

Young Key Populations at Higher Risk of HIV in Asia and the Pacific

# MAKING THE CASE WITH STRATEGIC INFORMATION



## Guidance Report



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Design and layout: Quo Keen ([www.quo-global.com](http://www.quo-global.com)), Bangkok, Thailand

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ISBN: 978-974-685-142-8

# Acknowledgements

This guidance is the product of a collaborative effort of a number of agencies and individuals who participated in an expert meeting on the *Methodologies for Obtaining Strategic Information on Young People at Higher Risk of HIV Exposure*, held in Bangkok, Thailand, from 3<sup>rd</sup> - 5<sup>th</sup> of September, 2012. This meeting brought together approximately 50 experts in HIV and behavioural surveillance, population size estimation, survey design and implementation, child advocates specializing on ethical issues regarding the inclusion of children in data collection, and innovators examining the use of new media and technologies for data collection among young key populations at higher risk. Attendees shared information and identified good practices through the presentation of experiences from government, civil society, the UN and other development partners, and research institutes and academic partners. This meeting was jointly organized and co-funded by the UNICEF East Asia and the Pacific Regional Office and the UNICEF Regional Office for South Asia, the UNESCO Asia-Pacific Regional Bureau for Education, the UNFPA Asia and Pacific Regional Office, and the UNAIDS Regional Support Team for Asia and the Pacific. Additional funding support was secured from AusAid's International Seminar Support Scheme for select participants from the region.

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# Acronyms

CRC	Convention on the Rights of the Child
GARP	Global AIDS Response Progress Report
GFATM	The Global Fund to Fight AIDS, Tuberculosis and Malaria
HTC	HIV testing and counselling
IBBS	Integrated Biological and Behavioural Survey
NAC	National AIDS Council
NACP	National AIDS Control Programme
NCCWD	National Commission on Child Welfare and Development
NGO	Non-governmental organization
RDS	Respondent-driven sampling
STI	Sexually transmitted infection
TLS	Time location sampling
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNDP	United Nations Development Programme
UNFPA	United Nations Population Fund
UNGASS	United Nations General Assembly Special Session on AIDS
UNICEF	United Nations Children's Fund
WHO	World Health Organization



# Terminology

**Adolescents** – Anyone between the ages of 10 and 19 years.<sup>1</sup>

**Child/Children** – Anyone under the age of 18 years,<sup>2</sup> unless the laws of a particular country set a younger legal age for adulthood.

**Key populations at higher risk of HIV exposure** – Anyone who is most likely to be exposed to HIV or to transmit it. In all countries, key populations include people living with HIV. In most settings, men who have sex with men, transgender persons, people who inject drugs, sex workers and their clients, and seronegative partners in serodiscordant couples are at higher risk of HIV exposure to HIV than other people.<sup>3</sup>

**Youth** – Anyone between the ages of 15 and 24 years.<sup>4</sup>

**Young people** – Anyone between the ages of 10 and 24 years.<sup>5</sup>

**Young key populations at higher risk of HIV exposure** – Anyone between the ages of 10 and 24 years<sup>6</sup> who is most likely to be exposed to HIV or to transmit it.<sup>7</sup>

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1 See WHO. Adolescent Health. Accessed at [http://www.who.int/topics/adolescent\\_health/en/](http://www.who.int/topics/adolescent_health/en/)

2 UNICEF. (1990) Fact sheet: A summary of the rights under the Convention on the Rights of the Child. Geneva, Switzerland. Accessed at: [www2.ohchr.org/english/law/pdf/crc.pdf](http://www2.ohchr.org/english/law/pdf/crc.pdf)

3 UNAIDS. (2011) UNAIDS Terminology Guidelines. Geneva, Switzerland. Accessed at: <http://www.UNAIDS.org>.

4 See UNESCO. What do we mean by “youth”? Accessed at: <http://www.unesco.org/new/en/social-and-human-sciences/themes/youth/youth-definition/>

5 UNICEF, UNFPA. (Undated) Guidance Brief: Community-based HIV Interventions for Young People. Geneva, Switzerland. Accessed at: [www.unfpa.org/hiv/iatt/docs/unicef.pdf](http://www.unfpa.org/hiv/iatt/docs/unicef.pdf)

6 IBID

7 UNAIDS. (2011) UNAIDS Terminology Guidelines. Geneva, Switzerland. Accessed at: <http://www.UNAIDS.org>.

# 1. OVERVIEW

## 1.1 What is this document for and how is it used?

The rationale for developing this guidance is to provide recommendations for collecting and reporting information about *young key populations at higher risk for HIV exposure* (henceforth, *young key populations*) in order to improve the availability and usefulness of **strategic information**.

### What is strategic information?

In relation to HIV, strategic information is data and knowledge that guides HIV prevention policy, planning and responses, and monitors progress and accountability in achieving programme goals and objectives.

#### **Sources of strategic information** include:

- 1) Existing information to define and understand the current situational and behavioural risks and vulnerabilities that increase exposure to HIV and other infections (this is examined in the section: *Building the case*).
- 2) Newly collected information to increase knowledge and fill in informational gaps (this is examined in the section: *Methodological considerations for collecting strategic information about young key populations*).

For more information, see:

WHO. (2010) HIV/AIDS Prevention, Treatment and Care in the Health Sector. Geneva, Switzerland. Accessed at: <http://www.who.int/hiv/pub/guidelines/9789241500234/en/index.html>.

UNAIDS has developed tools and guidelines to assist countries to strengthen HIV strategic information systems.

For more information, see: UNAIDS. (2007) Practical Guidelines for Intensifying HIV Prevention: Towards Universal. Geneva, Switzerland. Accessed at: <http://www.unaids.org/en/resources/presscentre/featurestories/2007/march/20070306preventionguidelines/>

Specifically, the age groups under consideration for this guidance are 10-14, 15-19, and 20-24 year olds. Typically, key populations include:

- Males who have sex with males;
- Sex workers and their clients;
- Transgender persons;
- Seronegative partners in serodiscordant couples;
- People who inject drugs; and
- People living with HIV.<sup>8</sup>

Vulnerability plays a key role in HIV exposure and transmission risk. Increased risk of HIV exposure and transmission is linked to various kinds of mobility, living situation (young people [ages of 10 and 24 years] who live on the street), exploitation (young people who are sexually exploited and/or trafficked) and abuse. Countries should define the specific populations that are key to their epidemic and response based on the epidemiological and social context.<sup>9</sup>

Asia and the Pacific are currently at the forefront of data collection among key populations. All countries in the region gather HIV sentinel surveillance data, and most have implemented one or more rounds of Integrated Biological and Behavioural Surveys (IBBS).<sup>10</sup> However, many of these surveillance activities do not collect data from persons under the age of 18 years. For instance, 20 of 31<sup>11</sup> country HIV surveillance systems in Asia and the Pacific region included persons under the age of 18 years.

Among those surveillance activities that do collect data from key populations under the age of 18 years, most fail to collect data for a reasonable proportion of persons in this age group to be analysed separately and/or few do not report data specific to these younger age groups.<sup>12</sup> For instance, fewer than 50 per cent of all 38 countries in the Asia and Pacific region reported key indicators (HIV prevalence and testing, condom use, access to prevention programmes and safe injecting practises [IDU only]) for key populations under the age of 25 years in the Global AIDS Response Progress Report (GARP) of 2012.<sup>13</sup>

In 2008, more than 95 per cent of all new HIV infections among young people in Asia were estimated to occur among young key populations,<sup>14</sup> presenting clear evidence that young people are engaging in risky behaviours.<sup>15,16</sup>

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8 UNAIDS. (2011) UNAIDS Terminology Guidelines. Geneva, Switzerland. Accessed at: <http://www.UNAIDS.org>

9 IBID.

10 See: HIV and AIDS Data Hub. Bangkok, Thailand. <http://www.aidsdatahub.org/en/reference-librarycols2/surveillance-situational-analysis-assessments/itemlist/category/38-integrated-biological-and-behavioral-surveillance-and-assessment-reports>

11 Afghanistan, Bangladesh, Cambodia, China, Fiji, India, Indonesia, Lao PDR, Malaysia, Maldives, Mongolia, Myanmar, Nepal, Pakistan, the Philippines, Papua New Guinea, Sri Lanka, Thailand, Timor-Leste and Viet Nam.

12 Amala Reddy. Regional Review of Strategic Information on Young Key Populations at Higher Risk of HIV Exposure. Presented at Methodologies for obtaining strategic information on young people at higher risk of HIV exposure, Thailand, September 3-5, 2012. Accessed at: <http://aidsdatahub.org/en/regional-profiles/key-presentations/item/24335-regional-review-of-strategic-information-on-young-key-populations-at-higher-risk-of-hiv-reddy-a-unais-rst-2012>

13 IBID.

14 Commission on AIDS in Asia (2008). Redefining AIDS in Asia: Crafting an Effective Response. Accessed at: <http://www.unaids.org/en/resources/presscentre/featurestories/2008/march/20080326asiacommission/>

15 The Asia Pacific Coalition on Male Sexual Health (APCOM). (2012) Addressing the Needs of Young Men who have Sex with Men. Bangkok, Thailand. Accessed at: <http://www.aidsdatahub.org/en/reference-librarycols2/hiv-prevention/item/24271-apcom-policy-brief-addressing-the-needs-of-young-men-who-have-sex-with-men-july2012>

16 UNAIDS (2011). HIV in the Asia and Pacific UNAIDS: Getting to Zero. Geneva, Switzerland. Accessed at: <http://www.hivapcop.org/resource/hiv-asia-and-pacific-unais-getting-zero>

Based on available data, young key populations in many Asia and Pacific region countries have a greater incidence of high risk behaviours compared to their adult counterparts (25 years and older). For instance, lower percentages ( $\geq 5$  per cent difference) of:<sup>17</sup>

- Young people who inject drugs in Indonesia and China used sterile injecting equipment during their last injection compared to older people who inject drugs.
- Young female sex workers in Myanmar, Papua New Guinea, Mongolia, China, Thailand, Sri Lanka, Lao PDR, and the Philippines have had an HIV test compared to older female sex workers.
- Young female and male sex workers in Myanmar, Mongolia, and Viet Nam were reached by a prevention programme compared to older sex workers.
- Young males who have sex with males in Bangladesh, Nepal, the Philippines, Thailand and Viet Nam had comprehensive HIV knowledge compared to older males who have sex with males.

The above available evidence demonstrates the urgent need:

- to consistently include persons 10-14, 15-19 and 20-24 year olds in HIV surveillance activities and surveys; and
- to provide the systematic disaggregation of data for those between the ages of 15-19 years and 20-24 years, and, if possible, between the ages of 10-14 years.

These data are essential for informing advocacy, policy development, planning and programming, national and international monitoring and reporting, and allocating funds. Nonetheless, these have been inadequate for a long time. This has led to a situation whereby HIV prevalence and incidence, as well as HIV related behavioural risk, knowledge, service access and size estimations, are not being accurately monitored among young key populations. Only by improving the collection and reporting of strategic information on young key populations can the United Nations General Assembly member states' commitment of reducing sexual transmission of HIV by 50 per cent by 2015<sup>18</sup> be met, leading to the UNAIDS vision of "Getting to Zero New HIV Infections".

