NATIONAL AIDS PROGRAMMES

A GUIDE TO MONITORING AND EVALUATION

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UNAIDS - 20 avenue Appia - 1211 Geneva 27 - Switzerland
Telephone: (+41 22) 791 46 51 - Fax: (+41 22) 791 41 87
E-mail: unaids@unaids.org - Internet: http://www.unaids.org

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This guide has grown out of the collective experience of a large number of people in monitoring and evaluation of HIV and AIDS prevention and care programmes at a national level.

The effort, co-ordinated by UNAIDS, WHO and the MEASURE *Evaluation* Project, was co-financed by the United Nations Joint Programme on HIV/AIDS and the United States Agency for International Development (Africa Bureau/SD and Global Bureau on HIV/AIDS). The process has involved repeated consultation with monitoring and evaluation specialists from many countries as well as with technical specialists in international institutions. Consultations have been held in Chapel Hill, USA (August 1998), Nairobi, Kenya (November 1998), Talloires, France (May 1999), Geneva, Switzerland (July 1999) and Berlin, Germany (April 2000). The final meeting was co-sponsored by Germany's Health Ministry and the Robert Koch Institute, Berlin, Germany.

Specialists from Brazil, Burkina Faso, Ethiopia, Mexico, Jamaica, Russia, Romania, Thailand, Senegal, Uganda, Kenya, Tanzania and Zambia all reviewed their national experience in monitoring and evaluation of AIDS programmes, preparing case studies for review during a major consultation in Nairobi. Technical input at that consultation came from a number of institutions including Family Health International/IMPACT, the Futures Group/Policy Project, Population Council/Horizons, Macro International/*DHS+*, University of North Carolina/MEASURE *Evaluation*, UNAIDS, the United States Centers for Disease Control and Prevention and WHO. The United Nations Development Programme, the United Nations Population Fund, UNICEF and the World Bank all made useful contributions, as did bilateral and multilateral development agencies from Australia, Germany and the United States, and the European Commission.

Following the Nairobi meeting, a draft version of this guide was prepared. The indicators suggested were extensively reviewed during a consultation in Talloires, in which specialists in particular areas of evaluation joined many of those who had been involved in earlier consultations. A revised guide was prepared. Another consultation, in Geneva, focused on reviewing and developing indicators in the difficult area of care and support. A number of the data collection instruments included in the toolkit that accompanies this guide were field tested. Field tests took place between August and December 1999, in Burkina Faso, Costa Rica, Nigeria, South Africa, Tanzania, Thailand and Uganda. The results of this and other field tests were discussed at a final meeting held in Berlin in April 2000, attended by investigators, technical specialists from a range of national and international institutions, and national AIDS programme staff from Brazil, Cambodia, Ghana, India, Malawi, Mexico, Senegal, South Africa and Tanzania. Following this meeting, the draft guide was revised and finalised.

This guide is the product of the inputs of many individuals, institutions, organisations and countries. Elizabeth Pisani did the bulk of the writing following the meetings, with substantial input from Ties Boerma, Bernhard Schwartländer, Amy Cunningham, Tim Brown, Deborah Rugg, Lisanne Brown and many others who contributed specific sections to the guide or to the instruments.

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List of Acronyms

ANC	Antenatal Clinic
API	AIDS Programme Effort Index
ARV	Anti-retroviral
BSS	Behavioral Surveillance Surveys (BSS): Guidelines for repeated behavioral surveys in population groups at risk for HIV
DHS	Demographic and Health Surveys
FHI	Family Health International
GPA	Global Programme on AIDS
IDU	Injecting drug user
IEC	Information, Communication, Education
LCR	Ligase Chain Reaction
M&E	Monitoring and Evaluation
MSM	Men who have sex with men
MTCT	Mother to child transmission
NGO	Non-governmental organisation
PCR	Polymerase Chain Reaction
PI	Prevention Indicator
PSI	Population Services International
RPR	Rapid Plasma Reagin
SIDALAC	The Regional HIV/AIDS Initiative for Latin America and the Caribbean
SPA	Service Provision Assessment
STI	Sexually Transmitted Infection
VCT	Voluntary counselling and HIV testing

1 Introduction to the Guide

In the early years of the HIV/AIDS epidemic, programme managers had little information about what interventions were likely to work in reducing the spread of the virus, and little idea of how they might measure the success of their interventions beyond simply tracking HIV or AIDS itself. What's more, it was widely believed that sensitive behaviours such as sex and drug injection – known to spread the virus – could not be reliably measured at all. There was an urgent need to respond in any way possible. Measuring the success of the response was not high on the list of priorities for most programme managers.

Over the last decade, this thinking has changed. Much more is known about how HIV spreads through a population, and what changes are needed to slow the spread. It has been amply demonstrated that people will answer questions about their sex lives, and there is growing evidence that their answers give a fairly reliable picture of trends in behaviour over time.

As the body of knowledge surrounding HIV grows, so does the interest in monitoring and evaluating the success of programmes designed to reduce the spread of infection and the impact it has on the lives of families and communities. This interest comes from national governments as well as from the taxpayers, programme directors and international donors who support their efforts. The need for better monitoring and evaluation has also spawned a growing number of data collection instruments and indicators.

Many different countries and institutions have contributed to the current understanding of how best to monitor and evaluate HIV and AIDS programmes. This guide, the result of a broad consultation with country programme staff, donor representatives and evaluation specialists from institutions all over the world, attempts to bring together their experience. It aims to summarise the best practices in the field of monitoring and evaluation (M&E) of national HIV and AIDS programmes at the end of the 1990s, and to recommend options for M&E systems in the future. By consolidating existing data collection instruments and creating a framework within which improved instruments can be developed, this guide and the toolkit which accompanies it aim to simplify an increasingly complex field.

This introduction outlines the contents of the toolkit and gives an overview of the different functions of surveillance, monitoring and evaluation. The next part of the guide describes the main features of a sound M&E system. Finally, indicators for key areas of HIV prevention, AIDS care and STI control programmes are proposed. It should be stressed that this is not an attempt to reinvent the wheel. In proposing indicators, the guide takes into account existing standards and experience. New indicators are only proposed in those areas where none previously existed, or where country experience suggests that existing indicators are not useful or have been overtaken by the HIV epidemic.

1.1 Components of the toolkit

This guide is accompanied by a number of data collection instruments and guidelines needed to construct the proposed indicators. These are based on existing materials from a variety of sources, and cover different areas of AIDS programmes: knowledge, attitudes, sexual behaviour; programme context, input and output; service provision; and health status. They include various types of data collection instruments, for example population surveys and health facility assessments. Some of the instruments have been in existence for many years and have been widely tested, others are relatively new, and a few are still being tested. If specific instruments improve with experience, previous versions can simply be replaced with newer versions. To enable users to access the latest version of a given data collection

instrument, all updates will be posted on the Internet at a UNAIDS Web site, initially operated by the MEASURE *Evaluation* Project (*www.cpc.unc.edu/measure* and *www.unaids.org*).

Panel 1 lists the data collection instruments included, grouping them according to which aspect of programming they measure. **Panel 5** cross references individual indicators by programming area data collection instrument.

The choice of indicators and therefore of data collection instruments will depend on a number of things, including the stage of the epidemic, available resources and capacity for data collection. These choices are discussed at greater length in the second section of this guide.

Panel 1: Monitoring and evaluation tools *(Instruments in italics are still under development)*

Monitoring of programme performance and context	Population Surveys	Facility-Based Assessment	
AIDS Programme Effort Index (Futures/ POLICY project)	General population survey (UNAIDS)	Assessment of STI services (WHO/UNAIDS)	HIV surveillance: policy guidelines (WHO/UNAIDS)
MEASURE Evaluation/WHO/PSI Compiled Condom Retail Availability and Quality Protocol	AIDS Module DHS (MEASURE DHS+)	Assessment of VCT services (UNAIDS)	HIV surveillance in subpopulations of high-risk behaviour (WHO/UNAIDS)
Monitoring spending and budget allocations (UNAIDS, Futures Group)	Youth target group behavioural surveillance (FHI/IMPACT)*	*Assessment of MTCT services (UNICEF, WHO, UNAIDS, Horizons)*	STI surveillance (RPR, other lab data, disease reporting) (WHO)
Assessment of discriminatory practices and legislation (UNAIDS)	Female sex workers behavioural surveillance (FHI/IMPACT)*	*Protocol for the evaluation of HIV/AIDS care and support (WHO/UNAIDS)*	
Media review-based tools and indicators (MEASURE Evaluation)	General adult population behavioural surveillance (FHI/IMPACT)*	*Blood safety draft protocol (MEASURE Evaluation)*	
	Men who have sex with men behavioural surveillance (FHI/IMPACT)*	*MEASURE Service Provision Assessment (SPA)*	
	Intravenous drug users behavioural surveillance (FHI/IMPACT)*		

* Part of the Behavioral Surveillance Surveys (BSS): Guidelines for repeated behavioral surveys in population groups at risk for HIV

Monitoring of programme context and effort

Programme context monitoring focuses on the compilation of input and output data that can be used to monitor changes in effort and context over time. This includes the assessment of condom distribution and quality, based on instruments developed by WHO/GPA and Population Services International (PSI), as well as indicators of STI drug distribution. The newly developed AIDS Programme Effort Index, co-ordinated by the Futures Group's POLICY Project, attempts to capture some of the contextual and programmatic aspects of the national response. UNAIDS Country Profiles provide a series of indicators that can help describe the socio-economic and demographic background of the epidemic.

Monitoring of knowledge, attitudes and sexual behaviour

Tools for monitoring knowledge, attitudes and sexual behaviour include guidelines for household surveys in the general population, and in specific sub-populations, including information on sampling methods and questionnaires.

Such surveys yield most of the information necessary for constructing indicators of knowledge, attitudes and sexual behaviour, together with some information that can be used in indicators of stigma. Surveys also give information about access to or utilisation of services such as counselling and testing, home-based care for the terminally ill, and orphan support services. Guidelines for the collection of qualitative data are also available.

The instrument for collection of behavioural data in the general population draws heavily on the general population survey section of the WHO/GPA's Prevention Indicators and other WHO/UNAIDS work, as well as on the new AIDS module of the Demographic and Health Survey (MACRO International). The sub-population surveys were developed by Family Health International (FHI), and are based on FHI's considerable body of experience in implementing Behavioural Surveillance Surveys (BSS). Recent surveys conducted with help from MEASURE *Evaluation* have also contributed to these tools.

Monitoring and evaluation of the availability and quality of health and other services

Information in this area can be gathered by conducting regular and systematic surveys at health facilities and at other facilities providing HIV-related services such as voluntary counselling and testing centres. Instruments include protocols for collecting information related to STI care, counselling and testing, prevention of transmission of HIV from mother to child and blood safety. The STI care section is based heavily on protocols developed by the WHO/GPA. However, it offers additional and/or alternative methodologies further developed and tested by several countries, often in collaboration with FHI.

In other areas covered by the facility survey, little existing material is available upon which to draw, and new guidelines have been developed.

Monitoring HIV, AIDS and STIs

The guidelines for monitoring the presence of HIV itself, together with syphilis and other STIs, have been developed by UNAIDS and WHO. They are based on a framework for second generation surveillance developed by the two institutions in partnership with others. The guidelines give advice on selection of sentinel groups and sites and provide information on using data from a number of sources for most effective monitoring of the spread of the virus in a given epidemic state. Other data collection instruments in this area include guidelines for STI surveillance (RPR, other laboratory data, syndromic or disease reporting), collection of specimens for HIV/STI testing in household or sub-population surveys and collection of data on AIDS-related morbidity and mortality. Guidelines on the collection of blood, urine, saliva or other specimens for HIV or STI testing are also available.

1.2 The importance of monitoring and evaluation for AIDS programmes

Monitoring and evaluation of programmes designed to improve health and promote development are old news. Basically, M&E systems track what is being done and whether the programme is making a difference. M&E systems allow programme managers to calculate how to allocate resources to achieve the best overall result.

All of this is familiar to anyone who has worked in family planning, child nutrition, primary education or a host of other health and development fields. Indeed, efforts by the Development Assistance Committee of the OECD and other bodies to develop evaluation and resource allocation tools in other fields of development have laid the groundwork upon which this guide is built. So is a separate guide for the monitoring and evaluation of HIV and AIDS programmes really needed? Yes. The HIV epidemic is different from many other issues in health and development because it is relatively new, and no one knows exactly where it is headed. New interventions are constantly proposed, and each must be shown to be effective to justify becoming part of a national or international response. Operations research can show that a given intervention can be effective – for example that sex education in selected high schools can reduce risk behaviour. For a strong national M&E system, much more is needed to track more generalised success. In this case, repeated behavioural surveys among a national sample of high-school students would be needed to reflect changes in risk behaviour following the integration of sex education into the nation-wide curriculum.

The epidemic itself continues to shift. For years, everyone's attention was focused on prevention. As HIV epidemics turn into AIDS epidemics in one country after another, care of the sick and social support to people with AIDS and their families become more important. These programmes are often hard to deliver and potentially expensive – monitoring their implementation and evaluating their impact will be important in ensuring that the best possible services are delivered.

HIV is politically charged in most countries. Important religious and political lobbies, along with the general population, may oppose intervention, and senior decision-makers may be reluctant to tackle the issue in consequence, preferring to focus on maternal mortality, child nutrition or other more "politically neutral" programmes. It is in this context that M&E is perhaps most useful of all. Only careful measurement and recording of the success of existing initiatives will persuade reluctant policy-makers to expand programme efforts.

When conducting monitoring and evaluation activities, because so many different disciplines contribute to the field of evaluation and there are cross-cultural variations, it is always useful to start with definitions that include not only surveillance, monitoring and evaluation, but also the terms "programme", "intervention", and "project". In the context of this document, "programme" refers to an overarching national or district-level response to HIV. Within a national programme there are typically a number of different areas of programming, such as the blood safety programme, the STI control programme or the HIV prevention programme for young people. The term "intervention" or "intervention strategy" refers to specific types of activities designed to achieve the goals of an area of programming. The training of a large number of teachers in HIV-related communication might, for example, be an intervention within the HIV prevention programme for young people. The term "project" is sometimes used interchangeably with intervention, since in practice interventions are often limited in scope to specific projects funded from a single source, at least in their initial or "pilot" phases. More often "projects" are a mix of interventions that aim at a specific population, defined geographically or otherwise.

1.3 The use of indicators at different levels

This guide identifies a set of indicators and methods for measuring them to be used at the national level. These indicators are intended to measure a broad range of issues regarding the HIV epidemic and the country's response to that epidemic. The selected indicators help to focus attention in the country on key prevention and care components of the response and the resulting impacts. They provide a way to track changes over time in specific prevention and care areas. They also allow comparison of the overall implementation and effectiveness of the national response in different countries.

However, because the set covers so many topics and because substantial resources can go into collecting indicators at a national level, the number of indicators in any particular area must remain limited. This means that the set presented here will not comprehensively address all the specific monitoring and evaluation needs of the national program in a given country, nor will it cover the much more detailed monitoring and evaluation needs of individual projects to prevent and mitigate the impacts of HIV. In this section we will briefly discuss the roles which these indicators play in monitoring and evaluation at three levels: international, national, and project.

International level

At the international levels, the collection of these indicators in different countries will help international agencies and donors to:

- track the trends in the epidemic and the response on a global scale
- identify regional trends or patterns in the epidemic and the response
- highlight persistent global and regional problems in responding to the epidemic
- advocate for expanded resources to address the pandemic
- allocate financial and technical resources so as to have the greatest impact on the global pandemic

It is therefore important that the indicators are defined and measured in the same way, so that they are understandable when viewing at the global level and between countries and regions. This guide provides detailed recommendations as to how to measure each of the indicators. Although contextual information is needed to form a full picture behind any particular indicator, taken roughly they can be compared directly from country to country.

National level

At the national level the indicators presented here can be used for many of these same purposes: tracking trends, identifying problem areas, advocating for and allocating resources. However, at the national level they will also inevitably contribute to evaluation of the effectiveness of the country's overall response, that is the sum total of all activities going on in a country which relate to the HIV/AIDS epidemic. For example, varied and aggressive prevention activities among young people might be expected to produce increased condom use or greater levels of abstinence from sexual activity. The young people's sexual behaviour indicators presented here can track whether this is happening or not.

In deciding on a national set of indicators, it is important that countries realise they are not limited to this set of indicators, nor should they necessarily collect all of them. The choice of indicators should be driven instead by the objectives, goals, and activities which constitute the national response to HIV and by the local epidemiology and nature of HIV and risk behaviours, keeping in mind that it costs time and money to collect and analyse data for each indicator. There is no point collecting information about risk behaviours or groups which are not relevant to the local epidemic. In this guide, the indicators have been divided into core and additional indicators, with this designation varying with the stage of the epidemic, as described below. Core indicators relate to important factors influencing the epidemic or tracking its course and are recommended for collection in all countries at a particular epidemic stage. Additional indicators are only recommended in countries where they have

relevance to the local epidemic or the local national response. The applicability of each additional indicator and suggestions for its use are discussed in detail in the indicator description later in this volume.

Where they fit the needs of a country, national AIDS programmes are encouraged to use the indicators defined here to ensure standardisation of information across countries and over time. When necessary, however, countries should add or delete indicators to make certain the data collected is linked to improving the national response. For example, in a low-prevalence country where voluntary counselling and testing for pregnant women is not a national program emphasis, little value will be added by collecting many of the indicators listed here on mother to child transmission. If resource constraints limit the number of indicators collected, these might be dropped or only one or two of them collected. On the other hand in a country with a severe generalised epidemic, a supplemental series of indicators measuring response at the local level might be required, e.g., the number of provinces implementing an active provincial AIDS committee chaired by the local governor. In a country with a concentrated epidemic among men having sex with men and injecting drug users, the set of indicators here might be expanded to include specific nationally relevant indicators such as percent of drug users in methadone treatment receiving counselling on HIV or percent of gay bars distributing condoms.

District level

In the context of decentralisation and health sector reform, districts are playing an increasingly important role in health programmes, including AIDS programmes. Even though monitoring and evaluation functions of districts have not been specified in most countries, it is likely that districts will have two main functions. The first pertains to district level monitoring of AIDS programmes, the second concerns the provision of data relevant for national level monitoring and evaluation.

Many of the indicators listed in this guide are suitable for district monitoring purposes. Resources however are much more limited at the district level. A large survey could easily consume more than half of a district's AIDS budget in a single year. Furthermore, districts generally do not have the human resources to carry out a population-based survey. In some districts it may be possible to carry out regular behavioural surveys of specific groups, such as school youth, with limited outside assistance. In general, however, district monitoring should focus on programme inputs and outputs and assess whether or not implementation of activities progress according to a district plan. A small facility assessment as part of routine supervision could serve to provide information on the quality of STI care or the availability and utilisation of voluntary counselling and testing services, or AIDS care by health facilities. In addition, districts can make use of the existing routine health information system to obtain data on the incidence of sexually transmitted infections. Between 3 percent and 5 percent of district financial resources for AIDS should be devoted to monitoring and evaluation activities.

The district contribution to national level monitoring and evaluation also focuses on reporting of input and output data in line with national guidelines. Good reporting by districts would tremendously help national level monitoring and evaluation. For instance, if a country had actual data on condom distribution by district instead of one national overall figure, monitoring of trends in condom use may become more meaningful and more accurate. In many ways the considerations listed below for project level evaluation also apply to districts.

Project level

There is often a strong desire to use the indicators presented in this guide for evaluation of specific prevention and care projects and a belief by many that this can be done easily. However, while some of these indicators may remain relevant at the level of monitoring and evaluating a specific project, they will certainly not cover the full range of project

monitoring and evaluation needs. Good project monitoring and evaluation requires a mix of input, process, output, outcome and impact indicators which are directly tied to the project activities, goals and objectives. These should then feed directly back into the project to improve the implementation of activities and maximise the project's impacts.

Many of the indicators in this volume are defined for use in the population at large or in specific HIV/AIDS service settings. Collection and reporting of the data in the way specified in this document may not, therefore, meet the needs of a specific project to be assessed. And even if they are, unless the data collection simultaneously includes measures of exposure to the project or an examination of other outcomes which are unique to the project's target audience, directly attributing any change in the indicator to the project will not be possible.

This is a limitation of general indicators such as those defined here when applied to national level assessment. Even if they measure behaviour change, the change cannot generally be tied to one specific project since the populations in question have also been exposed to mass media and other sources of HIV/AIDS information, friends and relatives with HIV and AIDS, and other national and local prevention and care activities in addition to the project undergoing evaluation.

Thus if it is necessary to determine or demonstrate the effectiveness of a specific project, the design of that project must include its own baseline and follow-up assessments which measure not only project-specific outcomes (e.g., increased condom use among a specific sub-population or increased social support for those living with HIV in the community), but also level of exposure to the project and its activities.

While much of the impetus for standardising indicators has come from international bodies wishing to make cross-country comparisons, the value of standardised indicators within a country cannot be overemphasised. In designing its own evaluation activities, a project should bear in mind the national standard for indicators in that field. Projects may have their own information needs that conform to a rigorous evaluation design. However they are often able to choose indicators with standard reference periods, denominators, etc. that would allow the data they collect to be fed easily into the national M&E system.

If a measurement method comparable to one proposed here is used or if the project evaluation activities can be altered slightly to allow data to be collected as specified in this document without compromising the evaluation of the project, then those indicators which are relevant to the project should be collected and reported to the national program.

Using comparable measures can provide the national program with valuable measures of the same indicator in different populations, permitting triangulation of findings and allowing regional or local inconsistencies and differences to be noted and addressed. This can help to direct resources to regions or sub-populations with greater needs, identify areas for intensification or reduction of effort at the national level, and aid in improving the overall effectiveness of the national response.

1.4 The different functions of surveillance, monitoring and evaluation

While surveillance, monitoring and evaluation serve different functions, they do overlap. This section attempts to clarify how the terms are used in this guide.

Surveillance, monitoring and evaluation all play a role in providing information to help determine the links between programme efforts and resources, and the goals the programme is trying to achieve. In the case of national AIDS programmes, the ultimate goals will be to reduce the spread of HIV, to improve care for those infected, and to minimise the social and economic impact on affected families and communities. For a programme to achieve its goals, **inputs** such as money and staff time must result in **outputs** such as stocks and delivery systems for drugs and other essential commodities, new or improved services,

trained staff, information materials, etc. If these outputs are well designed and reach the populations for which they were intended, the programme is likely to have positive short-term **effects** or **outcomes**, for example increased condom use with casual partners, reduced needle-sharing among drug injectors, or later age at first sex among young people. These positive short-term outcomes should lead to changes in the longer-term **impact** of programmes, measured in fewer new cases of STIs or HIV, or less HIV-associated death.

Monitoring

Monitoring is the routine tracking of priority information about a programme and its intended outcomes. This is likely to include monitoring of inputs and outputs through record-keeping and regular reporting systems as well as health facility observation and client surveys. Data are usually compiled at the district level and later forwarded to the national level to be aggregated. Such monitoring is called programme, process or output monitoring.

The linked interpretation of data from different sources is a key component of useful monitoring systems. Often, one indicator alone will be unconvincing – this is especially true of indicators that rely on self-reported data in sensitive areas such as extra-marital sex. The advocacy value of an indicator showing increased self-reported use of condoms is greatly strengthened if it is presented together with data showing an increase in condom distribution and a reduction in the caseload at STI clinics.

In tracking the status of HIV infection, the behaviours that spread it and the strength of different areas of response, monitoring indicators function like the "vital signs" of the HIV epidemic at a district, regional or national level. They help programme managers determine which areas are in need of greater effort, and flag questions which might contribute to an improved response but that can only be answered by more refined outcome research methods than those used in routine surveillance and monitoring.

Monitoring can also include the tracking of short-term programme outcomes and long-term impact. Such data frequently come from surveillance systems. **Surveillance** is the routine tracking of disease (disease surveillance) or, less commonly, risk behaviour (behavioural surveillance) using the same data collection system over time. Surveillance helps describe an epidemic and its spread, and can contribute to predicting future trends and targeting needed prevention programmes. In the case of HIV, surveillance systems typically track impact in terms of HIV and sometimes STI prevalence, and outcomes in terms of sexual risk behaviour. It is typically performed at both the district and the national levels.

Evaluation

Evaluation is a collection of activities designed to determine the value or worth of a specific programme, intervention or project. That means being able to link a particular output or outcome directly to a particular intervention. There are three sequential levels or phases of evaluation. The first phase – **process evaluation** – involves the assessment of the programme's content, scope or coverage, together with the quality and integrity of implementation. If the process evaluation finds that the programme is not even being implemented, or is not reaching its intended audience, then it is not worth going on to the next phase of evaluation. If the reality is that there is no programme, then the programme cannot be having any effect. However if process evaluation shows progress in implementing the programme as planned, then it is worth going ahead with an evaluation of short-term outcomes, a phase known as **outcome evaluation**. (In HIV prevention, HIV-related knowledge, attitudes and beliefs have conventionally been considered outcomes, as well as HIV-related behaviours. But as discussed on page 15 (Framework for indicator selection), an increase in knowledge about HIV can only be translated into lower infection rates through changes in sexual or drug-taking behaviour. This guide therefore does not consider simply monitoring changes in knowledge, attitude, and beliefs to be able to provide evidence of

the effectiveness of a specific program. Outputs of programme efforts to increase knowledge are important, but cannot lead directly to changes in impact without first being reflected in an outcome indicator such as higher levels of condom use or lower levels of sexual activity.)

What is the difference between outcome monitoring and outcome evaluation? Essentially, outcome *monitoring* tracks changes in outcomes following the implementation of a programme or project, but is not able to attribute those changes directly to the intervention. In outcome *evaluation*, however, the evaluation is designed specifically with the intention of being able to attribute the changes to the intervention itself. Without the appropriate evaluation design, the monitoring of outcome indicators alone cannot produce causal evidence about the effectiveness of a specific program. At the very least, the evaluation design has to be able plausibly to link observed outcomes to a well-defined program, and should also be able to demonstrate that changes are not the result of non-programme factors.

In evaluating HIV prevention programmes, if no positive changes can be seen in outcome measures such as risky sexual or drug-taking behaviour, then there is little point looking at impact measures such as HIV or STD prevalence. Even if there is a change in prevalence, the change cannot be plausibly attributed to programme activities unless it is preceded by a change in risk behaviour. Without changes in risk behaviour, observed changes in HIV prevalence may well be attributed to other factors such as rising mortality or changes in service use. However if outcome indicators show that behaviour is changing, then it is time for **impact evaluation.** True impact evaluations, able to attribute long-term changes in HIV infection to a specific programme, are very rare. Rather, monitoring impact indicators such as HIV prevalence or adult death, taken in conjunction with process and outcome indicators, are considered to be sufficient to indicate the overall impact of a national response to the epidemic. Taken together, monitoring indicators can give programme managers and decision-makers an idea of whether the sum total of all HIV-related efforts in a district, region or country is making any difference. For example, when HIV prevalence levels among young pregnant women attending antenatal clinics began to fall in Uganda, a wide range of monitoring indicators on condom distribution, condom availability, sexual activity among youth, the prevalence of multiple partnerships, and condom use were used to assess whether behavioural changes may have caused the decline in HIV prevalence among antenatal women.

2 A Monitoring and Evaluation System

Until the mid-1990s, most monitoring and evaluation has been done in a relatively piecemeal fashion. A surveillance system for HIV is often in place but not functioning well, a few behavioural studies may have been done here and there, though not necessarily using the same sampling methodologies or indicators. Very few countries are able to track changes in behaviour, and they may never be able to attribute such changes to interventions. Research studies may have contributed extra information in some areas, but the results are often not used for programmes and policy making. Extensive evaluation of a donor-sponsored project may have been carried out in an important area of programming, without the results ever being shared with others in the field. Rapid Plasma Reagin (RPR) for sero-syphilis testing may happen at local antenatal clinics (ANC) for diagnostic purposes without the results ever being passed on to the district or central level for use in monitoring. In short, the utility of much of the HIV-related measurement in a country may be lost because there is no coherent M&E system.

A coherent system has several advantages. It contributes to more efficient use of data and resources by ensuring, for example, that indicators and sampling methodologies are comparable over time and by reducing duplication of effort. Where resources are scarce, this is an important asset. Data generated by a comprehensive M&E system ought to serve the needs of many constituents, including programme managers, researchers or donors, eliminating the need for each to repeat baseline surveys or evaluation studies when they might easily use existing data. Good co-ordination should lead to better use of resources.

From the point of view of the national programme, a coherent M&E system helps ensure that donor-funded M&E efforts best contribute to national needs, rather than simply serving the reporting needs of agencies or legislatures overseas. A further advantage of co-ordination in monitoring and evaluation is that it encourages communication between different groups involved in the national response to HIV. Shared planning, execution, analysis or dissemination of data collection can reduce overlap in programming and increase co-operation between different groups, many of whom may work more efficiently together than in isolation.

The ultimate use of data and indicators for programme planning and evaluation is crucial in any M&E system. Data that cannot or will not be used should not be collected. Countries have different M&E needs, dictated in part by the state of the HIV epidemic in that country, in part by the efforts being made by the AIDS programme and in part by the resources available. Yet successful M&E systems will share common elements. A list of some of these elements is given in Panel 2.

Panel 2: Checklist of features of a good M&E system.

M&E UNIT	• An established M&E unit within the Ministry of Health • A budget for M&E that is about 10 percent of the national HIV/AIDS/STI budget • A significant national contribution to the national M&E budget • A formalised (M&E) link with the research institutions • A formalised (M&E) link with leading NGOs and donors • Epidemiological expertise in the M&E unit or affiliated with the unit • Behavioural/social science expertise in the M&E unit or affiliated with the unit • Data processing and statistical expertise in the M&E unit or affiliated with the unit • Data dissemination expertise in the M&E unit or affiliated with the unit
CLEAR GOALS	• Well-defined national programme goals and targets • Regular reviews/evaluations of the progress of the implementation of the national programme plans • Guidelines and guidance to districts and regions or provinces for M&E • Guidelines for linking M&E to other sectors • Co-ordination of national and donor M&E needs
INDICATORS	• A set of priority indicators and additional indicators at different levels of M&E • Indicators that are comparable over time • A number of key indicators that are comparable with other countries
DATA COLLECTION & ANALYSIS	• An overall national level data collection and analysis plan • A plan to collect data and analyse indicators at different levels of M&E • Second generation surveillance, where behavioural data are linked to HIV/STI surveillance data
DATA DISSEMINATION	• An overall national level data dissemination plan • A well-disseminated informative annual report of the M&E unit • Annual meetings to disseminate and discuss M&E and research findings with policy-makers and planners • A clearinghouse for generation and dissemination of findings • A centralised database or library of all HIV/AIDS/STI-related data collection, including ongoing research • Co-ordination of national and donor M&E dissemination needs

2.1 The monitoring and evaluation unit

Monitoring and evaluation of HIV/AIDS/STI programmes generally rests with the Ministry of Health at a national level. A special HIV M&E unit has often been set up within the national AIDS programme. Where the Ministry of Health has an effective health information system, HIV and the response to it can be monitored along with other diseases by a central epidemiological unit such as Thailand's Centre for Disease Control. Where the AIDS programme is steered by an inter-ministerial committee, the responsibility for co-ordination of M&E activities may be located outside the Ministry of Health, although this tends to make M&E more complicated. This co-ordination role of the national AIDS programme or its affiliates is one whose importance cannot be stressed strongly enough. Even while it is recognised that many countries have limited funding for tracking projects and inputs sponsored by different donors and researchers, maintaining an overarching picture of the inputs into the M&E system is crucial. To be sustainable, this must be in place as part of an effective and coherent national M&E system and national programmes should not hesitate to advocate for a better use of resources from both within and outside the national programme.

Clearly there is a wide variation in **funding** for HIV/AIDS and STI programmes from country to country. If spending on the programme is minimal, the amount dedicated to M&E systems for HIV will also be minimal. The reverse, however, is not always true. In some countries with relatively good resources for drugs and treatment, monitoring of the epidemic is either neglected, or funds for monitoring are allocated inefficiently. Donors wanting to see if their money is well spent often push for better monitoring and evaluation. In consequence, they also fund a disproportionate share of M&E activities. This has created anxieties for recipient countries, as the end of donor funding has in practice led to the collapse of many M&E activities. Since a good M&E system is crucial to ensuring resources are well used, it is recommended that about 10 percent of the HIV/AIDS budget be used for monitoring and evaluation activities, excluding the routine surveillance of HIV and risk behaviour. No M&E activity should be entirely donor-dependent.

