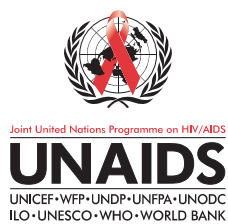


NATIONAL GUIDE TO MONITORING AND EVALUATING PROGRAMMES FOR THE PREVENTION OF HIV IN INFANTS AND YOUNG CHILDREN



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**NATIONAL GUIDE TO MONITORING
AND EVALUATING PROGRAMMES
FOR THE PREVENTION
OF HIV IN INFANTS
AND YOUNG CHILDREN**

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Abbreviations

ANC	antenatal care
ART	antiretroviral therapy
ARV	antiretroviral (drug)
FP	family planning
HIV	human immunodeficiency virus
IEC	Information, Education, Communication
M&E	monitoring and evaluation
MCH	maternal and child health
MTCT	mother-to-child transmission (of HIV)
NGO	nongovernmental organization
PHC	primary health care
PMTCT	prevention of mother-to-child transmission (of HIV)
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNGASS	United Nations General Assembly Special Session
WHO	World Health Organization

Introduction

Impact of mother-to-child transmission of HIV infection

HIV among children is an increasing problem, particularly in the countries hardest hit by the AIDS pandemic (Table 1). It is wiping out years of progress in improving child survival and is already responsible for substantially increasing the mortality rates of children under 5 years of age (Fig. 1). The overwhelming majority of infected children acquire the infection through mother-to-child transmission (MTCT). The prevention of HIV infection in infants and young children is now a high priority and has been the rallying point for enhanced prevention and care efforts.

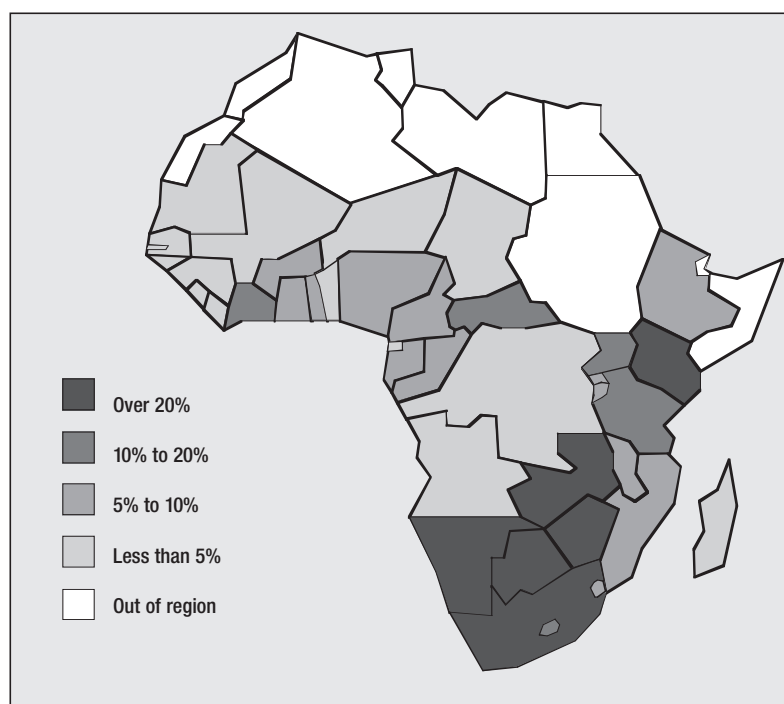
TABLE 1. HIV/AIDS AMONG CHILDREN, 2002

Children living with HIV/AIDS	3 200 000
Children who died of HIV/AIDS	610 000
Children newly infected with HIV	800 000

Source: Walker N, Schwartländer B, Bryce J. Meeting international goals in child survival and HIV/AIDS. *Lancet*, 2002 Jul 27; 360 (9329):284-9

FIG. 1. IMPACT OF HIV/AIDS ON CHILD SURVIVAL IN AFRICA

Proportion of under-5 mortality attributable to HIV/AIDS in sub-Saharan Africa, in 1999



Source: Walker, *Lancet* (2002).

In the absence of intervention, MTCT rates can vary from 15% to 30% without breastfeeding and can reach 30% to 45% with prolonged breastfeeding. Transmission can take place during pregnancy, labour or delivery and can affect infants and young children as long as breastfeeding continues.

Rates of transmission have been estimated as follows.

During pregnancy	5–10%
During labour and delivery	10–20%
During breastfeeding	5–20%
Overall, without breastfeeding	15–30%
Overall, with breastfeeding for 6 months	25–35%
Overall, with breastfeeding for 18-24 months	30–45%

Source: de Cock K, Fowler MG, Mercier E, de Vincenzi I, Saba J, Hoff E, Alnwick DJ, Rogers M, Shaffer N. Prevention of mother to child transmission in resource-poor countries: translating research into policy and practice. JAMA, 2000; 283 (9):1175-1182.

The United Nations General Assembly Special Session Declaration of Commitment

At the United Nations General Assembly Special Session (UNGASS) on HIV/AIDS in June 2001 the governments of 189 countries adopted the Declaration of Commitment on HIV/AIDS, thereby undertaking a comprehensive programme of international and national action against the pandemic. The Declaration established specific quantified and time-bound goals, one of which was to reduce HIV infection among infants and young children as follows:

“By 2005, reduce the proportion of infants infected with HIV by 20%, and by 50% by 2010, by ensuring that 80% of pregnant women accessing antenatal care have information, counselling and other HIV prevention services available to them, increasing the availability of and providing access for HIV-infected women and babies to effective treatment to reduce mother-to-child transmission of HIV, as well as through effective interventions for HIV-infected women, including voluntary and confidential counselling and testing, access to treatment, especially antiretroviral therapy (ART) and, where appropriate, breast-milk substitutes and provision of a continuum of care.”