## 1.2 Who the guidance is for?

This guidance is for national HIV and AIDS programme planners and managers and those working in local, national and international governmental and non-governmental organizations which commission, collect, and use data about young key populations to advocate for policies and funding for strengthening programme service delivery. Although this guidance is focused on the Asia and Pacific region, it may also have wider global application.

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17 Amala Reddy. Regional Review of Strategic Information on Young Key Populations at Higher Risk of HIV Exposure. Presented at Methodologies for Obtaining Strategic Information on Young People at Higher Risk of HIV Exposure, Thailand, September 3-5, 2012. Accessed at: <http://aidsdatahub.org/en/regional-profiles/key-presentations/item/24335-regional-review-of-strategic-information-on-young-key-populations-at-higher-risk-of-hiv-reddy-a-unaid-rst-2012>

18 UNAIDS (2011). HIV in the Asia and Pacific UNAIDS: Getting to Zero. Geneva, Switzerland. Accessed at: <http://www.hivapcop.org/resource/hiv-asia-and-pacific-unaid-getting-zero>

## 1.3 How this guidance was developed?

This guidance was developed based on experience sharing and problem solving from an expert meeting on *Methodologies for Obtaining Strategic Information on Young People at Higher Risk of HIV Exposure*, held in Bangkok, Thailand, from 3<sup>rd</sup> to 5<sup>th</sup> of September, 2012. This meeting facilitated the sharing of knowledge, and exchange of ideas and experiences in the collection, analysis and utilization of strategic information on young key populations. Main themes discussed over the three-day meeting included methodological and ethical issues, and support for data collection to provide evidence for including young key populations in data collection and reporting.

Open spaces were created during the meeting to allow participants time to share experiences, using participatory methodologies such as ‘gallery walks’ (participants work in teams to address topics related to collecting strategic information on young key populations) and the ‘world café’ (small group presentations of methodologies used to collect strategic information on young key populations). The latter provided participants with the opportunity to share what they felt would be most useful to include in this guidance report.

During the development of the guidance document, inputs were provided by members of the Strategic Information Guidance core team (UNICEF EAPRO and ROSA, UNESCO Bangkok, UNFPA APRO and UNAIDS RSTAP), participants at the expert meeting, colleagues from the Child Protection Section, UNICEF EAPRO and country offices. Colleagues from UNFPA and UNICEF Headquarters in New York and UNAIDS Geneva provided inputs. In addition, numerous reports, technical manuals and existing guidance were reviewed to improve the quality of information provided in this guidance.

## 1.4 What is this guidance for?

This guidance is intended to help countries strengthen the availability and use of strategic information to guide HIV programmes and responses targeting young key populations. Specifically this guidance provides recommendations and examples on how to:

- Ethically involve young key populations in research;
- ‘Build the case’ to encourage national and international programmes to collect and present HIV related disaggregated data on young key populations;
- Select and implement data collection methodologies for hard to reach populations; and
- Estimate the population sizes of young key populations.

This document does not provide step-by-step details on how to implement data collection methodologies. It offers references to a host of useful resources, but focuses on issues that are pertinent to using existing data collection methods with young key populations.

## 1.5 How this guidance can be used?

This guidance can be used as a reference tool in the planning, collection and dissemination of data among young key populations. At the end of most sections, references and links to useful resources are provided for further information.

## 2. ETHICAL ISSUES

In almost all countries, children are entitled to the protection of their rights under the Convention on the Rights of the Child (CRC), with Article 1 indicating that ‘children’ are defined as those persons under age 18, except where age of majority is attained earlier under national law.<sup>19</sup> Compared to adults, children are more vulnerable to exploitation, abuse, violence and other harmful outcomes of research and therefore require additional safeguards. Although informed consent from children is required in order for them to participate in research, consent from the child’s parent or guardian is usually also necessary. Therefore, it is important to ensure that data collection from children is necessary and justified, and that the best interests of the child have been given careful consideration. The inclusion of children in appropriate and relevant data collection activities will require building consensus of the value of their inclusion and promoting their right to participation, while at the same time, ensuring that they are protected from harm.

Below are some key areas to consider when developing ethical parameters of data collection involving children. Data collection methodologies can include face-to-face interviews, self-administered questionnaires and data acquired from groups, such as focus groups. This section of the guidance is borrowed from several resources identified at the end and organized in the following sub-sections:

1. Obtaining informed consent for studies involving children;
2. Domestic laws governing child protection;
3. Identification of and referral to services for children;
4. Interview location and data collection tools;
5. Staff training and support;
6. Use of incentives; and
7. Biological testing.

### 2.1 Obtaining informed consent for studies involving children

Before collecting data from children, governments need to be convinced of the importance of their inclusion in the research and the efforts to ensure their safety. This can be accomplished by working directly with governmental and non-governmental organizations (NGOs), involving the community (including parents) and by being fully aware of national laws and guidelines governing the collection of data from children.

Before collecting data from children (or other human subjects), it is essential to develop a research protocol that incorporates ethical guidance in line with standards endorsed by the national ethical review board, if

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19 UNICEF. (1990) Fact sheet: A summary of the rights under the Convention on the Rights of the Child. Geneva, Switzerland. Accessed at: [www2.ohchr.org/english/law/pdf/crc.pdf](http://www2.ohchr.org/english/law/pdf/crc.pdf)

one exists in the country where the research is to be conducted, or the institutional ethical review board of an associated institution. Informed consent for any population should include the provision of information on the purpose of the research, issues concerning confidentiality, a contact number in case the participant would like to learn more about the study or to make a complaint, an explanation that the participant does not have to answer questions with which he/she does not feel comfortable, and that the interview can be stopped at any time.

### **Box 1. Obtaining informed consent of children in the Philippines**

In 2009, a committee, consisting of a broad range of HIV and child protection stakeholders from government and civil society, reviewed data availability and challenges to the HIV response. While maintaining the principle of the best interest of the child, data about children was considered of critical importance to deliver prevention interventions and services. Concepts of evolving capacity and competence were considered. The committee agreed to make an exception from the principle of parental consent and to allow children to be involved in research without parental consent. There was interviewer training and the availability of psychosocial referrals for children or anyone in need. To operationalize informed consent, children were required to repeat the following four key items in order to participate:

1. participation is voluntary;
2. information is confidential;
3. participation involves an interview and blood draw with testing; and
4. participation will help improve services for the participant.

This survey also led to improvements in training HIV testing and counselling staff to work with youth and social workers to agree to act as consenting guardians. Since 2009, the minimum age for inclusion in the IBBS has been 15 years.

Source: Samonte GM. Capturing younger cohorts through surveillance systems: Philippines. Methodologies for obtaining strategic information on young people at higher risk of HIV exposure, Thailand, September 3-5, 2012.

In addition, it is important for the research team to:

1. Meet with and receive inputs from all relevant groups and agencies when designing a protocol and consent form.
2. Determine which children will also require parental/guardian consent. For instance in some countries:
  - The age of majority is younger than 18 years and children under that age will not require consent by their parents or guardians.
3. Children who have married, who are living independently or who live in child-headed households may be considered 'liberated minors' and thus may not require additional consent from a parent/guardian.
4. When requesting consent for a survey on sensitive issues from a parent or guardian on behalf of a child, it may be necessary to keep the nature of the survey vague. For instance, for a survey on sexual risk and drug use, mention the survey as a 'health' survey and list sex and drugs as one of many health issues being assessed.

5. Design a consent form which uses language that is easy for children to understand.
6. Provide the opportunity for children to express their views in a non-intrusive manner, while ensuring that their best interests are fully upheld.<sup>20</sup>

## 2.2 Domestic laws governing child protection

Some countries have specific regulations that any disclosures of violence, abuse, neglect or exploitation of a child would override confidentiality and must be reported to relevant authorities. In some countries it may be mandatory for government employees or particular professions (social workers, health workers, teachers, etc.) or any person who is aware of an incident to report it. If there are no exemptions for mandatory reporting for the purposes of research, it may be possible to receive a waiver from an appropriate authority so that interviewers are not required to report disclosures of abuse, without the child's approval. If specific professions are required to report disclosures, research teams may not want to include these professionals as data collectors. Below are some considerations when reviewing mandatory reporting laws:

1. Review the domestic laws about mandatory reporting of disclosures of child abuse, neglect, violence or exploitation and consider how mandatory reporting would affect the final outcome of the research (e.g., will children refuse to participate if they know that their information is not confidential? Will children refuse to report certain types of information? etc.) and decide whether a waiver is needed.
2. Discuss issues of including or waiving mandatory reporting with key persons including child protection officials, social workers, child rights advocates, and partner agencies. Approval of such waivers may only be possible through the national ethical review board or a senior level child protection authority.

## 2.3 Identification of and referral to services for children

To the extent that they exist, research planners should identify referral services for children as soon as research locations are selected.

1. Identify and develop a comprehensive list of potential services for children (services should not only include those that can address issues of violence, abuse, neglect or exploitation, but also general services such as drop-in centres and shelters, helplines, government and non-governmental social welfare services, vocational training, additional schooling programmes, health care, legal aid, etc., to respond to the special situations of high risk children [and all young key populations]). This list of services should be provided to all children who participate in a study, whether or not they disclose harm of high-risk behaviours. The list should be presented in such a way so that non-participants will not find the list and be able to identify which specific service a participant may need to access (i.e., do not have a list only containing referrals for those who need sexual abuse counselling or detoxification from drugs). The types of available services on the list should be explained in the child's native language.
2. Ensure that research protocols include clear procedures for making discreet, direct referrals to particular service providers, should the child participant make a request for such assistance. Unless there are mandatory reporting requirements for this study, confidentiality must be respected.

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20 Borrowed and adapted from: UNICEF CEE/CIS. (2007) Ethical Issues in Conducting Research with Adolescents Engaging in HIV Risk Behaviour. Geneva, Switzerland. Accessed at: [www.unicef.org/ceecis/Ethical-Protection\\_Guidance\\_for\\_MARA\\_Programming\\_Working\\_Doc.pdf](http://www.unicef.org/ceecis/Ethical-Protection_Guidance_for_MARA_Programming_Working_Doc.pdf)



3. Work with qualified child protection and health professionals in order to establish quality criteria and meet with potential service providers to assess their capacity, expertise and resources to respond to direct referrals, including how they can respond to urgent or acute cases of child abuse, neglect, violence or exploitation. Ensure that such providers can meet the standards of confidentiality.
4. If no services exist in the research site or are equipped to respond to referrals from children in your research, consider establishing a temporary team of trained service providers to whom children can be referred during and shortly following data collection. You may want to consider providing transportation arrangements so that service providers in nearby areas can meet with children who request support. Such arrangements should only be planned in cooperation with qualified child protection and health professionals.
5. Develop plans to determine how to accommodate children needing long-term and/or specialized support beyond your research. The costs, logistics and human resources needed to provide support to children involved in research must be included in the budget for the survey.

## 2.4 Interview location and data collection tools

If using a fixed interview location, select a setting that is accessible, safe, private and comfortable for children. As children of younger ages have different cognitive abilities and attention spans compared to children of older ages, questionnaires and other materials must be designed in conjunction with experts to ensure that they are appropriate for children. Make sure feedback on the questionnaire is obtained from all stakeholders, including children, to translate locally and back-translate them, to pilot-test them with the target population and make changes accordingly.

## 2.5 Staff training and support

Interviewers and other staff should already have experience working with children, especially children who are part of young key populations.

