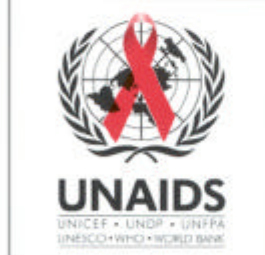




A measure of success in Uganda



*The value of monitoring
both HIV prevalence
and sexual behaviour*



UNAIDS Case study

May 1998

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Introduction

From the outset of the epidemic, a major constraint has been the lack of accurate data. People trying to combat the spread of the disease often lack information about the effectiveness of their efforts—unsure whether they have successfully encouraged behavioural changes, or the extent to which such changes have helped check the epidemic.

Few developing countries have made consistent efforts to monitor both HIV prevalence and risk behaviour. Many still do not consider HIV/AIDS a sufficiently high priority—or are reluctant to raise in the public domain matters considered too personal or intimate. Some countries may even believe that the publication of survey results will raise unnecessary alarm or discourage trade or tourism. At the beginning of 1997, probably fewer than ten developing countries had carried out repeated surveys to assess behavioural change and condom use at the population level.

Uganda is one of the African countries where the HIV epidemic was recognized early and is one of the most severely affected. Government, NGOs and other institutions in civil society have been determined to deal with the issues openly and directly, and have placed Uganda in the forefront of the fight against HIV/AIDS. This has ensured not only that Uganda has one of the most vigorous and wide-ranging programmes to combat the epidemic, with some success in limiting HIV spread especially among urban youths, but also that it has started to develop consistent systems of monitoring. These activities are far from perfect, and the results are still subject to a variety of interpretations, but they are a clear example of what can be achieved even in a country with few resources and poor infrastructure—and offer experience from which other countries can benefit.

This case study looks at the tools that Uganda uses to track trends in HIV and trends in reported sexual behaviour. It also demonstrates links between the two.

Monitoring HIV infection

The most precise way of monitoring the progress of the epidemic would be to track the HIV status of a representative group of people over time—a ‘cohort’. Changes in this group over time would not only indicate the HIV prevalence rate (the proportion of people infected) but also directly show the HIV incidence rate (the number of new infections during a certain period expressed as a proportion of the population at risk). The incidence is the most valuable indicator of the shape of the epidemic. So, in principle, well designed longitudinal studies, ideally cohort-based and randomized to include communities with and without intervention, would provide the most robust framework for the evaluation of the potential efficacy of intervention strategies.

Unfortunately, as a surveillance method, such cohort studies are generally beyond the poorest countries. Not only are they expensive, they take up scarce resources of skilled staff, and they are particularly difficult to sustain in countries that typically have weak infrastructure and are subject to substantial population movements that make it difficult to keep track of cohorts of people. A less expensive method would be to check the status of a different group of people each time. But this is still difficult since, even with guarantees of anonymity, few people will be willing to have their blood tested for HIV.

A more practical option is ‘sentinel surveillance’—monitoring the prevalence among groups whose blood is already being sampled for other purposes, such as blood donors, patients being examined for sexually transmitted diseases (STDs), or pregnant women attending antenatal clinics.

