

Guide to Monitoring and Evaluating National HIV/AIDS Prevention Programmes for Young People

Addendum to the UNAIDS “National AIDS Programmes: A Guide to Monitoring and Evaluation”

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Acronyms

ABC	abstinence, being faithful and using condoms
AIDS	Acquired immunodeficiency syndrome
ANC	antenatal care
API	AIDS programme effort index
ART	antiretroviral therapy
ARV	antiretroviral (drugs)
BSS	behavioural surveillance surveys
CDC	U.S. Centers for Disease Control and Prevention
CSW	commercial sex workers
DHS	demographic and health survey
FP	family planning
FHI	Family Health International
HIV	Human immunodeficiency virus
IDU	injecting drug users
IEC	information, communication, education
MCH	maternal and child health
MICS	multiple indicator cluster survey
M&E	monitoring and evaluation
MSM	men who have sex with men
MTCT	mother to child transmission (of HIV)
NGO	non governmental organization
NIDI	Netherlands Interdisciplinary Demographic Institute
PHC	primary health care
PMTCT	prevention of mother to child transmission of HIV
PSI	population services international
STI	sexually transmitted infections
T&C	testing and counselling
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNFPA	United Nations Population Fund
UNGASS	United Nations General Assembly Special Session
UNICEF	United Nations Children's Fund
USAID	US Agency for International Development
VCT	Voluntary counselling and testing
WHO	World Health Organization

Chapter 1: Introduction

Young people are at the centre of the global HIV/AIDS pandemic. They are at high risk of contracting HIV because they often have several, usually consecutive, short-term sexual relationships and do not consistently use condoms. In many countries, a significant proportion of young people start sexual activity before the age of 15; in others, intravenous drug use is spreading at an alarming rate in this age group (UNAIDS Report on the global HIV/AIDS epidemic 2002). In countries with both generalised or concentrated HIV/AIDS epidemic, young people are at its centre. Young people also tend to lack sufficient information and understanding of HIV/AIDS, including their vulnerability to it, how to prevent it, and the self-confidence necessary to protect themselves.

The devastation of the HIV/AIDS pandemic provides a vivid example of the need for investing in young people. In areas where HIV/AIDS is subsiding or even declining, there has been a genuine commitment to HIV prevention, particularly among young people. We now know that if young people are given the information, services and support necessary to adopt new safe behaviours, they can make responsible decisions about their health. We also know that with support, young people can help educate and motivate others to make similar safe decisions.

Research has demonstrated that if HIV/AIDS prevention programmes are to be effective, they must include young people in their design and implementation. We must tailor our programmes to include young people who already engage in high-risk behaviours (e.g., intravenous drug use), and to those who are made more vulnerable to HIV by the circumstances in which they live (e.g., young people who are orphans, those living below the poverty line, etc). Studies have also shown that the behaviours of youth are influenced by a number of different factors. Parents, extended families, communities, schools, and peers are critical in guiding and supporting young people to make safe choices about their health.

Young people represent an extremely valuable asset to the world. They are our greatest hope in the struggle against AIDS. In countries where there has been a reduction in HIV prevalence, young people have led the way (UNICEF, UNAIDS, WHO "Opportunity in Crisis: Young People and HIV/AIDS" 2002). Working with young people to make a healthy transition to adulthood is critical to the world's development both now and in the future.

Why do we need a separate Guide on Monitoring and Evaluating HIV/AIDS Prevention Programmes for Young People?

There have been significant developments made in the past decade in how data on young people and HIV/AIDS are collected, analysed, and used. Worldwide, people are realizing that young people are the key to stopping the spread of AIDS, and this is being reflected in the number of global indicators that relate to young people. This is particularly evident in the recent publication, *National AIDS Programmes: a Guide to Monitoring and Evaluation*, developed by UNAIDS with a range of partners. Many of the measures that were included in the UNAIDS publication built on indicators that had already been developed for monitoring and evaluating other aspects of adolescent sexual and reproductive health.