1. Train staff about the research protocol, questionnaire, obtainment of informed consent and referral process.
2. Train staff on how to deal with a child who is distressed (e.g. active listening, non-physical de-escalation techniques, etc.).
3. Ensure that staff know the content of the consent form and are trained on acquiring informed consent from children and/or their parent or guardian without coercing the child.
4. Provide support to staff who may be emotionally impacted by their exposure to children who sell sex, use drugs, have experienced violence or have other risks and vulnerabilities.

## 2.6 Use of incentives

In some countries, incentives for participation in research are not allowed by ethical review boards. If incentives are allowed or even encouraged, it is important to consider the following issues:

1. Do the country's ethical standards (often the internal review board associated with the Ministry of Health) for research allow for incentives to be provided to children? If so, what are the standards?
2. Is there a type of incentive that is appropriate for children (e.g., soap, food, phone card, money, etc.)?<sup>21</sup>
3. Ensure that incentives do not induce a child's participation (e.g. If it were not for the incentive provided, the participant would not enrol in a survey or would not withdraw from the survey early, given his or her better judgment)?

### Box 2. Non-coercive incentives for children

Numerous meetings were held with the technical working group (survey planners, NGOs, children and community members) to determine an appropriate incentive for an upcoming survey of street-working children in Eastern Europe. During the meetings, it was decided that incentives needed to be carefully selected in order to avoid inappropriate pressure on children to participate in the survey. It was noted that children and families living in poverty could be especially vulnerable to inducement and that some children might be pressured by friends and family members to participate in a survey. One idea was to give a donation or gift of school supplies to an organization or school that works with the children. Although this was an excellent idea, the group did not think the children in this survey would benefit since many neither use the organizations nor go to school. Another idea was to give the children the equivalent of a bus ride across the city (an estimation of how much it would cost them to travel to and from the survey location). Others suggested giving food or school supplies. In the end, it was agreed that children participating in the survey could receive a token for local transportation, a piece of fruit or fruit juice and a pen or notepad.

Source: Johnston LG, Thurman TR, Mock N, Nano L, Carcani V. 'Respondent-driven sampling: A new method for studying street children with findings from Albania'. *Vulnerable Children and Youth Studies*. 2010. 5(1): 1-11.

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21 See page 50 and 51 of: Schenk, Katie and Jan Williamson. (2005) Ethical Approaches to Gathering Information from Children and Adolescents in International Settings: Guidelines and Resources. Washington, DC: Population Council. Accessed at: [www.popcouncil.org/pdfs/horizons/childrenethics.pdf](http://www.popcouncil.org/pdfs/horizons/childrenethics.pdf)

## 2.7 Biological testing

HIV and other infection testing among children require numerous considerations. Parents and guardians will need to be informed of the specimens collected, the types of tests conducted and may even be entitled to the results of those tests. If results for sensitive tests must be shared with a parent or guardian, many children may not consent to being tested which will likely affect the outcome of your study. When considering the inclusion of a biological component in your research, find out:

1. Whether the country's ethical standards allow testing on children. If so, what are the laws governing the testing of children for HIV and other infections related to sexual behaviour and drug use?
2. How are pre- and post-test counselling conducted and how are test results provided to children and/or parents and guardians?
3. Whether there are available and appropriate referrals for care, management and treatment for children with positive test results (see 2.3 *Identification of and referral to services for children*).

*For further information on ethical considerations for children, please refer to:*

1. UNICEF Regional Office for CEE/CIS. (2008) Guidance on Ethical Issues in Conducting Quantitative Research with Adolescents Engaging in HIV Risk Behaviour. UNICEF Regional Office for CEE/CIS, Geneva, Switzerland. Accessed at: [www.unicef.org/ceecis/Ethical-Protection\\_Guidance\\_for\\_MARA\\_Programmemeing\\_Working\\_Doc.pdf](http://www.unicef.org/ceecis/Ethical-Protection_Guidance_for_MARA_Programmemeing_Working_Doc.pdf)
2. Save the Children. (2004) So You Want to Involve Children in Research?: A toolkit supporting children's meaningful and ethical participation in research relating to violence against children. Accessed at: <http://www.savethechildren.org.uk/resources/online-library/so-you-want-involve-children-research>
3. Chong E, Hallman K, Brady M. (2006) Investing When It Counts - Generating the evidence base for policies and programmes for very young adolescents: Guide and tool kit. New York: UNFPA and Population Council. Accessed at: [http://www.unfpa.org/upload/lib\\_pub\\_file/583\\_filename\\_investing.pdf](http://www.unfpa.org/upload/lib_pub_file/583_filename_investing.pdf)
4. Schenk, Katie and Jan Williamson. (2005) Ethical Approaches to Gathering Information from Children and Adolescents in International Settings: Guidelines and Resources. Washington, DC: Population Council. Accessed at: [www.popcouncil.org/pdfs/horizons/childrenethics.pdf](http://www.popcouncil.org/pdfs/horizons/childrenethics.pdf)
5. UNICEF/EAPRO. (2013) Guidance note on response planning for the National Baseline Surveys on Violence against Children. Internal discussion paper. Bangkok, Thailand.
6. UNICEF. (2007) Implementation Handbook for the Convention on the Rights of the Child: Fully Revised Third Edition. Geneva, Switzerland Accessed at: [http://www.unicef.org/publications/index\\_43110.html](http://www.unicef.org/publications/index_43110.html)
7. Council for International Organizations of Medical Sciences (CIOMS), WHO. (2008) International Ethical Guidelines for Epidemiological Studies. Geneva, Switzerland. Accessed at <http://www.who.int/ethics/research/en/>

# 3. BUILDING THE CASE

## 3.1 What needs to happen to ‘build the case’?

In order to ‘spotlight’ the situation of young key populations, researchers, decision-makers, programme planners and funding sources need to demonstrate to policy-makers why young key populations are important in their countries by quantifying their risk of HIV exposure and transmission, and justifying the extent to which young key populations should be a priority.

When there is a lack of quantitative data, building a strong case to justify the inclusion of young key populations can be accomplished through the collection of qualitative data and use of existing data sources, which may include qualitative and/or quantitative sources.

## 3.2 Building the case with qualitative methods

Use qualitative methods to build the case. Qualitative methods, as opposed to most quantitative methods, are usually less expensive, require less time and are easier to implement. Data collected through qualitative methods are often less rigorous than quantitative methods since they do not require large sample sizes and do not produce information that is statistically representative of the target population. However, there are standards that can be met in order to increase validity and reliability of qualitative research findings.

Qualitative methods can help demonstrate that young key populations exist and build up knowledge of their risk behaviours. Qualitative research is most useful when little is known about the population and can help to better inform the design of quantitative research. This is particularly important for understanding the needs of young people who do not identify with ‘key populations’ but are behaviourally at risk. Unexpected findings from quantitative research may need to be validated with qualitative research. For instance, further qualitative research may be warranted to learn more about findings that young injectors are using a previously unknown type of drug or that young sex workers are engaging in a previously unheard of behaviour.

There are many methods that can be used to gather qualitative data:

- *Participant observation*, used for collecting data about naturally occurring behaviours in their usual contexts, such as where young key populations ‘hang out’ with friends and peers and the types of activities they engage in.
- *In-depth interviews*, used for collecting data about individuals’ personal histories, perspectives, and experiences, particularly when sensitive topics are being explored.

- *Expert interviews*, used for collecting data about young key populations from persons working or in contact with young key populations.
- *Focus groups*, used for eliciting data on the cultural norms of a group and in generating broad overviews of issues of concern to young key populations.
- *Mapping*, used to identify and record sites where young key populations spend time, meet friends, find new sex partners, buy or sell drugs, etc. Some mapping strategies will also interview people at a site in order to characterize them and to map the sites where they are found.

### Box 3. Using targeted studies to build the case for lowering age cohorts in IBBS

In Pakistan, a geographical mapping and behavioural survey of adolescents 10-19 years-old living full time on the streets, engaging in sex work, and/or injecting drugs in seven districts was conducted to differentiate adolescents vulnerable to and at risk for HIV. Findings revealed that over 17 per cent of those mapped were engaged either solely in sex work or had been involved in a sexual exchange. Over half of the adolescents interviewed in the behavioural survey (51 per cent) had already had sex, 43 per cent for some gain and 38 per cent had paid for it in the last month. The mean age of adolescents mapped was 14.5 years of age. These findings, coupled with findings that 46 per cent of male sex workers mapped to be 15-19 years of age, were used to advocate with the government of Pakistan to lower the age of eligibility for the 4<sup>th</sup> Round of the IBBS survey from 15 to 13 years old.

Source: Emmanuel F. University of Manitoba. Presented by Schunter B, UNICEF EAPRO, Methodologies for Obtaining Strategic Information on Young People at Higher Risk of HIV Exposure, Thailand, September 3-5, 2012.

Using a mixed method approach to conduct a rapid assessment is useful in providing a broad range of information. Rapid assessments are conducted in situations where data are needed quickly, where time or cost constraints rule out the use of other, more conventional research techniques, and where stakeholders require current and relevant data. In addition there are comprehensive mapping techniques, such as, ethnographic mapping or the Priorities for Local AIDS Control Efforts (PLACE) method. Both of these methods use key informants to identify sites where young key populations spend time, meet friends, find new sex partners, buy or sell drugs.

*For further information on qualitative research and mapping, please refer to:*

FHI 360 (2012) Qualitative Research Methods: A Data Collector's Field Guide. Arlington, VA. Accessed at: [www.fhi360.org/en/RH/Pubs/booksReports/QRM\\_datacoll.htm](http://www.fhi360.org/en/RH/Pubs/booksReports/QRM_datacoll.htm)

*For examples of ethnographic mapping in the region, please refer to:*

HIV and AIDS Data Hub for Asia and the Pacific (hereafter, referred to as Data Hub) at: <http://aidsdatahub.org/en/component/acesearch/search?query=Mapping>

#### Box 4. Using multiple qualitative methods to build the case in Lao PDR

In Lao PDR, a rapid assessment was conducted among 65 adolescents and young people at risk of HIV as well as seven service providers. Data collection techniques included focus groups, and in-depth and expert interviews using semi-structured topic guides. Participants were found through observational techniques and network organizations working with lesbian, gay, bisexual and transgender persons, sex workers and people who use and/or inject drugs. Findings indicated that young key populations practice HIV high-risk behaviours. This information was used to demonstrate the need for further research about the risk of HIV infection among adolescents and young people in Lao PDR, and to advocate for the inclusion of age disaggregated data in HIV and STI epidemiological and surveillance research.

Source: UNICEF. (2011) Rapid Assessment: Most-at-Risk Adolescents and Young People to HIV in Lao PDR. Accessed at: [http://aidsdatahub.org/dmdocuments/Rapid\\_assessment\\_MARA\\_Young\\_people\\_Lao.pdf](http://aidsdatahub.org/dmdocuments/Rapid_assessment_MARA_Young_people_Lao.pdf). Also, hand outs at the Methodologies for Obtaining Strategic Information on Young People at Higher Risk of HIV Exposure, Thailand, September 3-5, 2012.