Human capacity is a major constraint to M&E in many countries. While M&E units or committees do exist in many national programmes, they are generally dramatically understaffed and their work is often limited to managing sero-surveillance systems. Capacity building is vital if M&E systems are to be strengthened. If capacity cannot be maintained within the national programme, networks can be created to access outside skills as necessary. At a minimum, M&E units should have access to an epidemiologist, a statistician, a social scientist and a data manager. Since available data are often poorly packaged and communicated, the team should also include a professional communications specialist/lobbyist.

The central M&E unit should maintain a formalised link with universities and NGOs, in the form of a **technical support group** for M&E. In this group academic researchers and donors are actively involved along with partners from the government, NGOs and other national institutions. This support group complements the technical capacity of the central M&E unit. The involvement of academic institutions, NGOs and others assures that data generated by these bodies are integrated into the central M&E system. Furthermore, the credibility of information generated by the M&E unit is much higher if supported by a technical group.

Where health programmes are organised vertically, it is important that working groups on M&E include monitoring and evaluation specialists from other sectors sharing interests with the HIV programme. Specialists and programmes with a focus on reproductive health including STI care and Tuberculosis (TB) programmes, for example, are obvious sources of

data which should be integrated into the M&E of HIV/AIDS/STI programmes.

2.2 Clearly stated programme goals

It is not possible to monitor – much less to evaluate – progress towards goals unless the overall national programme goals are clear. If the national programme has no interventions in place to reduce vertical transmission, there is not much point in monitoring efforts to reduce HIV transmission from mother to child. Time and money may be better spent on tracking whether knowledge, attitudes and sexual behaviour among school children are changing following the introduction of a sexual health education programme in primary schools. An important step in developing an M&E plan, therefore, is to understand interventions and systems in place and how they are currently monitored and evaluated.

A clear statement of programme goals will generally be made in a national strategic plan or other strategy document. Such a document generally includes an overall goal (something along the lines of: "to reduce transmission of HIV and minimise its negative impact on those infected and affected") and then more specific goals for particular areas of prevention and care. These may, for example, include a reduction of sexual transmission among adolescents, the increased provision and use of quality STI care services, or the provision of social support including health care and schooling to orphans. M&E systems should be designed with the nation's stated goals in mind. Ideally the national plan should include quantifiable goals, although in practice this is often not the case.

In the earlier years of the epidemic, the key national planning instruments were WHO/GPA-supported medium term plans, usually spanning five years. Review of a medium term plan was a very useful M&E exercise in many countries. Increasingly, planning exercises involve a greater breadth of actors and take more careful note of the existing situation and of the response to date. This process, supported by UNAIDS and its partners and described in the UNAIDS Guide to Strategic Planning for HIV and AIDS, includes a comprehensive situation analysis and response review. These exercises, which often increase the resources available for data collection and analysis, are likely to provide invaluable information to complement the routine M&E system. They also provide important opportunities for the dissemination of information and for the strengthening of partnerships necessary in a solid M&E system.

2.3 Indicators

The programme goals will dictate the areas in which progress might be expected, and therefore the areas in which it might be measured. But how can "progress" in these areas be measured? This is where the choice of indicators comes in. Indicators exist or can be constructed for many areas of programming. (Details on choosing and constructing indicators will be discussed further in part three of this guide.)

What indicators should be selected? A number of guiding principles can help us choose the most appropriate set of indicators for M&E of AIDS programmes. First, we need to use a conceptual framework for M&E to select indicators and to interpret results. Second, we should consider specific qualities of the indicators, such as the link with programme goals, the indicator's ability to measure change, the cost and feasibility of data collection and analysis, and comparability with past indicators, and comparability between countries or population groups.

Framework for indicator selection

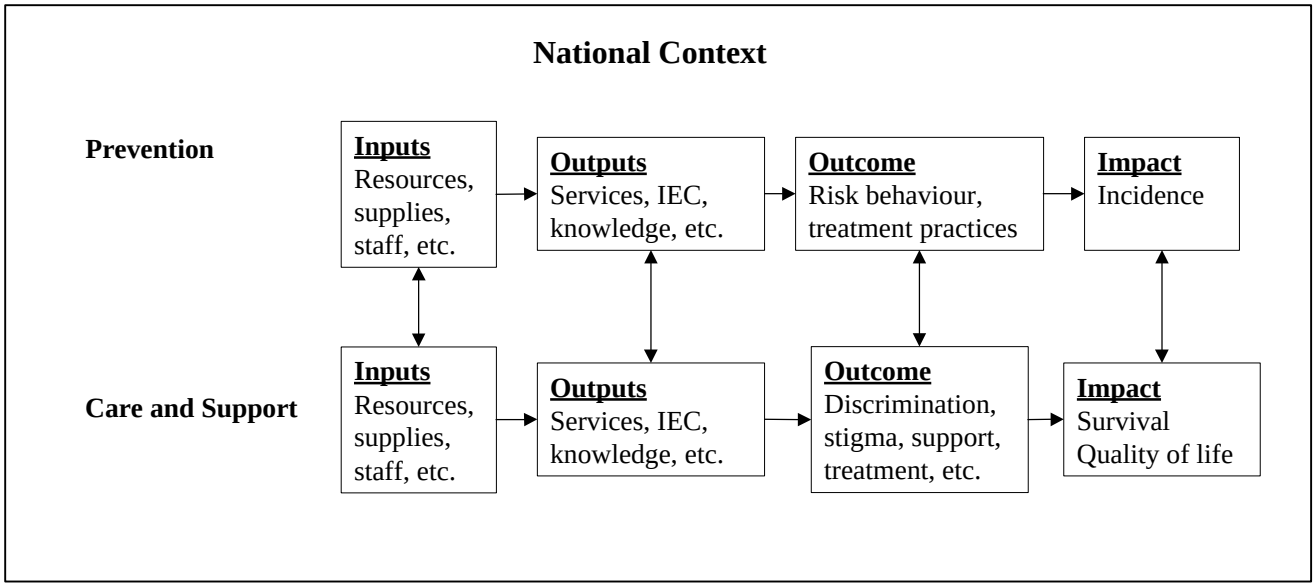
The most commonly used framework for the selection of indicators for M&E is the input-output-outcome-impact framework described in Panel 3. The indicators can measure what goes into a programme (money, number of condoms, drugs for treating opportunistic infection, test kits, training, etc. – these are known as the input indicators) and what comes out of it (trained nurses, safe units of blood, adolescents educated about safe sex, orphans supported with school fees, condom sales, etc. – these are known as output indicators). Programme outcomes are often described as better knowledge, changed attitudes, adoption of safer sexual behaviour, etc., and ultimately such outcomes may have impact on HIV or STI transmission.

The input and output of programmes and the extent to which outputs lead to short-term outcomes (such as behavioural changes or better STI treatment practices) are influenced by the context in which the programme operates. This context includes socio-economic factors, and health system factors, but also the level of political commitment. For instance, introducing the syndromic approach for STI treatment by training of health workers and improving drug supply is likely to be more successful in the context of a strong health system with well-paid workers than in a low-coverage weak health system. Promotion of condoms may be more effective if the policy and religious climate is favourable to condom use.

Short-term outcomes for HIV prevention programmes can be defined more strictly by using the same logic as that used in the proximate determinants frameworks used extensively in the study of the determinants of fertility and of child mortality. In this framework an outcome (or proximate determinant) must have two features: it can be changed by behavioural changes (and interventions), and, if it changes, it must have a direct effect on HIV transmission. Knowledge of HIV transmission is not a programme outcome indicator but an output indicator, since it has no direct effect on HIV transmission. Only if better knowledge leads to adoption of safer sexual practices can a reduction in HIV transmission be achieved.

Based on infectious disease epidemiology, several factors affect the spread of HIV and can be defined as programme outcomes:

Panel 3: Framework for monitoring and evaluation of AIDS programmes.



- *Risk of transmission per contact*: affected by condom use, by the presence of other STIs, by the age and sex of the uninfected person, by type of sexual practices, by the stage of the seropositive person's infection and by injecting practices
- *Risk of sexual or blood contact with an HIV infected person:* affected by the overall prevalence of HIV in the population, the number of contacts a person has, and the characteristics of those contacts, including their age and their levels of risk behaviour, as well as by needle exchange and drug preparation practices; risk of receiving contaminated blood: affected by blood screening and transfusion practices
- *Duration of infection:* affected by the treatment and care available for infected people

Social, cultural and economic context affect behaviour as well as programme implementation. They do not, however, greatly affect the link between behaviour and infection. If risk behaviours change, changes in new infection rates must inevitably follow, whatever the country context.

This specification of programme outcomes is most relevant to the prevention component of national AIDS programmes. Obviously, many national programmes do more than just HIV prevention work: they also try to care for people who are infected with the virus, and to reduce the impact of the epidemic on families and communities. These programmes, too, affect the proximate determinants of infection. Better care for an HIV-infected person means a longer, healthier life. Therefore, success in the care component of AIDS programmes can be measured in lower morbidity and mortality – the "impact" level indicator for care. But it also may mean that infected people remain in the pool of infectious partners, increasing the chances of epidemic spread. Many aspects of care and support aim to increase the quality of life of people with HIV, and do not directly affect the course of the epidemic. It is, however, recognised that there is a strong link between care and prevention programmes which is just now becoming a focus for attention among programme managers. Many aspects of care and support programmes also feed back into indicators at the context level and the success of care and support programmes depends upon the context in which they operate. For example, many programmes attempt to reduce the stigma surrounding HIV infection. Programmes address stigma mostly because stigma may lead to active discrimination against HIV-infected people. But addressing stigma has a wider implication for prevention efforts. Where HIV is highly stigmatised, people may avoid condoms simply because they do not want anyone to think they are concerned about their own HIV status. A reduction in stigma surrounding HIV produces a more favourable context in which programme inputs and outputs might affect behaviours. In this example stigma reduction could contribute to an increase in condom use, with a direct effect on the likelihood of transmission per act of sex, and therefore on HIV incidence. Another example: prevention programmes are beginning to provide services to reduce transmission of HIV infection from mother to child. Since little can be done to save the life of the mother, a reduction in HIV incidence among children born to HIV-positive mothers leads inexorably to an increase in orphanhood. Monitoring success in this part of the national prevention effort will illustrate the need to plan for more care and support services for orphans.

As links between care and prevention become clearer, the framework for monitoring HIV prevention programmes will certainly expand to include care and support components of national AIDS programmes. The prevention framework, however, already provides a good starting point for considering the measurement of HIV-related indicators.

Selection of indicators

Good indicators for the M&E of AIDS programmes need to be relevant to programmes, feasible to collect, easy to interpret and able to track changes over time. The choice of indicators will depend upon what the programme aims to do. Many commonly used indicators have grown out of international survey programmes such as Demographic and Health

Surveys (DHS), or out of protocols promoted by international bodies such as the United Nations. While such indicators allow for comparison between different countries, some may be of limited local relevance.

As a first step, programmes should monitor their inputs and outputs. Unless these change, any change in outcome can not in any case be ascribed to programme effort. Input and output indicators are often relatively easy and cheap to collect; where they register change, they indicate the need for monitoring and evaluation at the outcome or impact level.

Indicators should be chosen to measure change in areas of programme effort. Since most national AIDS programmes tailor their responses to the state of the epidemic in their country, it follows that the appropriate indicators will also differ according to epidemic state. This is discussed in far greater detail in the section of this guide dedicated to the choice of indicators.

Needs for data collection

Ideally, indicators should be measurable with already available data. Most frequently, however, special data collection efforts are needed to construct reliable indicators. In general, the costs and difficulty of data collection increase as indicators shift from input through output and effect to impact. It should be possible to collate data for input and output indicators centrally from regular health reporting systems, whereas data for many outcome and impact indicators must be collected through surveys (or surveillance) of health facilities, or in population-based surveys. The cost and incremental benefit of more regular or more extensive data collection must also be borne in mind. It may be worthwhile to increase the sample size for sentinel surveillance so that data can be disaggregated by age, yielding important information. The trade-off may, however, be to reduce the number of sentinel sites, or to reduce the frequency of surveillance.

Why use indicators?

Tracking changes in indicators over time will help programme managers and decision-makers tell how successful the national programme is in meeting its goals. Indicators are just that – they give an indication of the magnitude or direction of changes over time. They can not, however, tell managers much about why the changes have or have not occurred, and so are not always useful for diagnostic purposes. National level monitoring systems are generally unable to do much more than track changes in behaviour or infection country-wide. When HIV prevalence falls following a reported fall in risk behaviour, and the change in behaviour follows an intervention designed to promote just such a change, it may be inferred that the national response is contributing to the fall in HIV infection. It is rarely possible however to attribute the impact directly to a particular intervention.

Most indicators are not designed to explain why a situation has changed or has failed to change – they are designed simply to measure the change. Only smaller scale qualitative studies can answer the “why” question, although understanding “why” and inquiring about “how” change occurs are essential first steps in deciding what to do about a problem. While small explanatory studies do not necessarily form part of a nation’s regular tracking system for HIV and the behaviours that spread it, they are an essential link between M&E systems and policy formulation. It is worth stressing that small explanatory studies do not yield standard indicators that are comparable across countries: by definition they are trying to explain something that is situation-specific.

Operations research also has a contribution to make. Once small-scale research studies have demonstrated that an intervention can produce the desired result under ideal research conditions (in evaluation jargon, once the efficacy of the intervention has been demonstrated), operations research puts the intervention through its paces to demonstrate its effectiveness under real world conditions. Inputs and outputs are carefully monitored in a programme context rather than a strictly research environment, and the outcome is evaluated.

Composite indicators

In many areas of health and development, there is a tendency to develop indices, composite or summary indicators, which encompass several aspects of service provision or its outcome. These summary indicators are useful in that they limit the number of statistics that need to be presented at the highest policy level, or to people who are not specialists in the field and just need a general idea of whether things are getting better or worse.

The limitation of summary indicators is that changes are harder to interpret. A higher score may mean an improvement across all components measured by the index, or may be the result of a massive improvement in one area but an actual deterioration in another. Programme managers, who need to know about the performance of all components, will be interested in disaggregated data that allow them to see progress in each area of service provision separately. A good example is the WHO/GPA prevention indicator 6, which is correct management of STI patients using the syndromic approach. Correct management is defined as sound history taking, physical examination *and* appropriate treatment.

The history taking and examination practices may go up significantly, but if treatment practices don't improve because drugs are not available, then the best training programme in the world will have little effect on the composite indicator. The good news is that the same data set can usually meet both sets of needs – it is just a matter of aggregating or disaggregating the data. It is important to bear the potential uses in mind when designing the data collection instrument and in analysis. Aggregation too early in the process of data collection or analysis may mean that disaggregated indicators cannot then be calculated to meet the needs of programme or project managers.

2.4 A data collection and analysis plan

Once a decision has been made about what to measure, a coherent plan must be made. This plan foresees all necessary indicators and takes into account all major data collection efforts within the country, leading to the most efficient use of resources in data collection. For example, a large and nationally representative household survey on reproductive and sexual health may be planned. Such surveys are expensive and generally infrequent; they represent an opportunity to collect a range of data that may be important for monitoring progress in the national programme. They may, for instance, be expanded to include questions on antenatal care service use which could be used in the analysis of HIV prevalence data, or questions on orphans within the household which may be used in the analysis of orphan support data. The best-known international household survey programme is the Demographic and Health Surveys (DHS). In many developing countries, DHS surveys are conducted once every five years or so. In addition, regular census rounds, typically held every 10 years, can include questions which can help monitor some areas of programming, especially demographic and household impact.

The inclusion of an AIDS module in the DHS may be sufficient to obtain data on a number of key indicators at the national and sub-national level. Therefore, if possible, the timing of the last and next DHS should be taken into account in devising a data collection plan.

Data collection plans should not forget to include data that are already collected by agencies not directly involved in HIV work, and that can help in monitoring HIV-related trends or behaviours. Data generated by TB programmes can be useful in illustrating trends in HIV, particularly in the male population where sentinel surveillance data for HIV is scarce. Reproductive health programmes may already have data on service use or sexual behaviour which can eliminate the need for some data collection in general population surveys or health facility surveys. The data collection plan should stipulate systems by which data from other sources will be collected, reported and analysed by the M&E system for HIV.

A data collection plan will detail the sampling frame and the frequency of data collection. It will stipulate who is responsible for what, how much it will cost and who will pay. Since few countries have the financial or human resources to collect every bit of data they would like to monitor their programmes, the process of detailing responsibilities and a budget will often lead to a re-examination of priorities.

A national M&E system should act as a clearinghouse for both generating and disseminating data. A formal mechanism for screening data collection efforts can ensure that whatever is collected best meets the country's M&E needs. In general, every extra layer of bureaucracy carries with it the potential for unnecessary delays. The "clearinghouse" function should not be viewed as an approval process. Rather, it should be a registration and rapid review mechanism that ensures that the national programme is aware of all data collection efforts that could contribute to national needs. It also allows the programme to check that suggested indicators conform to the national standards chosen by the programme, so that comparisons can be made between different populations and across time. This is especially useful in countries where responsibility for data collection has devolved to the provincial or district level.

A centralised database or library of all HIV/AIDS/STI-related data collection contributes immensely to the efficiency of M&E efforts. What has already been done should be noted and tracked to avoid duplicating studies unnecessarily. Biological and behavioural data generated by the second generation surveillance system, baseline studies, academic research and project evaluation reports should all be centrally filed and universally available. (Tracking and accessing evaluation reports are the most problematic, since many government agencies, NGOs and donor agencies involved in programming are reluctant to share evaluation reports, especially if the project in ques-

tion has achieved less than spectacular results.) The database should list ongoing data collection efforts as well as those already completed, to avoid the duplication of studies before their results are published. It is also exceptionally useful to keep a record of research protocols and questionnaires so that they can be repeated to maintain consistency between populations and over time.

Unfortunately – partly because M&E of HIV/AIDS/STI-related interventions have been so fragmented to date – donors all have their own institutional requirements. Most programme managers are all too familiar with a repetitive and seemingly endless stream of reporting forms, log frames and mid- and end-of-cycle evaluations. Each of these may require indicators which differ only marginally but which require a new data collection effort each time. Even when donors are funding the data collection, the cost in time and national expertise of meeting all these different demands can be considerable. And yet where resources are strained, it is hard for national programmes to refuse to jump through the hoops set up by the many different supporters of the national response. A national M&E system should take into account the needs of the countries and the requirements of the donors, so that duplication of efforts and waste of resources can be minimised. Donors are increasingly aware of the need to adapt their own reporting needs to fit in with a national monitoring and evaluation system that is well designed and well co-ordinated. The indicators suggested in this guide have been endorsed by a large number of international supporters of HIV programmes.

Many countries are now engaged in decentralising their health systems, bringing decision-making, planning and resource allocation to the provincial or even district level. Part of the impetus for this move is a belief that decisions made at the local level will be more relevant to the beneficiaries than decisions made in a distant capital. In the best case scenario, monitoring of HIV prevalence and evaluation of the response at the local level does indeed provide information that is locally relevant. This information is far more likely to be acted upon in a decentralised system than more general, nationally aggregated information. Where M&E systems do function at a local level, there is still a need for central co-ordination of the M&E system. Indicators must be as compatible as possible and information exchange should be guaranteed between different provinces or districts. In addition, core indicators should be compiled on a national level for advocacy with the central government as well as to contribute to the information needs of the international supporters of the national response. Therefore, a national M&E system plan should include guidance to districts on indicators, data collection and analysis and dissemination.

Multisectoral response to HIV

In several countries attempts are being made to expand the response to the HIV/AIDS epidemic from the health sector to a "multisectoral approach." Planning, and in some countries implementation, of HIV prevention and AIDS care programmes has been broadened to include all social and economic sectors. To date, multisectoralism has been more talked about than implemented. However, if a substantial proportion of HIV-related programmes do indeed shift from health ministries to other sectors, multisectoralism will provide new opportunities to gather more data and have a broader basis to influence policy making. For example, data from the Ministry of Education may provide information about the schooling of orphans. On the flip side, the involvement of multiple sectors will also complicate the task of monitoring and evaluation. The more diffuse the response, the more important it becomes to have a strong centrally co-ordinated M&E system to which each sector can contribute information.

Cross level linking of indicators

A data collection and analysis plan should also focus on the linking of indicators at the different levels of measurement. Programme outputs should be interpreted in relation to programme inputs. Programme outcomes, such as an increase in self-reported condom use, should be analysed in relation to changes in programme

outputs, such as numbers of condoms sold. HIV prevalence trends should be interpreted in association with changes in sexual behaviour. The latter is one of the key principles of the "Second Generation Surveillance" initiative.

This global effort aims to strengthen or revitalise existing HIV surveillance systems and to improve the linking of behavioural data with biomedical surveillance for HIV. Panel 4 describes the main features of second generation surveillance.

2.5 A data use plan

There is no point at all in collecting data that cannot or will not be used. The ultimate use of the data should guide the design of a coherent M&E system, especially the selection of the most appropriate indicators in a country. A clear plan for data use and dissemination will include a stipulation of the end users for each indicator, and how the data will be presented to them. It may include a plan for developing a shared database of information, and for sharing data between programme elements, researchers, donor agencies and others. A framework for regular dissemination of information to the public may also be included. In general, the data generated by M&E systems are used in three major ways: advocating for action; planning, revising and improving programs; and attributing change in the epidemic to interventions undertaken.

Advocating for action

Good information about levels of HIV infection and the risk behaviours that spread it are critical to generating a will to act. Information about the social and economic impact of the epidemic is also powerful in this regard. In planning M&E systems, public health officials should consider individuals or groups with the power to act to change the course of the epidemic. Public health officials should generate data most likely to persuade those individuals or groups to act and should package it to meet the needs of their audience.

Planning, revising and improving programmes

Both monitoring systems and evaluation studies generate information that should be used to improve existing programmes and to plan more successful interventions in the future. Monitoring information can be fed into programming immediately to correct for weaknesses and improve performance. This mechanism can provide information on whether an intervention is on track or on budget, or whether it is producing the desired number of trained nurses or the targeted increase in condom sales outlets. Evaluation results can be used to inform future programme design, prompting a decision to replicate an intervention in other areas, or to scrap it altogether because it is expensive and not making any difference.

Information on HIV and STI prevalence and risk behaviour generated by second generation surveillance systems should produce a swift response from programmers, indicating new populations at risk and suggesting behaviours most in need of addressing through intervention.

Attributing change to interventions and generating resources

It is said that nothing succeeds like success. If successes in HIV prevention or care are not measured and recorded, the opportunity to generate further success is lost. Evaluation studies demonstrating the success of particular interventions or of national prevention efforts are instrumental in keeping HIV high on the agenda. They encourage increased funding of prevention and impact mitigation efforts and may bring in more resources for monitoring and evaluation.

Success stories should never be exaggerated, however. They demonstrate successful strategies rather than outright victory. A feeling that the war has been won often leads to a drop in interest and in resources. Many countries undertake comprehensive programme reviews as part of their regular planning cycle. As countries move to a more strategic, less normative planning framework for HIV programmes,

reviews and the situation analysis that precedes them become broader in scope. Planning also involves a broader spectrum of people, bringing representatives of all sectors of government together with others involved in the response. Strategic planning exercises provide an excellent opportunity to review the M&E framework itself, to ensure that indicators remain relevant and cover all priority areas of the response and to set up mechanisms for the regular sharing of data where they do not already exist.

Panel 4: Second Generation Surveillance Systems: What's new?

Second generation systems look at behaviour as well as HIV infection

Traditional surveillance systems tracked HIV infection or other biological markers of risk such as STIs. Since HIV infection among adults must be preceded by one of a limited number of behaviours, such as unprotected sex with an infected partner or injection with contaminated needles, we know that if these behaviours change, there will be a change in the spread of HIV. Second generation surveillance systems monitor risk behaviours, using them to warn of or explain changes in levels of infection. Thus, second generation surveillance uses data from behavioural surveillance to interpret data gathered from sero-surveillance efforts.

Second generation systems are tailored to the type of epidemic

As the diversity of HIV epidemics becomes more apparent, it also becomes evident that there is no "one-size-fits-all" surveillance system. Efficient surveillance of a predominantly heterosexual epidemic in a country where one adult in six is infected will differ radically from surveillance in a country where HIV infection is growing rapidly in drug injectors but has yet to spread to the general population. In general, surveillance systems can be divided into three broad types directly related to the type of epidemic:

- In *generalised* epidemics where HIV is over one percent in the general population, surveillance systems concentrate on monitoring HIV infection and risk behaviour in the general population.
- In *concentrated* epidemics where HIV is over five percent in any sub-population at higher risk of infection (such as drug injectors, sex workers, men who have sex with men), surveillance systems monitor infection in those groups and pay particular attention to behavioural links between members of those groups and the general population. They might ask, for example, whether male sex workers have wives or girlfriends, or whether drug users finance their habit through sex work. In these situations, surveillance systems also monitor the general population for high-risk sexual behaviour that might lead to rapid spread of the virus if it were introduced.
- In *low-level* epidemics where relatively little HIV is measured in any group, surveillance systems focus largely on high-risk behaviours, looking for changes in behaviour which may lead to a burst of infection. Such changes have recently been recorded in several Eastern European countries, for example, where a surge in injecting drug use was followed by very rapid growth in HIV infection.

Second generation systems use data in ways that maximise their power to explain the epidemic

A classic antenatal clinic (ANC) surveillance system may show that HIV prevalence among women 15-49 years attending ANCs rose rapidly from 0 to 12 percent over eight years, and then levelled off. In the rising phase the upward trend meant more new infections (increasing HIV incidence), probably at all ages. But once the curve flattens out, the explanatory power of that single figure is lost. Prevalence may be unchanged for any number of reasons: because as many women are dying as are becoming newly infected, for example, or because many infected women are no longer becoming pregnant and so have dropped out of the pool of women tested at sentinel sites.

Some of these problems of interpretation can be reduced by concentrating analysis to women in the youngest age groups, who are less subject to biases of mortality or reduced fertility and whose infection is more likely to reflect recent trends in the epidemic. Analysing the ANC data together with data from other sources, such as general population surveys or behavioural surveys, also increases the explanatory power of sero-surveillance systems. The need to focus on young women in antenatal clinics was acknowledged several years ago when WHO/GPA designated two of its prevention indicators to HIV and sero-syphilis prevalence among women 15-24 years.

Second generation systems make the best possible use of resources

By concentrating surveillance in areas where it provides the most information and tailoring systems to a country's capacity, second generation surveillance ensures that money and expertise are used as efficiently as possible. For example, sentinel sites are carefully chosen to provide reliable information from a minimum number of sites, while sampling for behavioural data collection takes sentinel sites into account so that strong inferences can be made in comparing behavioural and serological data sets.

Strengthened surveillance systems also make an effort to ensure that all data gathered are actually used, something which, perhaps surprisingly, has not been the case in the past. Syphilis data from ANC clinics have rarely been analysed for surveillance purposes, for example. Despite the association between HIV and TB, TB surveillance data are rarely included in HIV surveillance reports. For more information see *www.unaids.org*.

3 Indicators

An array of indicators has been used in attempting to measure HIV- and AIDS-related interventions. The single greatest effort to standardise indicators was made by the WHO/Global Programme on AIDS, which in 1994 published a methods package for the evaluation of HIV prevention programmes. The package identified 10 prevention indicators, known as PI1 – PI10, using five different methods of data collection. Many countries have used the PIs at some time, often adapting them to local circumstances. Only rarely have they been measured repeatedly over time. And yet PIs were designed principally as a means of tracking trends over time.

One of the reasons that PIs have not been widely repeated over time is that some countries feel the indicators do not provide the data most relevant to their programme assessment and planning needs, particularly in an evolving epidemic. What's more, a national-level survey of all 10 PIs is an expensive exercise – where outside funding for such an exercise has not been available, countries have tended to substitute other measures on an *ad hoc* basis. Other countries have no M&E plans that include the PIs.

In several countries, recent DHS surveys have included an AIDS module. However the questions have tended to differ slightly from those asked in a population-based survey designed to construct PIs, so the prevention indicators could not always be calculated from DHS data. While the factors being measured remain largely the same – high-risk sexual behaviour or access to quality STI care, for example – a plethora of different data collection methods, denominators, reference periods, etc. have been used or proposed. This has led to difficulties in comparing trends over time within countries, and has of course made comparison of basic measures between countries all but impossible.

One of the principal aims of this guide is to reassert the importance of choosing standard indicators and measuring them repeatedly over time. As countries review their experiences in monitoring and evaluation, they have identified the strengths and weaknesses of existing measures and staked out areas where new indicators are needed. The indicators suggested in this section are based on this review process. Protocols for the measurement of all the indicators in the main part of the guide are already available, and most have been field tested.

This section is organised by major area of programme intervention. Each section discusses briefly what HIV/STI prevention and AIDS care programmes aim to provide and/or achieve in a given area, in other words: what is there to measure? Key questions are identified to focus on key areas of programming. They are followed by a review of measurement challenges in the area, and proposed indicators. Each indicator is described in the context of programme goals. The data requirements are summarised, and reference is made to the questionnaire(s) or protocol(s) in the toolkit which would provide the necessary information to construct the indicator.

The tools are available from the Web site (*www.cpc.unc.edu/measure*; *www.unaids.org*) or on CD-ROM.

The choice of appropriate indicators will vary according to the goals of the programme, which will in turn be determined by the epidemic state. In the past, a single set of "core" indicators has been proposed for all epidemics. But the diversity of epidemics has grown. It is now thought more appropriate to suggest two different sets of "core" indicators – one for low-level and concentrated epidemics, and another for generalised epidemics. Countries will supplement these with the appropriate additional indicators, which may be drawn from the list that follows. There is a substantial amount of overlap between the core indicators for the different epidemic states. An overview of the indicators is given in Panel 5.

Panel 5: Overview of indicators by programme areas, tools for measurement, and priority for different epidemic states.