The experience of the last 10 years, however, has shown that some of these indicators must be tailored to measure the specific efforts directed at the prevention of HIV among young people. Young people are not a homogeneous group: in order to have any chance of success,

interventions must be tailored to specific sub-groups. For this, we need the data collected on young people to be disaggregated by such characteristics as age, sex, school attendance and marital status. In addition, we need data that helps us define and understand especially vulnerable young people, such as intravenous drug users, and men who have sex with men. Data are also needed that differentiate between individual and contextual factors that increase young people's likelihood of engaging in high-risk behaviour. This would make it possible to understand and monitor the kinds of behaviours that increase the risk of young people becoming infected with HIV, as well as the external factors in their families, peer groups, communities and societies that increase the risk of engaging in high-risk behaviour, and can limit their access to information, services, and support.

AIDS is clearly not an isolated issue. It is linked, in its cause and effect, to a number of other public health problems of young people (such as sexually transmitted infections, unplanned pregnancies, alcohol and substance abuse, and gender-based violence); these problems both result from and contribute to the failure to respect and protect young people's rights to health and development. Much research has focused on risk behaviours associated with these health issues, and two conclusions are of particular significance to preventive programming: 1) risk behaviours tend to cluster in individuals, and 2) risk behaviours have common determinants (that is, they are affected by the same risk and protective factors). These findings have great implications for what needs to be measured for planning and monitoring HIV/AIDS programmes for young people.

It is for these reasons that a special guide is needed to help advocate, plan, monitor and evaluate national policies and programmes for HIV prevention among young people. This Guide is intended to complement the indicators included in *National AIDS Programmes: a Guide to Monitoring and Evaluation*, by refining those indicators already defined, and by proposing new indicators in relatively early phases of development and use. These new indicators are included to ensure that policies and programmes benefit from the lessons learnt during the past decade and, at the same time, to provide experience collectively from measuring and using them.

This guide should also help to place HIV/AIDS within the broader context of efforts to improve young people's sexual and reproductive health and promote adolescent health and development. While impossible to cover indicators in all areas relevant to prevention of HIV/AIDS among young people, this guide presents a conscious effort to expand the measurement lens from a narrow focus on individual behaviours to the determinants of these behaviours. Hence a set of indicators focusing on the key determinants of behaviours, and a set focusing on minimal components of a national prevention programme. In addition, the set of behavioural indicators has also been expanded to include behaviours which may not be causally related to HIV infection, but which contribute to young people's vulnerability to HIV - such as forced sexual relations, and age-mixing in sexual partnerships among young women.

Summary of the main reasons for the Young People's Guide:

- To help advocate for, plan, monitor and evaluate policies and programmes for HIV prevention among young people
- To tailor existing widely-used indicators and methods so that they are relevant to the national programmes for HIV prevention among young people
- To introduce new measures specific to the determinants (risk and protective factors) which influence vulnerability and risk behaviours

For whom is this manual intended?

As with *National AIDS programmes: A guide to monitoring and evaluation*, which this manual is intended to supplement, this guide is intended for use by programme managers at the national level (an in particular, managers of National AIDS Programmes). It may also be useful for programme managers and planners at sub-national level to align their measurement efforts with national ones.

What does the Young People's Guide contain?

This guide identifies a set of indicators and methods for measuring them to help national AIDS programme managers in planning and monitoring HIV prevention programs for young people. The indicators are organized into four chapters according to a logic model which links programmatic action to expected outcomes, and ultimately, to epidemiological impact. The chapters are linked as follows: Programmatic indicators, Determinants (Risk and Protective Factors), Behavioural Outcomes, and Impact.

