDS cases are in women, surveillance systems should begin to track risk behaviour and identify sources of infection in the heterosexual population. If a heterosexual epidemic consistently records infection rates of over one percent in antenatal clinics in

urban areas, sentinel surveillance sites should be added in rural areas.

This document proposes modular surveillance systems, elements of which can be added or dropped according to the shifting needs of the epidemic.

Current systems do not always make best use of surveillance data

Data collection is not an end in itself. The main purpose of tracking an epidemic is to provide the information needed to change its course. Second generation surveillance systems provide information that helps identify who is at risk of infection and what behaviours put them at risk. But unless that information is used to design prevention programmes focused on those most at risk or most likely to benefit, and to plan for care and support needs brought about by the epidemic, the effort is wasted.

Often, in the past, data generated by surveillance systems have not been used as well as they might have been. Sometimes this has been because information about risky sex and drug-taking and the infection they lead to is considered too sensitive for public discussion. Data are not published until the epidemic is too serious or widespread to escape public notice. Often, however, data have simply not been presented in a way that end-users might understand or act on.

Different users have different needs, and these should be anticipated in packaging data for policy-makers and the public. An education ministry planning a reproductive health curriculum might be interested in behavioural data for young people, for example, while private sector corporations planning their training needs and insurance liabilities might want to see prevalence data broken down by economic region—mining areas, the industrial belt, agricultural provinces—rather than by more familiar provincial or rural/urban criteria.

II. An overview of data collection methods for HIV surveillance

Second generation surveillance systems do not propose any radically new methods of data collection. Rather, they focus existing methods on appropriate populations and sub-populations, and combine them in ways that have the greatest explanatory power.

This section describes the main data collection methods used in surveillance. All of these methods have been in use over the past decade, although some are more widely used than others.

Second generation systems aim to expand the use of some of the more rarely used methods, particularly behavioural data collection. Recommendations for the appropriate method mix for each epidemic state are made later in this document.

Data collection methods for HIV surveillance

1. Biological surveillance

- *Sentinel serosurveillance in defined sub-populations*
- *Regular HIV screening of donated blood*
- *Regular HIV screening of occupational cohorts or other sub-populations*
- *HIV screening of specimens taken in general population surveys*
- *HIV screening of specimens taken in special population surveys*

2. Behavioural surveillance

- *Repeat cross-sectional surveys in the general population*
- *Repeat cross-sectional surveys in defined sub-populations*

3. Other sources of information

- *HIV and AIDS case surveillance*
- *Death registration*
- *STI surveillance, TB surveillance*

1. Biological surveillance

Sentinel serosurveillance

The purpose of sentinel HIV serosurveillance is to track HIV infection levels in populations accessed through "watchpost" institutions. These institutions are generally selected because they provide access to populations that are either of particular interest in the epidemic, or representative of a larger population.

In general, sentinel institutions are already drawing blood for another purpose. STI patients, drug users and pregnant women are all likely to give blood for diagnostic reasons. Some groups such as military personnel or workers in chemical industries may have blood taken as part of a routine health check-up. Blood given to transfusion services has also been used to check levels of infection among donors. These are not strictly speaking sentinel populations, but data generated by such regular screening can be used in much the same way as sentinel surveillance data.

Where blood is taken for other purposes, leftover sera can be stripped of all identifying markers and tested for HIV infection without the consent of the individual concerned. This is known as unlinked, anonymous testing. Because the individual's consent is not required, biases introduced when people refuse to allow their blood to be tested are minimized.

Where blood or other specimens such as saliva or urine are being taken specifically for HIV testing, individuals providing the specimens should be informed of the purpose of sentinel surveillance, and must give their consent before their specimen is tested. Even where consent is sought, sentinel surveillance samples are generally stripped of identifiers so that the result can never be traced back to an individual, so protecting privacy. Voluntary anonymous testing is increasingly used in conjunction with a simultaneous offer of voluntary counselling and free testing for those who choose to know their results. Every effort must be made to ensure that populations among whom surveillance is conducted—and indeed all populations—have easy access to voluntary counselling and HIV testing.

Surveillance systems set up to track the course of the HIV epidemic test all samples taken in as short as possible a time frame, usually two to eight weeks. The short time period is intended to avoid the same individuals being included in the testing population more than once, and to provide an estimate of point prevalence—the prevalence of infection in a given population at a single point in time. Serosurveys in sentinel populations are usually repeated annually.

In populations where access is difficult and sample sizes are small (for example, among drug injectors newly admitted to treatment programmes) it may take a longer time to recruit large enough samples to give statistically meaningful results. In these cases, point prevalence figures might be replaced by period prevalence, measured over a stated time period. While this is less than ideal, it is sometimes a practical solution in difficult circumstances.

How representative are sentinel populations?

One of the biggest difficulties encountered in tracking the spread of HIV is determining the extent to which the population tested is representative of any larger population. In interpreting results of sentinel surveillance, programme managers and others need to estimate firstly the extent to which the people tested are representative of the sentinel population from which they are drawn, and secondly the extent to which the sentinel population is representative of any broader population, or indeed of the general population as a whole.

These issues are discussed for individual sentinel populations below. But using women tested at antenatal clinics as a general example, the

first task is to determine whether women tested during surveillance activities at such a clinic are representative of all pregnant women in the area served by the clinic. They may well not be, because the sentinel clinic is at a public hospital and wealthier women all go to private doctors, for example, or because since the introduction of user fees poor women have chosen to forgo antenatal care completely.

The next task is to determine the extent to which pregnant women represent all women in the population. Obviously women who are pregnant have recently had unprotected sex, so they are in fact not likely to be representative of the whole population of women including virgins, those who are abstaining from sex, and those who consistently use condoms or other methods of contraception. In many societies, pregnant women may be more likely to be in stable partnerships than those using contraception. The difficulties of extrapolating data from this sentinel population to the wider population is discussed at greater length below.

Besides the selection bias described, the representativeness of sentinel populations can be limited by participation bias. Participation bias arises when people who refuse to participate in sentinel surveillance differ from those who agree to participate. This bias is eliminated in populations whose blood is taken for other purposes and from whom consent for unlinked anonymous testing is not sought.

Sentinel populations used for HIV surveillance

- **STI patients**

Patients seeking treatment for STIs are a very useful sentinel population in assessing HIV infection levels among people who have unprotected sex with high-risk partners. Data from this group can act as an early warning system, since STI patients are among those at highest risk of acquiring or passing on HIV sexually.

Trends in infection among STI clinic clients must be treated with caution, however. They are not a reliable indicator of programme impact, since successful prevention programmes should reduce risky sex and lead to fewer STIs. People who do alter their behaviour may significantly reduce their exposure to HIV infection, but they are also likely to fall out of the denominator because they will not get STIs and therefore not seek treatment at clinics.

In addition, prevention programmes and other factors may change the profile of those attending clinics. In many countries, people overwhelmingly favour private clinics or self-medication for STIs, so government clinics which make up the bulk of sentinel sites capture only a small and possibly unrepresentative sample of men and women with STIs.

- **Intravenous drug users (IDU)**

Sentinel surveillance in IDU is generally linked to treatment clinics. Some countries test injecting drug users who have been arrested and imprisoned for their habit. Neither of these populations is likely to typify the bulk of injecting drug users who neither seek treatment nor are arrested. There are not many institutions offering services to drug injectors, so the scope for sentinel sites is limited.

Several countries have, however, successfully used outreach programmes for drug injectors to conduct voluntary anonymous surveillance using saliva specimens. Refusal rates have been low, and results appear robust. For more information on the methods used, see WHO's *Guide on Rapid Assessment Methods for Drug Injecting*, 1998.

- **Sex workers**

For sex workers, too, the major problem is access. Health clinics set up in red light districts especially to meet the needs of sex workers provide an excellent sentinel site for this population, but

they are rare. Some countries use data from women attending STI clinics in or near "red-light" districts as a close proxy for HIV prevalence among sex workers.

In a few countries sex workers must register with the authorities in order to work, and are required to undergo regular screening for STIs. Regular screening is also provided in a number of countries with controlled brothel districts. In such cases, leftover specimens taken for screening of STIs may be used for sentinel surveillance for HIV.

It should be noted, however, that illegal and unregistered sex workers exist even where sex work is regulated. Sex workers are often illegal immigrants, non-native speakers of the local language or otherwise marginalized compared with registered sex workers. They may also be at higher risk for HIV infection.

- **Men who have sex with other men**

In some countries, male-male sex happens within well-defined gay communities. These communities are generally served by health clinics and other institutions that can be used as sentinel sites. Elsewhere, however, men who have sex with other men do not necessarily think of themselves as gay, male-male sex is clandestine, and there are no easily accessed clinics or other sentinel sites for communities of men who have sex with men. In these situations, surveillance among men who have sex with other men is more difficult. Possible approaches include peer outreach services recruiting men for voluntary unlinked anonymous testing, or the establishment of health clinics designed to serve the needs of these populations.