(C=Core indicator; A=Additional indicator)

Programme area Indicator	Tools for Measurement	Priority Generalised Epidemic	Priority Concentrated/ Low level
Policy			
1 AIDS Programme Effort Index (API)	API questionnaire and protocols	**C**	**C**
2 Spending on HIV prevention	Under development		
Condom availability and quality			
1 Condoms available, nation-wide	WHO condom protocol (PI2)	**C**	**C**
2 Condoms available, retail	MEASURE Evaluation/WHO/PSI Compiled Condom Availability and Quality Protocol (for indicators 2 and 3)	**C**	**A**
3 Condom quality		**C**	**C**
Stigma and discrimination			
1 Accepting attitudes toward HIV+ people	Surveys (UNAIDS, DHS, FHI)	**C**	**C**
2 Employers not discriminating	UNAIDS protocol on discrimination	**C**	**C**
Knowledge			
1 Knowledge of HIV prevention	Surveys (UNAIDS, DHS, FHI)	**C**	**C**
2 No incorrect beliefs about HIV	Surveys (UNAIDS, DHS, FHI)	**C**	**C**
3 Knowledge of HIV prevention among MSM	FHI BSS among MSM*		**C**
4 Knowledge of HIV prevention among IDUs	FHI BSS among IDUs*		**C**
5 Knowledge that MTCT can be prevented	Surveys (UNAIDS, DHS, FHI)	**C**	
Voluntary counselling and testing			
1 People who requested test and received results	Surveys (UNAIDS, DHS, FHI)	**C**	**A**
2 Districts with VCT services	District assessment – no specific tool	**C**	
3 Quality of counselling and referral	UNAIDS VCT protocol	**C**	**A**
4 VCT centres with minimum conditions	UNAIDS VCT protocol	**C**	**A**
5 Quality of VCT laboratories	WHO testing protocol, blood safety protocol	**A**	**A**
Mother to child transmission			
1 Pregnant women counselled and tested	Surveys (UNAIDS)	**C**	
2 ANC clinics offering and referring for ANC	UNAIDS MTCT protocol; VCT protocol	**C**	
3 Quality HIV counselling for pregnant women	UNAIDS MTCT protocol; VCT protocol	**A**	
4 Provision of ARV therapy	UNAIDS MTCT protocol	**A**	
Sexual negotiation and attitudes			
1 Women's ability to negotiate safe sex	Surveys (UNAIDS, DHS, FHI)	**A**	
Sexual behaviour			
1 Higher risk sex in the last year	Surveys (UNAIDS, DHS, FHI)	**C**	**C**
2 Condom use at last higher risk sex	Surveys (UNAIDS, DHS, FHI)	**C**	**C**
3 Commercial sex in last year	Surveys (UNAIDS, DHS, FHI)	**A**	**C**
4 Condom use by clients at last paid sex	Surveys (UNAIDS, DHS, FHI)	**A**	**C**
5 Condom use by sex workers with last client	FHI BSS for sex workers*	**A**	**A**

Programme area Indicator	Tools for Measurement	Priority Generalised Epidemic	Priority Concentrated/ Low level
6 Higher risk male-male sex in last year	FHI BSS for men who have sex with men*		**C**
7 Condom use at last anal sex between men	FHI BSS for men who have sex with men*		**C**
Young people's sexual behaviour			
1 Median age at first sex	Surveys (UNAIDS, DHS, FHI BSS-youth*)	**C**	
2 Young people having premarital sex	Surveys (UNAIDS, DHS, FHI BSS-youth*)	**C**	**A**
3 Condom use at last premarital sex	Surveys (UNAIDS, DHS, FHI BSS-youth*)	**C**	**A**
4 Young people with multiple partners	Surveys (UNAIDS, DHS, FHI BSS-youth*)	**C**	**A**
5 Condom use at last higher risk sex	Surveys (UNAIDS, DHS, FHI BSS-youth*)	**C**	**A**
6 Condom use at first sex	Surveys (UNAIDS, DHS, FHI BSS-youth*)	**A**	**A**
7 Age-mixing in sexual relationships	Surveys (UNAIDS, DHS, FHI BSS-youth*)	**A**	
Injecting drug use			
1 Injecting drug users sharing equipment	FHI BSS for injecting drug users*		**C**
2 Injecting drug users never sharing equipment	FHI BSS for injecting drug users*		**C**
3 Drug injectors using condom at last sex	FHI BSS for injecting drug users*		**A**
Blood safety / nosocomial transmission			
1 Screening of blood units for transfusion	MEASURE blood safety protocol	**C**	**C**
2 Reduction of blood transfusions	MEASURE blood safety protocol	**A**	**A**
3 Districts / regions with blood bank	MEASURE blood safety protocol	**C**	**C**
4 Accidental transmission in health care settings	MEASURE service provision assessment (SPA)	**A**	
STI care and prevention			
1 Appropriate diagnosis and treatment of STI	WHO/UNAIDS STI facility survey	**C**	**C**
2 Advice on prevention and HIV testing	WHO/UNAIDS STI facility survey	**C**	**C**
3 Drug supply at STI care services	WHO/UNAIDS STI facility survey, SPA	**C**	**A**
4 Treatment seeking for STI	Surveys (UNAIDS, DHS, FHI)	**A**	**C**
Care and support			
1 Medical personnel trained in AIDS	MEASURE SPA, training statistics	**A**	**A**
2 Health facilities with capacity to deliver care	WHO protocol for care and support	**C**	
3 Health facilities with drugs in stock	WHO protocol for care and support, SPA	**A**	
4 Households helped with care of young adults	Survey (UNAIDS)	**C**	
5 Households helped with care of orphans	Survey (UNAIDS)	**A**	
Health and social impact			
1 HIV prevalence among pregnant women	WHO/UNAIDS protocols for surveillance	**C**	**C**
2 Syphilis prevalence among pregnant women	WHO/UNAIDS protocols for surveillance	**C**	**C**
3 HIV prevalence in sub-populations at risk	FHI sampling manual	**A**	**C**
4 Prevalence of orphanhood	Surveys (UNAIDS, DHS)	**C**	
5 Schooling of orphans	Surveys (UNAIDS, DHS)	**A**	

* Part of the Behavioral surveillance surveys (BSS): Guidelines for repeated behavioral surveys in population groups at risk for HIV

3.1 Policy and political commitment

HIV and AIDS have always been politically sensitive issues. They are spread by behaviours that were initially associated with marginalised groups. Even when it became clear that heterosexual transmission was the overwhelming mode of spread in countries most severely affected by HIV, policy-makers still hesitated to act. Sex with non-monogamous partners may be common, but it is often publicly frowned upon. Fearing they would lose support from religious or conservative constituencies, many governments were reluctant to recognise the problems posed by HIV or to commit resources to responding to those problems.

Decades of experience in other highly politicised areas such as family planning have shown that strong political commitment is crucial to programme success in such situations.

Programme goals

In many countries, AIDS programme staff and even Ministry of Health staff need no convincing of the importance of efforts to prevent HIV and care for those infected and affected. Their commitment, however, is not always reflected in other parts of government. AIDS programme managers often work to increase political commitment at other levels of government. They may do this through joint planning exercises, by collecting and presenting data to the head of state or cabinet ministers about the virus and the factors that spread it, by holding educational sessions for legislators, religious leaders, business people and others who may influence policy-makers at the top levels of government. National programme managers are often supported in these efforts by external agencies which believe that strong political commitment is critical to successful AIDS programming.

One of the goals of external agencies and programme managers is to convince senior policy-makers to recognise and understand the nature and magnitude of the problem, and then – where merited – to put the problem firmly on the national agenda. That means committing funds and other resources to responding to the epidemic. It means turning the rhetoric of multisectoralism into a reality. It means breaking the silence surrounding the epidemic, drawing the attention of citizens to the contribution they can make to curb the epidemic and its consequences.

More political commitment to dealing with HIV leads inevitably to a stronger national response and funds allocated to addressing the epidemic and care in several ways. A stronger national response also means there will be more activity to monitor and evaluate. Recording changes in political commitment may act as a reality check for other M&E efforts – if commitment is low and showing no signs of rising, it may be optimistic to expect a massive impact from the rest of the national response.

Key questions

- Do national leaders publicly recognise the importance of HIV/AIDS prevention and care?
- Do national leaders follow up verbal commitment with budgetary commitment?
- Are verbal and budgetary commitments to responding to HIV and AIDS translated into effective programmes?

Measurement challenges

The greatest difficulty with measuring political commitment is finding any objective measure. Most measures tend to include some subjectivity – that means they are of limited use for intercountry comparisons but, much more importantly, can be difficult to interpret in measuring trends over time.

Many policy measures are of the yes/no variety: does a stated policy exist in a given area, does joint planning exist? These may be helpful in pointing out gaps where advocacy or policy development work is most needed, but they are not very helpful in tracking incremental changes in the policy "climate" over time. It is also difficult to discern from yes/no indicators what the quality of the policies is. A

national strategic plan may exist, and it may be based on a broad consultation of interested groups. Its contribution to the national response depends not on its existence, however, but on the extent to which it is implemented. That is much harder to measure, and can certainly not be captured in a yes/no indicator. It may, however, be reflected in national accounts: within a strategic plan, programme elements that are backed up by a line item in a ministerial budget are more likely to be implemented than elements that are not financed.

In the field of family planning and reproductive health, composite indicators have been constructed to reflect the level of political support for the provision of reproductive health services. These are based on the opinion of a designated mix of "experts", chosen to reflect a variety of institutional and professional views about a number of different aspects of political context and commitment. A similar indicator is being developed for AIDS programmes (the AIDS Programme Effort Index); it is discussed further under Policy Indicator 1.

Following the logic that governments put their money where their real interests are, budget allocations can provide a useful indicator of changes in political commitment over time. However, funding-based indicators are not always useful for intercountry comparisons, since funding for AIDS programmes comes from various sources, both inside and outside the government.

A straightforward measure such as the proportion of the regular health budget allocated to AIDS may overlook the fact that a government knows it can more easily get donor funding for AIDS than for other health issues, and allocates its own budget accordingly. This dynamic may affect another potential indicator of political commitment: the proportion of all spending on AIDS that comes from the national coffers.

While a dramatic rise in domestic funding for HIV almost certainly reflects an increase in political commitment, the reverse is not necessarily true, since an increase in political commitment could equally be reflected in an aggressive search for outside funding for HIV-related activities. In addition, an increased funding level from either outside the national programme or from within does not automatically translate to a better response – how the funding is put to work is also important.

Precisely because of the political sensitivity of HIV and AIDS and the relative weakness of many AIDS programmes within the government structure, it may be more difficult for programme staff to calculate policy indicators than indicators in other areas of programming such as STI care or sexual behaviour. This is the area of M&E most likely to require outside evaluation, though clearly such an evaluation should be conducted together with the national programme.

Policy Indicator 1
The AIDS Programme Effort Index (API)

Core indicator for all epidemics

Definition

The average score given to a national programme by a defined group of knowledgeable individuals asked about progress in over 90 individual areas of programming, grouped into 10 major components

Measurement tools

The AIDS Programme Effort Index (API) questionnaire and protocol

What it measures

The AIDS Programme Effort Index is a composite index designed to measure political commitment and programme effort in the areas of HIV prevention and care. It tries to capture many of the inputs and outputs of a national HIV/AIDS programme. The score is made up of 10 main components of an effective national response: political support, policy formulation, organisational structure, programme resources, evaluation and research, legal and regulatory aspects, human rights, prevention programmes, care programmes and service availability.

How to measure it

The API uses key informants from a designated mix of institutions to give opinions about central areas of commitment and programming, compiling an index out of scores given in various areas. The score, which is calculated as a percentage with zero indicating no programme effort and 100 indicating maximum effort, may be converted into a grade to minimise informant variation. Suggested grades range from very weak and weak through moderate and strong to very strong, depending on the range in which the numerical scores fall.

Strengths and limitations

The major concern surrounding the API is its subjectivity and its reliability. The outcome depends entirely on the choice of informants and informants will likely change from year to year. Since the indicator is still under development, the choice of informants has not yet been standardised.

Questions have also been raised about the utility of a single composite score, in which improvements in some areas may be masked by deterioration in other areas. For diagnostic as well as monitoring purposes, it may be more useful simply to publish the indices separately by category. The separate category scores may stand alone as indicators, although for several areas of programme effort this document proposes alternatives which are based on measured parameters rather than expert opinion and may therefore be more useful in tracking trends over time.

One area in which the API process may yield a particularly useful indicator is in the area of policy formulation (Section 20 of the API protocol).

Policy Indicator 2

Spending on HIV prevention programmes

At the time this guide went to press, this indicator was still under development. A protocol has been developed by the Latin American AIDS body SIDALAC. It has been used successfully in several Latin American countries, including Brazil, Guatemala, Mexico and Uruguay. By early 2000, it had not yet been field tested in any other continent. National accounting structures in Latin America are fairly well developed, and access to information about budgetary allocations is relatively easily accessible. The same may not be true in other regions. It is felt that the methodologies developed need to be field tested in a wider variety of settings before this can be recommended as a core or additional indicator.

Proposed definition

The amount of money allocated in national accounts for spending on HIV prevention and care programmes, per adult aged 15-49

Measurement tools

SIDALAC protocol for the measurement of National Accounts for Expenditure on HIV and AIDS

What it measures

Measures of expenditure provide an indication of the government's willingness to back up policy with the resources that enable policies to be implemented. This indicator measures resources made available by a government in its budget and national accounts for the response to the HIV epidemic.

The methodology distinguishes between money spent on prevention and care.

Strengths and limitations

This indicator is restricted to spending and budgetary allocations from national accounts. It includes money loaned by international institutions, which may in effect amount to money borrowed at 30 percent or less of current money market rates. This may be influenced by the priorities of lending institutions as well as borrowers, but since the money must eventually be paid back by national taxpayers, it is included for the purposes of this indicator.

Spending by bilateral donors, non-governmental organisations and the private sector are not included. It is recognised that in many countries, spending from these sources far outweighs spending from national accounts. It is important to bear in mind, however, that this indicator is not intended as a measure of resource availability, but as an indicator of political commitment to responding to HIV on the part of national governments. All governments reflect their political priorities in their spending and allocation of internal resources. Changes in funding allocated to HIV prevention and care is therefore a good indicator of the political importance that responding to the epidemic is accorded, compared with other priorities such as defence, education or infrastructure development.

The primary weakness of this indicator is that it does not readily capture spending on HIV prevention in other sectors. Experience to date suggests that even in countries with extremely limited access to anti-retroviral treatment, the vast majority of spending recorded is on curative services. This may reflect the fact that it is easier to capture spending on care than spending on prevention, which may be integrated into other budget lines such as education. It is worth noting, however, that those countries that have made the most progress towards a truly integrated response – countries such as Thailand – also typically have significant budgetary line items for HIV prevention and care, in addition to the allocations made by other sectors.

Where STI and HIV prevention and care activities are well integrated into regular health sector activities at all levels, it will also be difficult to capture actual spending on HIV-related programmes. But again, the indicator is intended as one of political commitment rather than resource availability. As long as this imprecision does not affect trends over time, it will not severely limit the usefulness of the

indicator. It is, however, important to disaggregate the indicator by prevention and care spending wherever possible, since this balance may well be affected by political priorities. Increased spending on care may mask a decrease in spending on prevention activities. This would be worrying from the point of political commitment. Prevention is necessary in all countries, where as demand for care will vary according to the stage of the epidemic. A government politically committed to responding to HIV will maintain prevention spending even as care needs rise as early infections evolve into sickness and death.

This indicator is calculated on a per-capita basis for adults. It does not take into account the stage of the epidemic in a country, and is therefore far more useful for tracking trends in a country over time than for inter-country comparison. (Clearly, 10 dollars per adult spent on HIV prevention and care in a country where only one adult in 1,000 is infected with the virus may be considered more adequate than 10 dollars per adult in a country where one adult in three is infected.) In countries with reliable estimates of the number of individuals infected with HIV, it may be possible to calculate an indicator that reflects spending relative to the epidemic state. The indicator in this case would be allocations for HIV prevention and care spending in national accounts, divided by the number of people living with HIV. Any instability in estimates of the numbers of people infected may greatly affect this measure, however, and it is not recommended as a standard indicator.

3.2 Condom availability and quality

Programme goals

Since it is not sex itself but unprotected sex that spreads HIV in most countries, increasing condom use has been a central intervention strategy for many AIDS programmes. Availability and easy access to good quality condoms are a prerequisite for their use.

There are a number of dimensions to the accessibility of condoms. First, they have to be available in the country, either manufactured or imported in sufficient quantities to meet the needs of the population. Secondly, they must be distributed throughout the country and be conveniently available to the people who need them. Thirdly, they must be affordable to the people that want them. Other dimensions of accessibility include real or perceived barriers to condom acquisition such as restrictions on the age of those who can obtain them or social barriers to women or young people buying condoms.

The quality of condoms is also of great importance, since if they are of poor quality (poorly manufactured or improperly stored) they will not provide effective protection. In some cases misconceptions that condoms do not protect one from HIV transmission have been fuelled by distribution of poor quality condoms. Because increasing condom use is one of the keys to stemming the epidemic, it is essential that stocks of condoms are readily available and of high quality.

In general, AIDS programmes should try to make high quality, affordable condoms accessible to anyone who is likely to have sex, preferably at or near the venues where riskier sex is most likely to occur. For example, making condoms available at drinking and dancing establishments will make it easier for people to access them – many national programmes have begun incorporating such interventions in response to the reality of human behaviour. Measuring the effectiveness of the intervention will require new methods to include non-traditional retail and social establishments in condom distribution assessments.

The fact that condoms are available does not mean they are used. Indicators of condom use are discussed in the section on sexual behaviour.

Key questions

- Is there a national policy on social marketing of condoms?
- Are condoms consistently available within a country?
- Are condoms available to consumers at the right time, place and price?
- Are all condoms of reliable quality by the time they reach the consumer?

Measurement challenges

Condom availability ought to be among the easiest areas of programming to track. A condom is either there or it is not – surely that can be measured? Unfortunately, poor information systems, a plethora of sources of condoms and accountability problems conspire against simplicity. And barriers to accessibility other than simple absence of condoms are often subjective and therefore difficult to measure. Condoms may be widely available in pharmacies, for example. But what help is that to a woman who finds herself unexpectedly choosing to have sex with a new partner after all the pharmacies have closed? If condoms are not readily available to her at that stage, has the programme met its goals or not?

Previous attempts to measure condom availability at the peripheral level (such as by WHO/GPA Prevention Indicator 3) have combined retail surveys with survey questions asking people whether they know where they can get condoms. Responses to individual questionnaires may however be poorly correlated with actual distribution patterns. Such measurement efforts are therefore of limited use in assessing the success of condom distribution nation-wide.

All of the indicators of condom availability and accessibility could equally be used for the female condom.

Condom Availability Indicator 1

Condoms available for distribution nation-wide

(WHO/GPA Prevention Indicator 2)

Core indicator for all epidemics

Definition

Total number of condoms available for distribution nation-wide during the preceding 12 months, divided by the total population aged 15-49. This indicator was formerly the WHO/GPA Prevention Indicator 2.

Measurement tools

WHO/GPA protocol for estimating condom availability for distribution at the central and peripheral level

What it measures

The best distribution system in the world is not much help if there is nothing to distribute. The first challenge for national programmes promoting condom use is to ensure that there are enough condoms in the country to satisfy demand. This indicator measures the number of condoms available for use by those in the most sexually active age group. Where active efforts are made to promote the availability of female condoms, it should include female as well as male condoms, although the indicator should be disaggregated by condom type.

This indicator can be used together with indicators of sexual behaviour to give a powerful picture of the adequacy of condom provision. For example, if a third of all men aged 15-49 say they have had non-regular sex in the past year and 20 percent of married couples say they have used condoms to avoid pregnancy, and yet there are only three condoms available per sexually active adult per year, it can be deduced that the supply of condoms nationally is not sufficient to meet the potential demand.

How to measure it

The indicator is measured by estimating the number of condoms (male and female) available for in-country use during the last 12 months. Key informants are identified and interviewed to uncover all possible sources of condom manufacture, import, distribution and storage. Next, data are collected from all manufacturers and major commercial distributors as well as major donors, condom storage facilities, and government, parastatal and NGO bodies involved in acquiring and distributing condoms.

This indicator sums the condoms in stock nationally at the start of the 12-month period, plus condoms imported during the 12-month period, plus condoms manufactured in country during the same period, minus any exports of condoms over that period. The sum of all condoms available for use in the country during the past 12 months is then divided by the total population aged 15-49.

Strengths and limitations

The number of condoms available at the central level helps assess the adequacy of overall condom availability. It is important to note, however, that “availability” is not the same as “accessibility”, which includes dimensions of price, location and access by sub-populations at risk for unprotected sex and HIV. It is often the case that not all available condoms are distributed, or reach the individuals that most need them to protect against the spread of HIV. This indicator by itself cannot give a picture of how many “in-stock” condoms actually get distributed or used.

Ironically, efforts at the national level to encourage condom use sometimes complicate the measurement of this indicator. Many countries have deregulated condom imports in the face of AIDS, in order to maximise the number of condoms available. This means that condoms may be imported by a wide variety of companies, NGOs, donors and government departments (the health ministry, the defence ministry, etc.) without necessarily reporting numbers imported to a central body. Traditionally, there

is also a distinction between condoms distributed through family planning programmes and those distributed to reduce sexually transmitted infections. It is important to take both sources into account. If possible data need to be presented by programme, as family planning programme condoms are primarily intended for relatively low-risk acts within stable monogamous unions, while AIDS programme condoms aim at higher risk sexual contacts.

Where condom promotion activities are centred around marketing condoms at subsidised prices to people likely to be engaging in risky sex (social marketing), sales of particular brands of condoms can also provide a useful indicator of programme success. Organisations responsible for the social marketing of condoms typically keep very good records of condoms distributed down to the retail level. While these data tell only part of the story of condom availability, they provide a very low-cost source of information for the National AIDS Programme, and can be very useful for advocacy purposes. A rise in the number of condoms manufactured or imported into a country, or of condoms sold, can be useful in supporting other indicators measuring rises in self-reported condom use, or falls in self-reported STIs and eventually HIV prevalence.

Condom Availability Indicator 2

Retail outlets and services with condoms in stock

(Modified WHO/GPA Prevention Indicator 3)

Core indicator for generalised epidemics
Additional for concentrated epidemics

Definition

The proportion of randomly selected retail outlets and service delivery points that have condoms in stock at the time of a survey, of all retail outlets and service delivery points selected for survey

Measurement tools

MEASURE *Evaluation*/WHO/PSI Compiled Condom Availability and Quality Protocol

What it measures

This indicator measures actual distribution of condoms at designated points at any one point in time. It reflects the success of attempts to broaden the distribution of condoms so that they are more widely available to people likely to need them, and at locations and times when people are likely to need them.

How to measure it

A number of sites of different types are randomly selected for a retail survey. The sampling frame should be stratified to reflect sites in both urban and rural areas. Sites will be selected from a standard checklist of venues where condoms should be accessible, including bars and night clubs, different classes of retail shops (for example pharmacies, supermarkets, convenience stores, market stalls, petrol stations), STI clinics and other service provision points. Outlets that provide services to people who may find it difficult to access condoms at conventional sites – for example teenagers – should be included. The indicator is the number of sites with condoms currently in stock, divided by the total number of sites surveyed.

While the indicator gives a single summary figure, the data can also be disaggregated by outlet type. This will provide invaluable information for programme managers, and for those seeking to improve the marketing of condoms. Outlet types may be analysed by the populations they seek to serve. This provides an idea of the adequacy of efforts to meet the needs of people with potentially high-risk behaviour, such as young people or those in mobile occupations.

Strengths and limitations

The statistical departments or finance ministries of many countries conduct regular (usually quarterly) retail surveys that include price and availability data for a wide variety of commodities. These are usually conducted to help in the compilation of the consumer price index and other economic statistics, and are often contracted to private market research firms. They typically use a well-established sampling frame covering a wide variety of venues nation-wide. Where such surveys exist, condoms can simply be added to the basket of commodities for which data are collected. Certain venues (such as STI clinics, family planning clinics, etc.) may not be covered by the regular retail survey; in this case special surveys of these extra venues can be undertaken to provide the necessary extra data. Outlets such as bars, places where young people congregate and other high transmission sites may not be part of a current sampling frame for retail survey. It may be necessary to identify such sites through key informants. On the whole, however, the cost to the national AIDS programme of adding condoms to retail surveys (in both human and monetary terms) should be minimal.

It is recommended that this indicator use a standard list of venues in conducting the retail survey. However some countries may choose to modify the list to include non-standard venues where a special effort is being made to distribute condoms – secondary schools might be an example. It may be difficult to identify all distribution sites if they are non-formal venues. In others, not all of the venues will be relevant. This is especially true in low-level or

concentrated epidemics, where the focus may be distribution of condoms within a well-defined sub-population with particularly high risk. The fact that condoms are not widely distributed in convenience stores across the country will not be an indication of programme failure in this situation.

Countries may also wish to weight the different outlet types in constructing the aggregate indicator. It is not possible to recommend a standard weighting procedure. Any variation in venues or weighting will affect the comparability of the indicator across countries. These limitations will not affect the presentation of data disaggregated by outlet type, and should not affect trends over time in a single country unless the venue mix is changed.

A limitation of the measure is that it provides a "snapshot" of availability at a single point in time. Where distribution is relatively regular, this poses no major problems. However when there are serious disruptions to condom supply at the central level, the repercussions may be felt simultaneously at a large majority of venues. If a survey is carried out at this time, it will appear as though the peripheral distribution system is inadequate whereas in fact the fault lies at the central level. In countries where quarterly retail surveys are undertaken, it may be possible to report an annual average to better reflect consistency of supply.

Condom Availability Indicator 3

Condoms that meet quality control measures

Core indicator in all epidemics

Definition

The percent of condoms in central stock and in retail outlets that meet WHO quality specifications

Measurement tools

MEASURE Evaluation/WHO/PSI Compiled Condom Availability and Quality Protocol

What it measures

The quality of condoms at their time of use determines their effectiveness in preventing HIV, STIs and pregnancy. Quality (and more particularly poor quality) also affects popular perception of the value of condoms, which can in turn have a major impact on the success of prevention programmes.

There are many stages at which the quality of a condom may have deteriorated to the point of being unacceptable. Condoms may be poorly manufactured in the first place, and manufacturers' quality control may be inadequate. Condoms may be improperly stored at the central level. Or they may be in perfect condition at the time of distribution but sit in the sunshine for two months on a market stall before being sold. Since it is not practical to sample condoms once they have been acquired by end users, the indicator is based on condoms sampled both from central storage and from retail outlets.

The quality indicator will be aggregated into a single figure. However it is vital that the data be reported separately by source of sampled condom for programme purposes. If poor quality is detected at the central level, national tender specifications or quality control procedures will have to be remedied. Poor quality at the retail level may require changes in the distribution system or better advice to retailers on stock handling and storage.

How to measure it

The sampling frame for retail outlets used in Condom Availability Indicator 2 can be used for the retail portion of this indicator; indeed, condoms may be sampled from retail outlets during the retail survey. Care should be taken in the handling and storage of condoms between sampling and testing, to ensure that no deterioration in quality is attributable to the sampling and testing procedure itself. At the central level, a sampling frame can be constructed from the central level storage facilities identified in the calculation of Condom Availability Indicator 1, and condoms sampled at random from those facilities.

A variety of testing procedures are available for condom quality control. Although all measure should give similar results, it is advisable to adopt one methodology and stick with it, to avoid any disruption of trends over time.

Strengths and limitations

This indicator provides an objective measure of condom quality within a country. It is simple to measure, but does require equipment and trained staff. Since behavioural studies suggest that perceptions of poor condom quality contribute significantly to people's failure to use condoms, information about adequate quality can be used to good effect in promoting their wider use. It should be noted, however, that this indicator is a double-edged sword. If results are poor and immediate rectifying action is not taken, people's reservations about condom use are likely to be reinforced, and condom use might suffer further.

This indicator will miss deterioration which takes place after the acquisition of a condom by a client, but before its use. Poor storage practices at this point may contribute significantly to condom failure rates.

3.3 Stigma and discrimination

Stigma is literally a "mark" or "blemish" upon someone or something. HIV is often negatively viewed, and social attitudes may be damaging to those infected or suspected of being infected. Discrimination is defined more in terms of legal and human rights: when a person loses a job because of the negative connotation or impression of HIV, overt discrimination has taken place. HIV is heavily stigmatised in most societies. People who are infected are rejected and scorned because social prejudice against the disease runs so deep. In some cases, people are stigmatised simply because of a suspected association with HIV.

Stigma towards HIV and affected people has many roots, among them the association of the disease in the public eye with marginalised groups such as homosexuals, drug injectors and sex workers, and with "bad behaviour" or "wrongdoing" such as promiscuity. HIV is far more heavily stigmatised than other STIs or Hepatitis B or C, which share many of the same modes of transmission. The disease appears suddenly, strikes people in the prime of life, is disfiguring and incurable. Reactions of denial among politicians and scare stories in the media certainly increased the stigma attached to HIV. This stigma is expressed by open discrimination in some areas: people lose their jobs and families, are thrown out of school or are refused treatment in hospital, just because they (or people close to them) are HIV infected.

Programme goals

Stigma and discrimination are of concern to AIDS programmes for two main reasons. First, because they can make life unbearable for those who live with the disease. And secondly, because they affect prevention and care efforts. People who have been exposed to HIV through their behaviour or that of their partner may be unwilling to be tested or to change their behaviour in any way for fear of being suspected of being HIV-infected. If they are indeed infected, they may continue to spread the virus and will not be able to access adequate care. There are many ways that stigma can undermine prevention and care efforts. An HIV-positive woman may know that breastfeeding carries a risk of transmitting the virus to her infant, for example. But she may refuse alternative feeding methods (even when they are provided at no cost) because bottle feeding will brand her as HIV-infected and carry the risk that she will be thrown out of the family. Where stigma is high, people may avoid an HIV test that could provide an entry point for necessary care and support. Active discrimination has consequences for prevention, too. If a person is fired from their job because they are HIV-infected, they may have to resort to survival strategies such as selling sex, which further fuel the epidemic.

Programmes aim to combat active discrimination by changing laws to support those living with HIV and AIDS and by ensuring those laws are enforced. They seek to change attitudes towards infected people and their families. More supportive attitudes should translate into more supportive behaviour, transforming a hostile world into one that is compassionate and constructive. They seek to break the silence surrounding the disease, partly by involving people living with HIV and their communities in an active response. More open discussion, it is hoped, will reduce the fears and misconceptions that reinforce high-risk behaviour.

Key questions

- Do programmes exist to promote acceptance and support for the HIV-infected?
- Do laws exist to protect the HIV-infected against discrimination?
- Are these laws enforced?
- Is there a policy that prohibits mandatory testing requirements for employment, marriage, travel, etc.?

Measurement challenges

Stigma and discrimination, but especially the former, are among the most difficult aspects of the epidemic to quantify. It is perhaps for this

reason that, while many prevention and care programmes have the reduction of stigma and the fostering of more supportive attitudes as a stated objective, virtually none has developed a reliable way of measuring this most intangible of phenomena. In the first place, no clear definitions exist of stigma or the qualities that characterise it, and if something cannot be clearly defined, then it cannot be accurately measured.

While some stigmatising attitudes and discriminatory practices are all too obvious, others remain largely hidden. There is no clear relationship between attitudes and behaviour in this context. What people actually do in the face of something as frightening as AIDS may well differ from what they say they would do, and the discrepancy seems to run in different directions. Some studies have found, for example, that people expressing very negative attitudes to those infected with HIV actually provide supportive care for an HIV-infected relative in their own home. On the other hand, some people who deny any negative attitudes towards people with HIV may actively discriminate against them in specific settings, such as the provision of health care.

Interventions designed to reduce discriminatory attitudes may have a more rapid and/or profound effect on reported attitudes than on the embedded attitudes that drive an individual's behaviour. Decades of human rights campaigning in the United States have, for instance, greatly reduced the proportion of people who openly admit to being racially prejudiced. Whether this change in stated attitudes is reflected in a similarly large reduction in active discrimination is open to doubt.

To complicate matters still further, active discrimination is sometimes difficult to discern. It can take highly visible forms such as being fired from a job. But it can also make itself felt in the failure to provide services available to other members of society, or even the absence of compassion and supportive advice from church or community leaders.

It is difficult to collect information about behaviour towards those with HIV. Partly because of stigma itself, the HIV status of people who are in fact infected is rarely openly acknowledged, even within their own families. So most questions that attempt to measure stigma focus on hypothetical situations, such as the willingness to care for a relative with AIDS, or beliefs about whether people with HIV should be permitted to continue working with others. It is not clear to what extent hypothetical willingness to care for a sick family member is matched in practice, or, indeed, to what extent it is a useful indicator of social stigma. Other hypothetical questions such as a willingness to be tested for HIV have been shown to be very poor predictors of actual behaviour, possibly precisely because of the magnitude of social stigma. However, for want of anything better, hypothetical questions about people's attitudes are likely to remain central to attempts to track changes in negative attitudes towards people with HIV.

Measures of discrimination have tended to be of the yes/no variety. "Does legislation exist to protect against …" In some measures, there is also an attempt to judge whether or not the legislation is enforced. This may be useful in identifying important gaps and areas for programme effort; it is of limited use, however, in the regular monitoring and evaluation of national AIDS programmes. Composite indicators of these yes/no questions are nearly impossible to interpret. A gain in passing legislation in one area may be counteracted by a backsliding in enforcement in another. It is noted that the AIDS Programme Effort Index (API) will partly measure the extent to which the legal system protects the human rights of HIV-infected persons.

Stigma and discrimination Indicator 1

Accepting attitudes towards those living with HIV

Core indicator for all epidemics

Definition

The percent of people expressing accepting attitudes towards people with HIV, of all people surveyed aged 15-49

Measurement tool

UNAIDS general population survey; DHS AIDS Module; FHI BSS (adult); FHI BSS (youth)

What it measures

This is an indicator based on answers to a series of hypothetical questions about men and women with HIV. It reflects what people are prepared to say they feel or would do when confronted with various situations involving people living with HIV.

How to measure it

Respondents in a general population survey are asked a series of questions about people with HIV, as follows:

- If a member of your family became sick with the AIDS virus, would you be willing to care for him or her in your household?
- If you knew that a shopkeeper or food seller had the AIDS virus, would you buy fresh vegetables from them?
- If a female teacher has the AIDS virus but is not sick, should she be allowed to continue teaching in school?
- If a member of your family became infected with the AIDS virus, would you want it to remain a secret?

Only a respondent who reports an accepting or supportive attitude on all four of these questions enters the numerator. The denominator is all people surveyed.

Strengths and limitations

Methodologically, this is a relatively easy way to construct an indicator of attitudes to people with HIV. A low score on the indicator is a fairly sound indication of high levels of stigma, and for that reason alone it is worth measuring.

