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Working Group on Global HIV/AIDS/STI Surveillance

Guidelines for effective use of data from HIV surveillance systems



World Health
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EUROPEAN COMMISSION



Joint United Nations Programme on HIV/AIDS
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Preface

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) with other international institutions and partners. This guide is part of a series of technical resources on second-generation surveillance that started with the *Guidelines for second generation HIV surveillance* published by UNAIDS and WHO in 2000 and aims to address specific technical issues related to strengthening surveillance systems.

WHO and UNAIDS thank all the people who have provided valuable input and suggestions for this publication. Most of the data in this publication are taken from data collected by surveillance systems in developing countries, and we thank the public health professionals who have worked so hard to generate these data. Many of the examples of data use are also based on the growing experience of surveillance professionals and their many partners. We cannot acknowledge every country individually, but we are grateful for the lessons learned and shared from around the world.

Several people commented on an earlier draft of this publication, including many members of the surveillance working groups at WHO/UNAIDS and the United States Centers for Disease Control and Prevention as well as Sara Hersey, Chen Hong, Ye Htun, Penny Miller, Roeland Monasch, Jimmy Whitworth and Andrew Wilson. We thank Pandu Riono for helping to develop some of the interactive data presentation techniques presented here.

We especially thank Elizabeth Pisani for conceptualizing and writing this guide.

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Introduction

Many countries around the world have invested heavily in the past decade in collecting information about the human immunodeficiency virus (HIV) and the behaviour that spreads it. The World Health Organization (WHO), the Joint United Nations Programme on HIV/AIDS (UNAIDS) and partner organizations have supported this investment and have developed guidelines detailing the principles of what is now known as second-generation HIV surveillance. Second-generation surveillance includes biological surveillance of HIV and other sexually transmitted infections (STIs) as well as systematic surveillance of the behaviour that spreads them. It aims to use these data together to build up a comprehensive picture of the HIV/AIDS epidemic.

By tracking the past course of the HIV/AIDS epidemic, warning of possible future spread and measuring changes in infection and behaviour over time, second-generation surveillance is designed to produce information that is useful in planning and evaluating HIV/AIDS prevention and care activities over time.

This objective has been met in many countries, where useful, high-quality data are now available. Nevertheless, a gap remains between the collection of useful data and the actual use of these data to reduce people's exposure to HIV infection and to improve the lives of those infected. More effort has been put into improving the quality of data collection than into ensuring the appropriate use of data. Collecting high-quality data is an important prerequisite to using them well, but why are available data not used better? One reason is that surveillance systems are often fragmented. This means that many departments or groups are responsible for various aspects of data collection. Each considers its job done after it has held its own "dissemination workshop". No single entity is responsible for compiling all the data, analysing them and presenting them as a cohesive whole. Further, very few countries budget adequately for analysing, presenting and using data, either the financial or human resources. When financial resources are allocated, people often underestimate the skills and time required to use data well. Many surveillance officials responding to an informal WHO/UNAIDS survey gave one final reason: they simply do not know how to use the data. This is hardly surprising: most people responsible for surveillance systems are physicians and public health professionals who are good at interpreting trends in disease but who have limited training in the different ways HIV surveillance data can be used to improve programming, measure the success of prevention, lobby for policy change and engage affected communities in the response.

This publication aims to provide guidance in these areas. It discusses the three major areas of data use:

programme planning, programme monitoring and evaluation and advocacy, giving examples of how data can be used effectively in these contexts. The publication concentrates on the mechanics of using data: not just what can be done with data but how it can be done. How can data be packaged for different audiences? Who should be involved in dissemination? What makes a good press release? What steps are required to produce a national report? Practical guidance is given on how to develop interesting and persuasive presentations and how to present data effectively. Suggestions are made for bringing together programme planning and advocacy.

Different countries have different epidemics, different surveillance systems and different data use needs. It is hoped, however, that all countries can find some general principles that will provide pointers on how to improve performance in areas of data use relevant to them.

Technical resources on HIV surveillance and related topics

The primary audience for this publication is HIV/AIDS programme managers and surveillance professionals at the national and regional level. However, it is hoped that other partners in HIV/AIDS prevention and care will find parts of this publication useful in preparing presentations and reports, in using the press effectively and in engaging communities in reducing exposure to HIV and its impact.

Data use is not an isolated activity – it is the final stage in a series of activities that begins with planning health information systems and continues through collecting, managing and analysing data. It must bring together many different elements: second-generation surveillance comprises biological surveillance of HIV and STIs (which may include case reporting in addition to sentinel surveillance) as well as behavioural surveillance. Behavioural surveillance – the repeated measurement of risk behaviour over time in systematically sampled cross-sectional surveys – occurs in the context of broader behavioural data collection, which may include ethnographic and qualitative research, geographical information systems and other methods. Increasingly, systematic efforts are also being used to make formal, data-based estimates of the size of various populations at risk for HIV infection. All this information must be presented together in a coherent way to make the best use of the data collected.

This publication is a module within the technical resources on HIV surveillance and related topics listed in Table 1 together with their electronic addresses that aim to provide technical guidance on surveillance activities. In addition, at a global level, countries have compiled essential information in the

Table 1. Technical resources on HIV surveillance and related topics

Title	Year published	Site for electronic download
<i>Second generation surveillance for HIV: the next decade</i>	2000	http://www.who.int http://www.unaids.org
<i>Guidelines for sexually transmitted infections surveillance</i>	1999	http://www.who.int http://www.unaids.org
Guidelines for using HIV testing technologies in surveillance: selection, evaluation and implementation	2001	http://www.who.int http://www.unaids.org
<i>Initiating second generation HIV surveillance systems: practical guidelines</i>	2002	http://www.who.int http://www.unaids.org
<i>National AIDS programmes: a guide to monitoring and evaluation</i>	2000	http://www.who.int http://www.unaids.org
<i>Behavioral surveillance surveys (BSS): guidelines for repeated behavioral surveys in populations at risk of HIV</i>	2000	http://www.fhi.org
<i>Estimating the size of populations at risk for HIV: issues and methods</i>	2003	http://www.fhi.org http://www.who.int http://www.unaids.org

form of epidemiological fact sheets related to HIV, behaviour and STIs.

When this publication uses the terms surveillance, HIV surveillance or HIV surveillance systems, it is referring to all of this data collection activity taken as a whole. The different aspects of the surveillance system can be discussed separately in terms of financing and implementation (and to a much lesser extent in terms of planning), but they cannot be discussed separately for data use. One of the core principles of second-generation surveillance is that behavioural data and biological data are interpreted together to give a coherent picture of the epidemic. The data must therefore also be used together to improve programme planning and to promote better policies.

Most data used in this report are real data produced by current surveillance systems on four continents. Since this report aims to illustrate data use rather than to compare national surveillance systems or epidemics, the names of the countries and cities that generated the data have been changed.

Ensuring high-quality data

Data cannot be used well unless they are of high quality. Public health professionals use the output of the surveillance system as the raw material for data use. The data they present to policy-makers, the public and communities at risk are only as good as the surveillance systems that produce them. If surveillance systems produce poor data that lead to policy conclusions that are irrelevant or even inaccurate, then efforts to reverse the HIV/AIDS epidemic will be undermined. Public health professionals, including surveillance system managers and HIV/AIDS programme staff, are therefore interested in ensuring that the data surveillance systems generate are of high quality. Involving the final users or decision-makers at different levels, especially at the beginning and end of this process, is essential as well.

What follows is a simple checklist of some of the most common weaknesses encountered in surveillance data.

- **Does the surveillance system cover the right populations?**

The distribution and magnitude of the HIV/AIDS epidemic can only be identified by looking in the right places. This means that subpopulations engaging in behaviour carrying a high risk of HIV transmission must be included in the surveillance system. A surveillance system that focuses only on pregnant women and carries out surveys of sexual behaviour in the household will almost certainly overlook an HIV outbreak driven by men who have sex with men or injecting drug users. Good formative research is important in planning surveillance systems to ensure that all key groups are covered.

- **Is the sample population clear?**

Surveillance data cannot be correctly interpreted unless the population included in the surveillance sample is clearly defined. This is especially important when comparing infection and behaviour over time and in different geographical areas – one of the core functions of surveillance. The tighter the definition the better: comparing data from “sex workers” in two cities to examine the patterns of epidemic spread may be very misleading if the sex workers sampled in one city are women working in hotel discothèques whereas those sampled in the other city are women working in a roadside truck stop. Reports and presentation should state clearly what population the surveillance sample represents.

- **Is the sample size adequate?**

Although some leeway in setting sample sizes for surveillance is advisable, depending on local conditions, sample sizes should always be taken into account before conclusions are drawn from data. An HIV prev-

alence of 67% among transsexuals will certainly make headlines, but if only nine people were included in the “surveillance sample” it is highly unlikely to reflect a broader reality. Always look at the confidence intervals around your prevalence estimates to get a quick idea of how reliable the estimate from the sample size available will be.

- **Did the surveillance take place in a site used consistently over time?**

The main purpose of surveillance is to track trends over time. This is only possible when surveillance is comparable between rounds. This means that particular sites must be maintained over time. Trend data should only show data from sites used consistently over the time period in question.

- **What is known about testing?**

In subpopulations in which HIV prevalence is 10% or more, a single HIV test is usually considered enough for surveillance purposes. In low-prevalence epidemics, a single test can lead to a high proportion of false positives, even when tests are relatively specific.

- **What is being measured?**

Clear definitions are absolutely essential in using surveillance data effectively. If one wanted to look forward at the potential spread of HIV among young people, a core indicator would be the proportion who are sexually active and the proportion with multiple partners. But does “sexually active” mean “ever sexually active” or “currently sexually active”? How current is current? What counts as sex? Were these distinctions clear to the respondent?

- **Are data being overinterpreted?**

Huge strides have been made in improving methods of tracking HIV infection and risk behaviour, even in populations that are very hard to reach. Surveillance data are sometimes presented to two decimal points of accuracy, 95% confidence intervals give an air of statistical solidity and data weighting and multivariate analysis adds a veneer of high science. Nevertheless, significant room for error remains in almost every aspect of HIV, STI and behavioural surveillance. Random samples of many populations at high risk are virtually impossible to obtain, making comparisons across time problematic. Despite good internal consistency, the validity of self-reported data on sexual behaviour and drug use is frequently questionable. Poor specimen handling and laboratory error mean that biological data should also be treated with caution.

This does not mean that surveillance data are worthless. One should merely be cautious about jumping to quick conclusions about small rises or falls in infection, and surprising findings in behavioural

surveillance should be investigated further. Avoid presenting data as if they were more “scientific” than is possible in the context: present rounded numbers, use confidence intervals and tests for trend with caution and be as honest as possible about the limitations of the data. In public health surveillance, data do not need to be perfect; they just need to be good enough to give a reliable idea of the major trends in HIV infection and related risk behaviour.

• **Does selective data presentation influence interpretation?**

Surveillance data, like any other data, can often be interpreted in more than one way (Box 1). The selection of denominators and the selective presentation of indicators can greatly affect how the data are interpreted. People are very often driven by their own personal bias to give greater weight to one interpretation than to another. In addition, sometimes people miss the whole story simply because they focus too closely on the details. People look at pieces of data as separate entities rather than as different aspects of the same story. The importance of examining information on population size, HIV prevalence, STI prevalence and risk behaviour together cannot be overemphasized.¹

Box 1. Whose story is it, anyway? An exercise in creative data interpretation

If data from multiple sources are being used, always think about these sources. Does the organization that collected, that analysed or that is presenting the data have any vested interest in interpreting it in a certain way? The answer is often yes. Even international organizations – which are usually thought of “neutral” technical sources – sometimes want to present data in a particular light. They may highlight the worst aspects of a problem to draw global attention and increase funding for much-needed technical support. Conversely, they may rush to interpret a slight downward trend as a success story, because they need to be able to demonstrate that past funding has produced results. People may be driven by political, religious or financial agendas or simply by the conviction that they are keeping the most important issues in the spotlight.

Table 2 gives data from behavioural surveillance among students in the last 2 years of a high school in which an abstinence-only sexual health education curriculum was introduced in late 1998, 3 months after the first round of surveillance.

Consider the information in the table. Think about what these data mean. When you are ready, read onward for an example of how the same data can be interpreted differently to serve several different agendas.

Table 2. Results of surveys on sexual behaviour among high school students, 1998–2002

Year	Had sex in the past year (% of all)	Had multiple partners in the past year (% of all)	Always used condoms (% of those with multiple partners)
1998	73	9	50
1999	70	11	48
2000	68	15	41
2001	58	20	38
2002	48	24	35



¹ *Estimating the size of populations at risk for HIV: issues and methods.* Arlington, VA, Family Health International, 2002 (<http://www.fhi.org/NR/rdonlyres/e6axdwvytihsy6jtnwseglwebpydr537mncbdmaejwa5eck7zt5enezqa4xgroxaovonly5yfb63l/popsizedcontent.pdf>, accessed 10 November 2003).

The data can be interpreted in many ways, depending on how they are selected, manipulated and presented.

A lobbyist for abstinence-based sex education might respond as follows.

Figure 1. Percentage of students at a high school in which an abstinence-only sexual health education curriculum was introduced in late 1998 who report being sexually active, 1998–2002

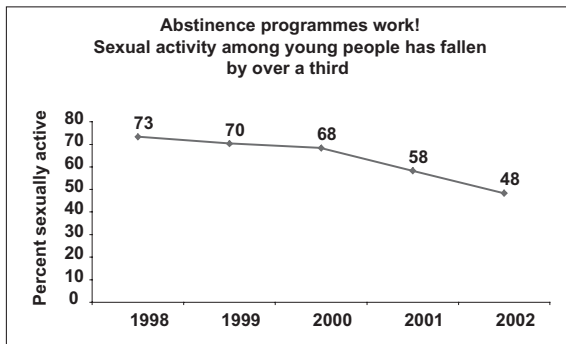


Figure 1 simply shows the first column of data in the table, to make the point that sexual activity decreased between 1998 and 2002.

An NGO seeking funding for condom promotion programmes in high schools might respond as follows.

Figure 2. Percentage of high school students who reported having sex in the past year who had multiple sex partners and percentage who always used condoms

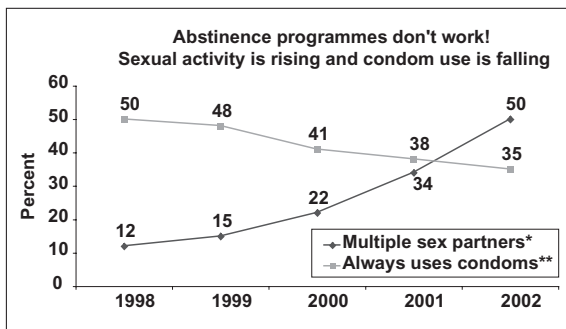


Figure 2 took a bit more work, because the person who made it wanted to show as sharp a rise in sexual activity as possible. Instead of just showing the proportion of students with multiple partners given in the table, they applied that proportion to the proportion who were sexually active. Because this is not the whole population, and because it is falling over time, it made the rise in multiple partnerships look steeper. The author does note the denominator in a tiny footnote under the graph. This is the sort of information that typically gets lost as graphs are reprinted in newspapers.

An HIV/AIDS programme planner who wants to give as comprehensive a picture of sexual risk in this population as possible might respond as follows.

Figure 3. Proportion of high school students having no sex in the past 12 months, sex with one partner or consistent condom use and unprotected sex with multiple partners, 1998–2002

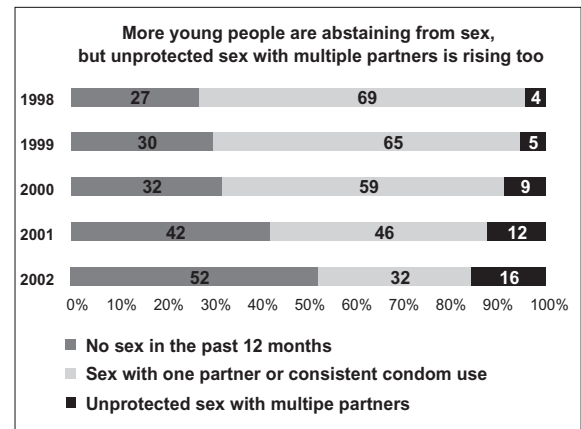


Figure 3 took still more work, because its author wanted to focus on changes in the risk of exposure to HIV infection. Unprotected sex with multiple partners poses the greatest risk of exposure. This was calculated by multiplying the proportion of the total population who had multiple partners by the proportion who did not always use condoms with multiple partners ((column 2 times (100 – column 3))/100). This produces the black part of the bars on the right. Those who are abstaining have no current sexual risk. This is (100 – column 1) and produces the dark grey part of the bars on the left. In between, at lesser risk, are those who have sex but do not have multiple partners (column 1 – column 2) or those who have multiple partners but always use condoms ((column 2 times column 3)/100).

This more comprehensive look at the data shows that the percentage of young people reporting no sex at all – the very safest behaviour in terms of transmitting HIV infection – almost doubled from 1998 to 2002. This may be considered a programme success. Nevertheless, another part of the same picture is that unprotected sex with multiple partners – one of the most dangerous types of behaviour for the sexual spread of HIV – has risen even more substantially, quadrupling over the same period. The reason is that more of those who are not abstaining have multiple partners than before and fewer use condoms consistently. The conclusion from these data might be that the abstinence-based programmes could be expanded while increasing services to promote safe sex among those who choose to be sexually active.

The examples above are just a selection. Others might choose to present data in other combinations, such as simply showing the proportion with multiple partners and the proportion not using condoms.

Data for programme planning

The first of the three major uses of surveillance data is for programme planning. This can be done at several levels. At the national level, surveillance data should be used to determine the magnitude of the epidemic and its distribution in different geographical areas and subpopulations. Estimating the number and distribution of those already infected is important in deciding how prevention resources should be distributed as well as in planning care and support needs on a national scale. At a more local level, however, within prevention programmes themselves, surveillance data can be used to identify problem areas, to seek solutions and to devise strategies appropriate to the ever-changing epidemic.

This section looks in detail at some of the ways surveillance data can be used in programme planning.

Programme planning at the policy level: who is affected, what is the extent of the problem and what comes next?

The first and most obvious use of HIV surveillance data is to determine the distribution of the current HIV/AIDS epidemic and to understand which types of behaviour are spreading HIV in various subpopulations.

Most countries have already used their data in this way. This is not, however, a one-time exercise. The HIV/AIDS epidemic is extremely dynamic: it evolves over time in different ways in different countries depending on the pattern of behaviour, the success of prevention programmes and a host of other geographical, biological and social factors. Successful prevention programmes may have managed to reduce risk behaviour drastically in a population that experienced high HIV prevalence early in the epidemic, but the risk and the relative levels of infection may have surged upwards in a different population. The basic task of tracking HIV infection and risk behaviour to identify populations affected or threatened by HIV must be repeated continually over time.

One limitation of HIV sentinel surveillance is that it only records people who have already become infected with HIV. Thus, it shows who is at risk once

it is already too late to prevent infections in at least a part of that population. Ideally, surveillance should be able to determine that a community is at risk for infection before HIV becomes well established in that group – before the biological surveillance system records significant levels of HIV infection. This is where behavioural and STI data come in. The vast majority of people who become infected with HIV do so by having sex or sharing needles with someone who is already infected. If HIV infection is known to be frequent in one group already included in surveillance, the behavioural links between that group and others can be examined to determine who might be exposed to HIV in the future. STI surveillance data can also be invaluable in this context. STIs are transmitted in the same way as HIV, and HIV also spreads more quickly when other STIs are present. High levels of STIs such as gonorrhoea and syphilis can therefore indicate the potential for the spread of HIV, even in countries that still have a low prevalence. Existing STI surveillance systems can act as an efficient early warning system for HIV.

Using surveillance data to determine who is affected

Here are a few basic tips in examining data to determine the distribution of infection.

- **Examine the data by site²**

Data may need to be aggregated in other parts of the process of using them, but data should always be initially examined at the lowest unit of analysis, since this most accurately reflects changes over time. Nevertheless, small sample sizes at individual sites may distort conclusions.

- **Examine the data by subpopulation**

In countries in which surveillance systems include many different subpopulations at risk for HIV, such as injecting drug users, men who have sex with men or sex workers and their clients, the need to examine data by subpopulation is very obvious. This may be less obvious in countries with generalized epidemics, where most surveillance concentrates on pregnant women or other clinical groups. Because only a few variables can be collected in unlinked, anonymous HIV surveillance, subpopulations in this case are usually confined to sex and age. Differences in the age of those infected with HIV – between populations and

² Most sentinel surveillance systems for HIV collect data repeatedly over time from health facilities that provide services for populations, such as antenatal clinics for pregnant women, clinics treating patients with sexually transmitted diseases or drug treatment centres. A few countries have established more comprehensive systems that collect specimens from subpopulations in the community. These systems usually designate a population group in one community area as a sentinel population (for example, female sex workers in the Bado Tuna red-light district). When this publication refers to a sentinel site, it is used interchangeably with a designated sentinel population.

especially over time – can have important implications for programme planning and evaluation.

• **Put the data on a graph**

Simple graphical representations can be very helpful indeed in bringing important issues into focus. Compare trends over time in different sites using a line graph or current HIV prevalence in different groups using a bar chart: major differences immediately become obvious even to audiences not used to interpreting numbers.

A note of caution is needed here. As Figure 4 shows, a very different scale of the epidemic in different populations can sometimes obscure or exaggerate changes when they are represented graphically.