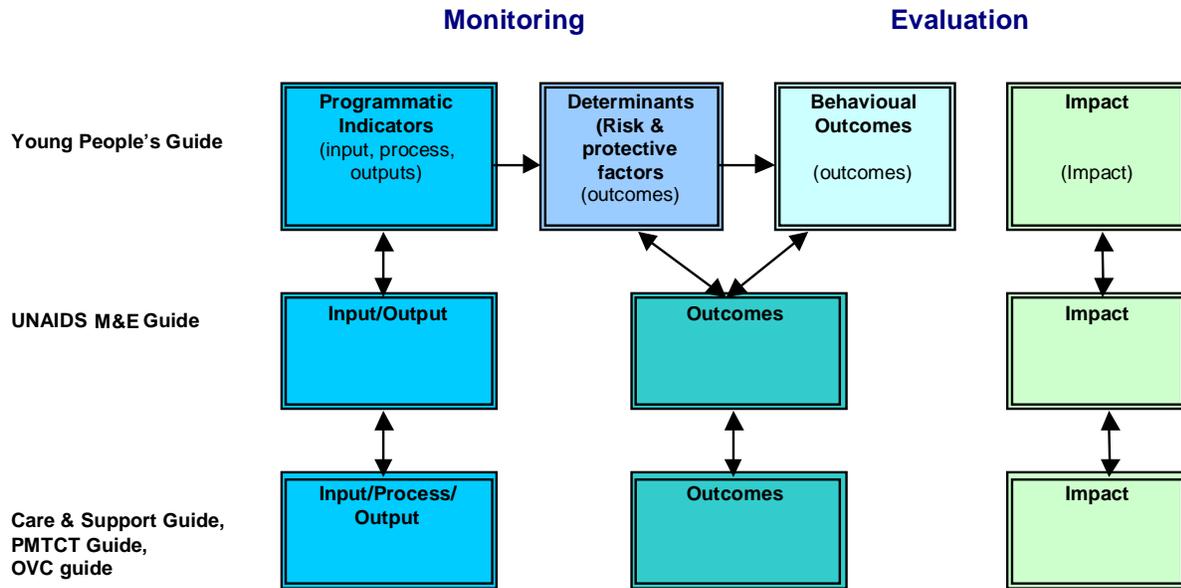
This model is closely linked to the established model of programme monitoring and evaluation, which classifies indicators into categories of input, output, outcome, and impact:

For a programme to achieve its goals, **inputs** such as money and staff time must result in **outputs** such as 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 **outcomes**, for example increased condom use, or reduced needle sharing among drug injectors. These positive outcomes should lead to changes in the **impact** of programmes, measured in fewer new cases of STI and HIV.

UNAIDS, National AIDS programmes: A guide to monitoring and evaluation

The main difference is that the outcomes considered in this guide are split up into the risk and protective factors and the behavioural outcomes. The category of programmatic “outcomes” is thus elaborated, according to the different effects a programme may have (i.e., targeting individual behaviour, or the determinants of that behaviour). This is based on more than a decade of research and programme evaluation attesting that adolescent development and behaviour change are influenced by a number of factors, including individual knowledge and attitudes, relationships with parents and peers, schools, economic status, faith beliefs, and the entertainment media. Some of these factors help us understand the context in which young people live and make decisions; others help guide our programmatic focus. Thus, it is also important to measure these and track trends in key indicators relating to these areas on the national level.

Graphically, this model, and how it relates to the other UNAIDS M&E Guides, is represented below:



This structure gives programme managers a classification system for organizing priority indicators and recognizing areas of imbalance in the planning and monitoring of HIV/AIDS prevention programmes for young people.

The following provides more detail on the chapters and categories of the indicators contained in this guide:

- 1. Programmatic Indicators:** Indicators that can be used to assess national-level HIV/AIDS prevention interventions for young people, that are intended to monitor the interventions at a national level, and that can often be used to track changes over time. The indicators in this chapter include measures relating to policy, funding, and specific programme coverage.
- 2. Determinants (Risk and protective factors):** Indicators that point to factors that are not causally related to HIV infection among young people, but that either contribute to risk taking and vulnerability, or provide some protection against it. The indicators in this chapter include young people's knowledge, attitudes and perceptions, general beliefs and attitudes held by adults regarding young people's access to health information, and measures of the quality of the relationship between young people and their primary caregivers.
- 3. Behavioural Outcomes:** Indicators that measure individual young people's actions which directly affect the biological outcomes. Indicators in this chapter include measures of condom use, injecting drug use, and commercial sex, as well as the proportion of young people who have already had sex by the age of 15, and the number of sexual partners that young people have had.
- 4. Impact:** Indicators that capture the epidemiologic population-level measures of impact, most notably HIV prevalence rates among young people and specific sub-groups of young people.

Overview of Indicators

The choice of appropriate indicators will vary according to the goals of the programme, which will in turn be determined by the stage of the epidemic. Because the diversity of HIV epidemics has grown, two different sets of "core" indicators are suggested -- one for low-level and concentrated epidemics, and another for generalised epidemics. Attention to HIV prevention and care among young people is important in both scenarios. Countries will supplement core indicators with the appropriate additional indicators, which may be drawn from the following indicator list.

