UNAIDS/WHO Working Group
on Global HIV/AIDS and STI Surveillance

Paediatric HIV surveillance among infants and children less than 18 years of age

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WHO Library Cataloguing-in-Publication Data

Paediatric HIV surveillance among infants and children less than 18 years of age.

1.HIV infections – epidemiology. 2.Acquired immunodeficiency syndrome – epidemiology. 3.Disease outbreaks. 4.Epidemiologic methods. 5.Child. 6.Infant. 7.Guideline. I.World Health Organization. II.UNAIDS.

ISBN 978 92 4 150583 3 (NLM classification: WC 503.4)

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Printed in Switzerland.

Design & layout: L'IV Com Sàrl, Le Mont-sur-Lausanne, Switzerland.

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Acknowledgements

Global surveillance of human immunodeficiency virus (HIV) and sexually transmitted infections (STI) is a joint effort of the World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS). The UNAIDS/WHO Working Group on Global HIV/AIDS and STI Surveillance, initiated in November 1996, is the main coordination and implementation mechanism for UNAIDS and WHO to compile the best information available and improve the quality of data needed for informed decision-making and planning at the national, regional and global levels.

WHO and UNAIDS would like to thank the individuals who contributed to this document, including Gina D. Etheredge, Justin Mandala Kol and Carolyn Smith for preparing this document.

WHO and UNAIDS would like to thank; Evelyn Kim, Christopher Murrill from the United States Centers for Disease Control and Prevention (CDC); Thomas Rehle (HSRC, South Africa), Jesus M. Garcia Calleja, Chika Hayashi, Nathan Shaffer, WHO; Mary Mahy, Karen Stanecki, Peter Ghys UNAIDS headquarters; members of the UNAIDS/WHO Working Group on HIV and STI Surveillance and members of the US Government's Surveillance and Surveys Technical Working Group.

Significant contributions were also received from Rand Stoneburner, UNAIDS headquarters; Renu Garg, Monica Alonso and Abdil Karem Alisalad, WHO Regional Offices.

The concepts and material presented in this publication were informed by many workshops and second-generation surveillance projects conducted worldwide over a period of ten years, from 2000 to 2010. WHO and UNAIDS would like to acknowledge the contributions of the participants of these meetings, including staff of national AIDS programmes and experts in various fields related to HIV epidemiology.

Contents

Acronyms and abbreviations

AEM	Asian Epidemic Model
AIDS	acquired immunodeficiency syndrome
ART	antiretroviral treatment
CDC	Centers for Disease Control and Prevention (USA)
CI	confidence interval
DBS	dried blood spot
DHS	demographic and health survey
DSS	demographic surveillance system
EID	early infant diagnosis (of HIV)
EQAP	external quality assurance programme
HIV	human immunodeficiency virus
M&E	monitoring and evaluation
MCH	maternal and child health
MOH	Ministry of Health
MTCT	mother-to-child transmission
PCR	polymerase chain reaction
PITC	provider-initiated testing and counselling (for HIV)
PMTCT	prevention of mother-to-child transmission (of HIV)
SAVVY	sample vital registration with verbal autopsy
STI	sexually transmitted infection
TB	tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
VA	verbal autopsy
WHO	World Health Organization

1. Introduction

Understanding the magnitude of the HIV epidemic is essential for planning, implementing and monitoring any program that attempts to mitigate the impact of HIV/AIDS. This is true for the paediatric HIV epidemic, for which prevention, care, and treatment efforts lag behind those implemented for adults.

Typically, the paediatric population is considered to be between 0 and 14 years of age. In this guide, we have included older children up to 18 years of age. In most countries, young people less than 18 years are considered minors. Often, modes of infection are different in adolescents than in younger children or infants.

This guideline provides approaches to measure the burden of paediatric HIV according to country-specific HIV epidemic contexts. It does not attempt to be comprehensive enough to cover all the issues related to paediatric HIV surveillance. Rather, it serves as a general reference. As "how-to" guides for surveillance data analysis and data use/dissemination are already available, such components will not be addressed in this guide. The guide cites additional materials and resources for further information on paediatric HIV surveillance and includes country examples.

1.1. Goal of this guideline and primary audience

The overall goal of this guideline is to help countries understand the HIV epidemic in paediatric populations less than 18 years of age. Paediatric HIV surveillance can be conducted routinely, either as:
- specific, paediatric-focused activities, or
- essential components of broader surveillance efforts.

The primary target audience of this guide includes the following:
- Surveillance specialists in resource-limited settings
- Programme implementers at national and subnational levels
- Providers of services in health facilities
- Donor agencies that support paediatric HIV prevention, care and treatment
- Global surveillance advisors.

For countries and partners that already have some form of paediatric HIV surveillance, the guide is intended to empower managers and decision-makers to consider additional options for strengthening surveillance systems to:
- Refine paediatric HIV surveillance strategies and activities.
- Strengthen data collection and the indicators used.

For countries without prior experience of paediatric HIV surveillance, the intent is to introduce management and staff to the basic principles of paediatric HIV surveillance so that they can:
- develop and implement essential surveillance systems
- measure key programme outcomes considering the options described.

1.2. Use of the guide

Users of this guide are encouraged to know the context of their HIV epidemic, the main modes of HIV transmission and which populations are most affected. Refer to the recent updated *Guidelines for second generation surveillance: know your epidemic* for guidance on the overall surveillance process and details.*(3)*

Countries have gained experience in when and how data collection activities for surveillance and monitoring and evaluation (M&E) can be designed so that they are complementary.*(4)* These data collection activities have some overlaps.

- The main objective of surveillance is to track how the epidemic in a country is changing.
- The main objective of M&E is to track how effectively programmes are responding to the epidemic, and whether the outcomes and outputs correspond to the activities planned.

This guide does not replace M&E guidance on prevention of mother-to-child transmission (PMTCT). It does not replace guidance on assessing the impact of PMTCT or paediatric HIV care and treatment programmes. Rather, it complements previous guidelines for these two activities "Countries should design data collection activities for surveillance and monitoring and evaluation (M&E) to be complementary".

- PMTCT and paediatric HIV care and treatment monitoring data can be transmitted to inform and complement surveillance data.
- Surveillance data can contribute to impact assessments of PMTCT and paediatric HIV care and treatment programmes.

In addition, this guide complements other guidelines on monitoring and evaluating programmes for young people.

1.3. Background

1.3.1. Sparse surveillance data on infants and children

In many countries, surveillance data on infants and children are sparse. The data that do exist are generally limited to *in utero* exposure and intrapartum infection, with some survival data for children infected with HIV through mother-to-child transmission (MTCT).*(5)*

Current understanding of paediatric epidemics is not informed by a direct measure of paediatric surveillance data. Rather, most countries rely on modelled estimates that are limited by both lack of data and general assumptions that may not be appropriate for all contexts.

Lack of data hampers prioritization and scale up of HIV prevention and care for infants and children, resulting in a gap that requires urgent attention. Reducing paediatric infections and improving the effectiveness of PMTCT interventions are critical to achieving Millennium Development Goal 4.*(6)*

Box 1. Recent HIV epidemic figures

- Worldwide, at the end of 2011, 54% of adults in need of treatment had accessed HIV treatment services. Only 28% of children (0–14 years of age) in need of treatment in low- and middle-income countries received it. *(7)*
- Worldwide, nearly half of new HIV infections each year occur in youth aged 15–24 years. This age group constitutes only 18% of the global population.*(8,9,10)*
- In 2011, an estimated 3.4 million children were living with HIV worldwide. There were 330 000 (280 000–380 000) new HIV infections in children and 230 000 (200 000–270 000) HIV-related deaths among children.*(11)*
- More than 90% of children living with HIV have been infected through MTCT.*(8)*

Most of the figures cited in Box 1 were generated using modelling approaches. The most common software package for deriving these figures is Spectrum. Spectrum relies on:

- estimated HIV prevalence in women aged 15–49 years
- fertility rates
- child mortality rates
- coverage with antiretroviral treatment (ART)
- MTCT probabilities and
- assumptions of the rate of survival of HIV-infected children and women.

These assumptions are used to obtain the number of children living with HIV. Key changes in the transmission rates from mother to children, the survival of children living with HIV and other demographic factors in Spectrum lead to changes in the estimates related to HIV in children and coverage rates.

1.3.2. International efforts to date

Since 2002, PMTCT and HIV care and ART programmes have expanded rapidly. Supported by multilateral and bilateral organizations, countries have embarked on a global strategy to eliminate MTCT by 2015,*(12)* by reducing the number of new paediatric infections by 90% between 2009 and 2015.

At a UN High-level Meeting on AIDS which took place in New York in 2011, the General Assembly adopted the *Political Declaration on HIV/AIDS.(13)* Under this Declaration, adequate HIV data on infants and children are required to monitor progress and to accurately guide resource distribution, planning and implementation efforts to address the HIV prevention, care and treatment needs of infants and children.

During the 2009 global HIV surveillance meeting in Bangkok, Thailand, a lack of standardized paediatric HIV surveillance methods was noted.*(14)* This gap severely limits knowledge of paediatric HIV and hampers the efforts to measure the impact of PMTCT and paediatric HIV care and treatment programmes.

This document is designed to be a basic guide for considering various options for paediatric HIV surveillance which could better inform or replace statistical models. Data from paediatric surveillance systems could be used to measure new infections, monitor HIV infection trends among children, and contribute to measuring the impact of PMTCT and care and treatment programmes.*(15)*

1.4. Consider how you will use paediatric surveillance data

During the planning stage of paediatric surveillance activities, consider how you will use the data.
The tabulation plan should indicate what and how data will be shared: as technical reports, presentations or press releases. *See* Section 5 for details on reporting.

Paediatric surveillance data could be used to address the following issues:

- *The need to define the burden of HIV disease in children.* As discussed above, current understanding of paediatric epidemics is not informed by a direct measure of paediatric surveillance data. Rather, most countries rely on modelled estimates that are limited by lack of data and general assumptions that may not be appropriate for all contexts. Targeted paediatric surveillance data are needed to better understand the scope and characteristics of HIV infection in the paediatric population.

- *The need to assess paediatric HIV infection due to causes other than MTCT.* Transmission of HIV to children after breastfeeding ceases and before sexual activity begins may occur through a variety of exposures, including unsafe therapeutic injections, injection of illicit drugs, blood transfusion and sexual assault. Horizontal transmission in children is thought to occur infrequently, but few attempts have been made to measure such transmission in developing countries, which are the most affected by HIV in children.

- *The need to assess the risk of and infection due to HIV in early- to mid-adolescence.* Demographic and Health Surveys (DHS) and surveys of higher-risk groups often only include participants who are 15 years and older, or 18 years and older. Methods to capture and/or include children younger than 18 years of age in routine surveillance activities need to be considered in surveillance plans. These issues may be more important for some high-risk populations, such as sex workers, men who have sex with men or injection persons who injectt drugs.

- *The need for surveillance data to inform programme management and policies at the local and national levels.* Data are lacking for evidence-based decision-making on programmes and policies targeting paediatric populations. Paediatric surveillance data will help programme managers to monitor their programmes and focus efforts on prevention, care and treatment needs in this population.

- *The need to assess the impact of PMTCT programmes.* HIV-free survival and reduced morbidity and mortality among HIV-positive children are important goals of the global efforts to eliminate new paediatric infections. Measuring the impact of PMTCT programmes requires surveillance of children 0–2 years of age, or until breastfeeding is completed.

The World Health Organization (WHO) is producing a short guide that summarizes different approaches to assessing specific PMTCT outcomes. In addition to providing an overview of methods to measure the impact of PMTCT programmes, the guide can also be used for planning impact assessment activities and estimating the cost of a particular method. The guide is accompanied by generic protocols that provide more information about each method and the practical steps necessary for implementation. When completed, the guide and generic protocols will be posted on the WHO web site (http://www.who.int/hiv/pub/me/en/index.html).

2. Ethical considerations

Of the three fundamental principles of research ethics outlined in the USA Belmont Report,*(1)* autonomy (the ability to make one's own decisions), beneficence (the charge to do good) and justice (equally distributing risks and benefits), autonomy poses the most concern for paediatric populations.

Autonomy addresses the ability of competent individuals to make decisions, and the protection of vulnerable populations who may not have the psychological or legal capacity to choose. Whatever may be the surveillance method proposed, informed consent and confidentiality are central. Informed consent, the heart of autonomy, is ceded to parents or guardians when paediatric populations are involved, as described in the Helsinki Declaration.*(2)* The benefits of surveillance activities must be evident for the paediatric population, such as being referred to care and treatment. In most surveillance activities, including paediatric HIV surveillance, the benefits outweigh the risks.