The rationale for this guide

UNAIDS and its partners have developed a set of core indicators that permit the monitoring of key international and national actions, national programme outcomes, and impact entitled *National AIDS programmes: A guide to monitoring and evaluation* (UNAIDS/00.17E, June 2000). This guide has been widely distributed and used. As a consequence of rapid developments in HIV/AIDS prevention and care in the last few years, however, some important areas are not covered. One important shortcoming is that insufficient attention is paid to the monitoring and evaluation (M&E) of programmes for the prevention of HIV infection in infants and young children. The present guide is an attempt to fill this gap.

What are programmes for the prevention of HIV infection in infants and young children?

In order to meet the UNGASS goal it is necessary to have a comprehensive approach to the prevention of HIV infection in women, infants and young children. For the purposes of this manual we use the WHO definitions of infants and children as persons aged 0-11 months and 12-59 months respectively. Interventions should be in place to address the following strategic areas (see Box 1 for UN framework for a comprehensive approach to the prevention of HIV infection in infants and young children).

BOX 1. A FRAMEWORK FOR ACTION TO PREVENT HIV INFECTION IN INFANTS AND YOUNG CHILDREN

All women	prevent HIV infection
HIV-infected women	prevent unintended pregnancy
HIV-infected women	prevent transmission to infants and young children
HIV-infected women, their infant and family	provide care and support

- **Primary prevention of HIV infection**

Avoiding infection in women can contribute significantly to the prevention of HIV transmission to infants and young children, as well as to other prevention goals. HIV prevention programmes should be directed at a broad range of women at risk and their partners. A particular effort is required in order to provide young people with relevant services. Because primary HIV infection during pregnancy and breastfeeding poses an increased threat of MTCT, efforts aimed at HIV prevention should also address the needs of pregnant and lactating women, especially in areas of high prevalence.

- **Prevention of unintended pregnancies among HIV-infected women**

Most HIV-infected women in the developing world are unaware of their serostatus. While fertility decreases with disease progression, family planning (FP) services should nevertheless be strengthened so that all women, including those infected, can receive support and services for the prevention of unintended pregnancies. Women known to be infected with HIV should receive essential care and support services, including FP and other reproductive health services, so that they can make informed decisions about their future reproductive lives.

- **Prevention of HIV transmission from HIV-infected women to their infants**

A package of specific interventions has been identified for the prevention of HIV transmission from infected mothers to their children. It includes the use of antiretroviral drugs (ARVs), safer delivery practices, and counselling and support for infant feeding (Box 2). Counselling and testing play a key role in enabling HIV-infected women to learn about their status in good time and thus to obtain the full benefits of the package.

- **Provision of care and support to HIV-infected women and their infants and families**

Programmes for the prevention of HIV in infants and young children can help to identify large numbers of HIV-infected women who need special attention. The strengthening of linkages among these and other programmes concerned with care and support services for HIV-infected women and their infants and families can ensure that the women gain access to the services they need. Such services may involve the prevention and treatment of opportunistic infections, the use of ART, psychosocial and nutritional support, and reproductive health care, including safer delivery, FP and counselling and support for infant feeding. Improvements in the survival and quality of life of mothers can be expected to be accompanied by important benefits for their children. Access to care and support should also enhance community support for programmes aimed at preventing MTCT and increase the uptake of critical interventions, e.g. HIV testing.

Debate has recently begun on the proportion of HIV infections in infants and young children that are attributable to unsafe injections and blood transfusions. It might seem reasonable to cover these issues in the present guide. However, it is an operating premise of this effort that the vast majority of infections in infants and young children result from vertical transmission, either in the peripartum period or subsequently through breastfeeding. More research is needed in order to establish how much HIV transmission to infants and young children is attributable to unsafe injections and blood transfusions. If it emerges that this is indeed a substantial problem, additional indicators addressing such transmission and its prevention will have to be adopted. Meanwhile, indicators on blood safety and nosocomial transmission are available in Chapter 3.11 of *National AIDS programmes: A guide to monitoring and evaluation* (UNAIDS/00.17E, June 2000).

Examples of possible interventions in each of the above strategic areas are presented in Box 2.

BOX 2. INTERVENTIONS TO PREVENT HIV INFECTION IN INFANTS AND YOUNG CHILDREN

Intensified prevention efforts aimed at young women. Evidence from countries with successful programmes, such as Uganda, has demonstrated that strong leadership and open discussion of the issues, coupled with a broad approach to prevention, can be effective in limiting HIV infection among young women. This broad approach should include the promotion of abstinence, monogamy and condom use. The experience gained in these countries suggests that no single approach is sufficient. The most effective and humane way to prevent HIV in infants is to help young women, by whatever means, to remain free from infection.

Prevention of unintended pregnancies among HIV-infected women. Often misinterpreted to be standard FP practice, this approach is much more than that and is crucial in preventing HIV in infants. Many women do not know if they are infected with HIV and hence make decisions about their reproduction without complete information. The provision of testing and counselling in FP services would allow more targeted counselling on FP and would increase the salience of counselling on dual protection. Furthermore, during antenatal care many women are identified as being infected with HIV. If they are referred for counselling on postpartum family planning with information on their infection status, it is to be expected that there will be increases in the effectiveness of such counselling and in the likelihood that subsequent pregnancies will result from conscious decisions.

Use of antiretroviral drugs. The recommendations on ARV drugs for prevention of MTCT are based on evidence on drug safety and efficacy in reducing MTCT. Of the recommended ARV drug regimens, the choice of an ARV regimen should be made locally by taking account of feasibility, efficacy, acceptability and cost.