There are, however, difficulties in interpreting indicators based on hypothetical questions, and a high score on the indicator is harder to understand. It could mean there is little real stigma attached to HIV. Or it could mean that people know they should not discriminate, and therefore report accepting attitudes. This may not change their behaviour, which may continue to be discriminatory towards people with HIV. Changes in the indicator could therefore reflect a reduction in stigma or simply a growing awareness that it is not nice to own up to one's prejudices. That in itself may, however, constitute the first step in programme success. High scores may also reflect the respondent's limited personal experience with someone who is HIV-infected.

The proposed indicator is similar to an earlier measure developed by WHO, but questions have been changed following field testing to better reflect situations in which people with HIV actually suffer from stigma. Field tests revealed that responses are greatly affected by the exact wording of the indicator. When the gender of the teacher was not specified, for example, one country registered very high levels of "discriminatory" attitudes on that question, for example. Further investigation showed that the negative attitudes were related to recent news reports of male teachers infecting female pupils with HIV.

The earlier WHO indicator has been little used, calling into question the utility of this measure. It is possible that it was little used because so little programming effort to date has gone in to reducing stigma surrounding HIV in most countries. As the power of stigma to obstruct prevention and care efforts becomes ever clearer, however, it is likely that more national AIDS programmes will turn their attention to this area. It is expected, therefore, that use of this indicator will increase.

It has been suggested that this indicator be used to measure differences in discrimination or stigma by gender. Although some research suggests that women are more likely than men to be treated and viewed harshly if they have HIV or AIDS, other recent surveys have shown little difference in response to gender specific questions about stigma and discrimination.

Stigma and discrimination Indicator 2

Employers ensuring no discrimination against people with HIV

Core indicator for all epidemics

Definition

The proportion of formal-sector employers sampled with non-discriminatory policies and non-discriminatory practices in recruitment, advancements and benefits for employees with HIV

Measurement tools

UNAIDS protocol for the identification of discrimination against people living with HIV

What it measures

This indicator measures one small but rather concrete aspect of HIV-related discrimination: discrimination in formal-sector employment. The indicator should be disaggregated to look separately at company policies and at practice.

How to measure it

A survey is conducted among major formal-sector employers, to determine their policies and practices concerning recruits and employees with HIV. At the time of going to press, the protocol was under development, and field testing had not begun. But it is likely that the employer survey will include a specified mix of government, local private sector and multinational employers. Within each company, survey respondents will include union or worker representatives as well as management.

The survey seeks to establish the existence of formal policies related to HIV, and to examine the enforcement of those policies. Policies will include those related to recruitment and employment itself – for instance practices related to pre-employment HIV testing or the termination of existing employees found to be infected – as well as policies relating to sickness and death benefits.

Strengths and limitations

Obviously, practices in formal-sector employment represent just a small fraction of all the situations in which HIV-related discrimination may take place. National AIDS programmes may work to reduce discrimination in different ways in different countries. However discrimination in the workplace will be a concern in virtually every country. National programmes may work directly with employers or workers' unions to reduce discrimination in the workplace, or they may choose to work through the regulatory and legislative environments. In either case, success in reducing the discrimination suffered in employment by HIV-positive individuals should be reflected in this indicator. This is because employer practices are influenced by many things, including the regulatory environment. Where legislation comes into force to protect the rights of people and workers with HIV, or where court rulings change the likelihood that this legislation will be enforced, changes in employer policies and practices are likely to follow.

The summary indicator sums up both policy and practice. However it will often be the difference between the two which is of most interest to programme managers. If employer policies become more supportive of HIV-positive employees in response to legislation or other pressure but discriminatory practices do not in fact change, then a shift in emphasis may be needed to ensure enforcement rather than simply existence of non-discriminatory policies.

Measurement of discriminatory practice is not straightforward, especially where it is illegal. Many companies will have reasons other than HIV status for the dismissal of an HIV-positive employee, and some of these reasons will be legitimate. Like Policy Indicator 1, this indicator of discrimination will be affected to an extent by the opinions of the individuals responding to the survey, hence the importance of ensuring a mix of respondents from within and outside management.

It is worth noting that discrepancies between policy and practice may arise in either direction. A company may have no stated policy on

HIV, but may nonetheless ensure that infected employees are not discriminated against in practice. The survey should ascertain whether employers have a policy on other terminal illnesses, and whether policies and practices relating to HIV differ from those relating to other terminal illnesses.

The indicator will be affected by which employers and companies are included in the survey. The protocol will determine the broad mix of national and international employers, including those in the public sector. Informed consent from companies will be needed even where the survey takes the form of a self-completed anonymous questionnaire. There may be considerable refusal bias in the measurement of this indicator, with companies that have a poor record less likely to respond than those that do not. It is also possible that the response rate from union or workers' representatives will differ significantly from that of management. It may be possible to negotiate a "blanket" informed consent for all members of the local chamber of commerce and industry, that would then allow data collectors to approach non-management employees directly. The refusal bias is especially worrying if it changes significantly over time. This may be the case when new legislation is introduced, but before compliance changes.

3.4 Knowledge about transmission of HIV

Since unprotected sex is the driving force behind most HIV epidemics, AIDS programmes have focused actively on increasing people's knowledge about sexual transmission and on promoting safer sex. Efforts have sometimes been made to change the underlying social attitudes that foster unsafe sex. Very often, these are attitudes that promote double standards in sex for men and women and that concentrate the power in sexual relationships in men's hands.

Although they are all strongly interrelated, goals and indicators in the areas of knowledge of sexual transmission and sexual behaviour itself will be presented separately.

Knowledge is an important prerequisite for prevention in other areas of HIV transmission. This section, therefore, also includes a measure of knowledge in drug injecting populations and of mother to child transmission.

Knowledge of HIV transmission: programme goals

Early assumptions that knowledge about AIDS and how to prevent it would lead to behaviour change have proved optimistic. However, there is no doubt that knowledge is an important prerequisite for behaviour change.

Most national programmes have put a great deal of effort into so-called "Information, Education, Communication" or "IEC" campaigns, which aim to increase knowledge about HIV, the behaviours that spread it and the ways it can be avoided. Many programmes have had a great deal of success in imparting this information. Indicators of knowledge are beginning to register high levels of correct knowledge. But behind this knowledge often lurks misinformation or misconceptions which influence the way people behave. Increasingly, programmes are turning their attention to breaking down these misconceptions.

Key questions

- Is there a national policy on the inclusion of HIV prevention messages in school-based education programmes?
- Do people know how HIV is transmitted and can be prevented?
- Do they hold misconceptions which may diminish the likelihood that they will act on correct knowledge?
- Do programmes exist to increase knowledge and reduce misconceptions, and are those programmes reaching their intended audiences?

Measurement challenges

Existing composite indicators of HIV-related knowledge focus on correct knowledge. While they ask about misconceptions, incorrect knowledge is not commonly included in an indicator.

One of the challenges in measuring knowledge is deciding how much to jog people's memory through prompted questions. It is probably true that spontaneous answers are a better reflection of the respondent's actual application of knowledge than prompted responses. For example, if a person regularly uses condoms to protect themselves from HIV, then condom use is likely to be the first answer they give when asked how HIV can be prevented. In spontaneous responses, people are also less likely to list prevention methods such as abstinence that they know intellectually to be preventive against HIV but that they do not consider to be viable options for themselves.

The trouble with unprompted or spontaneous responses (e.g., "What ways can one protect from HIV?") is that they tend to be extremely variable between populations and across time, and this variability does not always reflect true differences in knowledge. Rather, it is likely to be because of variation in the interviewer's ability to solicit spontaneous responses, and their preference for certain response codes. For the purposes of constructing standardised knowledge indicators that are comparable

across time, prompted responses to specific ways of protection may be more useful.

The way the question is asked is critical. In the past, most questions have been phrased: "Can people protect themselves against HIV by …?". As knowledge about HIV increases, field tests have shown that this phrasing produces responses that are hard to interpret. Respondents may know that it is safer to have sex with a condom than without one, but they may also know that a condom does not provide full protection against HIV because of the possibility of breakage. These indicators therefore word questions slightly differently, asking whether a certain behaviour can *reduce* the risk of HIV infection.

Correct information about how HIV is contracted and how it can be avoided does not often vary from place to place. Misconceptions do vary however, with particular rumours gaining currency in some populations both about how HIV is spread (by witchcraft, for example) and how it can be avoided (for instance by eating a certain kind of fish or having sex with a virgin).

Indicators of misconceptions can be varied to include misconceptions that are locally common. If the two most common misconceptions are used in every setting, this should not affect cross-country assessment of indicators. The indicator is not measuring knowledge about witchcraft, after all, it is measuring incorrect knowledge about AIDS. In many societies, the common misconceptions are already well known. In others, qualitative studies may have to be undertaken before deciding which elements to include in the indicator. It is worth noting that misconceptions themselves may change over time. Indeed it is the job of AIDS programmes to erode current misconceptions, but they may be replaced by others. A country may choose to measure different misconceptions at different points in time. Again, as long as efforts are made to select the two misconceptions currently most common, the indicator of incorrect knowledge about HIV and AIDS should be comparable over time.

The relative importance accorded to correct knowledge of the major modes of transmission and misconceptions may vary with the epidemic state. In generalised epidemics where a very high proportion of people answer correctly to questions about transmission, addressing misconceptions may become a major focus of IEC campaigns. In low-level or concentrated epidemics where past IEC activities have been more limited, attention may still be focused on improving basic knowledge about modes of transmission. Indeed, in concentrated epidemics more attention may be focused on increasing knowledge within specific subpopulations about prevention methods related to the behaviours which put those subpopulations at risk.

In all indicators of AIDS-related knowledge, the denominator should be the entire population of respondents, rather than just those who have heard of AIDS. This is because those who have not heard of AIDS (and who therefore cannot have any "correct" knowledge about it) definitely represent failures of IEC campaigns. In most countries at the end of the 1990s, these people constitute only a very small proportion of the population.

In areas dealing with knowledge, attitudes and sexual behaviour – even more than in other areas of programming – it is imperative that indicators be reported separately by gender.

Knowledge Indicator 1

Knowledge of HIV prevention methods

(Modified WHO/GPA Prevention Indicator 1)
Core indicator for all epidemics

Definition

The percent of all respondents who, in response to prompted questions, say that a person can reduce their risk of contracting HIV by using condoms or having sex only with one faithful, uninfected partner

Measurement tools

UNAIDS general population survey; DHS AIDS module; FHI BSS (adult); FHI BSS (youth)

What it measures

Most AIDS programmes targeting the general population promote mutual monogamy and condom use as the primary ways of avoiding HIV infection among the sexually active men and women who make up the majority of all adults in virtually every population. This indicator measures the extent to which those messages have reached the general population or the specific sub-population surveyed.

How to measure it

The indicator is derived from correct answers given for both primary sexual prevention methods for sexually active adults, following prompted questions in a survey. Someone only identifying one of the two ways is not counted in the numerator of the indicator. All respondents surveyed are included in the denominator, regardless of whether they have ever heard of AIDS or not. The indicator components should also be reported separately to show changes in specific knowledge areas.

The precise wording of the prompted questions must be given careful thought in each linguistic and cultural context. It should be noted that the correct prevention methods prompted for should be interspersed in the questionnaire with misconceptions used to calculate Knowledge Indicator 2.

Strengths and limitations

Data for this indicator are easy to collect in a population survey. In most countries the score on this indicator will be high, but disaggregation of the indicator by individual questions, residence, gender or age group may provide useful pointers to gaps in information flows.

Limitations of the use of prompted data were discussed in the introduction to this section. While the primary indicator should be constructed using prompted data, a comparison between prompted and non-prompted data where possible may yield interesting information. For instance, both the revised UNAIDS general population survey and the DHS AIDS module ask, “What ways can people protect themselves from getting HIV?” before asking specific “prompted” questions. To be of additional use to programme managers, this indicator should always be used in conjunction with Knowledge Indicator 2.

Previous knowledge indicators have included abstinence as a “correct” method of prevention used in this indicator. Abstinence is an extremely important prevention option for young people. However research in many settings shows that it is rarely used as a primary HIV prevention method among adults who are already sexually active. In addition, people who know that HIV is sexually transmitted are highly likely to know that not having sex can reduce the risk of transmission. Negative responses on this item are more likely to result from people believing that abstinence is not feasible than from their believing that abstinence does not provide effective protection. In surveys among young people, however, questions about abstinence continue to be important. Programmes focusing on delaying age at first sex among young people may choose to add a knowledge indicator that includes correct responses to a question about abstinence as a prevention method in the numerator.

Knowledge Indicator 2
No incorrect beliefs about AIDS

Core indicator for all epidemics

Definition

The percent of all respondents who correctly reject the two most common local misconceptions about AIDS transmission or prevention, and who know that a healthy-looking person can transmit AIDS

Measurement tools

UNAIDS general population survey; DHS AIDS module; FHI BSS (adult); FHI BSS (youth)

What it measures

Many of the people who know that condoms protect against AIDS also believe that AIDS can be contracted from a mosquito bite or other uncontrollable event. Why bother to reduce the pleasure of sex, they reason, if they might in any case be infected by something as random as a mosquito bite? At high levels of HIV-related awareness, a reduction in misconceptions that act as a disincentive to behaviour change may actually be a better reflection of the success of an IEC campaign than an incremental shift in already high levels of "correct" knowledge. This indicator measures progress made in reducing misconceptions.

How to measure it

In a series of prompted questions, respondents are given correct and incorrect statements about AIDS transmission and prevention. Responses to the correct statements about prevention are used to calculate Knowledge Indicator 1. Responses to a question about infection status in healthy-looking people and to two incorrect statements about transmission or prevention are used to calculate this indicator.

The incorrect statements will vary to reflect the misconceptions most common in the local context. Very often these will include the belief that AIDS can be spread through an insect bite or through witchcraft. Sometimes they will include beliefs about prevention or cure, such as AIDS being preventable by eating certain types of food or herbs, or being curable by having sex with a certain type of person such as a virgin (or simply being curable at all). One question will always centre on knowledge of the "healthy carrier" concept, that is, knowledge that a person may contract HIV by having unprotected sex with an apparently healthy person. The exact wording may vary locally. For example, in some areas "fat" may be synonymous with "healthy" in this context and may better reflect people's misunderstanding of who constitutes a "safe" partner.

The local misconceptions should be identified shortly before a survey takes place. They may vary over time within the same country.

To enter the numerator for this indicator, a respondent must correctly reject both misconceptions, and must know that a healthy-looking person can transmit AIDS. The denominator is all respondents, including those who have not heard of AIDS. For programme purposes, the indicator should be disaggregated by misconception, and the percentage believing that a healthy-looking person cannot transmit HIV should also be reported separately.

Strengths and limitations

Again, this is easy to measure. It gives a good picture of the level of false beliefs that may impede people's determination to act on correct knowledge. When the data are disaggregated, they provide invaluable information for programme managers planning future IEC campaigns, telling them which misconceptions must be attacked, and in which subpopulations.

A word of caution is in order, however. There is always a danger that the inclusion of misconceptions in a questionnaire actually increases their credibility. Preparatory research should be sure to establish commonly held misconceptions (rather than run the risk of promoting new ones), and the questionnaire should make very clear that some of the statements in the sequence are true while others are false.

One limitation is the indicator's ability to distinguish between misconceptions which are likely to influence behaviour and those which are merely incidental. Measurement of this indicator also requires preparatory work to determine which misconceptions are currently most likely to be common.

Knowledge Indicator 3

Knowledge of HIV prevention among men having sex with men

Core indicator for concentrated epidemics with identifiable populations of men having sex with men

Definition

Percent of men who, in response to prompting, correctly identify avoiding anal sex and using condoms during anal sex as means of preventing HIV infection

Measurement tools

FHI BSS (men who have sex with men)

What it measures

In HIV epidemics where there is a concentration of HIV infection or risk behaviours among men who have sex with other men, IEC campaigns are often designed to meet the specific needs of this population. Most of these campaigns promote non-penetrative sex and condom use during anal sex as ways of avoiding HIV infection. This indicator measures the extent to which those messages have reached members of a sub-population of men who have sex with men. It is intended for use only within that sub-population.

How to measure it

In a behavioural survey of men who have sex with other men, respondents are asked about their knowledge of AIDS, and whether it can be prevented. They are then prompted for various correct and incorrect means of prevention, including non-penetrative sex and condom use during anal sex. The indicator is derived from correct answers given for these two methods of preventing HIV transmission during sex between men. Someone giving correct answers to only one of the two is not counted in the numerator of the indicator. All respondents are included in the denominator, regardless of whether they have ever heard of AIDS or not.

Strengths and limitations

The greatest difficulty in collecting information for this indicator is likely to be accessing a representative sample of men who have sex with other men. Sampling issues for sub-population (target group) and population-based surveys are discussed in greater detail in FHI guidelines on behavioural surveillance surveys.

Clearly, there are many other ways of preventing HIV transmission in male-male sex. These include abstinence, condom use during oral sex, and mutually faithful partnerships among men who have tested HIV-negative and had no other partners since the test. The extent to which these different messages are stressed depends very much on the context in which male-male sex takes place. The “mutual faithfulness” message is, for example, much more likely to be emphasised in countries with well-established gay communities in which long term partnerships are common. It will be of far less importance in countries where a majority of men who have sex with men are also married, or where male-male sex is dominated by commercial exchanges. In order to make the indicator more comparable across different situations, the areas of knowledge cited are those that are a focus of prevention programmes for men who have sex with men in almost all contexts.

This indicator does not include common misconceptions about HIV transmission or prevention. However, similar to knowledge questions in general population surveys, the question sequence in a behavioural survey among men who have sex with men is likely to contain incorrect as well as correct prevention options, for example that the insertive partner is at no risk of HIV infection during anal sex. These questions will provide important information in improving IEC messages and preventative interventions. Again care must be taken to avoid introducing new misconceptions.

Limitations of the use of prompted data were discussed in the introduction to this section; while the primary indicator should be constructed using prompted data, a comparison between prompted and non-prompted data where possible may yield interesting information. To be of additional use to programme managers, data for this indicator may be disaggregated by prevention method, highlighting strengths and weaknesses in existing IEC campaigns.

Knowledge Indicator 4

Knowledge of HIV prevention among injecting drug users

Core indicator for concentrated epidemics with definable populations of injecting drug users

Definition

Percent of respondents in a survey of injecting drug users who, in response to prompting, identify switching to non-injecting drugs and avoiding sharing injecting equipment as methods of preventing HIV transmission

Measurement tools

FHI BSS (injecting drug users)

What it measures

In HIV epidemics where there is a concentration of HIV infection or risk behaviours among injecting drug users, some programmes actively promote HIV prevention in this population. Most efforts to reduce transmission between drug injectors try to encourage safer drug-taking, including using non-injecting drugs and not sharing injecting equipment. This indicator measures the extent to which drug injectors are aware of these methods of preventing HIV transmission.

How to measure it

In a behavioural survey in a community of drug injectors, respondents are asked about their knowledge of AIDS, and whether it can be prevented. They are then prompted for various correct and incorrect means of prevention, including switching to non-injection drugs and avoiding sharing injecting equipment. The indicator is derived from correct answers given for both prevention methods. Someone giving correct answers on only one way is not counted in the numerator of the indicator. All respondents are included in the denominator, regardless of whether they have ever heard of AIDS or not. Results for each component of the indicator should also be reported.

Strengths and limitations

The greatest difficulty in collecting information for this indicator is accessing a representative sample of injecting drug users. Sampling issues are discussed at greater length in the FHI module on sampling for behavioural surveillance surveys.

This indicator will only be useful where efforts are being made to reach injecting drug users with prevention messages that help them reduce exposure to HIV infection, both for themselves and for other members of the drug-taking community. Where such programmes exist but concentrate only on a single message backed up by appropriate services, it may be possible to restrict the indicator to knowledge about that means of prevention. Obviously it will be difficult to use these data if programmes are not openly informing the drug-using public about using clean needles and safer methods to use drugs.

In the past some HIV prevention programmes among injecting drug users promoted carefully cleaning injecting equipment with bleach between users as an HIV prevention method. Recent research calls into question the effectiveness of this method, and few programmes for drug users now actively promote it. It is therefore not included as a prevention method in this indicator.

Many programmes aimed at drug injectors also promote condom use in order to limit the spread of HIV from infected drug users to their sexual partners. This is covered in indicators of sexual risk, and is not included in the indicator of knowledge specific to prevention in drug-injecting situations.

Limitations of the use of prompted data were discussed in the introduction to this section; while the primary indicator should be constructed using prompted data, a comparison between prompted and non-prompted data where possible may yield interesting information about the methods most drug users consider to be effective in their personal circumstances.

Knowledge Indicator 5

Knowledge of prevention of mother to child transmission of HIV

Core indicator in countries with generalised epidemics and strategies to reduce mother to child transmission of HIV

Definition

Percent of women and men who correctly respond to prompted questions about preventing maternal to child transmission of HIV through anti-retroviral therapy and avoiding breastfeeding

Measurement tools

UNAIDS general population survey; DHS AIDS module; FHI BSS (adult)

What it measures

This indicator looks at whether women and men know of methods to prevent the transmission of HIV from mother to child. In this field as in the field of prevention of sexual transmission, knowledge is a prerequisite for decision-making and intervention, although by no means sufficient to ensure it.

This indicator measures people's knowledge of methods to prevent transmission from mother to child through anti-retroviral therapy and by avoiding breastfeeding. Men's knowledge in this area is also important, not least because in many societies men dominate decisions about family formation and childbearing, so the indicator is constructed for both sexes. Since most IEC campaigns in this area are aimed at women, programme managers will want to monitor their effectiveness by disaggregating the indicator by gender.

How to measure it

Respondents in a population survey are asked a series of questions about the transmission and prevention of HIV (see Knowledge Indicators 1 and 2). Among these are questions about whether HIV can be transmitted from mother to child, and about means of preventing mother to child transmission.

The indicator is the number of respondents who say that HIV transmission from women who have tested HIV positive can be prevented by the mother taking drugs during pregnancy, *and* by the mother avoiding breastfeeding, divided by the total number of respondents to the survey.

Strengths and limitations

This indicator presupposes that efforts are being made to educate women about maternal to child transmission of HIV, and that information about prevention forms part of that education.

The indicator does not distinguish in its denominator between those who know about maternal to child transmission and those who do not, since people who do not know that it can be prevented are definitely among those who have not been reached with information about prevention methods. The questioning sequence does, however, allow countries to construct an indicator of knowledge about HIV transmission from mother to child should they wish.

It is the knowledge that transmission from mother to child can be prevented that is likely to shape women's care-seeking and breastfeeding behaviour. A pregnant woman who simply knows that HIV can be passed on to her child is less likely to seek to know her HIV status than a pregnant woman who knows that transmission of HIV to her child can be avoided.

In many countries in Latin America and elsewhere, the demand for prevention has driven a radical improvement in service provision for pregnant women with HIV. Such a demand cannot arise unless people know that therapy exists and can be effective in reducing transmission of HIV to infants.

3.5 Voluntary counselling and testing services

Programme goals

Voluntary counselling and HIV testing (VCT) is becoming an increasingly important area of HIV prevention and care programming. People who have chosen to be counselled and then have gone on to have an HIV test have, in limited studies, registered some behaviour change that should contribute to lower rates of HIV spread. The ready availability of VCT services is also thought to be a factor in reducing stigma surrounding HIV and in encouraging community support and care for those affected. Perhaps most importantly, VCT services are an essential early entry point to social support services and medical and associated care for those infected with HIV, where these services exist.

Many national AIDS programmes are trying to increase the availability and quality of counselling and of testing services by supporting the training of counsellors and providing necessary inputs such as test kits.

In countries where efforts are being made to reduce transmission of HIV from mother to child, there is a special interest in the counselling and voluntary testing of pregnant women. This area of VCT programming is dealt with in the section on mother to child transmission.

Key questions

- Is there a national policy to provide HIV testing and counselling in all districts?
- Are voluntary HIV counselling and testing services widely available?
- Do they have the resources needed (staff, space, systems) to function as planned?
- Are they providing quality services?

Measurement challenges

In counselling – perhaps more than in any other area of service provision – service quality determines the outcome. Poor quality counselling can result in misunderstanding and even resistance to change, and circumstantial evidence suggests that poor counselling is not uncommon. But measuring quality of counselling is exceptionally difficult. Because confidentiality is a critical element of VCT, observational studies are difficult, though by no means impossible.

Mystery patient studies and exit interviews with clients are possibilities for assessing the quality of counselling; mystery clients in particular could help avoid some inherent problems of observation. For example, providers/counsellors may not provide the same level or type of counselling when being observed as they do in a normal routine. When using mystery clients to assess quality of counselling, mystery clients should undergo training and have ongoing support and feedback. In addition, mystery clients should be used according to the same guidelines used in sexually transmitted infection evaluation, e.g., the clinic is notified and agrees to having mystery clients over a certain defined time period. Finally, observations of the mystery clients should be used for improving counsellor work, but not for punitive measures and this should be stressed to the participating sites, managers and providers.

Issues of confidentiality also complicate other outcome and impact measures, such as the proportion of those testing positive who are adequately referred to care and support service, and who receive such care and support.

Special studies have followed up former clients to determine the extent of behaviour change. These studies are prone to bias introduced by loss to follow-up and are complex to carry out. They are unlikely to form part of a regular monitoring and evaluation system.

Demand for HIV testing is hard to measure. Survey questions asking about willingness to be tested typically get very high positive response rates. Yet when free counselling and testing is offered in the same populations, uptake is typically very low. The only reliable measures of demand are those based on uptake, and these will of course be biased by supply, by perceptions about confidentiality

and the quality of counselling, and by services available to (or, conversely, the degree of stigma likely to be encountered by) those testing positive.

Another difficulty in evaluating progress in the provision of quality VCT is deciding which service providers should be included in an assessment. While an increasing number of countries have special centres dedicated exclusively to counselling and testing for HIV, a high proportion of tests take place in private clinics or doctors' surgeries. The fact that tests are proposed for diagnostic purposes does not diminish the need for pre- and post-test counselling, confidentiality and other elements of quality service provision.

Voluntary Counselling and Testing Indicator 1

Population requesting an HIV test, receiving a test and receiving test results

Core indicator for generalised epidemics
Additional indicator in sub-populations with high-risk behaviour in concentrated epidemics,
Recommended in areas where VCT is being actively promoted

Definition

Percent of people aged 15-49 surveyed who have *ever* voluntarily requested an HIV test, received the test and received their results. It is suggested that data also be collected on those requesting an HIV test, receiving the test and receiving their results *in the last 12 months.*

Measurement tools

UNAIDS general population survey; DHS AIDS module; FHI BSS (adult); FHI BSS (youth)

What it measures

The coverage of quality VCT services will go a long way towards determining whether those services achieve their threefold aims of providing an entry point for care and support, promoting safe behaviour and breaking the vicious circle of silence and stigma.

This indicator aims to give an idea of the reach of HIV testing services in the general population and of the percentage of people who now know their HIV status. It can also be constructed for specific sub-populations with high-risk behaviour among whom counselling and testing services are being promoted. When calculated for sub-populations with high-risk behaviour, the numerator should include only those who requested a test and received their results in the last 12 months.

A breakdown of the indicator into its components parts (looking, for example, at people who requested and received a test but never received their results) can point to gaps in programme service provision and quality of care. Data on those who do not return for results or know their results may offer insight, for example, into levels of stigma and/or reluctance to learn their HIV status based on lack of available options for care.

How to measure it

In a general population or sub-population survey, respondents are asked whether they have ever requested an HIV test, whether they were tested and if so whether they have received the results. Those having ever requested a test and received the results form the numerator, while the denominator is all respondents in the survey.

The questionnaire prefaces the questions by saying, " I do not want to know the results of the test….". As for most indicators, results should be presented by component and separately for men and women. In addition to having information on the broad reach of VCT services over time, it will be useful also to know the percentage of the population surveyed who have been tested and have received the results *in the last 12 months*, a more time-sensitive measure.

Strengths and limitations

The survey question specifies that the test must have been requested by the respondent. In many situations, people may assume that their blood has been tested for HIV at some time, for example when giving a blood donation, when applying for insurance, or for surveillance purposes when attending antenatal services. These involuntary tests, whether real or perceived, are excluded in the calculation of this indicator. So are tests made for diagnostic purposes without the consent of the client, even if the client was then told of the results. Such tests do not reflect either the coverage of or the demand for testing services; nor do they take into account that the measure emphasises the "voluntary" element desired for HIV tests. For that reason, survey questions must specify that the person requested a test.

In many countries, many people will have been offered and accepted an HIV test in a health

care setting. To get an idea of the proportion of people who may be aware of their sero-status (regardless of who initiated the request for a test), data should also be collected on people having been offered a test, accepted it and received their results.

This indicator gives some idea of the increasing coverage of services that meet people's demand for testing. It is not, however, limited to voluntary testing and counselling services staffed by trained counsellors. It may therefore include tests requested from private doctors who do not necessarily provide any counselling.

In areas where HIV is highly stigmatised, respondents may be unwilling even to admit to having taken an HIV test, since it may be counted an admission that they fear they may be infected. This is all the more true when the question is posed in the context of a questionnaire about risk behaviour. On the other hand, in countries where testing has been heavily promoted as a "responsible" thing to do, some people may say they have been tested when in fact they have not. Despite these potential biases, the indicator is useful for getting a rough idea of the proportion of people likely to know their HIV status at all.

If the indicator is adapted to reflect the percentage of respondents requesting, receiving an HIV test and receiving results *in the last 12 months*, the measure will reflect recent changes in testing services, knowledge about testing among the population surveyed and desire for testing. Those people exposed to HIV more than once in a lifetime should be targeted for repeat testing. Note, however, that in high-prevalence populations with good coverage of testing services, trends in the time-bound indicator can be expected to be affected by the fact that people who have tested HIV positive will not return for further testing in future years.

The "ever tested" measure is less sensitive to recent trends in test-seeking behaviour than a time-bound measure such as "tested in the last 12 months", but it will provide an idea of the overall reach of testing services.

In low-level and concentrated epidemics, the indicator is likely to yield extremely low percentages if measured in the general population. However it can be used effectively in surveys of behaviour in sub-populations at higher risk of infection.

Voluntary Counselling and Testing Indicator 2

Districts with VCT services

Core indicator for generalised epidemics

Definition

Percent of districts that have at least one centre staffed by trained counsellors providing specialised HIV counselling and testing services free or at affordable rates

Measurement tools

No specific tool needed

What it measures

This is another measure of coverage, but focuses more particularly on coverage of specialised VCT services.

How to measure it

Using key informants and health systems records of counsellor training, a list is constructed of all facilities offering counselling by trained counsellors and HIV testing services. Since the object is to get an idea of accessibility of counselling and testing services, all specialised services that are open to and accessible to most members of the general public should be included, whether public, private or non-governmental. This will include VCT services that are integrated into hospital or primary health care services. It may, however, exclude those attached to services with limited clientele such as antenatal clinics or STI clinics.

Since price is a major part of accessibility, this should be considered in formulating this indicator. A suggested formula is the price of voluntary counselling and HIV testing does not exceed one half of the daily minimum wage, or one half of the gross national product per person per day, calculated at purchasing power parity. "Low" or "affordable" prices may vary by district, and thus the measures should be adjusted.

A further criterion is that the staff actually providing counselling are trained. Where a country has specified minimum standards of training for counsellors, staff providing counselling should meet these standards of training.

Facilities meeting the criteria for service provision, staff training and price are mapped by district or similar administrative unit. The indicator is the percentage of all districts in the country with at least one facility meeting the criteria. Since districts (or similar administrative units) are usually defined in relation to their population size, weighting of the indicator is considered unnecessary.

Strengths and limitations

The indicator gives a crude idea of coverage of VCT services. It is most useful in tracking changes over time as a national programme attempts to scale service provision up to meet need in a generalised epidemic. Once coverage has reached a certain level, it is unlikely to fall again and the indicator becomes obsolete.

A major limitation of the indicator is that it does not take into account the scale of the epidemic (and therefore the scale of potential need for VCT). It is not appropriate for use in low-level or concentrated epidemics. In those situations, VCT services will be more efficiently used if they concentrate on providing for the needs of populations with higher than average risk behaviour.

Voluntary Counselling and Testing Indicator 3

Quality post HIV test counselling

Core indicator for countries promoting voluntary counselling and testing for HIV

Definition

Percent of post HIV test counselling sessions at voluntary counselling and testing facilities that meet international standards for quality counselling

Measurement tools

UNAIDS protocol for the evaluation of voluntary counselling and HIV testing services

What it measures

Quality is central to the effectiveness of counselling. Many programmes have made great efforts to improve the quality of counselling, not least through the intensive training of counsellors. This indicator measures the extent to which such efforts have resulted in quality counselling. It is based on observation of post-test counselling sessions, and uses a checklist to create a score of quality that includes interpersonal skills, information gathering from the client, correct and complete information given to the client, discussion of personal circumstances and partner notification, reinforced prevention messages, referral for care and support where relevant, and other aspects of counselling.