Figure 4. HIV prevalence among injecting drug users and blood donors in Grevia City, 1994–2002

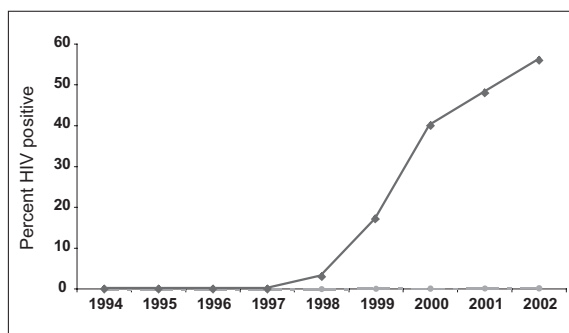
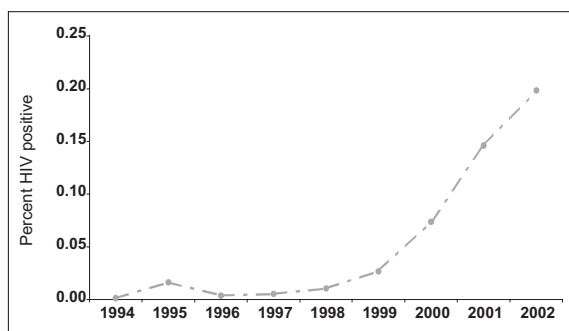


Figure 4 clearly shows that the prevalence among injecting drug users has risen immensely, but there appears to have been virtually no change among blood donors. However, if the scale is changed for blood donor data, as shown in Figure 5, the picture changes drastically.

Figure 5. HIV prevalence among blood donors in Grevia City, 1994–2002



• **Map the data**

Mapping is essential. It is the most effective way of quickly examining regional variation in HIV prevalence and has grown in importance in an age of increasing decentralization. Easy-to-use software packages such as HealthMapper, EpiMap and ChildInfo can be obtained free from WHO, the United States Centers for Disease Control and Prevention or UNICEF, including Internet downloading.³ The example in Annex 2 shows how mapping can help transmit large quantities of information in a way that is easy to understand.

• **Check the quality and validity of the data**

As obvious as it seems, some people forget to check the quality and validity of the data. Once numbers get picked out of a database or spreadsheet and presented as stand-alone “facts”, much of the information that would help people to gauge the quality of the data is lost. Once the data are mapped or graphed, if something really stands out as unusual or unexpected, go back to the database and check why. Perhaps the sample size was very small, there has been an error in coding or only one test was performed when the national protocol stipulates two.

Using surveillance data to estimate the size of the epidemic

One of the most common uses of surveillance data at the national level is in estimating the number of people infected with HIV. This is important for planning and budgeting purposes, for lobbying and often also for complying with national and international reporting commitments.

Examining sentinel surveillance data should give an idea of the distribution of HIV and the relative magnitude of the problem in different groups, but it does not automatically lead to an estimate of the absolute numbers of people infected. To get these estimates, surveillance data need to be further analysed together with information about population size and other types of surveillance data, such as behavioural data.

Methods for making estimates differ depending on the type of HIV/AIDS epidemic a country is experiencing. Methods, tools and supporting documentation including manuals are available from the web sites of several organizations, including UNAIDS (<http://www.unaids.org>), WHO (<http://www.who.int>) and the Futures Group International (<http://www.futuresgroup.com>).⁴

³ See <http://www.who.int/csr/mapping/tools/healthmapper/healthmapper/en> (accessed 10 November 2003) for details about acquiring HealthMapper from WHO. EpiMap can be downloaded from <http://www.cdc.gov/epiinfo> (accessed 10 November 2003).

⁴ UNAIDS Reference Group on Estimates, Modelling and Projections. Improved methods and assumptions for estimation of the HIV/AIDS epidemic and its impact: recommendations of the UNAIDS Reference Group on Estimates, Modelling and Projections. AIDS, 2002, 16:W1–W14.

In general, there are two major approaches, depending on the type of HIV/AIDS epidemic a country is experiencing. The first approach to estimating the prevalence of HIV infection in a population is best used in “generalized” epidemics common in sub-Saharan Africa, where HIV is being spread mostly through sex between men and women in the general population – people not necessarily exposed to high-risk behaviour such as drug injection, commercial sex or sex between men (Box 2). In this type of epidemic, a high proportion of the heterosexually active population is potentially exposed to HIV, and HIV surveillance usually concentrates on pregnant women in antenatal clinics. Since they are thought to be a good proxy for the general, sexually active population, the rates of HIV recorded among these women can be applied to the whole adult population. This can become a much more elaborate process if data are available, with estimates being made on a provincial or even district level. Age-specific estimates are also possible.

Box 2. General steps for estimating HIV prevalence in generalized epidemics

1. Compile HIV surveillance data from antenatal clinics
2. Use the Estimation and Projection Package (EPP):
 - to provide a geographical structure to the epidemic (at least a rural and urban component are recommended)
 - to weight surveillance data as appropriate
 - to estimate a national HIV prevalence rate

The second approach is appropriate for epidemics in which most infections remain concentrated among people who are exposed to HIV through their own or their partner’s drug taking or through risky sex between males or commercial sex (past or present). In this case, pregnant women in the general population do not represent those potentially exposed to infection. This is why surveillance systems in this situation should concentrate on measuring HIV and risk behaviour directly in the populations most likely to be exposed – usually injecting drug users, men who have sex with men, sex workers of all types and their clients.

Even when sentinel data for these populations are available, the leap to national estimates of infection is not simple. The prevalence of HIV infection in sex workers may be known to be 32%, for example, but estimating the absolute numbers infected requires knowing how many sex workers there are. Estimating the size of populations at risk for HIV has been a neglected area of HIV surveillance, although more attention has been paid recently as questions of intervention coverage have grown in importance.⁵

⁵ *Estimating the size of populations at risk for HIV: issues and methods.* Arlington, VA, Family Health International, UNAIDS, WHO, 2002 (<http://www.fhi.org>, <http://www.who.int/hiv/en>, <http://www.unaids.org>).

Software and guidance on estimations and projections in low-level and concentrated epidemics (the workbook method) are available at <http://www.unaids.org> and <http://www.who.int>.

Box 3. General steps for estimating HIV prevalence in concentrated and low level epidemics

- Determine which subpopulations are potentially exposed to HIV
- Estimate the size of each subpopulation
- Examine surveillance data for the index subpopulations
- Estimate HIV prevalence in exposed populations not included in surveillance
- Apply the HIV prevalence estimates to the population size estimates
- Sum up all estimates for a national HIV prevalence

Because potential exposure to HIV is so much more varied in “concentrated” HIV epidemics than in generalized epidemics, the methods for estimating the prevalence of infection vary more in these epidemics (Box 3). Essentially, however, all methods rely on defining the populations exposed to HIV and estimating the size of each of the populations exposed. Surveillance systems directly measure HIV prevalence for some of the exposed populations but not for all. For example, the regular partners of male clients of sex workers may not be included as a surveillance population. In addition, the estimates of prevalence for these groups usually have to be derived from a combination of HIV data from index groups and behavioural data that measure the level of exposure to the index group. Again, these can be estimated on a local as well as a national level.

Although this sounds complex, it can be done using relatively simple spreadsheets that show estimates for one province in a concentrated epidemic. The national estimate is the aggregation of the estimates for each of the exposed populations for all provinces.

For groups for which no data are available, assumptions are made based on information that does exist. For example, there may be no direct records or estimates of the number of sex partners of injecting drug users but behavioural surveillance among injecting drug users shows that 80% were sexually active and only a small fraction have sex with other injecting drug users. This allows the number of non-injecting sex partners of injecting drug users to be estimated. Similarly, the surveillance system does not collect

information on HIV prevalence among the wives of clients of sex workers. If HIV, STI and behavioural surveillance is performed among male client groups, however, the proportion married, how often they have sex with their wives and how often they use condoms are known. The proportions infected with HIV and STIs are also known. This, combined with biological information about the likelihood of HIV transmission per act of sex, gives a relatively robust estimate of HIV prevalence among the wives of the clients of sex workers.

Box 4 shows the software used to derive estimates of HIV/AIDS, based on HIV prevalence over time, and to explore policy options.

Box 4. Software used to calculate HIV/AIDS estimates and to explore policy options

SPECTRUM software

SPECTRUM is modular software that is used to examine the consequences of current trends and future programme interventions in reproductive health. The core of Spectrum is a demographic projection model, called DemProj, which projects the population by age and sex. Other modules interact with the demographic projection, including the AIDS Impact Module (AIM). The output of EPP or the Workbook method is transferred into SPECTRUM and its population projection. This software will then project the consequences of the HIV/AIDS epidemic, including estimates of the number of people living with HIV/AIDS, the number of new infections, the number of people who have died due to AIDS as well as orphans.

Asian Epidemic Model (AEM) software

The Asian Epidemic Model (AEM) has been designed to reflect the main groups and transmission modes driving HIV transmission in Asia. The user adjusts AEM modelling parameters until the HIV prevalence output from the model agree with observed epidemiological trends.

Using surveillance data to allocate resources

The process of making estimates by area, age, sex and exposure group is useful not just to get raw estimates of the total number of people living with HIV/AIDS nationwide but to make better decisions about allocating resources.

Take the example of an African country with a generalized HIV/AIDS epidemic that wants to plan HIV/AIDS care services. A glance at the prevalence figures in Table 3 might lead rapidly to the conclusion that more services are needed in urban areas in the north of the country, since that is where HIV prevalence is highest.

Table 3. HIV prevalence in antenatal clinics in the Republic of Kwandu, 2003

Province	Average HIV prevalence measured in surveillance		
	Urban	Periurban	Rural
North	36.2	12.4	No data
North-east	24.6	15.3	No data
Central plains	12.2	No data	4.4
South-east	6.2	5.8	2.4
Coast	7.3	5.9	No data

Such a conclusion has to be re-thought, however, once the population figures for these areas are examined (Table 4).

Table 4. Population by province in the Republic of Kwandu, 2003

Province	Population	
	Urban	Rural
North	48 000	124 000
North-east	23 000	430 000
Central plains	330 000	1.2 million
South-east	3.4 million	2.4 million
Coast	1.9 million	2.3 million

Local knowledge helps to fill in the missing data. The sentinel sites in the north and north-east are sited in towns along the Trans-African highway, but most of the people in these areas are nomads who rarely interact with townspeople. In the central plains, in contrast, public health officials believe there is little difference in health status between people in the city and the townships, with whom they interact on a daily basis. The south-east and coastal regions have good infrastructure and a high level of mobility and interconnectedness.

After imputing missing data and adjusting for male-female ratios, the estimated numbers living with HIV/AIDS are shown in Table 5.

Table 5. Estimated number of people living with HIV/AIDS by province and area of residence in the Republic of Kwandu, 2003

Province	Urban	Rural
North	11 664	1 860
North-east	4 589	8 600
Central plains	40 260	152 800
South-east	204 000	57 600
Coast	125 400	92 000

Suddenly, the northern areas that have such a high prevalence in the urban areas where data are collected look rather insignificant compared with the central,

coastal and southern areas, where populations are far larger. In planning care and support services, special attention must therefore be paid to providing services in the central, coastal and southern areas, where 95% of the people with HIV/AIDS live.

In concentrated epidemics, taking population sizes into account is even more important for resource allocation. A very high prevalence may sometimes be recorded in a subpopulation that is very small. The high prevalence figures are striking and may divert attention from groups with lower prevalence but a far larger population base and therefore more infected individuals.

Table 6 shows prevalence estimates and population sizes in a large urban area in a country with a concentrated HIV/AIDS epidemic.

Table 6. HIV prevalence and estimated population sizes in various subpopulations at risk for HIV in Hok An Metropolitan Area, 2003

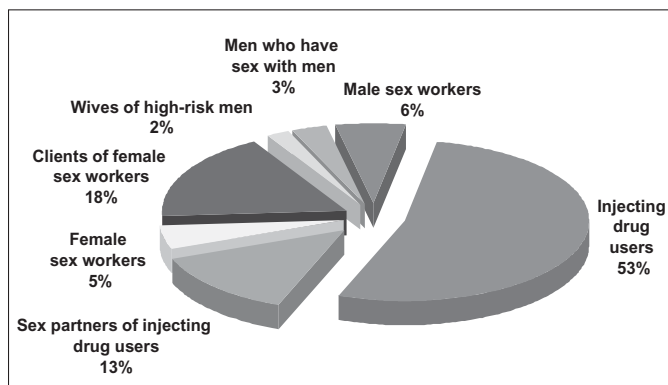
Population group	HIV prevalence	Estimated population size
Injecting drug users	37.5	27 500
Sex partners of injecting drug users	12.5	20 900
Female sex workers	2.8	32 400
Clients of female sex workers	0.28	1 257 000
Wives of clients of female sex workers	0.03	808 700
Men who have sex with men	1.3	47 800
Male sex workers	21.5	5 500
Wives and girlfriends of male sex workers	7.1	2 600

A first glance at the prevalence figures suggests that drug users and male sex workers are overwhelmingly the most important groups contributing to HIV transmission in this population. Female sex workers rank fifth in HIV prevalence, and their clients, at well under 1% prevalence, would barely register as a cause for concern. Nevertheless, if the prevalence figures are applied to the estimated population sizes, the picture changes drastically (Figure 6).

Most people living with HIV/AIDS in this city were indeed infected through drug injection, as expected. Nevertheless, 23% of infections were transmitted in commercial sex between men and women, and clients of female sex workers were the second most affected group after injecting drug users. Male sex workers accounted for only 6% of all current infections, because the city has relatively few male sex

workers, so although a high proportion are infected, the absolute numbers are not large.

Figure 6. Percentage of people living with HIV/AIDS by exposure group in Hok An Metropolitan Area, 2003



In summary, HIV surveillance data should be considered in the context of other factors such as the relative size of the populations included in surveillance.

Using surveillance data to project future prevention and care needs

The future of the HIV/AIDS epidemic has proved notoriously difficult to predict. In 1990, the worst-case scenario was that between 15 and 20 million people would become infected worldwide by mid-2000.⁶ That estimate turned out to be at least 30 million short of the horrifying reality.

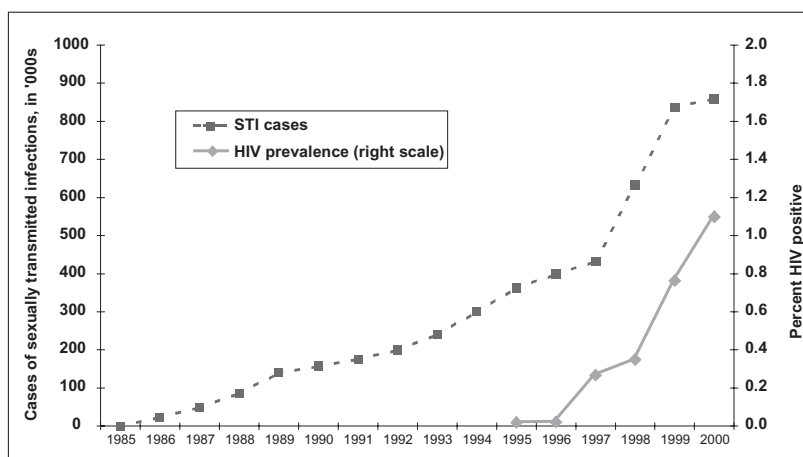
However good a country's surveillance system, it is unlikely to yield data that will allow the future course of the epidemic to be predicted accurately. Simple models can, however, allow countries to explore the epidemic's growth in the short term (up to 5 years) if current behaviour remains unchanged. This is especially useful for countries with emerging epidemics, when prevalence within groups with certain types of risk behaviour can explode and when interactions between these and other groups can lead to rapid changes in the course of the epidemic.

Behavioural surveillance and STI surveillance are especially important in thinking about where the epidemic might move next – the sort of forward-thinking analysis that is at the core of the best prevention programmes. If HIV surveillance shows high prevalence among injecting drug users but currently low rates of HIV in other groups, then asking injecting drug users with whom they are having sex is essential. If behavioural surveillance among injecting drug users shows that they are having sex with people who do not inject drugs, this should be a cause for concern. Are they having sex with a large number of partners,

⁶ Chin J, Sato PA, Mann JM. Projections of HIV infections and AIDS cases to the year 2000. *Bulletin of the World Health Organization*, 1990, 68(1):1–11.

for example, by being regular clients of sex workers or by working in the sex trade to finance drug-taking? Do those other partners have many partners? What about condom use? Is there any evidence that, if HIV made its way into a non-injecting population through the sexual behaviour of injectors, it would spread quickly (high rates of STIs in unmarried heterosexuals, for example)? After more than two decades of confronting HIV, the prevalence should not have to start to rise in a population before the members of the population who may be at risk for HIV infection because of their behaviour can be identified and prevention programmes started. Besides behavioural indicators, STI surveillance can function as an important warning of the potential for an HIV/AIDS epidemic.

Figure 7. Cases of STIs treated and HIV prevalence among people with STIs in Arcadia, 1985–2000



The data in Figure 7, for example, are from a large Asian country with a relatively strong public health surveillance system, show rises in the number of STI cases reporting for treatment as early as the mid-1980s. A decade later, the HIV prevalence began to climb among STI patients in the same country – in part because little action was taken when the STI surveillance figures began to indicate an increase in risky sex. Simple modelling can also help develop “what if” scenarios that can explore the effect of various interventions at different levels of coverage. These models cannot reproduce the full complexity of the epidemic but they can be very useful in identifying which types of behaviour are the most important to target and on what scale.

Programme planning and implementation: what are the key issues, what should be done about them and how should this be done?

HIV surveillance systems, like all public health surveillance systems, are designed to give a broad overview of trends in disease, risk and exposure over time, usually at the national or subnational levels.

HIV surveillance systems are not designed to meet all the needs of programme planning at the field level. They cannot provide all the information needed to determine what action is required and how this can be accomplished most successfully. However, surveillance systems can provide substantial information

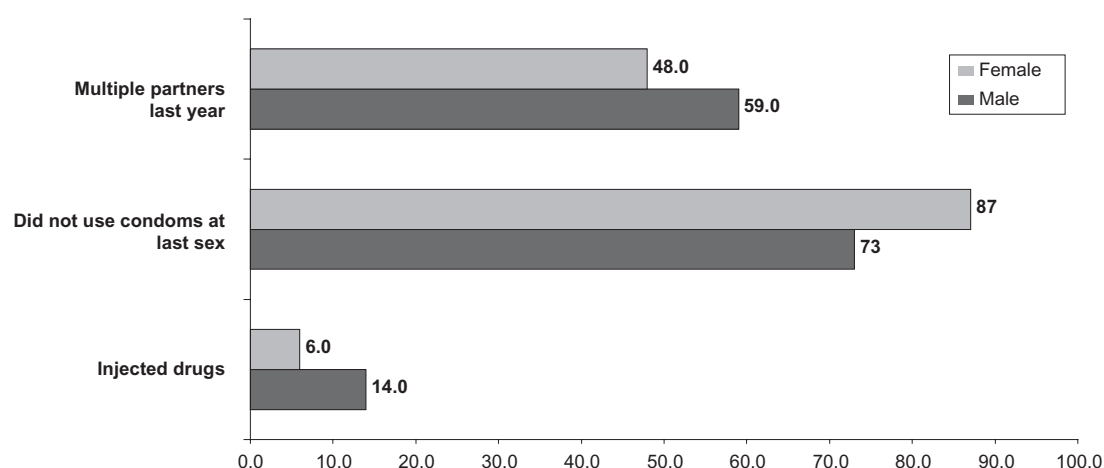
that allows people planning and implementing local and national programmes to move in the right direction. This is especially the case in the growing number of countries that use ethnography and mapping in planning surveillance activities and that supplement their regular quantitative surveillance work with small-scale qualitative studies.

Using surveillance data to identify the key issues

After two decades, much is known about which types of behaviour put people at risk for HIV. There is also no shortage of literature about who is at risk. This sometimes leads public health officials and other programme planners to make broad assumptions about risk behaviour and to plan interventions based on those assumptions. In truth, however, there is extraordinary diversity in the practice of risk behaviour, and global assumptions rarely apply in specific circumstances. This is where behavioural surveillance is of paramount importance: it allows confirmation of whether the broad assumptions made based on HIV surveillance data and background knowledge actually apply (Box 5).

Box 5. Using surveillance data to identify the key issues: an example

Global campaigns have focused on the fact that 50% of new HIV infections occur in people younger than 24 years, an age at which people are discovering their sexuality and likely to be engaging in risky behaviour of many sorts. A country with a rapidly growing epidemic pooled its national surveillance data and analysed them by age; they found that their situation was even worse than the global norm. Some 68% of all existing infections were in young people under 25 years. A front-page article in the leading newspaper reported that behavioural surveillance among high school children had found that over half the students had multiple partners and only 20% used condoms. The newspaper printed the graph shown in Figure 8.

Figure 8. Half our schoolchildren have multiple sex partners!

The Ministry of Youth and Education reacted rapidly, successfully lobbying for an allocation of US\$ 4 million to develop a life-skills curriculum, focusing on helping young people to avoid risky sex. The programme was implemented quickly.

Two years later, behavioural surveillance was repeated. This time, only a quarter of these people reported sex with more than one partner, and reported condom use rose two-fold. However, the number of infections in young people reported by the HIV surveillance system continued to grow. A parliamentary committee ordered an enquiry.

Public health officials went back to the behavioural surveillance data. The indicators reported in the baseline year were accurate – half of all students who had had sex in the previous year had multiple partners, and only 2 in 10 used condoms. But closer inspection showed that only 8% of all students reported ever having had sex at all, and only 4% reported sex in the past year. However, 10% of all high school students had reported injecting drugs in the previous year, and by the second round of behavioural surveillance, that fraction had risen to 14%.