As stated previously, these indicators are best analysed by disaggregating the data by age, sex, marital status, and other characteristics that are important to the national programme. The age breakdown is especially important because sexual behaviour can vary widely between age groups: adolescents aged 10-14, overall, are probably much less sexually active than their 15-19 year old peers, who are again different from 20-24 year olds. This breakdown of age groups allows national programme managers to look for cohort trends, or trends that occur over time. For example, if respondents ages 15-19 report lower proportions of sexual initiation before age 15 than respondents ages 20-24, it suggests a decline in early sexual debut. Whenever possible, data should be disaggregated into groups 10-14, 15-19, and 20-24. In addition, disaggregating the data by background characteristics (e.g., urban vs. rural residence, school attendance, marital status, etc) allows programme managers to determine which populations might be at increased risk, and also to make better-informed programmatic decisions, such as to include life-skills based HIV/AIDS education in younger grades in schools. Finally, if suitable data are not available, indicators should not be reported on (as it may lead to misinterpretations and erroneous programmatic decisions).

Below is an overview of the indicators by category, tools for measurement, and priority for different stages of the epidemic.

(C=Core Indicator; A=Additional Indicator)

Indicator	Tools for Measurement	Priority Generalized Epidemic	Priority Concentrated/ Low level
PROGRAMMATIC Indicators			
1. National index on policy related to young people and HIV/AIDS	<ul style="list-style-type: none"> o Country assessment questionnaire 	C	C
2. National funds spent by government on HIV/AIDS prevention programmes for young people	<ul style="list-style-type: none"> o UNAIDS/UNFPA/NIDI survey on financial resource flows 	C	C
3. Provision of life-skills-based HIV/AIDS education in schools	<ul style="list-style-type: none"> o School-based survey 	C	C
4. Institutionalising youth-friendly health services	<ul style="list-style-type: none"> o Nationally representative survey of health service delivery points o Nationally representative general population survey 	C	C
5. Use of specified health services by young people	<ul style="list-style-type: none"> o Nationally representative general population survey o Service statistics from a health services survey 	C	C
6. Condom availability for young people	<ul style="list-style-type: none"> o MEASURE Evaluation/WHO/ PSI Complied Condom Availability and Quality Protocol retail survey 	C	C
7. Young injection drug users reached by HIV/AIDS prevention	<ul style="list-style-type: none"> o Prevalence estimation methods o Service statistics from projects, 	A	C

	programmes and treatment facilities		
8. Young people's participation in HIV prevention programmes	o Nationally representative general population survey	A	A
DETERMINANTS (Risk and protective factors) Indicators			
9. Knowledge of HIV prevention among young people	o Nationally representative general population survey	C	C
10. Knowledge of a formal source of condoms among young people	o Nationally representative general population survey	C	C
11. Sexual decision-making among young people	o Nationally representative general population survey	A	A
12. Perceptions of peers' sexual activity	o Nationally representative general population survey	A	A
13. Connection to a parent or primary caregiver among young people	o Nationally representative general population survey	A	A
14. Parent or primary caregiver regulation of young people's behaviour	o Nationally representative general population survey	A	A
15. Adult support of education about condom use to prevent HIV/AIDS among young people	o Nationally representative general population survey	C	C
BEHAVIOURAL Indicators			
16. Sex before the age of 15	o Nationally representative general population survey	C	C
17. Higher risk sex among cohabitating and non-cohabitating young people	o Nationally representative general population survey	C	C
18. Abstinence, Being faithful, and use of Condoms among young people	o Nationally representative general population survey	C	C
19. Forced sex among young people	o Nationally representative general population survey	C	C
20. Age-mixing in sexual partnerships among young women	o Nationally representative general population survey	C	A
21. Sex with commercial sex workers among young men	o Nationally representative general population survey	A	C
22. Sex while intoxicated among young people	o Nationally representative general population survey	A	A
23. HIV testing behaviour among young people	o Nationally representative general population survey	C	A
24. Anal sex without a condom among young men who have sex with men (MSM)	o Special surveys among MSM	A	C
25. Safe practices among young injection drug users (IDU)	o Special surveys among injection drug users	A	C
26. Condom use among young commercial sex workers	o Special surveys among commercial sex workers	A	C
IMPACT Indicators			
27. HIV prevalence among young pregnant women	o Sentinel surveillance	C	C
28. HIV prevalence among young people	o Nationally representative general population survey	C	C
29. HIV prevalence in sub-	o UNAIDS/WHO Second	C	C

