Reaching regional consensus on improved behavioural and serosurveillance for HIV

Report from a regional conference in East Africa

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Introduction

This report documents a regional workshop on surveillance systems for HIV held in Nairobi, Kenya, on 10–13 February 1997. The UNAIDS-funded workshop gathered government epidemiologists, AIDS programme managers, and social scientists from Kenya, Malawi, Swaziland, Tanzania, Uganda, Zambia and Zimbabwe as well as specialists from UNAIDS and other partner institutions. The group aimed to present current data and to work together to suggest practical guidelines for improving HIV surveillance systems in a maturing epidemic.

Objectives of the workshop

The workshop aimed to:

- take stock of the current epidemiological situation and the strengths and weaknesses of existing surveillance systems in East African countries;
- examine the links between sentinel serosurveillance and behavioural surveillance;
- identify ways to improve both sero- and behavioural surveillance;
- create cooperative links between social scientists and epidemiologists;
- create a regional dialogue on improved surveillance, and ensure appropriate UNAIDS support for the process.

Working method

The workshop began by analysing a case study presented by one of the participant countries, Uganda. Uganda has strong HIV serosurveillance systems which indicate a drop in HIV infection rates in the youngest age groups in urban areas. The country also has repeat behavioural surveys, all showing that those same age groups are delaying sexual activity and using more condoms than in the past. But the two types of surveillance, serological and behavioural, had not previously been examined together. The exercise of analysing both sets of data in conjunction provided a graphic illustration of how behavioural surveillance can be used to help explain results found in serosurveillance.

The Ugandan case study was followed by presentations from other participant countries. Following these, participants divided into two groups, working on improvements in serosurveillance systems and behavioural surveillance systems respectively. Their recommendations were made in a plenary session, and became the departure point for country working groups. Social scientists and epidemiologists from participating countries worked together on country plans, incorporating the recommendations on improving surveillance made by themselves and their colleagues over the course of the workshop.

What follows is the substance of the discussions—the problems that were identified and the solutions that were proposed.

Identifying the problem

Why do we need surveillance?

HIV and AIDS have an immense impact on societies at every level, from the productivity of the workforce to the stability of the family unit. Governments and development specialists in many areas, including those of education, labour, health and finance, need to know how the epidemic is progressing through a population, what is driving it and what might be preventing its spread. Tracking the infection allows them to plan for the future, to identify weak links in the chain of transmission, and to assess the success of interventions.

What has been done so far?

In the early years of the epidemic, many countries set up systems to measure levels of infection in groups from whom they were already drawing blood for other purposes—pregnant women, blood donors and patients at clinics for the treatment of sexually transmitted diseases (STDs). By the time the blood samples were tested for HIV, they would usually be identified only by the sex and the age of the person from whom the blood was taken. By testing this blood, programme planners had some indication of HIV prevalence —the proportion of the people tested found to be infected with the virus. And they could generally say something about prevalence in five-year age bands. This information was invaluable in tracking the geographical spread of infection and in modelling and projecting the impact of the epidemic. It was also a crucial tool in advocating for a strong response to HIV with decision-makers and with the general public.

Isn't that good enough?

When an epidemic of a long-lasting disease is in its early stages, a continuous rise in prevalence is usually due to a continuous rise in new infections; no extra information is needed to explain the sentinel surveillance data. But as HIV settles into an endemic disease, as is now increasingly the case in sub-Saharan African countries, existing sentinel surveillance systems do not provide enough data to explain changing patterns of infection.

- DIFFICULTY 1: PREVALENCE FIGURES CAN BE MISLEADING

  Because HIV cannot be cured, an infected person will remain in the prevalence figures until they die or for some other reason drop out of the group being tested. If prevalence is stable, it means that there is one new infection for every person who is dying or who is no longer being tested. Most testing is currently done at clinics where pregnant women come to get antenatal care. But evidence is emerging that after a few years of HIV infection, women become less likely to conceive. This has been shown to be true independently of the association between HIV and other chronic STDs, which also contribute to reduced fertility. Although they are still infected, they may disappear from the prevalence figures because they are not becoming pregnant and so are not tested. Equally, stable prevalence figures may

mean that new infections are keeping pace with large numbers of deaths of people infected a decade ago in the early years of the epidemic.