*For tools on how to conduct a rapid assessment, please refer to:*

1. UNICEF. (2002) Rapid Assessment and Response on HIV/AIDS Among Especially Vulnerable Young People in Albania. Geneva, Switzerland. Accessed at: <http://www.unicef.org/albania/hivaidsalbania.pdf>
2. WHO. (1998) Rapid Assessment and Response Guide on Psychoactive Substance Use and Especially Vulnerable Young People (EVYP-RAR). Geneva, Switzerland. Accessed at: [http://www.who.int/substance\\_abuse/publications/epidemiology/en/](http://www.who.int/substance_abuse/publications/epidemiology/en/)
3. WHO. (2003) Rapid Assessment and Response Technical Guide, Version 1.0. Geneva, Switzerland, Department of Child and Adolescent Health and Development/HIV/AIDS. Accessed at: <http://www.who.int/docstore/hiv/Core/Index.html>
4. WHO. (2004) Rapid Assessment and Response Adaptation Guide on HIV and Men Who Have Sex with Men. Geneva, Switzerland. Accessed at: [http://www.who.int/hiv/pub/prev\\_care/en/msmrrar.pdf](http://www.who.int/hiv/pub/prev_care/en/msmrrar.pdf)

*For further information on PLACE method, please refer to:*

1. MEASURE Evaluation. Introduction: An Overview of the PLACE Method. Chapel Hill, NC. Accessed at: <https://training.measureevaluation.org/non-certificate-courses/place/introduction>
2. MEASURE Evaluation. PLACE: Priorities for Local AIDS Control Efforts. Chapel Hill, NC. Accessed at: <http://www.cpc.unc.edu/measure/tools/hiv-aids/place>

### 3.3 Building the case with existing data

Numerous existing data sources may be available to build the case. It is important to assess the quality and accessibility of secondary data sources. Some sources may not be readily available or easily located by researchers to provide answers to specific questions related to young key populations or may not be of good quality.

#### **1. Use secondary data sources from large-scale quantitative surveys**

Secondary data analysis involves using data collected by someone else for a purpose other than that for which the data were originally collected. The most useful secondary data sources may be from surveys conducted among key populations, especially HIV IBBS, behavioural surveillance data and other sexual risk surveys. Many reports from these types of surveys conducted in the Asia and Pacific Region can be found at the Data Hub website: [www.aidsdatahub.org](http://www.aidsdatahub.org)

Other useful secondary data sources are the Multiple Indicator Cluster Surveys (MICS) (<http://www.childinfo.org/>) and Demographic and Health Surveys (<http://www.measuredhs.com>), both of which sample age groups 15 and above, and include questions about sexual behaviours, illness, social risks, substance use, as well as GARP (formally UNGASS: <http://www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2012countries/>) targets on HIV/AIDS.<sup>22</sup>

Accessing actual data and conducting further analysis with age disaggregation may help to document trends (e.g., HIV infection and risk, socio-demographic information, etc.) with younger members of key populations that may have been missed in the original analysis.

**2. Use published data from quantitative surveys on adults** to learn more about their behaviours when they were younger. Many surveys about sexual risk include questions such as:

- “At what age did you first have sexual intercourse?”
- “At what age did you first sell sex in exchange for money?”
- “At what age did you first have anal penetrative sex with a man?”
- “At what age did you first inject drugs?”
- “Have you ever been forced to have sex?” and, if so “At what age?”

In addition, many of these types of questions have follow up questions such as:

- “Did you use a condom the first time you had sex?”
- “Did you share a needle the first time you injected drugs?”

These types of questions are usually included in HIV IBBS and sometimes in sentinel surveillance data, which have normally been conducted on adults, ages 18 and above.

For access to regional IBBS reports go to the Data Hub at: <http://aidsdatahub.org/en/reference-librarycols2/surveillance-situational-analysis-assessment>

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22 UNAIDS. Global AIDS Response Progress Reporting: Guidelines Construction of Core Indicators for Monitoring the 2011 Political Declaration on HIV/AIDS (2012). Geneva, Switzerland. Accessed at: <http://search.unaids.org/search.asp?lg=en&search=UNAIDS%20online%20location%20for%20available%20GARP%20FUNGASS%20>

### **3. Conduct a literature review** by using:

- Existing peer-reviewed scientific literature (sources specific and not-specific to young people)
- Abstracts from regional and international AIDS conferences
- *Grey literature* (literature that is not formally published in easily accessible journals or databases, e.g., programme evaluations and governmental reports)
- Needs assessments
- Situational analyses
- Survey reports
- Epidemiological factsheets

Peer-reviewed literature can be located using internet-based search engines, such as Entrez PubMed from the U.S. National Library of Medicine (<http://www.ncbi.nlm.nih.gov/pubmed>). Particular care needs to be taken with specifying keywords and search terms. For instance, do not make the terms so general (for example, HIV) that too much information will be identified, and do not make the terms so specific that nothing will be found. One good approach is to start with the name of a country, the keyword *youth* and *HIV*. For instance, using *Vietnam Youth HIV* more than 15 hits came up on a simple Google search. As information is found, additional search terms can be added, such as, the name of a specific key population. Once data sources have been identified, accessed and reviewed, their bibliographies should be reviewed to identify other sources.

Grey literature can also be located using the Internet. Good sources of HIV information for the Asia and Pacific region can be accessed at the Data Hub website [www.aidsdatahub.org/](http://www.aidsdatahub.org/), the UNICEF website at [www.unicef.org/eapro](http://www.unicef.org/eapro), and the UNAIDS website at [www.unaids.org/en/regionscountries/regions/asiaandpacific/](http://www.unaids.org/en/regionscountries/regions/asiaandpacific/). In addition, governments, donors or INGOs (Care International at [www.care-international.org](http://www.care-international.org), FHI 360 at [www.fhi360.org](http://www.fhi360.org), Population Services International at [www.psi.org](http://www.psi.org), Population Council at [www.popcouncil.org](http://www.popcouncil.org), etc.) produce monitoring and evaluation reports, which can be accessed through the Internet.

### **4. Use case reporting on HIV/AIDS and other reportable infections to identify the numbers of young key populations with infections**

Most countries have standard case reporting as part of their surveillance programme whereby limited demographic information, including age, is collected in association with a reported infection. Cases, along with demographic information, are usually collected by HIV testing and counselling centres, health care providers, laboratories and local health departments and stored, tracked and analysed at the national Ministry of Health or some other centralized facility.



### **Box 5. Using secondary data to build the case in Nepal**

In 2011, Swasti Health Resource Centre ([www.swasti.org](http://www.swasti.org)) used existing data to effectively develop a vulnerability framework to understand HIV and other risks among youth aged 10-24 years in Nepal. Because very limited youth specific data existed, numerous other existing data sources had to be found. These sources included the Demographic and Health Survey-2006, Census and HIV case records and prevalence. This exercise found that there is already a great deal of data available in many countries, much of which is neither analysed nor used, which can be used to help identify the HIV risk and vulnerability among young key populations and to highlight the necessity to include younger age groups in future research.

Source: Chaudhuri A. Swasti. How to make more out of what is available. Methodologies for Obtaining Strategic Information on Young People at Higher Risk of HIV Exposure, Thailand, September 3-5, 2012.

### **5. Use programme data to assess service utilization by young key populations**

Service providers working with adult and young key populations may collect data on the ages of people who seek their services. Information may be accessed through monitoring and evaluation reports from existing programmes and services. These programme data can be used to build the case that young people are an important recipient of services provided to vulnerable and high risk populations.

**6. Conduct stakeholder consultations and meetings** with adult and young key populations, people living with HIV and other marginalized groups. Also meet with the service providers, funders, community and religious leaders, child advocate groups and other organizations and persons who work with or have information about young key populations. Much of the time, useful information is never written down so the only way to access this information is through direct contact.

# 4. METHODOLOGICAL CONSIDERATIONS FOR COLLECTING STRATEGIC INFORMATION

Once the case is built to involve young key populations in quantitative research and all ethical issues are evaluated and addressed, it is time to consider methodological issues and their relevance to young key populations.

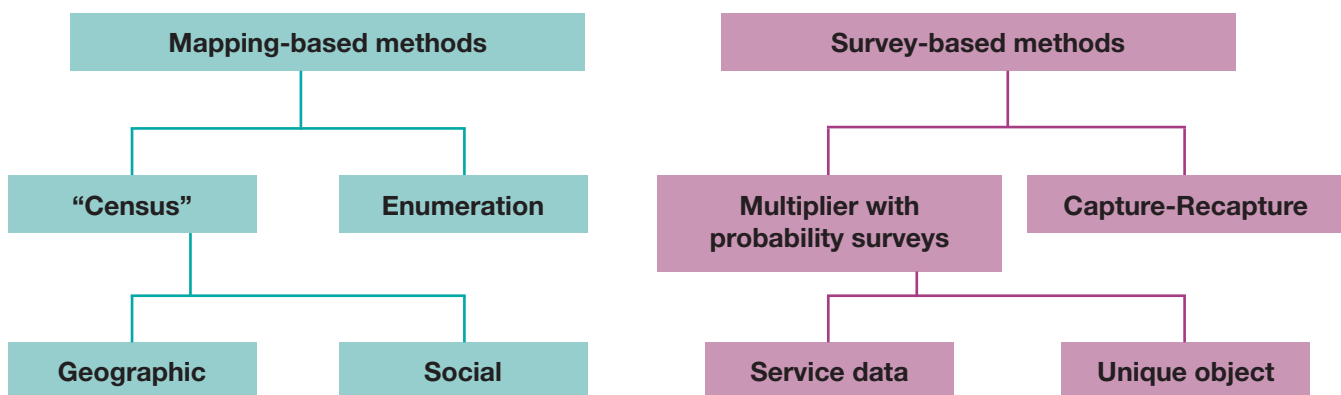
## 4.1 Estimating the population size of young key populations

Estimating the sizes of populations at highest risk for HIV is essential for informing decision-makers and programme managers of the extent to which young key populations are contributing to the HIV epidemic, as well as how to target interventions, plan services, and measure programme coverage in ways that are specific to young people. There is a tendency to overlook young people in programming and research because they are children and therefore ‘off-limits’ or ‘protected’. So it is important, even in terms of advocacy, to be able to highlight the number of young people at risk for HIV and other infections.

Obtaining size estimates for key populations is difficult under any circumstance, but it is even more difficult for young people, because of cultural and legal barriers to obtaining information about young people. The existing methods for population size estimation are not specific for young people per se, but it is important to think about how to adapt these methods for young people.

In general there are two types of methods most commonly used for size estimation of key populations. These are survey-based methods and mapping-based methods (see Figure 1).

**Figure 1. Main types of population size estimations**



To adapt the mapping-based methods to include young key populations, one could choose to either limit the mapping exercise to young people in the age category of interest, or map the entire population, while keeping track of age.

**Box 6. Population sizes among young female sex workers, people who inject drugs, males who have sex with males and transgender persons using mapping in Bangladesh**

In 2011, Bangladesh conducted a survey of young female sex workers, people who inject drugs, males who have sex with males and transgender persons, using a ‘geographical mapping’ approach in order to estimate the population sizes of each group. This approach involved identifying geographical locations where young key populations are concentrated and then to estimate the size of their populations through information from key informants and enumeration. Using this method, the mapping exercise estimated the total number of female sex workers aged 10-24 years old to be 31,101, of people who inject drugs to be 2,097, of males who have sex with males to be 5,820 and of transgender persons to be 6,096.