Children above the age of 15 years are generally thought to be able to understand concepts well enough to make autonomous informed decisions about participating in research. Youth living on the street are considered autonomous or emancipated because they often live on their own and are not under the effective guardianship of an adult. The participation of these emancipated children above the age of 15 years in surveillance activities provides important insights into sexual-, drug- and alcohol-related risk behaviours for acquiring HIV. When children are involved, referrals for psychological or social support or intervention services should be available to those who wish to modify their behaviours and access these services. Just as confidentiality and anonymity are important for all children, they continue to be paramount for those older than 15 years. Despite the fact that they may be emancipated, children have limited knowledge about how to rectify ethical violations and do not have a guardian to do so for them. It is also recommended that, as much as possible, children should have the opportunity to express their views about the information that is collected about them. Care should be taken to address the issues they voice.

Paediatric surveillance activities are designed to benefit those directly involved as well as the population as a whole. Nonetheless, individuals may be harmed. Examples of harm include stigma and discrimination against children identified as HIV-positive and lax data confidentiality on the part of service providers, because paediatric patients and their caregivers may not be aware of their rights. Extreme caution must be exercised when dealing with especially vulnerable children, including orphans and those who are physically or mentally challenged. In addition, surveillance activities may identify children who may have been subject to abuse or neglect. Clear guidance is needed on how best to protect these children from further abuse.

- National and international ethical guidelines must be met.
- Provisions for the supervision of data collection must be ensured so that the best interests of the children are met.
- Institutional and ethical review boards should be extremely vigilant in guaranteeing the protection of paediatric populations, who represent a highly vulnerable target group.

3. Paediatric HIV surveillance methods

3.1. Develop a strategy based on national objectives, needs and your epidemic

HIV surveillance efforts in infants and children younger than 18 years of age should at a minimum consider three areas:
- HIV prevalence
- risk factors
- the impact of prevention, care and treatment.

The process of developing a country paediatric surveillance strategy takes into account:
- the specific objectives of the surveillance activity or data needs
- the type of HIV epidemic (generalized, concentrated or low level) defined in Box 2.

Then consider the available methods. The methods presented are not in order of priority or importance, but rather constitute a menu that should be considered in different contexts. Select the method that fits your country situation.

3.1.1. Consider your objectives and data needs

Before deciding on the surveillance approach, consider what the data will be used for, what the appropriate indicators will be, what changes need to be measured and what decisions will be made based on the data. For instance:
- If annual changes in the number of child infections are needed to measure programme effectiveness, a measure that is repeated on an annual basis will be necessary.
- If a national trend is required then a nationally representative sample is needed.
- If the number of infections is not critical but the increase or decrease in trend is needed, then a proxy surveillance population can be used.

3.1.2. Consider your country's epidemic context

Box 2. HIV epidemic context

Generalized epidemic
- HIV is established in the general population.
- A large proportion of transmission occurs outside the context of commercial sex, injecting drug use or multiple partner male-to-male sex.
- Sex with multiple partners among the general population is at high enough levels to sustain epidemic growth.
- Populations with specific behaviours that increase their risk for HIV infection may contribute more to new HIV infections, even if the number of people with those behaviours is low.

Concentrated epidemic
- HIV transmission has taken root in one or more populations whose behaviour puts them at high risk, such as sex workers, clients of sex workers, men who have sex with men and persons who inject drugs.
- HIV is rarely transmitted to people outside of the most-at-risk populations or their regular sex partners.
- Unless behaviour changes or levels of other risk factors such as the prevalence of sexually transmitted infection (STI) reduces, HIV transmission will continue among the high-risk subpopulations. Transmission will occur most rapidly among persons who inject drugs or engage in unprotected anal sex.

- The size of populations most at risk for HIV and the degree of risk behaviours will determine the number of new infections. Most new infections among the general population can be linked to contact with a sex worker, men who have sex with men and persons who inject drugs.

Low-level epidemic

- HIV has not spread to significant levels in any subpopulation, including populations most at risk for HIV, such as sex workers, clients of sex workers, men who have sex with men and persons who inject drugs.
- The spread of HIV is slow and inefficient because there are infrequent and few repeated transmission contacts among high-risk group members. HIV may have only recently been introduced or may not have entered a high-risk group network.

3.2. Consider which method fits your national situation and goals

Table 3.1 summarizes the possible methods and surveillance measures, epidemic contexts, and strengths and limitations associated with each method. The methods proposed in this table are neither exhaustive nor are they in any priority order. They are options that local, subnational and national programmes should consider when planning paediatric HIV surveillance activities.

Table 3.1. Review of paediatric HIV surveillance methods

Methods	Surveillance measures	Epidemic context	Strengths	Limitations
Section 3.2.1. HIV case reporting	• Number of HIV-infected children • HIV prevalence • Newly diagnosed cases • HIV prevalence trends • Demographic and clinical characteristics of HIV-infected children • Mode of transmission among HIV-infected children • HIV-attributable mortality	Generalized, concentrated and low-level	• Individual-level data on paediatric HIV cases • Can use routinely collected programme data • Can identify HIV-exposed and HIV-infected children • Can provide nationally representative data • Captures children of all ages	• Logistical challenge to achieve complete reporting • Resources needed to maintain routine system • Duplicate reporting • Programme data may be of varying quality and coverage • Diagnostic capacity needed at various levels of the health system
Section 3.2.2. Household surveys	• HIV prevalence • Sociodemographic and behavioural risk factors associated with HIV infection • HIV prevalence trends	Some generalized: only in countries with HIV prevalence above 5% and large sample sizes	• Sociodemographic and behavioural data from questionnaires • Nationally representative data • Can identify HIV-exposed and HIV-infected children	• Not for concentrated or low-level epidemics • Large sample size requirements • Expensive • Social desirability bias in questions on behaviour • Selection bias
Section 3.2.3. Immunization clinic surveys	• Prevalence of exposure to HIV • HIV prevalence • HIV prevalence trends • PMTCT service coverage and access • Early MTCT rate • Infant mortality rate • HIV-free survival at 6 weeks	Generalized only	• Access to infants who are immunized • Access to caregivers for additional information • Population-based estimates possible with high coverage • Can assess early PMTCT impact (infections occurring perinatally and during delivery)	• Not for concentrated or low-level epidemics • Representativeness of results depends on access to and coverage of immunization • Unable to capture children older than 2 years • Requires follow up to get accurate information to assess the MTCT rate

Section 3.2.4. Mortality data: vital registration	• Infant mortality • Under-five mortality • Proportion of HIV-related deaths • Sociodemographic factors associated with death	• Generalized, concentrated, or low-level: vital registration, facility/programme data • Generalized only: survey-based mortality data	• Vital registration data are routinely collected • Survey-based methods provide representative estimates	• Vital registration systems are often incomplete and not representative of the country • Cause of death is often misdiagnosed in vital registration or in verbal autopsy data from surveys
Section 3.2.5. In-school youth surveys	• Sociodemographic and behavioural factors associated with HIV infection and risk • Access to services • HIV prevalence, if testing included	HIV testing: generalized Behavioural questionnaire: generalized, concentrated or low-level	• Opportunity to reach adolescent populations • Capture behavioural information on adolescents • Sampling frames available	• Parental consent and child assent needed • School schedule limitations • Inclusion of HIV testing and sensitive questions
Section 3.2.6. Out-of-school youth surveys	• HIV prevalence • Sociodemographic and behavioural factors associated with HIV infection and risk • Access to services	Generalized or concentrated	• Target youth who may be most at risk for HIV • Parental consent may be waived	• Hidden and hard-to-reach population • Youth may have limited incentive to participate • Confidentiality and privacy issues

The following sections provide an overview of the general aspects that should be considered when implementing a specific paediatric surveillance approach. See the recent updated guide on *Second generation HIV surveillance: know your epidemic* for detailed implementation strategies.(*3)* Additional resources are listed in the reference section.

3.2.1. HIV case reporting

The ideal surveillance approach would be a case-reporting system in which all paediatric HIV cases are reported to surveillance programmes.*(16)* However, children are not routinely tested for HIV and observed for its symptoms. Symptoms may not be present for a number of months or years after infection. For these reasons, HIV case reporting has limitations.

With paediatric HIV case reporting, paediatric HIV cases meeting a standard national case definition are reported and counted as reportable events. Each HIV-infected infant or child is reported using a single case report form containing information that pertains only to that person. Information flows from each facility where cases are captured to a central level. The information channelled is robust enough to measure indicators on HIV exposure, HIV prevalence, risk factors and access to prevention, care and treatment services.

HIV case reporting of paediatric cases will provide counts of diagnosed HIV-infected individuals. For systems with good reporting, both HIV prevalence and estimated incidence can be calculated, if all the information required is available.*(17)*

Methods

Case-reporting systems require routine data reporting at all levels of clinical facilities and data collection at central levels. Personnel at the facility and central levels must be trained and dedicated to case-reporting tasks, including completion of standardized forms or registries and following standard reporting procedures. The type of case-reporting system established will be determined by whether data are collected using active or passive surveillance methods.

- In active surveillance systems, surveillance officers visit facilities or programmes to collect data on all cases diagnosed with HIV infection on a regular basis, which are then aggregated at the central level.
- In passive surveillance systems, facility or programme staff forward case report forms on cases with HIV infection to surveillance units at the district/state/province/national level on a regular basis.

Because of practical reasons, at the central level, the Ministry of Health (MOH) may choose to collect data from a limited number of sentinel sites that are representative of various geographical areas and settings (rural/urban) in the country rather than from every site. Integration with other systems will improve the sustainability of this approach.

Data sources
Sources of paediatric HIV case reporting may vary according to each country's context. In most countries, individual-level data may already exist at the facility level in line-listed registers and medical records. Each country should determine the most appropriate data sources for capturing paediatric cases, with careful consideration of the strengths and limitations of each source. Examples of data sources include the following:

- PMTCT/maternal and child health (MCH) programme registers
- Early infant diagnosis (EID) and other laboratory requisition forms, database
- Hospital and health centre records, medical record systems
- Pre-ART registers
- ART registers
- Vital registration of HIV-related deaths.

Box 3. Use of EID programme data for paediatric HIV case surveillance

Early infant diagnosis (EID) programmes may be a useful data source for a paediatric HIV case-reporting system. Since most EID programmes use relatively few central laboratories to conduct polymerase chain reaction (PCR) testing to diagnose infants, data are naturally centralized. EID programme data provide counts of the number of infants infected with HIV, which may be used to estimate both HIV prevalence and incidence in infants. Depending on which data are collected and reported, and the ability to link to care and treatment services, data from these programmes could be used to estimate early MTCT rates (at 6 weeks of age). As these data are routinely collected and available at the facility level, EID-based data collection is potentially sustainable. EID data must be supplemented with data on HIV infections that occur in infants and children while breastfeeding to estimate the MTCT rate.

Strengths and limitations
The strengths of case-reporting systems lie in the quality and completeness of the individual-level data that are captured on each HIV-infected child. These data, when collected nationally, may provide information on the following:

- Demographic and clinical information on children diagnosed with HIV:
  - Prophylaxis (maternal and child)
  - Breastfeeding status
  - Age at diagnosis
  - Date of ART initiation, and
  - ART regimen
- HIV prevalence and trends over time, and
- Geographical differences in the epidemic, locally and nationally.
- Where routinely collected EID and/or MTCT data are reported:
  - Rates of new infection due to perinatal MTCT
  - Partial PMTCT programme impact,and
  - Prevalence of HIV-exposed but -uninfected infants.

Much of this information may already be available as routinely collected programmatic data at the facility level. In addition, the data produced by case-reporting systems may provide information that informs and monitors the effectiveness of prevention programmes, and determines the need for additional care and treatment at the heath service level. Case reporting may also measure HIV-attributable deaths. Paediatric HIV case-reporting data may include information that helps to examine the impact of PMTCT programmes, the need for care and treatment, effectiveness of prophylaxis for opportunistic infections and tuberculosis (TB), and ART outcomes in children. Finally, some case-reporting systems may identify both HIV-exposed and HIV-infected children who may be incorporated into registries for follow up to monitor programme effectiveness, timeliness of referral to care and treatment, and ART outcomes.

The establishment of an HIV case-reporting system is subject to a number of challenges. Active case surveillance is resource intensive and logistically challenging. Paediatric HIV case reporting may be sustainable if incorporated into routine systems or routine reporting of programme data; however, the resources necessary to maintain routine systems may be difficult to sustain. Case-reporting systems must also consider the effect of duplicate reporting, especially in programmes that implement repeat testing; however, the use of an effective unique identifier can minimize double counting. Finally, if case-reporting systems use programme or facility data to identify cases, the completeness and quality of reporting will depend on the coverage and quality of the programmatic or facility-based data, and these may vary significantly across programme sites and facilities.*(7,18,19)* For example, if EID data are used, the representativeness of reporting depends on EID coverage. Additionally, EID testing is recommended for HIV-exposed infants up to 18 months of age; therefore, information will not be available for children above 18 months of age.