How to measure it

In a survey of facilities providing counselling and voluntary HIV testing, between three and five post-test counselling sessions are observed per site, with different counsellors if applicable. Counselling skills are scored against a standard checklist of items which constitute the minimum standards for quality post HIV test counselling.

Strengths and limitations

This indicator relies on observation of counselling sessions. Observational studies are time-consuming, and counsellors may deviate from their standard practice in observed sessions because of the presence of the observer. Confidentiality is a major issue in observational studies of post-test counselling, and the consent of the client must be sought before observation can take place. Experience has shown that counsellors themselves often refuse to be observed. An alternative to direct observation is that counselling sessions may be audio-taped for later anonymous review. This may reduce reluctance to participate on the part of both the client and the counsellor, makes the review exercise more time efficient, and allows for checking of variation in scoring between reviewers. Both methods, however raise issues of ethics and confidentiality of information. Without specific procedures for informed consent and the capacity to maintain confidentiality, no taping should be attempted.

The measure looks only at post-test counselling sessions. It is recognised that the quality of pre-test counselling is also important in assessing a client's needs, in helping them to make decisions about testing and in preparing them for results. In managing and improving VCT services, the evaluation of the quality of pre-test counselling will be important. However since the time and resources available for observational studies are likely to be limited, for the purposes of routine M&E, facility surveys should concentrate on post-test counselling. Since quality is determined largely by the skills, knowledge and dedication of the counsellor, it is likely that scores on pre- and post-test counselling would be highly correlated, with the inherent bias being that many people do not return for results and counselling.

As with all composite indicators, improvements in some areas may mask deterioration in others. Programme managers will want to see scores reported separately by area of counselling skill and performance in order to identify areas of weakness and to improve training programmes.

Voluntary Counselling and Testing Indicator 4

VCT centres with minimum conditions to provide quality services

Core indicator for countries promoting voluntary counselling and testing for HIV

Definition

The percent of clients served by VCT services that meet minimum conditions necessary to provide quality counselling and HIV testing services

Measurement tools

UNAIDS protocol for the evaluation of voluntary counselling and HIV testing services

What it measures

In many countries voluntary counselling and testing has landed in the hands of under-funded and ill-equipped non-government and community organisations, or has become a corollary of private sector health service providers. Many of these lack even the most basic structural facilities necessary to provide quality counselling, such as a room where counselling can be undertaken privately, or a regular electricity supply to ensure the adequate storage of specimens until testing.

This indicator measures the proportion of providers of counselling and testing that have the basic structural requirements to provide quality counselling. Since sites are weighted by client volume, the indicator is given as the percentage of clients served by sites with adequate conditions.

How to measure it

A random sample of providers of counselling and testing services (including NGOs, private clinics and doctors' surgeries) are checked for the structural elements necessary to provide quality counselling and testing services. These include trained staff, adequate privacy for counselling, systems for maintaining confidentiality, a directory of services for referral, and adequate conditions for ensuring quality control of specimen tests.

The score obtained by each site in the random sample is weighted by the annual client load of that site. The indicator is the number of clients served in the last year by sites with adequate conditions to provide quality VCT services, divided by the total number of clients served in the last year by all sites sampled.

Strengths and limitations

This indicator is a measure of something that is necessary but not sufficient to guarantee quality counselling services. The percentage of clients served in a facility that meets conditions for quality counselling is also likely to reflect other factors, such as access, available testing services, or a history of positive experiences at the centre by other community members. Inevitably, a number of contextual variables are reflected in an indicator assessing quality. The goal of the indicator is to provide a framework for assessing some accepted goals and guidelines.

A potential difficulty in constructing this indicator is that sites with inadequate record keeping may be unaware of their overall client load, and it will therefore not be possible to weight the indicator by client load. It is possible to construct the indicator as a simple percentage, i.e., the percentage of facilities surveyed which meet minimum conditions for adequate service. However because poor conditions at a small facility with a low caseload is relatively less important than poor facilities at a large and busy centre, weighting should be applied where possible. (In truth, there may be a strong correlation between conditions and caseload: caseloads may be low *because* conditions are poor.)

As with other aggregate indicators, information on different elements may need to be provided separately for programme planning purposes. It may also be useful to disaggregate this indicator by type of service provider (NGO, hospital, private clinic, etc.).

Voluntary Counselling and Testing Indicator 5

VCT laboratories that follow quality testing protocols

Additional indicator for countries promoting voluntary counselling and testing for HIV

Definition

Percent of HIV tests requested by voluntary counselling and testing centres over a one-month period which follow recommended testing algorithms

Measurement tools

WHO recommendations for selection and use of HIV antibody tests;

MEASURE Evaluation blood safety protocol (section on blood screening laboratories)

What it measures

As countries work to expand access to quality voluntary counselling and testing procedures for HIV, great emphasis has been placed on the training of counsellors. In some countries, less attention has been paid to ensuring that the test results themselves properly reflect sero-status. This is of vital importance in the context of VCT, where people are informed of their HIV status. The consequences of wrongly informing people that they are HIV positive or HIV negative can be devastating, both for the individual and for their sexual partners. Because of this, the protocols recommended for HIV testing when a person is to be informed of their status are more rigorous than those used for surveillance or blood safety purposes.

While sensitivity and specificity of HIV test kits have reached very high levels, no test is infallible, and this is especially true of tests affordable enough to be used in high-volume screening sites such as VCT centres. WHO has therefore developed protocols, adopted by many countries, to minimise the risk that someone will receive an incorrect HIV test result. These protocols set down algorithms for the re-testing of samples using different tests. A minimum of two tests are required before a person can be informed of their HIV status. Where the first two tests disagree, further different test types are used to confirm a result.

This indicator tracks the extent to which these algorithms are followed by laboratories performing tests for VCT centres.

How to measure it

A retrospective record review is carried out at laboratories processing specimens taken at VCT centres. The review looks at all samples processed over a defined one-month period prior to the review. It examines whether testing algorithms are being followed according to national or international recommendations (in other words, whether samples are being re-tested using different test kits to eliminate false positives and false negatives to the extent possible).

The sample frame will depend on a country's national programme. In some countries, large VCT centres have their own laboratory facilities, while in others specimens are processed at central, provincial or district laboratories. In countries with centralised or limited facilities, the review may be conducted at all relevant sites where specimens are tested for VCT purposes. In countries with larger programmes, records from random samples of sites stratified by urban or rural location may be reviewed.

Strengths and limitations

This indicator has the virtue of being relatively simple to construct.

A major limitation is that it only addresses one dimension of laboratory quality. Any number of repeat tests will not improve the quality of the results available to clients of VCT centres if the laboratory procedures themselves are flawed. Poor cleaning of testing equipment or repeat use of simple equipment such as pipettes can compromise the quality of all tests performed, regardless of whether they are for surveillance, diagnosis or VCT.

It is expected that all countries promoting VCT have national guidelines on basic laboratory quality control, such as the re-testing of a proportion of all samples at a reference laboratory

using “gold standard” tests. More information on these quality control procedures can be found in the protocol for the testing of blood safety.

3.6 Mother to child transmission

Programme goals

Only recently have interventions to reduce transmission of HIV from mother to child been available even in industrialised countries. Now, as shorter, less complex and cheaper drug regimes are proving effective in reducing transmission, these interventions are becoming more widely available in developing countries. For instance, recent research has shown that a single oral dose of the fairly inexpensive anti-retroviral drug nevirapine given to an HIV-infected woman in labour and another to her baby within three days of birth results in a reduction in the transmission rate similar to that achieved by a short course of AZT. However even the cheapest regime remains costly relative to per capita spending on health in many countries, so careful monitoring and evaluation of the success of interventions to reduce transmission of HIV from mothers to children is important.

Strategies to reduce mother to child transmission generally begin by supporting primary prevention of HIV among women likely to become pregnant. It is only once this strategy has failed and sexually active women of child-bearing age are infected that other strategies come in to play.

Next in line is reproductive choice. Women considering pregnancy are informed of the implications of childbearing for the HIV-infected and are encouraged to find out their HIV status through voluntary counselling and testing. Those that test positive should be further counselled on the implications of pregnancy and given advice about appropriate contraceptive use.

HIV-positive women who become pregnant may have a number of options open to them if they know about their infection. For this reason, routine counselling and voluntary, confidential testing of pregnant women is an essential element in programmes designed to reduce transmission from mother to child. Once a pregnant woman knows her status, there are two major (and complementary) prevention strategies open to her. First, she may take anti-retroviral drugs (ARVs) for the last weeks of pregnancy or around delivery. Secondly, she may avoid breastfeeding the child. The second strategy is possible without the first – indeed it is likely to avoid up to half of all vertical transmission. It appears that anti-retroviral treatment followed by breastfeeding may also cut the risk of vertical transmission, at least for women who breastfeed only up to six months. Recent developments in treating mothers just before delivery and both mother and infant just after delivery have had success in reducing HIV transmission even among women exclusively breastfeeding for three months and weaning. As new methods are validated, programmes should be prepared to monitor service delivery and availability and evaluate effects.

Key questions

- Do national policy guidelines exist on incorporation of prevention of mother to child transmission in routine antenatal services?
- Are pregnant women in contact with the health system?
- Are programmes able to provide quality counselling and HIV testing for all pregnant women who choose to accept it?
- Are programmes able to deliver drugs and breastmilk substitute to women who test HIV positive?

Measurement issues

Indicators of service provision in mother to child transmission should ideally cover provision of counselling and voluntary testing services for pregnant women, the availability and affordability of AZT during pregnancy, provision of advice on infant feeding and the availability and affordability of alternatives to breastmilk. However, at the time this guide was written, no standard set of indicators had been decided on or tested.

Inputs must be a factor in assessing outputs. Counselling that includes information about

ARVs during pregnancy is not particularly helpful where ARV therapy is not available or affordable.

As with regular VCT services, the quality of counselling services will be an important component in evaluating the provision of prevention strategies to pregnant HIV-positive women. The issues are complex, involving shared confidentiality with a partner, future prevention and fertility decisions and infant feeding decisions. The latter in turn involves consideration of resources and possible exposure to illness (for the infant) and stigma (for the mother).

Confidentiality is an important factor which increases the challenges inherent in developing indicators. For example, the percentage of HIV-infected mothers not breastfeeding might be an important indicator of a successful prevention programme for vertical transmission, but collecting data for this indicator is virtually impossible in many settings.

Impact indicators in this area are extremely difficult to obtain. Unless prohibitively expensive PCR or LCR tests are used, HIV testing at birth (that is, ELISA antibody testing) gives no indication of the infection status of the infant. And in any case, around half of all vertical transmission in developing countries takes place after birth, during breastfeeding. Follow-up would be nearly impossible for routine surveillance systems. In many countries, particularly those with high pre-AIDS mortality in the under-fives and poor vital registration systems, infant and child mortality indicators are not specific enough to register changes in rates of HIV-associated mortality in infants.

Many countries have only extremely limited interventions in this area. Clearly, monitoring and evaluation choices in this area, as in any other, should depend on programme goals: if services to reduce mother to child transmission are limited, then M&E resources are likely to be better used tracking changes in other areas, where programming is stronger.

Mother to Child Transmission Indicator 1

Pregnant women counselled and tested for HIV

Core indicator for countries with generalised epidemics and strategies to reduce mother to child transmission of HIV

Definition

Percent of women who were counselled during antenatal care for their most recent pregnancy, accepted an offer of testing and received their test results, of all women who were pregnant at any time in the two years preceding the survey

Measurement tool

UNAIDS general population survey

What it measures

The principal active interventions to reduce mother to child infection depend on knowledge of HIV status. Knowledge of HIV status during pregnancy may also affect future reproductive choices. Ideally, women would learn their HIV status using VCT services before they choose to become pregnant. But the gap between this ideal and reality is often very wide. In practice, the first opportunity many women have to be counselled about HIV and to be offered tests may be at antenatal clinics that offer these services as a precursor to offering interventions to reduce transmission of HIV from mother to child.

To learn their HIV status in an antenatal care situation, women have to go through a number of steps. First, they must attend antenatal services. Then they must be counselled and offered an HIV test. Next they must accept a test. Finally, they must return to receive the test results. It is only after the post-test counselling that follows all of these steps that they will be able to take necessary decisions about therapy and infant feeding.

This indicator measures the percentage of women with a recent pregnancy who completed all of those steps. Data are collected in a general population survey, so the indicator gives an idea of the coverage of ANC-based counselling and testing country-wide, rather than just in specific pilot facilities.

How to measure it

In a general population survey, women are asked when their most recent child was born, and whether they received any antenatal care before that last birth. If so, they are asked whether clinic staff talked to them about HIV infection and offered them a confidential HIV test. If yes, they are further asked if they agreed to a test and if they received the results. The questions are preceded by an assurance that the interviewer is not interested in knowing the outcome of any test.

To measure recent trends, women whose most recent birth was more than two years ago are excluded from the analysis. The indicator is the number of women counselled and offered voluntary HIV testing at ANC before their most recent birth in the last two years and received their test results, divided by the total number of women surveyed.

Strengths and limitations

This is a broad measure of service provision to give an idea of coverage on a national scale. However, few countries may have the resources to introduce counselling and voluntary testing for pregnant women country-wide. Those countries providing prevention services for pregnant, HIV-positive women typically start with pilot projects in a few antenatal clinics. Even if all women in pilot clinics are counselled and offered testing, the indicator will typically remain low for some time. It should be used in conjunction with Mother to Child Transmission Indicator 2.

As a summary indicator, it does not attempt to diagnose at which point women are dropping out of the spectrum of care. For programme purposes, it will be important to know whether a poor result on the summary indicator is because of low initial attendance at antenatal services, because women attending services are not being offered tests, because they are refusing the offer of a test, or because they are tested but do not return for test results. Each of

these points of failure has a different implication for programming, and all can be calculated from the data collected for this indicator.

The summary indicator does not attempt to measure quality of counselling or other elements of service coverage.

Mother to Child Transmission Indicator 2

Antenatal clinics offering or referring for VCT

Core indicator for countries with strategies to reduce mother to child transmission of HIV

Definition

Percent of clients at public antenatal clinics that attend clinics offering counselling and voluntary testing for HIV by trained staff, or referring to VCT services

Measurement tools

UNAIDS guide to the monitoring and evaluation of prevention programmes for mother to child HIV transmission;

UNAIDS tool for evaluating HIV voluntary counselling and testing

What it measures

While the previous measure gave an idea of coverage of counselling and voluntary testing among pregnant women in the population, this indicator gives an idea of the proportion of public ANC clinics in the country that are offering the service. That is, it gives some idea of the extent to which the national programme is able to scale up interventions begun on a pilot basis. It should reflect efforts to expand prevention services for pregnant women more quickly than the population-based measure given by Mother to Child Transmission Indicator 1.

How to measure it

In a health facility survey, randomly selected public antenatal clinics are visited. Staff interviews and record reviews are conducted to ascertain whether any of the clinic staff are trained in counselling, and whether the clinic routinely counsels clients about HIV in pregnancy and offers HIV tests with post-test counselling or refers clients to qualified outside services. The annual client volume of the clinic is also recorded.

The indicator is weighted by client volume: the number of clients in the past year attending antenatal clinics offering voluntary testing for HIV and post-test counselling by trained staff (or referring to other services), divided by the total number of women attending antenatal clinics surveyed in the past year.

Strengths and limitations

Private sector clinics will often take the lead in providing services for those HIV-infected pregnant women who can afford to pay for interventions. Because such interventions are relatively expensive, the goal of national programmes is to extend their reach to less affluent members of society, through service provision in public facilities. It is therefore recommended that this indicator be confined to measuring service provision in public sector clinics. However, countries that are making an effort to increase training in counselling for staff at antenatal clinics in the private sector or among traditional birth attendants may want to include such groups in this indicator.

Ideally, this measure would include all public antenatal services in a country. Since this is likely to be impractical, sampling is adopted. However, clinics are likely to counsel all patients or none, so the profile of the clinics sampled will have a potentially huge effect on the indicator, and changes may be difficult to interpret over time.

This indicator is most useful in countries that are actively expanding coverage of maternal to child prevention services. A steady rise in the indicator is likely to reflect a steady expansion of service provision. However if sampling is necessary, the indicator may be slow to reflect progress.

Mother to Child Transmission Indicator 3

Quality HIV counselling for pregnant women

Additional indicator for countries with strategies to reduce mother to child transmission of HIV

Definition

Percent of post-test counselling sessions for women attending antenatal clinics offering counselling and voluntary HIV testing that meet international standards for quality counselling, including referral for care where necessary

Measurement tools

UNAIDS guide to the monitoring and evaluation of prevention programmes for mother to child HIV transmission;

UNAIDS guide to the monitoring and evaluation of voluntary counselling and testing services

What it measures

Counselling and HIV testing in antenatal situations differs from VCT at dedicated counselling and testing centres in that women have not consciously decided to come for testing. Indeed, they may know little or nothing about HIV, and may never have considered testing or its implications. It differs, too, in that counselling and testing in ANC situations should be linked to concrete interventions that potentially bring an almost immediate benefit to the woman and her infant. But many complex issues raise their heads. For example, how does one counsel women who are HIV positive but who risk being thrown out of their home if they reveal their status by not breastfeeding, for example?

If counselling and voluntary testing is to be widely offered to pregnant women, it is almost inconceivable that the resources will be found to provide dedicated counsellors for pre- and post-test counselling for all women at all ANC sites. It is much more likely that the bulk of the extra burden of counselling will fall on regular ANC staff with a brief extra training in counselling for HIV.

This indicator, based on observation of post-test counselling sessions, uses a checklist to create a score of quality that includes interpersonal skills, information gathering from the client, correct and complete information given to the client, discussion of therapy, infant feeding options, personal circumstances and partner notification, and other aspects of counselling. It is critical that interventions which focus on protecting infants from infection do not neglect the welfare of the mother. An especially important aspect of counselling for HIV-positive pregnant women is referral to care and support services through which the HIV-infected mother can improve her own health and well-being.

How to measure it

In a health facility survey at antenatal clinics providing counselling and voluntary HIV testing for pregnant women, between three and five post-test counselling sessions are observed per site. Counselling skills are scored against a standard checklist of items which constitute the minimum standards for quality post-test counselling in antenatal situations. The checklist is similar to that used in Voluntary Counselling and Testing Indicator 4, but in addition includes issues specific to the antenatal situation such as discussion of the risks and mechanics of vertical transmission, the proper usage of anti-retroviral therapy together with its pros and cons, and issues surrounding breastfeeding and substitute feeding. Counsellors are also assessed on the discussions they generate about shared confidentiality, reproductive choice referral for contraception, and referral for HIV-related care and support for the infected mothers.

Strengths and limitations

This indicator shares the strengths and limitations of other indicators for the provision of counselling. Observational studies are time-consuming, and performance of counsellors may deviate from their standard practice be-

cause of the presence of the observer. Confidentiality is a major issue in observational studies of post-test counselling, and the consent of the client must be sought before observation can take place. Experience has shown that counsellors themselves often refuse to be observed. An alternative to direct observation is that counselling sessions may be taped for later anonymous review. This may reduce reluctance to participate on the part of both the client and the counsellor, makes the review exercise more time efficient, and allows for checking of variation in scoring between reviewers.

The measure looks only at post-test counselling sessions. It is recognised that the quality of pre-test counselling is especially important in the antenatal setting, since many women will not previously have considered an HIV test, or will have had little or no information about mother to child transmission of HIV and potential prevention methods. However, current practice in pre-test counselling varies widely, ranging from group sessions with videotaped information to individual sessions. It would therefore be difficult to propose a standardised assessment in this area. Test results and at least part of post-test counselling, on the other hand, must always involve a private interaction between a counsellor and a client or couple.

Like all composite indicators, this indicator aggregates information which must also be reported separately for most effective programme management and planning.

Mother to Child Transmission Indicator 4

HIV-positive women provided with anti-retroviral therapy in pregnancy

Additional indicator for countries offering ARV therapy

Definition

The percent of women testing positive at selected antenatal clinics in the last year who are provided with a complete course of anti-retroviral therapy to prevent mother to child transmission according to national / international guidelines.

Measurement tools

UNAIDS guide to the monitoring and evaluation of prevention programmes for mother to child HIV transmission

What it measures

Taking a course of anti-retroviral therapy is an important watershed in prevention of maternal to child transmission of HIV (although it is not the end point, since alternate feeding regimes may have to be followed after delivery). This indicator gives an idea of the proportion of all women testing positive during pregnancy at antenatal facilities offering HIV prevention services who are provided with a complete course of therapy.

How to measure it

In a facility survey of antenatal clinics providing prevention services, client records are reviewed, along with records of HIV test results. Women who test HIV positive, come back for their results and are provided with a full course of anti-retroviral therapy (along with therapy for the new-born) as dictated by the nationally approved treatment protocol (or WHO /UNAIDS standards) enter the numerator. The denominator is all women who test positive for HIV, regardless of whether or not they returned for their test results.

Strengths and limitations

The principle limitation of this indicator is that it does not measure compliance with the anti-retroviral regime. Unless drug-taking is supervised under a regime like Directly Observed Treatments, Short Course (DOTS), it will not be possible to monitor compliance as part of a routine M&E system. It is recognised, however, that drugs provided does not necessarily equal drugs consumed, and the imbalance may go in either direction. Drugs may be provided to a woman and sold or passed on to someone else, or not taken for other reasons. On the other hand, clinics with no stocks of anti-retroviral drugs may prescribe them to women who may fill prescriptions elsewhere.

Private clinics providing prescriptions but assuming that drugs will be acquired individually are not included in this indicator, even though they may form the bulk of clinics providing mother to child prevention programmes for several years.

Research on prevention of mother to child HIV infection continues apace, and recommendations for preventative therapy are likely to change rapidly in years to come. That begs the question of which regime should be followed in calculating this indicator. It is suggested that the regime currently sanctioned by national guidelines be the benchmark for provision of therapy, even if international guidelines have since been revised. Where no national guidelines exist, the latest international guidelines sanctioned by UNAIDS, UNICEF and WHO should be used.

3.7 Sexual negotiation and attitudes

Programme goals

People's sexual behaviour is shaped in part by their attitudes (and those of the society around them) towards sex. If it is widely believed that men need many partners to stay healthy, for example, then messages centring on monogamy alone will have little chance of success. If a woman is considered family property, bought with a dowry to provide sexual and reproductive services to her husband, then messages encouraging women to use condoms with their husbands are likely to produce few results.

Effective campaigns promoting safe sex depend on an understanding of these norms and beliefs. Many national AIDS programmes aim to change these attitudes over the long term, creating a climate in which safer sex is easier to package to the public. Since social norms are usually deeply ingrained among older people, some programmes concentrate their efforts on young people whose attitudes are more easily influenced and whose behaviours are not yet established.

Key questions

- Is there legislation to protect women's rights?
- Do women have any sexual negotiation power?
- Can women refuse sex or insist on condom use?

Measurement challenges

Social norms may be specific to a culture, a religious group or an age cohort. It is exceptionally difficult to define attitudes that influence sexual behaviour in the same way across all cultures, thus it is difficult to come up with internationally valid indicators.

Attitudes are amorphous. They influence behaviour, but are less easily measured than behaviour. It is easier to get a straight answer to "Have you ever ….?" than to "Do you believe …?". The answer to the second question almost always includes a component of "It depends". In general, qualitative research methods are more appropriate for measuring attitudes than quantitative methods. However, qualitative methods are generally not appropriate for establishing trends over time.

Despite these difficulties, it may be possible to define some basic attitudes which influence sexual behaviour across all cultures. People's exact perceptions of condoms may differ, but they will all reflect either a willingness or an unwillingness to use them in a given situation. The relationships between men and women vary from culture to culture, but double standards in sexual behaviour is a fairly constant thread that may be investigated in many different contexts. It is worth bearing in mind that it is not worth tracking attitudes to the balance of power in a sexual relationship unless something is being done to try to change those attitudes.

Sexual Negotiation Indicator 1

Women's ability to negotiate safer sex with husband

Additional indicator for generalised epidemics

Definition

The percent of respondents who believe that, if her husband has an STI, a wife can either refuse to have sex with him or propose condom use, of all respondents having heard of STIs aged 15-49 in a population-based survey

Measurement tools

UNAIDS general population survey

What it measures

This indicator is designed to measure public perception of a woman's negotiating power in sex. It is confined to exploring norms within marriage, which in some cultures define a woman's sexual universe. By specifying that the husband has an STI, the indicator measures attitudes to a woman's ability to protect herself from the known risk behaviour of her husband.

How to measure it

This indicator is based on a hypothetical question put to respondents in a survey. Both men and women are asked to respond to a question about whether a woman can refuse sex with her husband if he has a STI, or can ask him to use a condom. The question is more specific than "can a woman protect herself" in this situation. In past use of the question, people have responded that a woman can protect herself, and on further questioning have responded that she can take medication. This has no bearing on her negotiating power, and so is excluded by the question.

Strengths and limitations

This is a useful indicator in areas where the rights of women within a sexual relationship are known to be low, and where efforts are being made to increase women's power to protect themselves in situations of known risk. A low score on this indicator may be very powerful in advocacy.

Earlier attempts at broader questioning (for example simply "Is it acceptable for a woman to refuse sex with her husband?") are hard to interpret. This is because there are many cultural situations in which it is acceptable (and indeed may be culturally prescribed) to refuse sex, such as for a certain number of weeks or months following the birth of a child, or during menses. The ability of a woman to refuse sex during these times may elicit a positive response to the survey question, but does not reflect a woman's ability to negotiate sex with her husband at other times.

3.8 Sexual behaviour

Programme goals

Promoting safer sexual behaviour has probably been the most important area of programming for most national AIDS programmes to date. Programmes seek to delay first sex among young people, and encourage lifelong, mutually monogamous partnerships. Recognising, however, that such partnerships are more the exception than the norm in many contexts, programmes also aim to encourage people to reduce the overall number of people they have sex with, and to use condoms, especially with partners other than their spouse.

Changing sexual behaviour is not an easy task. And in some high prevalence areas, there is a feeling that most sexually active adults with any risk behaviour are already infected, that is, that the adult population is "saturated" with HIV infection. As a result, attention is turning increasingly towards young people, who are not yet sexually active or who are just embarking on their sexual lives.

Establishing norms of safe behaviour among young people early on is thought to be easier than changing norms of unsafe behaviour in older people. Because of this emphasis on safe behaviour among young people, a separate but complementary set of indicators for sexual behaviour among young people is proposed.

Key questions

- What are the levels and patterns of sexual mixing in the population? (Who is having sex with whom?)
- What are the levels of unprotected sex? (Who is using condoms with whom?)

Measurement issues

Measuring changes in sexual behaviour is essential in the monitoring and evaluation of national HIV/AIDS and STI control programmes. In fact, indicators of sexual behaviour and condom use are probably the most important of all indicators in monitoring HIV prevention programmes and evaluating their success.

More has been done to measure sexual behaviour than was dreamed possible a decade ago, when it was believed that people would never tell the truth about their sex lives. In country after country, it has now been demonstrated that people do answer questions about sex, and that the trends derived from their answers match other forms of evidence such as condom sales and STI prevalence. However, there is still room for improvement. Women, especially, continue to underreport sex outside of marriage in standardised surveys. Qualitative data collection gives rather better results, but is rarely practical on a large scale and does not lend itself to the construction of indicators necessary for monitoring and evaluation.

Perhaps the trickiest issue in measuring sexual behaviour is how to filter relationships to get an idea of levels of risk involved. This question becomes more vexing as prevalence in the general population rises and the lines between "high-risk" partners such as sex workers and "low-risk" partners such as husbands become blurred. The matter of central interest is not numbers of partners but patterns of sexual networking, and this is all but impossible to analyse with simple indicators.

To date, the most common way of dividing relationships into high and low risk has been using a simple measure of time: any (non-marital) relationship that has lasted or is expected to last for more than a year is classified as "regular", while any other relationship is classified as "non-regular".

There is a growing feeling that a time-based definition of "non-regular" does not adequately capture the level of risk inherent in the partnership. For example, many men may consider a sex worker they visit frequently to be a "regular partner" under the time-based definition, although she clearly represents higher risk than a faithful wife.

It is therefore proposed that relationships be divided on the basis of cohabitation and marriage. Sex with any non-cohabiting, non-marital partner is considered to be higher risk

than sex with a cohabiting partner, regardless of the duration of the relationship. This definition has the advantage that it is equally valid for all age groups.

Sexual behaviour data are one of the central pillars of a monitoring and evaluation system. They should be used to inform and explain trends observed in HIV and STI surveillance data as much as possible. With this in mind, sampling for major surveys of sexual behaviour should be carried out in relation to the catchment areas for HIV sentinel sites.

Thought must also be given to the frequency of surveys of sexual behaviour. In the absence of a major and radically new programme effort, sexual behaviour is unlikely to change significantly in a single year, or even two, in the general adult population. Among young people, however, new behavioural trends may emerge more rapidly, especially if more programme resources are aimed at establishing safe behaviour in this group.

Sexual Behaviour Indicator 1
Higher risk sex in the last year

(Modified WHO/GPA Prevention Indicator 4)

Core indicator for all epidemics

Definition

Proportion of respondents who have had sex with a non-marital, non-cohabiting partner in the last 12 months of all respondents reporting sexual activity in the last 12 months

Measurement tools

UNAIDS general population survey; DHS AIDS Module; FHI BSS (adult)

What it measures

The spread of HIV depends upon unprotected sex with people who also have other partners. Most monogamous relationships are cohabiting, although the reverse is not necessarily true. Partners who do not live together – who have sex only occasionally – are those who are most likely to have other partners over the course of a year. These partnerships therefore carry a higher risk of HIV transmission than partnerships that do not link into a wider sexual network. AIDS prevention programmes try to discourage high numbers of partnerships, and to encourage mutual monogamy. This indicator aims to give a picture of the proportion of the population that engages in relatively high-risk partnerships and that is therefore more likely to be exposed to sexual networks within which HIV can circulate.

How to measure it

Respondents are asked about their marital status and the last three sexual partners within the last 12 months. For each partner, details are taken of cohabiting status as well as duration of the relationship, condom use and other factors. The numerator is those respondents who say they have had sex with someone who is not their spouse or the person they live with in the last 12 months. The denominator for this indicator is all respondents who report having any sex in the last 12 months.

Polygynous men who live with several spouses will not qualify for the numerator unless they also have sex with women who are not part of their household.

Strengths and limitations

This indicator gives a picture of levels of non-monogamous sex. If people stop having sex with all of their extramarital partners, the change will be captured by changes in this indicator. However, if people simply decrease from seven extra-marital partners to one, for example, the indicator will not reflect a change, even though potentially this may have a significant impact on the epidemic spread of HIV and may be counted a programme success.

This indicator proposes a different definition for higher-risk sex than that commonly used in the past, particularly in the calculation of WHO/GPA Prevention Indicator 4 (PI4). PI4 used the time-based definition of regular and non-regular described above. Obviously, a change in definition will upset trend data for countries that have collected data on PI4 using that definition. However, this difficulty is not insurmountable. The proposed data collection instrument allows for both the old PI4 and Sexual Behaviour Indicator 1 to be calculated simultaneously. In practice, in existing data which allow for the comparison between the two indicators, the difference has been small. The change is proposed largely because countries report dissatisfaction with PI4, arising mostly from respondents' difficulties in understanding the definitions of regular and non-regular partnerships.

Sexual Behaviour Indicator 2
Condom use at last higher risk sex

(Modified WHO/GPA Prevention Indicator 5)

Core indicator for all epidemics

Definition

The percent of respondents who say they used a condom the last time they had sex with a non-marital, non-cohabiting partner, of those who have had sex with such a partner in the last 12 months

Measurement tools

UNAIDS general population survey; DHS AIDS Module; FHI BSS (adult)

What it measures

If everyone used condoms every time they had sex with a non-marital or non-cohabiting partner, a heterosexually transmitted HIV epidemic would be almost impossible to sustain. While AIDS programmes may try to reduce casual partnerships, they must also, if they are to succeed in curbing the epidemic, promote condom use in the casual partnerships that remain. This indicator tracks changes in condom use in these partnerships.