These very high rates of injecting drug use had been overlooked because health officials were looking for evidence of unprotected sex. The Ministry of Health quickly ordered a rapid assessment of injecting drug use and found that 85% of injectors were under 25. Since most injectors in the country are young, most infections are in young people. Had behavioural surveillance data been better used at the start, it would have been clear that the greatest risk factor for HIV infection was not sex, or “youth”, but drug injection. Life-skills programmes were subsequently redesigned to focus more on helping young people stay away from drugs, harm reduction programmes were designed for those already injecting drugs and injecting drug users were added as a group to the national surveillance system.

Although the above example is an extreme case, it does illustrate the importance of fully exploring the data. Behavioural surveillance questionnaires tend to collect information on a wide variety of behaviours and beliefs, but in a typical report or dissemination workshop, only a very small number of standardised indicators are ever presented. The example also illustrates the need to be aware of what an indicator really means.

Using surveillance data to identify possible solutions

As mentioned earlier, surveillance systems are not designed to meet all the needs of programme planning and design. However, surveillance data, and especially behavioural surveillance data, can give general pointers as to what key areas may be addressed (Box 6).

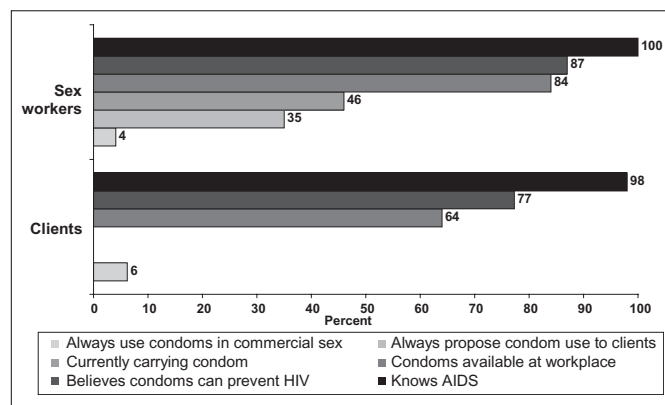
Box 6. Using surveillance data to redirect prevention efforts: an example

Behavioural data collected from female sex workers and clients showed that condom use was very low. Immediately, three nongovernmental organizations (NGOs) applied to the National AIDS Council for funding to begin peer outreach and condom distribution services for sex workers. The peer educators would talk to sex workers about the dangers of HIV/AIDS and would explain how condoms could prevent HIV infection. They would demonstrate how to use condoms, talk about negotiating their use with clients and then distribute condoms at a nominal price to the sex workers.

The National AIDS Council, considering a number of applications from different sources, asked for a more detailed analysis of the behavioural surveillance data before deciding to fund the peer outreach. They wanted to know whether sex workers knew about HIV/AIDS, whether they knew condoms were protective, whether condoms were available where they worked, whether they had condoms with them at the time of interview and whether or not they used them. They were also interested in the reasons sex workers gave for not using condoms. They requested that the same information be provided about clients of sex workers.

Not all the information requested was available, but most of it was. The surveillance data manager produced the graph in Figure 9.

Figure 9. Condom knowledge and use indicators among female sex workers and male clients in Nantha Tun, 2003

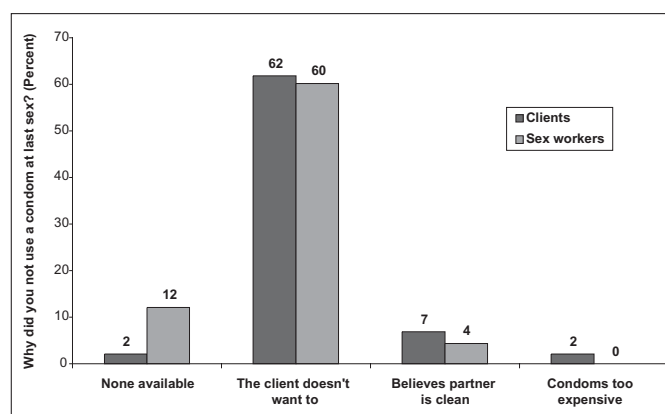


This graph shows that all sex workers and virtually all clients know about HIV/AIDS, and most described it as a fatal disease (data not shown). Most sex workers believe that condoms can prevent HIV transmission. Clients are less likely to believe this than sex workers are. Condom distribution does not seem to be an overwhelming gap in programming: 84% of sex workers sell sex in areas where condoms are easily available around the clock. Interviewers asked sex workers to show condoms if they were carrying them. Fewer than half were actually carrying condoms, perhaps because they were so widely available in the brothel or within a few metres of where they worked. Over one third of sex workers said they negotiated condom use with all their clients, but there was a huge gap between the proportion who proposed condoms to clients and the proportion who actually used them.

Of the 87% who knew that condoms could save their lives, only 4% had used condoms with all clients in the past week.

If knowledge and condom availability are not issues for sex workers, what is the problem? Figure 10 shows the data manager's second graph, showing the reasons sex workers and clients gave for not using condoms.

Figure 10. Reasons for not using condoms among sex workers and clients who did not use condoms at last sex in Nantha Tun, 2003



The major reason for not using condoms does not appear to be related to a sex worker's knowledge or to condom availability but rather to the fact that clients do not want to use condoms. Levels of knowledge and condom distribution systems must be maintained, but the data indicate that the immediate need in terms of increasing condom use is to work at changing men's attitudes towards using condoms in commercial sex.

In the face of this evidence, the National AIDS Council decided that peer outreach programmes for sex workers were not a high priority. After all, sex workers already know about condoms and have easy access to them, but even those that always negotiate their use with clients are not using them. They decided instead that, since clients continue to make all the decisions about condom use, the much higher priority was the more difficult task

of changing male attitudes. After extensive qualitative research with groups of men who buy sex and key opinion-formers, the funding was allocated to a mass media campaign and to workplace programmes aimed at men in mobile, high-paying professions.

Surveillance data will not provide all the information needed to design successful interventions. Nevertheless, the example in Box 7 shows how routine surveillance data can be used at least to investigate which aspect of a programme needs most attention in the current circumstances.

Using surveillance data to decide how to approach a problem

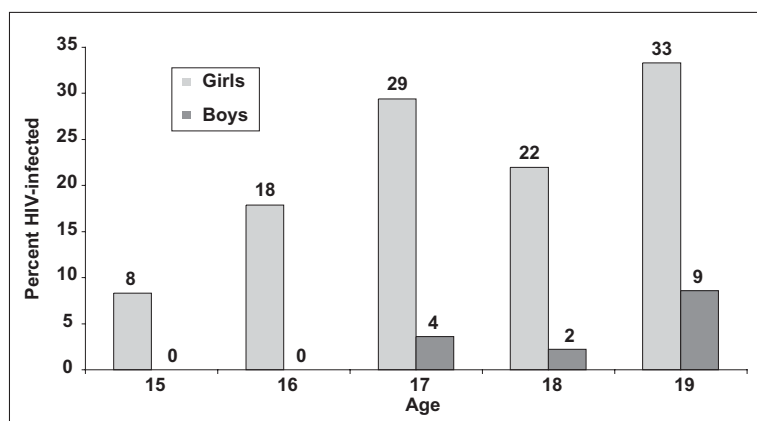
Deciding how to approach a problem is the most difficult area in which to use routine surveillance data, but there are examples – not all that dissimilar from the examples above – in which surveillance data can be used to give a broad-brush picture of what approach should be taken to achieve programme goals.

Box 7. Using surveillance data to decide how to approach a problem: an example

In a country with a well established generalized HIV/AIDS epidemic, a new AIDS Commission was established in the Office of the President. The AIDS Commission was charged with making recommendations about how best to establish programmes to prevent HIV/AIDS among young people. The Commission was asked especially to give an opinion about the controversial life-skills programme in secondary schools, which religious and parents' groups were trying to eliminate.

HIV surveillance data among women at antenatal clinics showed that half of all people living with HIV/AIDS were pregnant women aged 15–24 years. In addition, a study by the national university in one rural area recorded the rates of infection shown in Figure 11.

Figure 11. HIV prevalence among teenagers in the Bundu district, 1998



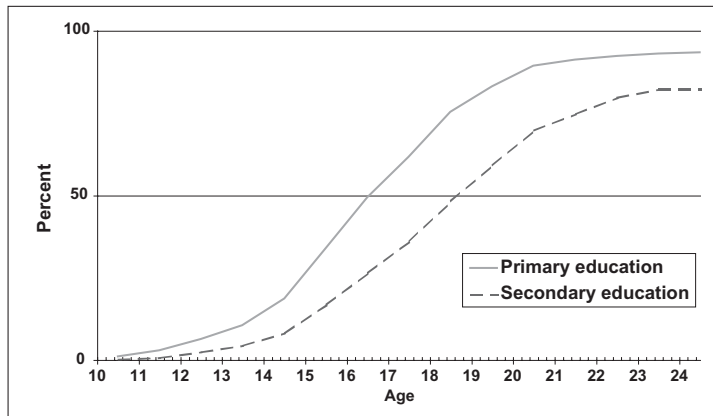
From this, the AIDS Commission concluded that women were becoming exposed to HIV at very young ages. This was confirmed by an analysis of behavioural surveillance conducted in randomly selected households nationwide. In this survey, half of all young women had had sex by the time they were 17, and men started having sex on average a year earlier. About 80% of the sexually active respondents of both sexes had had sex with someone to whom they were not married, and condom use was extremely low.

The Commission drew up a draft report suggesting that, since risk behaviour was more or less universal, there was no evidence that the life-skills education was effective

and recommending that it be discontinued. A member of the Commission who worked at the education ministry questioned this recommendation, suggesting that the analysis did not go far enough. She requested that the data be analysed by schooling status. The analysis, part of which is illustrated in Figure 12, did not support the draft recommendations. Although rates of unprotected extramarital sex were indeed high for all women, they were lower among women who had some secondary education (and who had therefore been exposed to the life-skills programme). When age was controlled for, risky behaviour was highest among women who were still in primary school or who dropped out of school completely before reaching secondary level.



Figure 12. Percentage of women 15–24 years old who ever had unprotected premarital sex according to age and highest level of education attained



Another commissioner suggested that this was particularly worrying in the light of statistics from the education ministry showing that 72% of all women aged 20–25 years had dropped out of school before receiving any secondary education at all.

Based on these findings and other similar analyses, the AIDS Commission changed its recommendation. Since one important aim of life-skills education for young people is to help them delay the start of their sexual activity, it seemed unhelpful to provide that education only in secondary school. After all, the data showed that most people never went to second-

ary school at all. Although unprotected sex among women who had attended secondary school was lower than among primary school dropouts, a high proportion of those who ultimately attended secondary school were sexually active while they were still in primary school. The AIDS Commission therefore recommended introducing life-skills and reproductive health education as a compulsory element in the curriculum in the last 2 years of primary school.

Many countries have similar data available to them either in the HIV surveillance system or from larger household surveys such as demographic and health surveys, which include information on sexual behaviour. Such data are rarely used as effectively as they could be in exploring questions similar to that posed to the AIDS Commission in the example in Box 7.⁷

⁷ The AIDS in Africa during the Nineties series developed by the MEASURE Evaluation Project (<http://www.cpc.unc.edu/measure/publications/?type=sr>, accessed 10 November 2003) is an example of powerful use of such data, especially the reports on Tanzania in 2001, Zimbabwe in 2002 and Kenya in 2003.

Data for programme monitoring and evaluation

Many good documents already exist about the use of surveillance data in evaluating HIV/AIDS prevention programmes.⁸ This publication is limited to a few general remarks in this area.

- **Surveillance systems are not designed to monitor or evaluate specific interventions**

The most important point is that HIV surveillance systems, including their behavioural component, are not designed to measure the success of specific programmes or projects. They measure the combined effect of the national response. Specific approaches to evaluating programmes are outlined elsewhere.⁹

- **Surveillance data can sometimes be used to monitor or evaluate specific interventions**

In some circumstances, however, routine surveillance data can indeed be used to evaluate specific programmes. This is most appropriate where there are very few interventions of any sort or where behavioural surveillance asks questions about a specific programme or intervention (Box 8). For example, if a city has only one needle exchange programme and behavioural surveillance asks injecting drug users about their use of the needle exchange, then the relevant data can justifiably be used to evaluate the success of that programme (for example, by comparing the behaviour of respondents who access the needle exchange and those who do not).

Box 8. Using surveillance data to monitor programme implementation: an example

After seeing a rise in drug use and drug-related crime, a major port city appealed to a donor agency for support in setting up a pilot needle exchange project to try to avert an HIV/AIDS epidemic. The programme began in late 1997, and behavioural surveillance among injecting drug users in the city began the following year. Surveillance data, depicted in Figure 13, showed a clear downward trend in needle sharing in the previous week among participants in the needle exchange programme between 1998 and 2002, while nonparticipants remained as likely to share needles as ever.

Figure 13. Needle sharing among participants and nonparticipants in the needle exchange programme in Thansa

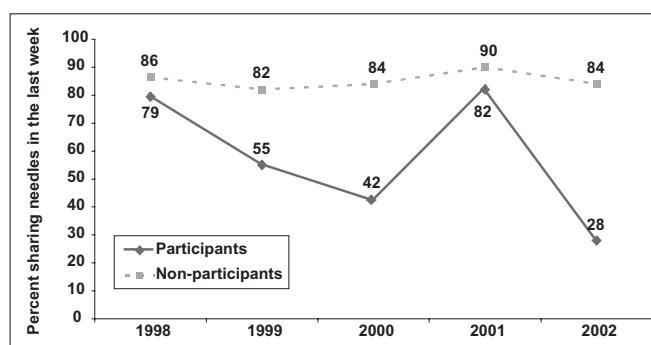


Figure 13 clearly shows that there was some aberration in 2001, but the immediate cause is not obvious. In fact, programme records show that a change of government in the donor country temporarily halted funding for needle exchange programmes but that this was resumed after a few months after strong public health lobbying. Indeed, the lobbying included showing the data from the national surveillance system from 1998 to 2000, to demonstrate that needle exchange programmes reduce injecting risk.

⁸ These documents include:

National AIDS programmes: a guide to monitoring and evaluation. Geneva, UNAIDS, 2000 (<http://www.who.int/hiv/pub/epidemiology/pubnap/en>, accessed 10 November 2003).

Monitoring the Declaration of Commitment on HIV/AIDS: guidelines on construction of core indicators. Geneva, UNAIDS, 2003 (http://w4.unaids.org/html/pub/Publications/IRC-pub02/JC894-CoreIndicators_en_pdf.htm, accessed 10 November 2003).

⁹ Rehle T et al., eds. *Evaluating programs for HIV/AIDS prevention and care in developing countries.* Arlington, VA, Family Health International, 2001.

- **Surveillance data can help to measure programme coverage**

Surveillance systems are increasingly attempting to provide reliable estimates of the size of populations at risk for HIV. These data can be used in conjunction with service provision data to arrive at estimates of programme coverage (Box 9).

Box 9. Using surveillance data to calculate programme needs and coverage: an example

The health department has recently begun working with an NGO to reduce the risk of HIV transmission in commercial sex between men. In its most recent round of estimates, the HIV/AIDS programme estimates that the capital city has about 800 male sex workers. Behavioural surveillance in this population records that only 7% of sex workers ever use water-based lubricant, and the average number of anal sex clients in a week is nine. Programme managers wish to increase lubricant use in all anal sex, because it reduces anal trauma and thus decreases the risk of HIV transmission. But they also want to ensure that water-based lubricant is used, so that the 36% of anal sex acts that are protected by condoms are not subjected to a higher risk of condom breakage.

After 6 months, programme records show that 6000 single-use sachets of subsidized lubricant are being distributed to male sex workers in the city each month. Nevertheless, if surveillance data are used to calculate demand, the minimum figures are:

93% of 800 sex workers not using lubricant	744
Clients per month = 9 per week times 4	36
Unlubricated sex acts per month	26 784

This means that the current programme is only meeting 22% of minimum demand. If the sex workers who were already using lubricant are assumed to have shifted to using the cheaper and more convenient sachets, the shortfall is even greater.

Another more straightforward use of surveillance data to measure programme coverage arises in generalized epidemics, in which HIV/AIDS prevention and care services are aimed not at particular subgroups but at most of the adult population. In these countries, behavioural surveillance is also best carried out through household surveys or other general population surveys, and these provide quite easy measures

of coverage. A country trying to scale up provision of HIV testing and counselling services, for example, might simply add a question to its household survey of HIV-related behaviour asking whether the respondent had requested and received counselling and an HIV test in the previous 12 months. If the survey is a random household survey, coverage would be reflected simply by the proportion of men and women reporting that they had received counselling and testing services in the previous year. Although these indicators are not strictly part of second-generation surveillance, they are derived from the behavioural surveys that form a core component of surveillance.

Trying to use surveillance data to measure coverage has an important limitation, especially for prevention programmes. Except for very concrete and salient examples such as needle exchange programmes, defining “exposure” to interventions can be extremely difficult. Asking young people whether they have participated in any HIV/AIDS prevention activities may provide a measure of those that go to HIV/AIDS clubs, those who designed a poster for a World AIDS Day display at school or those who heard a lecture on HIV/AIDS from their health worker at the youth club. But it will probably not capture those who listen to a radio soap opera with a subplot about HIV infection, those who went to their health centre when they had a cold and got some friendly advice about safe sex or those who listened to a sermon in church urging support for families with HIV/AIDS. Nevertheless, all these things may be part of the national effort to prevent HIV/AIDS. Qualitative methods (such as using rapid assessment methods) and careful pre-testing of questionnaires may improve the ability to measure exposure to specific interventions, but this becomes increasingly difficult as the response and interventions expand. Using routine surveillance data to measure the coverage of prevention programmes poses a real danger of underestimating the magnitude, scope and reach of the national effort.

- **Surveillance data can warn of a reversal in previously successful programmes**

Indicators can move in both directions. An important use of surveillance data is to warn when programme successes are starting to wear off and when risk behaviour and its consequences are rising again (Box 10).

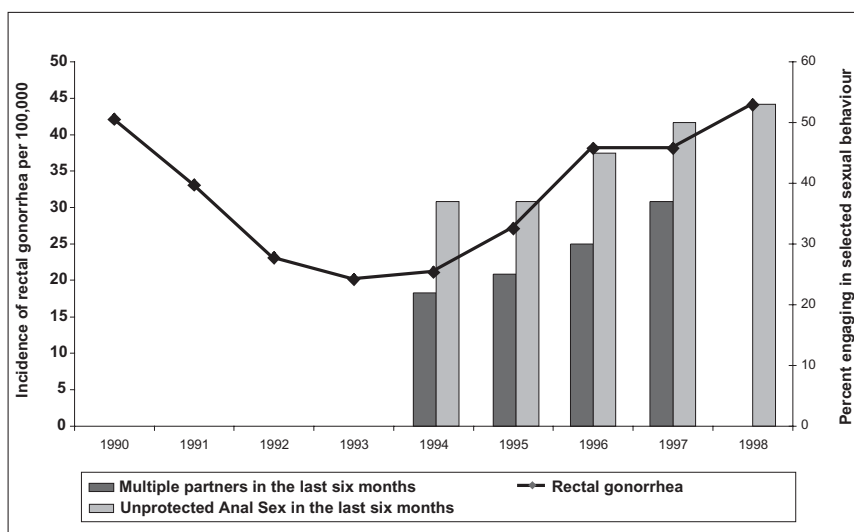
Box 10. Using surveillance to warn that prevention successes are fading: an example

Among the first communities to change behaviour radically in response to HIV/AIDS were communities of men who have sex with men in industrialized countries. As a new generation became sexually active and treatments became more widely available, however, programme managers began to worry that previous successes were being eroded and that unprotected anal sex between men was becoming more common.

The ever greater availability of life-prolonging therapy made measures such as HIV/AIDS case reporting and HIV prevalence hard to interpret. However, many areas with large concentrations of men who have sex with men conduct regular behavioural surveillance as well as STI reporting in this community. These data could be used to investigate suspicions that risk behaviour was rising.

Figure 14 shows the results of this surveillance.

Figure 14. Trends in rectal gonorrhoea and sexual behaviour among men who have sex with men in the 1990s in New Cheshire



The implications were clear: the suspected rise in unprotected anal sex was real. Men reported more risky sex, and with more partners, and the consequences were being measured directly in rising numbers of STIs. Since the background HIV prevalence in this population was high, small rises in risk may lead to significant rises in new infections. These data led to renewed prevention efforts in communities of men who have sex with men in the city from which the surveillance data were collected and elsewhere in industrialized countries.

Data for advocacy

This section gives an overview of some of the principles involved in the effective use of surveillance data for advocacy and then discusses how to package data for specific audiences. Later sections give practical guidance on how to prepare presentations and reports for greatest effect.

The question of packaging

Public health officials too often take a “one size fits all” approach to data use, believing that surveillance work ends when the official surveillance report is published. The report may indeed contain all the important information about levels and trends in HIV infection and related behaviour, but a single report can almost never meet the needs of all the key audiences – policy-makers, programme planners, the private sector, NGOs, affected communities, the general public and others. In the commercial sector, manufacturers of breakfast cereal or cosmetics have recognized that they sell their products better if they package and advertise them differently for different target markets. The same principle should apply to surveillance data. The same data need to be presented very differently for different audiences to be able to sell the messages implied by the data and ensure that they get acted upon.

Successful advocacy (or lobbying, as it is known in the commercial world) follows a number of relatively well defined rules. These are described here, and concrete examples are then given in the discussion of specific audiences.

Choosing the right product for the right audience requires:

- defining your goals
- defining your audience
- finding out what influences their thinking
- using the data to address their concerns
- using the right language
- getting the length right
- choosing the best messenger
- timing it right.