populations of young people with high-risk behaviour	<p>Generation Surveillance Guidelines</p> <ul style="list-style-type: none"> ○ FHI guidelines on sampling in sub-populations 		
30. Young people who have sexually transmitted infection	<ul style="list-style-type: none"> ○ Surveys among clinic-based groups (ANC attendees, gynaecology patients, blood donors, etc.) ○ Community-based surveys 	C	C

Note on Monitoring and Evaluation

The following brief section highlights the most important aspects of monitoring and evaluation. It is not intended to provide comprehensive explanation on the topic, but to situate the indicators presented in this guide within monitoring and evaluation efforts.

Monitoring and evaluating programmes designed to promote health and development is necessary not only to account for resources and improve the programmes, but also to show whether the interventions are having the intended effect, and to make appropriate changes based on the results. The following definitions are from the UNAIDS Guide to Monitoring and Evaluation of National AIDS Programmes:

- **Monitoring** is the routine tracking of priority information about a programme (at national or project level) and its intended outcomes. It includes monitoring of inputs and outputs through record-keeping and regular reporting systems as well as health observation and client surveys. It can be called programme, process or output monitoring.
- **Evaluation** is a collection of activities designed to determine a programme's effect or value. Evaluation focuses on whether the programme has had the intended effect on specified outcomes. In this guide, outcomes are considered to be both individual behaviours, as well as the determinants (risk and protective factors) of these behaviours. Evaluation exercises can also look for evidence of programme impact: that is, attributing long-term changes to the specific programme.
- **Surveillance** activities are related to, but are not the same as, programme monitoring and evaluation. Surveillance is the routine tracking of diseases or behaviours using the same data collection system over time, but not necessarily in relation to any specific programme or intervention. Surveillance helps describe and monitor an epidemic and its spread. In the case of behavioural surveillance, it helps describe behavioural patterns in a given population. Surveillance can contribute to predicting future trends in diseases or behavioural patterns. In the case of HIV, surveillance systems as part of Second Generation HIV Surveillance typically track HIV and STI prevalence, AIDS case reporting, and sexual risk behaviours.

True impact evaluations able to attribute change in HIV prevalence to a specific programme are very rare because they require a complex and costly experimental design, and are generally difficult to carry out for a national-level intervention. Rather, monitoring impact indicators such as HIV prevalence, 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. It is therefore important to track changes in behaviours that are causally related to the prevalence of a disease. Similarly, behaviour change can also take some time to be demonstrated in a target group. To better assess whether a programme can be expected to result in behaviour change, it is important to track changes in the

determinants of these behaviours – that is, changes in the risk and protective factors that contribute to these behaviours.

The indicators in this guide are intended to be used at the national level, but the guide does not provide instructions in designing a monitoring and evaluation plan for a national HIV/AIDS prevention programme. Such a plan must be tailored to the specifics of the interventions implemented at national, regional, and project levels. This guide provides the basic indicators common to most national programmes, and thus achieves several purposes:

- Provides guidance as to the common minimal components for implementation and monitoring HIV/AIDS prevention programmes for young people
- Provides guidance as to the measurement of common behaviours which drive the spread of the epidemic, and common determinants which influence these behaviours
- Provides a common way of measuring the progress in implementation and the effect of a national prevention programme so that the efforts may be comparable across time and between countries

In deciding on a national set of indicators, it is important that countries (National AIDS Programmes, or similar) 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 by the goals, objectives and activities of the national HIV/AIDS prevention programme, the stage of the HIV epidemic, as well as the main modes of HIV transmission in various sub-populations.