Clearly, prevalence figures can be confusing. If we want to know whether HIV infection is dropping off, we need to look at new infections, or incidence. This is very hard to do without testing the same group (or cohort) of people at regular intervals over several years to see how many of them have contracted the infection. Such studies do exist, but they are expensive and hard to set up on the scale needed to show what is going on in the population as a whole.

- **Difficulty 2: Serosurveillance does not tell us why people get infected**

Policy-makers are interested in levels of HIV infection because they want to be able to plan for the consequences of that infection. They also need to decide what to do to slow the spread of the virus, and want to judge the effectiveness of their past interventions. This means knowing not just how many people are infected but why they are infected. In other words, we need to investigate trends in infection alongside trends in behaviour that may lead to that infection. But there have traditionally been barriers between the medical community that governs serosurveillance and the social scientists who look at behaviour and what lies behind it, and those barriers are hard to break down. Even where information on trends in behaviour exists, it has rarely been used systematically to illuminate and explain epidemiological data.

Moving towards a solution

Surveillance systems appropriate in the early days of the epidemic need to be adapted and built upon as our knowledge grows. UNAIDS sponsored the Nairobi workshop on improved surveillance with this in mind. The workshop succeeded in illustrating the potential for using behavioural data to interpret serological trends and in suggesting what countries might aim for in a "second generation" of surveillance activities.

The best data so far

The centrepiece of the workshop was data from urban Uganda, where a dramatic fall in prevalence has been recorded in recent years, particularly in the youngest age groups (see *A Measure of Success in Uganda*, UNAIDS *Best Practice* Collection—Case Study, 1998). Epidemiologists had worked hard on quality control and protocol checks to determine whether the drop was real rather than the product of changes in measurement practices or other biases. But they had done little in collaboration with their colleagues in the social sciences to investigate whether the drop in infections among young people might be linked to a change in sexual practices. Social scientists from Uganda were able to present surveys of sexual behaviour from 1989 and 1995. Although not perfectly comparable, these surveys gave an idea of changes in current behaviour in various age groups in urban settings. Together with evidence compiled from more than 300 smaller-scale sociological studies, the survey results strongly suggest a rise in age at first sex and more use of condoms in cities. These changes in behaviour, and especially the behaviours being established as the norm in younger age groups, were certainly consistent with both a drop in new infections and a rise in the distribution and sale of condoms noted elsewhere.

Establishing that behaviour is changing at the same time as new infections are dropping is an encouraging start. In the Ugandan case, behavioural change is certainly among the most likely explanations for the apparent drop in infections in the youngest age groups. But it is extremely difficult to draw causal linkages between the two sets of data, not least because they were not designed from the outset to be used together.

Data presented by other country participants were harder still to interpret. The epidemiological data were in some cases incomplete or inconsistent and very few countries had any behavioural data that might help explain it. A dramatic rise in prevalence among pregnant women of all ages was recorded at some Kenyan sites that had previously shown a steady decline. This might be the result of poor testing protocols or it might reflect a bias in the presentation of data. It could also suggest a significant change in the make-up of the local population, or a change in behaviour or of the economic circumstance that helps shape that behaviour. If the recorded decline and subsequent rise are real, programme planners need to know what caused them in order to be able to design effective interventions. But with no demographic data on the clinic population and no studies of behaviour in the area to help them interpret the serosurveillance data, programme planners necessarily find it difficult to explain the rise and to identify the best points for intervention.

An emerging consensus

As the country presentations progressed, a consensus emerged around the major weaknesses of the existing systems and how they might practically be addressed. The major points of agreement are listed here.

Weakness: Poor testing procedures make for uncertain results

Technical and policy experts attending the workshop cautioned that in many countries of the region the usefulness of data from existing surveillance systems is compromised by poor testing procedures and inadequate quality control of the tests and their results. These problems are often rooted in a lack of funding or commitment at a central government level.

Response: Ensure the quality of existing systems

Existing sentinel surveillance systems will form the backbone of any second-generation surveillance. Existing systems need to be strengthened and adequately funded. This may mean concentrating resources in a small number of sites while protocols are established and quality control is systematised.