Define your goals

This publication, which is aimed primarily at public health professionals, assumes that its readers can analyse and interpret surveillance data. The first step in effectively packaging these data is to define the goal of any communication. A single round of surveillance data can lead to the formulation of many different goals. Each goal may have to be presented to different audiences in different language.

Define your audience

With whom must public health professionals communicate to ensure that the goals defined are attained? This step involves thinking about all the groups who have to be involved in achieving the stated goal. Who has the potential to push things forward and who could potentially obstruct progress? There is often more than one audience, and each may need to be approached separately, using different information.

Find out what influences their thinking

Once the audiences have been defined, the best way of communicating with them must be found. In advocacy just as in social life, the best communication happens when people have something in common. Understanding the concerns, motivations and objectives of each audience is therefore important.

Use the data to address their concerns

The true art of using data is in finding ways to use the data that address the particular concerns of the target audience. The health ministry may be interested in planning how to provide care for those with HIV/AIDS, whereas the chamber of commerce may be interested in the impact of HIV/AIDS on the workforce. The same data – projections of HIV infection, illness and death – can respond to these two concerns, but they have to be expressed differently for the two audiences.

Use the right language

After the goal, the audience, the key messages that will appeal to them and the data used to make the case are identified, language is important (Box 11). Will confidence intervals mean anything to this group, or will they confuse the picture? Does this group know the difference between incidence and prevalence, or would you be better off using terms such as “new infections” and “current infections”?

Box 11. The same information, different language

- The HIV incidence in the 15- to 19-year-old cohort is high, and the prevalence among 19-year-old women is 33%.
- New HIV infections are common in the late teens; a third of 19-year-old girls are already infected with the virus.
- Hundreds of teenagers get infected with HIV every week. If there are 30 girls in your daughter’s class, about 10 of them will have HIV by the time they graduate.

Get the length right

A report or presentation has no value if no one reads it or listens to it. This means fitting the key information into the time people are prepared to dedicate to it. If HIV/AIDS is a core interest for your audience, they may appreciate being given a full report they can read through and keep for reference. If HIV/AIDS is not a core area of interest, the audience is more likely to digest the information presented in a one-page fact sheet, a short brochure or a presentation.

Choose the best messenger

People listen to the people they trust, and every audience trusts different people: sometimes their peers. The minister for health may be the best person to present surveillance data at the cabinet level, for example, whereas young people will pay more attention to a pop star involved with the national HIV/AIDS programme as an AIDS ambassador.

Time it right

In advocacy, timing is everything. HIV/AIDS is not the only issue on people's agendas. One way of increasing the attention the message gets is to time the release of that message appropriately. Take advantage of events that are already scheduled such as World AIDS Day on 1 December or schedule the release of data to coincide with global conferences on HIV/AIDS, which generate huge interest among the press and public and may involve senior government figures. Avoid clashing with important events that will detract attention from your message: senior political leaders will pay little attention to routine health data if they are in the final stages of an election campaign, for example.

Presenting data to specific user groups

This section expands on the general principles outlined above by applying the principles to specific audiences who may prove to be important for HIV-related data.

Populations included in the surveillance system

Much lip service is paid to returning surveillance results to the populations from whom the data was collected, but this very rarely happens in practice. Neglecting these important audiences is short-sighted for several reasons. Firstly, the very fact that they are included in the surveillance system suggests that they are engaging in behaviour that carries a risk for HIV. Besides having a right to know about their levels of infection, exposure and risk, they are the people who can most immediately act on the data. Secondly, they are better able to interpret the data than most peo-

ple: if the needle exchange data shown in Box 8 and Figure 10 (repackaged appropriately) were presented to an audience of injecting drug users in the city, digging through clinic records would not be necessary to explain the blip in 2001. They would be able to tell you right away that the needle exchange was closed for 9 months, and its clients therefore returned to sharing. Thirdly – and perhaps most importantly – the whole purpose of doing surveillance is to lead to better programmes to prevent the spread of HIV and help cope with its consequences. The more the intended beneficiaries are involved in designing these programmes, the more likely the programmes are to meet community needs and therefore to achieve programme objectives.

A final reason is self-interest from the viewpoint of surveillance managers. Surveillance is an ongoing activity repeated every year or two. It is very difficult to go back again and again to the same communities to draw their blood and/or to ask them questions about their sex lives and drug-taking without ever feeding anything back. The most important thing to feed back to them is improved programming, but that takes time and may not be within the direct control of the surveillance manager. Surveillance staff do, however, have direct control over the feedback of information, which can be both rapid and inexpensive. They can work directly with community organizations to make sure that the results of surveillance are presented to the communities that were the sources of the data. This feedback process should help people learn more about their own community perceptions, behaviour and exposure and should engage the community in a debate about solutions.

In generalized epidemics, in which surveillance data come largely from pregnant women attending clinics, intensive community feedback may not be possible. In these cases, other mechanisms such as village council meetings organized for other purposes may be used to publicize data on HIV/AIDS and behaviour. When the affected population is essentially the general population, the mass media may also be an effective way of sharing surveillance results widely with the communities in which they were collected.

Appropriate language is key for community feedback

In general, the community is the audience whose day-to-day language is furthest from that public health officials usually use. Preparing to present data to this audience involves recasting it into the everyday language of whichever community group is involved. An example for an English-speaking audience: one cannot simply go to an audience of male sex workers and present a graph entitled "Rising prevalence of insertive anal sex among MSW in entertainment spots, 1998–2003". Firstly, lay communities do not commonly use the formal language of public health. Many laypeople (and some public health officials) do not know that MSW means male sex workers;

besides, the sex workers are more likely to describe themselves as rent boys or some local equivalent. Secondly, although all of them know what insertive anal sex means, none use that term on a daily basis to describe their work. Every industry – including the sex and illicit drug industries – has its own terms, and these should be used in communicating data to audiences in that industry. Saying “barebacking” is easier than saying “unprotected anal intercourse with a partner of unknown HIV status”, and more people in the audience will know what you mean and identify with what you are saying. Equally, young women in some countries will quickly understand if a presenter refers to “sugar daddies” but may have greater difficulty grasping the meaning of “partners at least 10 years older than the respondent”.

Appropriate language includes appropriate graphical presentation. Many workers in the sex profession have little or no schooling and may have difficulty in understanding even a simple line graph, let alone a stacked bar chart. One must be creative in presenting data to these groups.

Do you want to show a prevalence of syphilis of 24%? Draw 100 sex workers on a poster and colour 24 of them in red. Do you want to show that 65% of injecting drug users often share needles, 29% occasionally share needles and only 6% never share needles at all? Draw 100 syringes on a poster and colour 65 of them in red, 29 in orange and six in green and label them.

Tact is needed in presenting surveillance results to communities

Presenting data to the people from whom it was collected is a delicate matter. They know better about their community than you do, but people’s perceptions of their own community values and norms very often differ from the reality. A village meeting may not be very receptive to surveillance data suggesting that 57% of the men older than 40 years have had extramarital sex in the previous year with a teenaged woman.

This difficulty can be minimized somewhat by choosing the right messenger. Another approach, which

also contributes towards the important goal of extending community participation in planning, is to invite the audience to interpret and explain the data themselves.

A tactless approach might be to tell the audience: “In this community, 57% of the men older than 40 years are having extramarital sex with teenagers.”

Another approach is to say: “One of the things that is said to fuel the epidemic in some places is sex between older men and younger women.”. Response: “That does not happen here.”. Counterresponse: “Well that was what we thought, too, but we used a standard national questionnaire so we asked about it anyway, and it turns out that more than half of the men over 40 said they had sex with teenagers. Can you help explain why we might have got those results?”.

At this stage, an outspoken female elder may make a contribution, saying that in fact this does happen; remember the case of the schoolteacher’s brother. A lively discussion may ensue. These discussions are a necessary step in changing community attitudes, but they can be very fiery, and a strong community moderator should be prepared to guide the debate.

Community feedback can generate ideas for better programming

The real point of initiating discussion within communities about the data they have contributed to the national system is to draw on their expertise and resources in devising better solutions. The communities to whom the data are being presented are often best placed to identify what needs to be done.

The data must remain at the forefront of all of these debates. “The community” is sometimes idealized and thought of as a cooperative venture in which everyone has equal power, access and voice. This is never the case. Dominant voices may propose solutions that preserve the status quo – the source of their power but also the source of the behavioural norms that need to change to reduce HIV transmission. Any proposed solutions should be checked back against the reality portrayed in the data (Box 12).

Box 12. Data analysis and programme planning by transgender sex workers: an example

A transgender organization in Asia recently applied for funding to run a peer outreach and information, education and communication campaign among transgender sex workers who sell sex to men, based on the assumption that awareness of HIV/AIDS, knowledge about condoms and condom use were low. The application was put on hold pending the analysis of data from a new round of surveillance.

The surveillance results showed that 100% of transgender sex workers had heard of HIV/AIDS, almost all could volunteer that it was an incurable sexually transmitted disease and 96% knew it could be prevented by using condoms in anal sex, although condom use was indeed low. Distressingly, HIV prevalence was recorded at 23%, 17% had active syphilis and over 60% had had syphilis in the past.

These data were discussed with transgender leaders who had collaborated in surveillance, and a community meeting was called. With guidance from surveillance staff, community leaders had drawn up large posters showing 100 transgender sex



workers and coloured them in to represent levels of HIV infection and syphilis. They also drew up posters with 100 penises and covered some in differently coloured condoms to represent different levels of condom knowledge and use.

Transgender leaders were genuinely surprised by the results. Both awareness and infection rates were much higher than they had expected, and they recognized immediately that they had overestimated the need for information, education and communication programmes and underestimated the need for STI treatment and for care and support for those infected. They were especially concerned about care issues because transgender people often have difficulty accessing health services, which tend to be segregated by gender.

At the request of transgender leaders, the posters and other key findings arising from the data were reproduced in book form, which outreach workers used to inform other community members. A community planning process eventually led to the original information, education and communication proposal being replaced by a proposal for a clinic providing specialized services including voluntary HIV testing and counselling and appropriate STI care for transgender individuals. Transgender people are employed in the management of the clinic, and physicians specially trained in relevant sexual health issues and management of HIV-related opportunistic infections provide medical services.

Surveillance system personnel

Those who actually collect the surveillance data – taking the specimens, doing the lab work and implementing the behavioural surveys – must be informed of the results of surveillance. HIV- and STI-related surveillance activities are often added to the duties of already overburdened clinic or government staff. Knowing that their work is appreciated and used will boost morale and may help maintain the quality of data collection work. This is one of the audiences for whom dissemination workshops, perhaps in conjunction with regular activities such as training, can be most useful.

Politicians and policy-makers

The messenger can be as important as the message

Politicians and policy-makers require the right messenger more than any other group. Very senior policy-makers tend to have rather a small circle of senior advisers. These people may be easier to approach than the key policy-makers themselves, and they usually make very good messengers. Reaching the senior advisers can itself be a challenge and may require some creative thinking. Some possibilities: find someone who plays golf with them and recruit that person as an advocate. Approach them when they are at an overseas conference, when people tend to be more accessible. Use channels such as senior officials from international organizations or senior diplomats from donor countries. Following protocol and taking a front-door approach, with all the correct letters and formal presentations may still be necessary, but getting through the front door is usually easier if an informal approach has been made through the back door.

Policy-makers want clear action points

Senior politicians do not want more problems; they want solutions. In addition, they usually have a lot to worry about, and HIV/AIDS may not be high on the agenda. In communicating with policy-makers, pare your message to the bare essentials and tell them exactly what action they need to take. Box 13 shows two examples. Both provide the same information but package it differently.

Box 13. Your 30-second presentation to the cabinet

The low-risk, low-reward approach

HIV/AIDS has reached a worrying situation, entering into an expanded growth phase in a number of populations at risk. These populations are marginalized and highly vulnerable. Political commitment is needed to address the sensitive problems that arise as a result of this developing situation.

The higher-risk, higher-reward approach

One in two injecting drug users in the capital is already infected with HIV, and many are having unprotected sex with sex workers. That means that infection rates will soon rise among sex workers and their clients, and after that among wives and children. We need to protect the wives and children of this country by reducing needle sharing and increasing condom use. The clear first steps are to legalize needle exchange programmes and to lift the ban on condom advertising on television. We urge you to take these steps to protect our country.

AIDS programme managers in the health sector and other sectors

Managers of HIV/AIDS programmes are probably the most extensive users of second-generation surveillance data. Their needs are covered elsewhere in this publication. Even if surveillance data are collected within the national HIV/AIDS programme, the information will not automatically find its way to the key decision-makers within the programmes in the ministry of health or other sectors, such as in education or agriculture, concerned. Sessions must be scheduled for data feedback within the programmes. Programme managers are likely to be interested in much more detailed analysis than other policy-makers. Such issues as coverage and impact are critical to this audience.

The private sector

The private sector is frequently spoken of as a key partner in HIV/AIDS prevention, but how companies,

large or small, can best contribute is not always clear. Nevertheless, surveillance data may be directly relevant to the private sector in several ways.

Talk first to employers in sectors for which you have data

Behavioural surveillance is often conducted among occupational cohorts, such as truck drivers, plantation workers or miners. If the workplace has proven a good place to access people for HIV surveillance, then it will probably also be a good place to access them for prevention programmes. The results of HIV and behavioural surveillance in an occupational group will be of interest to all the companies in that sector and not just the handful that participated in surveillance. Presentation to such employers can lead to clear and direct recommendations for workplace-based prevention programmes and care policies.

“Trade” data for support for prevention programmes

Most companies spend considerable amount of time, energy and money in researching their markets or potential markets. However, very few have the reach and access to marginalized populations that is achieved by the best second-generation HIV surveillance systems. For some companies, HIV surveillance systems offer an unparalleled source of market information. Most obvious are condom and lubricant manufacturers, but pharmaceutical companies and others may also be interested in surveillance data.

Because these companies are also directly or indirectly in the HIV “business”, they are among the most obvious partners for HIV/AIDS prevention partnerships. Presenting them with comprehensive surveillance information in their area of interest (and even performing requested analyses and adding extra questions) can be an invaluable first step in setting up effective partnerships (Box 14).

Focus on financial and public relations concerns

Private companies exist to make a profit. This is what drives them and what dominates decision-making. Data analysis that demonstrates the potential loss to a company or industry because of the HIV/AIDS epidemic is always worth presenting. HIV/AIDS can eat away at productivity, at the workforce, at skills levels and at the consumer base and can leave a big hole in public budgets for health insurance and pensions.

Good public relations are also a concern. Many companies have sound HIV/AIDS policies, including supporting prevention programmes in the surrounding community, because they wish to present an image of social responsibility. If the HIV/AIDS prevention and care programme has high-level political support or is a personal interest of an influential local politician, engaging the support of private companies for the programme is often relatively easy. In this case, political figures can be a good choice as messengers in presenting data and making the case for private-sector involvement.

Some people tend to see the private sector as a source of money. In fact, because private companies always have an eye on the bottom line, money is one of the hardest things to get out of them. Nevertheless, besides supporting HIV/AIDS prevention for their workforce, companies may well be willing to donate services to the fight against HIV/AIDS. For example, soft-drink or beer companies can add condoms to their distribution chains so that they become easily available in every nightclub in the country. Similarly, advertising agencies might make free behaviour change commercials, and radio stations might provide air time for HIV-related programmes.

Respect people’s time and positions and always follow up

The job of the head of a large mining company is to run a firm that delivers ore to its customers and money to its shareholders. Do not expect this person to sit in

Box 14. Market research leads to products wanted by men who have sex with men: an example

One developing country recently added men who have sex with men to the national surveillance system for the first time. The first round of behavioural surveillance found that men were well informed about HIV transmission and about condoms, but there was a massive gap in knowledge surrounding safe lubricants. Most men used saliva or body lotion in anal sex even when using condoms, and very few even knew about water-based lubricants. Those who did know about lubricants complained that they are packaged in large tubes that are expensive and impractical to carry on an evening out, which is when sex is most likely to take place.

These data were compiled together with official estimates of the number of men who have sex with men and calculations of potential market size based on those estimates, together with surveillance data on the frequency of anal sex. A meeting was arranged with the only domestic producer of lubricant, who had until then marketed the product for use in medical situations and for menopausal women.

The manufacturer agreed to package lubricant in handy single-use sachets for men who have sex with men at an agreed price in exchange for the help of the HIV/AIDS prevention programme in accessing that market and in promoting lubricant use.

a three-day workshop on HIV in the private sector or even to meet for an hour with a public health professional. Any requests for such meetings are likely at best to get passed down to the corporate relations or human resources departments. This can be a useful starting-point for communicating with a single company, but it is not where the decisions are made.

Instead, try to communicate with senior executives in settings where they already gather. For example, many countries have regular chamber of commerce or industry association lunches, which are well attended by senior figures because they provide good opportunities for networking. A presentation on HIV in the workforce to such a gathering would be a useful way to introduce key concepts to a number of influential people at once. It also provides a contact list and creates an entry point for follow-up.

The legal profession

In some countries, lawyers have been instrumental in promoting the rights of people affected by HIV/AIDS and the communities to which they belong. Many of the continuing challenges to HIV/AIDS prevention have structural roots embedded in law. Tackling HIV transmission among injecting drug users effectively is difficult when harm reduction programmes are illegal. Reducing the negative effects of infection is difficult if children with HIV/AIDS can legally be excluded from school.

A supportive legal profession can widen the room for effective HIV-related prevention and care in many ways, and these are certain to grow as issues of access to treatment become more acute. The legal profession can also help to create a framework that supports research and protects essential public health functions such as unlinked anonymous surveillance for HIV.

Many of the tips for presenting data to the private sector also apply to the legal profession: be concrete about what you want to achieve, communicate through existing mechanisms such as legal association lunches where possible and do not waste people's time. The content of the message will differ, since lawyers are concerned less with the bottom line and more with procedures, rights, responsibilities and concepts of equity and justice.

Presenting data to the press

Whole volumes have been written on presenting data to the press. This section deals only briefly with some key concepts, and additional information is provided separately (Annex 3).

Journalists: friend or foe?

Many people, especially government officials, are extremely wary of dealing with journalists. Nevertheless, the mass media probably comprise the single most powerful tool to achieve advocacy goals. Television, radio, newspapers and magazines can

reach people that public health officials alone cannot reach. The mass media will carry stories about HIV/AIDS with or without our input. By working with journalists, public health officials can greatly increase the likelihood that information in the mass media is accurate and balanced. The mass media can also help create the political support that allows wider HIV/AIDS prevention and care programmes to work.

In general, then, journalists should be regarded as friends. Developing relationships with trusted journalists from key publications is worth some effort. For one thing, if you regularly provide them with reliable information, they will take much more care to ensure that you are never misquoted and that they reflect your message accurately.

Getting the best from the press

There are some basic rules for getting the best from the press (see Annex 3 for more details).

- Know who is who.
- Always return calls from journalists.
- Respect deadlines.
- Try to give written information, especially for data and names.
- Be clear about attribution and quotation (Box 15).
- Respond quickly to errors.

Box 15. Attribution of quotes and information: an example

On the record

"Our new estimates show that there are almost 2 million people living with HIV in the country, and about 200 000 of them need life-prolonging drugs right now", said Esther Mwambe, Senior Epidemiologist in the National HIV/AIDS Programme. "The trouble is, we only have enough money to buy drugs for around 2000 people. It's a tragedy", she added.

Off the record

A senior public health official said that close to 2 million people are infected with HIV, and one in 10 of them need drugs right now, but the government only has money for one in 100. "It's a tragedy," the official said.

Deep background

Critics say the budget for drugs is not nearly big enough to meet the need.

Using the press proactively

The discussion so far has centred mostly on how to deal with the press if they approach you. The most effective use of mass media to convey important public

health messages and information, including surveillance data, is to actively go to them with the messages. This means actively selling information or stories.

Packaging messages for journalists differs from packaging data for other audiences for one reason. People do not watch television, listen to the radio or read newspapers because they want information. They do it because they want stories.

Here are some points to think about in weaving HIV-related data into a story for journalists (see Annex 3 for more details).

- Make it human.
- Make it positive.
- Make it newsworthy.
- Target your market.

What makes a good press release?

If you hold a press conference or invite journalists to an event of any sort, issue a press release beforehand, and call the newsroom to make sure the press release has been received and the event entered into the news diary.

A good press release contains the following elements (see the example in Annex 4).

- The headline tells the story.
- The dateline includes the city and today's date and precedes the first paragraph.
- The first paragraph contains the most interesting and newsworthy information.
- Any new information is clearly sourced. For example: "Estimates released on Thursday by the National Centre for Epidemiology show ...".
- At least one quotation should be attributed to a senior official or other influential person. "We are saddened by the magnitude of the HIV epidemic in the country, but these new data show encouraging signs that we are winning the battle against new infections among teenagers", said Dr Lai Kwok Jin, head of the National Centre for Epidemiology."
- If data are being presented, the press release should have at least one graphic, with a separate table giving the numbers behind the graphic so it can easily be reproduced.
- There should be a concise and action-oriented conclusion.
- A contact person should be listed who can be reached for further information, with a phone number and e-mail address if possible. This person must exist, must know that he or she is the contact person for this press release and

must be available at the number given for at least the 2 days surrounding the press conference.

- All this should be included in two pages of A4 text or less.

How to hold a press conference

One of the most common ways of interacting with the press is to hold a press conference. Some key things to think about (see Annex 3 for more details).

- Plan ahead.
- Send invitations by letter, fax and e-mail, and follow up by phone.
- Time it carefully.
- Make it short.
- Pick good presenters.
- Think about photo opportunities.

Supplying data to international agencies

A limited but growing number of international agencies maintain HIV-related databases. They include UNAIDS, WHO and its regional offices, UNICEF, the United States Bureau of the Census and a number of universities or research programmes such as the MEASURE DHS Project, MEASURE Evaluation Project and the Synergy Project, which are funded by international organizations to collate international data.