Implementation considerations

In most cases where adult HIV case-reporting systems exist or are being developed, paediatric cases are included as reportable events. In these cases, the overall quality of paediatric case reporting within the larger system should be evaluated. Where HIV case-reporting systems have not been established, countries may consider the use of available paediatric-specific programme data to pilot a case-reporting system only for the paediatric population, which may expand in scope to include adults over time.

- As for all surveillance systems, confidentiality at all levels where individual patient information is processed (recorded, entered, collected and analysed) must be ensured.
- As for all surveillance that involves testing for HIV, adequate links to care and treatment for infected infants and their mothers must be assured.

In developing a case surveillance system, ensure that:

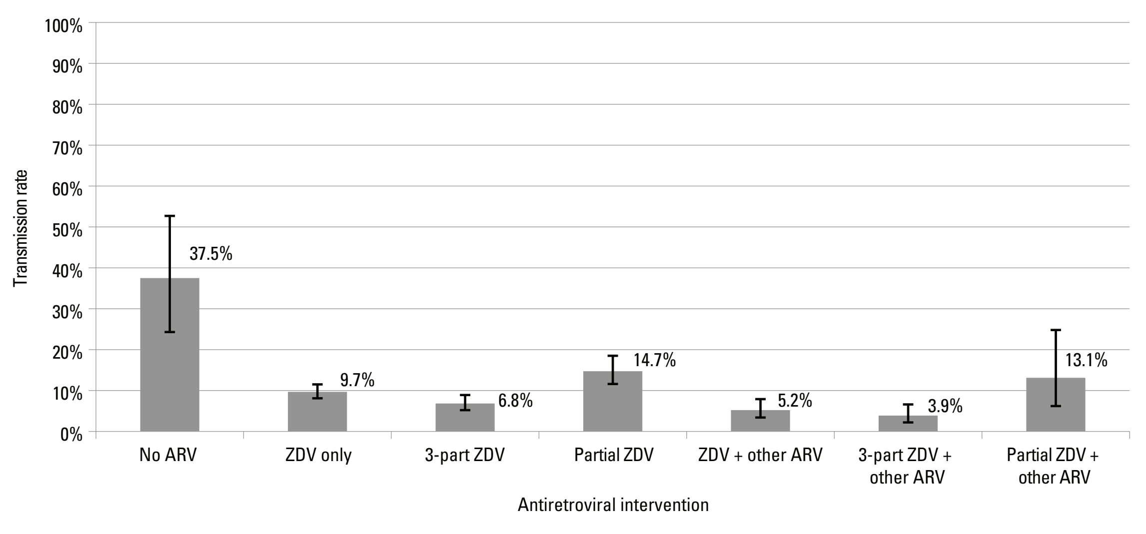
- Appropriate guidelines and policies are in place to report HIV infection in infants and children less than 18 years of age in the country, province or district considered.
- Access to health facilities is good.
- There is extensive coverage of HIV testing or opportunities to find cases, such as provider-initiated testing and counselling (PITC) of HIV-exposed and HIV-infected infants and children.
- Diagnostic services are of high quality and reliable.
- The reporting system respects the confidentiality and individual rights of persons in the system.

Box 4. Paediatric HIV case registry in Thailand*(20)*

In 2001, the Thai Ministry of Public Health established a case registry at 84 public hospitals in six provinces in Thailand for children born to HIV-infected mothers. The children were born with or diagnosed with HIV. The registry collected information on maternal antenatal care, mode of delivery, breastfeeding, and ART prophylaxis during pregnancy, labour and the newborn period. Additional follow-up information was obtained when the HIV infection status of the infant was known or the infant died or was determined to be lost to follow up. From 2001 to 2003, 2200 children born to HIV-infected mothers were registered. HIV infection status was determined for 75.8% of the registered children. Of these, 9.5% were found to be HIV-infected. Registry data were also used to determine transmission risk among mother–infant pairs by ART prophylaxis regimen. Among 761 mother–infant pairs that received a complete zidovudine regimen alone, the transmission risk was 6.8%. Among 361 mother–infant pairs that received a complete zidovudine regimen combined with other antiretrovirals (usually nevirapine), the transmission risk was 3.9%. Overall, the transmission risk in this cohort was estimated to be 10.2%.

Pediatric HIV case registry in Thailand Plipat T, et al. Reduction in mother-to-child transmission of HIV in Thailand, 2001-2003: Results from population-based surveillance in six provinces. AIDS, 2007, 21:145-151

HIV transmission rate by antiretroviral intervention among children born to HIV-infected mothers in Thailand, 2001–2003

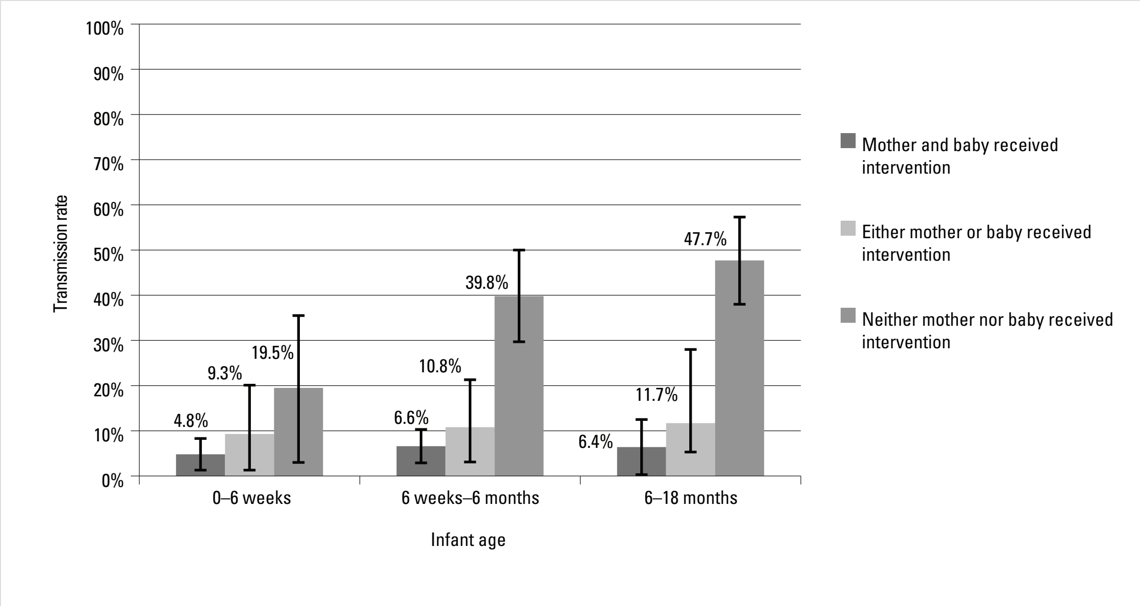


Box 5. Early infant diagnosis of HIV infection in southeastern Nigeria*(21)*

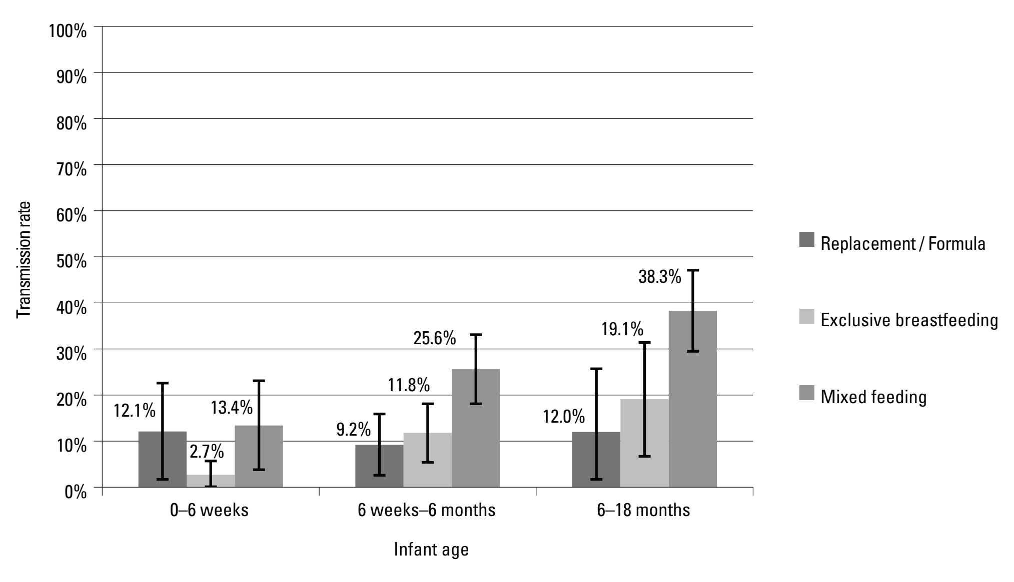
Data from the EID programme in Nigeria were used to determine the prevalence of HIV among HIV-exposed babies. Records of 702 perinatally exposed babies aged six weeks to 18 months who had had a DNA PCR test between November 2007 and July 2009 were retrospectively reviewed. Additional data on PMTCT regimen, breastfeeding and post-test ART enrolment status were collected. Two thirds of mother–baby pairs received ARVs. Transmission rates for mother–baby pairs who received ARVs for PMTCT was 4.8% (confidence interval [CI] 1.3, 8.3) at zero to six weeks of age compared to 19.5% (CI 3.0, 35.5) among pairs with no intervention. Regardless of intervention, the transmission rates for babies aged six weeks to six months who had mixed feeding was 25.6 % (CI 29.5, 47.1), whereas the transmission rates for those who were exclusively breastfed was 11.8% (CI 5.4, 18.1). A follow up of 125 HIV-positive babies found that 31 (25%) were enrolled in a paediatric ART programme, and nine (7%) were known to have died before the return of their DNA PCR results. 85 (67%) could not be traced and were presumed to be lost to follow up. These data demonstrated the reduction in MTCT of HIV with effective PMTCT intervention. In addition, the data were used to identify cases of paediatric HIV infection for follow up into care and treatment.

Early infant diagnosis of HIV infection in southereastern Nigeria Anoje C et al. Reducing mother-to-child transmission of HIV: findings from an early infant diagnosis program in south–south region of Nigeria. BMC Public Health, 2012, 12:184

HIV transmission rate by receipt of pharmacological intervention among HIV-exposed infants aged 0–18 months in Nigeria, 2007–2009



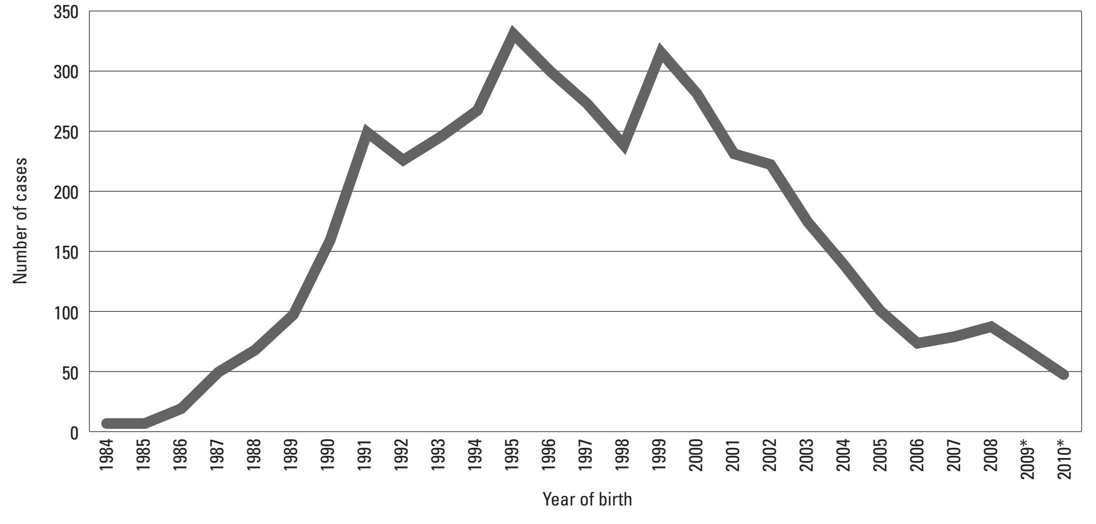
HIV transmission rate by feeding status among HIV-exposed infants aged 0–18 months in Nigeria, 2007–2009



Box 6. Effectiveness of a PMTCT programme in Argentina (http://www.msal.gov.ar/sida/pdf/boletines-inves-publi/boletin-epidemiologico-2011.pdf)

After the introduction of a PMTCTprogramme, the number of HIV cases registered in Argentina has declined to less than 50 per year.

Distribution of perinatal HIV transmission, 1984–2010



* delay in notifications

3.2.2. Household surveys

Household surveys are population-based surveys of households and individuals. These are designed to provide national or regional estimates of the outcomes of interest. Most household surveys include multiple data collection components, including household-level and individual-level data and biomarkers for eligible household members. Collection of HIV-related data typically targets adult household members; however, in recent years, some high-prevalence countries have started collecting questionnaire data and biological samples from children of different age ranges. In addition, household surveys that ask questions of men and women aged 15–24 years provide information on the behaviour of older adolescents.