- **Women at antenatal clinics**

Antenatal clinics provide the most accessible cross section of healthy, sexually active women in the general population, and have therefore become the most common sites for sentinel surveillance in most developing countries. Blood is usually (but not always) already being taken for syphilis screening, so the additional procedure of unlinked anonymous testing for HIV on samples taken over a specified period once a year is an efficient, low-cost method for serosurveillance.

There are a number of major sources of selection bias associated with women attending antenatal clinics.

Clinic attendance—As mentioned previously, women who attend the public antenatal clinics where sentinel surveillance is generally carried out may differ from those who attend private clinics or who do not attend clinics. The proportion of women in developing countries who attend antenatal clinics ranges from over 80 percent in parts of Africa to under 30 percent in some areas of Asia.

Fertility—Women who become pregnant may differ from women who do not become pregnant in ways significantly related to HIV infection. HIV infection itself reduces fertility progressively over time. HIV is often associated with other STIs known to cause infertility. The use of condoms will reduce both fertility and exposure to HIV. The use of non-barrier contraceptives will reduce fertility, but may be associated with sex with multiple partners that increases exposure to HIV.

It should be stressed, however, that studies comparing HIV prevalence levels at antenatal sentinel surveillance sites with levels recorded in population-based studies find that antenatal data are remarkably robust. In general, in mature epidemics, antenatal data tend to overestimate infection in the younger age groups, while underestimating it at older ages. Overall, studies in sub-Saharan Africa have shown that antenatal data and population-based data are generally very similar.

Populations regularly screened for HIV infection

- **Donated blood units or blood donors**

In the early days of HIV surveillance, voluntary unpaid blood donors could also provide

a fair picture of infection levels in the general population, and at no additional cost, since blood was in any case being screened for HIV under blood safety programmes. Donated blood is, however, becoming less useful for HIV surveillance because most countries now screen out blood donors with behaviours that put them at higher risk of HIV infection, and because in some countries those with risk behaviours increasingly choose not to donate blood as time goes on.

One of the principal advantages of using data from donated blood still remains, however. Since the blood is already being screened anyway, it is a "free" source of data on HIV prevalence in low-risk populations. Recording the percentage of blood units screening positive over a particular time period represents almost no extra cost to the country. Especially in low-level or concentrated epidemics where HIV prevalence among pregnant women may not be cost effective, it may be the only source of information on infection rates in populations not exposed to any particularly elevated risk of HIV. While the limitations of the data should be kept in mind, changes in prevalence in blood donors or donated blood units can provide useful material for advocacy.

Voluntary blood donors often donate repeatedly. Where there is no coding system that would allow for exclusion of samples given by repeat donors, it is suggested that the period for which HIV prevalence in screened blood units is reported for surveillance purposes be limited to a maximum of three months. Repeat donations in this time frame are unusual, so double-counting should be minimized.

- **Occupational cohorts**

Surveillance is sometimes carried out among occupational cohorts such as factory workers, migrant workers or the military, and is often linked to regular health checks or to work-based clinics. These people may differ from the general population in significant ways–they may be healthier, better off, or more likely to work away from home than men and women in the wider population, for example. And their health, economic or travel status may be related to their exposure to HIV infection.

In some countries, the majority of young men of a given age are required to perform military service. Elsewhere, new recruits to the military are chosen by random ballot from the general population of young men in a given age range. In these cases, new recruits provide a relatively unbiased population for unlinked anonymous HIV testing. It should be stressed that the same is not true for cohorts of soldiers; once they have been in the military for some time, young men may be exposed to risks or may adopt risk behaviours which are far from typical of the general population.

Changes in bias over time

If selection and participation bias remain similar over time, then trends in infection recorded in sentinel sites will reflect trends in the population represented by those sites. However, bias may change over time. In that case, trends recorded over time may reflect changes in the sentinel population rather than real changes in HIV infection levels. Sources of changing bias over time may include changes in the fees charged for services, changing in reporting requirements such as the introduction of mandatory named reporting of HIV cases, or the introduction of user-friendly services that attract higher numbers of people at risk of HIV infection.

Cross-sectional serosurveys in sub-populations at risk

Sentinel sites as described above exist for many sub-populations at high risk of contracting or passing on HIV and are the recommended access points for serosurveillance in these groups. However, where they do not exist, experience has shown that repeated cross-sectional HIV surveys

among members of the sub-population can successfully be used in order to track HIV prevalence among people at high risk of infection. Instead of standard venous blood, these may use blood taken on filter paper, saliva or urine specimens.

Cross-sectional serosurveys require the informed consent of participants. Experience has shown that refusal rates are lowest when peer educators and other members of the sub-population at risk are actively involved in mapping, sampling and recruitment, and where they are linked to the provision of services that meet the specific needs of the sub-population. The point of access for cross-sectional serosurveys is often a nongovernemental organization (NGO) or other institution working to prevent HIV transmission and provide educational, health or support services to at-risk sub-populations such as sex workers or drug injectors.

While testing may be usually voluntary and anonymous, the community contact essential to this type of surveillance provides an opportunity to offer counselling and confidential testing to those who want it.

Sampling is often convenience-based, and the methods by which sampling frames for a hidden population are established are often not clearly described, so care must be taken in extrapolating results to the wider sub-population. Whatever methods are used, building up the necessary community contacts and establishing a sampling frame is frequently time-consuming and expensive. While the cost is likely to diminish with successive rounds, it may not be practical to repeat cross-sectional surveys in high-risk populations with great frequency, and their use as part of routine surveillance systems may therefore be limited.

General population-based HIV serosurveys

Population-based serosurveillance attempts to get around selection bias associated with sentinel surveillance sites by testing specimens taken after obtaining informed consent from people randomly selected from the general population. Sampling is usually household-based.

Population-based serosurveillance requires informed consent. Experience differs across countries and cultures, but refusal and therefore participation bias has been shown to vary substantially, even when specimens are taken by non-invasive procedures—saliva or urine as opposed to blood.

General population-based serosurveys can be very helpful in indicating possible sources of bias in sentinel populations. They are expensive and difficult to conduct, and are not recommended as a routine part of serosurveillance. However, where they have been carried out for research or other purposes, their results should definitely be used to calibrate the results of routine surveillance systems.

Some countries conduct regular population-based studies for research or planning purposes in which blood is drawn (e.g. National Health Surveys, studies on Hepatitis B, malaria, etc. Demographic and Health Surveys drawing blood for anaemia testing). In such cases, the samples collected can be used for unlinked anonymous HIV testing. National AIDS programmes should, where feasible, make use of any population-based specimen samples for HIV testing. They will need to try to ensure that the population sampled can be correlated with existing sentinel sites, so that the two data sets can be compared reliably. This may require supporting oversampling of the population in the area of one or more sentinel sites.

2. Behavioural surveillance

Just as HIV surveillance refers to repeated cross-sectional serosurveys in a representative population, behavioural surveillance refers to

repeat cross-sectional surveys of behaviour in a representative population.

There are two major types of behavioural survey for HIV: surveys in the general population, and surveys in specific sub-populations of interest.

General population-based behavioural surveys

Behavioural surveys of HIV-related behaviour in the general population ask a sample of people about their sexual and sometimes their drug-injecting behaviours. The sample may be restricted to a certain age band and to men or women. Otherwise, however, general population-based surveys usually try to capture the broadest possible cross-section of individuals.

The most cost-effective way of achieving this broad cross-section is generally to survey individuals in a random sample of households in a district, province or nation, depending on the scale of the study.

General population-based surveys are the most appropriate tool for tracking changes in exposure to risk of HIV infection in the general population over time. While they may be adapted somewhat for a particular country situation, they generally yield rather standardized data that are comparable over time and geographic areas. They are useful for investigating levels of risk behaviour and links between the populations with low and higher risk behaviours. However, their ability to track changes in rare behaviours such as drug injecting is limited.

General population-based surveys can also be very important in monitoring changes in behaviour following prevention campaigns. This helps in evaluating the combined impact of the various components of the national response to HIV: the impact of a single campaign or initiative cannot be determined with this methodology.

Many decades of experience with household surveys of contraceptive use and reproductive health have shown that refusal bias is usually low in general population-based surveys that do not involve taking physical specimens. General population-based surveys of sexual behaviour (also known as KABP studies, or studies of knowledge, attitudes, behaviour and practices) have been undertaken in a large number of developing countries since the late 1980s, and have proven useful for advocacy as well as for informing programme design and interpreting changing trends in HIV infection in the general population. Integrating HIV and sexual behaviour components into Demographic and Health Surveys (DHS), National Health Surveys or other regular survey rounds can significantly reduce the cost of periodic population-based surveys of HIV-related behaviour and attitudes. Indeed, after successfully adding AIDS modules to DHS in a number of countries, the international DHS survey programme intends to include AIDS modules in all future surveys in countries significantly affected by the epidemic.