These organizations do not generally require any special packaging: they have staff that can reformat data for their databases if necessary. However, it is worth ensuring that these organizations are on your regular distribution list for any HIV, STI or behavioural surveillance data available.

Supplying information to these organizations is a matter of enlightened self-interest. Many of them are required to make estimates and projections regularly, whether or not they have access to recent, complete and accurate data. If data are made available to them promptly, their databases will certainly reflect the current situation more accurately than if they are working on partial data that are several years out of date. Since many of the large international and donor organizations also use these databases to inform their funding decisions, the more accurately the database reflects the current situation, the more likely resources appropriate to that situation will be made available.

Annex 5 lists important international databases with their areas of interest and contact details.

How to use data effectively: the content

The preceding section discussed packaging information differently for different audiences. Good packaging requires choosing the right content but also presenting it well. Some common rules improve the effectiveness of data presentation, regardless of the target groups for which it is packaged. This section discusses these rules.

Get people's attention

In any report or presentation, the amount of time to get key points across is limited. Making an impact right at the start is important; key pieces of information should be presented before people switch off (Box 16).

Box 16. Does my presentation tell the right story?

If you have thought about your goals and your audience, you should already understand what the key information is. A good way of checking whether you are presenting the right information is to imagine yourself in the following situation.

You have been working late at the office to finish the presentation for tomorrow's meeting with the Working Group on Drug Abuse. You are meeting two friends (who work as accountants) for dinner, and you arrive late. What do you tell them?

You might say: "I'm sorry I'm late. I was finishing up an important presentation for a meeting with the drug group tomorrow." When your friends ask what the presentation is about, you'll say something like this: "HIV has really exploded among injecting drug users recently, and our new data show that half of all injectors are having sex with sex workers. None are using condoms, so unless we get some harm reduction policies in place the epidemic is going to spread to sex workers and clients."

You would probably not say: "We conducted a survey using multiple wave sampling methods among injecting drug users and found that 20% of them are 15–19 years old, 45% are 20–24 years old and 30% are 25–29 years old. Forty percent of drug injectors dropped out of middle school and only 10% finished high school."

Think about what you would say to your friends. You will almost certainly pick the information that is most important and most interesting. This information should appear in the first few slides of your presentation, the first page of your brochure or the first paragraph of your press release.

People who are used to writing scientific papers tend always to describe methods in detail before describing results. This is essential in writing for peers in medical research but is likely to lose an audience of non-scientists in the first few minutes. It is important to document methods. Every report or presentation should have enough detail about methods to allow people to make some judgement about the quality

of the information. But this information does not have to come right at the beginning – the small window in which you have to present key messages.

So what?

Too often, presentations of data simply follow the reporting forms or questionnaires. Because most behavioural surveillance questionnaires begin with sociodemographic variables, many data presentations begin with graphs showing the age distribution of respondents or other background information that may be useful for analysis but does not necessarily have any stand-alone interest.

An audience looking at a slide should react to the information in it. A good presentation of data will elicit: "I never would have guessed it", "I can't believe it", "That's very worrying", "That's not as bad as I thought it might be" or "Thank goodness for that". The very worst reaction is for someone to look at a slide or graphic and say "So what?". Nevertheless, keep in mind the objective that you have in presenting the data; picking sensational findings that have very limited programme relevance (because they are only relevant to a tiny fraction of the population, for example) just to get a reaction from the audience would not be advisable.

Develop a narrative

It should by now be clear how to identify the objectives and key messages: the story the data tell. Presenting key elements of the story very early on to get people's attention is usually a good strategy. Nevertheless, as anyone who reads good fiction knows, narratives or stories can develop in different ways. Data can also be used in a narrative way, to lead people through a series of thought processes towards an objective (Box 17).

One example of this was in Box 6: determining what to do about low condom use. Each bar on the graph represents one element of the story, and each examines assumptions about why people do not use condoms in commercial sex.

Box 17. Telling tales: an exercise in developing a narrative

For many years, the official government policy has been to promote a prevention programme that centres on ABC: Abstinence, Be faithful, use Condoms. However, because of political sensitivities, condoms are only promoted in all-adult settings such as beer halls. Prevention efforts among young people have centred on creating awareness and on promoting abstinence until marriage, followed by mutual monogamy.

New analysis of a household survey among young people has led to a re-evaluation of this policy. Using the data in Table 7, you have been asked to make recommendations for any necessary changes in policy to the parliamentary commission on youth welfare.

Table 7. Data on knowledge, attitudes and sexual behaviour from a household survey among people 15–24 years old

	1990		1995		2000	
	Women	Men	Women	Men	Women	Men
	n = 2463	n = 1896	n = 2061	n = 1560	n = 2974	n = 1954
Knows AIDS	97.0	96.8	98.2	100.0	99.0	99.1
Can name three correct ways of preventing HIV infection	NA	NA	0.9	1.9	4.5	2.6
Can name at least one correct way of preventing HIV infection	34.5	28.6	72.2	69.5	66.5	80.5
Knows that a healthy-looking person can have HIV	19.7	17.2	73.6	62.7	74.1	80.2
Has no major misconceptions about HIV	6.2	8.1	26.0	27.6	79.3	79.5
Can name at least one correct way of preventing HIV infection and has no major misconceptions	4.0	5.2	21.7	19.8	54.9	66.6
Used a condom during last sex (of single people who have ever used a condom)	54.0	70.2	45.1	68.1	49.9	66.1
Used a condom during last sex (of single people who have had sex in the past year)	6.2	12.8	9.3	28.4	14.8	42.4
Used a condom during last sex (of single people with multiple partners in the past year)	7.0	34.2	14.2	38.1	16.0	43.6
Used a condom during last sex with a extramarital partner (of married people with an extramarital partner in the past year)	2.1	17.0	3.1	40.0	5.3	51.6
Used a condom during last sex with a non-marital partner (of all young people)	1.8	7.2	2.6	16.1	3.2	23.9
Recent unprotected sex with a non-marital partner	24.1	42.5	21.6	43.5	18.7	31.7
Sexually active by 15 years of age	11.8	24.6	15.2	27.7	14.5	32.8
Sexually active by 18 years of age (of those aged 18+ years)	49.0	64.8	51.5	72.8	53.0	69.4
Median age at first sex	16.9	16.1	17.2	15.8	17.2	16.0
Ever had premarital sex	46.0	55.2	52.0	60.1	50.1	67.3
Had premarital sex (of those ever sexually active)	72.4	85.7	78.1	98.2	78.2	97.8
Had premarital sex in the past year (of those still single)	39.6	49.2	38.9	53.2	32.4	57.9
Average years of premarital sex (of those already married)	2.0	3.8	2.2	5.4	2.2	5.7
Sex with more than one partner in past year (of single people having sex in the past year)	23.3	51.9	17.3	50.9	13.1	51.6
Sex with more than one partner in the past year (of married people having sex in the past year)	4.7	38.9	2.5	29.8	1.6	29.8
Sex with more than one partner in the past year (all young people)	7.4	26.6	4.6	44.1	3.1	29.1
Ever used a condom (of singles who have ever had sex)	18.4	25.8	12.1	52.5	17.0	60.2
Ever used a condom (of singles with more than one partner in the past year)	38.2	41.5	17.2	58.5	30.9	68.1
Feel at moderate or high risk for HIV infection (of those having recent unprotected sex)	14.4	26.9	47.1	65.8	37.1	28.8

Think about the key message of these data. How you would use these data to build up a story?

When you are ready, see Annex 1 for some suggestions.

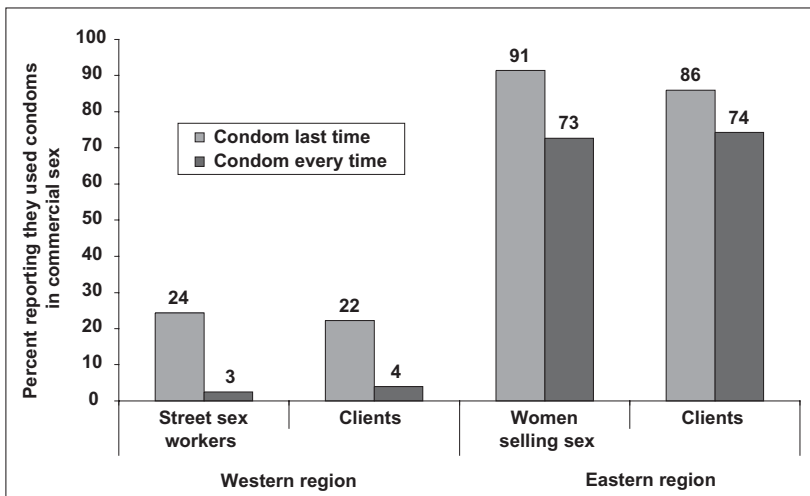
Anticipate reactions

One of the tricks in developing a story line is to anticipate how people will react to the data and to integrate the answers to their questions or concerns into the text or presentation. The condom story above uses this technique to an extent, by walking through the sequence of explanations that many people have in their heads based on common assumptions about the knowledge and behaviour of young people.

The technique can also be used more aggressively. If an audience is known to have a certain belief that is not supported by the evidence, addressing it directly before they can raise objections is sometimes worthwhile. For example, many audiences, notably those with a background in clinical medicine, strongly distrust behavioural data of any sort, because these sorts of data are very hard to validate.

People making reports or presentations based largely on behavioural data would do well to convince the audience that the data are worthy of attention before presenting the data. Raise the issue of data validity early on and acknowledge that it is problematic. Then show a graph demonstrating the internal consistency of the data. Figure 15 – made from real data – shows very clearly that different groups in the same region, questioned separately, give very similar responses about levels of condom use, increasing the confidence that the data reflect true differences between the two regions included in surveillance.

Figure 15. Self-reported condom use in eastern and western Karansia, 2001. Sex worker reports are very consistent with client reports.



If you are giving a presentation to an audience that will have an opportunity to comment or ask questions, anticipating issues and having answers ready is also worthwhile. In a country where newspapers have recently been full of a controversy over whether HIV can pass through the gaps between molecules in a latex rubber condom, for example, prepare a graph that shows the results of studies demonstrating condom effectiveness. If the issue arises, show the graph, end the discussion and move quickly back to the key issues.

Use data from other countries and sources to fill gaps

This publication is written as though readers work in countries in which the surveillance system produces perfect data meeting every local advocacy need. This is never the case. When local surveillance data are presented, data from other sources, including other countries, can be used to help fill in any important gaps as long as the source is made very clear.

Using data from other countries can be especially effective in settings with very low prevalence, where surveillance systems have recorded very little HIV infection. If behavioural data show similarities in risk profiles between a country with a relatively new exposure to the virus and one with a much more advanced epidemic, they can be used in conjunction to warn of what might potentially happen if no action is taken.

How to use data effectively: the presentation

This chapter gives guidance on the physical presentation of information to achieve the greatest impact.

Use headlines for impact

Most people who work in public health can look at a graph or a table and understand what it means, but many people in other fields cannot. In graphics, tables and presentations, headlines should be used to tell people what the data mean rather than simply describing the data.

Consider the two graphs in Figures 16 and 17. They are virtually identical, but the caption and labelling differ. Figure 16 is labelled with a caption, in the usual manner, giving a classical description of the contents of the graph. It uses jargon familiar to scientists (variable A by variable B) but does not explain what the data show or what they mean.

Figure 16. Percentage engaging in commercial sex in the past 12 months according to condom usage status among two populations of male injecting drug users in Da Tan, 2002

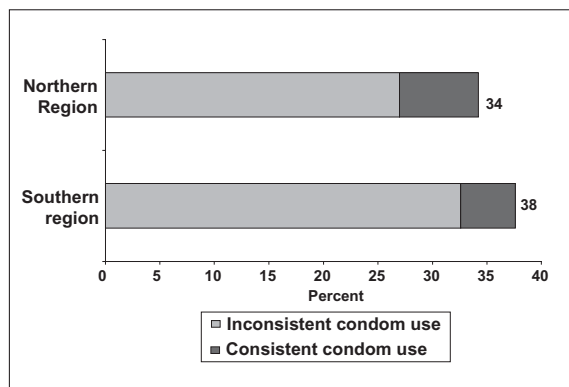
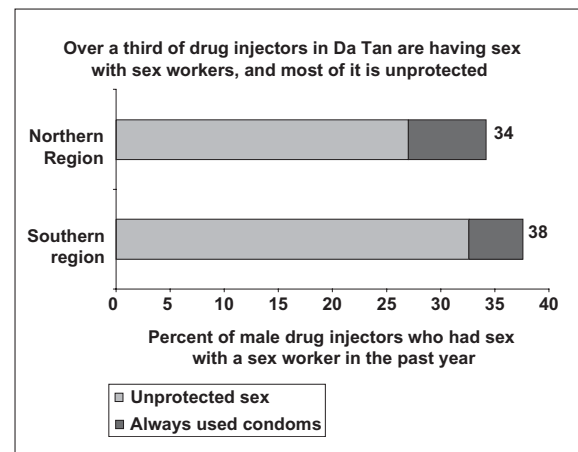


Figure 17 uses everyday language in both the headline and the legend to reinforce in viewers' minds the key message of this graph: this behaviour has a high risk of HIV transmission.

Figure 17. Percentage of injecting drug users in Da Tan who visited sex workers in 2001, showing the proportion who had some unprotected sex



This approach can be problematic. Graphs like this are often prepared for presentations, and the presenter can do the job of actually filling in the detailed description of the data. In a document, the details can be given in the surrounding text. But if this graph is cut and pasted out of context, important information might be lost. One way to minimize this risk is to label the axes with as much of the descriptive detail as possible, as in this example. Another approach, adopted throughout this publication, is to use a news-like headline but also to label the figure with a more complete description of the contents of the graph. If the information in a table or figure has any important limitation, make sure that this is noted on the figure itself. Otherwise the caution will get lost as the figure is reproduced and will eventually lead to misinterpretation of the data.

Use graphics wisely

The headings on charts are very important in helping people to understand and interpret their content, but many other aspects of charts are also very important in contributing to data communication.

The fundamental rule is to keep it simple.

Avoid chart junk

Every element of a chart or graph should impart information. If a chart element does not add to the understanding of the data portrayed, delete it. This includes many of the elements that feature as defaults in the most commonly used software packages, such as frames, background shading of the chart area and gridlines across the chart.

Creative use of colours

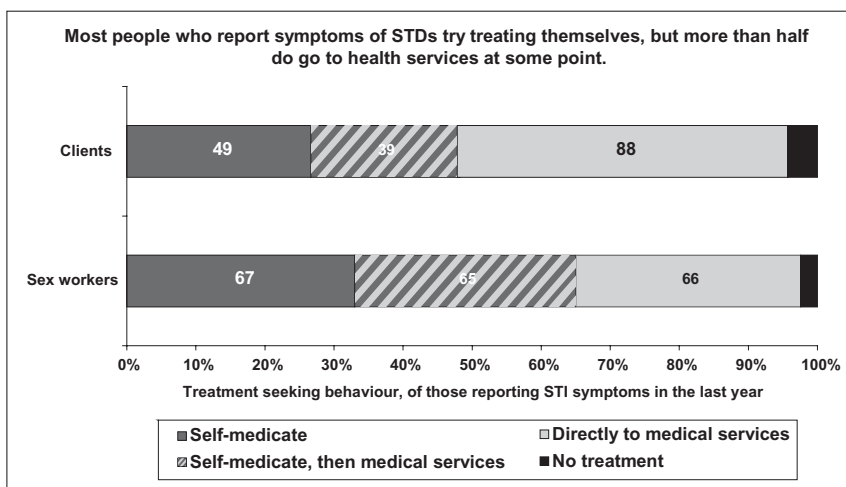
Colours can be used to impart extra information on a graph. In general, try to use a consistent theme throughout a document or presentation and use colour codes that are commonly understood. If your data are portrayed in maps, use conventions such as blue for water, green for forest and yellow for desert.

In portraying HIV-related behavioural data, think about an appropriate colour code. Figure 17, for example, could use dark grey for relatively safe behaviour and dark grey for relatively risky behaviour (following the Western conventions that red means “danger” or “stop” and light gray means “safe” or “go ahead”). One reason that Figure 17 is more effective than Figure 16 is that the eye is drawn to the light grey, and so the viewer focuses on the “dangerous” activity. In Figure 16, the “protected sex” section is a much stronger colour, and attention focuses on that area, even though it is smaller than the other part of the bar.

If you are making a presentation or preparing a document that will be published in colour, avoid using “patterns” in the colours on the graphs – they distract attention from the facts without adding extra information.

As with all rules, there are exceptions. In Figure 18, one of the blocks uses a patterned colour code, but it was not chosen randomly. The “patterned” block is a mixture of dark grey and light grey. The dark grey block is those who self-treated, the light grey block is those who went straight for health care, and the patterned block is, logically enough, those who tried self-treating, and then went to health services when it failed. In this case, the pattern carries information about the population and makes the graph easier to understand.

Figure 18. Treatment-seeking by sex workers and their clients reporting STI symptoms in the past year in Punto Azul, 1999 (the numbers in the bars are the actual numbers of people in each category)



Data labels

Putting numbers (data labels) on graphs is generally useful. This allows people to refer to numbers precisely and facilitates reproducing charts accurately if this is necessary. However, because too many numbers can clutter up a graph and block the clear presentation of data, showing only the useful information is key. Consider again Figure 17. The point was to show that a high proportion of injecting drug users also had sex with sex workers. A data label at the end of each bar therefore shows the exact proportion. To illustrate how high the risk is, Figure 17 also shows the high proportion of insufficiently protected sex. However, in this instance it is not important that the audience knows exactly what proportion of sex is insufficiently protected: they can quickly see that it is a significant majority. Figure 17 does not, therefore, show data labels for the “insufficiently protected” section of the bar.

In most of the examples given in this publication, percentages on graphs are rounded to the nearest whole number. Because surveillance data generally carries quite wide margins of error, numbers shown to one or two decimal points may give a false impression of the precision of the information. Thus, members of the audience who know that such precision is false may begin to question the validity of other parts of your presentation.

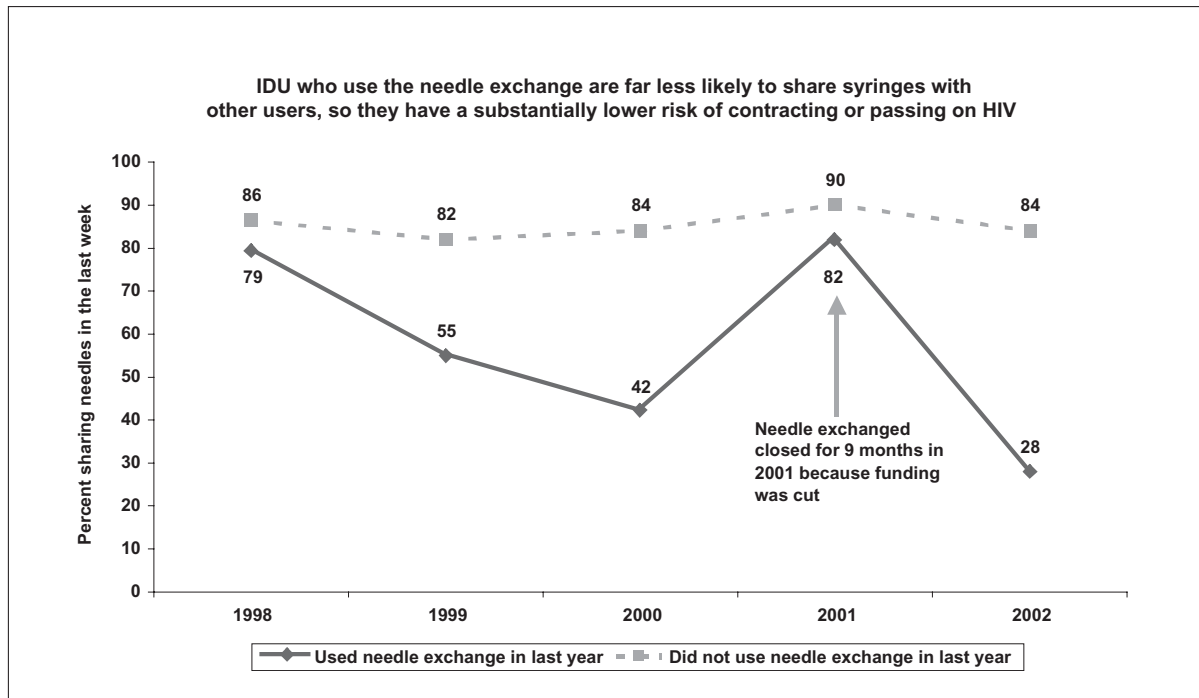
Text boxes, arrows and other highlighters

Sometimes attention must be drawn to a specific point on a graph or some unexpected departure from a trend must be explained. One way of doing this is by varying data labels so that the most important ones stand out. For example, make them bold or put them in a different colour. Another way is to add text or data arrows directly to the graph.

Look back at Figure 13, which used data on injecting behaviour to help to evaluate the effect of a needle exchange programme. The text noted that “Figure 13 clearly shows that there was some aberration in 2001, but the immediate cause is not obvious.” It took an investigation of needle exchange programme records to determine that the programme was temporarily shut down after funding evaporated. Now the data are available, and they can be added

¹⁰ Readers interested in more information about good graphics are strongly recommended to read: Tufte ER. *The visual display of quantitative data*. Cheshire, CT, Graphics Press, 1983. Tufte coined the phrase chart junk.