How to measure it

For each partner listed in the last 12 months, respondents are asked whether they used a condom the last time the couple had sex. Other questions will allow for the classification of partnerships as cohabiting or non-cohabiting. All those who report at least one non-marital, non-cohabiting partner in the last 12 months (i.e., the numerator of Sexual Behaviour Indicator 1) form the denominator. The numerator is the number of those in the denominator who used a condom the last time they had sex with their *most recent* non-cohabiting partner.

Strengths and limitations

A rise in this indicator is an extremely powerful indication that condom promotion campaigns are having the desired effect among their principle target market.

Since condom promotion campaigns aim for consistent use of condoms with non-regular partners rather than simply occasional use, some surveys have tried to ask directly about consistent use, often using an always/sometimes/never question. While this may be useful in sub-population surveys (see below), it is subject to recall bias and other biases and is not sufficiently robust for use in a general population survey. Asking about the most recent act of non-cohabiting sex minimises recall bias and gives a good cross-sectional picture of levels of condom use. It is recognised that consistent use of condoms is an important goal. But inevitably, if consistent use rises, this indicator will also rise.

Sexual Behaviour Indicator 3
Commercial sex in the last year

Core indicator for concentrated epidemics
Additional indicator for generalised epidemics with defined populations of sex workers

Definition

Proportion of men reporting sex with a sex worker in the last 12 months

Measurement tools

UNAIDS general population survey; DHS AIDS Module; FHI BSS (adult)

What it measures

In concentrated epidemics, sexual mixing between groups with a high likelihood of infection and the general population is of central interest. In heterosexual concentrated epidemics, the initial focal point of infection is among sex workers and their clients. Those clients then spread infection to their wives and girlfriends in the general population, as well as to other sex workers. In such situations, AIDS programmes often focus on trying to reduce the proportion of men having sex with sex workers, as well as increasing condom use in these encounters. This indicator measures progress towards the first of these goals.

How to measure it

This indicator is intended *only* for countries with well-defined populations of sex workers (see below). In general population surveys or in specialised surveys among groups of men who fit the profile of clients of sex workers (the military, truck drivers, etc.), men are asked directly if they had sex with a sex worker in the previous 12 months.

While there may be several different types of definable sex workers in a given country, each with different perceived levels of risk, all these groups should be combined into an indicator of commercial sex use for monitoring and evaluation purposes.

The indicator is the number of men who report that they have had sex with a sex worker in the past 12 months, divided by all male respondents.

In some countries, this indicator has been collected in the past using only sexually active men (rather than all male respondents) as the denominator. In order to maintain trends over time, it is recommended to continue calculating the indicator using sexually active men, but to collect this new indicator using all men in the denominator for several years in parallel with the former.

Strengths and limitations

This indicator is useful in concentrated heterosexual epidemics in countries where commercial sex (and especially brothel-based sex) is common, and where a “prostitute” has a clearly defined role. This means it is most likely to be used in parts of the world where commercial sex has played a dominant role in the epidemiology of HIV, e.g., many countries in Asia.

Attempts to collect and analyse data using a wider definition of commercial sex (questions such as “Have you given or received money or gifts in exchange for sex?”) have not yielded useful information. In epidemic terms sex workers are of interest because they have a high turnover of partners and therefore have a high probability of being exposed to infection and passing on infection. In many cultures, this is true of only a fraction of the people who have “received money or gifts in exchange for sex”. If there is no locally specific term for prostitution, the chances are that this indicator is not relevant to the programme. It should not be used in these situations.

The indicator is also of limited use in very high prevalence epidemics, since differences in risk associated with sex with a sex worker compared with any other casual partner may not be very substantial.

It is possible to construct a similar indicator for clients of male sex workers in special surveys of men who have sex with men.

Sexual Behaviour Indicator 4

Condom use at last commercial sex, client report

Core indicator for concentrated epidemics
Additional indicator for generalised epidemics with defined populations of sex workers

Definition

Proportion of men reporting condom use the last time they had sex with a sex worker, of those who report having had sex with a sex worker in the last 12 months

Measurement tools

UNAIDS general population survey; DHS AIDS Module; FHI BSS (adult)

What it measures

This indicator gives an indication of the success or failure of campaigns to increase condom use among clients of sex workers. It measures condom use by men with partners they consider to be commercial partners.

How to measure it

As with Sexual Behaviour Indicator 3, this indicator is only relevant to settings where commercial sex or prostitution is well defined. In general population surveys or in specialised surveys among groups of men who fit the profile of clients of sex workers (the military, truck drivers, etc.), men are asked if they had sex with a sex worker in the previous 12 months. If they reply yes, they are further asked whether they used a condom the last time they had sex with a sex worker.

The indicator is the number of men who report that they used a condom at last sex with a sex worker, divided by all those say they have had sex with a sex worker in the last 12 months.

Strengths and limitations

This indicator is invaluable in tracking the success of major programmes to promote condom use in commercial sex.

Most AIDS programmes aim to increase consistent use of condoms with sex workers. Surveys of clients of sex workers will almost certainly want to ask whether they use a condom always, sometimes or never in sex with sex workers over the last 12 months. However the pressure to say “always” is strong. Asking about a particular, and recent, act of sex may give a more robust measure of levels of condom use in commercial sex. This measure should therefore be used as the core indicator. However it is strongly recommended that programmes focusing prevention resources on increasing condom use in commercial sex also construct an indicator of consistent use of condoms in commercial sex. If both questions are asked, the “last time you had sex with a sex worker” question should precede the “always, sometimes, never” question.

Where there are several distinct populations of sex workers with different levels of perceived risk – for example, brothel-based prostitutes may be thought of as having riskier behaviour than girls in night-clubs – data may be collected separately for separate categories of sex worker. This can provide important information for programming. For example, men may report very high levels of consistent condom use in brothels, but much lower levels with women working out of night-clubs. This may be a warning signal for a shift of the high prevalence from one group to another. In constructing the indicator, however, only the last commercial sex partner of any sort should be considered.

It is possible to construct a similar indicator for clients of male sex workers in special surveys of men who have sex with men.

Sexual Behaviour Indicator 5

Condom use at last commercial sex, sex worker report

Additional indicator for concentrated and low-level epidemics, and for generalised epidemics with defined populations of sex workers

Definition

Percent of sex workers who report using a condom with their most recent client, of sex workers surveyed having sex with any clients in the last 12 months

Measurement tools

FHI BSS (sex workers)

What it measures

This indicator measures the success of campaigns to promote condom use in commercial sex from reports given by sex workers. Although many surveys and the previous indicator gather data from actual clients of sex workers, this indicators looks to men and women actually working as providers of sex. Collected in conjunction with self-reported client data, this indicator will validate levels of commercial sex and condom use. In areas where patronage of commercial sex is highly stigmatised, clients may hesitate to report visits to commercial sex workers. As well, clients may desire to give the 'good' answer that they used a condom at last sex, especially in areas where programs have stressed condom use at commercial and other sex. This indicator seeks responses from sex workers, who may not have the same motivation to give socially desirable answers and who offer a different perspective.

How to measure it

In special surveys of sex workers, sex workers are asked whether they used a condom with their most recent client. The indicator is the number of sex workers who say they used a condom with their most recent client, divided by the total number of sex workers interviewed who report sex with clients in the last 12 months.

Strengths and limitations

The goal of most AIDS programmes working with sex workers is an increase in the number of sex workers who *always* use a condom and thus are protected from HIV infection. As with clients, surveys of sex workers will almost certainly want to ask whether they use a condom always, sometimes, or never with their clients. But again, the pressure to say "always" is strong. And again, asking about a recent act of sex may give a more robust measure of levels of condom use with clients. However it is strongly recommended that programmes focusing prevention resources on increasing condom use in commercial sex also construct an indicator of consistent use of condoms in commercial sex. If both questions are asked, the "last client" question should precede the "always, sometimes, never" question.

The difference between the two answers can be useful for programme purposes. What proportion of those who say they used a condom at last sex also say they are not regular condom users, for example? Do any sex workers who claim to "always" use condoms with their clients also say that they did not use one with their last client?

Since a sex worker typically sees more clients than vice versa, it is unlikely that there will be an exact match between condom use reports from sex workers and from their clients. However if both data sets show trends in the same direction, confidence in this self-reported data is likely to be strengthened.

It is possible to construct a similar indicator for male sex workers in special surveys of that group.

Sexual Behaviour Indicator 6

Higher risk male-male sex in the last year

Core indicator for concentrated and low-level epidemics

Definition

The percent of men who have had anal sex with more than one male partner in the last 6 months of all men surveyed who have sex with a male partner

Measurement tools

FHI BSS (men who have sex with men)

What it measures

Unprotected anal sex is by far the highest risk behaviour for transmission of HIV among men who have sex with men. Most interventions in this group aim both to decrease the overall number of partners and to increase condom use in all partnerships.

This indicator is similar to Sexual Behaviour Indicator 1 in that it attempts to measure the extent of exposure to sexual networks. Since in many countries cohabitation with same-sex partners is rare, this measure drops distinctions based on cohabitation or regular partnership and looks just at sexual activity with multiple partners in the past six-month period.

How to measure it

This indicator is intended for use in special surveys among men who have sex with other men. In a behavioural survey in a sample of men who have sex with men, respondents are asked about sexual partnerships in the preceding six months. For male partners, they are asked how many they had anal sex with. If the response is more than one, the respondent enters the numerator for this indicator. The denominator is all respondents; it is assumed that the sampling strategy focuses on men who are likely to be sexually active.

Note that the time reference period for this denominator differs from those used for other groups. The standard time reference period for indicators of sexual behaviour is 12 months. The six month period is used because in most cases where BSS is used in sub-populations of men who have sex with men, the sampling strategy tends to focus on cruising areas and other areas where men congregate specifically to seek other male partners. This means that those included in the sample are likely to be at the higher end of the spectrum of risk behaviour, and to have a high turnover of partners. Indeed these are precisely the individuals of greatest interest to HIV prevention programs.

Groups with a high average turnover of partners are likely to have difficulty recalling the total number of partners over one year, the reference period commonly used in indicators of sexual behaviour. The time reference period is reduced to six months to provide for more accurate recall. In situations where rapid assessment shows that a high proportion of men sampled have very high levels of sexual behaviour, a time reference period of one month may even be considered for all indicators of sexual behaviour among men who have sex with men.

Strengths and limitations

As with other sub-population surveys, there are difficulties associated with sampling and extrapolation of results, and this in turn may lead to difficulties in comparing indicators both across different countries and across time.

Increasingly, respondents in surveys of sexual behaviour are questioned specifically about their last three partners. Most sexual behaviour indicators are constructed on the basis of information given about the last three partners, minimising recall bias. However that is not possible in the construction of this indicator, since not all male partners with whom anal sex took place necessarily fall within the last three sexual partners. This measure may therefore be more subject to recall bias than other measures of sexual behaviour.

In many societies, men who have sex with men also have sex with women. In general, the risk of HIV transmission in anal sex between men is greater than the risk of transmission in vagi-

nal sex between men and women. Men who have sex with men and women may represent an important "bridge" group between a subpopulation at high risk for HIV infection and a larger population at lower risk for infection. To track the risk of bridging between men who have sex with men and the heterosexual population, programmes in countries where bisexual activity is common will probably want to ask men about their female as well as their male partners. However most HIV prevention programmes aimed at men who have sex with men concentrate on decreasing risky sex between men, and put very little emphasis on behaviour with female partners. It is therefore not suggested that female partners be included in calculating this indicator.

Sexual Behaviour Indicator 7

Condom use at last anal sex between men

Core indicator for concentrated and low-level epidemics

Definition

Percent of men or their partners who used a condom at last anal sex with a male partner, of those who have had anal sex with a male partner in the last 6 months

Measurement tools

FHI BSS (men who have sex with men)

What it measures

The single most common intervention among men who have sex with men is the promotion of condom use during anal sex. This indicator measures progress towards increasing the proportion of acts of anal sex that are protected against HIV transmission. It focuses on the last act of anal sex for reasons similar to those given for Sexual Behaviour Indicator 2. The indicator measures condom use by the insertive partner during the last anal act, but because details of the sex act may not be known, the respondent is asked whether he *or* his partner used a condom.

How to measure it

This indicator is intended for use where special surveys among men who have sex with other men are possible. In a behavioural survey in a sample of men who have sex with men, respondents are asked about sexual partnerships in the preceding six months, about anal sex within those partnerships, and about condom use at last anal sex.

The numerator is the number of men reporting that a condom was used the last time they had anal sex. The denominator is all men who reported having anal sex *at least once* in the previous six months.

Strengths and limitations

This measure suffers from the same difficulties of recall as Sexual Behaviour Indicator 6. Its most serious limitation is that it does not distinguish between regular and non-regular partners and that information about sero-status may not be known. Many couples who know their sero-status and are sero-concordant may choose not to use condoms within their regular partnership. Provided they use condoms in any sex with other partners, this represents no increased risk of transmission within the partnership. Where non-use of condoms within stable partnerships is common, the indicator will suggest higher levels of risk than actually exist.

However, defining “regular” partnerships in the context of men who have sex with men is fraught with difficulty, particularly in communities where male-male sex is clandestine. Condom use at last anal sex with any partner probably gives a good indication of overall levels and trends of protected and unprotected sex in populations surveyed.

As with Sexual Behaviour Indicator 6, this indicator does not give any idea of risk behaviour in sex with women, among men who have sex with both men and women. In countries where men in the sub-population surveyed are likely to have partners of both sexes, condom use with female as well as male partners should be investigated. In these cases, data on condom use should always be presented separately for male and female partners.

3.9 Sexual behaviour among young people

Programme goals

The importance of young people in determining the future of the HIV epidemic has been described above. As HIV prevalence rises in a generalised epidemic, the chances of encountering an infected partner early in one's sexual life rises. The importance of establishing safe behaviour early on therefore also grows. The success of prevention programmes will increasingly be judged on their success in persuading young people to delay first sex, to restrict the number of partners they choose (or the type of sexual partners they have or choose) and to use condoms when they do have sex.

Key questions

- When do young people initiate sexual activity?
- How safe is their sexual behaviour when they do become active?
- Is there a national policy on condom promotion among young people, both in and out of school?

Measurement issues

One of the difficulties in choosing indicators of sexual activity among young people is defining an appropriate age group. The most common age group chosen in this context is 15-24. However the relevance of this spectrum may vary considerably from country to country. In many countries with high prevalence HIV epidemics, a sizeable proportion of young people are sexually active before 15. In these cases, surveys focusing on young people should sample respondents below 15. There is also wide variation in the proportions sexually active across the entire age range typically thought to represent "youth". Most indicators of sexual behaviour in young people should therefore be presented separately for the age groups under 15 (where relevant), 15-19, and 20-24. It is possible that the age range sampled in youth surveys will vary by gender within a country. As with all indicators of sexual behaviour, indicators for young people should be presented separately by gender, even when the age range chosen is identical for both sexes.

Past attempts to track sexual behaviour among young people have sometimes been hindered by opposition from parents, teachers or other "gatekeepers" who believe that questions about sexual behaviour are, in the words of the education ministry in one high HIV prevalence country, "not relevant to this cohort". Tracking sexual behaviour among young people is a critical part of good monitoring and evaluation of HIV programmes in countries with generalised epidemics. However programme managers should be aware that these monitoring activities need to be carefully prepared so that their purpose is clearly understood and potential opposition is minimised.

Special attention also needs to be paid to sampling strategies for young people, since those most at risk may well be outside the conventional frameworks that afford access to young people, such as the school system. Sampling strategies then may consider sites where out-of-school youth may gather, such as work sites, night-clubs and soccer fields. Focusing on high transmission sites or locations where sexual activity takes place should also be considered.

Young People's Sexual Behaviour Indicator 1

Median age at first sex among young men and women

Core indicator for generalised epidemics

Definition

The age by which one half of young men or young women aged 15-24 have had penetrative sex (median age), of all young people surveyed

Measurement tools

UNAIDS general population survey; DHS AIDS module; FHI BSS (youth)

What it measures

A major programme goal in many areas is delaying the age at which young people first have sex. Clearly, young people are protected from infection by abstinence. But there is evidence to suggest that a later age at first sex also reduces susceptibility to infection per act of sex, at least for women. This indicator measures the age by which half of the adolescent population is sexually active. An upward shift in the indicator suggests that programmes promoting abstinence among young people are working.

How to measure it

This measure is constructed from data on current virginity status among young people, *not* from retrospective questions about age at first sex. In household or special surveys focusing on young people, respondents are asked whether or not they have ever had penetrative sex. A curve is plotted according to the percent who say they have had sex by each single year of age. The age at which the curve exceeds 50 percent is taken to be the median age at first sex. On average, people reporting they are a certain age will be six months older than that age. (For example those who say they are 15 will range from those who turned 15 on the day of the survey to those who will turn 16 the following day. Assuming an even age distribution, they will be on average 15.5.) Half a year should therefore be added to the exact ages used in the calculation of the median age at first sex.

Strengths and limitations

Because this indicator is constructed from a question about current virginity status, it is sensitive to recent changes in the age at first sex. The indicator itself does not, however, give any idea of the full distribution of ages at sexual initiation. In some circumstances, such as when a significant proportion of girls is exposed to sex at very young ages, it may be the tails rather than the middle of the age curve which interest those designing prevention programmes.

To allow for the construction of a robust indicator using this "current status" methodology, reasonable sample sizes are needed at each single year of age (preferably at least 100 respondents of each sex in single years, especially the single years at which the median age is expected).

Most questionnaires also include questions such as "How old were you when you first had sex?". These data are *not* used in the construction of this indicator. This is because they exclude people who have not yet had sex, and therefore tend to bias the median age downwards. Retrospective data can be used from age cohorts at which virtually everyone is already sexually active. However an indicator constructed in this way is not sensitive to recent changes in the age at first sex, and it is these recent trends that are of interest in monitoring the success of HIV prevention programmes.

The indicator is most useful where the median is rather young – between 15 and 19 years. Where the median age at first sex is over 19 for both men and women, promoting abstinence among adolescents may be replaced by other priority interventions within the programme and this indicator will diminish in importance and may not even be measured.

Young People's Sexual Behaviour Indicator 2

Young people having premarital sex in last year

Core indicator for generalised epidemics
Additional indicator for concentrated epidemics

Definition

Percent of young single people (aged 15 – 24) who have had sex in the last 12 months of all young single people surveyed

Measurement tools

UNAIDS general population survey; DHS AIDS module; FHI BSS (youth)

What it measures

This indicator is a measure of premarital sex among young people. A high score on this indicator reflects a failure of prevention messages stressing abstinence until marriage.

The converse of this indicator (that is, the indicator score subtracted from 100), functions as an indicator of abstinence among unmarried young people. Success in promoting abstinence should be reflected in a later age at first sex, as measured by Young People's Sexual Behaviour Indicator 1. This indicator, however, captures an additional dimension: anyone who has been abstinent for more than a year (regardless of whether they have ever had sex) will *not* be counted in the numerator for Young People's Sexual Behaviour Indicator 2. So the inverse indicator of abstinence will include not only virgins but people who have given up sex for at least the last year as a protective measure against HIV and other STIs. Given that young people should be the focus of education and prevention programs at all ages, deciding to abstain from sex after having precocious sexual activity would be an expected program outcome.

How to measure it

In a survey among people aged 15-24, respondents are asked about their marital status and their sexual partnerships. Those that are single and report any sex in the last 12 months enter the numerator. The denominator is all respondents who are not married.

The indicator should be reported separately for men and women. It may also be constructed separately for those aged 15-19, <15 and 20-24, as appropriate. In some settings, the proportion of those aged 20-24 who are single will be very low, at least among women, and it may not be appropriate to construct the indicator for this age group in these cases.

Strengths and limitations

This indicator has a critical role in advocacy. Resistance to improved sexual education and service provision for young people frequently comes from parents or other authorities who believe that abstinence until marriage is the only acceptable message for young people. An indicator that tracks premarital sex tracks the success or failure of this message and may point to gaps in the current approach. In addition, this indicator measures changes in what may be culturally and socially ascribed norms for early sexual activity. Where programs are advocating a delay of first sex or abstinence outside of a married, monogamous relationship, the indicator should show a decrease.

A limitation may also be that small sample sizes of the different age strata could make analysis and interpretation of results quite difficult. As well, in areas where early marriage is both encouraged and acceptable, prevention programs may have limited affect on changing prevailing social and cultural norms around marriage.

Young People's Sexual Behaviour Indicator 3

Young people using a condom during premarital sex

Core indicator for generalised epidemics
Additional indicator for concentrated epidemics

Definition

Percent of young single people (15 – 24) who used a condom at last sex, of all young single sexually active people surveyed

Measurement tools

UNAIDS general population survey; DHS AIDS module; FHI BSS (youth)

What it measures

In many high HIV prevalence epidemics, it is clear that a high (and rising) proportion of HIV infections take place before marriage, but reluctance to provide services to decrease risk among people who choose to be sexually active before marriage is sometimes intense. Some national programmes are beginning to actively promote the provision of services to young and unmarried people. This indicator tracks their success in reducing the risk of HIV infection in premarital sex by increasing condom use.

How to measure it

In a survey among people aged 15-24, respondents are asked about their marital status and their sexual partnerships, including condom use at last sex with each partner. Those that are single and report using a condom the last time they had sex in the last 12 months enter the numerator. The denominator is all single respondents sexually active in the last 12 months.

The indicator should be reported separately for men and women. It may also be constructed separately for those aged 15-19, <15 and 20-24, as appropriate. In some settings, the proportion of those aged 20-24 who are single will be very low, at least among women, and it may not be appropriate to construct the indicator for this age group in these cases.

Strengths and limitations

This indicator tracks levels of risk in premarital sex. Clearly, it should be presented together with the previous indicator, since low levels of condom use and high levels of premarital sex will be much more worrying than low levels of condom use and very low levels of premarital sex. The indicator makes no distinction between partner types. Non-marital relationships among young people are inherently unstable, and partner exchange is common, so any partner is considered to be a risky partner.

Young People's Sexual Behaviour Indicator 4

Young people having multiple partners in last year

Core indicator for generalised epidemics
Additional indicator for concentrated epidemics

Definition

Percent of young people (15 – 24) who have had sex with more than one partner in the last 12 months, of all young people surveyed

Measurement tools

UNAIDS general population survey; DHS AIDS module; FHI BSS (youth)

What it measures

Prevention messages for young people tend to begin with abstinence and often focus also on mutual monogamy. But because sexual relationships among young people are frequently unstable, relationships that were intended to be mutually monogamous may break up and be replaced by other relationships in which similar intentions prevail. Particularly in high HIV prevalence epidemics, serial monogamy is not greatly protective against HIV infection. This indicator measures the proportion of young people that have been exposed to more than one partner in the last year. That is, the proportion for whom the "one, mutually faithful partner" message has failed.

How to measure it

In a survey among people aged 15-24, respondents are asked about their sexual partnerships in the last year. Those that report more than one partner in the last 12 months enter the numerator. The denominator is all respondents.

The indicator should be reported separately for men and women. It may also be constructed separately for those aged 15-19, <15 and 20-24, as appropriate.

Strengths and limitations

This indicator does not distinguish between marital and non-marital partners. It tracks all multiple partnerships, regardless of their relative levels of risk. In the very similar adult sexual behaviour indicator (Sexual Behaviour Indicator 1) a distinction is made between marital and cohabiting partners, and all other partner types. This is partly to cope with the measurement challenge posed by men in polygynous societies, who may have multiple partners within marriage. However polygyny among men under 25 is extremely rare. It is therefore not necessary to make the distinction in an indicator for young people.

The indicator also suffers from the expected respondent and social desirability bias. For young people saturated with prevention messages, there will be high motivation to underreport partners. Likewise, social pressure for women to give untruthful answers may be strong.

Young People's Sexual Behaviour Indicator 5

Young people using a condom at last higher risk sex

Core indicator for generalised epidemics
Additional indicator for concentrated epidemics

Definition

Percent of young people (aged 15 – 24) who have had sex in the last 12 months and used a condom at last sex with a non-marital, non-cohabiting partner, of all young people surveyed

Measurement tools

UNAIDS general population survey; DHS AIDS module; FHI BSS (youth)

What it measures

The indicator differs from Young People's Sexual Behaviour Indicator 3 in that it includes the non-marital partners of young people who are currently married, as well as all reported partners of those who are still single or not in a stable enough relationship to be cohabiting with their partner.

It differs from Sexual Behaviour Indicator 2 in that, for reasons given under Young People's Sexual Behaviour Indicator 3, it includes in the denominator all respondents, rather than just those who report risky sexual activity in the last year.

It should be reported across the 15-24 age range and separately by sex. It may also be reported separately for those aged 15-19, 20-24 and under 15 year, where relevant.

How to measure it

In a general population or targeted youth survey all respondents are asked about their sexual partnerships in the last year. For each partner a young person reports, cohabitation status is established. Where a general population survey is undertaken for people aged 15-49, the data can simply be stratified by age groups to calculate this indicator. The denominator is all young people aged 15-24. The numerator is the percentage of those persons using a condom at last sex with a non-marital, non-cohabiting partner in the last 12 months.

Strengths and limitations

In terms of advocacy, this indicator of young people's sexual behaviour can have powerful effects. Where the indicator shows low levels of condom use with higher risk sex among youth, programmes will need to focus efforts around abstinence after initiation of sexual activity, but primarily on condom use. But there could also be major constraints where programmes do not wish to address youth sexual activity.

Like Young People's Sexual Behaviour Indicator 4, it will capture all unmarried people having sex; the proportion of which will generally be fairly high, especially among men. In addition, it will capture married young people having sex outside of marriage.

The indicator suffers from the same reporting bias problems inherent in surveys asking about sexual behaviour; depending upon the degree of programmes effort saturation and/or existing cultural or religious mores, young people may actually be more willing than adults to report details about their sexual behaviour.

Young People's Sexual Behaviour Indicator 6

Condom use at first sex

Additional indicator for all epidemics

Definition

The proportion of young people (aged 15-24) who used a condom the first time they ever had sex, of those who have ever had sex.

Measurement tools

UNAIDS general population survey; FHI BSS (youth)

What it measures

It is generally believed that it is easier to maintain safe behaviours established from the onset of sexual activity than to change risky behaviours once they have become habitual.

In addition, data from a number of African sero-surveys suggest that high proportions of young women become infected with HIV during their first few acts of sex.

Life skills programmes for young people have therefore concentrated on promoting safe behaviour right from the beginning of young people's sex lives. This indicator measures progress towards establishing safe behaviour from the outset of people's sexually active lives.

The indicator should be disaggregated by gender. Disaggregation by age and concentration on those aged 15-19 will increase the sensitivity of the indicator to recent changes in condom use at first sex, but sample sizes will need to be large.

Strengths and limitations

One limitation of this measure is that where it is high, it may create a false sense of complacency. HIV and STIs are far from being the only concern for young people. Many adolescents are more concerned about the immediate threat of pregnancy than they are about HIV and STIs. Integrated life skills and reproductive health programmes for young people stress avoiding unwanted pregnancies as much as they stress avoiding STIs, including HIV. High levels of condom use at first sex may in fact reflect growing use of condoms as a use of contraceptives. When sexual activity becomes more regular, young women may adopt longer-term forms of contraception, and abandon condom use. Because of this, it is important to present this indicator in conjunction with other indicators in this guide of condom use among young people.

Young People's Sexual Behaviour Indicator 7

Age-mixing in sexual relationships

Additional indicator for generalised epidemics

Definition

The proportion of women aged 15-19 who have had non-marital sex with a man 10 years or more older than themselves in the last 12 months, of all those who have had non-marital sex in the last 12 months

Measurement tools

UNAIDS general population survey; DHS AIDS module

What it measures

One of the principle forces driving the heterosexual spread of HIV is age-mixing. Often, the virus is introduced into a new pool of uninfected young people when people in that age group have sex with people in an age group that is already heavily infected. Most commonly, the younger partners are girls, the older partners men. These types of partnerships are especially good at spreading the virus since, for physiological reasons, there is a high risk of infection per act of sex between a young, uninfected girl and a more mature infected man.

In some countries this pattern of mixing is common enough to have been given a name: the "sugar daddy syndrome". AIDS programmes sometimes try to address it directly from both ends: through IEC campaigns aiming to make sex with younger women socially unacceptable among older men, and through initiatives to increase girls' negotiating power. This indicator measures progress made towards reducing the proportion of young women having non-marital sex with older men.

How to measure it

In a general population survey or a survey of young people, respondents are asked about their three most recent sexual partnerships. The question sequence includes a question about the age of the partner, as well as a question about the relationship between the partner and the respondent.

The indicator is calculated by including in the numerator all women aged 15-19 who report sex with a man who is 10 years or more older than themselves, and to whom they are not married. The denominator is all women aged 15-19 who report sex with any man to whom they are not married.

Strengths and limitations

There are two major limitations to this measure. The first is that people often do not know the exact age of their sex partners. This is more likely to be true for casual partners than for spouses. The second is that it is not clear exactly what age difference constitutes an elevated risk of exposure to HIV.

When uncertain about a partner's age, respondents frequently give numbers that "heap" around round numbers such as 30 or 40. This may well distort the indicator. However, it should be noted that the biases introduced through age heaping or age misreporting are unlikely to change greatly over time, so this may be of little consequence in looking at trends.

This measure will not give an exact picture of patterns of age-mixing, and it will not capture small shifts in the age gap between partners. But the substantial changes in age-mixing that HIV-prevention and life-skills programmes promote will be captured, since women are unlikely to mistake an age-mate for a man many years older than themselves. If women increasingly choose to have sex with their age-mates rather than with older men, or if older men become less likely to seek out substantially younger partners, these changes will be reflected in the indicator, regardless of errors in age reporting.

The indicator is confined to extramarital relationships. Young women may also be placed at higher than average risk of HIV infection if they enter a marriage with a substantially older man. However large age differences between men and women in marriage are both common

and socially sanctioned in many societies, and few if any HIV prevention programmes are acting specifically to try to reduce the age gap between marital partners. These partnerships are therefore not included in constructing this indicator.

3.10 Injecting drug use

Programme goals

In many countries with concentrated epidemics, HIV has spread most rapidly among injecting drug users (IDUs). Prevention in this group has been relatively neglected in many countries, largely for political reasons, even though affordable and effective interventions do exist. Politically, many countries and programmes do not want to provide supportive services openly to a population whose risk behaviour is in any case illegal.

Public health advocates have, in recent years, been able to demonstrate that effective interventions for drug injectors – including efforts to reduce the number of people injecting drugs – can provide health and economic benefits to society as a whole.

Since the sharing of needles and syringes provides a very efficient vector for the spread of HIV infection, the most effective interventions reducing the risk of HIV infection among drug injectors are those that reduce the sharing of needles and injecting equipment. The sterilisation of injecting equipment, the reduction of high-risk practices in the preparation of batch drugs and the promotion of condom use with sexual partners are also common interventions. Efforts to encourage injecting drug users to switch to other non-injecting drugs can also reduce the risk of an injector contracting or passing on HIV. Programmes also attempt to promote safe sexual behaviour among drug injectors, to minimise the risk that they will pass HIV infection acquired through injecting to sexual partners who are not themselves injectors.

Key questions

- Is there a national policy on needle exchange for injecting drug users?
- How common are risky injecting practices?
- How consistent are safe practices?
- Might the sexual behaviour of IDUs spread HIV to a wider population?

Measurement challenges

The greatest difficulty in monitoring and evaluating interventions with drug injectors is access to the population. Drug injecting is usually illegal and almost always stigmatised, and populations of drug injectors are often hidden. It is therefore often difficult to establish a sampling frame for behavioural and/or specimen surveys which is in any way replicable over time. Basing measurement on drug injectors presenting for treatment at rehabilitation clinics, or among those arrested for drug-related offences, will provide highly biased information unlikely to give a useful picture of behaviour or infection in the larger population of drug injectors.

Mapping techniques involving drug injectors as key informants have proved useful in identifying communities of drug injectors and in assessing their HIV prevention and health service needs. Provision of these services through community-based or outreach organisations provides an entry point for surveillance and M&E activities.

Injecting Drug Use Indicator 1

Injecting drug users sharing equipment at last injection

Core indicator in low-level and concentrated epidemics with significant or growing IDU populations

Definition

Percent of injecting drug users active in the last month who report sharing injecting equipment the last time they injected drugs

Measurement tools

FHI BSS (injecting drug users)

What it measures

Sharing of injecting equipment is both the biggest risk factor for HIV transmission among drug injectors, and the most common focus of interventions. While equipment sharing is now relatively uncommon in industrialised countries with long histories of preventative interventions among drug injectors, the same is not true of many of the countries in which drug injecting populations are exploding.