Source: National AIDS/STD Programme (NASP) of Bangladesh. (2012). Mapping and Behavioral Study of Most at Risk Adolescents to HIV in Specific Urban/Semi Urban Locations in Bangladesh.

For survey-based methods (which generally include a multiplier), the survey can either be limited to young people, or it can include all ages while keeping track of the proportion who are young. Restricting surveys to young people only will be more straightforward because concerns with sample sizes (i.e. having large enough surveys to get a robust measure) can be avoided. But it will still be necessary to obtain age-specific multipliers to use in conjunction with the survey.

### Box 7. Population sizes among young people who inject drugs using service multipliers with probability surveys in Ukraine

In 2009, Ukraine conducted a probability survey of people who inject drugs using respondent driven sampling (RDS). In order to calculate a population size of young people who inject drugs ages 14-19 years, overlapping data of clients of an HIV programme were matched to data collected in the probability survey. Specifically, the young people who inject drugs who enrolled in the survey (n=345) were asked whether they had received services from an HIV prevention project during a specified time period (n=38). This information was used to calculate the adjusted proportion of young people who inject drugs who received services from the HIV prevention project (8.3 per cent). The other data, given by the service providers, were the number of young people who inject drugs who were clients of the HIV prevention project during the same specified time period as used in the probability survey (n=4,147). Using these data, the following equation was used to derive the number of young people who inject drugs in Ukraine:  $4147/.083 = 49,964$ .

Source: UNICEF. (2011) Population Size Estimate of Most-At-Risk Children and Youth in the 10–19 Age Group. Geneva, Switzerland. Accessed at: [www.unicef.org/ukraine/Ocinka\\_chiselnosti\\_ditey\\_eng.pdf](http://www.unicef.org/ukraine/Ocinka_chiselnosti_ditey_eng.pdf)

For further information on population size estimation techniques, please refer to:

1. UNAIDS/WHO Working Group on HIV/AIDS/STI Surveillance. (2003) Estimating the Size of Populations at Risk for HIV. Issues and methods update. Geneva, Switzerland. Accessed at: <http://www.who.int/hiv/pub/surveillance/populations/en/index.html>
2. UNAIDS/WHO Working Group on Global HIV/AIDS/STI Surveillance. (2011) Guidelines on Surveillance among Populations Most At-Risk for HIV. Geneva, Switzerland. Accessed at: <http://www.unaids.org/en/dataanalysis/datacollectionandanalysisguidance/surveillance>
3. UNAIDS. (2010) Training Manual on Methods for Size Estimation of Key At-Risk Populations in the Asia-Pacific Region. Accessed at: <http://aidsdatahub.org/en/tools-guides/training-manuals/item/24123-training-manual-on-methods-for-size-estimation-of-key-at-risk-populations-in-the-asia-pacific-region-unaid-2010>

## 4.2 Difficulty in sampling key populations

Key populations, including younger cohorts, are considered difficult to reach for research purposes because of the illegal status or stigma towards the behaviours they practise. Younger key populations may even be more averse to being identified by researchers due to fears surrounding behaviours that are often criminalized (regulated under numerous national and international laws) and the risk that researchers may be required to report young key populations to the authorities.

There are two recommended probability-sampling methods for sampling hidden or highly marginalized populations, including young people that are considered difficult-to-reach. These methods are *Respondent Driven Sampling* (RDS) and *Time Location Sampling* (TLS) (also known as Venue-Day-Time Sampling) and are described in more detail below. Each method should be considered in place of convenience sampling

or non-probability sampling methods, such as, snowball sampling. Although convenience sampling is easier to conduct than probability sampling because a sampling frame is not needed, data collected through convenience methods produces biased samples and are not generalizable to the population from which the sample was collected.

For further information on probability and non-probability sampling methods, please refer to: Surveillance of Most at Risk Populations at: [globalhealthsciences.ucsf.edu/prevention-public-health-group/training-resources/hivaids-epidemiologic-surveillance-trainings](https://globalhealthsciences.ucsf.edu/prevention-public-health-group/training-resources/hivaids-epidemiologic-surveillance-trainings)

### 4.3 Defining the population (eligibility)

A clear definition of the population being surveyed is essential to design the research and for interpretation of the data and the estimates that come as a result of analysis. Eligibility criteria describe the characteristics required for inclusion in a study. This guidance recommends collecting data in order to provide the systematic disaggregation of data for those between the ages of 15-19 years and 20-24 years, and if possible, between the ages of 10-14 years.

Aside from age, other characteristics used to define eligibility for studies of young key populations might include:

- Sex (biologic and physiologic characteristics that define males and females)
- Gender identity (self-described identity that may define a person's perception of their sex)
- Sexual orientation
- HIV-related-risk behaviour
- Reference period of behaviour (i.e., injected drugs in the *past six months*)
- Geographic area or residence

Although many studies currently lump young key populations as one group, it is useful to define these populations based on the behaviours or vulnerable situations that increase their risk. This will allow researchers greater confidence that findings are relevant to a specific measurable group.

The behaviours and vulnerable situations that put young key populations at risk of HIV infection and transmission are:

- Penetrative vaginal or anal sex without a condom with multiple partners;
- Injecting drugs with non-sterile equipment that has been shared;
- Living on the streets; and
- Sexual abuse or exploitation.

It is important to describe the behaviour (i.e., anal sex with another male) rather than label of the behaviour (i.e., males who have sex with males, sex workers) – which researchers tend to do – as many young key populations do not necessarily consider themselves as part of the adult populations that engage in high-risk behaviours and vice versa. Some behaviours often overlap (i.e., a young person who uses drugs may sell sex in order to buy drugs).

Countries should agree on the same eligibility criteria to describe each young key population group, using the same age range, in an effort to compare findings within and between countries and regions.

## 4.4 Significance of formative research in designing surveys of young key populations

Formative research occurs during the design stage of a study, or while the study is being conducted to inform data collection. As with any data collection efforts, formative research should undergo some ethical review process and researchers should be fully aware of the country laws and guidelines governing the involvement of children and adults in research. Formative research often uses qualitative techniques to collect information (See Section 3 to learn more about qualitative research methods).

Formative research can help:

- Define and understand distinct young key populations.
- Tailor research design in ways that will be attractive to young people (to encourage and sustain participation).
- Answer logistical questions such as whether young people are willing to:
  - Provide biological specimens and what types.
  - How to provide test results and where to make referrals for follow up care, management and treatment.
  - Where and how to refer young key populations if they reveal that they are exploited, in danger, need psychological or medical care, etc., and request a referral. Referrals should be requested and not be made without the person's informed consent, unless the law indicates otherwise.
  - Be interviewed by females, males, transgender persons, adults or other young people.
  - Discuss personal sexual risk and drug use behaviours.
- Select appropriate sampling techniques determined by whether:
  - Young key populations are most easily located through public venues for TLS.
  - Social networks exist among young key populations making it possible to reach them through RDS.
- Pilot a survey and ensure that it is appropriate for the age groups sampled:
  - Questions may need to be tailored differently for young key populations from 10-14 years of age, compared to older key populations at higher risk to be understandable and relevant.
  - In some situations, interview questions may require modifications such as using language, current slang terms and topics appropriate to young key populations.
  - Sections of a questionnaire may have to be skipped for especially young key populations.
  - Young key populations may not have an attention span to complete a long questionnaire.

Formative research should be an integral part of developing and adapting surveys. Researchers should endeavour to provide avenues for involving young people in the planning, design and implementation of formative research as well as in the analysis and presentation of research results. Such involvement increases the relevance of the research design – for example, young people may have insight into current behaviour trends, such as, which drugs young people are using, that researchers might not have known about.

## 4.5 Factoring young key populations into sample size calculations

Sample size calculations are dependent on the sampling design. There are three feasible considerations for sampling young key populations:

1. **Sampling young key populations in a targeted survey:** Conduct a targeted survey of young key populations for which standard sampling calculations could be used (see Annexes 1.1 and 1.2 for calculations).

*Note: This may be the most straightforward way to accurately measure the risks of young key populations.*

2. **Sampling young key populations proportional to the adult population in a survey of young people and adults:** Conduct a survey of young and adult key populations but ensure that a large enough proportion of young key populations are reached mathematically adjusting your entire sample size. In most cases, the sample size will need to be increased to ensure that sufficient numbers of young people are included in the survey to enable disaggregation by age groups. To ensure an adequate number of young key populations in the survey, calculate the sample size needed just for young people using an indicator specific for that age group. For example, if the sample size calculated is 150 and young key populations make up 20 per cent of the total sample (including all ages), then the sample size would need to be 750 ( $0.20 * 750 = 150$ ). In addition, a design effect of at least 2 will need to be added (see Annexes 1.1 and 1.2 for calculations).

*Note: Although this method is statistically appropriate, it is not likely to be cost effective since this method requires the inclusion of a lot more adults to get the correct proportion of young people in the sample.*

3. **Oversampling young key populations in a survey of young people and adults:** Conduct a survey with key populations age groups, but 'oversample' young people in the analysis phase. For instance, assume a sample of 1,000 people who inject drugs of which 80 per cent are 18 years and older ( $n=800$ ). Also, assume that 40 per cent of the general population comprises those between the ages of 10-17 years. Simple oversampling will select each young person more than one time, which will result in a balanced dataset of 1,334 people who inject drugs with 40 per cent young people ( $n=534$ ).

*Note: This may be the most economical way to measure young key populations in a larger survey of adults. However, it is necessary to know what proportion of the population is young in order to calculate the oversampling.*

## 4.6 Quantitative sampling methods

Many countries collect quantitative data on key affected populations through HIV IBBS surveys, which typically exclude participants under the age of 18 years or do not report age-specific data that provide more information about young key populations. In some cases, special, one-time surveys on HIV risk and prevalence are conducted among young key populations. This section will suggest some methods for conducting either IBBS or one-time surveys.

For further information on IBBS, please refer to:

1. UNAIDS, WHO. (2000) Guidelines for Second Generation HIV Surveillance. Geneva, Switzerland. Accessed at: [www.data.unaids.org/publications/irc-pub01/jc370-2ndgeneration\\_en.pdf](http://www.data.unaids.org/publications/irc-pub01/jc370-2ndgeneration_en.pdf)
2. UNAIDS/WHO Working Group on Global HIV/AIDS/STI Surveillance. (2011) Guidelines on Surveillance among Populations Most-At-Risk for HIV. Geneva, Switzerland. Accessed at: <http://www.unaids.org/en/dataanalysis/datacollectionandanalysisguidance/surveillance>
3. HIV Sero surveillance, Surveillance of HIV Risk Behaviours, and Surveillance of Most-at-Risk Populations at: [globalhealthsciences.ucsf.edu/prevention-public-health-group/training-resources/hivaids-epidemiologic-surveillance-trainings](http://globalhealthsciences.ucsf.edu/prevention-public-health-group/training-resources/hivaids-epidemiologic-surveillance-trainings)
4. FHI 360 (2003) Guidelines for Repeated Behavioural Surveys in Populations at Risk for HIV. Arlington, VA. Accessed at: [www.who.int/hiv/strategic/en/bss\\_fhi2000.pdf](http://www.who.int/hiv/strategic/en/bss_fhi2000.pdf)

#### 4.6.1 Time-Location Sampling (TLS)

TLS can be used to sample young key populations when they tend to gather or congregate in identifiable and accessible locations, such as certain street corners, markets, transportation centres or other areas. The method entails identifying days and times when young key populations congregate at specific locations (i.e., brothels, city blocks, bars, etc.), constructing a sampling frame of time and location units, randomly selecting and visiting time and location units (the primary sampling units), and systematically intercepting and collecting information from consenting young key populations. The number of young key populations at each location provides a sampling weight that can be used *a priori*, to draw a self-weighting sample, or *post priori*, in analysis. Data collection may take place at the venue, if space (or venue owner) permits, or in a mobile site near the location, such as, a van or by making appointments for young key populations to come to a designated study site.