Those countries that have repeated national level household surveys of sexual behaviour—Uganda and Thailand, for example—have found that establishing trends over time through repeat surveys has contributed significantly to understanding the dynamics of the epidemic. Data generated by repeat surveys have served as a powerful tool for advocacy, increasing national and international support for the response to HIV.

Sub-population-based behavioural surveys

Certain sub-populations are more at risk of contracting and passing on HIV infection than others. Depending on the local circumstances, these may include injecting drug users, men who have sex with other men, and sex workers and their clients.

The behaviour of people in these groups may be critical in promoting or arresting the spread of

HIV, especially when the epidemic remains concentrated among those whose behaviour carries a higher risk of infection. However, they are not easily captured in a general population-based survey.

In the past, behavioural surveys in sub-populations at risk have generally been linked to the design and/or evaluation of specific interventions, with no effort made to produce data that can be used to monitor trends over time. It is strongly recommended that sub-populations be sampled independently of the general population, but in ways that allow surveys to be repeated to track changes in risk behaviour over time.

Sub-population-based surveys generally attempt to define and map the sub-population of interest, and then reach a random sample of individuals in that community. This procedure is described in some detail in Family Health International's (FHI) *Survey Measurement and Sampling Guidelines for Repeated Behavioural Surveys,* Arlington, 1999.

Constructing a reliable sampling frame can be very challenging. In a few countries, sex workers are grouped into registered brothels that provide a ready sampling frame, but in others they operate from more hidden sites or operate free-lance. Where populations at high risk of HIV infection such as sex workers and drug injectors exist at the margins of society, random sampling is often not possible. Sampling frames are constructed following mapping of sites, but it is often difficult to ascertain what proportion of existing sites have been mapped, or how many individuals are associated with each site. In addition, even when there are clearly defined sites such as brothels, access to the sites for interviews is sometimes denied by the owners or managers.

Every effort should be made to ensure that the survey is as representative as possible of the sub-population as a whole. Frequently, however, for reasons of ethics or feasibility, non-random sampling techniques are inevitable. Sampling techniques in sub-populations must be carefully documented and conducted in a consistent fashion so that subsequent rounds yield results that can illustrate trends with some degree of confidence. The most likely sources of bias should be clearly presented along with the survey results. Sampling methods become more reliable if members of the communities at risk are actively involved in mapping, sampling and recruitment.

Bias in behavioural surveys

Some continue to question whether behavioural surveys are useful, arguing that people generally lie about their sexual and drug-taking behaviours, especially when those behaviours expose them to both social sanction and HIV infection. Certainly, there is a tendency to downplay "undesirable" behaviour, especially among women. But several studies have shown that trends in reported risk behaviour are usually reflected in STI trends, that trends in reported condom use are matched by trends in condom distribution, and that there is remarkably high agreement between couples when questioned separately about their sexual behaviour. Where literacy is high, self-administered anonymous questionnaires may encourage greater honesty on the part of respondents than face-to-face interviews, where the desire to give "correct" or socially acceptable answers may be stronger.

Behavioural surveys cannot take place without the informed consent of the respondent. Experience has shown that, with some exceptions, respondents are more likely to refuse to participate if they are simultaneously asked to provide a specimen for HIV testing.

It may also be ill-advised to try to collect behavioural data from people in sites chosen as sentinel sites for HIV testing. For example, collecting information about recent sexual behaviour and condom use from women at antenatal clinics—that is, women in the later stages

of pregnancy—is likely to yield results that are far from typical of the general population.

It is therefore recommended that behavioural and seroprevalence data are drawn from different individuals broadly representative of the same source population. This has implications for the data collected. In order to ascertain the extent to which the two groups are similar, basic sociodemographic questions must be asked of each.

3. Other sources of information

There are a number of other types of data collection that add to the explanatory power of behavioural and biological surveillance for HIV. Some of these are already in place in many countries. Countries may choose to strengthen existing systems or begin to add them to behavioural and biological surveillance as resources allow.

HIV and AIDS case reporting

Many countries have set up case reporting systems for AIDS, and some have done so for HIV. In developing countries these systems generally involve regular passive reporting of AIDS cases and deaths. AIDS case reporting is based on a case definition that may or may not require an HIV positive test. For this purpose, several AIDS case definitions have been developed taking into account differences in capacities and resources in countries. In many cases, countries have initially reported both HIV and AIDS cases, usually abandoning HIV reporting when the number of HIV infected increased considerably.

Before effective treatment was available, many industrialized countries with relatively complete AIDS case reporting used AIDS case data together with predictable information about the natural history of infection to "back-calculate" the progression of the epidemic. This procedure was never common in developing countries, where AIDS case reporting is generally far from complete. Industrialized countries, too, are searching for alternatives because antiretroviral therapy is now altering the natural history of HIV infection and AIDS in unpredictable ways, making AIDS case data much more difficult to interpret. Increasingly, industrialized countries are turning their attention back to HIV case reporting.

HIV and AIDS reporting may be integrated into the communicable disease reporting system. However, data generated by this system are usually rather sparse, concentrating simply on gross numbers of cases. In the case of AIDS, particularly at the start of the epidemic when little is known about major patterns of risk or of the distribution of opportunistic infections, a greater breadth of information may be particularly helpful. Information on the age and sex distribution of cases, on major risk exposures, and on the distribution of AIDS defining conditions and opportunistic infections can be invaluable in helping to target prevention efforts and plan for appropriate treatment and care needs in a given country or population. Since this level of detail in data collection is rarely available in regular communicable disease reporting systems, many countries have set up special structures for HIV and AIDS case reporting.

Even dedicated HIV and AIDS reporting systems need to be strengthened if their utility is to be maximized. Many people living with HIV never come into contact with the health system at all until they develop symptomatic AIDS; so AIDS case reporting presents an opportunity for capturing levels of infection previously unnoticed. At the moment, however, poor diagnostic facilities and heavy underreporting, due to weaknesses in the system and unwillingness to record an HIV or AIDS diagnosis because of stigma or loss of benefits, all contribute to limit the completeness of

case reporting. Some countries that have set up AIDS case reporting systems estimate that they actually capture fewer than 10 percent of actual cases, and others have no idea how complete the reporting system is likely to be, or whether reporting completeness has changed over time. This clearly limits the utility of case reporting as a tool designed to track the magnitude of the epidemic, or even trends over time.

Case reporting does, however, have a very important role in advocacy. The HIV epidemic is, in its early years, largely silent. HIV case reporting brings to the attention of policy-makers and health planners the existence of the virus in different geographic areas and among different communities, populations and sub-populations. AIDS case reporting does the same for an epidemic in its more developed stages. In many countries, experience has shown that the epidemic is not perceived as "real" until AIDS cases and deaths are recorded.

Case reporting may also contribute to the validation of data generated by sentinel surveillance. The age structure, sex ratios and reported modes of transmission of both AIDS and HIV cases can be compared with that of HIV prevalence to suggest changes over time. Case reporting can also provide information about the presence of the virus in sub-populations that may have been missed by existing HIV surveillance systems, suggesting a reappraisal of surveillance needs.

More information on HIV and AIDS reporting is available in the *WHO Recommended Surveillance Standards, Second Edition,*1999.

Paediatric AIDS case surveillance

In the developing countries which are home to nine out of ten of the world's HIV positive children, there is no sentinel surveillance for the virus among children. HIV rates among children have always been derived from HIV rates among their mothers.

In the last few years, however, initiatives to reduce transmission rates from mother to child have been promoted. These range from short-course antiretroviral therapy during pregnancy to the avoidance of breastfeeding in HIV-positive mothers.

Unfortunately, the HIV antibody tests commonly used for HIV surveillance are of no use in children under around 18 months old, since they may inherit antibodies from their mothers. Tests for the virus itself are complex and extremely expensive, and are not practical for routine surveillance of children born to HIV-positive mothers in developing countries. At present, therefore, the only practical form of surveillance that might help evaluate the success of these interventions in reducing the rate of vertical transmission is AIDS case surveillance among children.

Surveillance of paediatric AIDS cases is even less complete than adult AIDS case surveillance, partly because children often fall ill and die without coming into contact with the health services. Because of the difficulty of establishing serostatus in young children, paediatric AIDS case definition is complex and many children die before they can be diagnosed. Special efforts should be made to strengthen AIDS surveillance among children and to promote fuller reporting of child mortality by cause of death.