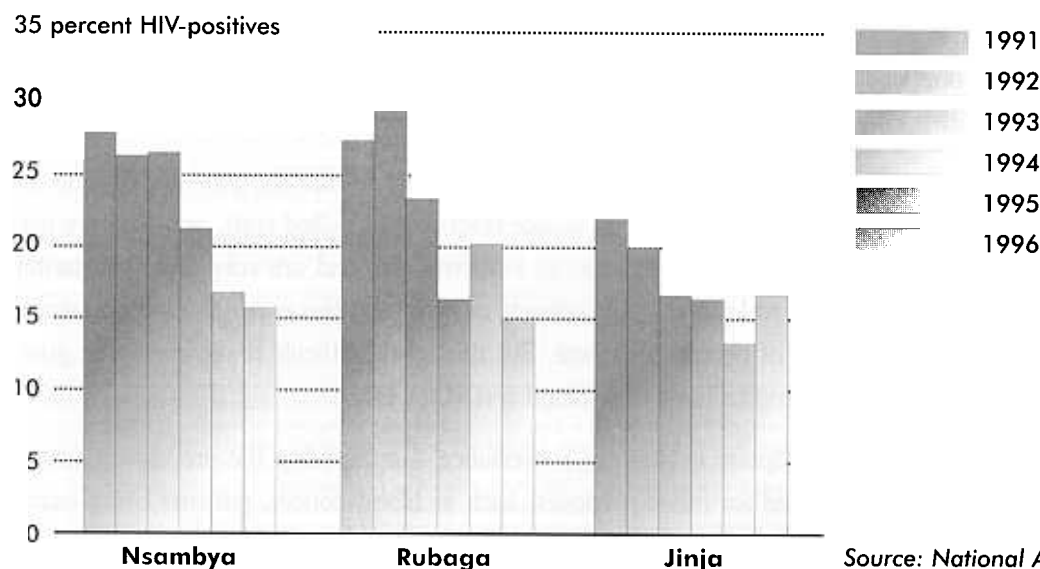
These groups may have higher levels of infection than the population as a whole. Groups of blood donors, for example, may include injecting drug users who are selling their blood to pay for their habits or where self-deferral policies are in place or where active recruitment of voluntary donors is done; they may disclose lower levels than the male adult population. Patients with STDs also tend to have higher risk behaviours than the population as a whole and their diseases also make them more vulnerable to HIV infection. Finally, even pregnant women are at greater than average risk since they will recently have engaged in unprotected sex (intercourse without a condom). Nevertheless, changes in HIV prevalence among such groups can give an indication of trends in society as a whole:

Of these groups, the most representative of all adults is likely to be pregnant women. So in Uganda, as in other countries, the main surveillance system involves testing samples of blood taken routinely at antenatal clinics. Surveillance started in 1989 at six sites in major cities and has since been extended to 20 sites to cover the whole country, including rural areas. Testing takes place over the first three months of each year. During this period, health workers take samples from each pregnant woman on her first visit to the clinic, and continue to do so until they have obtained the required number of samples (250–400). This usually takes 6–8 weeks and makes it possible to establish the levels of HIV infection for these periods—the ‘point prevalence’. It would be possible to take samples over a longer period, but given the dynamic nature of the epidemic it is thought better to have smaller, more regular analyses that can capture changing trends.

Samples are labelled only with the age of the women, not their identity, then taken to the Uganda Virus Research Institute in Entebbe where the serum is tested for antibodies to HIV-I using the ELISA system. The WHO Global Programme on AIDS evaluated six of these sites during 1994 and 1995 and confirmed that they were following recommended procedures for the selection of women, the collection of blood, and the separation, storage, and testing of serum.

The results are striking. All the urban sentinel sites showed evidence of a significant decline in HIV infection during the first half of the 1990s—in some cases the percentage of mothers testing HIV-positive almost halved. This is illustrated in Figure 1 below for three urban areas.

Figure 1. HIV infection rates among pregnant women. Selected sites 1991–96



Source: National AIDS Programme, 1997

While these data are encouraging, there are several reasons why the results might be misleading:

■ **Errors in enrolment.** This is possible, but unlikely. First, child-bearing women constitute a well identified group—in urban areas more than 90% of urban women attend an antenatal clinic at some time during their pregnancy. And supervisory field visits to these sites failed to detect any mistakes in enrolment. But even if some samples were missed at particular sites this is unlikely to account for such a consistent pattern of decline.

■ **Errors in analysis.** Again this is unlikely since all samples were analysed at a central laboratory that was following the prescribed procedures.

■ **A change in the composition of the group.** During the first half of the 1990s, Uganda was subject to a large influx of refugees from Rwanda, many of whom have since returned home, and this could have changed the composition of the group of women appearing at urban antenatal clinics. Also there will have been some rural–urban migration: HIV-positive women may, for example, have been returning to rural areas to be cared for by their families. This is difficult to correct for, as no data were retained on the background of the women other than their age.

A further possibility is that the profile of ‘pregnant women in Uganda’ might have changed over this period, possibly reducing the group’s level of HIV infection. This could be because of:

■ **A change in the average age of the group.** Concerns about HIV infection should lead to a delay in the first sexual experience and greater condom use, both of which should delay the women’s first pregnancy. While this constitutes success in terms of behavioural change, it will change the average age of pregnant women over this period making them older and less comparable with earlier groups. However, the change will probably not be sufficient to distort the results seriously.