The major contribution of TLS over other cluster sampling methods is the ability to account for the fact that populations of interest are not statically associated with a particular location and often move between multiple locations during the course of a single day. As such, TLS allows researchers to construct a sample with known properties, make statistical inferences to the larger population of location visitors, and theorize about the introduction of biases that may limit generalization of results to the target population.

There are some considerations when using TLS to sample young key populations. These include:

- Sites frequented by young key populations may not be the same as those frequented by their older cohorts, so it is useful to involve young people and groups working with young people to help identify and map out venues.
- Sampling times and periods should be considered based on when young key populations are most visible.
- Because TLS involves researchers approaching participants, consider involving young people as interviewers or to approach participants in a manner that will be least likely to intimidate young respondents.
- If testing, HIV and other testing procedures should be as non-invasive as possible.



- If intercepting young key populations in the street or at a venue and needing to escort them to another location for an interview and/or testing, plan for them to be joined by a friend or trusted person. Similarly, for situations in which a young person needs to be escorted or transported to a location other than the interception point, do so in a manner that does not seem threatening to either the young person or any on-lookers.
- Some places identified as ‘hot spots’ may change between the time of the mapping and the time of the sampling. If this happens, new hot spots may need to be identified.

Table 1 describes some of the challenges and recommendations in using TLS to sample young key populations.

**Table 1. Current challenges and recommendations in using TLS<sup>23</sup>**

Best used when young key populations are accessible at several public locations in numbers large enough to build a sampling frame	
Challenges	Recommendations
Representativeness of young key populations found at accessible locations	Conduct high quality formative research to understand young key populations and where they are found.
Difficult to record non-response	Create rapid, accessible and meaningful individual and venue non-response instruments.
Lack of appropriate analyses based on cluster sampling	Retain a statistician, use correct analyses.
Weighting for analysis may not be accurate	Take steps to assure quality of cluster size determinations.
Systematic bias if locations are missed	Assess potential for missed locations and minimize these. Account for potential biases in reporting.
Bias if certain population sub-groups do not attend locations	Assess potential for missed sub-populations, especially younger young key populations, and minimize these. Account for potential biases in reporting.
Venue owners may block access	Meet with venue owners/gatekeepers before sampling. Document those sites with blocked access and collect as much information as possible about the types of individuals missed.
Venue owners may allow you to talk with the population briefly and then ask you to access them off-hours and at another venue.	Meet with venue owners/gatekeepers before sampling. Be prepared to make appointments to meet with individuals off-site. Keep track of those who are approached at the venue and who do not show up for an off-site appointment.
Safety issues	Develop and implement protocols to maintain the safety of staff, especially if using young people, and respondents in the field, and include security personnel on interview team if needed.

23 Adapted from: Johnston LG, Sabin K, Prybylski. ‘Update for sampling most-at-risk and hidden populations for HIV biological and behavioral surveillance.’ *Journal of HIV/AIDS Surveillance & Epidemiology*. 2(1). [http://www.ieph.org/ojs/index.php/jHASE/article/viewArticle/%5BjHASE%202010,%202\(1\)%3A2%5D](http://www.ieph.org/ojs/index.php/jHASE/article/viewArticle/%5BjHASE%202010,%202(1)%3A2%5D)

For further information on using TLS, please refer to:

1. Time Location Sampling (TLS) Resource Guide at: [globalhealthsciences.ucsf.edu/prevention-public-health-group/training-resources/hivaids-epidemiologic-surveillance-trainings](http://globalhealthsciences.ucsf.edu/prevention-public-health-group/training-resources/hivaids-epidemiologic-surveillance-trainings)
2. FHI 360 (2003) Guidelines for Repeated Behavioural Surveys in Populations at Risk for HIV. Arlington, VA at: [www.who.int/hiv/strategic/en/bss\\_fhi2000.pdf](http://www.who.int/hiv/strategic/en/bss_fhi2000.pdf)

#### **Box 8. TLS among young people who live on the streets in Russia and Ukraine**

A targeted TLS survey of young people who live on the streets aged 15-19 and 20-24 years was conducted in Russia and the Ukraine in 2006-2008. Aside from age criteria, other eligibility criteria were that young people lived part or full-time on the street OR lived out of family care OR self-identified as a young person living on the streets OR attended school irregularly or not at all. Young people who live on the streets were identified through a comprehensive mapping of venues including metro or train stations, street markets, feeding centres or fast-food sites, parks and computer clubs. Each survey used two mobile teams in vans in which participants consented to participate, were interviewed, and underwent pre and post-test counselling and a rapid HIV test. Findings revealed that almost all young people living on the streets were sexually experienced, few used condoms during sex and many used injection drugs. In Kiev, 18.6 per cent, in St. Petersburg 37.4 per cent, in Odessa 26.7 per cent, and in Donetsk 9.8 per cent of surveyed young people living on the streets were HIV positive. Overall, participation rates were high, with more than 90 per cent of eligible young people living on the streets providing informed consent.

Source: Kissin, D. (2011) Using Time-Location Sampling for HIV Surveillance in Street Youth. Access at: <http://www.slideserve.com/Patman/using-time-location-sampling-for-hiv-surveillance-in-street-youth>

### **4.6.2 Respondent Driven Sampling (RDS)**

Certain sub-populations of young key populations (e.g., young injectors who do not share drugs with others or young males who have sex with males who do not go to clubs, etc.) do not congregate in identifiable and accessible locations and are not adequately represented by TLS. RDS, an adaptation of chain-referral sampling, is useful for recruiting hard-to-reach young key populations. This method requires that young key populations belong to social networks and are able to recruit their peers into a survey. Beginning with a handful of non-randomly selected participants (referred to as seeds), each participant is provided with coupons to use in recruiting their peers. The participants recruited by the seeds make up the first wave of participants, who in turn recruit the second wave of participants. This recruitment process continues until the sample comprises multiple recruitment waves and ends once the sample size is reached. RDS provides a primary incentive for completing an interview and for recruiting peers. The use of uniquely numbered coupons identifies who recruited whom, without using personal information. Information of who recruited whom and each participant's social network size (the number of peers they know) are used in the analysis of RDS data.

Table 2 describes some of the challenges and recommendations in using RDS to sample young key populations.

**Table 2. Current challenges and recommendations in using RDS<sup>24</sup>**

Best used when young key populations are sufficiently socially networked to sustain peer-to-peer recruitment and when young key populations are not accessible at public locations.	
Challenges	Recommendations
Popularity of RDS has resulted in ignoring rigorous adherence to implementation and analysis requirements	Review and understand relevant materials on conducting RDS; use the RDS manual (referenced below); seek out others who have properly conducted RDS studies; obtain professional technical assistance; use a written protocol that has been reviewed by experts and assure adherence to the protocol.
Difficult to assess non-response bias	Incorporate a brief follow-up interview to collect data about persons to whom participants tried to give a recruitment coupon and reasons for not accepting a coupon. This is important especially if young key populations are not enrolling.
Difficult to measure the assumptions of random recruitment within personal networks	Compare recruitment to the reported composition of young key population's sub-groups with respect to visible attributes and then comparing these self-reports to actual recruitment patterns.
Ensuring the attainment of equilibrium within sample sizes and time-frames	Ensure very long recruitment chains (ideally >9 waves); pay careful attention to the number, degree and diversity of selected seeds. Ensure an ample number of young seeds to capture a sufficient number for analysis.
Selection of seeds to maximize equilibrium attainment	Conduct formative research in advance of a study to select seeds that are broadly representative of young key populations.
Determining the appropriate incentives to maximize participation	Conduct formative research in advance of a survey to determine appropriate types of incentives; assess the economic value of goods in each setting; ask young key populations their motivation for participating in an RDS survey to plan incentives for future studies; be creative.
Determining the appropriate incentives to minimize repeaters	Conduct formative research in advance of a survey to determine appropriate types of incentives; assess the economic value of goods in each setting; if available, use a computer programme to record and search participants' biometric measurements/fingerprints; explain to participants that if they give their coupon to someone found to be ineligible due to prior participation, they will not receive a recruitment incentive for that person; be creative.
Managing multiple data collection sites and staffing	Assess the reasoning behind having multiple recruitment sites; hire staff with either personal or work experience with young key populations; have designated staff roles with adequate training; develop a communication protocol to ensure crossover among sites and to coordinate data collection.
Verification of membership in the sampled group	Hire and train a 'screener' whose only job is to verify eligibility and enrol participants; use young key populations as screening staff; know the behaviours and develop screening questions to which only the young key populations can accurately respond.

24 IBID.

There are some special considerations when using RDS to sample young key populations. These include:

- Incentives used for adults may not be appropriate for young people. For instance, although money is commonly used as an incentive in most RDS surveys, incentives appropriate for young people may include food items, soap, clothing, games and other useful, in-kind (non-monetary) items. Organizations working with young key populations can help determine appropriate incentives (Also see *Section 2.6 Use of incentives*).
- The social network size question is an open-ended question and providing a response to this question requires the participant to focus. Special probing techniques might be needed to encourage accurate reporting of social network sizes, especially among children.
- Seeds should be selected to ensure the inclusion of young key populations in a survey that also includes adults. For instance, if selecting eight seeds for a survey of people who inject drugs between the age of 13-49, consider having at least three seeds in the age categories below 18 years. Have young seeds available in case recruitment chains stop growing or original seeds do not recruit anyone and new seeds need to be added later on.
- If conducting a targeted survey of young key populations only, special considerations may be needed on how to diversify seeds (e.g., rather than marital status, diversify on living at home or not or being sexually active or not; rather than occupation, diversify on being in school or not, or ability to read and write or not).
- Use an interview site that is easy to get to and comfortable for young key populations. Consider special times for young people to come to a survey when adult participants will not be present. Avoid having interview sites located close to schools, homes, places of solicitation, etc.
- Simple coupon design may be needed; consider the use of pictures in place of words to convey important coupon information.
- Have a dedicated staff member to engage the younger key populations with toys and activities while they are waiting for an interview.
- Consider what to do with family members who bring young key populations to participate in a survey. For instance, an older sibling, parent or other care taker who brings a young person to participate in the survey will have to be allowed to wait in the waiting room or be asked to return at a later time.

### **Box 9. RDS among young people who use drugs in Thailand**

A targeted RDS survey of young Thai males aged 15-24 years who ever used illicit drugs including marijuana, amphetamine, ecstasy, inhalant, opium, heroin, *mitragyna speciosa* or cocaine was conducted in two districts of Kanchanaburi province, Thailand, in 2004. The survey was initiated with 17 seeds identified through local health workers, village health volunteers, and abbots of local temples. All participants underwent a consent process and an interview. Over the course of 41 days, 749 participants enrolled in the survey, 61 per cent of whom were between the age of 15-19 years and 52 per cent reported using drugs in the past month (unclear if analysis was properly weighted). Overall, participation rates were high with more than 90 per cent of eligible young people providing informed consent.