Death registration

In countries where vital registration systems are well established, death certificates may provide a source of information about AIDS deaths which can be used to validate data gathered from other branches of the HIV and AIDS surveillance system. Careful examination of the age structure of deaths can indicate the influence of HIV. Most HIV deaths occur among younger adults, a group in which mortality is generally low. In the absence of other catastrophic events such as war or famine, a dramatic rise in death rates among 15 to 45 year-olds can provide an indication of excess mortality due to HIV.

Death registration suffers from many of the same difficulties as AIDS case reporting—AIDS as a cause of death is commonly underreported in most developing countries. However other cause of death data—e.g., data on tuberculosis (TB), pneumonia and non-Hodgkin Lymphoma—may be compiled to give an indication of changing patterns of mortality that may be attributable to HIV-related causes.

STI indicators and other biological markers of risk

Curable sexually transmitted infections are an important indicator of potential exposure to HIV infection, both because they are co-factors for infection and because they indicate unprotected sex with non-monogamous partners. High levels of STIs can act as a warning system for HIV even in populations where the HIV virus itself is as yet uncommon.

Sexually transmitted infections generally reflect risk behaviour in the relatively recent past better than HIV prevalence data, because curable STI are usually of relatively short duration. HIV infection may indicate risk behaviour in the recent past, but it may equally capture the risk behaviours of several years previously. An increase in safe behaviour is therefore reflected much more quickly in lower STI rates than it is in lower HIV rates. It should be borne in mind, however, that lower STI rates may reflect improvements in the quality and coverage of treatment as well as changes in risk behaviour.

For these reasons, good STI incidence and prevalence data can contribute significantly to tracking trends in risky sex and potential exposure to HIV infection, and to monitoring the success of measures aimed at promoting safer sex. Many countries systematically test for STIs in order to diagnose and treat—for example pregnant women are routinely tested and treated for syphilis in many countries. However data from these screening programmes are rarely systematically collected and used as a surveillance tool for HIV.

Countries with routine STI screening programmes in any population should work on strengthening reporting systems so that STI data can be integrated into HIV surveillance systems. Other countries with sufficient resources should consider setting up STI monitoring systems. The World Health Organization has developed a document, *Guidelines for Sexually Transmitted Infections Surveillance, 1999*, to help countries in this task.

A recent upsurge in TB infection around the world has been associated with the HIV epidemic. In some countries, over half of registered TB patients are HIV infected. Most TB programmes have surveillance systems of their own, or surveillance for TB is integrated into the communicable disease surveillance system.

In some countries, TB patients are systematically tested for HIV because dual infection may have implications for treatment. There is some evidence that the relationship between rising seropositivity rates among TB patients and rising HIV rates in the population as a whole is rather consistent. HIV prevalence among new TB patients can help validate trends observed in other sentinel populations. It should be noted that, as an opportunistic infection associated with HIV, TB is likely to develop only after a number of years of HIV infection. HIV rates in TB patients are therefore likely to be indicative of HIV incidence some years earlier.

Even when there is no HIV testing, TB data can be used as an additional source of information on HIV. In particular, shift in the age pattern of TB infection over time can act as persuasive evidence of a rise in HIV-associated TB.

III. Major indicators used in HIV surveillance

The indicators used in HIV surveillance have developed over the first decade of surveillance into a relatively standardized set which allow for comparison across time and between geographic areas.

Most of these indicators should be presented by age and sex, and some will be presented by other variables such as risk category. They are described in much greater detail in the relevant technical guidelines.

a summary

Major indicators used in HIV surveillance

1. Biological indicators

- *HIV prevalence*
- *STI prevalence*
- *TB prevalence*
- *Number of adult AIDS cases*
- *Number of paediatric AIDS cases*

2. Behavioural indicators

- *Sex with a non-regular partner in the last 12 months*
- *Condom use at last sex with a non-regular partner*
- *Youth: age at first sex*
- *Drug injectors: Reported sharing of unclean injecting equipment*
- *Sex workers: Reported number of clients in the last week*

3. Sociodemographic indicators

- *Age*
- *Sex*
- *Socioeconomic and educational status*
- *An indicator of residency or migration status*
- *Parity (for antenatal sites)*
- *Marital status*

1. Biological indicators

In most cases, HIV and STI prevalence will be reported for the youngest sexually active age groups (15-24) as well as across the reproductively most active age range of 15-49. Reporting of HIV prevalence by five-year age group should also be standard. AIDS case reporting should include a number of variables such as age, sex, assumed mode of transmission, AIDS-defining illness, and month of diagnosis and reporting. These criteria are discussed more fully elsewhere. Hepatitis and TB prevalence may be collected by specialized programmes or in the regular communicable disease reporting system.

- HIV prevalence
- STI prevalence
- TB prevalence
- Number of adult AIDS cases
- Number of paediatric AIDS cases

2. Behavioural indicators

The major behavioural indicators in sexually driven epidemics form part of a set of prevention indicators (PIs) described in WHO's *Evaluation of a National AIDS Programme: A Methods Package 1. Prevention of HIV infection, 1999*. Indicators and questionnaires focusing on risk behaviour among drug injectors are described in WHO's *The Guide on Rapid Assessment Methods for Drug Injecting, 1998*.

UNAIDS and WHO are currently working with MEASURE Evaluation and other partners to update the guide and methods package for monitoring and evaluating HIV and AIDS prevention and care programmes. The joint guide will include revised indicators and updated data collection instruments.

The choice of behavioural indicators may vary slightly according to the group surveyed, but they will generally include:

- Percentage of respondents who report at least one non-regular sex partner in the last 12 months;
- Percentage who say they used a condom the last time they had sex with a non-regular partner, of those who have had sex with a non-regular partner in the last 12 months.

In addition, the following indicators may be considered in specific populations:

- *Youth:* age at first sex;
- *Drug injectors:* reported sharing of unclean injecting equipment;
- *Sex workers:* reported number of clients in last week;
- *Sex workers:* reported condom use with last client.

3. Sociodemographic indicators

As has been mentioned, it is recommended that behavioural and biological information should be collected from different individuals who represent the same source population. In order to compare the extent to which the tested population and the population questioned about behaviour are in fact similar—and to assess systematic differences between the groups—basic sociodemographic data should be collected from both groups.

At present, a minimum of sociodemographic data is collected at sentinel sites. The only variables attached to samples sent for HIV testing are generally age and, where relevant, sex. It is recommended that more extensive information be collected from both survey populations and at sentinel sites, although the constraints on the time of clients and facility personnel should be kept in mind. At sentinel sites, these

data should be collected routinely from all clients, regardless of whether sentinel HIV testing is currently in progress.

Where samples are large and relatively homogeneous, basic sociodemographic variables may be attached to specimens for HIV testing. This allows for comparison of those tested with the clinic population as a whole, as well as for comparison with the population questioned in behavioural surveys. Questions of confidentiality should, however, be borne in mind. The more descriptive variables attached to a sample, the greater the likelihood of breaches of the anonymity that is a basic premise of unlinked anonymous sentinel surveillance. Even where sociodemographic data are not linked directly to a specimen, a simple comparison of the characteristics of the sentinel site population to the behavioural survey population will be possible. It will not, however, be possible to detect systematic differences between the group tested in the sentinel surveillance period with the wider clinic population.

The indicators to be collected will vary according to local circumstances that may dictate the most likely sources of bias. However, they are likely to include:

- Age;
- Sex;
- Socioeconomic and educational status;
- An indicator of residency or migration status;
- Parity (for antenatal sites);
- Marital status.

IV. Principles of second generation surveillance

This document has summarized the state of surveillance systems after more than a decade of experience and progress. Clearly, some gaps exist, and many of those gaps can be filled by building on and strengthening existing surveillance systems.

This section describes the fundamental principles around which second generation surveillance systems are based. Specific recommendations for different epidemic states are made in the section that follows.

a summary

Principles of second generation surveillance

Second generation surveillance systems should:

- *Be appropriate to the epidemic state*
- *Be dynamic, changing with the epidemic*
- *Use resources where they will generate most useful information*
- *Compare biological and behavioural data for maximum explanatory power*
- *Integrate information from other sources*
- *Use data produced to increase and improve the national response*

Surveillance systems should be appropriate to the epidemic state

Recognizing the heterogeneity of HIV epidemics around the world, second generation surveillance meets different surveillance needs in different epidemic states. Surveillance systems are designed to answer the needs of a particular country situation at a particular point in its epidemic evolution.

Surveillance systems should be dynamic, changing with the needs of the epidemic

HIV epidemics evolve differently in different situations. Second generation surveillance systems track this evolution. Where necessary, the surveillance system evolves, expanding its reach or changing its focus to meet changing information needs. In some cases, such as when the choice of sentinel sites is altered to better reflect the national epidemic, it will be difficult to produce data that are directly comparable with earlier years. In other cases, such as when sample sizes among younger women are increased to give a better idea of trends in incidence, a subset of data can still be analysed as before to give figures that are directly comparable over time.