■ **Reduced fertility among HIV-positive women.** Women rendered less fertile by HIV infection, STDs or the illness/death/reduced fertility of their sexual partners would be excluded from this sample. This would tend to make ‘pregnant women’ an increasingly less infected group than women as a whole. Over time, increased condom use and other modern contraceptive methods may also affect the pregnancy rate.

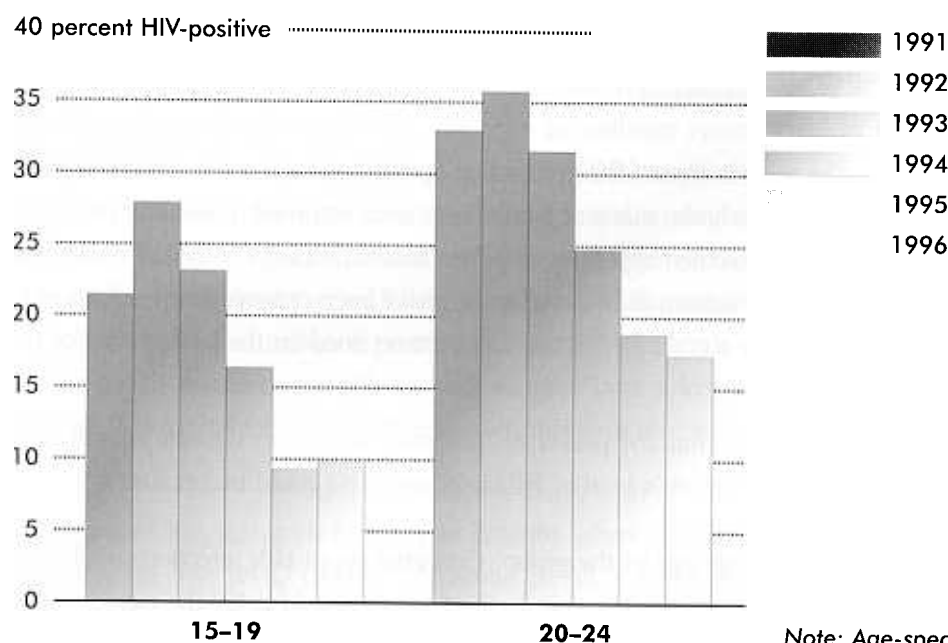
These factors are difficult to control for and are most probably playing a role in the decline of HIV prevalence but even taking these reservations into account the results are encouraging—they do at least point in the right direction. In addition, they are supported by similar findings among male attendees at STD clinics in Kampala among whom HIV prevalence has fallen from around 45% to 35%.

However, a reduction in prevalence does not necessarily imply a reduction in new HIV infections. The reduced prevalence among pregnant women, particularly the older ones, could also be because those who have developed AIDS have died before they could come to the antenatal clinic.

Many of these reservations become less significant when the analysis is confined to the youngest women—aged 15–19 years. This limits the scope of distortions caused by ageing and by infertility since younger women are less likely to have had the disease long enough to have become infertile or sub-fertile. Moreover, in this case the prevalence will actually be much closer to the incidence, since few people within this age group will already have died.

Here again, the results are encouraging. Between 1990 and 1996, for the Jinja site, the prevalence among pregnant women aged 15–19 fell from 21% to 5%. At Nsambya the drop over the same period was from 22% to 10% (this is illustrated in Figure 2). At the Rubaga site there was also a fall over this period though the trend was not consistent.

Figure 2. HIV prevalence by age group, Nsambya



Note: Age-specific data not available for 1993

The steady and significant drop for the youngest women suggests a real fall not just in prevalence but also incidence—and may well correspond to a reduced incidence for the population as a whole. Why has incidence dropped? It is possible, for example, that there has been some change in the virulence of the virus, or that treatment at STD clinics has become more effective, so that women with STDs are treated and hence less vulnerable to HIV. But one of the likeliest causes is a real change in sexual behaviour. Recent surveys indicate that such changes have indeed taken place—to such an extent that they reinforce confidence that the surveillance data are giving a representative picture of trends in prevalence.

Population-based surveys of sexual behaviour

Most surveys that question people about their sexual behaviour have taken place on a relatively small scale and would not claim to be widely representative of the population as a whole. Moreover, few have subsequently been repeated in the same area, making it more difficult to gauge real behavioural changes over time.