Methods

Using a multistage stratified cluster design, a random sample of households is selected within a sampling frame and weighted to be representative of the entire population. Most household surveys include multiple components:

- A household questionnaire that collects data on characteristics of the household
- Individual behavioural questionnaires for eligible household members, usually men and women 15–49 years of age

In addition the surveys collect biological samples for testing for HIV and other biomarkers.

The approaches taken to include children in household surveys will vary, as each country's context should be taken into account when determining specific survey methods. Some countries may choose to prioritize and target specific age ranges (such as children five years and younger) rather than include all children less than 18 years in households. HIV testing methods for children may also vary, depending on whether infants less than 18 months are to be tested. If applicable, questionnaires specific to adolescents may be incorporated, as well as caregiver questionnaires for younger children. Some countries may choose to select all populations for the surveys, regardless of age.

Household surveys are generally conducted every three to five years in countries with generalized epidemics. Additional information on sampling and multistage stratified cluster design can be found in Chapter 22 of *Household sample surveys in developing and transition countries.(22,23)* Household surveys are typically designed in consultation with a statistician. Large sample sizes are needed to measure differences in HIV prevalence among subpopulations, including for specific age ranges.

Data sources

If HIV status is collected among children, household surveys can be used to estimate HIV prevalence, as well as sociodemographic risk factors associated with HIV status. Depending on whether paediatric questionnaires are implemented, information on risk factors may be limited for young children but will be available for older adolescents. When repeated periodically, household surveys can be used to monitor trends in HIV prevalence over time although they will require very large sample sizes to measure significant changes.*(24.25)*

If children below 18 months are included in the surveys, PCR testing should be used for diagnosing HIV among them. If maternal antibody testing is conducted, the results can be used to estimate HIV exposure in young children 0–17 months. These biological data can also be linked to survey data on the mother's receipt of antenatal care services.

Separate questionnaires may be incorporated for specific age ranges to capture additional information, including risk factors, health-related information and access or use of services. For children younger than 12 years, caregivers may be queried to report information on the following:

- Relationship to caregiver
- School attendance
- Sexual abuse
- Communication of knowledge on HIV prevention and transmission
- HIV testing and status.

Among 12–14-year-olds, questionnaires might include self-reported knowledge, behaviours and access to care:

- Age at first sex
- Knowledge, attitudes and practices related to HIV
- Condom use
- Drug and alcohol use
- History of STIs
- Stigmatizing attitudes towards people living with HIV
- HIV testing and status
- Circumcision (males)
- Access to services
- Frequency of sexual activity (including number of partners).

Strengths and limitations

Combining HIV testing with individual questionnaires allows for collection and detailed analysis of social, demographic and behavioural factors associated with HIV. The addition of paediatric questionnaires and biomarker testing to upcoming household surveys may provide an opportunity to access large numbers of children and provide nationally representative results that may include children without access to health services. The detailed information obtained from household surveys can be used for programme planning and for monitoring the impact of HIV interventions.

Household surveys with HIV testing are not recommended for concentrated or low-level epidemics. Household surveys, especially of HIV prevalence in children, require large sample sizes and therefore may be prohibitively expensive and time-consuming. It can take up to three years to design, implement and produce reports for a nationally representative survey. As with other surveys, household surveys are subject to bias:

- Individuals may give socially desirable responses and high-risk behaviours may be underreported.
- Selection bias may also be present when certain individuals opt out of the survey.

Implementation considerations

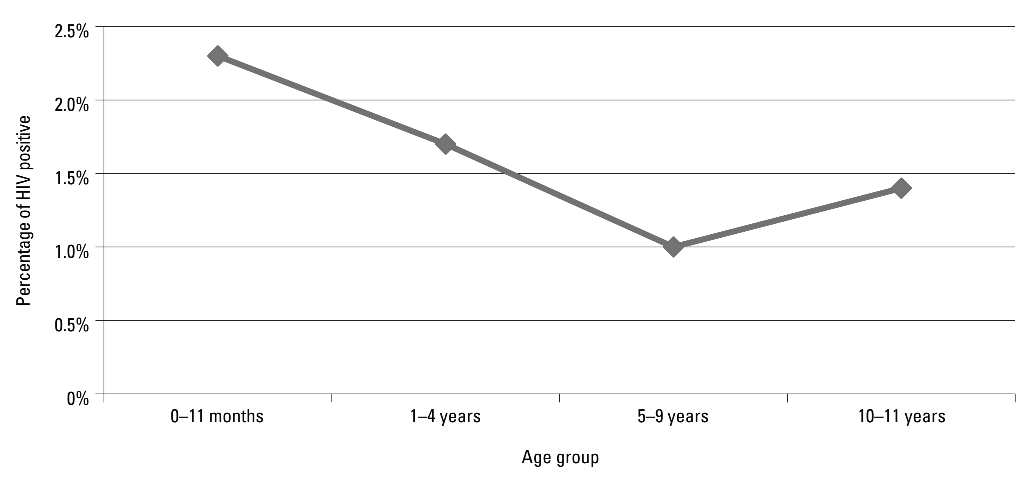
Because of the resources involved, including children in upcoming national household surveys should be considered carefully. The incremental cost of including children in an existing survey may be less than mounting a stand-alone survey. However, the resources associated with adding questions specific to children to the questionnaire and incorporating diagnostic testing for children, in addition to large sample size requirements, may be prohibitive and are not likely to be sustainable. Careful consideration of the costs and benefits of including paediatric populations in household surveys is strongly recommended.

Ethical issues associated with conducting household surveys include ensuring privacy and confidentiality, and obtaining informed consent from caregivers and assent from children to the extent possible. Adding HIV testing to surveys raises additional concerns around safety, return of results, provision of co-trimoxazole prophylaxis, treatment for HIV-positive individuals, follow up for indeterminate results, long-term financing of care and treatment, and use of specimens taken for other studies.*(26)* Some household surveys do not provide test results to the participants; the results are delinked so it is not possible to link an individual to his/her test result. Instead, respondents are offered a voucher for free voluntary counselling and testing at a nearby site, as well as an educational pamphlet explaining the available services and the benefits of testing. This approach may not be appropriate for paediatric populations.

Box 7. Mozambique national survey on prevalence, behavioural risks and information about HIV/AIDS, 2009*(27)*

In 2009, a national survey was conducted in Mozambique to obtain national and provincial data on behaviours and social risk factors for HIV infection and HIV prevalence in the entire population aged 0–64 years. All men and women aged 15–64 years and adolescents aged 12–14 years living in selected households were eligible to be interviewed and provide a blood sample for HIV testing. In half of the selected households, information about children aged 0–11 years was collected through caregiver interviews. These children were also eligible for HIV testing. The survey found a national HIV prevalence of 1.4% among children aged 0–11 years and 1.8% among adolescents aged 12–14 years.

HIV prevalence by age, children 0–11 years, Mozambique, 2009



Box 8. South Africa national population HIV survey, 2002–2008*(24)*

South Africa has conducted three national population-based surveys with HIV testing, which included children aged 2–14 years. A signficant decline in prevalance was noted between 2002 and 2008, as presented below. HIV prevalence in the age group of 15–24 years was stable.

HIV prevalence by age, South Africa, 2002, 2005 and 2008

	2002			2005			2008		
Age	**N**	**%**	**95% CI**	**N**	**%**	**95% CI**	**N**	**%**	**95% CI**
Children (2–14 years)	2348	5.6	3.7–7.4	3815	3.3	2.3–4.8	3414	2.5	1.9–3.5
Youth (15–24 years)	2099	9.3	7.3–11.2	4120	10.3	8.7–12.0	3617	8.7	7.2–10.4

3.2.3. Immunization clinic surveys

Testing of children at immunization clinic visits has been used as a method to evaluate the early impact of PMTCT programmes, but can also be used as an active surveillance approach. By testing all children during their first immunization clinic visit and surveying caregivers, information on early (up to eight weeks) MTCT and HIV-free survival among HIV-exposed children can be gathered, as well as the prevalence of HIV exposure and infection. If combined with active follow up of exposed infants, MTCT rates and HIV prevalence can be measured.

Methods

Immunization clinic facilities may be selected through multistage, probability proportional to size, and systematic sampling methods to obtain samples representative at the national and subnational levels. In the selected immunization clinics, children 4–8 weeks of age attending their first immunization clinic visit are systematically or consecutively enrolled upon obtaining consent from caregivers. Dried blood spot (DBS) samples are collected from participating infants and tested for HIV antibody to determine HIV exposure, and PCR testing is conducted on samples from HIV-exposed children to determine HIV infection status. Questionnaires may also be administered to caregivers to collect additional information on demographics, family birth history and PMTCT services. Though this method is cross-sectional, testing at immunization clinics should serve as an entry point for follow-up studies of HIV-exposed infants to determine the final outcome of their HIV status. Exposed infants with negative PCR tests may be followed and retested at 6, 9, 12 and 18 months. The United Nations Children's Fund (UNICEF), Centers for Disease Control and Prevention (CDC) and WHO are developing standard protocols for an immunization clinic-based method to assess PMTCT impact.

Data sources

In this method, data are provided through HIV antibody testing of all participating infants to determine the prevalence of HIV exposure, and PCR testing of exposed children younger than 18 months to determine the HIV infection status. PCR testing of exposed children may be done multiple times until their final HIV status can be determined, depending on the breastfeeding practices in the country.

In addition, immunization clinic surveys have incorporated caregiver questionnaires to collect information on the following:

- Demographic information
- Access to PMTCT services
- PMTCT regimen received
- Infant-feeding practices
- Data on other children/siblings(birth history).

Some of the above information may be gathered from caregiver-held antenatal clinic or PMTCT cards. The information collected through these data sources provide the following estimates:

- Prevalence of HIV exposure in infants attending immunization clinics
- Prevalence of HIV infection in infants/children attending immunization clinics
- Coverage of or access to PMTCT services among mothers and infants/children attending immunization clinics
- Effectiveness of PMTCT services
- Infant/child mortality rate and derived HIV-free survival (through reported birth histories).

Strengths and limitations

Preliminary evidence shows that the acceptability of testing in immunization clinics may be high. High coverage in this setting provides an opportunity to reach the targeted population (infants and children) at one place.*(28)* If immunization services are robust, the additional data collection activities for clinic staff may be merged into routine immunization tasks. With high coverage of immunization services, this method may provide population-based estimates. Caregivers accompanying infants to immunization clinics are a good source of information on PMTCT service access and use, infant-feeding practices and birth history.*(28)* In addition, immunization clinic surveys serve the dual purpose of providing paediatric surveillance data, as well as evaluating the overall impact of PMTCT services.

The representativeness of immunization clinic surveys for paediatric HIV estimates is dependent on the coverage of immunization services. Immunization clinic surveys are limited by the age range covered by immunization services or the follow up of these services. Immunization clinic surveys will not capture children older than 2 years because the vaccination calendar is completed by 2 years in most countries. Finally, immunization clinic surveys are not a cost-effective paediatric surveillance method for low and concentrated epidemic contexts.

Implementation considerations

The coverage and quality of immunization services should be carefully considered to assess the feasibility of adding HIV testing to routine activities in immunization settings. Where the workload is manageable, the same health-care workers who carry out immunization activities may collect data. The financial resources needed are likely to be moderate, depending on the scope and frequency of survey implementation. Immunization clinic surveys may be routine or periodic. Where resources are available, more frequent surveys can be considered. It is also possible to envision "sentinel sites" in immunization clinics for paediatric HIV surveillance (that is, a limited number of selected sites for more routine or frequent surveillance). The selected immunization clinics should be representative of the catchment areas for the survey results to be generalizable to the region or country.

Some immunization clinic surveys have been conducted using unlinked, anonymous testing. This approach is not recommended, and surveys should ensure appropriate consent, confidentiality and counselling or psychosocial support for participants, as well as referral to care and treatment.

Box 9. Use of immunization schedules for paediatric HIV surveillance in South Africa

In a recent study in KwaZulu Natal, South African researchers implemented routine HIV testing of infants 6, 10 or 14 weeks of age brought in for immunization in three clinics.*(28)* DBS samples were collected by heel prick and tested for HIV antibodies. Positive samples were then tested for HIV DNA by PCR. Mothers were interviewed to assess the acceptability of this approach and to provide additional information on birth history and receipt of PMTCT services. The study found that screening of infants at immunization clinics was acceptable (over 90% of mothers agreed to HIV testing of their children) and feasible as a means for early identification of HIV-infected infants and referral for care and treatment. With high coverage of immunization services, routine HIV testing at immunization clinics for paediatric HIV surveillance can measure the HIV prevalence among infants, and the coverage and effectiveness of PMTCT interventions. Birth history data can also provide mortality rates among the siblings of infants whose positive HIV antibody tests indicate the mother's HIV infection.