Weakness: Prevalence data do not tell us much about new infections

As the epidemic takes off and in the absence of effective treatment, rising HIV prevalence can only mean rising incidence. In a maturing epidemic, stable or falling prevalence can be the result of any number of things. Where an increasing number of people who were infected early in the epidemic is entering older age groups, becoming less fertile or dying, falling prevalence across the whole age spectrum of sexually active adults may actually mask rising incidence in younger age groups. Prevalence data bring information from people recently infected together with those from people who have been infected for many years. While long-standing infections are important, they will not reflect recent changes in behaviour, and will tell us little about how the virus is spreading right now.

Response: Concentrate on the younger age groups

It is important to continue monitoring infection in all age groups. However it is clear from the shape of the prevalence curve in sub-Saharan African countries that most of infections take place in the teen years and the early 20s. So testing young people who are likely to have been infected recently gives a clearer picture of new infections, or incidence. It is likely that most sentinel surveillance will continue to centre on pregnant women. Concentrating on these age groups has the added advantage of minimizing the likelihood that a large proportion of infected women will have become infertile or have died. If women are surviving through the ages tested and continuing to become pregnant and so present at clinics, we can be more confident that any changes in prevalence are not simply due to changes in the group of women tested.

Weakness: Five-year age groups can mask important differences in infection

In analyses of surveillance data, prevalence has usually been given for the 15–49-year-old age range that coincides with a woman's reproductive life, or at best has been broken down into five-year age groups. This is in part because large sample sizes are needed to give statistically significant results, and such sample sizes are often hard to achieve for single years of age. But sexual behaviour can change radically over a five-year period, especially during adolescence. Grouping 15-year olds with 19-year olds may mask significant differences in behaviour and levels of infection.

Response: Increase the sample size and analyse by single year of age in young age groups

By increasing the size of the group of young people tested or surveyed, researchers should be able to break their analysis down into narrower age bands, within which sexual behaviour is likely to be more homogeneous. By looking at 15-year olds separately from 19-year olds, for example, epidemiologists and social scientists may detect significant differences in behaviour and rates of infection. Understanding these differences should help programme planners to tailor responses to address the needs of the most vulnerable individuals. If the sample size is big enough, analysis by single year of age may be possible. Otherwise cases might be grouped into two- or three-year age bands at the youngest ages, and one- or two-year bands thereafter.

Weakness: Resources are scarce and will not stretch to larger samples

The cost of enrolling and testing or questioning large numbers of people is one of the prime factors limiting sample sizes at present.

Response: Select key sites for expansion

Participants noted the epidemiological and political importance of maintaining a wide coverage of sentinel surveillance sites. However they felt that certain key sites could be identified for expanded sample sizes among young people. In some cases, sites in areas where operational costs are high and recruitment for testing is low may be sacrificed in the interests of concentrating resources where they will be most useful.

Weakness: The sentinel population may not reflect the general population

The overwhelming majority of sentinel surveillance testing is of pregnant women attending antenatal clinics. This gives us little idea what is going on in the male half

of the population. And it is not entirely clear what the relationship is between pregnant women and other women in the population. Infection with HIV and other STDs can reduce fertility, so it may be that the most heavily infected sections of the female population are being missed by sentinel surveillance because they are not getting pregnant. On the other hand pregnancy is a consequence of unprotected penetrative sex—a behaviour that also allows the virus to be transmitted. Women who have adopted safe sexual practices such as abstinence or consistent condom use will not become pregnant and thus not be tested. In this case, sentinel surveillance may overestimate prevalence among all women. Data presented at the workshop comparing sentinel surveillance with general population serosurveys show that the relationship can go in different directions at different stages in the epidemic, and for different age groups.

To get the best picture of the behavioural characteristics of those who are HIV infected and those who are not, the ideal would be to collect behavioural data from the people whose blood is used in sentinel surveillance. But the principle of sentinel surveillance is that it uses left-over blood collected from people for other purposes and tested anonymously, so it would be extremely difficult to find an ethically acceptable way of collecting behavioural information and linking it to blood samples. In addition, workshop participants thought it unlikely that pregnant women attending a clinic would welcome questions about casual partners, condom use and other aspects of sexual behaviour, and their answers to such questions may well be unreliable.