In addition to the national level, these indicators have an international role in helping donors and agencies in:

- Tracking the trends in the epidemic specifically among young people, and the global response to it
- Identifying regional trends or patterns in the epidemic among young people
- Highlighting persistent programmatic problems
- Advocating for expanded resources for programmes focusing on young people

There are other important topics that national programme managers might want to consider when deciding on an evaluation plan. These include:

- The structure and function of a monitoring and evaluation unit
- Matching monitoring and evaluation methods and selection of indicators to project goals and objectives
- Data collection and data analysis plan
- A plan for using the data for advocacy, revision of programme, generating resources

The UNAIDS “Guide to Monitoring and Evaluation of National AIDS Programmes,” to which this Guide is a companion, includes a discussion on these topics (refer to UNAIDS website: <http://www.unaids.org>). Other resources relevant to the monitoring and evaluation of programmes for young people include:

- “A Guide to Monitoring and Evaluating Adolescent Health Reproductive Health Programs: FOCUS on Young Adults project,” (refer to YouthNet website: <http://www.fhi.org/en/Youth/YouthNet>)
- “Evaluating Programs for HIV/AIDS Prevention and Care in Developing Countries” from Family Health International (refer to FHI website: <http://www.fhi.org>).
- “Learning to Live: Monitoring and evaluating HIV/AIDS programmes for young people” from Save the Children (refer to Save the Children website: <http://www.savethechildren.org.uk>)

Note to users: New developments and lessons learned in the field of monitoring and evaluation of HIV/AIDS prevention programmes for young people will invariably result in the need to revise and update the indicators presented in this Guide. This is the first time global indicators targeting national-level programmes for HIV/AIDS prevention among young people have been brought together. Over time and with feedback, these indicators will be improved. The current guide is, therefore, a work in progress and will be refined in future editions.

Chapter 2: Methodological Considerations

INTRODUCTION

This chapter focuses on issues related to collecting data from individual young respondents, which are particularly relevant for Determinants (Risk and Protective Factors), Behavioural Outcomes, and Impact Indicators (Chapters 4-6). There is also a section about the specific challenges associated with gathering data from young adolescents, primarily those between the ages of 10-14 years. The Methods Annex provides a comprehensive description of some of the issues of data collection.

1. Validity, reliability, and bias:

One of the most important concerns in collecting data on young people is that it be comparable over time. When data are comparable, national programme managers can identify trends and changes in the HIV epidemic among young people. To achieve this, data must be *valid*, *reliable* and *unbiased*. **Valid** data are data that are as close to the truth as possible. **Reliable** data are data that are consistently answered the same when the same or similar questions are asked. When data errors are systematic or follow a regular pattern, they are called bias.

There are several types of biases that can occur in data collection. One type of bias that affects data collection among young people is **interviewer bias**. An interviewer can influence the responses in many ways, even by the tone in his/her voice. Other characteristics, such as gender, age, race, ethnicity, education status, and attitudes may also influence how a young person responds to questions. Researchers have found that participants are generally most likely to develop trust with people who are like themselves, and thus may report sensitive behaviour to such interviewers. For example, the most appropriate person to interview a rural adolescent girl may be a young woman of a similar background.

Interviewer bias can be reduced by ensuring all interviewers are well trained and tested in interviewing skills, the research protocol and research ethics. Interviewer training should also involve a discussion of the importance of valid data, ways to reduce bias, and the research goals themselves to foster the interviewers' sense of ownership and personal commitment to those goals even in the absence of supervision (Bachrach and Newcomer, 2002).

Another type of bias that may be especially common among young respondents is **social desirability bias**, which occurs when study participants do not answer questions honestly because they perceive the truth to be socially unacceptable or undesirable. For example, a person may falsely deny having had a sexually transmitted infection because of fear of the social stigma related to it. Researchers have generally found that behaviours that are seen as socially undesirable will be under-reported rather than over-reported (Catania, 1990). However, perceptions of desirability may vary within a population, and what may be considered unacceptable for one group may be considered desirable for another. In some cultures, for example, young women's abstinence from sex is highly valued, so they may under-report their total number of sexual partners to interviewers, while young men in the same culture may take pride in sexual experience, and thus exaggerate their total number of partners (Siegel et al., 1998; Catania, 1993).

A number of techniques have been developed to reduce social desirability bias. One is to explain the research goals before the interview, including their social value and legitimacy, and the importance of honest reports. Another is to ensure the privacy of the interview and the

confidentiality of any information obtained from it, and to make this as evident as possible to respondents.