This can be presented simultaneously with data from the strengthened system to give an idea of the extent to which any observed changes in prevalence might be an artifact of changes in the

surveillance system. In making changes to the system, countries should always consider the net gain of data quality in the new system against the cost of losing comparability with earlier data sets.

Surveillance systems should use resources efficiently, focusing on populations or sub-populations at particular risk

Surveillance systems should focus resources where they can provide most useful information. This will often mean tracking behaviour and infection in sub-populations whose members are at high risk of contracting or passing on HIV infection. This focus will vary according to the epidemic state, and may shift over time.

Behavioural data should be used to guide biological data collection and explain trends in HIV infection

Behavioural data collection is a central part of second generation surveillance systems for HIV. Behavioural data should be used to identify which populations or sub-populations are at risk of HIV infection, and to identify where HIV sentinel surveillance should be focused. Biological data derived from HIV surveillance as well as surveillance for other biological markers of risk may in turn indicate where more behavioural data collection is needed.

Behavioural data should help explain trends observed in biological surveillance. Sampling methods as well as questions asked in behavioural surveillance should be designed with this in mind.

Behavioural and biological data should be used to validate one another

Biological and behavioural data should be used to validate one another. Two sets of data pointing in the same direction make a more convincing case than just behavioural data or HIV prevalence alone.

Information from other sources should be integrated into HIV surveillance systems

Where other sources of information exist that might contribute information on sexual or drug-taking behaviour or exposure to HIV, this should be integrated into HIV surveillance systems wherever possible. These sources might include surveillance for STIs and TB, as well as death registration systems.

Information generated by surveillance must be used to design and promote preventative interventions, to plan for impact and to measure change

There is no point at all strengthening surveillance systems unless the data generated are made available and acted upon. Data should be used to identify sub-populations at risk, to pinpoint behaviours which continue to expose people to infection, and to design interventions to reduce those risk behaviours. They should be used to plan for care and support needs. And they should be used to measure national progress over time in slowing the spread of the epidemic.

The needs of end users should be taken into account when building up second generation surveillance systems, and data should wherever possible be packaged to meet those needs.

V. The different epidemic states

Classification of epidemic states has shifted as the world has learned more about the heterogeneity of HIV. For the purposes of surveillance, UNAIDS and WHO suggest a classification that describes the epidemic by its current state—low-level, concentrated, or generalized. This typology recognizes that a country may shift from one state to another over time. It is important to stress, however, that such a shift is by no means an inevitable progression. The various epidemic states are described below. The rationale for categorization is given, followed by a classification based on prevalence in different populations. These numerical cut-off points are not rigid scientific classifications. They act, rather, as a convenient proxy for classification based on the dynamic of an epidemic.

Three different epidemic states

Low-level

- *Principle: Although HIV infection may have existed for many years, it has never spread to significant levels in any sub-population.*

  Recorded infection is largely confined to individuals with higher risk behaviour: e.g. sex workers, drug injectors, men having sex with other men. This epidemic state suggests that networks of risk are rather diffuse (with low levels of partner exchange or sharing of drug injecting equipment), or that the virus has been introduced only very recently.
- *Numerical proxy: HIV prevalence has not consistently exceeded five percent in any defined sub-population.*

Concentrated

- *Principle: HIV has spread rapidly in a defined sub-population, but is not well-established in the general population. This epidemic state suggests active networks of risk within the sub-population. The future course of the epidemic is determined by the frequency and nature of links between highly infected sub-populations and the general population.*
- *Numerical proxy: HIV prevalence consistently over five percent in at least one defined sub-population. HIV prevalence below one percent in pregnant women in urban areas.*

Generalized

- *Principle: In generalized epidemics, HIV is firmly established in the general population. Although sub-populations at high risk may continue to contribute disproportionately to the spread of HIV, sexual networking in the general population is sufficient to sustain an epidemic independent of sub-populations at higher risk of infection.*
- *Numerical proxy: HIV prevalence consistently over one percent in pregnant women.*

The issues faced by countries tracking HIV and risk behaviour differ in different epidemic states. The remainder of this document is therefore organised around those different epidemic states. It is recommended that each HIV and STI prevention and care programme identify which epidemic state the country is in and focus surveillance on the needs of that state.

Although the surveillance needs for low-level and concentrated epidemics differ, the issues faced by planners aiming to strengthen systems in these epidemics are largely similar. Issues faced in low-level and concentrated epidemics are therefore discussed together, although separate recommendations are made for surveillance in the two epidemic states.

Obviously, there is a certain circularity implicit in designing surveillance systems according to epidemic state. Without surveillance systems, how can a country determine the shape and magnitude of its epidemic and so know which state it is in?

In practice, most countries have some existing surveillance systems or at least know enough about their epidemic to identify into which broad category it falls. Again, large and diverse countries may tailor surveillance systems to needs at a provincial or lower level, using data generated to plan and evaluate responses locally within a national framework.

Where no data at all are available, countries should consider following recommendations for low-level epidemics. If these initial surveillance activities reveal that the epidemic has already progressed to a concentrated stage, they can then expand surveillance activities as needed.

VI. Surveillance in low-level and concentrated epidemics

Low-level epidemics are those in which HIV infection exists at low levels in sub-populations whose behaviour carries a high risk of contracting or passing on HIV. The virus is not, however, widespread in the general population. In these situations, HIV has often not been thought of as a priority. Even when HIV prevalence rises rapidly in defined sub-populations, countries may fail to recognize the danger because such populations are often overlooked or marginalized. Many countries with low-level and even with concentrated epidemics have virtually no systematic surveillance.

But countries ignore the possibility that risk behaviour exists at their peril. Some countries have recently seen HIV explode from virtually nothing to substantial levels. With no surveillance in place it is not possible to identify changes in risk behaviour which may lay the groundwork for an emerging epidemic.

Key questions for low-level and concentrated epidemics

- *Is there any risk behaviour that might lead to an HIV epidemic?*
- *In which sub-populations is that behaviour concentrated?*
- *What is the size of those sub-populations?*
- *How much HIV is there in those sub-populations?*
- *Which behaviours expose people to HIV in those sub-populations and how common are they?*
- *What are the links between sub-populations at risk and the general population?*

a summary

Principal goals of surveillance in low-level and concentrated epidemics

In both low-level and concentrated epidemics surveillance systems can provide early warning of risk that might lead to the spread of HIV. By definition, little HIV is recorded at the low-level stage of the epidemic. So surveillance systems here rely greatly on behavioural data collection and on other markers of risk such as STIs.

Because HIV is usually competing for attention and action with many other development challenges, it is often difficult to generate political commitment to staving off an epidemic while the virus is still virtually invisible, or when it is concentrated in marginalized populations such as sex workers, drug injectors or men who have sex with men who may not strike a chord with policy-makers or the public. By looking at indicators of risk, surveillance systems should be able to warn of the potential for HIV spreading.

Behavioural surveillance data in low-level epidemics can be used to identify who is at high risk of infection and which behaviours commonly put them at risk. In concentrated epidemics, surveillance systems should investigate whether and how

frequently sub-populations at higher risk interact with people in the general population of lower risk. Do men who have sex with other men also have sex with women? Are the clients of sex workers married? How many regular and occasional clients do sex workers have? Do they use condoms with some partners but not with others?

Because people at high risk of HIV infection in low-level and concentrated epidemics are often members of marginalized communities, political commitment to providing services for them and supporting safer behaviour may be low. Surveillance data demonstrating that these individuals also interact with people with lower levels of risk behaviour can, however, help galvanize preventive measures. Active prevention at this stage can help minimize the spread and impact of infection in sub-populations at higher risk, keeping the critical mass of infection low and averting the spread of HIV into the wider community.

It is particularly difficult to interpret stabilization or downward trends in HIV prevalence as an indicator of programme impact in low-level or concentrated epidemics, since it is impossible to predict what the course of the epidemic would have been in the absence of interventions.

Focusing surveillance efforts in low-level and concentrated epidemics

Surveillance efforts in low-level epidemics should focus on tracking behaviour and other markers of risk in sub-populations where risk of HIV infection is concentrated.

Identifying these sub-populations is the first task; a significant amount of formative research may have to be undertaken before an efficient surveillance system can even be set up. This research, which aims to identify sub-populations at risk, to develop appropriate behavioural questionnaires, and to construct sampling frames through which surveys might be administered, is described in greater detail in the rapid assessment and behavioural survey guidelines published by WHO, UNAIDS and FHI listed in the *References*.