In Uganda, however, there have been two wide-ranging population-based surveys—in 1989 and 1995—with sufficient overlap between them to permit comparisons, meaning same population

range, same survey methodology and same key questions on sexual behaviour. Both surveys also covered two geographical areas—urban Kampala and urban Jinja—where seroprevalence surveillance was carried out over this period. In 1989 the sub-sample of the behavioural surveys that corresponded to the surveillance areas totalled 1186 people and in 1995 it totalled around 1600. These two sub-samples proved comparable in most respects—the age distribution of respondents was not significantly different between the two periods, nor was there much difference in educational attainment.

The 1995 survey also included questions on whether respondents had changed their sexual behaviour over the previous five years. However retrospective questioning can give unreliable results. Ugandans have been so deluged with educational information on HIV/AIDS that they will be well aware of the socially desirable response to questions about behavioural change. In any case, it would not be surprising if that those who had been sexually active longer had changed their behaviour over the years—having sex less frequently, or with fewer partners.

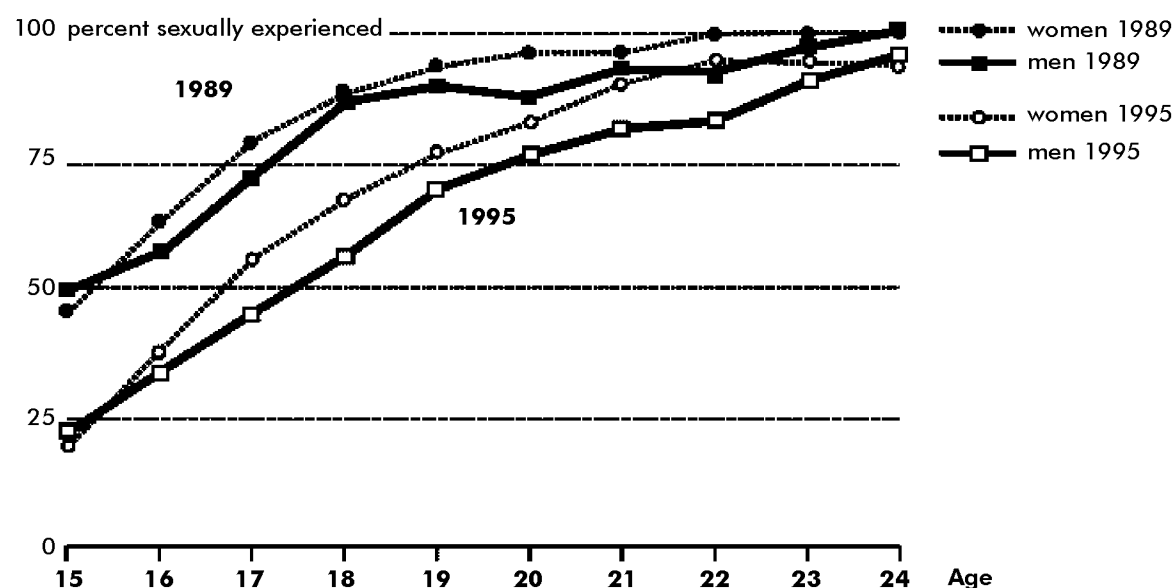
More interesting are the answers to questions concerning the current behaviour of young people—and the comparison of them with those of their predecessors at the same age. Again such responses, especially in the recent survey, will be biased towards the ‘correct’ answer, but probably to a lesser extent.

These results do indicate substantial differences in sexual behaviour in almost every aspect that was investigated. The data given below are for the sub-samples of both surveys that corresponded to the seroprevalence surveillance areas.

a) Delayed age at first sex

Between 1989 and 1995, the proportion of women aged 15–19 reporting that they had never had sex from rose 26% to 46%. For men aged 15–19 the proportion rose from 31% to 56%. For the youngest, the 15-year olds, the proportion of boys or girls reporting that they had never had sex rose over this period from around 20% to around 50%. Sexually experienced by current age rates are shown in Figure 3 below.

