

**The People Living with HIV  
Stigma Index**

An index to measure the stigma and  
discrimination experienced by people  
living with HIV

# USER GUIDE



THE PEOPLE  
LIVING  
WITH HIV  
STIGMA  
INDEX



THE PEOPLE  
LIVING  
WITH HIV  
STIGMA  
INDEX

“Being interviewed by another person living with HIV does make a difference – as you feel they really would understand more about how you feel about things related to being HIV positive.”

RESEARCHER, PILOT  
WORKSHOP, SOUTH AFRICA

**THIS IS THE PEOPLE LIVING  
WITH HIV STIGMA INDEX.**

**IT IS AN INITIATIVE THAT HAS  
BEEN DEVELOPED AND  
IMPLEMENTED BY AND FOR  
PEOPLE LIVING WITH HIV.**

**IT AIMS TO COLLECT  
INFORMATION ABOUT THE  
EXPERIENCES OF PEOPLE  
LIVING WITH HIV RELATED  
TO STIGMA, DISCRIMINATION  
AND HUMAN RIGHTS.**

## CONTENTS

Who is this publication for?	2
<b>INTRODUCING THE PEOPLE LIVING WITH HIV STIGMA INDEX</b>	<b>3</b>
PART 1 Introduction – background and objectives of the index	4
PART 2 The approach – a survey conducted by and for people living with HIV	9
PART 3 Ethical issues – informed consent and confidentiality	11
PART 4 Sampling – some guidelines and suggestions	14
<b>WORKING WITH THE INDEX IN YOUR COMMUNITY</b>	<b>17</b>
PART 5 Preparing to implement the index in your community	18
PART 6 The questionnaire – becoming familiar with the content	23
<b>USING THE EVIDENCE FOR ADVOCACY</b>	<b>35</b>
PART 7 Working with the data – issues related to the management, analysis and reporting of data	36
PART 8 Communicating the findings and next steps	39
APPENDIX 1 Key definitions and concepts	43
APPENDIX 2 Information sheet	48
APPENDIX 3 Informed consent form	50
APPENDIX 4 Interviewee contact list and questionnaire codes	51
APPENDIX 5 Confidentiality agreement: interviewer	52
APPENDIX 6 Confidentiality agreement: interpreter	53
APPENDIX 7 Confidentiality agreement: team leader	54
APPENDIX 8 Confidentiality agreement: data clerk	55
APPENDIX 9 Confidentiality agreement: data analyst	56
APPENDIX 10 Template: key steps in the local implementation process	57
APPENDIX 11 Template: three-day training programme for interviewers	59

## WHO IS THIS PUBLICATION FOR?

This user guide has been created for teams implementing the People Living with HIV Stigma Index in their communities.

This user guide has been created for teams implementing the People Living with HIV Stigma Index in their communities.

This user guide contains background information on the index and its intended purpose; an introduction to the questionnaire and the data gathering process; and practical guidance for training interviewers, ensuring the interview process is conducted in an ethical manner, and for effective data entry and analysis. The guide also includes tips for communicating the research findings and using them to advocate for the rights of people living with HIV.

The user guide and the accompanying questionnaire are for:

- managers or implementers of the People Living with HIV Stigma Index (for example, the team leader);
- people living with HIV who are going to conduct the interviews that form the basis of the index;
- those responsible for entering the data into the computer so that they are ready for analysis; and
- those responsible for analysing and reporting on the data.

The user guide can also serve as a useful background document for local networks of people living with HIV that have an important role in ensuring that the index is facilitated by and for people living with HIV within their communities.



**INTRODUCING  
THE PEOPLE  
LIVING WITH HIV  
STIGMA INDEX**

# PART 1

## INTRODUCTION – BACKGROUND AND OBJECTIVES OF THE INDEX

People living with HIV often face stigma and discrimination. Many do not know what their rights are and how they can help to change things for the better.

### WHAT IS THIS INDEX ALL ABOUT?

People living with HIV often face stigma and discrimination. Many do not know what their rights are and how they can help to change things for the better. There are a number of organizations that are campaigning against stigma and discrimination and fighting for improved rights for people living with HIV. This index aims to collect information on stigma, discrimination and the rights of people living with HIV that will help in these advocacy efforts.

We are calling this index the **People Living with HIV Stigma Index**. It is a project that has been developed and implemented by and for people living with HIV. It aims to collect information about the experiences of people living with HIV related to stigma, discrimination and their rights. The information that we gather from people living with HIV will allow us to:

- document the various experiences of people living with HIV within a particular community or country regarding HIV-related stigma and discrimination;
- compare the situation of people living with HIV in one country or across different countries with respect to a particular issue;
- measure changes over a period of time so that we can answer questions like, “Has the situation with respect to stigma, discrimination and rights of people living with HIV worsened or improved over the last couple of years in this community?”
- provide an evidence base for policy change and programmatic interventions.

The main aim of collecting this information and presenting it in the form of an index is to broaden our understanding of the extent and forms of stigma and discrimination faced by people living with HIV in different countries. The intention of the participating organizations is to make the index widely available so that it can be used as a local, national and global advocacy tool to fight for improved rights for people living with HIV.