Research and surveillance in sub-populations at high risk of HIV infection should try to identify not only the behaviours and networks of risk within those populations, but the links between any defined grouping of higher risk and the general population. This becomes increasingly critical if the level of infection rises in sub-populations at higher risk and the epidemic shifts from a low level to a concentrated state.

The ethics of tracking HIV in marginalized sub-populations

An effective surveillance system requires not just that sub-populations at high risk be identified, but that they be accessible for regular monitoring of behaviour, risk markers and HIV infection. Perhaps the greatest challenge for surveillance in low-level and concentrated epidemics is gaining access to these communities in order to track both behaviour and infection. Community members are very often marginalized, and sometimes their behaviour is illegal.

If community members fear information about their behaviour (or indeed their HIV status) may be used against them, they will either lie to investigators or refuse to participate in monitoring studies. Successful surveillance in marginalized communities depends on minimizing participation bias by ensuring fully informed consent and absolute confidentiality.

Many successful surveillance efforts in sup-populations at higher risk of contracting or passing on HIV have centred on clinics and educational programmes designed specifically to meet the needs of people most vulnerable to HIV and its impact. These clinics provide services to the community, and in doing so, provide a sentinel site at which serosurveillance can be conducted. Where sentinel sites do not exist, the advice and participation of community members in designing and

helping carry out cross-sectional serosurveys have been invaluable to successful surveillance.

Certainly, information gathered for the purposes of surveillance must be shared with the communities in question to help them mobilize to act against the spread of HIV and cope with its consequences, and should inform future prevention efforts. However, in low-level epidemics, careful consideration should be given as to whether or not to publicize information about HIV infection and related behaviour in marginalized groups to a wider audience. Experience has shown that in the early stages of an HIV epidemic, the general public's reaction to information about HIV infection in sub-populations with higher risk behaviour is sometimes to call for restrictive and prohibitive measures. Experience has equally shown that such measures simply drive risk behaviour further underground, making prevention and care programmes more difficult and ultimately encouraging the spread of the virus.

Recommendations for surveillance in a low-level epidemic

- *Cross-sectional surveys of behaviour in sub-populations with risk behaviour*
- *Surveillance of STIs and other biological markers of risk*
- *HIV surveillance in sub-populations at risk*
- *HIV and AIDS case reporting*
- *Tracking of HIV in donated blood*

Cross-sectional surveys of behaviour in sub-populations at risk

In a low-level epidemic, cross-sectional surveys of behaviour in sub-populations at high risk of HIV infection are recommended. The existence of these sub-populations—which commonly include sex workers and their clients, the STI patients who are often a proxy for those with high heterosexual risk behaviour, drug injectors, and men who have sex with other men—and their potential relevance to the local epidemic must be confirmed through formative research.

Since social circumstances change over time, countries need constantly to re-evaluate the existence and importance of different sub-populations. In Eastern Europe, for example, rapidly changing social circumstances had led by the mid-1990s to an epidemic of injecting drug use unimaginable just a few years earlier. Similarly, in parts of China, economic growth is giving rise to increased internal migration, a rapid resurgence of the sex industry and an increase in STIs.

After a sub-population at risk has been identified, behavioural surveys should attempt to track changes in patterns of unprotected sex and risky drug injecting within the sub-population.

Behavioural surveys should collect indications of sexual links between sub-populations at high risk and the general population. Behavioural surveys can include direct questions about links with people outside the sub-population in question. Drug injectors might, for instance, be asked about sexual partners who are not drug injectors. Sex workers might indicate that their clients are concentrated in occupational groups such as transport workers, the military or migrant workers.

It is also possible to explore links from the opposite side of the risk spectrum, by asking people in the general population about links with sub-populations at higher risk. For example, men might be asked in a household survey about contact and condom use with sex workers.

Since general population surveys are complex and expensive, it not considered cost-effective to set up such surveys simply to look for possible links between higher and lower risk populations in a low-level epidemic. However, if regular household surveys such as the Demographic and Health Surveys are being planned, it would be useful to add questions on HIV-related behaviour.

Surveillance of STIs and other biological markers of risk

STI surveillance in individuals with higher risk sexual behaviour is recommended at this stage of an epidemic as a physical marker of unprotected sex with multiple partners. Surveillance of blood-borne infections such as Hepatitis B and C may be useful in tracking risk behaviour among drug injectors and men who have sex with other men.

HIV serosurveillance in sub-populations at risk

Sentinel surveillance should be established among sub-populations at high risk of contracting or passing on HIV. Existing sentinel sites such as drug treatment centres or STI clinics should be used where possible. When no sentinel sites exist, interventions providing services for sub-populations at high risk may provide an entry point for the collection of samples for voluntary HIV testing. Cross-sectional serosurveys of consenting members of the sub-population are also possible.

In low-level epidemics, the initial purpose of HIV surveillance is to detect if HIV is present or not in the sub-population being monitored. Unless HIV prevalence is above one percent or so, it may not be possible to accurately assess trends over time.

HIV and AIDS case reporting

Like HIV surveillance, HIV and AIDS case reporting systems can signal the existence of the virus in a given area or population, and may point to previously unrecognized behaviours or population sub-groups that should be included in further surveillance efforts.

These systems tend to be extremely incomplete, however, and are therefore of limited value in describing the magnitude or trends of an epidemic.

Screening of donated blood

In low-level epidemics, widespread routine sentinel surveillance of general population groups is not likely to be cost-effective. Where HIV infection rates in the general population are very low, huge sample sizes would be needed to detect any trends in sentinel surveillance data. The level of the epidemic at this stage does not justify the logistic and financial resources needed for such an exercise. Routine sentinel surveillance of low-risk populations such as pregnant women is therefore NOT recommended in low-level epidemics.

Since most countries are in any case screening their blood supply for HIV, data from HIV testing of blood donations can provide a general indication of the level of infection in the general population. However, the interpretation of data generated will depend very much on national blood safety policies.

Countries that turn away donors who admit to high-risk sexual or injecting behaviour, and that inform infected donors to avoid repeat donations, can expect to record very much lower levels of HIV in their donated blood samples than countries that use paid donors or take blood from relatives of sick people, have no deferral policies and do not inform donors of their serostatus. This difference will persist even where background levels of HIV infection in two populations with different screening policies are actually very similar.

Data collected from blood screening constitute "free" information which can be useful as an advocacy tool in low-level epidemics.

However, data from blood donors screening need to be interpreted with caution.

Recommendations for surveillance in a concentrated epidemic

HIV surveillance in a concentrated epidemic will contain all of the elements recommended for a low-level epidemic, but will add elements that focus more on the intersection between groups with different levels of risk.

- *HIV and behavioural surveillance in sub-populations with risk behaviour*
- *HIV and behavioural surveillance in bridging groups*
- *Cross-sectional surveys of behaviour in the general population*
- *HIV sentinel surveillance in the general population, urban areas*

HIV and behavioural surveillance in sub-populations at risk

The classification of an epidemic state as concentrated presupposes that the major sub-populations at high risk of contracting or passing on HIV are known. In these groups, both repeat cross-sectional surveys and sentinel serosurveillance should be carried out as recommended for low-level epidemics.

HIV and behavioural surveillance in bridging groups

Behavioural surveillance among sub-populations at higher risk may indicate substantial links with other sub-populations that may in turn provide a conduit (or bridge) for the virus into the general population. The most common of these bridging populations is probably the clients of sex workers. Men who visit sex workers often have wives or other regular partners who would not consider themselves to be at high risk for HIV. In addition, they may move between populations of sex workers, carrying HIV from one group of women to another across geographical areas.

Sometimes, these bridging populations are concentrated in a defined occupational or socio-economic group that is relatively easily identified. Mine workers, labourers on commercial farms, truck drivers and other transport workers, soldiers and students are all examples of bridging groups that have been identified in different countries.

Behavioural surveys in sub-populations at high risk in a low-level epidemic state may already have identified defined groups of partners that may intersect with or act as a bridge to the general population with lower risk behaviour. In a concentrated epidemic, repeat cross-sectional behavioural surveys should also be carried out in these bridging populations. They should focus on identifying the relationships and behaviours that threaten to spread HIV to a wider population.

HIV serosurveys among such groups often provide warning for the impending epidemic in the low-risk population. In many settings, STI clinic clients represent the overlap between high- and low-risk populations. High seroprevalence among STI patients is often followed by increasing HIV rates among pregnant women. Wherever scope

exists, sentinel sites should be used for observing trends in HIV among bridging populations. In the absence of suitable sentinel sites, repeated sero-surveys may be considered.