Figure 3. Percentage sexually experienced by current age (15–24 year olds) in 1989 and 1995



b) Fewer sexual relations with non-regular partners

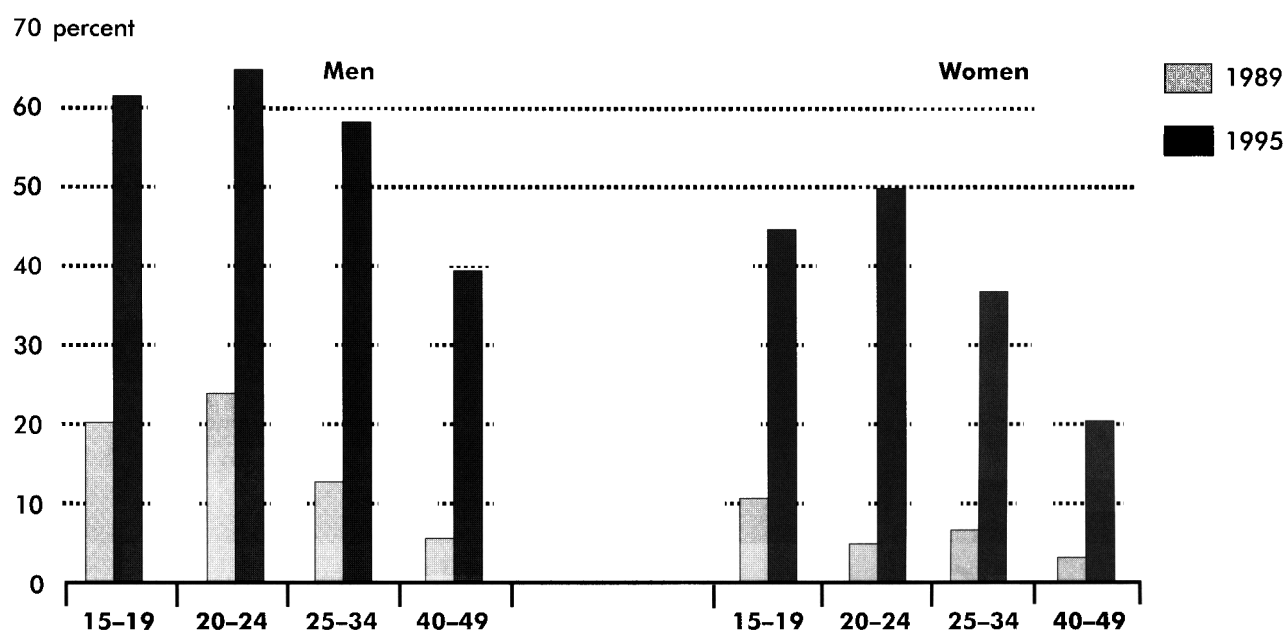
A regular partner is defined as someone with whom the sexual relationship has lasted for more than one year. There were changes here too, but less marked. Between 1989 and 1995, the proportion of men who reported sex outside a regular partnership in the previous 12 months fell from 22.6% to 18.1%. And the number of additional sexual partners tended to be fewer—the mean number falling from 2.3 to 2.0. For women, however, there did not appear to be any significant change—the proportion reporting sex with non-regular partners rose from 6% to 8%—but this difference was not statistically significant.

In addition, the two surveys showed that for both men and women the age of first marriage had risen—although the mean age at first marriage even in 1995 remained below the legal minimum of 18 years.

c) Increased condom use

Between 1989 and 1995, the percentage of sexually active people claiming to use condoms increased significantly. For men, the proportion of people who said that they had ever used a condom rose from 15% to 55%, and for women from 6% to 39%. As Figure 4 illustrates, for both men and women the proportion was highest for the age group 20–24.

Figure 4. Condom use in urban Uganda, 1989 and 1995



The 1995 survey also showed that condom use tended to be greater for those who had sex with a non-regular partner in the past 12 months. Here, reported condom use was 66% for men and 49% for women in their last sexual intercourse of risk.