HIV prevalence among HIV-exposed infants aged 6 weeks in selected district sites in South Africa, 2004 (N=2473)

	Exposed	Infected	Prevalence (%)	CI
Total	**907**	**189**	**20.8**	**18.2–23.6**
Women who reported themselves as infected	486	77	15.8	12.7–19.4
Women who reported themselves as uninfected	189	59	31.2	24.7–38.3
Women who did not report their status	232	53	22.8	17.6–28.8

3.2.4. Mortality data

Data on HIV-related paediatric mortality may be obtained through a variety of surveillance methods.

- In countries with complete vital registration systems, paediatric mortality surveillance uses information from vital records to determine the number of deaths due to HIV/AIDS in paediatric populations.
- In countries without strong vital registration systems, mortality surveillance may be done through sample vital registration with verbal autopsy (SAVVY), adding a mortality component to population-based surveys, facility or programme registers (such as care and treatment registers), and burial surveillance.

Methods

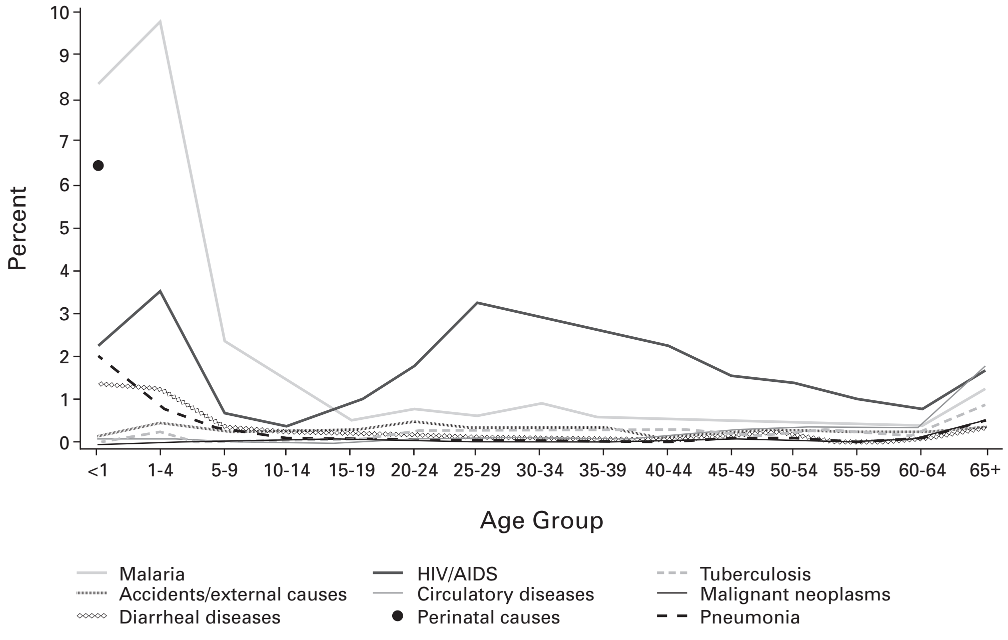
Where complete and representative vital registration systems are present, vital records are collected and analysed to determine the number of HIV-related paediatric deaths. However, in the absence of vital registration systems, the following methods may be implemented to provide surveillance information on paediatric mortality:

- *SAVVY:* this approach starts with the selection of representative sample areas to provide regionally or nationally representative vital statistics. A baseline census is conducted to account for all households and residents in those sample areas, and this information is updated on an annual basis. Key informants notify verbal autopsy (VA) interviewers of all deaths occurring in the sample area. VA interviewers follow up by conducting interviews in the households where deaths have occurred to collect information about the deaths. This information is then analysed to determine the cause of death using the WHO International Classification of Diseases.*(29)*

Box 10. Estimating the cause of death in a representative household survey, Mozambique ***(27)***

Furthermore, malarial deaths in children under age 15 accounted for 22 percent of all enumerated deaths. However, for adults age 15 and above, HIV/AIDS overtook malaria as the leading cause of death. Deaths due to HIV/AIDS in adults age 15–30 accounted for 6 percent of total deaths across all ages. When that age range is expanded, deaths due to HIV/AIDS in adults age 15–49 accounted for 15 percent of all enumerated deaths. Furthermore, about one in five enumerated deaths was to an adult age 15 and above with HIV/AIDS as the cause of death.

Percentages of Leading Causes of Death by Age Group: 2006–2007



Source: INCAM, 2006-2007

- *National population-based surveys on cause of death:* some countries have conducted population-based surveys on data collection for the cause of death among adults and children. Questionnaires collect information on multiple deaths in each household. Additional demographic and health information on deaths and their possible causes is collected based on a VA method.
- *Facility or programme registers:* health-care and programme facilities that routinely track patient outcomes and record death information may actively or passively report paediatric HIV-related deaths.

Data sources

Mortality data may be available through national (or other administrative regions) vital statistics registers. If using other methods, additional data sources may be available. For SAVVY and survey-based methods, standard questionnaires are available depending on the age of the deceased. Data collected may include demographic information, history of chronic illnesses, signs and symptoms and their duration, and a verbal account of the events leading to death, including services sought. When a cause of death is ascertained, a death certificate may be prepared. Paediatric HIV-related mortality data may also be available through facility and programme records and registers.

Strengths and limitations

Vital registration systems usually collect mortality data on an ongoing basis and at a national level. If the national vital registration system is functioning at a high level, additional resources are not needed, except for special needs such as for conducting subanalyses. In the absence of vital registration systems, multiple methods may be utilized to collect mortality data, according to what is available and appropriate for each country context. SAVVY and survey-based methods may provide representative mortality estimates for HIV-related deaths as well as other causes of death. Reporting of deaths from facility or programme records utilizes routinely collected data for mortality surveillance purposes.

Incomplete vital registration in many settings adds to the complexity of using such systems as a reliable means of measuring paediatric mortality resulting from HIV infection. Mortality data are fraught with cause-of-death misdiagnoses, even in the best of circumstances,*(30)* and must be interpreted cautiously. Stigma related to deaths from HIV infection may result in underreporting, both in VAs and in vital registration systems. In addition, many paediatric deaths may not be reported when they occur at home or in very young children. If a SAVVY is relying on key informants to identify deaths in the community, deaths among young children might be missed. Young children might not yet have been registered with the national authorities and thus may not figure in the vital registration system for either births or deaths. For children, most vital registration systems classify only infant mortality, neonatal mortality and perinatal mortality, and do not report AIDS-related deaths.

Verbal autopsies, often used to determine the cause of death when the death occurs outside of the formal health sector, are known for both poor sensitivity and specificity of diagnosis, particularly for children. Depending on who is interviewed about the paediatric death, the accuracy and detail of the responses vary widely.

Implementation considerations

Reporting of mortality data for small age categories in small administrative units should be avoided so as to reduce the risk of identifying individuals and the potential of stigma for families who have suffered a death. In addition, the limitations of underreporting due to stigma and limited vital registration systems should be considered in interpreting mortality data.

Box 11. Confirmation of estimates of population-based child mortality rate using SAVVY*(31)*

In 2002, a continuous-registration demographic surveillance system (DSS) was established in the Karonga district of Malawi. A baseline census was conducted and demographic surveillance was started in 230 geographical clusters. Within each cluster, a village informant recorded births, deaths and migrations. All births recorded in the DSS, which were not reported to have died or migrated, were visited at 12 months of age to evaluate the completeness of infant death registration. A follow-up census in 2004 showed that the DSS had registered 99% of deaths, 97% of births and 92% of migrations. VA interviews were conducted with the most immediate caregiver using standard semi-structured questionnaires, and three physicians or clinical officers independently reviewed each VA to assign the likely underlying cause of death following WHO VA standards. Data provided infant and under-5 mortality rates for the region, by sex, age and cause of death, including HIV. VA results were also compared with the DHS results and antenatal clinic attendance information used to estimate HIV exposure and HIV-related deaths.

Confirmation of estimates of population-based child mortality rate using SAVVY Jahn A et al. Declining child mortality in northern Malawi despite high rates of infection with HIV. Bulletin of the World Health Organization, 2010, 88:746–753

Kaplan–Meier mortality risk by age group, per 1000 live births, in Karonga district, Malawi, 2002–2006

Age group	Death	Boy and girls, all causes[a]			Boys and girls, AIDS[a]			Boys and girls, non-AIDS[a]		
	between ages	**Deaths**	**Risk**	**95% CI**	**Deaths**	**Risk**	**95% CI**	**Deaths**	**Risk**	**95% CI**
Neonatal	0–28 days	83	22.4	18.1–27.7	0	0		80	21.6	17.4–26.9
Postneonatal	29 days–12 months	112	31.0	28.4–33.6	22	6.2	4.1–9.4	87	24.1	22.0–26.2
Infant	0–12 months	195	52.7	46.0–60.4	22	6.2	4.1–9.4	167	45.2	39.0–52.4
24 months	0–24 months	256	70.0	62.2–78.7	39	11.3	8.3–15.4	210	57.5	50.4–65.6
Child 1–4 years	1–5 years	109	34.0	31.7–36.4	28	8.9	7.3–10.4	76	23.8	22.0–25.6
Under 5 years	0–5 years	304	84.8	76.2–94.6	50	15	11.4–19.7	243	67.9	60.1–76.7
Child 5–14 years	5–15 years	38	15.5	14.4–16.7	13	5.4	4.5–6.3	25	10.2	9.4–11.2
Child <15 years	0–15 years	342	99.1	89.5–109.7	63	20.3	15.8–25.9	268	77.4	68.9–87.0

a Eleven deaths from unknown causes were censored, so non-AIDS and AIDS-specific mortailty risks do not total the all-cause mortality risk

3.2.5. In-school youth surveys

Surveillance of older children and adolescents may target schools as settings to conduct surveys that measure knowledge, attitudes and practices related to HIV and sexual activity. Given the topics covered in these questionnaires, in-school youth surveys are usually conducted among adolescent boys and girls (e.g. aged 12–17 years) during school hours at public or private secondary schools. In-school surveys are not specific to HIV-related topics; thus, an HIV component can be added to broaden existing surveys.

Methods

A sampling frame of all secondary schools can be used to set up a stratified randomized sampling approach. Children may be selected randomly or systematically in selected classes or schools.*(32)*

Data sources

Anonymous, unlinked questionnaires are administered to students to collect data on HIV knowledge, attitudes and practices, including the following:

- Knowledge of HIV prevention and transmission
- Stigmatizing attitudes towards people living with HIV
- Age at first sex
- Frequency of sexual activity (including number of partners)
- Condom use
- Drug and alcohol use
- History of STIs
- History of sexual and physical abuse
- HIV testing history
- Circumcision (males)
- Access to services

In-school surveys may incorporate voluntary HIV counselling and testing, if feasible.

Strengths and limitations

In-school surveys provide an opportunity to capture data from an adolescent population approaching or at their sexual debut, when behaviour patterns begin to be set. Students are an easy-to-reach population. Because complete sampling frames of schools are usually available, probability sampling can be used. In addition, with the participation of ministries of education, broad access to students may be provided.

Student participation in in-school surveys must be approved by several parties: ministries of education, school authorities, parents and the students themselves. The need for both parental consent and child assent may limit participation and decrease sample sizes. Survey administration is bound by school schedules and must account for school terms, examinations and holidays. Finally, it may be difficult to include HIV testing and sensitive questions due to countries’ mores, attitudes*(33)* and laws. HIV testing of youth may be a particularly complicated issue.

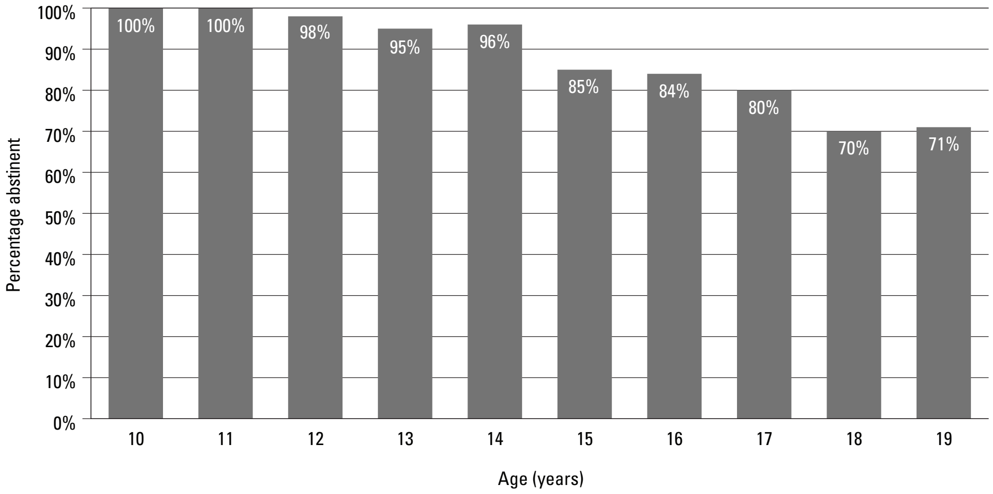
Implementation considerations

The implementation of in-school surveys must take considerable ethical concerns into account. Care must be taken to ensure that schoolchildren do not feel coerced to participate. Depending on the setting in which the survey is administered, it may be difficult to protect the confidentiality of sensitive personal information. If HIV testing is included, considerable effort is needed to ensure proper procedures for obtaining consent for adolescents. In addition, attention must be paid to the type of test chosen, pre- and post-test counselling, how the results are delivered, to whom they are delivered, and how they are followed up in the context of an adolescent age group.*(33)* Though access to services may be limited, the youth may desire services (such as voluntary counselling and testing) because of survey participation, and referrals to health services must be provided. Local facilities should be available and able to respond to a possible increased uptake of services after the survey.