Figure 19. Needle sharing among those who did and didn't use the Da Tan needle exchange, 1998 - 2002



directly to the graph (Figure 19) to make an important advocacy point:¹⁰

Presentation software

Software packages that allow presentations to be made and projected overhead, such as Microsoft PowerPoint, are now a standard tool in public health. This software has made it very easy to create slides and templates embellished with logos and other decorative elements. They also allow for visual effects such as “flying” headings and blinking data series.

These elements do not generally add any information to the data being presented; on the contrary,

they can be very distracting. They are best avoided, except when they add value. An example might be in presenting a slide of Figure 6. When constructing the “condom story” that this graph represents, it would be useful to be able to bring in the data series one at a time, as the story unfolds.

If these guidelines produce a presentation that sounds very austere, it can be livened up with photographs or other light relief on slides between the data slides. The important thing is that, when the audience is looking at the actual data, they should not be distracted by bells and whistles that add no information.

Starting comprehensive data use: a meeting on interactive data analysis, planning and advocacy

This publication has covered a great deal of ground, encompassing what appear to be disparate issues and varied audiences. Practically, how can a small and overstretched surveillance or public health staff put all these things into practice?

It does not all have to be done at once. Good data use cannot be achieved in a half-day, one-size-fits-all dissemination workshop. Data use is an ongoing process, some of which is largely opportunistic and depends on local needs, opportunities and resources.

The different data use activities do not all have to be entirely separate, however. This section describes a potential starting-point for a data-use meeting that, over a 3-day period, covers many of the activities and uses mentioned previously and sets the stage for several more (Table 8). This format is by no means a prescription. It was devised for one specific setting – a relatively affluent urban province in a decentralized government structure – and it may translate poorly into other settings. It is included here to provide ideas about the various things that can be achieved in a single, well planned data-use meeting. It requires a great deal of preparation, with previous compilation of data

from the surveillance system (HIV, STI and behavioural data) but also other sources where possible: census data, estimates of the size of risk populations, data from health surveys such as demographic and health surveys and other health information systems (such as data on tuberculosis and hepatitis and on service utilization). It also assumes that meeting organizers are prepared to work hard during the meeting, spending evenings summarizing the day's proceedings and analysing data to resolve unanswered questions.

The main focus of this meeting is the use of data in planning and evaluating programmes at the local level. The core participants are therefore public health workers, local HIV/AIDS control board members, community members and NGOs, government departments and other agencies that provide services for communities at risk and members of the security services (such as the police), which strongly influence the local conditions in which HIV/AIDS prevention and care programmes operate. On the third day, the audience changes to become policy-makers, and the presenters change too, to meet the needs of that new audience.

Table 8. Proposed format for a 3-day meeting on using surveillance data

Day 1		
Activity	Presenters	Audience
Interactive data presentation	Surveillance and public health staff and NGO staff	Other core Participants
Summary of key points	Designated core participants	Other core participants
Debate about priorities	All	
Day 2		
Unanswered questions	Surveillance staff	Other core participants
Summary of priorities	Public health staff, NGO staff and community representatives	Other core participants
Planning around priorities	All	
Day 3		
Summary of action plan	AIDS control board staff	
Formulation of messages	All	
Finalization of presentation	All	
Rehearsal of interactive presentation	Designated public health and NGO staff	Other core participants
Presentation to policy-makers	Designated public health and NGO staff	Senior local policy-makers and donors
Press conference	Senior policy-maker, supported by designated public health and NGO staff	

Before the inevitable opening speeches common at such public-sector meetings in many countries (not shown in the table above), participants should be given five minutes to fill in a very simple multiple-choice questionnaire asking them about the HIV/AIDS situation in their city – questions such as which sub-population is most affected by HIV in terms of prevalence, which is most affected in terms of numbers, which behaviour accounted for most new infections in the past year and what the level of condom use in extramarital sex was in the past year. Before the meeting starts, a spreadsheet should be set up to display the data graphically, so by the time the opening speech is over the data have already been entered and “analysed”. This means that they can be shown at the start of the data presentation to give an overview of the assumptions that participants are bringing to the meeting, before having seen the data. This provides very useful information for later discussion but it is also a good, practical example of data use in action.

Activity 1: present data interactively

The crucial starting-point for the meeting’s real business is presenting the new data. The data presentation should be put together using many of the principles of analysis, packaging, story development and presentation discussed previously. One successful model is to have a two-person team presenting the data. An official from the surveillance bureau (usually the HIV surveillance manager or the like) presents most of the data, and a colleague from an NGO or one of the affected communities acts provocatively, raising questions about the data and prompting the audience to think more deeply about them and to give reactions right from the start of the presentation. The dialogue between the two members of the team must be carefully planned and rehearsed if it is to succeed.

This two-person method has several advantages. It holds people’s attention better than a single, monotonous presentation by one person, and this is important in presenting large amounts of quite technical information. It creates an atmosphere of questioning and provides many opportunities to prompt audience members for responses. This seems to work quite well even in hierarchical cultures in which public debate is generally rather limited.

Having one of the presenters on the team be from outside the government provides an opportunity for raising controversial issues and viewpoints that arise from the data without the official who is actually controlling the data presentation having to raise them himself or herself. Finally, the two-person method allows the story to be developed in line with the presentation, because the second presenter can raise the explanations, assumptions or objections that allow for smooth transition to the next slide.

Having surveillance data sets and a data analyst available at this point is a very good idea. If the presenters

cannot answer the audience’s questions immediately, the data analyst can often crunch the numbers and give a data-based response before this discussion moves on. This is useful because it makes the debate more informed but also because it encourages people actively to examine the data for answers to questions that arise in discussing programme priorities.

Meeting organizers should have handouts with hard copies of the data presentation printed and ready but not distribute them until the presentation is over. Participants should give their full attention to the slide that is currently being shown and discussed and not be glancing through the presentation in a printed handout.

Activity 2: summarize the key points

After the interactive data presentation, which may take much of the first day depending on how many data are available and the level of debate, participants should try and summarize for themselves what they consider to be the key epidemiological and behavioural points arising from the data: what are the key issues? This can be done individually or in small groups. Whichever method is chosen, participants should understand that they are being asked to select the issues illustrated by the data that define the existing challenges in HIV/AIDS prevention or care and that suggest potential solutions.

Activity 3: debate priority action

The main purpose of all surveillance systems is to provide solid evidence on which to base decisions about action. After individuals or groups have discussed what they think the key evidence and thus the key issues are, the next step is to discuss what the key evidence implies for programming: what should be done about it?

The summary of the key information points leads directly to a group debate about priorities. People from different sectors, communities and backgrounds inevitably have different views on what the priority action should be. Even people who reach easy agreement on what the problem is often have very different views on what should be done about it. A working group might look at all the available data and agree that one of the key pieces of information is that sex workers in brothel complexes are far less likely to use condoms with clients than are sex workers in upmarket night-clubs. So far so good. In the debate about priority action, one participant says that this obviously means that more peer outreach is needed for sex workers in brothels; another says that it is essential to start promoting condom use among men in well paid, mobile, blue-collar occupations who are the most common clients of brothel-based sex workers; a third maintains that the obvious solution is to burn down the brothel complexes. A fourth participant says these data are of little importance because the clients are all from a

different province and therefore not the responsibility of the local health department anyway.

This is a good time to try to foster a common understanding of the facts and to correct any remaining misunderstandings or misconceptions – hence the need for facilitators with a good grasp of the data.

Activity 4: clarify unanswered questions

Some of the points arising in discussion may be difficult to analyse on the spot; they may require recoding or data manipulation. This can be done overnight, and any unanswered questions can be clarified at the start of the second day.

Activity 5: summarize priorities

The second day should begin by summarizing the priorities for action participants identified the first day. This is not feedback on group work but a single, coherent summary of the priorities identified by the group as a whole. This short presentation can be prepared overnight and forms the basis of the core planning activity that follows.

Activity 6: planning around priorities

Participants have now decided what the key issues are (based on the evidence in the surveillance data) and have identified some priority areas for programmes to resolve those problems. Nevertheless, more concrete plans are needed if these vaguely identified strategic priorities are to turn into effective prevention and care programmes. The debate should move from “What is the problem?” and “What should we do about it?” to “How should we do it?” (Box 18).

These debates are an essential part of the process of moving from data to planning, because they allow people to find synergy and common ground in their work towards a common objective. They also allow for a rational discussion of comparative advantage in what is often a rather competitive field.

The debate can benefit from taking place in small groups, which can be chosen beforehand to bring together specific individuals or organizations who may discover opportunities for cooperation. Again, technically sound and credible facilitators are essential to keep these discussions on track.

Box 18. Data analysis and planning in action: an example

Data were presented showing that condom use is extremely infrequent in commercial sex. Only 25% of sex workers reported having experienced symptoms of STIs in the past year, and of those, only half sought any health care treatment. However, 73% said they had received an injection in the past month “to prevent STIs and HIV”. The health department used to give regular penicillin injections to sex workers, but the programme was discontinued some years ago because it was not effective in controlling the most common STIs. STI surveillance showed that 48% of sex workers were currently infected with an STI.

Meeting participants identified as key evidence the fact that the prevalence of asymptomatic STIs was high, treatment-seeking was limited and ineffective injections were continuing, possibly giving sex workers a false sense of security and discouraging condom use.

In small group work, the health ministry official suggested that a priority activity was to train nurses at primary health centres in the syndromic management of STIs. A representative from a sex worker organization argued that this would be useless, since sex workers do not attend primary health centres. The group requested that the data analyst give them more detailed data on treatment-seeking behaviour. The detailed analysis, which a surveillance worker did on the spot, revealed that the sex worker was right: only 6% of those reporting STI symptoms sought treatment at a primary health centre, about the same proportion as went to a clinic in the brothel area. Forty percent went to private physicians, and half sought no treatment.

At this point, another group member, head of the local medical council, himself an STI specialist, complained that private physicians were handicapped because no national guidelines on the syndromic management of STIs were available. The health ministry official was amazed by this, pointing out that syndromic management guidelines had been published more than a year previously. He offered to try to arrange for health ministry staff to provide training sessions for private-sector physicians in syndromic management, and this offer was quickly accepted.

A participant from the social affairs ministry then pointed out that half of sex workers got no treatment at all, mostly because they did not want to go to public clinics and could not afford to go to private physicians. She objected that extra training for private physicians would allow them to increase their fees and benefit even fewer sex workers. Here the sex worker representative came up with an idea: if the health ministry would provide proper training to private physicians, then outreach workers could refer sex workers to these physicians. In return, the physicians would agree to provide syndromic management of STIs in accordance with national standards at an agreed price.

After some initially heated debate, this planning group managed to come up with a win-win solution to a priority problem.

Activity 7: summarize the action plan

The action plans that participants develop can be summarized at the start of the third day to ensure that everyone agrees before going public. This summary might usefully be presented by someone who represents a broad range of the participants, such as a senior member of the multisectoral HIV/AIDS control board.

Activity 8: formulate key messages

The rest of the meeting should be dedicated to communicating the key information and decisions to other audiences: first policy-makers and then the press. All participants should be involved in packaging the material for these different audiences. Depending on the circumstances, separate presentations may be warranted for policy-makers and the press conference. Even if the same presentation is used, the speakers at the press conference need an outline of key messages and very few essential statistics. Summaries of the final presentation may be given to policy-makers, and a press briefing sheet is almost certainly needed, even if a press release was issued earlier.

In practice, the discussions of the first two days will clearly show what participants consider to be the key data points and what they have decided to do about it. This means that draft key messages can be prepared overnight after the second day and discussed and finalized at this stage. The other materials can also be prepared in draft and adjusted as needed based on these final discussions.

Remember that this presentation is for people who can decide whether the programmes that have been planned are to be implemented. Be direct in telling them exactly what you need from them to succeed in combating HIV/AIDS and its impact.

Activity 9: finalize the presentation

The final presentation should be prepared in draft form overnight. Slides that summarize the action plan will still be required, and other changes may also be needed in the light of the final discussions.

Activity 10: rehearse the presentation

The presentation should not normally last more than 15–20 minutes, should be given by meeting participants and may follow the same two-presenter format as the data presentation on the first day. The same presenters could be chosen, or the group may nominate other participants who have been especially engaged and eloquent during the meeting. Whoever is chosen, and especially if the two-presenter format is used, rehearsal is vital. The presenter or presenters should rehearse it once by themselves or with a facilitator and once for the rest of the participants. This provides practice in presenting while allowing meeting participants to ensure that their discussions are being accurately represented.

If the presenters are not very experienced at speaking to audiences of senior policy-makers, speaker-notes prepared with the presentation may help. The rehearsal should allow the presenters to give the presentation without referring to the notes, but having them there is always comforting.

Activity 11: present the key messages to policy-makers

Senior policy-makers (such as cabinet ministers, provincial or district governors and members of parliament) are invited for the final session only and are presented with the key messages: the essential data, the priorities that arise from the data and the priority action planned. The most important message is what they can do in very specific terms. Remember that these people have full schedules. You may have to plan the meeting several months in advance and time it to fit their availability.

Activity 12: hold a press conference

Ideally, the press conference would feature the most senior policy-maker to attend the final session together with one or two meeting participants (at least one, if possible, from one of the most affected communities). Discuss this with the policy-maker's office in plenty of time and ensure that this person is well briefed and has clear talking points. Offer to provide presentation materials if necessary. In the briefing notes, include a section detailing controversial questions that the mass media might raise and suggesting appropriate answers.

Publishing a national report on HIV/AIDS

This publication has mentioned the idea of a national report on HIV/AIDS in many places. There are many other ways to present surveillance data in printed form. For example, some audiences want small pamphlets focusing on their particular interests. Nevertheless, many countries (including most industrialized countries) regularly produce a comprehensive surveillance report that is intended to compile all the key data. Surveillance reports are invaluable, but they are often dry and somewhat technical documents whose primary audience is people in the health sector. They generally do not tell the story of the epidemic in a way that grabs the attention of the press, finance ministries and donors, or people who have a broad human interest in the epidemic rather than a technical interest.

In recent years, some countries have started to produce national reports on HIV/AIDS that look very different. They contain all the latest data but weave these data into a story that puts the spotlight on emerging issues and key challenges and interpret the data rather than just reporting it. They tend to be professionally designed, with attractive layout and high-quality printing, and are often launched to the press and the public by senior figures on public occasions such as World AIDS Day. In several countries, reports of this type have drawn public attention to the HIV/AIDS epidemic and led to a significant increase in the financing of HIV-related activities.

This publication has already covered most of the key issues in developing a good national report on HIV/AIDS in previous sections. This section simply gives annotated checklists – one for content and the other for operations – with some practical tips about issues to think about in planning and publishing a national report on HIV/AIDS.

The report described here goes beyond the needs of a regular surveillance report. In countries in which the epidemic is not changing very rapidly and public attention does not need to be drawn to important changes in the situation, producing a comprehensive report for public consumption every year may not be necessary. Countries may choose to produce a report every 2 years much like that described below to coincide with a biennial global or regional HIV/AIDS conference and to publish a more limited report focusing exclusively on surveillance results in the alternating year.

Content: what to put in a national report on HIV/AIDS

Who exactly is the audience for this report?

You cannot be all things to all people. Mixing technical audiences – who want details of sampling methods and confidence intervals – with general audiences

who want to know why HIV/AIDS is an issue for them is especially difficult. For this type of report, accept sacrificing the first audience in favour of the second.

What message do you want to communicate?

What is the story? This should flow more or less directly from the data you have to report.

What data do you have that tell the story?

HIV and behavioural surveillance data are normally available as well as STI surveillance data. Data may also be available from a national estimation process, research studies, household surveys (such as a demographic and health survey), programme evaluation and the private sector (such as data on condom sales). A decision has to be made about whether to confine the national report to data from the national surveillance system or to use these other sources of data. All credible data should definitely be used, but understanding the sources of different data is important.

Many classical surveillance reports start with information about the number and distribution of reported AIDS cases, and also include HIV case reports. This is largely a relic of the days before good second-generation HIV surveillance systems were established. The value of these data depends on a country's surveillance system. Except for a few industrialized countries with very strong health systems, HIV case reports are very fragmentary. AIDS case reports may be more reliable, but they reflect the development of the epidemic a decade ago and not now. Since the national report is intended to tell the story of the current epidemic, using data that more accurately reflect the current situation, such as HIV sentinel surveillance data, is very much preferable. Try to avoid using both: it confuses people and leads to claims that the government is trying to play down the epidemic by using case reports as the "official" figures while knowing full well that case reports represent only a fraction of the infections.

How should the report be structured?

The structure of the report depends on the nature of the epidemic and the story being told. A report may be structured around risk behaviour, describing how each type of risk behaviour is contributing to the national epidemic. It may be structured around a story that progresses logically through different prevention options. It may be structured geographically. The structure of the report should be clearly decided before writing begins.

What other elements should be included?

Most of the report will focus on the current epidemiology of HIV/AIDS in the country, and it will almost certainly include graphics showing key pieces of

data and perhaps tables. Every report should have acknowledgements and references. However, other elements may also be desirable. Information on the socioeconomic background of the country or a specific area may help in interpreting the data and may be especially important if the report is intended in part for foreign audiences such as donors. Human-interest stories, which tell the story of the epidemic from the viewpoint of an individual affected by HIV, can help break up the presentation of data and make the epidemic more real to readers. Some countries include case studies of successful interventions and programmes, which give readers a sense that something can be done and indeed is being done. Lessons from other countries can help in interpreting local data.

Information may also be included about the national HIV/AIDS programme: its structure, its activities and future plans. The annexes should certainly list key contacts (ministry of health, national HIV/AIDS council, NGO forum, major NGOs and international partners), with phone numbers, e-mail addresses and web sites if available.

Many national reports include a foreword by a senior figure, often the president, minister for health or chairperson of the HIV/AIDS commission. If you ask someone to put their name to a foreword, make sure they are also willing to participate in launching the report.

How should the report look?

Getting a professional design firm to design and lay out the report is best, but the report committee has to have some ideas about the format. Should it be printed in full colour, two colours or black and white? This will affect the graphics, including any maps. Will photographs be used? Should some of the case studies be taken out of the main text and put in boxes? Should you use pull quotes (short sentences taken from the main text but put in large, bold text in a box or the margin, an effective way of drawing attention to key messages)?

Besides the graphics showing key data in the body of the report, will you present extra data in tables in the annexes?

Making it happen: the practical tasks of producing a national report on HIV/AIDS

Deciding on the content of the report is just one part of the task. Many other decisions must be made in writing and publishing a report. Key considerations are mentioned here.

What is the deadline?

In planning a report, always start with a deadline and work backwards. It is wise to plan to launch a national report on HIV/AIDS in conjunction with a major news-generating event such as World AIDS Day or a

national, regional or global HIV/AIDS conference. From that deadline, work back every step of the way: distribution, printing, final approval, proofreading, layout, design, copyediting, getting the content approved, writing the final draft – and continue through all the steps needed in writing a report. Plan exactly how long each of these things should take and then multiply each by 1.5, except getting the content approved, which should be multiplied by 2. This may be a realistic time line for developing a national report on HIV/AIDS.

Table 9 is provided as an example, but different parts of the process take different amounts of time depending on the country. The first national report on HIV/AIDS takes longest, because the process is unfamiliar. It speeds up in subsequent years.

What is the budget?

The budget affects everything else: the number printed, the number of pages, design possibilities and distribution options. Before proposing a budget, it may be useful to estimate the cost of two or three options: expensive (such as full colour, high-quality paper and many copies), inexpensive (for example, black and white throughout and small type) and an intermediate option. This will permit the benefits and costs to be discussed and make the final proposal more certain. Similar to the schedule, include some contingency funds in case problems arise that incur additional expenses (for example, missed writing or approval deadlines may result in extra charges for editing, layout or printing to keep the original schedule).

Who will determine the content of the report?

A committee is often formed to guide the production of the report, including deciding all the questions of content listed previously. Who should be on the committee? The surveillance manager or a similarly responsible person who has a very good grasp of the surveillance data on HIV, STI and behaviour is an essential member. Other HIV/AIDS programme or HIV/AIDS commission staff are also important, and other sectors may also want a voice. At least one person should represent affected communities, perhaps from an association of people living with HIV/AIDS or an NGO forum. The government may see an interest in including key international organizations and donors.

If the list gets too long, perhaps a steering committee and a small core working group would function best. The steering committee could discuss and determine the main story of the report, which the working group then develops into a draft. The steering committee then actively comments on the draft and the working group finalizes it.

Who will write the report?

The committee is often vaguely assumed to write the report. Committees do not write reports; people write reports. The committee is strongly recommended to

designate one person to actually draft the report, under their guidance. A professional writer may be used if none of the committee members wants to or can take the lead in writing a draft report.

Who will approve the report?

The HIV/AIDS control commission or the health ministry usually publishes the national report on HIV/AIDS. All official documents (and many unofficial documents) have to be approved. Determine well in advance what the approval process will be and give the people involved plenty of warning when a draft is about to arrive and what the deadline for approval is. The approval process is often the major stumbling block in producing a report on time, not because the content is controversial but because bureaucratic procedures are slow. These can be accelerated somewhat by prior agreement on the structure and timetable of the approval process.

In what languages should it be published?

Most national reports are published in the official national language or languages. However, it may be beneficial to publish the report in English or another international language as well when the report is timed for launch in conjunction with an international event such as an HIV/AIDS conference or when the international development community is a major target audience for the report. This decision must be made early on, because the translation process can add considerably to the timeline. If translation is required, it must be budgeted for, and the appropriate translator must be scheduled and any paperwork processed well in advance. A cost-effective solution may be to translate a summary for international purposes.

Who will design the report?