There are a number of ways to reduce the possibility of bias through questionnaire wording and design. For a further discussion on this topic, including tips on questionnaire design, please refer to the Methods Annex.

2. Data Collection Methods

The recommended methodology of data collection for most indicators included in this guide is a national or regional **household survey** of young people. In addition, **school-based surveys**, which have been widely implemented, must also be recognized as a relevant source of data about young people. There are advantages and disadvantages to each method, which are explained in more detail in the Methodological Annex. One of the main advantages of school surveys as compared to household surveys is the cost: school surveys are, overall, much less expensive to implement. The lower cost of these surveys is largely due to a more accessible sample (the advantage of having a group of young people in a school, rather than having to find each young person in his/her household), and the fact that most school surveys use self-administered questionnaires (that is, they do not require an interviewer to pose questions, as young people fill out the questionnaire themselves).

However, the major drawback of school-based surveys - and the main reason why they are not suggested as a means of data collection in this guide - is that they are not representative of the overall population of young people. There are two main arguments:

- In countries where overall school attendance is low (and usually lower with increasing age), a substantial proportion of the overall young population would not be included in a school-based sample.
- This guide recommends most of the indicators to be collected with young people aged up to 24 years. In countries where school attendance is high, young people in the higher age bracket (18 and above) are no longer in school, and would therefore be excluded from the sample.

Indicators in this guide were compiled for the purpose of monitoring and evaluating national programmes, and for tracking national behavioural and biological trends relevant to HIV. Given the limitations specified above, school-based surveys cannot be substituted for household surveys.

Nevertheless, school-based surveys can be a valuable additional source of information, which could be used in conjunction with a household survey to give insight into specific issues, particularly those related to school-based interventions.

Ultimately, the most important point is the synergy of different methods and efforts of data collection in providing a comprehensive picture of issues relevant to preventing and treating HIV/AIDS among young people. All surveys - whether household-based, school-based, or with special populations - should include a key set of core indicators relevant to HIV and young people. The indicators in this guide are such a proposed set, with the aim contributing to comparability of data across surveys, across regions and across time, and therefore improving data collection efforts overall.

For most of the indicators included in this guide, data will need to be collected by conducting a national or regional **household survey** of young people. Among the more prominent ongoing household surveys that collect data in a sizeable number of countries include the Demographic

and Health Surveys (DHS), the Behavioural Surveillance Surveys (BSS) developed by Family Health International, and the UNICEF Multiple Indicator Cluster Surveys (MICS). Most of these surveys are based on adult samples, and the sample size and sampling techniques have to be adjusted to ensure a representative number of young people within the overall sample. There are also household surveys that are adolescent-specific, such as Reproductive Health and Adolescent Reproductive Health Surveys undertaken by the U.S. Centers for Disease Control and Prevention (CDC), and the Asian Young Adult Reproductive Risk Surveys, supported by USAID. In addition to these "international" surveys, many countries also undertake annual or more frequent national surveys (e.g., quarterly labour force or economic surveys). The volume and types of data on adolescents varies tremendously across these national surveys. However, as such surveys might serve as a vehicle for adding questions on adolescent health and development, they are worthy of note.

For an in-depth discussion of different surveys and methods of sampling populations of young people, refer to the "Guidelines of sampling of youth" paper, which is available on www.childinfo.org.

3. Collecting Data on 10-14 year olds: Challenges of Data Collection and Analyses

To date, most large-scale surveys of young people and most programmes (from life skills to provision of health services to livelihood interventions) are targeted at young people ages 15 and older. In many cases, this may be too late, as by 15 many young people have matured sexually and begun to have sex, and in many settings a large proportion of girls have already been married.

There is clearly a need to collect data from - and to target appropriate interventions at - adolescents aged 10-14. However, there are a number of methodological and ethical issues surrounding data collection with this population. Some school-based surveys (see the Methodological Annex) have indeed included adolescents younger than 15 years of age, and have provided valuable lessons in collecting data with this population. Still, there is overall little information available about the best practices in collecting data with this age group particularly in household surveys, and this clearly deserves further investigation. The principal areas of consideration are outlined below.