Safe delivery practices. Elective caesarean section can help to reduce the risk of MTCT. However, this intervention may not be appropriate in resource-constrained settings because of limited availability, its cost and the risk of complications. Invasive obstetric procedures, such as the artificial rupture of the membranes, fetal scalp monitoring and episiotomy, may increase the risk of transmission of HIV to infants. Their use in HIV-infected women should therefore be limited to cases of absolute necessity.

Counselling and support for infant feeding. Breastfeeding can increase the risk of HIV transmission by 5-20%. If breastfeeding does not occur, however, children may be exposed to an increased risk of malnutrition or infectious diseases other than HIV. The avoidance of breastfeeding may seem logical if a mother is HIV-infected, but striking the necessary balance of risks is more complicated. HIV-infected mothers should receive counselling that includes information about the risks and benefits of various infant feeding options and guidance on selecting the most suitable option in each set of circumstances. The avoidance of all breastfeeding by HIV-infected mothers is recommended if replacement feeding is acceptable, feasible, affordable, sustainable and safe. Otherwise, exclusive breastfeeding is recommended during the first months of life and should be discontinued as soon as the conditions for replacement feeding exist. Replacement feeding should involve the use of a suitable breast-milk substitute during the first six months. After six months both a suitable breast-milk substitute and complementary foods should be given.

1. Why it is important to monitor and evaluate programmes aimed at the prevention of HIV infection in infants and young children at the national level

Programmes for the prevention of HIV infection in infants and young children are gaining increased commitment and support. Many countries are expanding their programmes in response to the growing HIV/AIDS pandemic. Such programmes are expensive and represent a major commitment of funds and energy in the countries concerned. It is clearly necessary to set standards for monitoring and evaluating these programmes at the national level and for assuring that the investments are yielding the greatest possible benefit.

National M&E should involve monitoring progress in implementation, identifying problems, refining and adapting implementation strategies, assessing the effectiveness and impact of interventions, and testing strategies for optimizing the effectiveness, impact, cost-effectiveness and sustainability of the programmes.

National programme indicators should cover the goals and the four strategic areas of the comprehensive framework for action to prevent HIV infection in infants and young children, including referral linkages (i.e. prevention of HIV infection in young women; prevention of unintended pregnancies, especially in HIV-infected women; provision of antiretroviral drugs and counselling on infant feeding in order to prevent transmission from HIV-infected women to their neonates; and referral to care and support for women, their infants and their families). In addition, the indicators should measure cross-cutting themes essential for programme development and scaling up, such as policy development and the development of health system capacity.

2. For whom is this manual intended?

The present guide supplements *National AIDS programmes: A guide to monitoring and evaluation* and, like that manual, is intended for use by programme managers at the national level.

3. What does this manual cover?

This manual provides guidance on M&E of national programmes for the prevention of HIV infection in infants and young children. It complements existing M&E guides, including *Monitoring the Declaration of Commitment on HIV/AIDS: Guidelines on construction of core indicators* (UNAIDS, 2002), in which there are two indicators on programmes for the prevention of HIV infection in infants and young children (see Section 3, core indicators 5 and 6, and Table 2). It is principally aimed at national MTCT prevention programme managers and reproductive health and HIV/AIDS programme managers. Its purpose is to determine the level of success of programmes for the prevention of HIV infection in infants and young children, to identify areas where further support is required and to inform adaptation and scaling-up strategies.

The manual presents a list of core indicators and additional indicators. All countries with programmes for the prevention of HIV infection in infants and young children should aim to cover at least the core indicators. Countries with the need and resources to cover additional indicators are encouraged to do so. For each indicator the manual provides guidance on:

- its definition;
- a rationale for its use and what it measures;
- its measurement and the available measurement tools;
- its strengths and limitations.

In proposing indicators the document takes account of existing indicators, experiences and standards. Wherever possible, established indicators are recommended if adequate experience has been gained in their use. If this is not possible, new indicators and new tools for their use are proposed. This mainly applies to additional indicators.

As with *National AIDS programmes: A guide to monitoring and evaluation*, the indicators described in the present document are for use at the national level. However, the implications of national monitoring extend beyond that level. The obtainment of national indicators requires data collection at the local level and leads to information that is also useful at the international level. However, for monitoring and evaluation to be effective at the regional or local level, more detailed information is required than is necessary at the national level. Such detail is not covered in the present guide. Nevertheless, many of the indicators proposed here will be useful at the provincial and district levels, even though these levels are not the intended target.

4. Data quality

A balance has to be struck between the cost and the quality of data. National programmes should attempt to ensure that the data obtained are of sufficient quality to support appropriate management decisions but not too costly to collect. In each country this requires a judgement to be made on the necessary level of precision or quality and the costs that can be afforded. These factors may change over time as programmes develop, expand and become more routine.

5. Terminology

The term *mother-to-child transmission of HIV* (MTCT) is often used to refer to the transmission of HIV to infants. In this guide we use MTCT to refer to the biological process of vertical transmission.

The term *prevention of mother-to-child transmission* (PMTCT) is often taken to be synonymous with the provision of ARVs to HIV-infected women in order to prevent MTCT. Because this is only one component of the prevention strategy recommended in the present guide, we use the term *prevention of HIV infection in women, infants and young children* to refer to the broad range of recommended strategies described above.

Indicators

Definitions, including numerators and denominators where appropriate, are given below for all indicators, together with information on what the indicators measure, how to measure them and their strengths and limitations.

1. Core indicators

The following core indicators are recommended for M&E in all countries, irrespective of the type of epidemic. Some are newly developed whereas others have been used for several years and can also be found in other M&E guides.