This indicator measures progress in program efforts to reduce the most risky practice – the sharing of injecting equipment – among people who continue to inject drugs. It is especially valuable for tracking trends over time for programmes that support needle-exchange initiatives, or that work to improve easy access to safe injecting equipment.

How to measure it

In a behavioural survey among injecting drug users, respondents are asked about their injecting habits. Those that report sharing needles, syringes or other injecting equipment the last time they injected drugs in the last month form the numerator. The denominator is all respondents reporting injecting behaviour in the last month.

Drug injecting practices vary from place to place. In order to capture as wide a range of risk injection as possible, questionnaires should specify all the locally relevant types of "equipment" that may result in the exchange of body fluids. These will include needles and syringes, but other paraphernalia such as "cooking" equipment can also become contaminated, depending on local drug preparation methods.

Strengths and limitations

As with all indicators measured among drug injectors, the biggest difficulty is access. Random sampling is all but impossible, and convenience samples are biased in ways that are often unpredictable. It is therefore difficult to determine the extent to which those surveyed are representative of the larger population of injecting drug users. Where the representativeness of the sample is variable, trends over time will be hard to interpret.

It is assumed that these surveys take place among people identified as members of a community of drug injectors. It is possible that, in response to HIV-related interventions, some injectors stop taking drugs entirely or switch to non-injected drugs. Since the indicator is designed to track changes in risky injecting practices over time among people who continue to inject drugs, people who cease to inject will not be included in the denominator for the indicator.

Some education programmes have focused on sterilising needles between users. Users may continue to inject drugs and even share needles, but may sterilise between uses. It is, however, difficult to know the success of individual efforts to sterilise equipment. Experience in some settings has demonstrated that inadequate cleaning of equipment is common, and many programmes have ceased to promote equipment cleaning as a prevention method, preferring to concentrate efforts on putting an end to the sharing of injecting equipment. This indicator includes in its numerator of those with risky behaviour injecting drug users who sterilise, but still share, their equipment.

Because it restricts those included in the indicator to those who have injected in the last month, this indicator is very sensitive to recent trends in injecting practices. Countries with

inconsistent policies supporting safe drug injection may see large variations in this indicator. Police crackdowns on users, distributors or support services such as needle exchange centres may lead to dramatic changes in injecting practices over a very short period of time.

The indicator does not attempt to look at consistency in avoiding needle sharing. It asks only about a single recent act of injection. This method minimises recall bias and has proved very robust in other areas such as condom use at last sex. Issues of consistency are covered by the next indicator.

Injecting Drug Use Indicator 2

Injecting drug users never sharing equipment in the last month

Core indicator in low-level and concentrated epidemics with significant or growing IDU populations

Definition

Percent of active injecting drug users surveyed who report never sharing injecting equipment during the last month

Measurement tools

FHI BSS (injecting drug users)

What it measures

Sharing injecting equipment between HIV-infected and uninfected drug injectors is an extraordinarily effective way of spreading HIV. Because the risk of contracting infection per single act of risky injection is so high, programmes must aim not just for a reduction in the sharing of equipment between drug users, but for a complete halt to this behaviour.

The previous indicator uses a robust methodology that will give a good picture of rising safe injecting behaviour, but will not capture entirely the rises in consistently safe behaviour for which prevention programmes among drug injectors strive.

This indicator measures trends in consistently safe behaviour among drug users who continue to inject drugs.

How to measure it

In a behavioural survey among injecting drug users, respondents are asked about their injecting habits. Those that report sharing needles, syringes or other injecting equipment at any time in the last month are excluded from the numerator. The denominator is all respondents reporting injecting behaviour in the last month.

As with the previous indicator, questionnaires should specify all the locally relevant types of "equipment" that may result in the exchange of body fluids.

Strengths and limitations

This indicator shares the strengths and limitations of Injecting Drug Use Indicator 1. In addition, it is likely to suffer more from recall bias. Depending on the local drug scene, drug users may be injecting several times each day. Recalling the circumstances of every act of injection over the past 30 days may be problematic.

Trends measured by this indicator should confirm changes registered in the indicator that looks only at behaviour at last injection. The difference between the two indicators may be used to pinpoint areas of programme weakness.

Injecting Drug Use Indicator 3

Drug injectors using condoms at last sex, by partner type

Additional indicator in low-level and concentrated epidemics with significant or growing IDU populations

Definition

Percent of injecting drug users surveyed who used a condom the last time they had commercial sex, or sex with a non-regular partner, or sex with a regular partner, of those who have had sex in the last 12 months

Measurement tools

FHI BSS (injecting drug users)

What it measures

Drug injectors frequently have sexual partners who do not inject drugs. Because of the high HIV prevalence typically found among injecting drug users, these partners are at especially high risk of infection through sex unless a condom is used. They provide a conduit by which the virus may enter the larger population of people who are sexually active but have no direct contact with drug injectors.

While interventions with drug users centre on safer injecting practices, many also actively promote condom use during sex, aiming to minimise the spread of HIV from drug users to the general population. This indicator tracks changes over time in condom use by injecting drug users, by partner type.

How to measure it

Three types of partners are distinguished which can result in three potential sub-indicators.

In a survey of injecting drug users, respondents are asked about commercial sex in the last 12 months. They are further asked whether commercial partners were paid or paying, and the timing of the most recent paying client. The indicator is the number reporting that they used a condom the last time they had sex for drugs or money, divided by all those who have sold sex in the last 12 months.

In a survey of injecting drug users, respondents are also asked about sex with non-regular and regular partners in the last 12 months and about condom use at last sex with the most recent partner of each type. The indicator is the number reporting that they used a condom the last time they had sex with a given partner type, divided by all those who have had sex with that type of partner in the last 12 months. It is reported separately for each partner type.

Strengths and limitations

For reasons given in the section on sexual behaviour, a cross-sectional measure of condom use at last sex gives a rather reliable picture of overall levels of condom use. The major limitation of this measure among drug injectors is that it does not distinguish between partners who are themselves injectors and those who are not. Men and women who inject drugs are far more likely to be at risk for HIV because of their injecting behaviour than because of their sexual behaviour – unprotected sex with another injector is likely to represent only a small incremental risk of infection for them. In addition, couples who know that they are both HIV-infected are unlikely to use condoms with one another. In this case, unprotected sex does not represent any risk. It is when a drug injector has unprotected sex with someone who does not inject drugs that the risk of sexual transmission is greatest.

Distinguishing between injecting and non-injecting partners may not, however, be practical. People may not know their partner's injecting status – this is especially likely to be the case among injectors who support their habit through commercial sex. And inaccuracies in recall are more likely if people are asked to report condom use with the most recent partner who was not an injector.

The indicator distinguishes between partner type for programmatic reasons. While epidemiologically the risk of a drug injector passing on HIV infection in sex is not dependent on partner type, the implications for the further spread of HIV are substantial. Low condom

use with commercial partners among drug injectors who support their drug purchases by selling sex is epidemiologically more worrying than low condom use with regular partners, simply because partner turnover in commercial sex is higher. Different types of interventions may be needed to more effectively promote condom use with different partner types.

3.11 Blood safety

Programme goals

During the initial years of the AIDS epidemic a major effort was made to reduce the transmission of HIV associated with blood transfusions. These efforts focused on HIV antibody screening, blood donor selection, prevention of avoidable transfusions, blood banking and other measures.

Much of this work was actively supported by WHO/GPA. While efforts to guarantee an HIV-free blood supply are continuing, the dissolution of GPA contributed to blood safety issues slipping down on the agendas of resource-strapped countries and donors. This is especially problematic in sub-Saharan Africa. With both HIV prevalence and the number of blood transfusions high, the risk of transfusion-associated HIV transmission is highest in this area. In 1995, UNAIDS estimated that a quarter of the 2.3 million blood donations in sub-Saharan Africa were not screened for HIV.

Many of the transfusions given in sub-Saharan Africa are unnecessary, despite high levels of actual need for transfusions in populations where fertility is high and malaria and anaemia are common. In some hospitals, donors are not routinely screened for HIV risk, because they are relatives of the patients. Where blood screening policies are in place, implementation is often hindered by a lack of reagents, skilled staff, or equipment.

Many countries are now renewing their attention to this important and recently neglected area. They are trying to establish and enforce guidelines on blood safety, and are especially keen to ensure quality control.

Contaminated blood transfusion probably remains the greatest source of HIV infection in health care settings. But there are also risks of infection associated with other aspects of care. Health service providers may become infected with HIV through needle stick injuries and injuries during surgery. Poor caring practices by HIV-infected medical staff may also carry a risk of infection for the patient. And when injecting and other equipment is poorly sterilised, HIV may be carried from an HIV-infected to an uninfected patient in the health care setting. “Universal precautions” are designed to minimise these events, but irregular supplies of surgical gloves or sterile needles, poor sterilisation equipment and overburdened staff unable to follow time-consuming safety routines often contribute to the breach of these precautions.

Key questions

- Are there national policy guidelines on HIV screening of donated blood?
- Does a national policy exist on the use of voluntary unpaid blood donors and blood banks?
- Do unnecessary blood transfusions occur?
- Are blood donors pre-screened to minimise risky donations?
- Is the blood supply adequately screened?

Measurement challenges

There are very few systematic indicators for any aspect of blood safety, from the screening of donors to the quality of existing HIV screening systems. Standardised prevention indicators in the area of blood safety are desperately needed, and need to include measures of donor screening and transfusion rates as well as the screening of blood units. It is worth noting, however, that in very high prevalence epidemics, for example, where more than one adult in five is HIV infected, the utility of donor screening policies is perhaps less useful. Resources may be better used for monitoring the quality of blood screening procedures. Indeed, the higher the population prevalence of HIV, the higher a priority blood safety should be for the national programme.

The lack of trained staff and other essential inputs such as reagents and reliable refrigeration are important constraints to maintaining a safe blood supply in many countries. It is safe to assume that these constraints will also apply

to the ability to monitor and evaluate blood safety.

The monitoring of blood safety is much easier in countries where all blood for transfusion is collected by a centrally administered national blood transfusion service, or where all blood, regardless of its provenance, is screened in central laboratories. However such services are comparatively rare. Private blood banks are common in many countries, and in many cases, individual hospitals manage their own blood supplies. And many transfusions will take place in private hospitals or clinics, increasing the chances that records of the total number of transfusions may be incomplete. Donor screening and screening of blood units can vary substantially between services. This means that where universal quality control is not possible the sampling frame for facility-based monitoring and evaluation will be critical.

Blood Safety Indicator 1

Percent of transfused blood units screened

Core indicator for all epidemics

Definition

The percent of blood units transfused in the last 12 months that have been adequately screened for HIV according to national or WHO guidelines

Measurement tools

MEASURE *Evaluation* blood safety protocol

What it measures

Blood safety programmes aim to ensure that the overwhelming majority (ideally 100 percent) of blood units are screened for HIV, and those that are included in the national blood supply are indeed uninfected. This is demonstrably not the case in many countries. Some blood units are not screened at all, others are screened by poorly trained personnel using outdated equipment or insufficient inputs. What's more, poor blood testing facilities mean that some blood is screened using antibody tests at a time after the donor has become infected with HIV but before they have developed antibodies to the virus. Together, these factors mean that a significant proportion of blood units may be classified as safe even though they are infected. This indicator gives an idea of the overall percentage of blood units that have been screened to high enough standards that they can confidently be declared free of HIV.

How to measure it

Three pieces of information are needed for this indicator: the number of blood units transfused in the previous 12 months, the number of blood units screened for HIV in the previous 12 months, and among the units screened, the number screened up to WHO or national standards.

The number of units transfused and the number screened for HIV should be available from health information systems (see Blood Safety Indicator 2). Quality of screening may be determined from a special study that re-tests a sample of blood previously screened, or from an assessment of the conditions under which screening occurred. In situations where this approach is not feasible, data on the percentage of facilities with good screening and transfusion records and no stockouts of test kits may be used to estimate adequately screened blood for this indicator.

Strengths and limitations

Where sufficient information exists to construct it, this measure is a strong indicator of the overall safety of the blood supply. However changes in the indicator could reflect changes in the proportion of blood units screened or changes in the quality of the screening process. A successful campaign to reduce unnecessary transfusions may also be reflected in the indicator, since the overall number of transfused units would fall and the proportion of those screened to WHO/national standards should rise in consequence. However, the different elements of the indicator should therefore be reported separately for programmatic purposes.

Where health systems are decentralised, or where the private sector is involved in blood screening and blood banking, it may be difficult to obtain good enough information to construct a robust indicator on a national scale. In this case, it will probably be necessary to select sentinel hospitals and laboratories in both the public and the private sector for facility-based surveys of blood transfusion and screening quality.

Blood Safety Indicator 2
Reduction of blood transfusions

Additional indicator for all epidemics

Definition

The number of blood units transfused in the previous 12 months, per 1000 population

Measurement tools

MEASURE *Evaluation* blood safety protocol

What it measures

A high proportion of all blood transfusions in many countries are unnecessary, and this is also true in the African countries with high HIV prevalence. It follows that a substantial proportion of blood transfusions that result in HIV infection are in fact unnecessary. Recognising this fact, many countries have introduced or strengthened measures designed to reduce the number of unnecessary transfusions. This indicator provides a crude measure of success towards that goal.

How to measure it

The numerator – the total number of blood units transfused in the previous 12 months – forms the denominator of Blood Safety Indicator 1. In countries with centralised blood transfusion services or with adequate health information systems, the number of units transfused annually country-wide can be compiled from routine service records. The denominator comes from census or other routine population data.

In some countries, it may be necessary to introduce systematic record-keeping at sentinel hospitals, and base estimates on experience at the sentinel sites. In such a case, the denominator will be the population of the district or city served by the hospital.

Strengths and limitations

This indicator is not able to distinguish between necessary and unnecessary blood transfusions and is therefore at best a crude measure of progress in reducing overall transfusions. However, supplemental data on transfusion practices can be collected where further insight is desired and the added effort warranted. This indicator is not comparable across countries, since the genuine need for transfusions may vary greatly from country to country, but it does give an idea of trends over time in a single country. If there are national guidelines for blood transfusion, it may be possible to assess the proportion of transfusions that were unnecessary using a hospital record review.

Blood Safety Indicator 3

Districts or regions with donor recruitment and blood transfusion services

Core indicator for all epidemics

Definition

Percent of districts or regions with access to blood transfusion services which do not pay blood donors, and do not recruit donors from among relatives of the patient

Measurement tools

MEASURE *Evaluation* blood safety protocol

What it measures

If no blood bank is available, blood donors are often sought among relatives of the person needing blood transfusion, or among individuals wishing to donate blood for a fee. In some cases, the family must find a replacement donor before blood can be released for transfusion. These practices have been found to increase significantly the risk of transfusing infected blood, even when the blood can be screened for HIV. Recruitment of voluntary donors among low-risk groups, such as secondary school students, and use of simple screening questions to defer donors have been used to lower the risk of HIV transmission through blood transfusion. In some countries a payment to the donor may be customary, while in others, paid donations are prohibited. Paid donors usually represent a much higher risk than voluntary donors, even when obviously "high risk" cases are deferred or self-deferred on the basis of simple screening questions.

Many countries working to improve access to safe blood have established blood transfusion services including blood banks at the regional or district level, and are working systematically to enhance the recruitment of voluntary donors, and to reduce or eliminate reliance on blood donations from relatives and paid donors. This indicator assesses to what extent this has been implemented at the level dictated by national policy.

How to measure it

A district or region is considered to score positively on this indicator if at least 95% of blood transfused at the largest hospital is supplied by a regional or provincial blood transfusion service that screens donors for risk behaviour and excludes donations from relatives and paid donors.

Strengths and limitations

The indicator considers only the blood supply at the main health care facility. In many districts or regions, different facilities will follow different practices. This indicator needs to be interpreted in conjunction with the other blood safety indicators. The mere existence of a blood transfusion service does not guarantee adequate quality of blood collection and storage practices, nor does it guarantee access to adequate HIV antibody screening.

Blood Safety Indicator 4

Health care settings with guidelines and practices for prevention of accidental HIV transmission

Additional indicator for generalised epidemics

Definition

Percent of health care facilities in a facility survey that have guidelines to prevent nosocomial transmission of HIV, adequate sterilisation procedures, and surgical gloves in stock

Measurement tools

MEASURE Service Provision Assessment (SPA facility survey); MEASURE *Evaluation* blood safety protocol

What it measures

As HIV prevalence rises among patients seen at health facilities, the danger of accidental transmission of HIV between health care provider and patient or from one patient to another also rises. This transmission may occur because of improper sterilisation or careless disposal of supplies or equipment that have come into contact with body fluids, or through accidental injury with equipment during surgery or routine care.

The risk of accidental transmission can be reduced by the routine use of surgical gloves in all caring functions, by the proper sterilisation of medical equipment, and by careful handling, storage and disposal of equipment. This indicator gives an idea of the proportion of health care facilities meeting these minimum conditions for the reduction of accidental transmission of HIV.

How to measure it

In a survey of randomly selected health facilities at the primary, secondary and tertiary levels, service providers are asked to show written guidelines for avoiding the accidental transmission of HIV. A stock check is also carried out for surgical gloves and sterilisation equipment. Sterilisation practices should be observed to see that they conform with these guidelines. In the absence of written guidelines, sterilisation practices should conform to national (and, failing that, international) standards. If there is no opportunity to observe sterilisation practices, health workers can be asked. Such interview data are more likely to be biased.

Those facilities with written standards on safe practices, with adequate sterilisation practices and with surgical gloves currently in stock form the numerator of the indicator. Facilities that do not score positively on all three conditions are not included in the numerator. The denominator is all facilities surveyed.

Strengths and limitations

This indicator has the virtue of being relatively easy to construct during routine health facility surveys undertaken for the monitoring of care and support services.

This is an indirect measure of the risk of HIV transmission in health care settings. The existence of guidelines does not necessarily mean that the guidelines are routinely followed. Nor does the presence of gloves mean that gloves are always worn in situations where their use could minimise HIV transmission. Indeed, in some settings where the risk of transmission is low, service providers deliberately avoid wearing gloves in order to avoid stigmatising HIV-positive patients. The extent to which practice conforms to existing guidelines will be reflected in the score on the sterilisation component, which is measured through observation of practice against a checklist derived from local, national or international standards.

A record of actual incidents carrying a risk of HIV transmission – for example, needlestick injuries, gloves ripped during surgery – might give a more direct measure of risky practices in health care settings. However, experience suggests that completeness of reporting of such events varies widely. In countries where HIV is both common and highly stigmatised, service providers frequently choose not to report injuries because of policies enforcing HIV tests for those affected. (These tests are often required as a precursor to providing post-exposure prophylactic treatment with anti-

retrovirals.) Reported accidents also fail to reflect the danger of transmission between patients.

For programme purposes, the indicator should be disaggregated by component, as well as by level of health facility.

3.12 STI care and prevention

Programme goals

Sexually transmitted infections (STIs) are a major public health problem in many countries. Since the presence of other STIs increases the likelihood of HIV transmission, the advent of AIDS has led to a new push to treat and prevent STIs. This package of care includes the syndromic management of STIs. A patient is questioned and physically examined. If the symptoms through their presentation suggest an infection, the patient is then treated for a spectrum of organisms which may have caused the symptoms from which they are suffering. This removes the need for logistically difficult and sometimes expensive laboratory testing.

Many programmes also focus on increasing use of STI treatment facilities, especially among young people whose needs were largely neglected by earlier systems. In terms of monitoring and evaluation, there is a need to continue monitoring programme efforts to provide high quality STI treatment services. The use of STI services as an entry point for prevention of further sexual risk behaviour, as well as a point of access (through partner referral) to other people at high risk for HIV and STIs, should also be monitored.

Key questions

- Do national guidelines exist on the appropriate management of STIs in health services?
- Are there guidelines on syphilis screening in antenatal clinics?
- Are STI services providing adequate care for men and women infected with STIs?
- Are drugs necessary for treatment available?
- Are STI services used effectively as an entry point for HIV prevention?

Measurement challenges

There is more experience with M&E of STI programmes than with most other areas of HIV-related programming. In terms of the HIV epidemic, monitoring STIs is especially important at two levels: effective treatment of STIs is important because STIs significantly increase the chance of HIV transmission per act of unprotected sex between an infected and an uninfected partner. At an impact level, STIs can be used as a proxy measure for the impact of HIV prevention programmes because STIs are, like HIV, a marker of unprotected sex with a non-monogamous partner. Unlike HIV, however, bacterial STIs are curable, and therefore new cases are likely to reflect much more recent risky sexual activity than HIV, which can be a marker of risk behaviour as long as a decade before. So HIV prevention programmes ought to have a visible impact on STIs before any significant changes in HIV prevalence can be seen. Impact indicators are discussed in the final section of this document.

STI Service Indicator 1

Appropriate diagnosis and treatment of STIs

(Modified WHO/GPA Prevention Indicator 6)

Core indicator for all epidemics

Definition

The percent of patients with STIs at selected health care facilities who are appropriately diagnosed and treated according to national guidelines, of all STI patients at those centres

Measurement tools

WHO/UNAIDS revised guidelines on evaluating STI services; MEASURE Service Provision Assessment (SPA)

What it measures

STI programmes are focusing on syndromic management of STIs as the most practical approach in high prevalence, low resource situations. The shift to syndromic management has increased the potential coverage of care, since there are fewer bottlenecks in diagnosis. It has required a huge investment in training for nurses and other health care providers who were new to the approach and often to STI care in general.

This indicator reflects the success of that training, combined with efforts to ensure adequate supplies of drugs and other necessary materials to care provision points. It tracks changes in the provision of adequate care to patients seeking care for STIs.

Choosing which STI service delivery points to survey is important. Traditionally, this indicator has been constructed primarily for public sector STI clinics. This is largely because most of the early training in syndromic management was of public sector employees. However it is widely recognised that people with STIs often seek treatment in other sectors – either at private sector clinics, from pharmacies or from traditional healers. Some countries have begun to include these sectors in training programmes for syndromic management, and evaluations using this indicator have successfully been carried out in these sectors. Service delivery points surveyed should include representative service providers from any sector that has received training in syndromic management of STIs.

How to measure it

Data are collected in observations and interviews with providers at selected health care facilities providing STI care. Providers are assessed on history taking, examination and treatment of patients. A provider must score positively on all three items in an interaction with a client for that client to enter the numerator of the indicator.

Since the development of WHO/GPA Prevention Indicators 6 and 7 (PI6 & 7) protocol researchers have tried several alternative data collection methodologies. Instead of, or in some cases in addition to, observation and provider interviews, data have also been collected through exit interviews with clients and interactions with “mystery” clients – that is, trained assessors posing as clients.

“Appropriate” diagnosis and treatment is assessed according to national guidelines governing STI services. In developing countries these will most commonly include protocols for the syndromic management of locally common sexually transmitted pathogens, including treatment with drugs specified in national drug lists. In some countries, both syndromic and aetiological management are recognised as appropriate, according to the diagnostic capacity of the service provider. Where national guidelines are not available, WHO guidelines on the syndromic management of STIs may be used to guide assessment of appropriate treatment.

Strengths and limitations

This indicator, measured through observation but including provider interviews in the process of data collection for validation purposes, has been widely used and proved to be feasible. There has been discussion of the extent to which the direct observation and provider interview methodologies bias data. It is thought

that service providers perform better under observation than they normally would, or over-report "correct" diagnosis and treatment, diminishing the gap between knowledge and practice. The application of client exit interviews and mystery patient methodologies, as well as proving feasible, has demonstrated that the biases are not as great as was assumed. The gap between knowledge and practice in the area of treatment is often shaped by the service provider's not following "correct" protocols simply because they know drugs are unavailable or unaffordable. Because of this, it is recommended that this indicator be presented together with indicators of drug availability such as that proposed in STI Service Indicator 3.

As with all composite indicators, improvements in some areas may mask deterioration in others. If service in one area is poor, the facility will score poorly on the indicator, even if service provision in other areas has progressed significantly. Programme managers need scores reported separately by area of knowledge and performance in order to identify areas of weakness and to improve training programmes.

STI Service Indicator 2

Advice to STI patients on prevention and referral to HIV testing services

(Expanded WHO/GPA Prevention Indicator 7)

Core indicator for all epidemics

Definition

Percent of patients with STIs who are given advice on condom use and partner notification and who are referred for HIV testing

Measurement tools

WHO/UNAIDS revised guidelines on evaluating STI services; MEASURE Service Provision Assessment (SPA)

What it measures

STI services seek not just to treat STIs but to prevent their recurrence, by promoting condom use and by encouraging the treatment of partners to avoid reinfection. Increasingly, STI care is seen as an entry point for referral for voluntary testing for HIV. This indicator measures the extent to which these aspects of STI service provision are functioning.

How to measure it

WHO/GPA Prevention Indicator 7 (PI7) only included the first two elements of this indicator. A health care provider must score positively on both condom advice and partner notification advice for the client to enter the numerator for this indicator. The current indicator, STI Service Indicator 2, includes a third element: referral for voluntary testing for HIV. However, if it is not a national policy to refer STI patients for HIV counselling and testing, or if VCT services are not available and not being actively promoted by national AIDS and STI programmes, referral for counselling and voluntary HIV testing should be excluded from the indicator. Both PI7 and STI Service Indicator 2 are measured in health facility surveys through direct observation of interaction between care providers and clients.

The different components of this indicator should be reported separately, for reasons given below.

Strengths and limitations

If a client is at an STI clinic, previous efforts to promote safe behaviour have failed them. This measure does not contribute to the evaluation of success of prevention initiatives, merely the extent to which service providers are complying with standards.

There has been discussion of the extent to which the direct observation methodology biases data. It is thought that service providers perform better under observation than they normally would. Also, it is suggested that exit interviews with clients may be a more cost-effective method than observed interactions in compiling this indicator. However, there is a possibility that clients may misreport the actual content of counselling. Further research is needed to determine the reliability of exit interviews in collecting data for this indicator.

Condom promotion, advice on partner referral and referral for HIV testing are in fact quite distinct activities. The value of an aggregate indicator in this field is therefore somewhat limited, at least to programme staff. In addition, referral to HIV testing services will depend upon the availability of those services locally. And the addition of this component will disrupt trends over time in those countries where the similar indicator WHO/GPA Prevention Indicator 7 has been calculated in the past. For these reasons, special care must be taken to ensure than the three elements of this indicator are reported separately.

STI Service Indicator 3

Drug supply at STI care services

Core indicator for generalised epidemics
Additional indicator for other epidemics

Definition

Percent of clients served by health facilities providing STI care that have a current supply of essential STI drugs and report no stockouts lasting longer than one week in the preceding 12 months

Measurement tools

WHO/UNAIDS revised guidelines on evaluating STI services; MEASURE Service Provision Assessment (SPA)

What it measures

Correct history-taking, diagnosis and prescription are all very well, but if drugs are not available these will not translate into cases cured and will therefore have no positive impact on the likelihood of HIV infection.

National AIDS programmes engaged in improving STI services have put time and money into improving drug distribution services and in attempting to ensure adequate manufacturing or importing of drugs for the syndromic management of STIs. This indicator measures the extent to which those efforts have been successful in ensuring that service providers are consistently supplied with the drugs they need to work efficiently.

How to measure it

Countries promoting syndromic management of STIs usually have protocols for the prescriptions of drugs by syndrome. These are backed up by the inclusion of the relevant drugs on the nation's essential drug list. Drugs necessary to treat each of the important syndromes should be included in the stock-check for this indicator.

A survey of randomly selected facilities providing STI services checks for current supplies of designated drugs. Clinic management is questioned about stockouts in the last 12 months, and clinic stock records are reviewed for that period. Client numbers are also recorded. The sampling frame for the selection of sites may include private clinics and hospitals and non-government services, as well as public facilities.

In constructing the indicator, each facility is weighted by its client load. This is because a rupture of stock at a small rural clinic will have less impact on the epidemic at a national level than a stockout in a large urban clinic that sees many times more patients.

The indicator is the total number of clients attending facilities providing STI services that have adequate drugs currently in stock to treat each of the important STI syndromes and that report no stockouts of these drugs lasting more than one week in the past 12 months, divided by the total number of clients attending all STI service facilities surveyed.

Depending on national policy, it is possible to include a variety of outlets providing services for HIV care in this indicator. This may include integrated reproductive health services, private sector facilities, and pharmacies with special training in STI care provision.

Strengths and limitations

This is a good measure of consistent supplies of drugs to STI service facilities; it provides a minimum measure of the availability of drugs. It is recognised, however, that clients very often buy drugs from other sources, even when they have been to an STI facility for diagnosis. Indeed, in countries where control of drug supplies are lax, a stockout in a public clinic may simply mean that the supply of drugs has been diverted to another nearby outlet. This is likely to affect the cost of the drug to the client (and therefore accessibility), but it may not affect the physical availability of the drug.

Again, the selection of STI facilities may have a major influence on the indicator. The facility survey should attempt to include a mix of all major provider categories in both the public and the private sectors.

STI Service Indicator 4

Men and women seeking treatment for STIs

Additional indicator in generalised epidemics
Core indicator among sub-populations with high-risk sexual behaviour in concentrated epidemics

Definition

Percent of men and women reporting symptoms of STIs in the last 12 months who sought care at a service provider with personnel trained in STI care, of all respondents in a population-based or targeted survey aged 15-49

Measurement tools

UNAIDS general population survey; DHS AIDS module; FHI BSS (adult)

What it measures

STI programmes seek not only to improve the quality of services but to increase the proportion of people recognising their infection and seeking those services. This indicator tracks changes in care seeking behaviour among men and women who believe they may be STI infected, following initiatives to promote health seeking behaviour.

How to measure it

The construction of the indicator will depend on the country's STI programme strategy. It will include in the numerator men and women who sought care from service providers considered "appropriate" by that strategy because care was provided by people trained to national standards in STI care. In most countries this will be limited to formal health facilities, including STI clinics. In a few countries it will include pharmacies and traditional healers.

Respondents in a population-based survey (or, in concentrated epidemics, a sub-population survey of men or women belonging to groups with typically high-risk sexual behaviour such as sex workers or migrant workers) are asked whether they noticed a genital discharge or ulcer in the last 12 months. If yes, they are asked whether they sought treatment, what sort of treatment they sought, and what was the first thing they did for advice or treatment. Respondents are prompted for sources of care including health centres, pharmacies, traditional healers and friends or relatives. If any one of the sources of care they visited is staffed by people trained to national standards in STI service provision, the respondent enters the numerator.

The indicator is the number of men or women who say they sought care from a service provider classified by national standards as providing trained care, (e.g., health worker in a clinic, hospital or pharmacist), divided by the total number of men or women who reported symptoms suggestive of STIs.

The indicator should be reported separately for men and women. For programme purposes, it should also be disaggregated by type of service provider.

Strengths and limitations

The indicator gives an idea of the reach of approved STI service provision. The interpretation of this indicator is confused by two different aspects of programming. First, IEC campaigns may work to increase recognition of STIs and their symptoms and to increase treatment seeking. Second, they work to lower high-risk sexual behaviour and thus reduce new cases of STIs. If the indicator shows a rise in the percentage of men or women with self-reported STIs seeking treatment, it may mean that the prevalence of STIs has risen between surveys, but that the proportion of infected people seeking treatment is unchanged. On the other hand, it may mean that there has been no change in infection rates, but that more infected men and women recognise and report that they are infected, and seek treatment.

A greater challenge to interpretation is posed by poor coverage of training in STI management. For example, if the national programme has made an effort to train pharmacists in the syndromic management of STIs but has succeeded so far in training only 20 percent of all pharmacists, should pharmacists qualify in this

indicator as a trained service provider or not? It is suggested that a category of service provider should not be included unless over 50 percent of providers in that category have been trained in STI service provision.

The utility of this indicator depends on the existence of an active campaign to increase health-seeking behaviour, and more particularly a campaign that promotes the use of specific categories of service providers.

While the relevant survey questions prompt for all types of service providers seen, (and the indicator is constructed using multiple responses), respondents are also questioned about their first source of care. This information should help programme managers in targeting future IEC and training efforts.

3.13 Care and support for the HIV-infected and their families

In the early years of the HIV epidemic, attention in both programming and monitoring and evaluation focused on prevention of infection. Now, early prevention failures are turning into care needs. Already, there is an urgent need for health care for people living with HIV/AIDS. A large proportion of hospital beds are occupied by patients with HIV infection in many countries, and given the chronic nature of the disease and the dynamics of the epidemic, the burden of HIV on the health care system will increase in most countries in the future.