Response: Collect demographic data from the sentinel population and demographic and behavioural data from the general population

Researchers need to know how a sentinel population relates to the general population before they can understand what trends shown by sentinel surveillance imply about HIV infection in the general population. Differences in behavioural characteristics are vital, but it is not possible to collect behavioural data from the same individuals whose blood is tested, so policy-makers must draw behavioural inferences from socio-demographic profiles. For example, behavioural research in the general population might show that 17-year-old girls who have dropped out of school are more likely to engage in high-risk commercial sex than 17-year-old girls who are still in school. Clinic staff cannot collect data on the sexual partners of pregnant girls coming for care, but they can ask about age and school attendance. If the proportion of school drop-outs among 17-year-olds attending an antenatal clinic is far higher than the proportion in the general population, researchers may infer that the HIV prevalence rates recorded at the sentinel site for that age group are likely to over-represent the rates in the general population.

Workshop participants thought that sentinel sites should collect data on age, marital status, education and perhaps occupation, allowing them to build up a clear picture of the profile of clinic attenders. Behavioural research should then include people with a similar socio-demographic profile in its sample, which should ideally be drawn from the same catchment population. Migrants, who in some parts of sub-Saharan Africa constitute up to two thirds of the adult population, further complicate the picture. Where there is much migration, repeated cross-sectional surveys may be measuring very different populations over time. Participants discussed how to formulate questions on place of origin or length of residence to help give an idea of the relative mobility of both the local and the sentinel populations.

When considering data collection at clinics, the workshop took note of the additional burden it would represent for already overworked clinic staff, and recommended that questions should be chosen with care and kept to a minimum.

Participants also recommended that thought be given to which groups of men might be included in sentinel surveillance systems. Besides STD clinic attenders, military recruits were suggested as a possibility.

Weakness: There is no consensus on which behavioural data to collect

The relationship between behaviour and HIV infection is extremely complex and poorly understood. Many would argue that to understand the spread of the virus we need to look not at specific sexual behaviours but at the whole fabric of cultural, social and economic circumstances that prompts people to behave in one way or another. Only small-scale in-depth studies can hope to clarify this socio-cultural picture, but small-scale studies are rarely generalizable to larger populations and may therefore not help identify behaviours in the general population.

Response: Back to basics—monitor trends in risk behaviour

It is important to recognize the social and cultural roots of risk behaviour, but it is not central to the task of sentinel surveillance, which seeks simply to monitor trends in infection and the way it is spread. Whatever the background factors determining the spread of HIV, the infection can ultimately only be transmitted physically, most often by having unprotected sex with an infected partner. For the purposes of behavioural surveillance, the behaviours that should be monitored are those which are most likely to lead to infection, or to prevent it. After much discussion, the workshop settled on the following factors:

- ***Age at first sexual intercourse and age at marriage.*** *If age at first sex rises, we can expect to see a decrease in infection in the youngest age groups. Since many couples are monogamous or have fewer partners than single people, marriage tends to reduce the risk of infection. The gap between age at first sex and age at marriage may indicate the length of time a young person is exposed to relatively higher risk.*
- ***Number of sexual partners.*** *If individual and social norms change and people begin reducing their number of partnerships over time, then the potential for infection is also likely to decrease. The change in the timing of partnerships may also be important: it is becoming apparent that concurrent partnerships have a greater impact on the spread of the epidemic than sequential partnerships, even when the actual number of partners is the same.*
- ***HIV-related characteristics of partners.*** *The nature of the partnership—the relationship between the partners—also determines the risk of HIV infection. If young women are having sex with much older men, their partner is more likely to pass on infection to them. Sex with a professional sex worker is likely to be higher risk than sex with another man's wife, while for a woman sex with a long-distance truck driver may well be riskier than sex with her own husband.*
- ***Use of condoms with various types of partners.*** *The major risk activity is not sex but unprotected sex. If a group of young people consistently uses condoms in high-risk partnerships, then infection is less likely to spread into regular partnerships.*

Weakness: Definitions of partnerships and behaviour differ widely

To monitor trends, we need to be able to compare the same behaviours over time. Ideally, we would also like to be able to compare behaviours in different populations, to help explain why patterns of infection differ. And yet little effort has been made so far to ensure that the same questions are asked in all surveys. This is partly because different cultural circumstances demand different questions. But it also reflects a lack of consensus, coordination and guidance.