This Guide recommends that in each setting, the possibility of collecting data with 10-14 year old adolescents should be explored. In some cases it may be possible to ask sexuality-related questions of this age group; in others, it may not. For settings where such questions cannot be asked, the Guide recommends to focus (for this age group) on the indicators in the Determinants chapter relating to relevant knowledge of HIV prevention, to young people's perceptions of peers' sexual activity, and to describing the context in which young people take sexuality-related decisions.

3.1. Collecting biological data

By and large, this group is left out of the estimations of HIV prevalence. Prevalence data is largely drawn from testing pregnant women at antenatal services. Young girls aged 10-14 are likely to comprise a very small proportion of this clientele in any given setting, even in settings where sexual activity is not uncommon at an early age. Data collection at antenatal sites should be in any event collected by specific age (year-specific), allowing for analysis according to different age brackets. Population-based surveys usually do not include this age group either, and gathering biological specimens from this age group presents ethical and parental consent issues. By and large, HIV prevalence estimation among this group will likely remain based on modelling prevalence from other age groups.

3.2. Appropriateness of survey questions

In many settings, parents and other adults may resist asking sexual behaviour questions of adolescents aged 10-14. In settings where behavioural questions can be asked of younger adolescents, the wording of the questions must be carefully considered to ensure their full comprehension and cultural sensitivity.

Sometimes, proxy behavioural questions are used. For example, young adolescents are asked whether they think their peers have already had sex (or have used drugs, etc), as it is assumed that the respondent is answering about a group similar to him/herself. It is not possible, however, to assume that these types of questions substitute self-response questions. Some research has shown, for example, that adolescents often believe their friends are engaging in risk behaviours at a much higher rate than they actually are (Robinson, Telljohann, and, Price, 1999; Romer et al., 1994).

Questions about perceptions of certain actions are also used as a proxy for predicting whether young adolescents are engaging in such actions (i.e., whether the respondent considers it acceptable or not for him/herself to be having sex). It has been found that attitudes about sex are strongly related to actual sexual activity. However, the onset of sexual activity may be brought about by circumstances unrelated to the young persons' attitudes (e.g., forced sex), and therefore this measure cannot substitute direct behavioural questions.

Some surveys have opted for designing an additional module to replace the sexual behaviour questions where these are not possible to ask (e.g., "Optional core module for countries that cannot ask sexual behaviour questions," in the Global School-based Student Health Survey, World Health Organization.) However, in some settings, even attitude and knowledge questions about sexuality, contraceptives, and reproductive health services can be judged as inappropriate for this age group.

3.3. Consent & parental permission issues

Obtaining appropriate consent from the young person and/or his or her guardian is in many countries mandated by the laws which protect minors; often they are also mandated by the ethical policies of investigating bodies. The process of obtaining consent is influenced by a number of factors: the development of the young person involved, the setting in which he or she is interviewed, and the social perceptions of the appropriateness of young people to be interviewed regarding the topic at hand.

a) **Development:** emotional and brain development in this age group is in fact not homogeneous: it differs by year, and also between boys and girls. Regardless of the stage of development, however, written or oral consent is usually sought from the respondent. Most often, parental consent is also sought.

b) **Settings:** the most common settings where young people are interviewed are their own homes, and schools. In both, there is usually a need to obtain parental permission or consent to conduct the interview. There may be a bias introduced in both cases between the parents that allow their child to be interviewed and those that do not. The setting itself can also influence the interview, that is, whether the young respondent considers it comfortable and confidential. When young people are reached through other settings, such as the street, or a workplace, parental consent is often not sought.

c) **Social perceptions:** Parental consent may be more or less difficult to obtain depending on the topics to be covered in a questionnaire, and on the prevailing norms and perceptions

about appropriate topics for this age group. A survey focusing on sexuality, for example, is probably likely to get a lower rate of parental consent than a survey focusing on a broader range of health and development outcomes.

There are many unanswered questions in deciding on the best methodology of collecting data with 10-14 year olds. These questions should be recognized and acknowledged, but should not paralyse efforts to collect data from this group. We need data to design better programmes, because while young adolescents are more vulnerable, they are also resilient and flexible. Much can be done to remedy their situations before the architecture of their later life becomes set.