Cross-sectional household surveys of behaviour in the general population

In addition, it is recommended that behavioural surveys be carried out in the general population, and particularly in young people. These surveys aim to investigate levels of risk behaviour in the general population, gauging the potential for generalized spread of HIV if it were introduced into the general population. They also provide a baseline for assessing future behavioural changes. Behavioural surveys in the general population should also try to assess links between people with low-risk behaviour and sub-populations in which HIV has been shown to be concentrated; in other words, to identify potential bridging populations.

Repeat cross-sectional household surveys of sexual behaviour are relatively costly. In addition, behaviour in populations where risk behaviour is relatively low is unlikely to change rapidly. It is therefore recommended that such surveys be undertaken once every four or five years at most. Where possible, relevant questions on sexual behaviour should be added to existing DHS, reproductive health or national health survey rounds.

HIV sentinel surveillance in the general population

In concentrated epidemics where HIV is well established in certain sub-populations with links to the general population, particularly sex workers, HIV sentinel surveillance among pregnant women should be initiated. The purpose of this surveillance is to verify whether HIV is indeed following links between sub-populations of higher risk and the general population and becoming established in the general population. At this stage, resources for sentinel surveillance should be concentrated in areas that reflect likely exposure to populations in which risk behaviour is concentrated. Urban centres, transport centres and locations surrounding areas of migrant labour such as mines or military camps may prove suitable.

VII. Surveillance in generalized epidemics

In generalized epidemics, HIV is clearly established in the general population of sexually active adults, with over one percent of pregnant women infected. Although heterosexual transmission is always the dominant mode for the spread of HIV in generalized epidemics, the virus may also be over-represented in sub-populations with higher than average risk behaviour, including drug injectors and men who have sex with other men.

However, small changes in prevalence in the general population are likely to have a more significant effect on the overall impact of the epidemic than larger changes in prevalence in minority sub-populations, simply because the sheer numbers in the general population are so much larger. Small shifts in general population prevalence can translate into a massive burden for health services, especially in large countries.

Key questions for surveillance in a generalized epidemic

- *What are the trends in HIV infection?*
- *To what extent do trends in behaviour explain trends in prevalence?*
- *Which behaviours have changed following interventions and which continue to drive the epidemic?*
- *What impact is the epidemic likely to have on individual, family and national needs?*

a summary

Principal goals of surveillance in a generalized epidemic

The surveillance issues in generalized epidemics differ somewhat from those of low-level and concentrated epidemics. The time for early warning is passed. Surveillance systems should rather focus on strengthening their capacity not only to track but also increasingly to explain changing trends in HIV prevalence recorded by existing sentinel serosurveillance systems and to indicate the effectiveness of prevention programmes.

By definition, if HIV has become well established in the general population then prevention efforts have been less than completely effective, and need strengthening. Demonstrating which risk behaviours continue to drive the epidemic and pointing to possible areas of intervention to break the chain of transmission should be an important focus of surveillance work at this stage.

The impact of HIV and AIDS will be greatest in a generalized epidemic. Surveillance data should invest more resources at this stage in data collection that helps governments and communities plan for countering the impact of the epidemic.

Stabilizing prevalence

Stabilizing prevalence has in recent years become a common feature of many of the longer-established generalized epidemics. As has been mentioned, stabilizing prevalence brings difficulties in interpretation. Second generation surveillance systems attempt to address these difficulties in two ways:

- Repeated behavioural surveys examine the extent to which trends in behaviour might contribute to trends in prevalence;

- Sentinel surveillance systems among pregnant women focus on the youngest age groups, where HIV prevalence most closely reflects incidence, or new infections.

Age at infection

In the early part of a heterosexually driven epidemic, sexually active people linked in a network of multiple partnerships are all simultaneously at risk of HIV infection. As the epidemic matures, however, most of the people whose behaviour puts them at risk of infection will already be infected. Increasingly, therefore, new infections will be concentrated in people who are close to the start of their sexual lives.

Verifying levels of infection and risk behaviour in men

The relationship between male and female prevalence rates in a generalized epidemic is not a simple one. And yet, with the exception of some occupational-based clinics, sentinel surveillance sites are rarely available for men in the general population.

Most evidence in mature generalized epidemics points towards higher infection rates in young women than in young men. This is partly for physiological reasons, and partly because young women are more likely to have sex with older men, who may have had more exposure to infected partners in the past.

These effects are, however, hard to confirm empirically. Even in household-based studies, HIV infection in men is hard to track with any accuracy. Men are more often away from home than women, and those that are away (and therefore not captured in a household-based serosurvey) may be disproportionately more likely to have high-risk behaviour and to be seropositive than men who are found at home. Having said that, population-based serosurveys remain an important tool for estimating the relationship between HIV infection levels in men and women. Where they exist, the results of population-based surveys should be used to guide assumptions about the relationship between male and female infections in the general population. AIDS case reporting can also give an indication of the sex ratio of infection levels, although AIDS cases will not provide information about recent trends in new infection. It should, however, be noted that men may be more likely to be hospitalized prior to death with AIDS than women, and are therefore more likely to be diagnosed with AIDS. Completeness of reporting may therefore be greater for men than for women, and the sex ratio of reported AIDS cases should be interpreted with caution.

The urban/rural divide

Many sentinel surveillance systems have chosen or been logistically obliged to focus on major urban areas. But in most generalized epidemics, infection quickly spreads from urban areas along major transport routes into the rural population. Monitoring trends in rural as well as in urban areas is essential for planning appropriate preventative and supportive services.

Since a large proportion of the population in many developing countries lives in rural areas, an idea of prevalence rates in these areas is also essential for making robust national level estimates of HIV infection.

Monitoring morbidity and mortality

It is more important in a generalized epidemic than in low-level and concentrated epidemics to collect quality data on morbidity and mortality associated with HIV. These data help plan for the provision of health and other services such as orphan support.

Recommendations for surveillance in generalized epidemics

- *Sentinel HIV surveillance among pregnant women, urban and rural*
- *Cross-sectional surveys of behaviour in the general population*
- *Cross-sectional surveys of behaviour among young people*
- *HIV and behavioural surveillance in sub-populations with high-risk behaviour*
- *Data on morbidity and mortality*

HIV and behavioural surveillance in sub-populations at risk

Even where HIV epidemics are well established in the general population, sub-populations with higher risk behaviour may contribute disproportionately to the continued spread of the virus. In a generalized epidemic state, this is especially true of sex workers, who have extensive contact with clients who usually have other partners with lower risk. Behaviour change in these groups may also have a disproportionate effect on slowing the spread of the virus. Cross-sectional surveys of behaviour and HIV infection in these groups on an annual basis continue to play an important part in monitoring trends in the epidemic.

Sentinel surveillance among pregnant women

Besides sub-populations at higher risk, sentinel serosurveillance systems in generalized epidemics should generally focus on pregnant women at antenatal clinics. However, several important steps are needed to increase the utility of the information gathered at these sites.

Site selection

The selection of sites themselves should be reviewed so that they provide an optimum balance between efficiency, explanatory power and political imperative. In some countries, it may be necessary to opt for a wide range of locations (which may increase cost and complexity of data collection) in order to demonstrate the distribution of infection across different geographic or ethnic regions. In others, with homogenous populations differentiated principally by their level of urbanization, for example, it may be more efficient to concentrate urban sites in a single city in order to capture the variations between different socioeconomic groups in the urban environment, while rural sites may be distributed according to area of economic activity. In every case, sentinel sites should be selected for both urban and rural areas.

Focus on younger age groups

Surveillance efforts in generalized epidemics should attempt as much as possible to focus on tracking relatively recent infections. Although it is not possible to measure incidence with a regular HIV surveillance system, it is possible to concentrate resources on younger cohorts whose infection is likely to be relatively recent and less likely to be biased by reduced fertility. It is recommended that keym high volume sentinel sites be identified, and sample sizes at those sites be increased considerably to ensure large enough sample sizes for the 15–24 year-olds.

This will allow improved tracking of spreading infections among the young, while allowing the whole sample to be weighted to ensure direct comparability with previous sentinel data. It will also be necessary to maintain sampling among older women in order to make accurate estimates of HIV infection nationwide.

Since sexual behaviour varies greatly at younger ages (and since one of the aims of preven-

tion campaigns is to encourage a delay in early sexual activity) data for these age groups should be disaggregated wherever possible by single or two-year age band. Such disaggregation is likely to be meaningful only in the highest volume sites. In some countries, especially those with lower fertility, it will not be possible at all. Indeed, meeting recommendations for larger sample sizes at younger ages may become more challenging as HIV prevention programmes grow more successful in reducing young women's exposure to unprotected sex with multiple partners, since there will be fewer pregnancies among young women. Technical guidelines intended to give more information on sample sizes and sampling methods are planned.