Response: Standardize questions where appropriate, but stay flexible
Some behaviours directly affecting the transmission of HIV will be more relevant to some societies than to others. So in some places, particular questions must be asked that will not be relevant elsewhere. But much more could be done to devise a set of "core" questions that would ensure that many data are comparable. At a minimum, data collection should take account of what has been done before in the same population, so that changes over time can be explored. And there are many areas of questioning, such as condom use, which could be standardized across all cultures. Standard indicators have been developed in many areas, and UNAIDS and its cosponsors are continuing the work of refining those indicators. But they are often not well known at a country level. More needs to be done to make researchers from national institutions and NGOs aware of standard indicators in appropriate areas.

WEAKNESS: THERE IS NO CLEARLY-DEFINED POPULATION FOR BEHAVIOURAL SURVEILLANCE
Sentinel serosurveillance is usually carried out in clearly defined populations who are already giving blood. But there is no clearly defined population on which to base behavioural surveillance. National level population-based surveys are expensive and time-consuming, and do not serve the needs of surveillance, which is all about getting a quick picture of trends in what may be a rapidly changing environment. Population-based or household surveys may be more useful for tracking behaviour if they are focused more closely on the areas from which sentinel serosurveillance sites draw their participants. Focused household surveys can be repeated every few years to validate the findings of behavioural surveillance in more easily accessible groups.

Response: Bring the principles of serosurveillance to behavioural surveys
Workshop participants mapped out a "behavioural surveillance" approach similar to sentinel serosurveillance. Questions should be asked cross-sectionally of anonymous respondents in an easy-to-reach population such as factory workers or students. Even though surveys are repeated over time, they do not follow individuals, but track behaviour in a generally similar population. This will give trends over time in people of similar ages and perhaps in similar socio-economic circumstances.

As mentioned, such surveys should collect basic socio-demographic information which would help identify how they overlap with or differ from the population covered by sero-surveillance. Indeed surveys may be designed in part to capture data on women with the same socio-demographic characteristics as surveillance clinic attenders and the men likely to be their sexual partners. The surveys should be planned with sample sizes large enough to allow for analysis in narrow age bands, at least in the youngest groups.

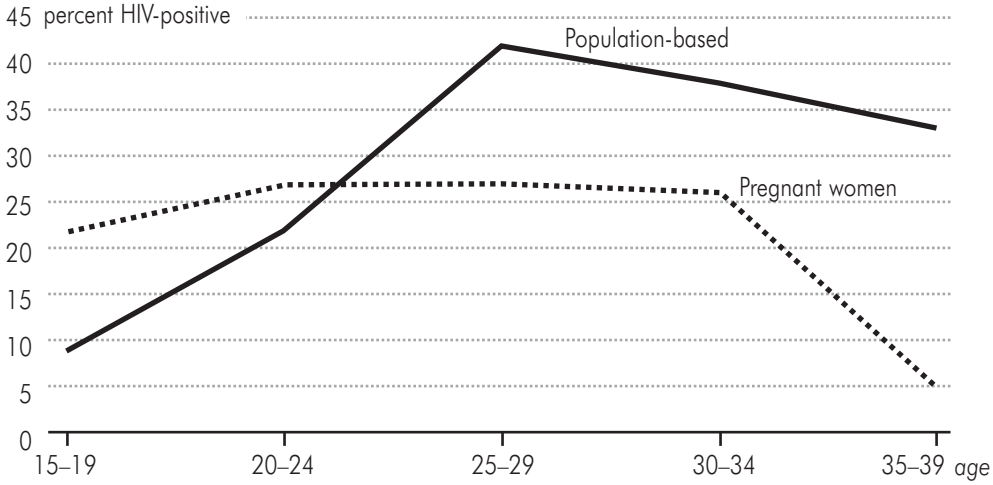
Testing the hypothesis

Coming to a consensus about how to improve surveillance of HIV is easier than demonstrating that the new ideas will make a real difference to understanding the spread of the epidemic. In general, the validity of a new approach can only be known after it has been tried in the field.

However, in the Nairobi workshop on surveillance participants were able to test at least in part their own recommendations. Knut Fylkesnes and his colleagues from Zambia had presented data comparing sentinel surveillance with the results of a survey of HIV in the general population, the first ever to use saliva testing. In common with every other presentation, the data were shown in five-year age groups.

The results, shown in Figure 1, illustrate the difference in HIV infection between the sentinel population and the general population from which it is drawn. Pregnant women in the teenage group were far more likely than their peers in the general population to be HIV positive. The difference was less marked among 20–24-year olds, while at all other ages the seroprevalence was higher in the general population than in the group of women attending antenatal clinics, and the gap was greatest in the highest age groups. This, it was suggested, was because of the increasing impact of HIV infection on fertility over time—the longer a woman has been infected, the less likely she is to get pregnant and so show up in the sentinel surveillance figures.