As the index moves from the concept to scale-up phase, it will be adopted by a variety of different groups in different communities, countries and continents.

### WHAT IS THE PURPOSE OF THE USER GUIDE?

The user guide is intended to provide local research teams with the necessary information and guidance to implement the People Living with HIV Stigma Index questionnaire in their own community or country. It has been designed to allow organizations and individuals to independently use the index to document, analyse and report on the experiences of people living with HIV with regard to HIV-related stigma and discrimination in their locality.

The user guide is also viewed as a living document – something that will need to be adapted over time, particularly as the index is implemented within countries and as teams bring back lessons from the field.

Importantly, once the People Living with HIV Stigma Index has been implemented within a country, the perspective of people living with HIV can then be triangulated with other surveys that explore HIV-related stigma and discrimination from other

perspectives such as health care providers working at the facility level and the general community.<sup>1</sup> The repeated use of this index over time in conjunction with other surveys will be key to increasing our collective understanding of these issues.

## HOW WILL THE INDEX BENEFIT ME?

It has long been recognized that action is needed to address HIV-related stigma and discrimination. By implementing the People Living with HIV Stigma Index within a country, evidence can be obtained so as to:

- inform the development and implementation of national policies that protect the rights of people living with HIV; and
- shape the design of programmatic interventions so that they consider the issue of HIV-related stigma and discrimination within their content.

However, the benefits of the index, particularly for those conducting it, go further than just collecting this much-needed evidence. The process of implementing the index is intended to be an empowering one for people living with HIV, their networks and local communities – a critical ingredient for ensuring that the Greater Involvement

### SEE ...

#### APPENDIX 1:

#### Getting familiar with the concepts

We have created a table of the key definitions and concepts that we use in this project and specifically refer to in the People Living with HIV Stigma Index questionnaire. You will find this in Appendix 1. We recommend that you review these concepts and definitions before you familiarize yourself with the content of the questionnaire. In this way you will then be able to read the questionnaire with an understanding of what we are trying to explore in asking each question, and what is implied by some of the words that we use.

of People Living with HIV and AIDS (GIPA) Principle is renewed. It is hoped that the index will foster change within communities as it is being used, as well as being a tool to advocate for the broader changes needed according to the index data.

Ultimately, it is hoped that the index will be a powerful advocacy tool that acts to support the collective goal of governments, community-based organizations, activists and people living with HIV alike to reduce the stigma and discrimination linked to HIV.

## WHO CAME UP WITH THE IDEA OF THE INDEX?

The People Living with HIV Stigma Index is the joint initiative of several organizations who have worked together since 2005 to develop this survey. These include:

- the Global Network of People Living with HIV/AIDS (GNP+);
- the International Community of Women Living with HIV/AIDS (ICW);
- the International Planned Parenthood Federation (IPPF); and
- the Joint United Nations Programme on HIV/AIDS (UNAIDS).

Here is a brief introduction of each, their role in the People Living with HIV Stigma Index and how they will benefit from it.

### NETWORKS OF PEOPLE LIVING WITH HIV

Two networks in particular – the International Community of Women Living with HIV/AIDS (ICW) and the Global Network of People Living with HIV/AIDS (GNP+) – are involved in the People Living with HIV Stigma Index. They see the index as providing a way of documenting stigma and discrimination and providing evidence that can be used as an advocacy tool for effecting change.

- **The Global Network of People Living with HIV/AIDS (GNP+)** is a global network run for and by people living with HIV. Its overall aim is to improve the quality of life of people living with HIV. Its work is based on a policy

The user guide is viewed as a living document – something that will need to be adapted over time.

<sup>1</sup> Information about such studies can be found at [www.measuredhs.com](http://www.measuredhs.com)

“I have learnt a lot. Before I thought you needed to be a graduate to conduct research. So I feel confident that I participated well and can conduct this research.”

RESEARCHER, PILOT WORKSHOP, SOUTH AFRICA

platform, the Global Advocacy Agenda, which focuses on promoting global access to HIV care and treatment, ending stigma and discrimination against people living with HIV, and promoting the greater and more meaningful involvement of people living with HIV in the decisions that affect their lives and the lives of their communities. GNP+ achieves its mission through advocacy, capacity building and communications programmes. It has a secretariat based in the Netherlands and affiliated regional networks in Africa, Asia-Pacific, the Caribbean, Europe, Latin America and North America.

- **The International Community of Women Living with HIV/AIDS (ICW)** is the only international network run for and by HIV-positive women, and its purpose is to promote the many voices of women living with HIV and advocate for changes that improve their lives. Since its birth in 1992, it has blossomed into a network of 5,000 HIV-positive women in 138 countries and has developed expertise on the issues of HIV-positive women. The work of ICW is framed by a human rights strategy that focuses on three areas: gender equity; access to care, treatment and support; and the right to meaningful involvement in all decisions that affect the lives of women living with HIV. In all these areas ICW pays special attention to issues facing young HIV-positive women. Central to its work is the reduction of stigma and discrimination faced by HIV-positive women all over the world.