Core indicator 1 (for all epidemic types). Existence of guidelines for the prevention of HIV infection in infants and young children	
Definition	<p>Existence of national guidelines (either approved or in draft form) for the prevention of HIV infection in infants and young children and the care of infants and young children in accordance with international or commonly agreed standards.</p> <p>Guidelines should be available for all four components of the comprehensive strategy for preventing HIV infection in infants and young children. These components are as follows (specific interventions are given in Box 2):</p> <ol style="list-style-type: none"> 1) intensified prevention efforts aimed at young women (this may or may not be specifically included in these guidelines and may be addressed elsewhere); 2) prevention of unintended pregnancies among HIV-infected women; 3) specific interventions to prevent HIV transmission from infected mothers to their children, including ARVs, safe delivery practices, and counselling and support for infant feeding; 4) referral or care for HIV-infected mothers and their children. <p>In some countries each of these issues may be addressed as part of comprehensive national HIV/AIDS guidelines. In others, individual guidelines may be available. Information on HIV and infant feeding may be incorporated into national guidelines on the feeding of infants and young children.</p>
Rationale	<p>National guidelines are commonly based on existing international standards or on standards about which there is general agreement but which have not yet been formally presented as international guidance. Without guidelines, services of unknown quality and impact could be implemented on an ad hoc basis, making it difficult to monitor and evaluate efforts.</p>
What is measured	<p>The indicator identifies whether guidelines exist that are in line with international or commonly agreed standards.</p>
What is covered by policies and guidelines for the prevention of HIV infection in infants and young children?	<p>The prevention of initial infection among HIV-negative women; the prevention of unintended pregnancies among HIV-positive women; ARV prophylaxis; safe delivery practices; counselling and support for infant feeding among HIV-infected pregnant and lactating women; and referral or provision of care and support for HIV-infected women and their children.</p> <p>Whatever components of prevention and care are ultimately adopted, countries should adapt their guidelines to their particular circumstances.</p>
Measurement tools and how to measure the indicator	<p>A survey among key informants at the national level or in health care facilities is used to determine whether there are guidelines for each intervention prong. The key informants in this situation at the national level are the persons responsible for HIV/AIDS, maternal and child health or infant feeding and nutrition. At the health facility level the key informants include practitioners and clinic directors.</p> <p>When enquiries are being made as to whether such guidelines exist the following additional questions may be asked if time and resources allow.</p> <ul style="list-style-type: none"> • How were the guidelines formulated? (Explore the process: ask by whom and on what basis they were formulated.) • Are the guidelines nationally accepted (even if only draft versions are available)? • To what extent are they implemented? (Explore the extent of implementation and the barriers and opportunities that were or are being encountered in implementation.) • How often and by whom are they updated? <p>The indicator should be measured and the above questions answered for each intervention as outlined in the indicator's definition.</p> <p>This indicator should be measured every year until guidelines are found to exist.</p>
Strengths and limitations	<p>This indicator is not concerned with the quality of guidelines or that of their implementation. Furthermore, because it does not capture new developments in the field, the guidelines have to be reassessed periodically in order to guarantee that they remain consistent with changing standards.</p>

Core indicator 2 (for all countries). Number and percentage of health care workers newly trained or retrained	
Definition	<p>The number and percentage of health care workers newly trained or retrained in the minimum package during the preceding 12 months.</p> <p>Retrained health care workers are those that have undergone in-service training, i.e. they are already in the work force and have been practising for several years. Training includes both in-service and preservice training.</p> <p>The minimum package varies between different types of health care facility. Several kinds of facility that may provide services for the prevention of HIV infection in infants and young children are outlined below, together with the services that should be available. Providers working in these settings should be trained in each of the components mentioned.</p> <p><i>Antenatal care (ANC) / maternal and child health (MCH) clinics:</i> counselling on risk reduction, counselling on infant feeding, and referral or provision of the following: HIV counselling and testing, ARV prophylaxis, FP (including counselling on dual protection), attended delivery in birth facilities where safe obstetric practices are observed, long-term care.</p> <p><i>Family planning clinics:</i> counselling on dual protection; referral to or provision of HIV counselling, testing and long-term care; and referral to ANC/MCH services if appropriate.</p> <p><i>Maternity hospitals:</i> observance of safe obstetric practices, and referral to or provision of HIV counselling and testing, ARV prophylaxis, counselling on infant feeding, MCH services, FP and long-term care.</p> <p><i>Primary health care (PHC) facilities:</i> referral to HIV counselling and testing, ANC/MCH and FP.</p>
Numerator	The number of health care workers newly trained or retrained in the minimum package during the preceding 12 months.
Denominator	The total number of health care workers working in facilities that have implemented the minimum package, with women who could benefit from it, for preventing HIV infection in women and infants.
Rationale	For the purpose of planning it is important to assess the resources available to address health needs. Before the implementation or expansion of services it is vital to know not only what facilities and equipment are available but also what training and human resources exist. Only with this information can health systems provide services that meet the needs of and are acceptable to the populations concerned.
What is measured	This indicator quantifies the human resources that are trained in preventing HIV infection in women and children and are available to provide the required services.
Measurement tools and how to measure the indicator	<p>The numerator can be calculated on the basis of a review of training records in each facility that has implemented services or serves women who could benefit from the minimum package for preventing HIV in infants and young children. If, however, such records do not exist, a survey of facilities can be carried out. A random sample of health care providers in these facilities should be asked about training they may have received in the prevention of HIV infections among infants and young children. (In some countries a national, provincial or district training coordinator keeps records of the training given to individual health workers. Such data can be used instead of a facility survey.) Interviewers should investigate the composition of the training, which varies with the type of site. The minimum package for each type of facility is outlined in the definition of the indicator.</p> <p>The denominator, i.e. the number of staff able to provide preventive services for HIV infection among infants and young children, is calculated on the basis of the number of health care providers working at sites where women could potentially receive the services included in the minimum package. These data can be obtained from ministry and health facility records.</p> <p>The numerator should be collected every year. The denominator, if based on facility surveys, is more expensive but is necessary for the calculation of the percentage and should be obtained every two years. After the initial collection of data it may be of interest to disaggregate data for those health care workers who have been newly trained or retrained during the preceding 12 months as well as to maintain a record of how many health workers have been trained since the first time the indicator was measured.</p>