Figure 1: HIV prevalence in population and sentinel populations, Zambia

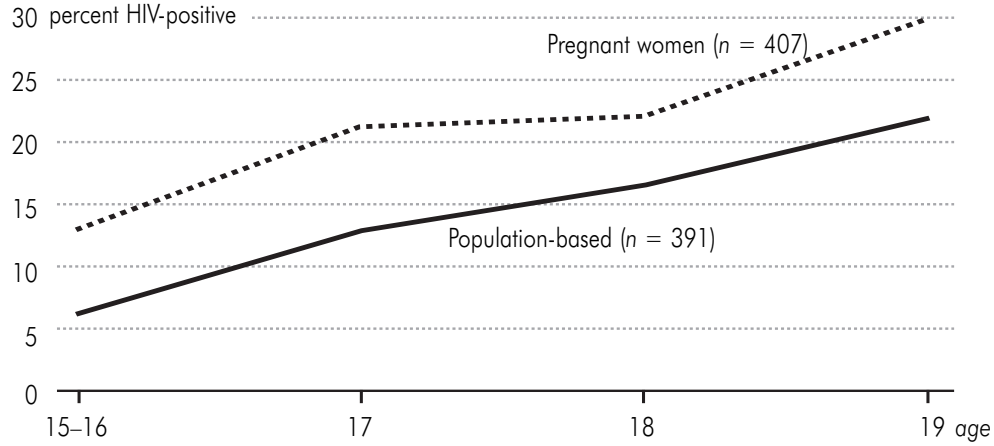


In the youngest age groups, prevalence appears much higher in pregnant women than their peers

The difference in levels of infection in the youngest groups was thought to be an encouraging sign, an indication, perhaps, of behavioural change. It was suggested that teenage women in the general population may be less likely to be infected than those pregnant because the bulk of them were waiting longer before having sex for the first time. If that were the case then the sentinel population, who are pregnant and therefore by definition sexually active, would not be representative of the general population in that age group.

After discussions in the workshop about the dangers of aggregating data by five-year age groups, the Zambian data were re-analysed by single year of age. The results, shown in Figure 2, showed an extremely striking similarity in patterns of infection between pregnant women and their peers in the general population—although HIV infection was at every age slightly lower in the general population than in clinic attenders, the difference was nothing like as great as that suggested by the five-year age grouping. That difference does not reflect vastly different risk behaviour between the two groups, but rather a disproportionate loading of pregnancy in the higher ages of the five-year band, where the infection rate for both groups is highest. A higher proportion of older women in the five-year cohort therefore gives a higher proportion of infected women, and so disproportionately higher HIV prevalence figures.

Figure 2: HIV prevalence in population and sentinel populations, Zambia, by single year of age, 15–19



Single years of age data reveal striking similarities in HIV infection

These findings confirm the crucial importance of looking at data by single year of age if we are to understand trends in infection. They also illustrate the importance of gathering behavioural data, rather than jumping to conclusions about behaviour from purely epidemiological evidence. In this case, no behavioural data were available, so researchers were not able to validate their assumption that the apparent difference in infection rates was due to different behaviour between the two groups. If behavioural data had been available, and had shown no evidence of a rise in age at first sex in the general population, then researchers would have been quicker in changing their assumptions when explaining the different levels of infection seen in the five-year age groupings.

Outcomes of the regional exercise and lessons learned

To summarize, the regional workshop:

- identified the major limitations in current surveillance systems
- made recommendations to improve existing systems in specific areas of monitoring and data collection
- established the major components of second-generation systems
- demonstrated the importance of collecting behavioural data to inform epidemiological data
- produced action plans for integrating the conclusions of the workshop into surveillance activities at a country level (some participant countries have already turned these action plans into concrete working proposals)
- contributed to building up working partnerships between epidemiologists and behavioural scientists in East African countries.

As a consequence of the workshop, UNAIDS has already formulated guidelines for second-generation surveillance. These will cover recommendations for sentinel serosurveillance and behavioural surveillance, and will be made available to all countries. They will be especially useful to countries facing a maturing epidemic in specific regions.