Source: Thayansin, S. 2011. 'Respondent-Driven Sampling: Reaching Male Youth with Drug Use Experience in Thailand.' *Journal of Population and Social Studies*, 20, 1: 43-56. Access at: [http://www2.ipsr.mahidol.ac.th/Journal/index.php?option=com\\_content&view=article&id=118:cont-vol20-no1-03&catid=140:cat-vol20-no1&Itemid=96](http://www2.ipsr.mahidol.ac.th/Journal/index.php?option=com_content&view=article&id=118:cont-vol20-no1-03&catid=140:cat-vol20-no1&Itemid=96)

For further information on using RDS, please refer to: [www.respondentdrivensampling.org](http://www.respondentdrivensampling.org)

For a manual on conducting RDS, please refer to: Johnston LG. (2007) Introduction of Respondent Driven Sampling. Accessed at: [globalhealthsciences.ucsf.edu/prevention-public-health-group/training-resources/hivaids-epidemiologic-surveillance-trainings](http://globalhealthsciences.ucsf.edu/prevention-public-health-group/training-resources/hivaids-epidemiologic-surveillance-trainings)

#### **Box 10. Using TLS and RDS in the Philippines**

Two to three rounds of IBBS surveys have been conducted among female sex workers and people who inject drugs, aged 15 years and older using RDS and TLS in the Philippines. Based on formative research with female sex workers of all ages, it was determined that female sex workers would be best sampled using TLS since they were easily identified at visible locations and that people who inject drugs were best sampled using RDS since they formed large social networks through their social activities as well as through the sharing, buying and selling of drugs. Although TLS was able to attain the calculated sample sizes, it may have missed the more hidden (i.e., internet and phone-based) types of female sex workers. Younger female sex workers and people who inject drugs were not adequately represented in the final sample to provide meaningful disaggregation of data specific to young people. This highlights the point that extra care is needed to ensure that sufficient numbers of young key populations at higher risk are included in any survey including adults.

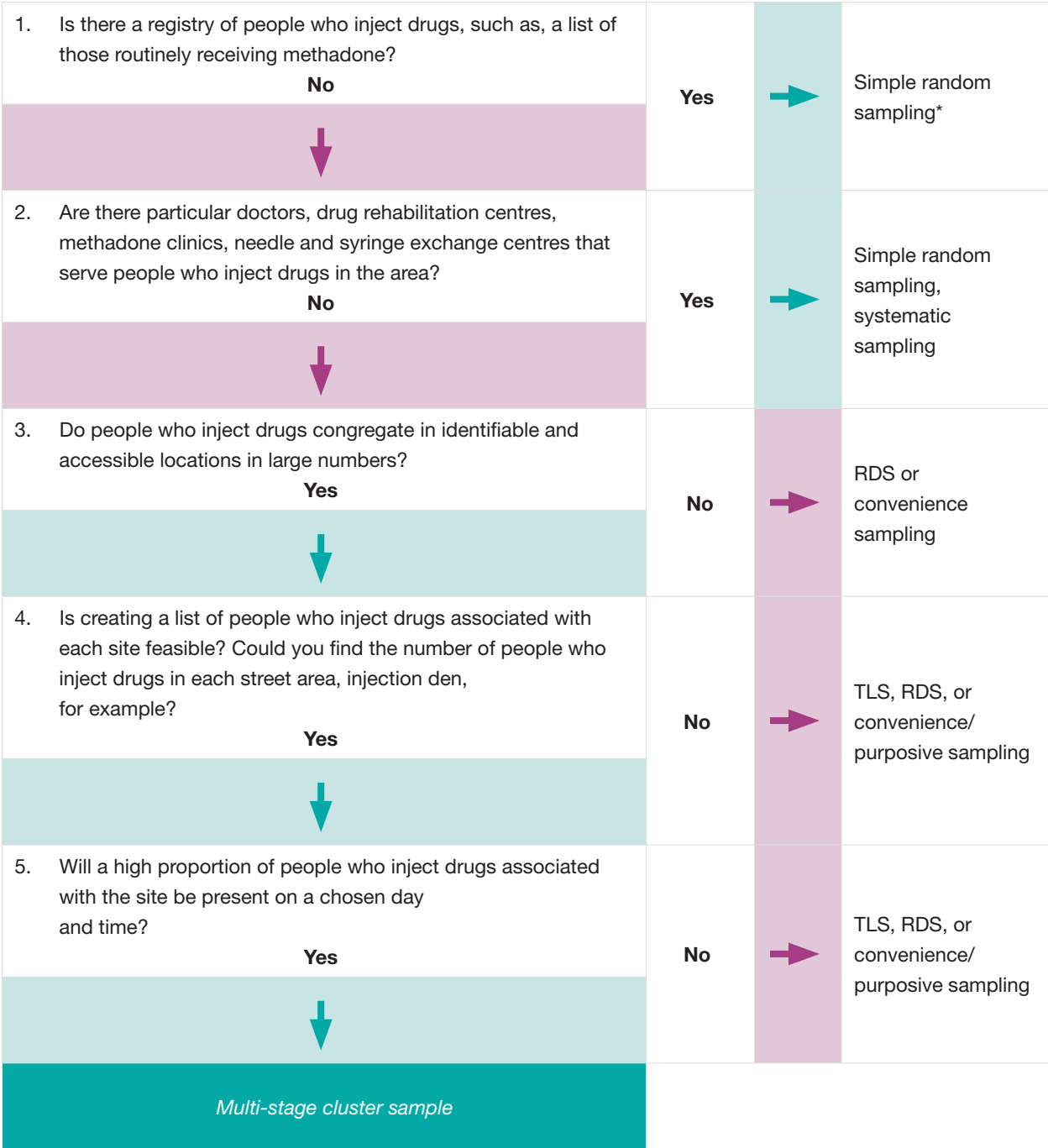
Source: Samonte GM. Capturing Younger Cohorts Through Surveillance Systems: Philippines. Methodologies for Obtaining Strategic Information on Young People at Higher Risk of HIV Exposure, Thailand, September 3-5, 2012.

## **4.7 Selecting a sampling method**

Selecting the most appropriate sampling method requires assessing numerous factors such as whether there is a sampling frame or list of young key populations, whether they are socially networked, and whether they spend time at venues that can be mapped and approached.

Figure 2 is useful for selecting a sampling method to sample young key populations. This example assumes young key populations who inject drugs.

**Figure 2. Algorithm to selecting a sampling method<sup>25</sup>**



\*Note that a simple random sample of people who inject drugs registered at a drug rehabilitation, needle and syringe exchange or methadone centre may miss populations at high risk, such as, those who are not seeking any treatment or not using clean needles and syringes.

25 For a complete description of all sampling methods described and for more detail on this figure, see: Surveillance of Most at Risk Populations at: <http://globalhealthsciences.ucsf.edu/prevention-public-health-group/training-resources/hivaids-epidemiologic-surveillance-trainings>

## 4.8 Conducting research with young key populations

Many methods to sample young key populations are the same as those that have been used to sample adults. When conducting research on young key populations, it is important to consider how the research should be modified in order for it to be accepted by, and appropriate for, young people. For instance:

- Some surveys among adults that include young key populations may not work well if they include very young key populations (10 to 15 years). For instance, it may be impossible to design a questionnaire that relates to all ages in one study.
- Interviews should be short and respondents should be allowed to take breaks during an interview.
- Forms and other materials that are to be read should be easy to read using language that is commonly used and understood by young people. Keep in mind that many young key populations may not be able or want to read something, especially very young key populations. In addition, materials for young people in the higher age ranges (e.g. 15 to 20 years) will need to be tailored differently from materials for young people in the lower age ranges (e.g. 10 to 14 years).
- Many labels used by researchers to describe adult key populations (i.e. people who inject drugs, male or female sex workers) or high-risk young people (young key populations) may not be recognized by young people engaging in the same behaviours. Refer to the behaviour, rather than using the label.
- Meetings with and involvement from parents or guardians may be necessary to ensure young key populations participate in surveys.
- Community meetings (without disclosing the full nature of the research which could result in further stigma or reprisals) may be useful to garner community acceptance of collecting information from young key populations.
- Keep questionnaires as short and simple as possible.
- Conduct formative research to determine if sampling can be enhanced with communication technologies, such as through websites or eliciting questions programmed into cell phones and computers.
- Have available a professionally trained social worker or child advocate (a person or service provider with qualifications to provide information and support to a child in distress).

### **Box 11. Using the Internet to reach males who have sex with males in Viet Nam**

The first banner-based online survey among males who have sex with males in Viet Nam was conducted from October 2008 to January 2009. The banner received 6,859 clicks. Of those, 4,861 potential participants reported that they were 18 years old or older. Among the 2,640 participants who completed the socio-economic questionnaire, 23.9 per cent were 18-19 years old and 38.8 per cent were 20-24 years old. In recent years, Viet Nam implemented a number of banner-based online surveys of HIV risk factors and behaviours among males who have sex with males, aged 18 years and older. Banners for completing a short behavioural survey were placed on websites frequented by males who have sex with males. One challenge to using the Internet to reach young key populations, as well as other populations, is that it is impossible to verify someone's age and to collect biological specimens. Nevertheless, web-based methods were found to be an effective way to quickly and economically reach large numbers of males who have sex with males, many of whom are hidden and hard-to-reach in Viet Nam.

Source: Quoc NC. Web-surveys among men who have sex with men: Experience from Viet Nam. Methodologies for Obtaining Strategic Information on Young People at Higher Risk of HIV Exposure, Thailand, September 3-5, 2012.

## **4.9 Future directions for sampling young key populations**

Effective sampling strategies may require innovations that will encourage young key populations to participate in research. Future directions for sampling young key populations could include developing novel data collection strategies, such as, using game interfaces with colours, sounds and levels of earning points disguised as questionnaires in an effort to keep young people engaged. For instance, many young people have no trouble responding to information elicited for signing up for games (e.g., choose your name, put in your birth date, choose which team you will play on, etc.). With some creative thinking, a questionnaire can be designed as a computer game whereby each section of questions answered allows the 'player' to move to the next section.



## 5. DISSEMINATION AND SUPPORT FOR USE OF STRATEGIC INFORMATION

The underlying reason to gain and then disseminate strategic information on young key populations is to ensure it is appropriately considered for use in reaching decisions, making changes, or taking other specific actions designed to improve outcomes. The goal of dissemination is utilization in policy, programmes and funding. Unfortunately, one of the biggest barriers to dissemination of strategic information is the lack of resources and time for properly analysing the vast amount of data collected in surveys. Research budgets must account for the time it takes to properly clean, code and analyse data, especially when analysing data from more complicated sampling methods, such as, RDS and TLS, both of which require weighting data.

### **Box 12. Dissemination of strategic information from a study of young key populations in Cambodia**

In 2009 a survey of 2,489 young persons was conducted to collect strategic information in eight provinces in Cambodia. National and sub-national dissemination workshops, with wide participation of government and NGOs were held to ensure that the results of, and recommendations from, this survey were shared with a large audience. In addition, strategic information was presented in an innovative 15-minute film which documented the survey methodology and findings. Importantly, the survey findings were not contested and were used to inform the new national multi-sectoral strategic plan on AIDS in Cambodia (2011-2015). Along with providing important age- and sex-disaggregated information on the behaviours of young key populations in Cambodia, the survey identified that the main barriers to young people using health services were concerns for confidentiality, non-same-sex health providers, long waiting times and user fees.