Core indicator 2 (for all countries). Number and percentage of health care workers newly trained or retrained (continuation)	
<i>Strengths and limitations</i>	<p>This indicator tracks the number of health workers trained to provide services for the prevention of HIV infection in infants and young children over time. It attempts to document increasing capacity to deliver preventive interventions. However, no conclusions should be drawn regarding quality, because this is affected by the practices employed rather than by the existence of trained personnel. It should not be expected that all health workers in all countries will have been trained, nor even that a high percentage of those who could be trained will have been trained. The indicator should be interpreted in relation to the size and nature of the epidemic in particular countries.</p> <p>Difficulties may occur in determining the denominator, as some countries may have limited information on the pool of human resources available in various facilities. Frequent transfers of personnel between facilities, or high rates of attrition, may complicate the interpretation of the indicator. It should be noted that the assumption is made that only formal health workers are counted, i.e. those remunerated either financially or in kind. In many settings, however, informal health workers make a significant contribution.</p>

Core indicator 3 (for all epidemic types). Prevention and care service points	
Definition	The percentage of public, missionary and workplace venues (FP and PHC clinics, ANC/MCH, and maternity hospitals) offering the minimum package of services for the prevention of HIV infection in infants and young children in the preceding 12 months.
Numerator	The number of public, missionary and workplace venues (FP and PHC clinics, ANC/MCH, and maternity hospitals) offering the minimum package of services for the prevention of HIV infection in infants and young children in the preceding 12 months.
Denominator	All public, missionary and workplace venues (FP and PHC clinics, ANC/MCH, and maternity hospitals).
Rationale	In order to be effective the prevention of HIV in infants must be applied as broadly as possible at all relevant treatment sites. It is generally acknowledged that a large proportion of preventive services occurs in ANC settings. As services become integrated, however, it will become important to consider other outlets as well.
What is measured	The indicator measures the coverage of the services at each of the outlets where prevention or care opportunities arise. These opportunities comprise either referrals to other services or the provision of on-site services.
Measurement tools and how to measure the indicator	<p>The information required for this indicator can be obtained by various methods and depends on resource availability and the amount of detail sought. It focuses on the minimum package of services, which is defined, as with the previous indicator, by the type of clinical setting. An outline is given below of facilities that may provide services for the prevention of HIV infection in infants and young children, together with indications of the services that should be available.</p> <p><i>ANC/MCH clinics:</i> counselling on risk reduction, counselling on infant feeding, and referral or provision of HIV counselling and testing, ARV prophylaxis, FP (including counselling on dual protection), attended delivery in birth facilities where safe obstetric practices are observed, and long-term care.</p> <p><i>FP clinics:</i> counselling on dual protection; referral or provision of HIV counselling and testing, and long-term care; and referral to ANC/MCH services if appropriate.</p> <p><i>Maternity hospitals:</i> observance of safe obstetric practices, and referral or provision of HIV counselling and testing, ARV prophylaxis, counselling on infant feeding, MCH services, family planning and long-term care.</p> <p><i>PHC facilities:</i> referral to HIV counselling and testing, ANC/MCH and family planning.</p> <p>Two options for measuring this indicator are proposed below.</p> <p>Option 1</p> <p>A questionnaire should be sent to all public, missionary and workplace health facilities offering FP and PHC clinics, ANC/MCH and maternity services. It should be facility-specific, outlining the specific services on offer. A column should be included to show whether services are provided on site or if referrals are made.</p> <p>Scoring should not be of the “all or nothing” kind. The numerator should reflect those elements of the package that are present (or for which there are in-house referral mechanisms). The denominator is all public, missionary and workplace venues (FP and PHC clinics, ANC/MCH, and maternity hospitals).</p> <p>If the number of possible sites to be surveyed is too great for all to be covered a stratified random sample can be drawn, each stratum being a different type of service delivery, and the questionnaire can be sent to the selected sites.</p>

Core indicator 3 (for all epidemic types). Prevention and care service points	
Measurement tools and how to measure the indicator	<p><i>Option 2</i> Other instruments can be adapted and used as exemplified below.</p> <p>For overall coverage the following instruments can be adapted.</p> <ul style="list-style-type: none"> • WHO draft protocol for the evaluation of HIV/AIDS care and support • UNAIDS protocol for evaluation of care and support <p>These instruments involve the performance of surveys of health facilities.</p> <p>For HIV testing and counselling the following tools can be adapted.</p> <ul style="list-style-type: none"> • UNAIDS tool for evaluating HIV voluntary counselling and testing <p>Irrespective of the method adopted for measuring the indicator it is essential to note the type of service providing the information (e.g. ANC, FP centre). This makes it possible to determine the more common outlets for prevention and care among women and infants.</p> <p>The indicator should be measured every two to three years.</p>
Strengths and limitations	<p>The indicator provides critical information on the national availability of prevention and care efforts for women and infants. While it is useful to programme planners seeking to determine where services are needed or where facilities are providing the full spectrum of services for preventing HIV infection in women and infants, it cannot measure the quality of the services being provided in each facility. Moreover, not all countries should be expected to have all, or a high percentage of all possible, health care service points offering services to prevent HIV in infants and young children. Rather, this indicator needs to be interpreted in light of the size and nature of the epidemic a country is facing.</p>