Collect data on site and population characteristics

Second generation surveillance systems attempt to ensure that data are as comparable as possible, and to describe potential biases in biological or behavioural data collected. To that end, sentinel sites should collect data on basic population characteristics. In many antenatal clinics, these data are already collected. As a part of routine HIV surveillance, they should be used to compare the clinic populations with the general population, and with the population among whom behavioural surveys are carried out.

Behavioural surveillance in the general population

In a generalized epidemic, repeat cross-sectional household surveys are recommended for tracking changes in sexual behaviour. Such surveys should be conducted every three to five years. The exact mix of questions will depend on particular risk factors and vulnerabilities in a country, but indicators should be selected as far as possible from a standardized list so that results are comparable over time and place.

Household questionnaires should also record the same basic sociodemographic information as is recorded at antenatal clinics and other sentinel sites, to allow for the comparison of populations and the identification of possible bias.

Behavioural surveillance among young people

In a mature, generalized epidemic, anyone who has unprotected sex with a partner whose HIV status is not known may be at high risk of infection. Saturation of older age groups means that new infection in such epidemics appears to be concentrated increasingly in younger age groups.

Establishing safer behaviour from the outset of young people's sexual lives may be far more effective in altering the course of the epidemic than changing behaviour in older groups. This is not least because young people are more open to new norms and attitudes than their elders. Many countries work hard to establish safer behaviour in young people, and some countries have been rewarded by significant falls in both reported risk behaviour and in HIV prevalence in this group. These successes have provided hope and strengthened the resolve of those contributing energy and resources to preventing the spread of HIV.

It is therefore very strongly recommended that surveillance systems in generalized epidemics include a component of behavioural surveillance among young people. The exact age groups covered will vary from country to country. In cultures where sex starts early—where HIV infection, STI or pregnancy are commonly recorded in adolescents—behavioural surveillance among young people may start in the early teens.

A rise in the age at first sex is an important response to HIV prevention campaigns, so behavioural surveillance among young people should continue through the early 20s. However since patterns of marriage, partnership and sexual behaviour may differ significantly over the early years of people's sexual lives, it is recommended that teenagers and the 20–24 year-old age group

be sampled separately. Household-based surveys will minimize bias in sampling for both groups.

Whereas in the 20-24 year-old age group the standard adult questionnaire on sexual behaviour may be appropriate, modifications are likely to be necessary for teenagers, especially in defining types of partnership. However as far as possible, indicators should overlap with those used in other types of surveys to allow for a comparison between groups.

Because behaviour changes more rapidly among young people than among older adults whose sexual habits are already well established, it is recommended that behavioural surveys among young people take place every two years.

Sampling for greater explanatory power

A central tenet of second generation surveillance is that behavioural and biological surveillance data be used to inform and explain one another. The power of the two sets of information to illuminate real trends in the epidemic and the behaviours that spread it is greatly increased if they are designed from the start to be used together.

The collection of data that allow behavioural and biological surveillance populations to be compared has been discussed. But there is also room for increasing the explanatory power of surveillance systems through improved sampling.

It is important, firstly, that populations sampled for behavioural surveillance be chosen as much as possible to reflect the areas from which key sentinel surveillance sites draw their clients. In a national or regional household survey of behaviour, that may mean oversampling around sentinel sites.

It has been recommended that second generation surveillance systems attempt to focus on new infections by increasing sample sizes of younger women at key antenatal clinics. Surveillance systems ought to take the location of these sites into account when planning the household-based behavioural surveys of young people that are recommended as an integral part of surveillance in a generalized HIV epidemic.

Indicators of morbidity and mortality

Countries with generalized epidemics often face massive increases in incapacitating sickness and death in young adults which have implications for economic production and family structure, and generate increased needs in terms of social and medical services.

Data about real levels of sickness and death can help countries plan for these needs. At present, HIV and AIDS case reporting and records of AIDS-related death are at best erratic. Efforts should be made to strengthen reporting systems to improve their utility to planners and policy-makers.

Better use can also be made of data generated by regular death registration systems in recording increases in both adult and child death from causes likely to be HIV-related.

Surveillance for HIV: A step-by-step summary

Low-level epidemics

Main questions	Core surveillance	Additional surveillance / Studies
Are there groups with risk behaviour?	• Formative research and mapping of groups with potential risk behaviour • Analysis of available STI surveillance data	• Mapping to cover a larger geographical area, and to be conducted more frequently • Estimate size of groups with potential risk behaviour
What are the main risk behaviours?	• Risk behaviour surveys in groups considered at high risk for HIV infection	• Increased geographical coverage of risk behaviour surveys • STI prevalence and incidence studies in groups with risk behaviour
How much HIV infection is there?	• HIV serosurveillance in identified groups with risk behaviour • Analysis of available blood donor HIV screening data	• Larger coverage and increased frequency of HIV sero-surveillance in identified groups with risk behaviour • HIV sentinel serosurveillance in pregnant women in urban areas
Who else might be affected and to what extent?	• AIDS case reporting • HIV case reporting	• Risk behaviour surveys focused on potential bridging populations

Concentrated epidemics

Main questions	Core surveillance	Additional surveillance / Studies
How much HIV infection is there?	• HIV serosurveillance in groups with risk behaviour • Annual HIV sentinel serosurveillance in pregnant women in urban/high exposure areas • Analysis of available blood donor HIV screening data	• Wider geographical coverage and increased frequency of HIV serosurveillance in identified groups with risk behaviour • HIV serosurveillance in bridging populations and pregnant women
What are the main risk behaviours and how do they change over time?	• Repeated risk behaviour surveys in groups with risk behaviour • Repeated risk behaviour surveys in bridging populations • Analysis of STI data in groups with risk behaviour and bridging populations	• Wider geographical coverage and increased frequency of repeated behavioural surveys in groups with risk behaviour and bridging populations • Surveys of health seeking behaviour for STI
Who else might be affected and to what extent?	• Repeated risk behaviour surveys in the general population in urban/high exposure areas • AIDS case reporting	• Repeated risk behaviour surveys in the general population in all areas • HIV case reporting

Generalized epidemics

Main questions	Core surveillance	Additional surveillance / Studies
What are the trends in HIV infection?	• Annual HIV sentinel serosurveillance in pregnant women in urban and rural areas • Increase sample size in high volume sites to enable analysis by age groups • AIDS case reporting	• HIV sentinel serosurveillance in pregnant women in a larger number of sentinel sites • HIV serosurveillance in groups considered at high risk (e.g., sex workers and their clients) • Population-based HIV prevalence studies to validate surveillance data
Is behaviour changing? Do recorded changes help explain trends in HIV infection?	• Repeated behavioural surveys in groups considered at high risk of HIV infection • Analysis of STI surveillance data in groups considered at high risk of HIV infection • Repeated risk behaviour surveys in the general population with a focus on young people • Analysis of STI surveillance data in the general population	• Larger coverage of behaviour surveys
What is the impact of HIV?	• Vital registration data • Surveillance of TB and other HIV/AIDS related illnesses	• Other death data (census and studies) • Studies of access to care

References

The three principal sources for materials listed here are UNAIDS, WHO and FHI. The latest versions of the published technical guidelines can be found on the internet at:

http://www.unaids.org *or* http://www.who.int *or* http://www.fhi.org

Technical guidelines

UNAIDS and Family Health International, May 1998: Meeting the Behavioural Data Collection Needs of National Programmes on STD/HIV and AIDS

This document discusses behavioural data collection needs by different epidemic state. It reflects recent thinking about the best use of resources in behavioural data collection in the context of second generation surveillance.

Family Health International, 1999. Survey Measurement and Sampling Guidelines for Repeated Behavioural Surveys. Arlington.

These guidelines focus on sampling frameworks in sub-populations of particular interest for behavioural data collection in HIV epidemics. They include hard to reach populations such as sex workers.

UNAIDS/WHO 1999: Guidelines for Sexually Transmitted Disease Surveillance

These technical guidelines provide information on STD surveillance in a number of different country settings. They discuss STD case reporting, prevalence assessment and monitoring and assessment of syndromic aetiologies, as well as other aspects of surveillance.

WHO Programme on Substance Abuse, 1998: The Guide on Rapid Assessment Methods for Drug Injecting – *Draft*

Includes protocols for assessing HIV prevalence and risk behaviour among injecting drug users.

WHO Programme on Substance Abuse, UNAIDS, 1998: The Rapid Assessment and Response Guide on Substance Use and Sexual Risk Behaviour – *Draft*

Focuses more closely on sexual risk behaviour among users of injecting and non-injecting drugs and other substances such as alcohol. Includes information on sampling, and questionnaire development.

UNAIDS: Reaching Regional Consensus on Improved Behavioural and Serosurveillance for HIV, 1998

UNAIDS: The Relationship of HIV and STD Declines in Thailand to Behavioural Change, 1998

UNAIDS: A Measure of Success in Uganda, 1998