Box 12. Perceptions about sexual abstinence and knowledge of HIV/AIDS prevention among in-school adolescents in a western Nigerian city*(34)*

In 2006, secondary school students in Ibadan Southwest and Oyo State, Nigeria were interviewed to assess their knowledge of the causes and prevention of HIV infection, prevalence of abstinence and factors related to abstinence. A multistage sampling technique was used to select 14 secondary schools, from which 30 students were randomly selected. The local education authority and school principals of selected schools approved the implementation of the survey. Parents' written consent and students' verbal consent were obtained prior to administering the questionnaire. Data were collected using semi-structured questionnaires that collected information on demographic characteristics, sexual activities, self-efficacy at refusing sex, attitude towards abstinence, knowledge of HIV/AIDS, self-esteem, parental control and communication, and peer pressure for premarital sex. The survey found a high level of knowledge on HIV transmission and prevention, and high levels of sexual abstinence (79% among boys and 98% among girls). Factors associated with abstinence were also analysed, and the study findings were applied to health education programmes and policies.

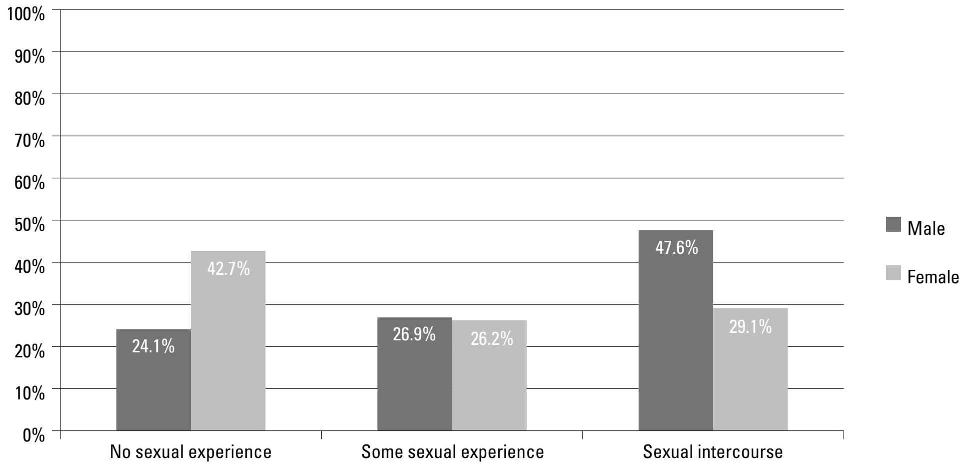
Percentage of abstinent respondents by age in Ibadan Southwest and Oyo State, Nigeria, 2006



Box 13. Sexuality among senior high school students in Papua and West Papua Provinces in Indonesia *(35)*

In 2009, a total of 1082 unmarried Year 11 students from 16 randomly selected senior high schools in the Papua and West Papua provinces of Indonesia were asked to complete anonymous questionnaires. These included questions on demographic characteristics, previous sexual experience, pregnancy, contraceptive use, STI symptoms and treatment-seeking behaviour. Gender and age were associated with sexual experience: 47.6% of male students and 29.1% of female students reported having had sexual intercourse, and 51.8% of students aged more than 19.2 years reported having had sexual intercourse compared to 32.7% of those aged 18.2–19.2 years, and 30.3% of those aged less than 18.2 years. The survey found a low incidence of condom use. Almost one third of female students who reported having had sexual intercourse also reported having had an unintended pregnancy. In addition, a qualitative survey was conducted among senior high school teachers and students, as well as staff of education offices, staff of nongovernmental organizations, health-care professionals, youth sex workers and indigenous tribal leaders.

Sexual experience among male and female Year 11 students in Papua and West Papua provinces, 2009



Box 14. The 2008 Thailand Global School-Based Health Survey

The Thailand Global School-Based Health Survey (GSHS) was a school-based survey of students aged 13–15 years conducted in 2008. A two-stage cluster sample design was used to collect data representative of Grades 7 through 10 students in the country. Schools were selected with probability proportional to their reported enrolment size. Classes in the selected schools were randomly selected. All students in the selected classes were eligible to participate, regardless of age. A total of 2767 students self-completed ten questionnaire modules focusing on substance use, dietary behaviours, physical activity and sexual behaviours that contribute to HIV infection and other STIs. Sexual intercourse in the past 12 months was reported by 11% of adolescents, with a higher percentage of boys than girls reporting sexual intercourse in the past 12 months (14.6% and 7.6%, respectively). Current alcohol use was associated with recent sexual intercourse.

The 2008 Thailand Global School-Based Health Survey WHO, CDC. Global school-based student health survey: Thailand. 2008. Available at:http://www.who.int/chp/gshs/GSHS_FINAL_Report_Thailand_2008.pdf (accessed on 19 July 2012).

Peltzer K, Pengpid S. Prevalence and social correlates of sexual intercourse among school-going adolescents in Thailand. Scientific World Journal, 2011, 11:1812–1820.

Sexual behaviours that contribute to HIV infection, other STI and unintended pregnancy among students, by sex, Thailand, 2008

Question	Total % (CI)	Sex	
		Male % (CI)	Female % (CI)
Ever had sexual intercourse	3.1 (4.0–8.1)	7.5 (4.5–10.5)	4.9 (3.0–6.7)
Initiated sexual intercourse when they were 13 years old or younger	4.5 (3.4–5.7)	8.0 (6.2–9.8)	1.3 (0.4–2.3)
Had sexual intercourse with two or more people during their life	5.5 (4.6–6.3)	9.8 (8.2–11.4)	1.6 (1.1–2.1)
Had sexual intercourse during the past 12 months	11.0 (9.1–12.9)	14.6 (11.8–17.5)	7.6 (5.7–9.4)

3.2.6. Out-of-school youth surveys

Out-of-school youth surveys measure knowledge, attitudes and practices related to HIV, and may include HIV testing conducted among youth who are neither in primary nor secondary school. Participants are usually 15–17 years of age. However, some surveys may target youth younger than 15 years, as with street children.

Methods

Out-of-school youth are generally not a fixed population. Thus, there is no sampling frame. Participants for behavioural surveys and testing may be recruited using the following methods to recruit hard-to-reach populations:

- In time–location sampling, youth are sampled where they congregate. *(32,36)* Personnel working with these groups provide initial insights as to locations where youth can be found. Mapping is then conducted to record locations, days and times when the youth are present and the approximate number of youth. Venues and recruitment periods are chosen according to the time–location sampling methodology. Individuals at the sites are chosen randomly or using the take-all approach.
- Respondent-driven sampling is a chain-referral recruitment method characterized by specific features (limited recruitment and network size estimation) to adjust for recruitment biases and obtain population estimates.

The *Guidelines on surveillance among populations most at risk for HIV*(38) provides additional guidance on conducting surveillance among hard-to-reach populations.

Data sources
Survey participants are administered questionnaires to collect data on HIV knowledge, attitudes and practices, including the following:

- Knowledge of HIV prevention and transmission
- Stigmatizing attitudes towards people living with HIV
- Age at first sex
- Frequency of sexual activity (including number of partners)
- Condom use
- Drug and alcohol use
- History of STIs
- History of sexual and physical abuse
- HIV testing history
- Circumcision (male)
- Access to services

To protect patient confidentiality, questionnaires may be anonymous and unlinked. Some surveys may include HIV voluntary counselling and testing to obtain HIV prevalence.

Strengths and limitations
Out-of-school youth surveys target children who are not captured in in-school youth surveys and who may be at increased risk for HIV infection. In some situations these children might even be excluded from household surveys. Depending on their age and the setting in which they are recruited, out-of-school youth can often consent for themselves and are relatively free from coercion to participate in a survey.

- Using time–location sampling methods, youth are found where they usually congregate. There is no need to assemble them.
- If using respondent-driven sampling methods, youth actively recruit their peers, thus minimizing staff and resource needs for recruitment.

However, out-of-school youth are often hidden and difficult to access. Thus, sampling methods may not capture youth who do not congregate at identified sites (time–location sampling) or youth who are not socially networked (respondent-driven sampling). Out-of-school youth may also have limited incentive to participate. Depending on the survey setting, maintaining privacy and confidentiality during survey completion may be difficult. Because of the limitations in sampling these hidden populations, indicators from these surveys are often not comparable over time.

Implementation considerations
Out-of-school youth may be difficult to define as a population and recruit. Thus, a formative assessment should be conducted prior to designing and implementing the survey. The assessment should include substantial input from people working with this target group so that appropriate inclusion/exclusion criteria and the most effective sampling method are chosen. In addition, these stakeholders should be engaged to determine the frequency of implementing the survey based on demographic changes within this group.

Careful attention must be paid to ensure that proper ethical procedures, including consent/assent, counselling and referrals are properly instituted based on country- and community-specific guidelines, especially if surveys include HIV testing. Youth who are not of age but do not live with a parent/guardian may be allowed to give primary consent. If parental consent is required, out-of-school youth surveys may be limited to individuals above a certain age, since the survey setting is not usually conducive to obtaining parental/guardian consent. Similar to in-school youth surveys, out-of-school youth may be spurred to action and desire services (such as voluntary counselling and testing) because of the survey questions or referrals to services. Thus, it must be ensured that local facilities are able to respond to a possible increased uptake of services after the survey.

Box 15. Multicity HIV seroprevalence in street youth, Ukraine*(37)*

In 2008, street and out-of-school youth aged 15–24 years residing in Odesa, Kyiv and Donetsk were recruited for a behavioural survey and HIV testing using an adaption of time–location sampling. Outreach workers systematically approached all observed youth at mapped sites to obtain informed consent from eligible youth before administering counselling and testing and a structured interview. Youth with positive rapid HIV test results were referred to care and treatment facilities. Participation was high (97%), and reported rates of HIV-related social, sexual and substance-use risk factors were also high. Overall HIV prevalence was 18.4%, and factors associated with HIV infection were assessed. The results were shared with a broad range of collaborating partners to contribute to the development of HIV prevention recommendations for this population.

Prevalence of HIV among street youth, overall and by characteristics, stratified by age, Ukraine, 2008

	% HIV positive		
	15–17 N/N (%)	18–24 N/N (%)	Total N/N (%)
Overall HIV seroprevalence	28/254 (11.0)	143/675 (21.2)	171/929 (18.4)
Demographic characteristics			
Gender			
Male	22/190 (11.6)	108/516 (20.9)	130/706 (18.4)
Female	6/64 (9.4)	35/159 (22.0)	41/223 (18.4)
Sexual risk factors			
Ever had sex			
No	11/63 (17.5)	0/12 (0.0)	11/75 (14.7)
Yes	16/190 (8.4)*	142/662 (21.5)	158/852 (18.5)
Last sex unprotected			
No or never had sex	17/182 (9.3)	56/306 (18.3)	73/488 (15.0)
Yes	10/70 (14.3)	86/368 (23.4)	96/438 (21.9)*
Lifetime sex exchange**			
No	26/240 (10.8)	128/644 (19.9)	154/884 (17.4)
Yes	1/13 (7.7)	14/30 (46.7)*	15/43 (34.9)*
Substance use behaviours			
Lifetime use of any drug			
No	0/78 (0.0)	12/171 (7.0)	12/249 (4.8)
Yes	28/176 (15.9)*	131/504 (26.0)*	159/680 (23.4)*
Lifetime injection drug use			
No	10/200 (5.0)	30/416 (7.2)	40/616 (6.5)
Yes	18/54 (33.3)*	113/259 (43.6)*	131/313 (41.9)*
Lifetime needle-sharing			
No	16/218 (7.3)	55/505 (10.9)	71/723 (9.8)
Yes	12/36 (33.3)*	88/170 (51.8)*	100/206 (48.5)*
Got drunk ≥ 10 days in past month			
No	27/242 (11.2)	118/587 (20.1)	145/829 (17.5)
Yes	1/12 (8.3)	25/88 (28.4)	26/100 (26.0)*

* Statistically different at P<0.05 based on x2 test comparing the distribution of HIV by youth characteristics, conducted separately for youth aged 15-17 years, youth aged 18-24 years and the total sample of youth

** Defined as exchanging sex for drugs, money, food, clothes, shelter or other goods

Box 16. Sexual behaviours of street children in Greater Cairo and Alexandria, Egypt*(38)*

Time–location sampling was used to recruit a sample of 857 street children aged 12–17 years in Greater Cairo and Alexandria, Egypt. Key informants and field observation were used to create a sampling frame of time periods and locations where street children congregated in the two cities. A random sample of time–locations were selected from the complete list and children at the selected time–locations were intercepted, screened for eligibility and, if eligible, interviewed to gather demographic information, sexual and drug-use behaviours, and HIV/AIDS knowledge. Among 15–17-year-olds, 67% reported ever having engaged in sex and nearly one fifth (19%) reported having sold sex. The majority of girls in both Alexandria and Greater Cairo (88% and 54%, respectively) experienced being forced to have sex.