Core indicator 4. Women completing the testing and counselling process	
Definition	The percentage of pregnant women making at least one ANC visit who have received an HIV test result and post-test counselling. ¹
Numerator	The number of pregnant women who have received an HIV test result and post-test counselling in the preceding 12 months.
Denominator	The estimated number of pregnant women giving birth in the preceding 12 months who have made at least one ANC visit.
Rationale	For PMTCT to be effective, it is necessary to know a woman's sero-status in order to tailor prevention and care to her needs. A successful PMTCT program will reach as many pregnant women as possible to ensure knowledge of sero-status.
What is measured	The indicator provides a broad measure of programme coverage in the country concerned. However, issues of poor access to services and poor uptake result in only a small percentage of women knowing their status. It is therefore important to refer to the programme-level indicator described in the footnote below.
Measurement tools and how to measure the indicator	<p>The indicator requires that programme records be reviewed in order to count how many women have completed the testing and counselling process, i.e. have received their test results and post-test counselling. The number of women who have made at least one ANC visit is estimated by multiplying the number of births in the preceding 12 months, as given in a census or the best available source, by the rate of ANC attendance (Demographic and Health Surveys-type sample survey).</p> <p>In some cases the numerator may be obtainable by examining national records. If this is not possible the required data are likely to be available at the district level, where they can be collected directly from facilities providing the services in question.</p> <p>In some cases the denominator may be obtainable by examining national ANC registries. This is the preferable denominator and should be used if possible. If this number is not available or reliable the estimate of the number of pregnant women described above can be substituted but this approach involves an increased possibility of misinterpretation.</p> <p>The indicator should be measured annually.</p>
Strengths and limitations	<p>As stated in <i>National AIDS programmes: A guide to monitoring and evaluation</i>, this indicator provides a broad measure of service provision and gives an idea of coverage in ANC settings where PMTCT interventions are available. It does not attempt to inform service providers about the points in the counselling and testing cycle at which women drop out.</p> <p>It is important that programme managers employ a series of lower-level indicators for determining losses to follow-up. Because the quality of services is not being measured, information on drop-outs and the points at which they occur is of limited use if not followed up with operations research aimed at discovering why women are failing to complete the cycle.</p>

¹ An additional important programme-level counselling and testing indicator must be considered when a PMTCT programme is being managed. The indicator measures the points in the provision of counselling and testing for pregnant women at which women drop out. This information can be used to investigate further why women drop out at specific points, and, ultimately, to reduce the percentage of drop-outs. Such information is therefore important for programme planning. The indicator includes the following three components.

- The number of pregnant women who have made at least one ANC visit and have been counselled at a PMTCT site, divided by the total number of pregnant women.
- The number of pregnant women who have accepted testing for HIV, divided by the total number of pregnant women who have made at least one ANC visit and have been counselled at a PMTCT site.
- The number of women receiving post-test counselling and HIV results, divided by the total number of pregnant women who have made at least one ANC visit and have been counselled at a PMTCT site.

Core indicator 5. Antiretroviral prophylaxis¹	
Definition	The percentage of HIV-positive pregnant women receiving a complete course of ARV prophylaxis to reduce MTCT in accordance with a nationally approved treatment protocol (or WHO/UNAIDS standards) in the preceding 12 months.
Numerator	The number of HIV-positive pregnant women receiving a complete course of ARV prophylaxis to reduce MTCT in accordance with a nationally approved treatment protocol (or WHO/UNAIDS standards) in the preceding 12 months.
Denominator	The estimated number of HIV-infected pregnant women giving birth in the preceding 12 months.
Rationale	This is an UNGASS national programme and behaviour indicator. It is important for measuring the outcome of providing ARV prophylaxis to pregnant HIV-positive women.
What is measured	The indicator assesses progress in the prevention of MTCT by ARV prophylaxis.
Measurement tools and how to measure the indicator	<p>The information is obtained by means of programme monitoring and estimates.</p> <p>Whether women who receive ARV prophylaxis from the private sector and NGO clinics should be included in the calculation of the indicator is left to the discretion of the country concerned. This decision should be based on a frank appraisal of how often ARV for pregnant HIV- infected women is provided outside the government sector, and should be noted and applied consistently in calculating both the numerator and the denominator. Private sector and NGO clinics that provide prescriptions for ARVs but assume that the drugs will be acquired elsewhere by the individuals in question are not included in this indicator, even though such clinics may be the major providers of services for the reduction of MTCT. The key feature is the actual provision of the drugs.</p> <p>The number of HIV-infected pregnant women who have been provided with ARV prophylaxis during the preceding 12 months in order to reduce the risk of MTCT is obtained from programme monitoring records. Only those women who have completed the full course should be included.</p> <p>The number of HIV-infected pregnant women to whom ARV prophylaxis for reducing the risk of MTCT could potentially have been given is estimated by multiplying the total number of women who gave birth in the preceding 12 months (central statistics office estimates of births) by the most recent national estimate of HIV prevalence in pregnant women (HIV sentinel surveillance antenatal clinic estimates).</p> <p>A tool for the measurement of this indicator is provided in <i>Monitoring the Declaration of Commitment on HIV/AIDS: Guidelines on construction of core indicators</i> (UNAIDS, 2002).</p> <p>This indicator should be measured every two to three years.</p>
Strengths and limitations	<p>This indicator has the following weaknesses.</p> <ol style="list-style-type: none"> (1) ANC data are often incomplete and may not reflect the true situation. (2) There may be selection bias because only those women are included who self-select to access services. (3) Every country has its own definition of a full course of ARV treatment. (4) The indicator does not assess treatment compliance, and, as currently defined, measures need. It does not assess what percentage of women accessing ANC services where PMTCT services are available actually avail themselves of the intervention. (5) As the number of women provided with HAART increases over time the need for specific ARV distribution to prevent vertical transmission may lessen. It will be necessary to develop specific indicators in order to capture information on this matter.

¹ From: *Monitoring the Declaration of Commitment on HIV/AIDS: Guidelines on construction of core indicators* (UNAIDS, 2002).