Other studies on sexual behaviour

In addition to these two population-based surveys, there have been numerous other smaller scale investigations—quantitative and qualitative—into behavioural change in Uganda in recent years. Although these do not provide for such direct comparisons over time they do strongly support the proposition that there has been a significant shift in attitudes and behaviour. UNAIDS commissioned a literature survey that covered more than 300 documents. The subjects included:

a) Age at first sex

Other researchers, anthropologists and demographers (UDHS, 1996) have also noted recently a lower proportion of current youth 20–24 (male and female) who report first sex under the age of 19 compared to results in the late 1980s.

b) Age at first marriage

The trend in the 1980s and early 1990s has been for the median age of first marriage of girls to move downwards. In the 1980s this was probably linked with hardship, war and insurgency while more recently it may have been due to the fear of AIDS and the desire on the part of men for a non-infected partner. Nevertheless, a more recent national survey has found that, even though the average age is stable, fewer women are marrying in their early teens.

c) Sexual relations with non-regular partners

There is relatively little reliable quantitative evidence from other studies but qualitative observations do suggest that people are increasingly being faithful to regular partners.

d) Condom use

Many different studies indicate an increase in condom use, and some of these have followed the same cohorts over time. Taken together, these would suggest that the proportion of sexually active people who had ever used a condom at the national level rose between 1987 and 1996 from about 3% to 25%.

Measurement of behavioural change is always difficult, since people wish to give socially desirable answers. And there are often inconsistencies between different studies in terminology and in the indicators chosen. Nevertheless, a broad range of independent studies suggest that patterns of sexual behaviour have changed significantly over time, with younger people in urban areas less likely to behave in ways that put them at risk of HIV infection.

***Best Practice* criteria**

Relevance

In Uganda, one of the African countries with the most severe epidemic, as in many other countries, doubts are raised about the links between prevention programmes, changes in sexual behaviour and ultimately in HIV incidence and prevalence. The experience in Uganda has demonstrated that declines in prevalence are more than expected from the natural history of the epidemic and probably result from behavioural change. Demonstrating that it is possible for behaviour to change is an essential step in maintaining a commitment to programmes designed to promote such change. In addition, mapping how such prevalence–behaviour links vary geographically or in areas with different prevention interventions can provide useful information for tailoring and modifying prevention programmes to increase their effectiveness.

Efficiency

The Uganda experience showed that once the scope, the timing and the type of behavioural survey have been adequately selected, the resources required for good quality data are not beyond the capacity of a National AIDS Programme. Repeated surveys of the general population cost within a range of US\$ 20–30,000 each and took less than 5 months to be completed; the costs compared favourably with those for other countries.

Effectiveness

This case study demonstrates a plausible link between the epidemiological data showing declining HIV prevalence in urban areas and behavioural data showing growing adoption of safer sex among youths. The prevalence–behaviour links that were demonstrated by the Ugandan surveys and the surveillance and behavioural survey techniques used have been independently reviewed and found to be sound. Future efforts could further improve the usefulness of their results if additional socio-demographic data (e.g. education, residence, occupation and marital status) were collected from the surveillance sites, which could be used to better correlate results with behavioural surveys and control for biases due to changes in the population sampled. The choice of sample populations for behavioural surveys should in the future be better matched with sentinel surveillance sites.

Sustainability

The Uganda experience in sentinel serosurveillance (where the effort has already been sustained for over 10 years) has shown that when reliable information on the dynamics of the epidemic is nationally disseminated in an appropriate format at the highest policy level, using local expertise, the technical support and the funds required to ensure sustainability can be mobilized from both national and international sources.

Ethical soundness

The ethical requirements of the WHO guidelines on anonymous unlinked sentinel surveillance of HIV infection were strictly applied in the case of Uganda. In carrying out surveys on sexual behaviour and HIV and STD prevalence, special attention was given to issues of informed consent and confidentiality (e.g. the interview forms were anonymous).

Lessons learned

Recent information from Uganda offers grounds for optimism. Sentinel surveillance indicates that the prevalence, and probably the incidence, of HIV infection is falling for pregnant women in urban areas. And surveys of changes in sexual behaviour in the same areas suggest that any decline in incidence is the result of one or more of the following: increase in condom use, a delay in the onset of sexual intercourse, and to a lesser extent a reduction in the number of sexual partners. However, other studies in rural areas show that the number of new infections even among young age groups is still high, with no signs of decline.

Given the uncertainties in measurement and interpretation, it is still difficult to make a direct link between behavioural changes and declines in prevalence—still less to estimate what degree of behavioural change is required to produce a specified reduction in prevalence. But the available evidence does underline the importance of urging new patterns of safe behaviour.

Uganda's experience also highlights the importance of gathering parallel sets of data—on HIV seroprevalence and on behaviour. Each set is valuable on its own, but taken together they provide a much more robust picture of progress in the fight against HIV/AIDS (UNAIDS, 1998).

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