Sexual behaviours of street children in Greater Cairo and Alexandria, Egypt Nada KH, Suliman EDA. Violence, abuse, alcohol and drug use, and sexual behaviors among street children of Greater Cairo and Alexandria, Egypt. AIDS, 2010, 24(suppl 2):S39–S44.

Sexual experiences, street children aged 15–17 years in Greater Cairo and Alexandria, Egypt, 2007

	Greater Cairo		Alexandria		
	Boys	Girls	Boys	Girls	Total
Participants (%)	185	55	182	19	441
Ever had sex with someone of the opposite sex	112 (61)	39 (71)	127 (70)	17 (90)	295 (67)
Mean age at first intercourse with opposite sex (range in years)	13 (6–16)	14 (9–17)	14 (7–16)	14 (10–16)	14 (6–17)
Partners of opposite sex in past 12 months					
One partner	49 (44)	20 (51)	30 (24)	3 (18)	102 (35)
More than one partner	49 (44)	14 (36)	84 (66)	11 (65)	158 (54)
No opposite sex partners in past 12 months	14 (13)	5 (13)	13 (10)	3 (18)	35 (12)
Condom use with someone of the opposite sex					
Always use condom	9 (8)	0 (0)	48 (38)	3 (18)	60 (20)
Sometimes use condom	21 (19)	6 (15)	44 (35)	3 (18)	74 (25)
Never use condom	80 (71)	30 (77)	33 (26)	11 (65)	154 (52)
Ever had sex with someone of the same sex	38 (20)	2 (4)	66 (37)	0 (0)	106 (24)
Provided commercial sex	23 (12)	14 (26)	38 (21)	11 (58)	86 (19)

Box 17. Sexual risk behaviours and HIV seroprevalence among men who have sex with men in Campinas, Brazil*(39)*

Respondent-driven sampling was used to recruit 658 men who have sex with men for a cross-sectional survey and HIV testing in Campinas, Brazil. Audio-assisted computer self-interview was used to collect data on demographic information and sexual behaviours. Eligibility criteria included being 14 years or older, living in the Campinas area, and having had oral or anal sex with a man within the past 6 months. The interview included questions regarding sex work, defined as receiving money, drugs or gifts in exchange for sex, in the two months before the survey. The Respondent-Driven Sampling Analysis Tool was used to calculate population-based estimates. Over a quarter of the men who had sex with men were between 14 and 19 years of age (26.0%, 95% CI: 13.0%–37.4%). About one quarter had ever received payment for sex, and 14.8% (95% CI: 11.1%–19.0%) were paid for sex in the previous two months, almost exclusively with men. In comparing male sex workers who had sex with men and non-sex workers, sex workers were significantly less educated and more likely to self-identify as transgendered. Sex workers were also more likely to have unprotected receptive anal sex (22.4% vs 4.6%).

Comparison of some characteristics of men who have sex with men who sold sex (N=106) in the past two months with those who did not (N=525), Campinas, Brazil

	MSM who sold sex		MSM who did not sell sex	
	Sample %	Population estimates % (95% CI)	Sample %	Population estimates % (95% CI)
Age, years				
14–19	31.1	26.0 (13.0–37.4)	24.4	27.2 (20.6–32.8)
20–24	20.7	21.5 (12.3–35.3)	30.7	31.0 (20.6–32.8)
25–34	23.6	29.1 (15.9–41.8)	19.6	18.8 (14.9–24.5)
35+	24.5	23.3 (12.2–37.9)	25.3	22.9 (17.0–29.2)
Sexual orientation				
Homosexual	56.6	52.1 (39.5–66.2)	76.2	72.5 (67.5–77.8)
Heterosexual	8.5	10.6 (3.2–18.3)	1.9	3.3 (0.8–6.4)
Bisexual	32.1	37.3 (23.6–51.3)	21.7	24.3 (19.6–28.7)
Ever took HIV test	59.0	61.8 (46.9–75.3)	59.0	56.6 (51.2–63.0)
Tested positive for HIV	13.0	13.5 (2.9–27.3)	5.8	5.5 (3.2–8.7)
Had an STI symptom in past 12 months	37.1	40.4 (27.5–54.4)	26.6	23.9 (20.1–29.3)

4. Quality of the paediatric surveillance system

The ability to make reasonable estimates of HIV prevalence among the paediatric population using any surveillance method relies heavily on the coverage and quality of data, and the quality of diagnostics. The data and laboratory systems involved in paediatric surveillance should be regularly evaluated to ensure that quality standards and procedures are in place and being followed.

4.1. Data system quality

This section discusses overall issues relating to data coverage and quality relevant to all surveillance methods described in this document, broadly categorized as survey-based surveillance methods (immunization clinic surveys, population-based surveys and special surveys) and routine data-based methods (case reporting, mortality data).

4.1.1. Data coverage

Data coverage is the proportion of the target population that is accessed by a particular surveillance method. It may be an indicator of how representative the surveillance data are of the target population. To assess the representativeness of surveillance data, you would need to identify the potential selection biases involved in a particular surveillance method. Thus, additional variables that may predict inclusion in a particular surveillance method should be collected.

For example, if PMTCT programme data are used to calculate the number of HIV-exposed infants, one must consider the extent to which PMTCT services exist and are used in that setting. Questions to be asked and described in any analysis or dissemination of results include the following:

- What percentage of HIV-positive pregnant women are accessing services?
- What percentage of these women accept HIV testing?
- What factors predict differential testing rates for subgroups of pregnant women (for example, those with a known HIV status)?

4.1.2. Data quality

Data quality has four general components: completeness, timeliness, consistency and accuracy.

Completeness refers to the extent to which data are reported fully for any given surveillance method. This may be assessed at multiple levels:

- The number of observed paediatric infections divided by the number of expected paediatric cases through modelling or other prevalence estimates
- For survey-based approaches, the survey and/or testing response rate among children
- For routine data-based methods, the proportion of facilities that are reporting paediatric cases
- The full reporting of paediatric surveillance data elements or the completion of data fields (forms, surveys, testing).

Timeliness refers to the speed with which data are available through a surveillance system. Surveillance data are timely when they are current and when the information is made available rapidly; timeliness can be assessed at facility, subnational and national levels. For example, timeliness for a paediatric case-based surveillance system can be calculated from the time of diagnosis of paediatric HIV infection to the time of receipt of the paediatric case report form at the national level. In general, the frequency and timeliness of data from survey-based surveillance will be less than that of routine data-based surveillance, where data are collected on a more continuous basis. For surveillance data to be useful for implementation of prevention, care and treatment programmes, health staff must receive timely feedback on the results of the surveillance. Timeliness can also be assessed by the rate at which surveillance data are incorporated into policy planning and programme implementation.

Consistency or reliability of surveillance data depends on the use of standard protocols and consistent procedures at each site over time. The use of standard protocols and procedures allows the data to be collected consistently, regardless of who does the data collection or how often data are collected.

Accuracy is also known as validity, meaning that the data correctly measure what they are intended to measure. Accurate data have minimal errors.

- For survey-based surveillance methods, errors include interviewer bias, or sampling or data collection errors.
- For routine data-based surveillance methods, errors include overcounting or undercounting cases, and transcription errors (whether the information on the abstraction form matches information in the patient record at the health facility).

4.2. Laboratory quality

Quality laboratory testing is critical to any surveillance programme. Poor laboratory results can lead to inaccurate estimates, misdiagnoses, incorrect treatment or delays in treatment. Laboratory testing in the context of paediatric HIV surveillance must include the appropriate testing methodologies for children of different ages, as well as quality assurance of the testing algorithms. In addition, blood sample collection may enable further surveillance activities among paediatric populations, including CD4 or viral load testing, drug resistance and ART exposure. Therefore, it is recommended that laboratory quality be considered an integral and vital component of paediatric HIV surveillance programmes.

Evaluation of laboratory quality should include the following:

- Availability and regular maintenance of written standard operating procedures for all procedures and staff training
- Appropriate sample collection (e.g. serum, plasma, whole venous or capillary blood), processing and transport
- Appropriate storage of reagents and biological samples
- Use of validated or approved diagnostic test kits, reagents and controls
- Use of test kits and reagents within their manufacturer-provided shelf-life
- Inclusion of positive and negative controls within each batch of tests
- Calibration and routine maintenance of laboratory equipment
- Safety guidelines and procedures in place
- Participation and satisfactory performance in an external quality assurance programme (EQAP) or interlaboratory comparison
- Proper recording and evaluation of individual and summary results, and quality control of data
- Maintenance of patient confidentiality in all laboratory records and throughout sample processing.

4.3. Validate paediatric surveillance data against other sources

Given the general lack of paediatric surveillance data in most settings, it is useful to validate existing surveillance data through alternative methods. In this section, we describe how to use mathematical models to verify the results of a surveillance system. This is especially important among new and developing surveillance systems such as paediatric HIV surveillance systems. It is important to note that models cannot replace surveillance systems. Models rely on assumptions and are likely to change as the HIV epidemic is better understood. For these reasons, models should be used cautiously and should themselves be validated based on empirical data.

Models can be used to supplement and validate results from surveillance systems. Examples of how models have been used to validate adult surveillance data include validating the decline in HIV prevalence in Zimbabwe and its link to changes in behaviour*(40)* and the decline in mortality in Botswana after widespread ART coverage.*(41)* Examples of how models have been used to validate paediatric surveillance are not available.

4.3.1. How models work

There are a large variety of models that help to understand epidemics and demographic changes. Mathematical models simply describe a system and the dynamic change in that system with different inputs and assumptions. In the case of HIV, HIV prevalence and epidemic changes are often modelled, given HIV risk and exposure in the population and variations in transmission modes and transmission rates.

4.3.2. Currently used software modelling packages

Many countries use the Spectrum computer package to estimate the impact of their HIV epidemic. Spectrum can describe the HIV epidemic at the country and subnational levels. Spectrum is a discrete compartmental model, which means that it progresses individuals by age group through different disease states. More information on the model and how it works can be found elsewhere.*(42,43)* Additional information on Spectrum is provided below.

The Asian Epidemic Model (AEM) is used to determine national HIV prevalence and track new HIV infections in a country to determine where new infections are arising. Similar to Spectrum, the AEM supplements existing HIV surveillance systems to inform policy and programmes.*(44)*

Outputs from Spectrum are available for various paediatric age groups and include the following:

- The number of new HIV infections in the previous year
- The current number of prevalent HIV infections
- The number of children who need co-trimoxazole prophylaxis
- The number of HIV-related deaths
- The number of children needing its coverage
- The number of pregnant women living with HIV.

To estimate the number of children living with HIV, the Spectrum model incorporates assumptions about MTCT rates and survival of HIV-infected children. Country-specific inputs are also used, such as the estimated HIV prevalence in women (aged 15–49 years), and coverage of PMTCT and ART programmes.

The accuracy of Spectrum estimates depends on the quality of the data included in Spectrum to develop the model, as well as the assumptions and parameters used in the model. Spectrum is revised routinely based on new information resulting from research on HIV. In addition, countries improve their models whenever country files are updated with additional surveillance data.

Currently, estimates from Spectrum of HIV prevalence among young children are not informed by direct paediatric surveillance data. In addition, Spectrum-generated paediatric estimates can be unreliable for concentrated or low-level epidemics. In these settings, there is usually very little information on fertility among the populations with the highest levels of HIV prevalence (sex workers, partners of clients of sex workers), making it difficult to estimate the number of children infected with HIV through MTCT. Thus, paediatric surveillance activities are particularly important in concentrated or low-level epidemics.

4.4.3. Using models to validate or supplement surveillance

In countries where there is no functioning paediatric surveillance system, models can be used to get a rough understanding of the potential number of children who might be HIV-positive. Spectrum currently estimates only the number of children (younger than 15 years of age) infected through MTCT. Other routes of transmission are not captured. The results from models can roughly estimate the trends of new infections and the distribution of existing infections to determine the magnitude of HIV among children.