Core indicator 6. HIV-infected infants born to HIV-infected mothers¹	
Definition	The percentage of HIV-positive infants born to HIV-infected women.
Rationale	This UNGASS indicator measures the impact of providing ARV prophylaxis to pregnant women in order to prevent vertical transmission.
What is measured	The indicator measures the impact on MTCT reduction of the provision of ARVs to infected women.
Measurement tools and how to measure the indicator	<p>This indicator is measured by taking the weighted average of the probabilities of MTCT for pregnant women receiving and not receiving ART, the weights being the proportion of women receiving and not receiving ARVs respectively.</p> <p>The indicator is calculated using the following formula.</p> <p>Indicator score: $\{T*(1 - e) + (1 - T)*v\}$</p> <p>Where:</p> <p>T = proportion of HIV-infected pregnant women given ART (this is the proportion obtained in the UNGASS indicator on ARV prophylaxis, i.e. core indicator 5 of the present guide);</p> <p>v = MTCT rate in absence of treatment;</p> <p>e = efficacy of treatment provided.</p> <p>Default values of 0.25 and 0.50 respectively can be used for v and e. However, if scientific estimates of the efficacy of the specific forms of treatment (i.e. combination therapies) employed in the country are available they should be used, and this should be noted in the calculations.</p> <p>The complete tool for measuring this indicator can be found in <i>Monitoring the Declaration of Commitment on HIV/AIDS: Guidelines on construction of core indicators</i> (UNAIDS, 2002).</p> <p>The indicator should be calculated every two to three years.</p> <p>This indicator should be measured every two to three years.</p>
Strengths and limitations	<p>If an infant becomes positive the indicator cannot distinguish between different causes of infection, i.e. treatment failure or infection during breastfeeding. The indicator may therefore underestimate the rates of MTCT in countries where long periods of breastfeeding are common.</p> <p>Conversely, rates may be overestimated in countries where other MTCT prevention interventions are common, e.g. caesarean section.</p> <p>T, the proportion of HIV-infected pregnant women given treatment, may be a poor estimate in places where the usage of ANC clinic services is low.</p>

¹ From: *Monitoring the Declaration of Commitment on HIV/AIDS: Guidelines on construction of core indicators* (UNAIDS, 2002).

Table 2 summarizes the relationship between the indicators presented and the essential elements in the prevention of HIV in infants.

TABLE 2. MATRIX DEMONSTRATING LINKS BETWEEN CORE INDICATORS AND THE STRATEGIC FRAMEWORK FOR PREVENTING HIV INFECTION IN WOMEN AND INFANTS

	INPUT → (resources, supplies, staff, etc.)	PROCESS → (provider practices, numbers accessed, etc.)	OUTPUT → (services, IEC, knowledge, etc.)	OUTCOME → (care and treatment practices, discrimination, etc.)	IMPACT (incidence, survival, etc.)
Prong 1: Prevention of HIV infection in women	core indicator 1	core indicator 2	core indicator 3		
Prong 2: Prevention of unintended pregnancies in HIV-positive women	core indicator 1	core indicator 2	core indicator 3		
Prong 3: Specific interventions to prevent transmission to infants	core indicator 1	core indicator 2 core indicator 4	core indicator 3	core indicator 5	core indicator 6
Prong 4: Care and support	core indicator 1	core indicator 2			

2. Additional indicators

Additional indicators should only be used by countries experiencing specific epidemic types and only if there are adequate resources. The additional indicators outlined below can be used by countries in accordance with their needs and resources. Each indicator is presented with a recommendation concerning the most appropriate epidemic level at which it should be employed. Countries should use their own discretion in selecting the indicators best suited to their needs.

Additional indicator 1 (for concentrated and generalized epidemics) Women referred to FP services from ANC services offering the minimum package to prevent HIV in infants and young children	
Definition	The number of HIV-infected women referred to FP services for postpartum contraception from ANC services offering the minimum package to prevent HIV in infants and young children.
Numerator	The number of HIV-infected women, calculated on the basis of estimates of prevalence of HIV at each site, referred to FP services for postpartum contraception from ANC services offering the minimum package to prevent HIV in infants and young children.
Denominator	All women referred to FP for postpartum contraception from ANC services offering the minimum package to prevent HIV in infants and young children.
Rationale	The referral of HIV-infected women to postpartum contraception services reduces the probability of unintended pregnancy in the future and thus reduces the overall risk of MTCT. The referral of HIV-negative women to such services reduces the probability of them becoming infected in the future assuming that dual protection is advised and adopted), while helping to reduce the incidence of unintended pregnancies.
What is measured	The indicator measures the quantity of referral for postpartum contraceptive advice for HIV-positive and non-infected women. It is directly relevant to the second prong of the strategy for the prevention of HIV in infants and young children.
Measurement tools and how to measure the indicator	The indicator can be obtained by means of programme reports, monitoring tools and observation. Programme reports can provide an estimate of HIV prevalence at each site. Monitoring tools can determine the number of women referred. Observation can be used to determine the extent to which women receive information on the most effective forms of contraception. The monitoring of FP clinic records can determine methods selected by referred women.
Strengths and limitations	The indicator suggests the extent to which women are referred to postpartum counselling on FP but does not attempt to ascertain either the different contraception options that are selected or the regularity with which they are used. Consequently, it cannot reveal anything about the effectiveness of the advice given.