A report of this type should be attractive, which means that the design phase is important. Some governments have their own in-house design units. If they do not, design work needs to be planned well in advance, so that bidding can take place and contracts can be issued. The design unit or company can benefit from a report outline (with the different levels of chapter headings etc.) and a few pages of text with one or two graphics very early on so that they can prepare a design template. The draft text they use at this stage does not have to be final: they just need to have a general idea of paragraph length, heading types and other factors in producing an optimal design.

Who will copyedit the report?

A national HIV/AIDS report benefits tremendously from professional editing. Getting an experienced editor with fresh eyes to ensure consistency and make the report easier to read and understand is an important part of a professional product. Copyediting takes place after the surveillance manager (or someone

else very familiar with the data) and other members of the report committee provide technical input to the draft and after the content has been approved. Report planning sometimes assumes that the writer has edited the text, but writers know what they meant to say and often correct errors in their brain without seeing them on the page. The copyediting process should be incorporated into the budget and time schedule. Good editors may be busy and therefore need to be scheduled in advance. The writer and surveillance manager must carefully read and approve the copyedited version before layout.

Who will proofread the laid-out report?

If the copyediting process has ended with a correct and approved text, the proofreading process ensures that the final layout reproduces the approved text accurately. Proofreading can be very tedious but is necessary despite modern electronic word processing. Converting word-processing documents and laying out the text often introduces errors into graphics and tables as well as text. The copyeditor should be the main proofreader, but the writer and the surveillance manager or the like should also carefully proofread the laid-out document.

Who will pay for the printing?

The answer may determine the colour content and quality of the report. This needs to be decided from the start.

What logos will be on the report?

Again, reaching early agreement on this point is good. Will it have the national HIV/AIDS commission logo and the ministry of health logo? Which should take precedence? Have any other agencies taken a major role in producing or financing the report? Should their logos appear? On the front or the back cover?

To whom will the report be distributed and how?

A report is only valuable if it is read, and that means disseminating it to readers. A distribution strategy is needed. If this is to include electronic publishing, the designers need to know before they start so they can provide appropriate electronic files for publishing on the Web.

What will the dissemination strategy be?

Will the report have a press launch? If so, this needs to be planned long before the report is actually ready. Will it be launched in one site or in several sites nationwide? Will the international press show any interest? Who should be the spokespeople for the report launch? National leaders, celebrities, members of affected communities or all of the above?

Table 9. Example of a timeline for developing a national report on HIV/AIDS incorporating serological and behavioural data

	Report preparation	Who is responsible?	Approval process	Who is responsible?	Dissemination strategy	Who is responsible?
Week of						
June 4	Gather data		Estimate cost of report		Estimate cost of dissemination activity	
June 11	Develop and present outline		Approve outline			
June 18	Write first draft				Identify key media	
June 25					Identify key contacts	
July 2						
July 9	Submit first draft		Approve first draft			
July 16			Submit revisions			
July 23	Final revisions					
July 30			Approve revisions			
August 6	Copyediting and translation				Plan press trip, contact partners	
August 13						
August 20	Send report to designer					
August 27	Proofreading		Approve proofs		Brief partners	
September 3	Send report to printers				Set up interviews	
September 10					Brief local HIV/AIDS commissions	
September 17					Press trip	
September 24					Press session in capital and provinces	
October 1					Press session at international conference	

Who should do what?

There are many different types of data use and many different activities involved. This publication has assumed that the national HIV/AIDS programme or the surveillance manager is responsible for many of these, but other divisions of labour are possible. Private public relations firms may be best able to deal with the press-related side of data use, for example, whereas NGOs may be better placed than surveillance officials to organize data presentation and feedback sessions with communities affected by HIV/AIDS. Surveillance staff may often find themselves preparing presentations and briefings for other people, including ministers and politicians, who will have greater access to the intended audience.

This section discusses some important issues in determining roles and responsibilities in disseminating or using data.

Strong government leadership is critically important

Regardless of who is actually chosen to implement different activities, it is absolutely critical that the government lead the process. This is important for several reasons.

The first is coherence. As this publication has demonstrated, the same data can be presented in many different ways. If different groups disseminate surveillance data to the same or overlapping audiences without any central coordination, then the audience may get mixed messages, which can lead to disjointed and even contradictory programme efforts.

The second reason is credibility. Many partners involved in using data at the field level for implementing programmes are other government agencies or work in partnership with government. They are more likely to be influenced by “official” figures, interpretations and publications than by any data published by NGOs or other institutions.

The third reason is more practical. Surveillance is inherently a function of government, and usually of central government. Because it runs the surveillance system, the government – almost always the ministry of health – has most immediate access to the data and is therefore in a position to coordinate its use. In some countries, tensions have arisen between the ministry of health and the multisectoral HIV/AIDS commission over the right and the duty to control the use of data and its publication. Any such tensions should be resolved through open discussion, leading to a clear division of labour. If this does not happen, conflict risks leading to one group deliberately concealing data or restricting access to it – one of the worst possible outcomes for public health surveillance.

Donors can make or break an efficient system of data use

Many attempts to “use” data in the past have been fragmentary but ultimately duplicative. This very often results from anomalies introduced by donor agencies that fund parts of the surveillance or data collection systems. Each donor agency requires an epidemiological or a surveillance report, giving methods and results for the part of the surveillance system they funded. Sometimes, a single component of the system – such as behavioural surveillance – is supported by multiple partners, each of whom want their own report. Some donors fund different implementing agencies to do overlapping work, such as one developing an epidemiological report and another developing an advocacy report. This is not inherently bad: data always need to be packaged differently for different users. The problem arises when organizations perceive themselves as competitors, and conceal data from one another rather than sharing it. All these scenarios clearly lead to an inefficient use of resources and to confusion. They also reduce a country’s ability to get the most out of its surveillance data. One of the central aims of second-generation surveillance systems is to use data from behavioural, STI and HIV surveillance systems to build up a single, coherent picture of the HIV/AIDS epidemic.

The solution is to get all major donors to support a coordinated data-to-action planning process as well as a concerted and tightly coordinated effort to develop a single national HIV/AIDS report that includes data contributed by all parts of the surveillance system. Donor agencies should be able to agree to accept a single, comprehensive and high-quality report on the national epidemic as a deliverable from agencies involved in supporting surveillance. One advantage is that surveillance data generated by implementing agencies outside the government will get more attention in the programme planning process. This has not always been the case. In fact, donor-funded behavioural surveillance and STI surveys have often been completely overlooked in the national planning process because no effort was made to integrate them into national data systems beyond holding a single dissemination workshop.

Strong leadership from government surveillance authorities (backed up by the minister for health if necessary) can help to minimize demands by donors for their “own” report. Discuss a single national report on HIV/AIDS with donors, including acknowledgements and logos. Putting a donor’s logo on the inside cover of a national report is a lot less painful than seeing resources wasted in a separate report. Governments may also want to make clear to donors that a single national report on HIV/AIDS would help ensure that

data from the national system are contributed to international databases in a timely way.

Mechanisms for an efficient system for using data: the surveillance working group

Efficiency in data use is a fine objective, but what mechanisms are there for coordination? One mechanism that has proven very useful in improving coordination is a surveillance working group, which sometimes takes the form of a working group on monitoring and evaluation or on data and research. The working group is led by senior officials from the ministry of health or HIV/AIDS commission, and its core members are the people responsible for data collection and surveillance. This includes people from other government sectors as well as university researchers, private firms involved in market research

such as monitoring condom use, technical advisers from international institutions supporting surveillance, and key donors. Other individuals and institutions are invited to attend the working group on an ad hoc basis, depending on the topic under discussion. Members of affected communities may or may not be included as core members; if they are not core members of the technical team, they are among the most frequent ad hoc members.

The working group is a very good forum in which to plan data use. It can be responsible for the core work of defining key messages and target audiences and can designate different institutions to take on different specific tasks of data analysis, packaging or advocacy. It also provides an obvious starting-point for designating a committee to develop a national report on HIV/AIDS.

Data use is a moral responsibility: plan on it

Second-generation surveillance for HIV is an intrusive business. It involves collecting specimens of people's body fluids and asking them questions about some of the most intimate aspects of their lives. Continuing to do this over time is morally unacceptable unless the data are actively used to improve life for the people from whom they are collected and their communities.

This publication has tried to stress that data do not get used spontaneously. This requires planning, creative thinking, substantial energy and money.

No data should ever be collected without some idea of how they will be used in planning and evaluating programmes or in advocacy. Time and time again, people in affected communities are subjected to half an hour of questioning for a data set that is only ever used to produce three or four key indicators. Review

how past data sets were used and either improve the scope of analysis or delete any sections of the questionnaire that are not regularly used for advocacy or to inform programme planning. If you cannot think of how a piece of information might inform programming, do not collect it.

Some research or surveillance budgets contain a small line item for a dissemination workshop – and some do not. Good data use requires far, far more than that, and using data well requires investing considerable surveillance and research funds in supporting data use. As a rule of thumb, at least 20% of surveillance and data collection resources should be spent on using the data in all the ways described above.

The bottom line is that unless surveillance data are used well, data have no value at all.

Annex 1

Answers to exercises

What is the story? A possible approach to the exercise on developing a narrative (Box 16)

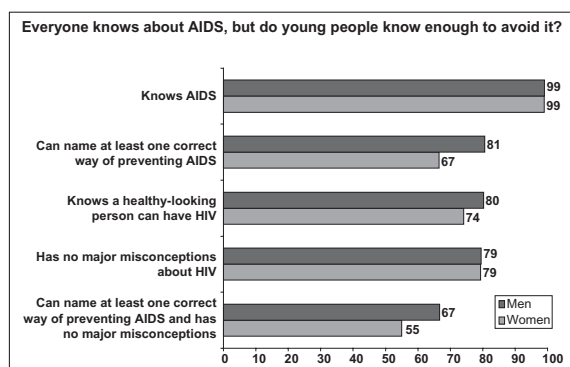
These data may be approached in several ways. One effective way to build up a narrative is to take readers or viewers through a logical flow that reflects the thinking behind the current approach to prevention, confirming or challenging assumptions along the way. This would be especially appropriate, since you have been specifically tasked with re-evaluating current approaches.

First, think about the current approach to preventing HIV transmission among young people in this population. It centres first on promoting awareness and then on promoting abstinence until marriage and mutual monogamy. Condoms are not actively promoted for this population. So each of these factors needs to be examined individually, and if the current approach is failing, potential solutions suggested by the data need to be explored.

Knowledge and understanding: what do young people know about HIV/AIDS?

At first glance, knowledge seems very high. Almost all young people have heard of HIV/AIDS, and more than three quarters know that someone who looks perfectly healthy can carry HIV. However, exploring this in greater detail shows that knowledge tapers off.

Figure A1. Knowledge about HIV/AIDS among people 15–24 years old according to gender, 2000



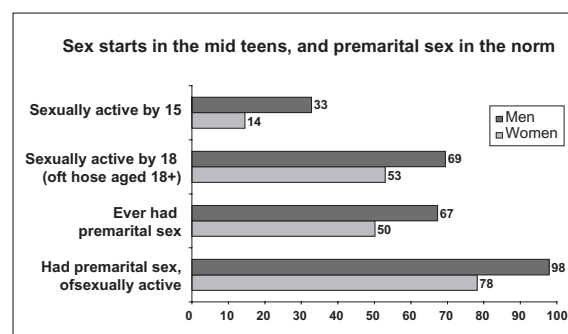
A third of young women cannot name a single way of preventing HIV infection, and just over half can name one correct way of preventing it and are free of any major misconceptions about the transmission of HIV. Young men are a little better off, but the lack of knowledge of the basic facts is unacceptably high in both sexes.

Abstinence: are they renouncing sex until marriage?

The data show very clearly that the “abstinence until marriage” message is not very effective. A majority of both sexes start having sex before they turn 18, and of those who have ever had sex, almost all young men and 8 of 10 young women have sex before marriage. On average, young men are sexually active for 6 years before marriage, while young women start having sex more than 2 years before they get married.

Sex starts in the mid-teens, and premarital sex is the norm

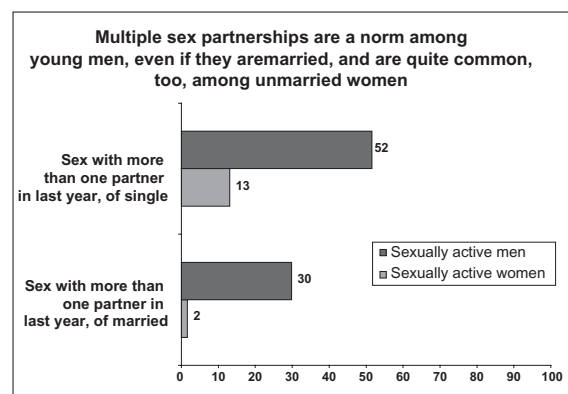
Figure A2. Sexual debut and experience among people 15–24 years old according to gender, 2000



Monogamy: are they sticking to one partner?

Multiple sex partners is the norm among young men, even if they are married, and are also quite common among unmarried women

Figure A3. Multiple sex partners among people 15–24 years old according to marital status and gender, 2000



The monogamy message may be reaching some women, but young men have apparently not adopted it. More than half of young men engaging in premarital sex have had sex with more than one woman in the past year, and even a third of married men have extramarital sex.

Condoms: how much sex is protected?

Not enough! The huge differences between men in women may be explained partly by the fact that some of the extramarital partners reported by men may be sex workers, with whom they are more likely to use condoms but who are not captured in the female portion of these household surveys.

Figure A4. Condom use among people 15–24 years old according to gender, 2000

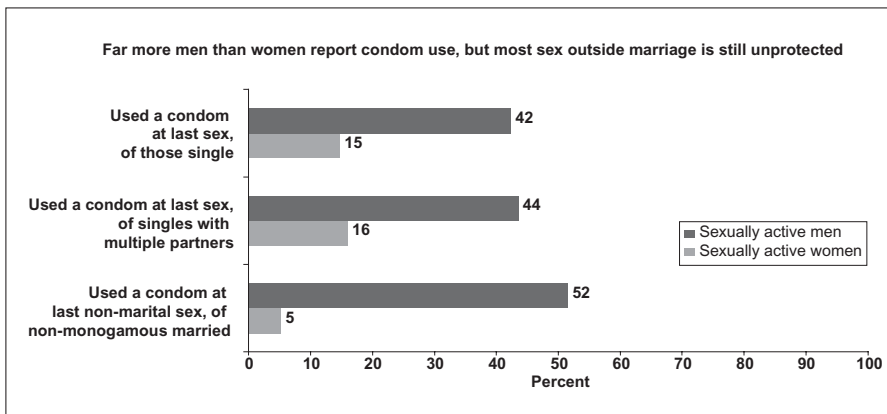
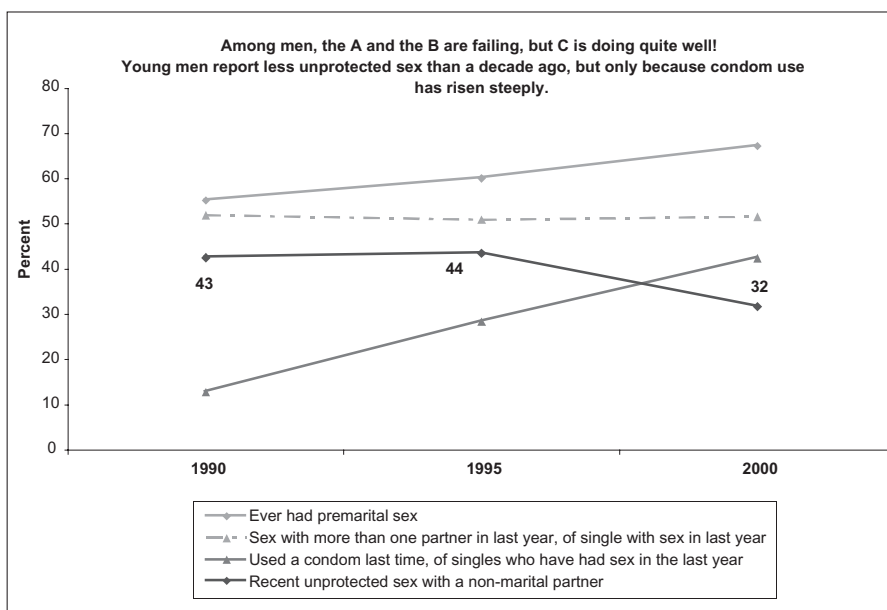


Figure A5. Sexual activity and protection among men 15–24 years old according to gender, 2000



In any case, most sex outside marriage, including premarital sex, continues to take place without condoms. The only group that uses condoms more than half the time with extramarital partners is married men, and in this age range this is the smallest population group.

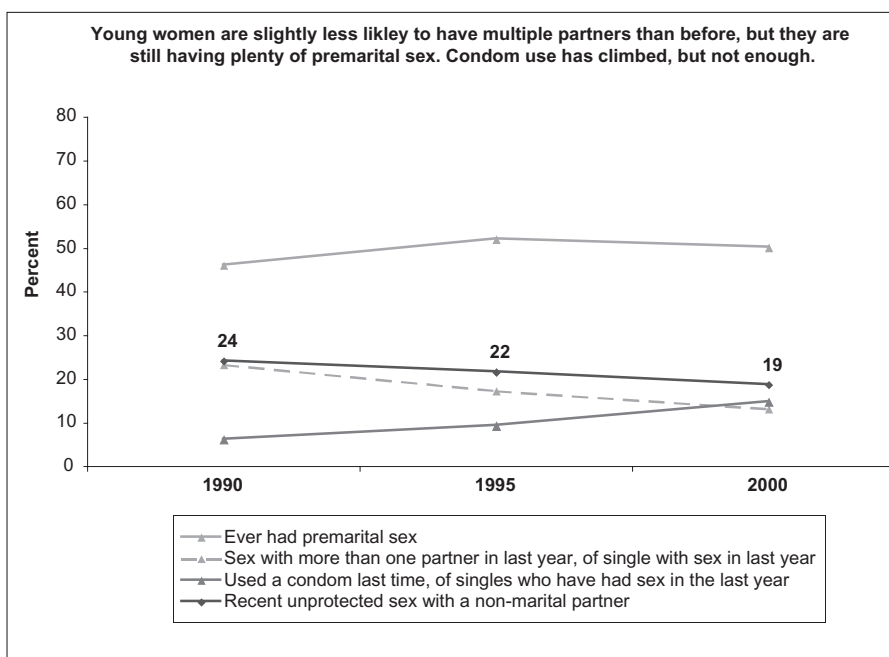
Trends over time: has behaviour become safer since prevention programmes began?

These data were collected in household surveys using the same methods at every round, so they should allow behaviour to be compared over time. Since these data are collected from men and women aged 15–24 years, some of these types of behaviour, especially premarital sex, may have taken place before the prevention campaigns promoting abstinence and monogamy were initiated. A good way of determining whether these messages have made any difference

is to examine whether these types of behaviour have changed over time by comparing the most recent data with earlier surveys.

Figures A5 and A6 show that unprotected sex with non-marital partners has indeed declined in the past decade, but most of this has not resulted from rising abstinence and monogamy but from rising condom use.

Figure A6. Sexual activity and protection among women 15–24 years old according to gender, 2000



Conclusion: condoms are key

Clearly, despite all the programme messages promoting abstinence until marriage, and strict monogamy, a high proportion of young people are still choosing to have sex outside marriage, and many of them, especially men, are having sex with more than one partner over the course of a year.

The messages advocating reducing the number of sexual partners do seem to be making some limited headway with young women. But overall, the most important behaviour change in terms of protecting young people against HIV/AIDS has been a substantial rise in condom use. This rise is encouraging, especially since condoms have not been actively promoted in these populations of young people. But much remains to be done. One fifth of all women aged 15–24 years and one third of men still report unprotected sex with people to whom they are not married. Since condom use has increased more without promotion than abstinence and monogamy have with promotion, there is probably room for more success in this area. Condoms should be actively promoted to young people who are choosing to have sex outside marriage.

Annex 2.

Using mapping to transmit large quantities of data

The following example shows data reported from a very large number of sentinel sites from around Nigeria, Africa's most populous country. The tables give details of sample sizes and the number of positive HIV tests for each site along with 95% confidence intervals. This is all very useful information to a national programme manager but would be far too much information to present to an audience of policy-makers who simply want to know which areas of Nigeria are most severely affected and need most prevention and care resources.

The map shown after the tables (Figure 17) is a concise way to describe this very complex picture in a single slide. For the purposes of a policy presentation, the map is a much more effective way of imparting key information than a long series of tables.