In countries where some surveillance data are available for children, models can provide figures to compare against surveillance estimates to determine quality and/or validity. For example: if the only available paediatric surveillance data come from case reports, a programme manager might assume that this is an undercount of the actual number of children living with HIV, since some children may not come into contact with testing or care and treatment services. In such settings, a model might be able to estimate the number of expected child infections, thus providing an adjustment for the case-reporting system. Similarly, if a surveillance system is operational in only a limited number of areas, a programme manager might assume that the results are not representative. Models could be used to extrapolate how many HIV-positive children living in those areas were not captured in the surveillance system.

Models can also be used to supplement surveillance data. Often, countries have fairly good systems to monitor HIV prevalence but do not have good systems to measure deaths due to AIDS. Mortality surveillance is especially challenging among young children who might not yet have been recorded in national vital registration systems. Models can estimate HIV-associated paediatric mortality. However, mortality rates from models will only be as good as the assumptions used in the models.

4.5. Triangulate data

Paediatric surveillance data should be triangulated with other data sources to validate and better understand observed results. According to the WHO guidelines on data triangulation,*(45)* "triangulation can be broadly defined as the synthesis and integration of data from multiple sources through collection, examination, comparison and interpretation. By first collecting and then comparing multiple datasets with each other, triangulation helps to counteract threats to the validity of each data source." Triangulation can be applied to better understand and explain HIV trends for M&E purposes, as well as for resource allocation and advocacy. More importantly for paediatric HIV surveillance, triangulation can help redirect interventions. For further information on data triangulation and its processes, challenges and end-points, please refer to additional triangulation guidelines.*(46,47)*

5. Use and dissemination of paediatric surveillance data

Paediatric surveillance data are useful for characterizing the HIV epidemic and informing programmes and policies targeting children. Data will establish the burden and scope of paediatric disease, aid in making evidence-based decisions to prevent paediatric infections, and provide care and treatment for HIV-infected children. Paediatric surveillance data should also be used to evaluate the impact of paediatric programmes, including PMTCT activities.

When available, paediatric surveillance results should be regularly reported for routine data-based methods or in a timely manner for survey-based surveillance methods. Paediatric surveillance reports should include the following:

- Paediatric HIV prevalence
- Number of HIV-infected children
- Number of newly infected or newly diagnosed children
- Number of HIV-associated paediatric deaths
- HIV prevalence, incidence and mortality trends
- Paediatric HIV infection by transmission (mother to child, nosocomial, sexual, etc.).

Paediatric surveillance data, as with all surveillance data, should be reported in the most effective format to the appropriate audience.

- The report audience may include programme managers and policy-makers at local, subnational and national levels, as well as site or study staff collecting surveillance data.
- Reports should also target those developing national strategic plans and allocating resources for paediatric HIV programmes.

As part of the paediatric surveillance strategy, a dissemination plan should be developed. This should identify which key data elements should be reported to specific stakeholders. The dissemination plan should indicate how data will be shared, including technical reports, presentations and press releases.

In most settings, surveillance data that can be used to better understand the paediatric HIV epidemic and programmatic needs of paediatric populations are lacking. With intensified efforts to eliminate MTCT and ensure care and treatment of HIV-infected children, the need for paediatric surveillance data, as well as their appropriate use, dissemination and triangulation, should be prioritized. Country epidemic contexts should be carefully considered while choosing the most appropriate paediatric surveillance methods for implementation.

References

1. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. *The Belmont report*. Available at: http://ohsr.od.nih.gov/guidelines/belmont.html(accessed on 19 July 2012).
2. World Medical Association. *Declaration of Helsinki: ethical principles for medical research involving human subjects.* Available at:http://www.who.int/bulletin/archives/79(4)373.pdf (accessed on 19 July 2012).
3. UNAIDS/WHO. *Guidelines for second generation HIV surveillance: an update: know your epidemic.* Geneva, WHO, 2011 (forthcoming).
4. Global Fund/UNAIDS/WHO. *Monitoring and evaluation toolkit: HIV, tuberculosis and malaria and health systems strengthening.* Geneva, The Global Fund, 2009.
5. Newell ML, Brahmbhatt H, Ghys PD. Child mortality and HIV infection in Africa: a review. *AIDS*, 2004, 18 (suppl 2):S27–S34.
6. Stringer EM et al. Monitoring effectiveness of programmes to prevent mother-to-child HIV transmission in lower-income countries. *Bulletin of the World Health Organization*, 2008, 86:57–62.
7. WHO, UNAIDS, UNICEF. *Progress report 2011: global HIV/AIDS response: epidemic update and health sector progress towards universal access.* Geneva, WHO, 2011. Available at: http://www.who.int/hiv/pub/progress_report2011/en/index.html (accessed on 9 January 2012).
8. WHO, UNAIDS, UNICEF. *Report on the global AIDS epidemic 2010.* Geneva, WHO, 2010, Available at: http://www.unaids.org/globalreport/documents/20101123_GlobalReport_full_en.pdf (accessed on 8 November 2011).
9. UNICEF, UNAIDS, WHO. *Young people and HIV/AIDS: opportunity in crisis.* New York City, UNICEF, 2002.
10. United Nations. *World youth report 2007: young people's transition to adulthood—progress and challenges.* New York, United Nations, 2007.
11. UNAIDS. *Together we will end AIDS.* Geneva, UNAIDS, 2012. Available at: http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/20120718_togetherwewillendaids_en.pdf (accessed on 21 July 2012).
12. WHO. *PMTCT strategic vision 2010–2015: preventing mother-to-child transmission of HIV to reach the UNGASS and Millennium Development Goals.* Geneva, WHO, 2010.
13. United Nations. *Political Declaration on HIV/AIDS: intensifying our efforts to eliminate HIV/AIDS.* New York, United Nations General Assembly, 2011. Available at:http://www.un.org/en/ga/aidsmeeting2011/ (accessed on 17 July 2012).
14. The Second HIV/AIDS global surveillance meeting.*New strategies for HIV/AIDS surveillance in resource-constrained settings-II.* Bangkok, Thailand, 2–5 March, 2009. Available at:http://www.hivsurveillance2009.org/ (accessed on 17 July 2012).
15. WHO, UNAIDS, UNICEF. *Consultative meeting on evaluating the impact of prevention of mother-to-child transmission of HIV (PMTCT) services in low- and middle-income countries in averting new HIV infections in children and improving child survival.* Nashville, TN, Vanderbilt University School of Medicine, 12–13 February 2009.
16. Patel SV et al. Filling a gap: HIV pediatric surveillance in resource constrained settings. *Journal of HIV/AIDS Surveillance & Epidemiology*, 2010, 2:6.
17. UNAIDS/WHO Working Group on Global HIV.AIDS and STI Surveillance. *When and how to use incidence assays for recent infection to estimate HIV incidence at a population level.* Geneva, WHO, 2011. Available at: http://www.who.int/diagnostics_laboratory/hiv_incidence_may13_final.pdf (accessd on 21 July 2012).
18. UNAIDS, UNICEF, WHO. *Children and AIDS fourth stocktaking report,2009.* New York, UNAIDS, 2009.
19. Cherutich P et al. Optimizing paediatric HIV care in Kenya: challenges in early infant diagnosis. *Bulletin of the World Health Organization*, 2008, 86:155–160.

20. Plipat T et al. Reduction in mother-to-child transmission of HIV in Thailand, 2001–2003: results from population-based surveillance in six provinces. *AIDS*, 2007, 21:145–151.

21. Anoje C et al. Reducing mother-to-child transmission of HIV: findings from an early infant diagnosis program in south–south region of Nigeria. *BMC Public Health,* 2012, 12:184.

22. Levy PS, Lemeshow S. *Sampling of populations: methods and applications.* New York, Wiley, 1999.

23. Vaessen M, Thiam M, Le T. The demographic and health surveys. In: *Household sample surveys in developing and transition countries.* New York, United Nations, 2007.

24. Shisana O et al. *South African national HIV prevalence, incidence, behaviour and communication survey, 2008: the health of our children.* Cape Town, HSRC Press, 2010.

25. Rehle T et al. Trends in HIV prevalence, incidence, and risk behaviors among children, youth, and adults in South Africa, 2002 to 2008. *17th Conference on Retroviruses and Opportunistic Infections,* San Francisco, California, USA, 16–19 February 2010. Available at: http://retroconference.org/2010/Abstracts/37244.htm (accessed 19 July 2012).

26. Boerma JT, Holt E, Black RE. Biological and clinical data collection in surveys in less developed countries. *Population and Development Review*, 2001, 27:303–314.

27. Instituto Nacional de Saude (INS), Instituto Nacional de Estatistica (INE), ICF Macro. *Inquerito Nacional de Prevalencia, riscos comportamentais e infomacao sobre o HIV e SIDA em Mocambique 2009*. Calverton, MD, INS, INE, ICF Macro, 2010.

28. Rollins N, Little K, Mzolo S, et al. Surveillance of mother-to-child transmission prevention programmes at immunization clinics: the case for universal screening. *AIDS*, 2007, 21:1341–1347.

29. MEASURE Evaluation. *Sample Vital Registration with Verbal Autopsy (SAVVY*). Available at: http://www.cpc.unc.edu/measure/tools/monitoring-evaluation-systems/savvy/ (accessed on 19 July 2012).

30. Hallett TB et al. Measuring and correcting biased child mortality statistics in countries with generalized epidemics of HIV infection. *Bulletin of the World Health Organization*, 2010, 88:761–768.

31. Jahn A et al. Declining child mortality in northern Malawi despite high rates of infection with HIV. *Bulletin of the World Health Organization,* 2010, 88:746–753.

32. FHI, IMPACT. *Behavioral surveillance surveys: guidelines for repeated behavioral surveys in populations at risk of HIV.* Arlington, FHI, 2000. Available at: http://www.fhi.org/en/HIVAIDS/pub/guide/bssguidelines.htm (accessed on 8 November 2011).

33. Schenk K, Williamson J. *Ethical approaches to gathering information from children and adolescents in international settings: guidelines and resources.* Washington, DC, Population Council, 2005.

34. Oladepo O, Fayemi MM. Perceptions about sexual abstinence and knowledge of HIV/AIDS prevention among in-school adolescents in a western Nigerian city. *BMC Public Health,* 2011, 11:304

35. Diarsvitri W et al. Beyond sexual desire and curiosity: sexuality among senior high school students in Papua and West Papua Provinces (Indonesia) and implications for HIV prevention. *Culture, Health and Sexuality,* 2011, 13:1047–1060.

36. UNAIDS, WHO. *Guidelines on surveillance among populations most at risk for HIV.* Geneva, WHO, 2011. Available at: http://whqlibdoc.who.int/publications/2011/9789241501668_eng.pdf (accessed on 8 November 2011).

37. Robbins CL et al. Multicity HIV seroprevalence in street youth, Ukraine. *International Journal of STD and AIDS,* 2010, 21:489–496.

38. Nada KH, Suliman EDA. Violence, abuse, alcohol and drug use, and sexual behaviors among street children of Greater Cairo and Alexandria, Egypt*. AIDS*, 2010, 24(suppl 2):S39–S44.

39. Tun W et al. Sexual risk behaviours and HIV seroprevalence among male sex workers who have sex with men and non-sex workers in Campinas, Brazil. *Sexually Transmitted Infections*, 2008, 84:455–457.

40. Hallett TB et al. Assessing evidence for behaviour change affecting the course of HIV epidemics: a new mathematical modeling approach and application to data from Zimbabwe. *Epidemics,* 2009, 1:108–117.

41. Stover J et al. Estimated HIV trends and program effects in Botswana. *PLoS One,* 2008, 3:e3729.

42. Stover J *AIM: a computer program for making HIV/AIDS projections and examining the demographic and social impacts of AIDS.* Glastonbury, CT, Futures Institute, 2009. Available at: http://data.unaids.org/pub/Manual/2009/20090414_aim_manual_2009_en.pdf (accessed on 19July 2012).

43. Stover J. The Spectrum projection package: improvements in estimating incidence by age and sex, pediatric treatment needs and double orphans. *Sexually Transmitted Infections*, 2010, 86 (suppl 2):ii16–ii21.

44. Brown T, Peerapatanapokin W. The Asian Epidemic Model: a process model for exploring HIV policy and programme alternatives in Asia. *Sexually Transmitted Infections*, 2004, 80 (suppl 1):i19–i24.

45. Global Fund, WHO, UNAIDS. *HIV triangulation resource guide: synthesis of results from multiple data sources for evaluation and decision-making.* Geneva, WHO, 2009.

46. FHI. *Data triangulation for HIV prevention program evaluation in low and concentrated epidemics.* Bangkok, FHI, 2010. Available at: http://www.fhi.org/en/HIVAIDS/pub/res_DataTriangulation.htm (accessed on 8 November 2011).

47. UNAIDS. *An introduction to triangulation*. Geneva, UNAIDS, 2010. Available at: www.unaids.org/en/media/unaids/contentassets/documents/document/2010/10_4-Intro-to-triangulation-MEF.pdf (accessed on 8 November 2011).

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ISBN 978 92 4 150583 3