Additional indicator 2 (for concentrated and generalized epidemics) PMTCT services that refer to care and support facilities	
Definition	The percentage of venues offering the minimum package for preventing HIV in infants and young children (see core indicator 3 for definition) which have specific written guidance on how to make referrals to facilities offering long-term care and support.
Numerator	The number of venues offering the minimum package of services which have specific written guidance on making referrals for HIV-positive women to facilities offering long-term care and support for HIV-infected women.
Denominator	The total number of venues offering the minimum package of PMTCT services (numerator for core indicator 3).
Rationale	The indicator attempts to capture the full referral cycle.
What is measured	The indicator estimates the coverage of referral services from clinics offering PMTCT services to long-term care and support facilities for HIV-positive women.
Measurement tools and how to measure the indicator	The indicator can be measured during a health facility survey by asking if there is written guidance for referrals. If the answer is in the affirmative a copy of the guidelines should be requested or later review.
Strengths and limitations	The indicator only considers whether there is written guidance and therefore does not reveal whether referrals are actually made.

Additional indicator 3 (for concentrated and generalized epidemics) Women receiving counselling on infant feeding at first infant follow-up visit	
Definition	The percentage of HIV-infected women receiving counselling on infant feeding at their first infant follow-up visit.
Numerator	The number of HIV-infected women receiving counselling on infant feeding at their first infant follow-up visit.
Denominator	All HIV-infected women making their first infant follow-up visit.
Rationale	It is necessary to provide HIV-infected mothers with counselling on the feeding needs of their infants, the alternatives that are available and the different risks involved with each approach, in order that informed decisions can be made as to which approach is best in individual circumstances.
What is measured	The indicator measures coverage of counselling efforts in infant feeding.
Measurement tools and how to measure the indicator	Reviews of clinic records can be used to determine how many HIV-infected women have made their first infant follow-up visit during a specified period and how many of the records indicate that these women have been counselled on infant feeding.
Strengths and limitations	One of the limitations concerns data collection methods. There is a reliance on record-keeping by facilities. It is assumed that all encounters in which there is counselling on infant feeding are covered by visit records and that women's serostatuses are known. This indicator may seem to measure an intervention that takes place rather late in the process but it is considered preferable to asking about infant feeding <i>intentions</i> at the time of delivery.

Additional indicator 4 (for all epidemic types) Condom distribution in ANC clinics	
Definition	The number of condoms distributed and the average number of days out of stock in ANC clinics.
Rationale	<p>ANC clinics are a significant component of programmes for the prevention of HIV in mothers and infants. It is therefore important to monitor the distribution of condoms and their availability in these settings. This relates to what is sometimes an increased risk of HIV infection during pregnancy, when men are reported to be more likely to engage in sexual behaviour with other partners. The use of condoms during pregnancy and lactation is therefore an essential element in the prevention of HIV in mothers and their infants.</p>
What is measured	The indicator assesses the volume of distribution and any stockouts of condoms in ANC clinics.
Measurement tools and how to measure the indicator	<p>Information on the number of condoms distributed can be obtained from programme monitoring records, which usually include details of condom distribution per week, month or quarter. If this information is not available the number of condoms ordered per quarter or some other substitute can be used.</p> <p>In order to measure stock outs a random sample of ANC clinics is asked about the number of days during the preceding month on which no condoms were available for clients. The records are checked and the days are counted. The average number of days on which condoms were unavailable is then presented as the indicator.</p>
Strengths and limitations	The indicator gives a measure of how many condoms are distributed and the continuity of their availability but cannot provide information on their ultimate use.

3. Other indicators of potential value

HIV prevention in infants and young children cuts across a number of other programmes that may or may not be well integrated. The information yielded by the core and additional indicators described above can be enhanced if they are interpreted in the light of important indicators that may already be routinely collected for the monitoring and evaluation of these other programmes. Some of these standard indicators, drawn from other guides and sources, are outlined below. If the data for these indicators are readily available in countries, programme managers may find them of value in connection with the monitoring and evaluation of efforts to prevent HIV in infants and young children.

HIV prevalence in pregnant women aged 15-24 years

- Percentage of blood samples taken from women aged 15-24 years who test positive for HIV during routine sentinel surveillance at selected antenatal clinics.

Percentage of population aware of methods of preventing MTCT

- Percentage of women and men who correctly respond to prompted questions about preventing MTCT through ARVs and safer infant feeding practices.

Percentage of pregnant women counselled and tested for HIV

- Percentage of women who have received counselling during ANC for their most recent pregnancy, who accepted an offer of testing, and who received their test results, based on all women pregnant at any time in the two years preceding the survey in question.

Antenatal clinics offering testing and counseling or referral for testing and counseling

- Percentage of public antenatal clinics offering testing and counseling for HIV by trained staff or referral to testing and counseling services.

Existence of comprehensive HIV/AIDS care and support policies, strategies and guidelines

- Existence of national guidelines for long-term care and support for HIV-positive adults and children.

Quality HIV counselling

- Percentage of post-test counselling sessions for women attending for ANC in which counselling and voluntary HIV testing meet international standards for testing of satisfactory quality, including referral for care where necessary.

Family planning during post-test counselling

- Percentage of HIV-positive women receiving FP information during post-test counselling.

Antenatal care coverage

- Percentage of women who are attended at least once during pregnancy by skilled health personnel for reasons related to pregnancy.

Percentage of births attended by skilled health personnel

- Percentage of births attended by doctors and/or persons with midwifery skills who can manage normal deliveries and diagnose or refer obstetric complications.

Percentage of pregnant women attending antenatal clinics who are screened for syphilis**Availability of basic essential obstetric care**

- Number of facilities with functioning basic essential obstetric care per 500 000 population.

Family planning method mix

- Percentage distribution of contraceptive users or, alternatively, acceptors, for each contraceptive method.

Characteristics of users of family planning methods

- Sociodemographic profile of current users of contraceptive methods relevant to programme planning and/or marketing.

Partner testing

- Percentage of male partners of women attending preventive services that is tested and receives results.

Reported feeding choices at delivery

- Percentage of women in PMTCT programmes who report plans at delivery to either exclusively breastfeed or exclusively use replacement feeding.

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