Table A1. Summary results of HIV prevalence in Zone A (south-east)

State	Site	Site status	Total sample	Number HIV positive	% HIV positive	95% CI
Abia	Umuahia	Urban	299	8	2.7	1.16–5.20
	Aba	Rural	299	12	4.0	2.09–6.90
	Total		598	20	3.3	2.05–5.12
Anambra	Awka	Urban	254	17	6.7	3.94–10.49
	Onitsha	Urban	299	18	6.0	3.61–9.34
	Ekwulobia	Rural	250	17	6.8	4.01–10.66
	Total		803	52	6.5	4.87–8.40
Ebonyi	Abakaliki	Urban	300	20	6.7	4.12–10.11
	Afikpo	Rural	300	17	5.7	3.34–8.92
	Total		600	37	6.2	4.38–8.40
Enugu	Enugu (Unth)	Urban	248	5	2.0	0.66–4.64
	Enugu Parklane	Urban	300	14	4.7	2.57–7.71
	Achi	Rural	110	15	13.6	7.84–21.49
	Total		658	34	5.2	3.60–7.14
Imo	Owerri	Urban	300	12	4.0	2.08–6.88
	Orlu	Rural	300	14	4.7	2.57–7.70
	Total		600	26	4.3	2.85–6.29
Zonal total			3262	169	5.5	4.45–5.99

CI: confidence interval

Table A2. Summary results of HIV prevalence in Zone B (south-west)

State	Site	Site status	Total sample	Number HIV positive	% HIV positive	95% CI
Ekiti	Ado Ekiti	Urban	300	7	2.3	0.94–4.75
	Ikole Ekiti	Rural	300	12	4.0	2.08–6.88
	Total		600	19	3.2	1.92–4.90
Lagos	Ikeja	Urban	300	4	1.3	0.36–3.38
	Lagos Island	Urban	300	6	2.0	0.40–4.30
	Surulere	Urban	257	8	3.1	1.35–6.04
	Badagry	Rural	233	13	5.6	3.00–9.35
	Epe	Rural	204	14	6.9	3.80–11.25
	Total		1294	45	3.5	2.55–4.63
Ogun	Abeokuta	Urban	243	7	2.9	1.10–5.84
	Ijebu–Ode	Rural	300	12	4.0	2.08–6.88
	Total		543	19	3.5	2.12–5.41
Ondo	Akure	Urban	300	19	6.3	3.86–9.10
	Ondo	Rural	300	21	7.0	4.39–10.50
	Total		600	40	6.7	4.81–8.90
Osun	Osogbo	Urban	300	9	3.0	1.38–5.62
	Ilesa	Rural	300	17	5.7	3.34–8.92
	Total		600	26	4.3	2.85–6.29
Oyo	Ibadan	Urban	300	10	3.3	1.61–6.04
	Saki	Rural	300	14	4.7	2.57–7.71
	Ogbomosho	Urban	278	13	4.7	2.51–7.86
	Total		878	37	4.2	2.98–5.76
Zonal total			4515	186	4.1	3.56–4.74

CI: confidence interval

Table A3. Summary results of HIV prevalence in Zone C (north-west)

State	Site	Site status	Total sample	Number HIV positive	% HIV positive	95% CI
Jigawa	Dutse	Urban	300	7	2.3	0.94–4.75
	Hadejia	Rural	300	4	1.3	0.36–3.38
	Total		600	11	1.8	0.92–3.26
Kaduna	Kaduna	Urban	300	12	4.0	2.08–6.88
	Zaria	Urban	300	10	3.3	1.61–6.04
	Kafanchan	Rural	300	28	9.3	6.29–13.20
	Total		900	50	5.6	4.15–7.26
Kano	Kano Mmsh	Urban	300	11	3.7	1.84–6.47
	Kano Akth	Urban	300	10	3.3	1.61–6.04
	Rano	Rural	300	13	4.3	2.33–7.29
	Total		900	34	3.8	2.63–5.24
Katsina	Katsina	Urban	300	11	3.7	1.84–6.47
	Funtua	Rural	300	10	3.3	1.61–6.04
	Total		600	21	3.5	2.18–5.30
Kebbi	Birnin Kebbi	Urban	300	10	3.3	1.61–6.04
	Argungu	Rural	300	14	4.7	2.57–7.71
	Total		600	24	4.0	2.58–5.89
Sokoto	Sokoto	Urban	300	9	3.0	1.38–5.62
	Dogon Daji	Rural	300	8	2.7	1.16–5.19
	Total		600	17	2.8	1.66–4.49
Zamfara	Gusau	Urban	300	15	5.0	2.83–8.11
	Talata–Marafa	Rural	300	6	2.0	0.74–4.30
	Total		600	21	3.5	2.18–5.30
Zonal total			4800	178	3.7	3.19–4.28

CI: confidence interval

Table A4. Summary results of HIV prevalence in Zone D (north-east)

State	Site	Site status	Total sample	Number HIV positive	% HIV positive	95% CI
Adamawa	Yola	Urban	300	17	5.7	3.33–8.91
	Mubi	Rural	300	10	3.3	1.60–6.04
	Total		600	27	4.5	2.98–6.48
Bauchi	Bauchi	Urban	300	20	6.7	4.12–10.11
	Azare	Rural	261	18	6.9	4.14–10.68
	Total		561	38	6.8	4.84–9.17
Borno	Maiduguri	Urban	300	13	4.3	2.33–7.30
	Biu	Rural	300	14	4.7	2.57–7.71
	Total		600	27	4.5	2.99–6.48
Gombe	Gombe	Urban	300	12	4.0	2.08–6.88
	Kaltungo	Rural	300	37	12.3	8.83–16.59
	Total		600	49	8.2	6.10–10.65
Taraba	Jalingo	Urban	299	20	6.7	4.13–10.14
	Zing	Rural	300	17	5.7	3.34–8.91
	Total		599	37	6.2	4.39–8.41
Yobe	Damaturu	Urban	300	15	5.0	2.83–8.11
	Geidam	Rural	185	2	1.0	0.13–3.85
	Total		485	17	3.5	2.05–5.55
Zonal total			3445	195	5.7	4.91–6.49

CI: confidence interval

Table A5. Summary results of HIV prevalence in Zone E (northern central)

State	Site	Site status	Total sample	Number HIV positive	% HIV positive	95% CI
Benue	Makurdi	Urban	299	43	14.4	10.60–18.87
	Otukpo	Urban	300	33	11.0	7.69–15.10
	Ihugh	Rural	300	45	15.0	11.15–19.55
	Total		899	121	13.5	11.29–15.86
Fct	Garki	Urban	300	33	11.0	7.69–15.10
	Gwagwalada	Urban	300	16	5.3	3.08–8.51
	Nyanya	Rural	300	43	14.3	10.57–18.81
	Total		900	92	10.2	8.32–12.38
Kogi	Lokoja	Urban	300	11	3.7	1.16–5.18
	Ankpa	Rural	300	23	7.7	4.92–11.28
	Total		600	34	5.7	3.53–7.25
Kwara	Ilorin	Urban	300	11	3.7	1.84–6.47
	Offa	Rural	231	12	5.2	2.71–8.90
	Total		531	23	4.3	2.76–6.42
Nasarawa	Lafia	Urban	300	32	10.7	7.41–14.72
	N/Eggon	Rural	266	14	5.3	2.90–8.67
	Total		566	46	8.1	6.01–10.69
Niger	Minna	Urban	300	17	5.7	3.34–8.92
	Wushishi	Rural	300	10	3.3	1.61–6.04
	Total		600	27	4.5	2.98–6.48
Plateau	Jos	Urban	300	34	11.3	7.69–15.10
	Shendam	Rural	300	17	5.7	3.35–8.91
	Total		600	51	8.5	6.25–10.84
Zonal Total			4696	394	8.4	7.53–9.13

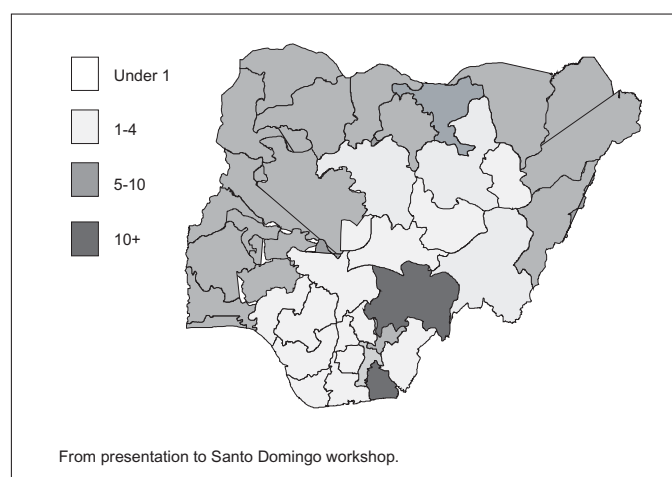
CI: confidence interval

Table A6. Summary results of HIV prevalence in Zone F (south south)

State	Site	Site status	Total sample	Number HIV positive	% HIV positive	95% CI
Akwa Ibom	Uyo	Urban	300	39	13.0	9.41–17.34
	Essien–Udim	Rural	300	25	8.3	5.47–12.6
	Total		600	64	10.7	8.31–13.42
Bayelsa	Yenogoa	Urban	132	10	7.5	3.16–12.54
	Sagbama	Rural	104	7	6.7	4.03–15.79
	Total		236	17	7.2	4.58–11.78
Cross River	Calabar	Urban	300	25	8.3	5.47–12.01
	Ikom	Rural	300	23	7.7	4.92–11.28
	Total		600	48	8.0	5.95–10.47
Delta	Warri	Urban	300	7	2.3	1.16–5.19
	Agbor	Rural	300	28	9.3	6.29–13.20
	Total		600	35	5.8	4.24–8.21
Edo	Benin City	Urban	300	13	4.3	2.33–7.30
	Ekpoma	Rural	300	21	7.0	4.38–10.50
	Total		600	34	5.7	3.95–7.83
Rivers	Port Harcourt	Urban	298	21	7.0	4.68–10.96
	Bonny	Urban	293	24	8.2	5.44–11.76
	Bori	Rural	291	23	7.9	5.35–12.02
	Total		882	68	7.7	6.24–9.92
Zonal total			3519	266	7.6	6.71–8.48

CI: confidence interval

Figure A7. HIV prevalence among women attending antenatal care in Nigeria according to state, 2001



Annex 3

Working with the mass media

Getting the best from the press

- **Know who is who**

Different publications and journalists have different points of view. Understanding the local press landscape can help you to choose the right message for the right audience and can avoid having your ideas misrepresented.

- **Always return calls from journalists**

Some people try to avoid dealing with the press by refusing to be interviewed or by not returning calls. This is almost never a good idea. If you do not speak to the press, your data or your viewpoint is guaranteed not to be represented.

- **Respect deadlines**

Unlike civil servants or academics, journalists work to strict deadlines. If you do not give them the information they need by the deadline, they will print the story without your input or with inaccurate data.

- **Try to give written information, especially for data and names**

Virtually all journalists would never wilfully get facts wrong, but they may be working on more than one story, and always to a tight deadline, and making mistakes is easy. If you are being interviewed, make sure the journalist is taking written notes. (Openly taping interviews yourself can also make journalists check quotes a bit more diligently before going to press.) Wherever possible, provide copies of any data or numbers in written form, and always give them your name card or write down your name and title. In a telephone interview always spell out your name.

- **Be clear about attribution and quotation**

Good journalists use a code of conduct in attributing quotes and information. Most journalists would prefer to have a named source, and if you are confirming surveillance data, which is a matter of public record, there is rarely any reason not to give a quote on the record. This means that they can use your name, title and organization name. Sometimes you want to give a journalist information that you would like to see appear in the story but do not want to be quoted by name for political or personal reasons. In that case, tell the journalist that you are speaking off the record. This means that they can quote what you said word for word or print any of the information you gave them but cannot use your name or attribute the information in any way that would identify you. If you want to give a journalist background information to help the journalist with investigation but do not want that information used in print in any way, you can talk to them

on deep background. Do not use deep background unless you know and trust the journalist to whom you are speaking.

- **Respond quickly to errors**

If a journalist misquotes you, do not ignore it. Go back to the example in Box 15. If you say “Our new estimates show that there are almost 2 million people living with HIV in the country, and about 200 000 of them need life-prolonging drugs right now. The trouble is, we only have enough money to buy drugs for around 2000 people. It’s a tragedy.” and the next day you read in the paper: “‘There aren’t enough drugs. This government is a disgrace!’ said Esther Mwambe, head of the National HIV/AIDS Programme.”, you should set the record straight. This also applies if a news outlet publishes information that is simply not true (“What all teenagers should know: condoms do not protect you from HIV/AIDS”). Do not ignore these types of errors. Respond quickly with a letter to the editor and follow with a phone call to the editor’s office to ensure that the letter gets published.

Using the press proactively

- **Make it human**

All the best stories are about people. If you have important new surveillance data showing that HIV infection in sex workers has tripled because of a rise in drug injection among sex workers, do not just give out the numbers. Try to arrange for a journalist to meet a peer educator who is educating sex workers about the dangers of injecting or to visit a new methadone maintenance clinic in the red light district. This will allow them to make the story human, but it will also allow them to make it positive.

- **Make it positive**

The press does a good enough job of playing up the negative side of most stories. Try to help them focus on the good. In the example above, if you give only the numbers, you will get only the bad. If you arrange for them to visit intervention sites (and if those sites provide the human interest), then a significant part of their report will focus on what is being done or should be done about the problem.

- **Make it newsworthy**

All journalists are interested in stories, but most also work for news organizations, so they have to relate their stories to recent or upcoming events or to “hot” issues. In fact, if you can relate your data to a current event, you are almost certain to get press coverage. Events used in this way are called news pegs (because you can hang a story on the peg).

The importance of timing was mentioned earlier. Nowhere is it more important than in selling stories

to the press. Think about upcoming news pegs, such as World AIDS Day or international conferences, and be prepared for them. Plan field visits, press conferences or interviews shortly before the event so that the stories will be ready to run at the right (newsworthy) time.

Keep your eye on the newspapers and jump at any opportunities. Imagine this scenario: you are trying to interest the press in stories about successes recorded in prophylactic tuberculosis treatment for HIV-positive people. It is not a very exciting story, but you want to see it in print to increase pressure on the finance ministry to fund an expansion of the programme. You speak to a few journalists, but no one seems very interested. Then scientists in Europe announce they have found a wonderful new treatment for tuberculosis, but are pricing it at US\$ 15,000 per person per year. An international controversy breaks out, and the press is full of stories about tuberculosis. Now is the time to call the journalists again, to sell your story about the tuberculosis programme which is not being funded even though it is successful, cheap and home-grown.

- **Target your market**

Generally, one does not want press coverage for the sake of press coverage, but because one wants to reach a specific audience with a specific message. Interesting journalists in the story is a free way of reaching the audience, but you still need to package according to the audience. If you want to reach private-sector executives, try to get a story in the leading business daily. If you want to reach teenagers, try the music television channel. If you want the broadest possible coverage, concentrate on the news agencies (local and international), because anything they print or film can be used by the hundreds of other mass media outlets that subscribe to their services.

- **Do it yourself**

Newspapers are almost always happy to accept commentary articles from well informed officials or public health workers. If there is an issue that you think is important and you (or the head of the national HIV/AIDS programme or some other senior figure) want to express an opinion about it, decide which newspaper you want it in, call the editor and give a brief outline of your idea, saying why you think it is important. Nine times out of 10, you will be invited to submit a commentary article (also called an op-ed, short for opinion and editorial).

How to hold a press conference

- **Plan ahead**

A press conference is linked to a newsworthy event, such as the launch of a new national report or the

inauguration of a new national HIV/AIDS council, so there is usually lots of advance warning. Do not wait until the last minute to book a venue, confirm who the speakers will be, write press releases or invite the press.

Send invitations by letter, fax and e-mail, and follow up by phone

Newsrooms are chaotic places, and bits of paper can get misplaced. Send the invitation in more than one way (to a named person who makes decisions about what gets covered) and follow up by phone.

- **Time it carefully**

Media have different time cycles, but the key news slot is usually the evening news broadcasts and the front page of the morning papers. Increase your chances of filling these slots by holding press conferences in the late morning or very early afternoon. Too early and no one is at work yet (many journalists work from 10 or 11 in the morning until after the evening news broadcasts or after the paper is put to bed); too late and you miss the deadlines.

- **Make it short**

News conferences are sometimes seen as an opportunity for politicians to show off, with a succession of important people wanting to give a speech. This is time-consuming, boring and unnecessary. Journalists will leave, often before the main event, and coverage will be limited. No news conference should last more than 1 hour.

- **Pick good presenters**

People are often asked to speak at press conferences merely because they are the most important person in the room. This does not, however, mean they are the best person to convey the key information and messages. Try to pick people who are naturally good presenters to speak at press conferences. If that is not possible, make sure that the speaker is briefed well, with a limited number of talking points and some warning about questions that might arise. When choosing presenters, think also about introducing human interest. Members of at-risk communities and people living with HIV/AIDS can be good advocates.

- **Think pictures**

Stories often get a better run in the print media, and always get a better run on television if they are accompanied by good visual images. Try to think about this when planning a press conference, so that the television cameras are not left with nothing but talking heads in official uniform. If the press conference is well located, the cameras could be taken on a field visit directly after the press conference or to film interviews with officials in the field.

Annex 4

A press release

This press release was adapted from a UNAIDS press release.

Most HIV is still spread sexually in Africa, experts say

Geneva, 14 March 2003 – HIV experts today disagreed with a controversial analysis suggesting that HIV in Africa is spread by unsafe injections, reaffirming that most people living with HIV in the continent are still infected in unprotected sex. They said sub-Saharan African HIV/AIDS programmes must continue to focus on promoting safer sex.

The experts made the statement at a consultation hosted by the World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) in Geneva. The consultation was called following the publication of a paper that claimed, controversially, that unsafe injection and other poor practices in health care contexts contributed significantly to HIV transmission in sub-Saharan Africa. The authors of the injection paper took part in the consultation.

“We have reviewed all of the evidence very carefully, and the claim that HIV is transmitted largely by unsafe health care practices just does not stand up”, said Dr Bernhard Schwartländer, who heads the Division of HIV/AIDS at WHO. “If we want to beat this disease, we have to keep focusing on promoting safer sex.”

This position is strongly supported by epidemiological and biomedical data. For example, children between 5 and 14 years old, who are generally not yet sexually active, have very low infection rates; age-specific infection rates among young women and men strongly follow patterns of sexual behaviour and those of other sexually transmitted infections (such as herpes simplex virus-2); in sexually active couples, both partners are often infected; and there is no consistent association between higher HIV rates and lower injection safety standards.

Modelling of the epidemic with the best available information also shows that the overwhelming majority of the 26.4 million adults living with HIV in Africa were infected sexually, and nearly 3 million children are now living with a disease acquired from an infected mother. WHO has previously estimated that unsafe injection practices account for about 2.5% of HIV infections in sub-Saharan Africa. Although there is a margin of uncertainty around this estimate, the conclusion remains that unsafe sex is by far the predominant mode of transmission in sub-Saharan Africa.

With approximately 3.5 million Africans becoming infected in 2002 alone and a total of 29.4 million living with HIV/AIDS in the region, preventing HIV through the practice of safer sex should be the mainstay of the response to AIDS in the region. Discussions about the importance of other modes of transmission should at no time weaken this central part of the response.

The expert consultation also emphasized the importance of achieving safe and appropriate use of injections in both the formal and informal health care sectors of low and middle-income countries, as in high-income countries. An estimated 16 billion injections are given globally each year, of which an estimated 30% are unsafe because of the reuse of equipment. The participants of the consultation fully agreed that safe medical injections are crucial to minimize the risk of transmission of not only HIV but other pathogens such as hepatitis B and hepatitis C in health care settings and to maintain confidence in the health care system.

Injections are vital for immunization programmes and for providing life-saving treatment. Injections should be used only when medically necessary and should be given

using single-use equipment, which is then disposed of safely. In the past several years, major efforts and resources have been devoted to enhancing injection safety in the health care setting by improving the planning of services including immunization, training of care providers and vaccinators, providing single-use injection equipment and ensuring proper disposal of “sharps”. More needs to be done to eliminate unsafe injection practices throughout the world. To further this work, WHO has just issued a framework to assist countries with all aspects of the provision of safe injections entitled Managing an Injection Safety Policy.

In the context of the AIDS epidemic, WHO and UNAIDS continue to strive to understand the global and local epidemiology of HIV, consider new information as it arises and provide leadership to prevent HIV infection from all sources, including unsafe sex, mother-to-child transmission, blood and blood products and unsafe injections.

For more information on this subject or to arrange interviews with participants in the consultation, call Dr ... or contact us through the UNAIDS or WHO web sites ...

Additional examples of press releases are available at <http://www.unaids.org/en/media/press+releases.asp>.

Annex 5

Important international databases

http://www.who.int/emc-hiv/fact_sheets	UNAIDS/WHO epidemiological fact sheets on HIV/AIDS and sexually transmitted infections
http://www.who.int/GlobalAtlas/home.asp	The UNAIDS/WHO Global HIV/AIDS Online Database collates the most recent country-specific data on the spread and impact of the virus, together with information on risk behaviour
http://www.unaids.org/en/resources/epidemiology/epi_methods.asp	Regional fact sheets on the epidemiological situation produced by UNAIDS
http://www.synergyaids.com/summaries.asp	HIV/AIDS country profiles of countries supported by the United States Agency for International Development (USAID) include country-specific information on epidemiology and factors contributing to the spread of HIV/AIDS, national response activities, USAID support and cooperating agency activity and challenges in confronting the epidemic
http://www.measureprogram.org	Demographic and health survey with HIV/AIDS survey indicators database
http://www.census.gov/ipc/www/hivaidsd.html	United States Bureau of the Census HIV/AIDS Surveillance Data Base
http://www.census.gov/ipc/www/hivtable.html	United States Bureau of the Census HIV/AIDS Surveillance Data Base summary tables
http://www.cdc.gov/brfss	United States Behavioral Risk Factor Surveillance System
http://www.eurosurveillance.org/index-02.asp	Eurosurveillance weekly and monthly

The current guidelines are based on the large experience gained by various projects and programmes in using data from HIV Second Generation Surveillance systems in developing countries. The support to produce this guide stems from the project –“Surveillance on HIV/AIDS”– geared towards strengthening the implementation of Second Generation HIV Surveillance principles into action.

These guidelines aims are primarily to programme managers and surveillance professionals at the national and regional levels. In addition, other partners in HIV/AIDS prevention and care, including policy and decision-makers interacting with professionals or the press or the communities, will find parts of this publication useful as well.

The guidelines should be instrumental in taking the findings of surveillance data far beyond the mere “dissemination workshops”. They provide guidance on the different ways and examples in which HIV surveillance data can be used in the broader context of national activities to improve programming, measure the success of prevention, lobby for policy change and engage affected communities in the response.

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