Programme goals

Like prevention, the term "care and support" covers a multitude of different programming areas and services. These include clinical management, nursing and home care, counselling and psychological support for those infected with HIV and their families, and social support for those infected with HIV, their families and communities. Some areas of programming that fall in the ambit of care and support, such as counselling and testing and the reduction of stigma and discrimination, are dealt with in separate parts of this guide.

Most countries dream of providing a full range of services from anti-retroviral therapy to counselling support for family caregivers, and a few developing countries, mostly in Latin America, come close to doing this for at least part of the population. The reality in most high-prevalence countries is far more rudimentary, however. Basic primary health care was often patchy even before the HIV epidemic, and is now over-stretched where it does exist. Secondary and tertiary level facilities are only available to a small fraction of the population. The HIV epidemic has increased the strain on health systems at all levels. Unable to provide adequate care through the health system, many countries are turning to community-based models of care. The capacity of communities to provide this care is not easy to assess.

The identification of core and additional indicators in the area of care and support will vary considerably according to a country's strategy for providing care and support. Where the emphasis is on community- and home-based care, the indicators of coverage may be considered as core. In countries that are concentrating on the widespread provision of more sophisticated medical care for those with HIV, facility-based indicators will take precedence. The identification of core and additional indicators in this guide is based on the needs of resource-poor countries where HIV prevalence is highest – essentially the high-prevalence countries of sub-Saharan Africa. Countries with generalised epidemics but different resources will make different choices.

Key questions

- Is there a national policy to incorporate care for HIV-associated conditions into medical curricula?
- Are drugs for opportunistic infections included in the essential drugs list?
- What is being done to care for individuals with HIV and their families?
- Is the coverage of services adequate?
- Is the quality of services adequate?

Measurement challenges

Monitoring of care and support is not easy. In the first place, HIV status is rarely known and can not be asked about in population surveys for M&E purposes, so it is impossible to know how many people with HIV have access to the care and support they need. Health facility-based surveys give no idea of coverage, and may give only a limited idea of the extent to which care is given at the "appropriate" (most accessible and cost-effective) level of the health care system.

Even when people are being cared for, the need to protect patient confidentiality stands in the way of any systematic assessment of the quality of care. Direct observation of care provision may be possible for conditions which are commonly associated with, but not exclu-

sive to, HIV. “Exit” type interviews with those living with HIV are only rarely possible, and are hard to generalise. Interviews may, for example, be attempted in the context of an anonymous self-administered questionnaire of people active in support groups for people living with HIV, but this is a selected population that is usually far from typical of all those living with HIV.

Another difficulty in assessing quality and completeness of care is in setting the “gold standard” or even the minimum standards of care in a given country. Few nations have any clear idea of the services they expect to provide for those living with HIV, either at the community level or within the health system. Fewer still have formal guidelines for care and support, against which service quality might be measured. WHO is actively developing minimum standards of care in these areas, but much remains to be done. What constitutes adequate orphan support? Help with food, support for school fees, psychological counselling? What about home-based care for people with AIDS? Is it possible to define, let alone measure, “quality of life” of individuals or families affected by AIDS? Until standards for these services are set, it will be difficult to monitor implementation, let alone to come up with internationally comparable indicators.

Providers of care and support at the community level are often small private organisations reacting to an urgent local need. They have limited capacity to provide services, let alone to collect data and feed it in to a monitoring and evaluation system.

Care and Support Indicator 1

Medical personnel trained in the care of HIV-related conditions

Additional indicator in all epidemics

Definition

The percent of graduates of medical school, nursing school and continuing medical education facilities in the last 24 months trained in natural history of HIV and in diagnosis and care of common opportunistic infections

Measurement tools

MEASURE Service Provision Assessment (SPA); Statistics of medical training schools

What it measures

Knowledge about appropriate management of HIV and the infections associated with it is an important prerequisite for quality care at all levels of the health care system. Many national AIDS programmes are providing training to existing health service staff, upgrading their skills and knowledge in this area. However, the easiest and most sustainable way to ensure adequate knowledge in the long term is to integrate HIV-related information into the routine medical training for doctors, nurses and paramedics.

This indicator measures the extent to which such information has been integrated into the regular training curricula of all medical personnel.

How to measure it

There are two ways to measure this indicator. First, in a health facility survey health workers are asked about specific topics that were covered in their basic medical training and this provides the relevant information. Using the year of graduation will provide information about the time period (e.g., graduates in the two years preceding the survey).

Alternatively, from the records of the health or education ministries, a list is constructed of all institutions providing professional training and issuing medical degrees, nursing or paramedical qualifications or conducting approved continuing medical education. A questionnaire is sent to each of these institutions, containing a checklist of items associated with training in knowledge of HIV and management of HIV-infected patients. The checklist may be constructed according to national or international standards in the care and management of patients with HIV. It will typically include items on the epidemiology and natural history of HIV infection, on basic preventative counselling, on the diagnosis and management of common opportunistic infections, and of referral practices. Institutions are also asked for the number of students graduating at each level in the last 24 months.

The indicator is the number of medical graduates in the last 24 months (including nursing and paramedical staff where relevant) trained in all essential aspects of HIV knowledge and management, divided by the total number of medical graduates in the last 24 months. Graduates of refresher or ongoing medical education courses are included in the indicator.

Strengths and limitations

This indicator is relatively easy to construct as long as institutions involved return the questionnaire. Its major limitation is that it does not attempt to measure the quality or the depth of the training given.

The indicator measures the training of current graduates. Where HIV-related training is new to medical curricula and where retraining programmes are uncommon, it will not give a good picture of current levels of knowledge within the health system, since many existing staff will have been trained before the curriculum was introduced. However, it should provide a robust measure of trends in the minimum proportion of health service providers trained in HIV and associated care over time.

The curricula should follow national guidelines for care of HIV-infected patients. The absence of such guidelines is in itself an indication that care and support services for HIV-infected people are likely to be inadequate. However,

where they do not exist, international standards may be substituted as a measure of the curriculum's adequacy.

Care and Support Indicator 2

Health facilities with the capacity to deliver appropriate care to HIV-infected patients

Core indicator in generalised epidemics

Definition

The percent of health care facilities at different levels of the health care system that have the capacity to deliver appropriate palliative care, treatment for opportunistic infections and referral for HIV-infected patients, according to national guidelines

Measurement tools

WHO draft protocol for the evaluation of HIV/AIDS care and support; UNAIDS protocol for evaluation of care and support

What it measures

In the early years of the HIV epidemic, a high proportion of patients with HIV-associated conditions were automatically referred to tertiary level institutions because health services at other levels had neither the trained personnel nor the capacity to cope with them appropriately. Even guidelines on what constituted "appropriate" treatment were rarely available. The constant referral to higher levels of care clearly led to inefficient use of resources within the health system.

In recent years, attempts have been made to ensure that HIV-related conditions are dealt with at appropriate levels within the health system, with referrals in both directions when necessary. Many countries have produced national guidelines to help guide service providers in the appropriate care of HIV-infected patients. Palliative care and treatment for common and minor opportunistic infections may be given at the primary level, while more complex opportunistic infections may be referred to higher levels of the health care system. Referrals should also be made for social and psychological support where appropriate.

This indicator measures the extent to which health services have the capacity to meet treatment, care and referral needs of HIV-infected patients at appropriate levels of the health care system, according to national guidelines.

How to measure it

In a health facility survey that includes facility inspection, interviews with service providers and records reviews, health facilities are assessed against a standard checklist. The checklist, which will be modified according to local standards, will differ according to the level of the institution within the health care system. It will typically include the availability of trained staff, the adequacy of diagnostic facilities, the adequacy of sanitation, the adequacy of nursing care, procedures for record keeping, preventative counselling, and referral to higher level care and community support organisations as appropriate.

The assessment of "adequate" or "appropriate" conditions and services should follow national guidelines for care of HIV-infected patients. The absence of such guidelines is in itself an indication that care and support services for HIV-infected people are likely to be inadequate. However, where they do not exist, international standards currently being developed by WHO may be substituted in determining standards against which facilities are to be measured.

The availability of drugs and procedures to prevent accidental transmission of HIV within the health care setting are covered by separate indicators and are not included here. (See Blood Safety Indicators, page 105.)

The indicator is the number of health facilities matching or exceeding the minimum score for adequate capacity to manage HIV-infected patients, divided by the total number of health facilities surveyed. For programme purposes it should be disaggregated by level of health facility as well as by area of service provision.

Strengths and limitations

This indicator is a compendium of many different aspects of care and service provision, all of which must score a minimum amount if the

facility is to be included in the numerator of the indicator. Because services tend to improve unevenly, especially in resource constrained settings, the resulting indicator may remain low for some time. Disaggregation of the indicator will indicate the areas in which services have improved and those in which they continue to lag.

The scoring of the components of the indicator will necessarily include a measure of subjectivity. This may influence comparisons between different countries, as well as trends over time if the monitoring team changes.

The indicator is not weighted by client load. This is because it includes facilities at different levels of service provision. Weighting by client load is likely to give tertiary institutions and reference hospitals excessive influence in the indicator, despite the fact that most patients first come into contact with the health system at the primary level.

This indicator is similar, but not identical, to the WHO's Care and Support Indicator 1 (CSI1). Since CSI1 has not yet been widely used, this is unlikely to affect trends over time in many countries.

Care and Support Indicator 3

Health facilities with drugs for opportunistic infections and palliative care in stock

Additional indicator for generalised epidemics

Definition

Percent of health facilities that are currently stocked with nationally approved drugs to treat common opportunistic infections and to provide palliative care, and report no stock-outs in the past 12 months

Measurement tools

WHO draft protocol for the evaluation of HIV/AIDS care and support; MEASURE Service Provision Assessment (SPA); UNAIDS protocol for care and support

What it measures

However good the diagnostic, nursing and counselling skills of health service providers, they will have little impact unless the necessary drugs are available. At the end of the 1990s, the provision of anti-retroviral drugs outside an antenatal care setting was so low in the countries most affected by HIV that measuring it could hardly be seen as a good use of resources. The provision of drugs to treat common opportunistic infections is a more realistic target, and one that in itself may deliver years of healthy and productive life to infected people at relatively reasonable cost. Palliative care, too, can improve the quality of people's lives at low cost. In consequence, many national AIDS programmes have been attempting to provide drugs to treat opportunistic infections and provide palliative care in public health facilities.

This indicator aims to measure the uninterrupted supply of drugs in public facilities to treat locally common opportunistic infections and provide palliative care.

How to measure it

During a health facility survey, a stock-check is taken for drugs defined by national guidelines as appropriate treatment for three locally common opportunistic infections, along with one drug for palliative care. The drugs will vary according to locally common pathogens and approved drugs, but are likely to include ORS for diarrhoea, anti-fungal drugs and painkillers. Clinic management is questioned about stockouts in the last 12 months, and clinic stock records are reviewed for that period. The presence of anti-tuberculosis drugs would be very important as well, but cannot be measured in all clinics as such drugs are usually distributed by designated TB clinics.

The indicator is the number of health facilities that have two designated drugs for opportunistic infections and one for palliative care in stock currently, and that report no stockouts of these drugs in the past 12 months, divided by the total number of health facilities surveyed. Facilities surveyed should include primary health care facilities as well as higher levels.

Strengths and limitations

Where no national guidelines for care exist and reliable data about opportunistic infections is limited, it will be difficult to determine which drugs should be included in the stock-take. WHO and UNAIDS provide international guidelines on essential drugs for opportunistic infections: in some cases these may be substituted for national guidelines.

Countries that are not focusing efforts on providing appropriate care at all levels of the health care system will have little interest in this indicator. Even in countries that are making a significant effort at this level, this indicator may be very low since the inconsistent supply of drugs is a persistent weakness of many health systems. However, unless serious efforts are made to rectify this weakness, investments in training staff in the adequate management of HIV-related conditions will be wasted. It is therefore worth monitoring progress in this area.

Care and Support Indicator 4

Households receiving help in caring for chronically ill young adults

Core indicator for generalised epidemics

Definition

The percent of households with an adult aged 15-59 who has been ill for at least three consecutive months during the last 12 months that received external help in caring for the patient or replacing lost income

Measurement tools

UNAIDS general population survey

What it measures

As health systems become strained to the breaking point by the HIV epidemic, the onus of providing care for those affected is in many countries being shouldered by families and communities. In some countries, the national AIDS programme and its partners are making an active effort to support families by providing services to reinforce home-based care. These services range from psychological support to help with nursing, from provision of training to home caregivers to income substitution to compensate for lost earnings.

These efforts, where they exist, frequently reach only a small proportion of those in need. One of the greatest challenges for countries promoting home-based and community care of people with AIDS is ensuring adequate coverage. This indicator aims to give a picture of the proportion of households touched by potentially HIV-related incapacity that are reached by home-based care or other community support programmes.

How to measure it

Respondents in a population-based survey are asked whether anyone in their household has been too ill to work or perform their normal duties for three consecutive months or more out of the previous 12 months. The question should include people who have died within the past 12 months and who were incapacitated for at least three months before their death. Households that report incapacitated members are asked the age(s) of that/those person(s), and whether the household received any help in caring for them from sources outside the household. Those that received help are asked for the source of the help, and read a list of potential sources, including family members, church groups, village health care workers, hospital extension workers, traditional healers, private doctors, etc. Furthermore, for each source of help they are asked whether they paid for the help.

The indicator is the number of households receiving unpaid help in caring for a person aged between 15 and 60 years who has been ill for more than three out of the last 12 months (or who was ill for three months before their death in the last 12 months) from any source other than family or neighbours, divided by the total number of households caring for a person under 60 who has been ill for more than three out of the last 12 months, or who was ill for three months before their death in the last 12 months.

Strengths and limitations

This indicator attempts to give an idea of the coverage of home-based care programmes by assessing the potential need and measuring the extent to which the need has been met. In doing so, it uses a measure of need which is at best imperfect. Not all households caring for sick people actually need outside help. And some may need help in caring for household members who are ill but have continued to work throughout much of their illness, so may not qualify under this measure.

The indicator makes no attempt to distinguish between HIV and other serious illness, beyond restricting the age band to the ages in which the majority of sickness in high-prevalence areas is HIV-related. While it would be possible to ask about specific symptoms generally associated with HIV such as chronic diarrhoea, misreporting is likely to be substantial. It is clearly not possible to ask directly about HIV status. In fact, lacking this information is not critical inasmuch as it reflects a growing trend

among home-based care programmes not to distinguish between HIV and non-HIV related illness. This trend has arisen because in some communities care services were causing problems because they branded their beneficiaries as HIV-infected.

The indicator does nothing to assess the quality of home-based care – a much more vexing issue although clearly one of central importance to programmers. The question sequence does ask what types of care are provided, and the information can be used by programmers but is not included in the construction of the indicator. Where services are practically non-existent, a measurable growth in coverage of *any* home-based care services may be counted a success. But clearly, measures of the quality of care must be developed.

Disaggregating this indicator by the sex of the chronically ill person may reveal differences in care seeking behaviour by families (or care services offered by providers) according to whether the sick person is male or female.

The indicator is useful only in generalised epidemics.

Care and Support Indicator 5

Households receiving help with orphan care

Additional indicator for generalised epidemics

Definition

In households caring for orphans, the percent receiving free help with care from outside the household within the last 12 months

Measurement tools

UNAIDS general population survey

What it measures

Orphan support is one of the areas of care and support that has received the most attention. It represents a real and growing need. It is relatively uncontroversial and is widely supported by both communities and donors. Besides reducing the difficulties faced by children who have lost their parents, good orphan support systems can play an important role in HIV prevention. This is because orphans who do not receive support are disproportionately likely to drop out of school, to live an unstable life, to be subject to sexual abuse and vulnerable to high-risk survival strategies.

Orphan support programmes may take the form of regular visiting of orphans and their caregivers in the household, provision of psychological support, help with clothing or school fees or income generating activities. While such efforts are being expanded in badly affected countries, they are rarely able to keep up with the growing need.

This indicator attempts to measure the coverage of orphan support programmes. Orphans are defined as children under 15 who have lost one or both of their parents.

How to measure it

Respondents in the household schedule portion of a population-based survey are asked whether their household is currently caring for any children under the age of 15 whose mother, father or both parents have died. If so, they are asked whether they received any help within the last 12 months in caring for that child from outside the household. Those that received help are asked for the source of the help, and read a list of potential sources, including family members, church groups, village health care workers, social services extension workers, etc. For each source they are asked whether they paid for the help.

The indicator is the number of households receiving free help in caring for orphans within the last 12 months from sources excluding family or neighbours, divided by the total number of households currently caring for orphans.

Strengths and limitations

The greatest limitation of this indicator is its inability to distinguish whether needs are being met. Not all households caring for orphans need help. The needs of households with multiple orphans may be greater than those with a single orphan, but this will not be captured in this measure. Unfortunately, needs assessment is beyond the scope of a regular population-based survey. Experience shows that response rates are very high when people are asked whether they need extra support, though more qualitative work distinguishes large differences in actual coping capacity of households that say they would like extra help. Although it gives a picture of overall coverage or orphan support programmes, this indicator does not measure the extent to which support is reaching the neediest.

Orphans are a very mobile population. Those most in need of care may be in child-headed households that do not even qualify for inclusion in a household survey. Street children and others who live outside regular households will also be missed; in some urban areas these children may make up a substantial fraction of orphans in greatest need of care.

By using a measure based on children currently in care, the measure will also miss households who have recently passed on orphans to other homes (perhaps precisely because the received no help with care). Using a measure based on orphan residence in house-

holds in the previous 12 months would, however, lead to problems of double counting and other measurement difficulties.

3.14 Impact: HIV, STIs, mortality and orphanhood

Programme goals

All aspects of HIV and STI prevention programmes funnel into a single goal: to reduce the transmission of HIV and other STIs. If programmes are successful in bringing about changes in exposure to HIV infection, then HIV incidence will necessarily change, too.

Key questions

- Is there a national plan for HIV / STI surveillance?
- What are the levels and trends of HIV and STIs in various populations that may be at risk for HIV?
- How representative of larger populations are the levels and trends in surveillance populations?
- To what extent can changes in impact be attributed to programme effort?

Measurement issues

Less transmission of HIV means fewer new cases. However, it is very difficult for regular monitoring systems to measure new cases – incidence data generally come only from sophisticated and expensive longitudinal cohorts. National M&E systems therefore tend to use cross-sectional prevalence data to monitor the spread of infection. But with chronic diseases such as HIV, prevalence data are problematic as a proxy indicator for recent infections. This is especially so when the data come from sentinel surveillance systems built around selected populations such as women in antenatal clinics. ANC data for HIV are biased by mortality, by a reduction in fertility in HIV-positive women and by other factors.

Second generation surveillance aims to make better use of data generated by sentinel surveillance, partly by changing sampling and analysis strategies so that data better reflect more recent infections (see Panel 4).

One of the constraints of sentinel HIV surveillance in generalised epidemics is that few sentinel systems provide any data on men. Other proxy measures of impact in men can be used, for example the incidence of self-reported or clinical STIs. Since interventions aimed at reducing the spread of HIV ought also to have an impact on STIs – and a much more rapid one at that – STI measures can be useful as indicators of recent changes in risk behaviour for HIV.

In theory at least, pregnant women presenting for antenatal care are regularly screened for syphilis and treated where necessary. This regular screening is potentially an important source of impact data for AIDS programmes, since it is at least somewhat more responsive to recent trends in risk behaviour than is HIV prevalence data. However even where testing is systematic, these data have rarely been systematically reported through the AIDS programme. This is a prime example of where existing data could be better used in M&E systems.

Measures of HIV and STI incidence and prevalence give an idea of the health impact of the HIV epidemic and of programmes designed to limit it. Mortality data also provide powerful impact indicators. It is recognised, however, that the impact of HIV and AIDS goes far beyond health or even mortality. Indicators of illness or long-term incapacity and orphanhood give a crude idea of the potential social and economic impact of the epidemic at a household level; they will grow in importance as the epidemic matures. More refined indicators are needed to measure the social and economic impact of HIV and AIDS – and of the success of national AIDS programmes in mitigating that impact. It is hoped that the existing toolkit will be expanded to include more measures of socio-economic impact as new methodologies are developed.

Impact Indicator 1

HIV prevalence among pregnant women

Core indicator in all epidemics

Definition

Percent of blood samples taken from women aged 15-24 that test positive for HIV during routine sentinel surveillance at selected antenatal clinics

Measurement tools

UNAIDS/WHO Second Generation Surveillance; WHO guidelines for HIV surveillance

What it measures

Women who are pregnant have by definition had unprotected sex sometime in the last ten months. Levels of HIV infection in these women do not reflect levels among women who are not having sex, among women who are infertile, or among women who are systematically using contraception, including barrier methods such as condoms which also prevent HIV transmission.

Confining the indicator to women aged under 25 aims to give a picture of recent trends in infection. Most infections in this age group are relatively new, and data from these younger women are also less subject to bias than data for the whole reproductive age span. The indicator is reported for women aged 15-24. However it is strongly recommended that two separate figures be reported: one for women aged 15-24 and one for women across the whole reproductive age range of 15-49. Since many countries have in the past failed to report HIV prevalence broken down by age, it is important to continue to report a figure for HIV prevalence across 15-49-year-olds, to allow for the comparison of trends over time.

Additional information may be gained by looking at HIV prevalence by parity of mother. Such information is often routinely collected in sentinel surveillance and analysis of trends among women of parity 0 and 1 combined is a good additional indicator of trends in HIV incidence among young women.

How to measure it

The data for this indicator are obtained from the national sentinel surveillance system for HIV, and the indicator is calculated through unlinked anonymous testing for HIV of blood samples taken from women at sentinel antenatal clinics chosen to reflect urban, rural, ethnic and other socio-geographic divisions in a country.

Even where programmes exist that simultaneously offer counselling and voluntary HIV testing for pregnant women to reduce mother to child transmission, only the results of unlinked, anonymous screening of blood taken for other purposes should be used in calculating this indicator of HIV prevalence. Refusal and other participation bias are considerably reduced in unlinked anonymous HIV testing compared with other forms of testing.

Strengths and limitations

The indicator gives a fairly good idea of relatively recent trends in HIV infection nationwide in countries where the epidemic is heterosexually driven. It is less reliable as an indicator of overall epidemic trends in areas where the bulk of HIV infection remains confined to sub-populations with especially high-risk behaviours.

Even in countries with generalised heterosexual epidemics, there are wide regional, ethnic or other differences in trends in HIV infection. These will be lost when data are aggregated into a single national figure. For programme purposes, prevalence should thus always be reported separately by site as well as by a single national figure. Care should be taken in reporting HIV prevalence estimates by sites, however, given the possible political sensitivity of results.

In the past, sample sizes in regular sentinel surveillance have been selected in order to measure changing trends across the whole age range of 15-49. Numbers in each five-year age band may have been too small to yield any reliable trend data, particularly at individual

sentinel sites. In order to construct a reliable indicator around the narrower age range, larger sample sizes in the younger age groups will be needed.

Clearly, trends in HIV infection among pregnant women will not adequately reflect some of the most important changes in behaviour supported by AIDS prevention programmes – abstinence and consistent condom use in all populations and not simply the antenatal care clients. Trends in HIV infection are beset by a number of biases, as described above. Prevalence among pregnant women gives an idea of trends in prevalence in the general population, but is not an accurate reflection of overall levels in all women, let alone in all men.

Prevalence data should therefore be reported together with behavioural data (such as mean age at first sex or condom use at last sex) for better explanatory power.

Impact Indicator 2

Syphilis prevalence among pregnant women

Core indicator in all epidemics

Definition

Percent of blood samples taken from women aged 15-24 that test positive for syphilis by Rapid Plasma Reagin (RPR) testing during routine sentinel surveillance at selected antenatal clinics.

Measurement tools

WHO surveillance guidelines for STI and for HIV

What it measures

STIs are transmitted in the same ways as HIV, and will be prevented by the same safe behaviours being promoted by HIV prevention programmes. Because bacterial STIs are curable, STIs will usually reflect more recent risk behaviour than HIV, which stays with an infected person until death. All the more so because HIV prevention programmes aim to increase recognition and treatment of STIs besides HIV. So measures of STI prevalence are a relatively good guide to recent trends in sexual risk behaviour.

How to measure it

Most countries regularly test pregnant women attending antenatal clinics for syphilis with RPR tests in order to treat those infected and prevent neonatal syphilis infection in infants. Indeed it is blood taken for the purpose of routine syphilis screening and treatment of pregnant women that provides the ethical justification for unlinked anonymous HIV testing of leftover blood. Syphilis screening, therefore, ought to be conducted throughout the year in all antenatal clinics nation-wide. However, reporting systems can be erratic and testing quality difficult to ensure. Linked samples must be tested for syphilis so that a woman can be appropriately treated. However for the purposes of constructing this indicator, it is recommended that blood samples sent to a central laboratory for unlinked anonymous testing of HIV are also re-tested for syphilis. This ensures consistency between data sets regarding site selection and sample collection period, and facilitates quality control.

In calculating this indicator, countries with strong health information systems may wish to include data on syphilis prevalence from a wider selection of antenatal sites than just those included in the sentinel surveillance system for HIV.

It is strongly recommended that two separate figures be reported for syphilis prevalence: one for women aged 15-24 and one for women across the whole reproductive age range of 15-49.

The indicator is the number of blood samples from women aged 15-24 testing positive for syphilis divided by the total number of blood samples from women aged 15-24 tested for syphilis.

Strengths and limitations

Since syphilis is curable, infection tested by RPR probably reflects relatively recent infection. It is therefore recommended that it be measured for women across the whole reproductive age range of 15-49 to give an idea of ongoing risk behaviour. It is, however, recognised that the indicator will be biased to a certain extent by the association between syphilis and infertility.

For programme purposes, especially in order to track changes in risk behaviour among young people, the data should also be disaggregated by age group and presented for 15-19, 20-24 and 15-24 as well as for the entire 15-49 year age range.

Impact Indicator 3

HIV prevalence in sub-populations with high-risk behaviour

Core indicator in concentrated epidemics
Additional indicator in generalised epidemics

Definition

HIV prevalence among members of a defined sub-population at higher risk of contracting or spreading HIV

Measurement tools

UNAIDS/WHO Second Generation Surveillance guidelines; FHI guidelines on sampling in sub-populations

What it measures

In countries with concentrated epidemics, tracking of HIV infection among pregnant women may be a waste of resources. In any case, the bulk of interventions in concentrated epidemics are often focused on the behaviours or groups which are contributing most to the expansion of the epidemic. In a concentrated epidemic, these generally include one or more of the following: injecting drug users, men who have sex with other men, sex workers and frequent clients of sex workers.

The design of a second generation surveillance system should take into account the epidemic state. In countries with low-grade or concentrated epidemics, surveillance for the HIV virus as well as behavioural surveillance should focus on those groups where both infection and interventions are concentrated. Changes in HIV prevalence in these groups should reflect the success or failure of prevention attempts.

How to measure it

Tracking HIV in sub-populations can be logistically and ethically difficult, especially if the groups are marginalised or their activities are illegal. Sampling and estimation of total population sizes are key issues. An understanding of how the sampled population relates to any larger population sharing similar risk behaviours is critical to the interpretation of the indicator. For some groups, population-based sampling strategies will be necessary. In other cases, sentinel sites are available. Sentinel sites for these populations tend to be linked to the provision of health services, for example, a men's health clinic in an area with a high concentration of gay sex bars, or a drug rehabilitation centre.

The indicator is the number of members of the at-risk sub-population testing positive for HIV at sub-population sentinel sites, divided by the total number of members of the at-risk sub-population tested for HIV.

Strengths and limitations

Because of the difficulties in access to sub-populations, the biases in sub-population sero-surveillance data are likely to be far greater (and much less predictable) than in data from a more generalised population such as women at antenatal clinics. Where sentinel sites provide health services to the sub-population in question, for example, the use of the facility may be associated with problems that are themselves related to HIV infection.

It is especially difficult to minimise biases associated with age, since the age of participation in especially high-risk behaviours may vary widely. It is not, therefore, desirable simply to restrict the analysis to young people as it is in ANC sentinel sites.

Despite these difficulties, it is essential to track HIV infection in those with higher risk behaviours in concentrated epidemics. The information will not be perfect, but some measure of progress or lack thereof will be essential to maintain support for prevention programmes in critical sub-populations.

Impact Indicator 4

Percent of children who are orphans

Core indicator in generalised epidemics

Definition

The percent of children under 15 in a household survey whose mother, father or both parents have died

Measurement tools

Household schedule in UNAIDS general population survey; DHS household schedule; Census data

What it measures

HIV is changing the face of adult mortality in many communities, killing men and women at just the ages when they are normally forming families and bringing up children. Their deaths leave behind orphans who must be cared for, generally by other members of the community. The social and economic impact of rising orphanhood can be considerable; national AIDS programmes tracking orphanhood will be better equipped to plan for impact mitigation efforts. This indicator tracks levels of orphanhood in a country.

How to measure it

In a household survey or a national census, respondents are asked the ages of all children in the household and whether the mothers and fathers of those children are alive. Those children who are currently under the age of 15 and whose mother or father or both are dead form the numerator for this indicator. The denominator is all children currently under 15 listed by respondents in the survey.

It is useful to break the results down into maternal orphanhood, paternal orphanhood, and double orphanhood.

Strengths and limitations

Data on an increase in orphanhood can be a very powerful indicator of the impact of an AIDS epidemic. Besides tracking the impact of AIDS deaths on communities, this indicator also has multiple advocacy uses.

One limitation of this measure is that it is not able to distinguish AIDS-related orphanhood from orphanhood due to other causes. However since young adult death was stable or falling in most countries for some years before the arrival of HIV, it is not unreasonable to assume that the bulk of any rise in orphanhood over baseline levels is attributable to HIV.

Orphans may be more mobile than other children. Those most in need of care may be in child-headed households that do not qualify for inclusion in a household survey. Street children living in orphanages will also be missed. Households with AIDS-related deaths often completely disintegrate following the death of heads, and children are sent to live with relatives in the same or another area. Using a household survey and asking about whether the parents are still alive will help alleviate the primary household disintegration issue.

Definitions of orphanhood differ among countries. In some countries, the legal definition includes all children under 18 who have lost either or both parents, for example, while in others it includes all children under 15 who have lost their mother. It is suggested that the standard definition given in this indicator is used to allow for comparison across populations. However, countries may also wish to compile an indicator based on their own national definition of orphanhood. The methodology for constructing the indicator remains unchanged.

Impact Indicator 5

Ratio of orphans to non-orphans who are in school

Additional indicator in generalised epidemics

Definition

The ratio of orphaned children aged 10-14 in a household survey who are currently attending school to non-orphaned children the same age who are attending school

Measurement tools

Household schedule in DHS; Household schedule in UNAIDS general population survey

What it measures

A few community studies suggest that one of the early effects of AIDS sickness and death is that children get taken out of school. This can happen for many reasons: the children may be needed at home to care for sick parents or for younger siblings that their mother is no longer able to look after. This indicator focuses only on those who have lost one or both parents. Children may also be taken out of school to earn money to replace earnings lost through the death of an adult. Or, the loss of earnings and cost of care may mean that the family can simply no longer afford to send children to school. In some cases, girls seeking to supplement family income by seeking payment or rewards for sex drop out of school following pregnancy – sometimes an indirect effect of parental death.

School drop-out can in turn lead to reduced opportunities and high-risk survival strategies, carrying heightened vulnerability to HIV into another generation.

Trends in schooling, however, are affected by many factors other than orphanhood. In an attempt to isolate the effect of orphanhood on school attendance from secular trends in school attendance, the indicator is constructed as a ratio of orphans to non-orphans in school. It provides a crude measure of the effect of parental death on children's schooling.

How to measure it

In a household survey, respondents are asked to list the children in the household, their ages, whether their mother and father are alive, and whether they are currently attending school. The indicator is constructed by comparing the proportion of children aged 10-14 that are defined as orphans who are in school with the proportion of children the same age who are not orphans who are in school.

Countries may also wish to look separately at trends over time in the percentage of orphans in school and non-orphans in school. The gap between the two will give an idea of the impact of parental death on schooling.

The indicator is confined to children 10-14 years old because age at entry into school varies widely in many countries, so including younger age groups would lead to large variations not related to parental death. It should be presented separately for boys and girls.

Strengths and limitations

As with similar measures of social and economic impact, this measure does not directly distinguish the cause of orphanhood. It is assumed that a high proportion of deaths of adults with school-aged children in generalised HIV epidemics are likely to be HIV-related.

A potential limitation of this indicator is that orphans out of school are disproportionately likely to be outside of stable households and so be missed in a household-based survey.