Source: Presented at: Methodologies for Obtaining Strategic Information on Young People at Higher Risk of HIV Exposure, Thailand, September 3-5, 2012. For more information, see: [http://aidsdatahub.org/dmdocuments/MoEYS\\_\(2010\)\\_Most\\_at\\_Risk\\_Young\\_People\\_Survey\\_Cambodia\\_2010.pdf](http://aidsdatahub.org/dmdocuments/MoEYS_(2010)_Most_at_Risk_Young_People_Survey_Cambodia_2010.pdf)  
To watch the documentary film, see: <http://www.youtube.com/watch?v=CYd9AUXfu8g>

## 5.1 Topics to include in a dissemination plan

Given the stigmatized and illegal behaviours practised by key populations, and the especially vulnerable situation faced by young key populations, it is helpful to plan the dissemination of strategic information at the beginning of research activities. Before conducting a wide scale dissemination of information, consider whether or not a validation process with stakeholders is needed. One way to validate the findings and assess dissemination needs is to have feedback sessions with the community, study participants and other stakeholders. Dissemination planning should involve those who have most to gain from it: young key populations.

Topics to include in a dissemination plan are:

- The rationale behind needing the plan. Anticipate where the key alliances and barriers to more effective prevention for young key populations might exist.
- The goals, objectives and key activities of the dissemination of strategic information and whether the dissemination will pose any risks for research participants.
- The scope and characteristics of the ‘potential users’ of strategic information.
- The type of strategic information to be disseminated to each of the potential user groups identified.
- The medium (i.e., reports, conference presentations, meetings, Data Hub, etc.) and language through which strategic information will be delivered to potential users.
- How monitoring and evaluation can be undertaken to determine if dissemination was successful.
- The strategies for promoting awareness of the availability of strategic information.
- The potential barriers that may interfere with users’ access or utilization of strategic information and the development of actions to reduce these barriers.
- The strategies to bring an effective group of stakeholders (including formal groups of young people, service providers, funders, policy makers, programme designers, child protection experts, community, school and religious leaders, etc.) together to respond to the findings and implement the recommendations.

*Note: As a population that is practicing illegal behaviours and is stigmatized as a result of those behaviours, it is necessary to strategically disseminate information so as not to cause harm to young key populations.*

## 5.2 How to disseminate strategic information

Although a general report is an effective way to disseminate strategic information, different audiences may require different information, types of presentations and dissemination strategies.

For each group, assess the following:

- What outcomes are expected through the dissemination (what will be accomplished)?; what are the key concerns of the group? (e.g., young key populations might be most interested in how the information will directly affect them; policy planners might be most interested in how the information will support new policies and legislation; NGOs and service providers working with young key populations might be most interested in how their programmes can respond to the information disseminated).
- What are the existing levels of knowledge?

- In which languages should the information be delivered?
- What will likely motivate the group to take action?
- What information would be of most interest and use to this audience? (e.g., young key populations might be most interested in knowing about the direct findings on risk and vulnerability; NGOs working with young key populations might be most interested in programme use and access).
- What type/method of presentation would be most appropriate? (e.g., NGOs, policy planners and service providers might be most interested in receiving a report and/or PowerPoint presentation; young key populations might be most interested in receiving information in leaflets, brochures, posters, drama, one-on-one discussions through outreach, comics or other creative dissemination methods;<sup>26</sup> community members might be most interested in receiving information through posters, television advertisements and other media sources).

Regardless of the type or method of dissemination, all information should communicate a consistent, clear, and easy-to-understand message that emphasizes what has been, and will be done in response to the findings.

In addition to disseminating strategic information about young key populations through printed and on-line reports, papers and fact sheets, and presentations, dissemination through workshops should be conducted among analysts, programme planners and implementers, and the community within and between countries and regions to share information on the experiences of collecting strategic information on young key populations, including protocols, methodologies, and lessons learnt. These types of workshops will be especially important in the next few years as more young key population data collection efforts using best practices are being implemented. Also consider reaching out to private funders' networks, bilateral and multi-lateral donors to organize donor briefings on new data that may be relevant to their funding strategies.

### 5.3 Evaluate dissemination efforts

Each community and group is unique and dissemination plans must therefore be customized. It is useful to monitor the strengths and weaknesses of dissemination efforts in order to provide feedback and, where necessary, make corrections that maximize the efficacy of future dissemination efforts. Seek feedback from stakeholders, especially the populations being targeted, to assess reactions and determine whether to respond to or modify dissemination messages.

*For further information on data dissemination and use, please refer to:*

FHI 360 (2009) *From Analysis to Action: The A2 approach*. Arlington, VA. Accessed at: <http://www.fhi360.org/en/CountryProfiles/Asia/aroprogrammes.htm>

UNAIDS. (2004) *Guide to Monitoring and Evaluating National HIV/AIDS Prevention Programmes for Young People*. Geneva, Switzerland. Accessed at: [www.who.int/hiv/pub/me/en/me\\_prev\\_intro.pdf](http://www.who.int/hiv/pub/me/en/me_prev_intro.pdf)

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26 Be sure to involve young people in designing and developing materials, such as, leaflets, brochures and posters.

# REFERENCES

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# ANNEX 1

## Formulas for Sample Size Calculation

### 1.1 Formula for sample size calculation of IBBS

The sample size needed to conduct IBBS surveys can be based on the number of participants needed in each round (or year) to detect a change in the proportion of an indicator from one round to the next. For instance, if in a survey of female sex workers (FSW) between the ages of 15-24 years one would like enough participants in each survey round to show that condom use at last paid sex increased from 20% in the year 2012 to 30% in 2013.

The general formula for the needed sample size (n) is:

$$n = \frac{D \left[ Z_{1-\alpha} \sqrt{2P(1-P)} + Z_{1-\beta} \sqrt{P_1(1-P_1) + P_2(1-P_2)} \right]^2}{(P_2 - P_1)^2}$$

Where:

n	=	Sample size required per survey round (year)
D	=	Design effect (see below)
$Z_{1-\alpha}$	=	The z score for the desired confidence level, usually 1.96 for 95%
$Z_{1-\beta}$	=	The z score for the desired power, usually 0.83 for 80%
$P_1$	=	The proportion of the sample reporting indicator in year 1
$P_2$	=	The proportion of the sample reporting indicator in year 2
P	=	$(P_1 + P_2)/2$

Choosing the values of these numbers is based on the following considerations:

**D:** The design effect is an adjustment for how much a cluster or other types of sampling method differ from a simple random sample. The design effect multiplies the sample size by the factor of D to account for the loss of diversity by using a sampling method other than a simple random sample. For RDS surveys, a design effect of 2.0 or more is recommended. For cluster sampling and TLS, a design effect of 2.0 is recommended. **The bigger the D, the larger the sample size needed.**

**$P_1$  and  $P_2$ :**  $P_1$  and  $P_2$  are the measures of interest for which you wish to see a change between survey rounds. For example, to show that condom use at last paid sex for young SWs increased from 20% in 2012 ( $P_1$ ) to 30% or greater in 2013 ( $P_2$ ).  $P_1$  is usually based on previous surveys in the same or similar population, or an educated guess at what the level will be.  $P_2$  is ideally set at the goal you would like to achieve (for example, a 10% or greater increase in condom use). In practise, it is usually set at the smallest change you think is meaningful; for example, a 10% increase in condom use would be considered a meaningful improvement, whereas a 1% increase would not be considered meaningful. **The smaller the change you wish to detect, the larger the sample size needed. Also, the closer  $P_1$  and  $P_2$  are to 50%, the larger the sample size needed.**

**$Z_{1-\alpha}$ :** The  $Z_{1-\alpha}$  score is a statistic that corresponds to the level of significance desired. Usually, a significance level of 0.05 (or equivalently, a 95% confidence level) is selected and corresponds to a value of 1.96. This value is used when the change in the indicator might be either up (an increase) or down (a decrease) from year to year (a ‘two-tailed’ statistic). ***The smaller the significance level (i.e. the higher the confidence level), the larger the sample size needed.***

**$Z_{1-\beta}$ :** The  $Z_{1-\beta}$  score is a statistic that corresponds to the power desired. Usually, 80% power is selected and corresponds to a value of 0.83. This value is used when the change in the indicator might be either up (an increase) or down (a decrease) from year to year (a ‘two-tailed’ statistic). ***The higher the power, the larger the sample size needed.***

Table 1, below, provides pre-calculated sample size estimates for a range of possible scenarios in behavioural and sero-surveillance.

**Table 1.** Sample size needed per survey wave to detect a change in the proportion of an indicator between survey waves, using a 95% confidence level, 80% power, and a design effect of 2.0.

Indicator level in wave 1 (P1)	Indicator level in wave 2 (P2)	Sample size needed for each wave with a design effect of 2.0
.10	.20	395
.10	.25	197
.20	.30	581
.20	.35	274
.30	.40	706
.30	.45	322
.40	.50	768
.40	.55	343
.50	.60	768
.50	.65	336
.60	.70	706
.60	.75	301
.70	.80	581
.70	.85	239
.80	.90	395
.80	.95	149

For more information about sample size calculations for IBBS, please see:

FHI 360 Guidelines for Repeated Behavioral Surveys in Populations at Risk for HIV. 2003. Arlington, VA. Accessed at: [www.fhi360.org](http://www.fhi360.org)

University of California, San Francisco. Surveillance of Most at Risk Populations. <http://globalhealthsciences.ucsf.edu/prevention-public-health-group/training-resources/hivaids-epidemiologic-surveillance-trainings>



## 1.2 Formula for sample size calculation for measuring HIV prevalence

The sample size needed to conduct BBSS can be based on the number of participants needed to accurately measure HIV prevalence in a population. This is referred to as sample calculation 1. The general formula for the needed sample size (n) is:

$$n = D \frac{Z_{1-\alpha}^2 P (1-P)}{d^2}$$

n	=	Sample size required per survey round
D	=	Design effect
$Z_{1-\alpha}$	=	The z score for the desired confidence level, usually 1.96 for 95% confidence
P	=	Expected proportion
d	=	precision (usually set at 5%)

### Example of sample size calculation

For instance, to calculate the sample size for a survey to estimate the prevalence of HIV among persons aged 15-24 years old who have injected drugs in the past six months, and live in Hanoi it is necessary to have an estimate of HIV prevalence in this group. For an estimated HIV prevalence of 20% (P=0.2), a design effect at 2 (D=2), confidence at 95% ( $Z_{1-\alpha}$  1.96) and precision at 5% (d=0.05) the calculation would be as follows:

D	=	2
$Z_{1-\alpha}$	=	1.96; $(1.96)^2 = 2.58$
P	=	20%
d	=	0.05; $(0.05)^2 = .0025$

$$330.24 = 2 \frac{2.58 * 0.2 (1-0.2)}{0.0025}$$

For more information about sample size calculations for IBBS see:

University of California, San Francisco. Surveillance of Most at Risk Populations.

<http://globalhealthsciences.ucsf.edu/prevention-public-health-group/training-resources/hivaids-epidemiologic-surveillance-trainings>

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