One of the most recent tasks that these networks were involved in was pilot testing the draft version of the questionnaire that forms the basis of the People Living with HIV Stigma Index. Between October and December 2006, after having received the necessary training, two representatives from local networks of people living with HIV in four countries (Kenya, Trinidad and

Tobago, India and Lesotho) pilot tested the questionnaire. Collectively this team interviewed a total of 64 people living with HIV across these four countries and gathered together very valuable information about how to improve the first draft of the questionnaire.

#### **THE INTERNATIONAL PLANNED PARENTHOOD FEDERATION (IPPF)**

The International Planned Parenthood Federation (IPPF) is a global service provider and a leading advocate of sexual and reproductive health and rights for all. It is a worldwide movement of national organizations working with and for communities and individuals. IPPF works on providing prevention, treatment and care services for people living with HIV, building on the crucial policy and programmatic linkages between sexual and reproductive health and AIDS. A key part of its work is to address the sexual and reproductive health and rights of people living with HIV. Recognizing that stigma and discrimination are barriers to providing the necessary services for people living with HIV, IPPF spearheaded the development of the index as an important advocacy tool. It is committed, along with other partners, to coordinating and providing support and limited seed funding to the implementation of the survey.

#### **THE JOINT UNITED NATIONS PROGRAMME ON HIV/AIDS (UNAIDS)**

UNAIDS is an innovative joint venture of the United Nations, bringing together the efforts and resources of the UNAIDS secretariat and 10 United Nations system organizations to respond to AIDS. The secretariat's headquarters is in Geneva, Switzerland with staff on the ground in more than 80 countries. Coherent action on AIDS by the United Nations system is coordinated in countries through theme groups and joint programmes on AIDS. UNAIDS cosponsors are: the Office of the United Nations High Commissioner for Refugees (UNHCR); the United Nations Children's Fund (UNICEF); the



World Food Programme (WFP); the United Nations Development Programme (UNDP); the United Nations Population Fund (UNFPA); the United Nations Office on Drugs and Crime (UNODC); the International Labour Organization (ILO); the United Nations Educational, Scientific and Cultural Organization (UNESCO); the World Health Organization (WHO); and the World Bank.

UNAIDS seeks to build and support an expanded AIDS response – one that engages the efforts of many sectors and partners from government, civil society and the private sector. Its five focus areas include: mobilizing leadership and advocacy for effective action on the epidemic; providing strategic information and policies to guide efforts in the AIDS response worldwide; tracking, monitoring and evaluation of the epidemic and the response to it as the world’s leading resource for AIDS-related data and analysis; engaging civil society and developing partnerships; and mobilizing financial, human and technical resources to support an effective response.

### WHO NEEDS TO BE INVOLVED IN IMPLEMENTING THE INDEX?

There are a number of other key stakeholders that will play an increasingly important part in implementing the People Living with HIV Stigma Index at a country or community level in the future. These include:

- the interviewers, who are people living with HIV;
- the interviewees, who are also living with HIV; and
- those supporting the implementation of the index in a managerial or technical capacity, for example, the team leaders, the data capturers and the data analysts, who may or may not be living with HIV.

Let’s consider the role that each of these local stakeholders plays in this process.

### THE INTERVIEWERS

The interviewers will be members of a network of people living with HIV within the country in which the index is being implemented. They will be HIV-positive. It is important that the interviewers are openly living with HIV (i.e. they are comfortable disclosing their HIV-positive status to others) so as to provide the interviewees with a supportive environment during the interview process and, it is hoped, to encourage them to talk more openly about their experiences.

The interviewers will be trained locally to carry out the interviews using the People Living with HIV Stigma Index questionnaire and this user guide. They will also be trained in interviewing, facilitating participatory group discussions and recording case studies. In addition, they will receive guidance on dealing with difficult emotional situations and referring people for counselling or further sources of advice and information. These are all important skills that may be of use to the interviewers in future if they are (or wish to become) involved in similar projects or other research studies. Past experience suggests that they will find the training process empowering and will learn a lot from interviewing other HIV-positive people. Interviewers may also wish to provide feedback to the networks on broad suggestions from the interviews about issues that require advocacy action or capacity building and to become more involved with the networks in deciding future funding priorities and developing policies from the perspective of people living with HIV.

### THE INTERVIEWEES

The interviewees will be people living with HIV who are either members of a network of people living with HIV or are known by or have a link to the networks, even though they might not be members of the network. Interviewees will fill in the questionnaire with the help of the interviewer, providing data for the index.

The process of going through the

The interviewers will be trained locally to carry out the interviews using the People Living with HIV Stigma Index questionnaire and this user guide.

“I felt I got informed by the process myself as we did the interview.”

RESEARCHER, PILOT WORKSHOP, SOUTH AFRICA

The process of going through the issues in the questionnaire is designed to be participatory and allow interviewees to think through issues that they are facing.

issues in the questionnaire is designed to be participatory and allow interviewees to think through issues that they are facing in a comprehensive manner. This should help them to assess their own capacities and opportunities for action in relation to the issues raised.

The approach to interviewing, which we discuss in the next section, is designed to allow the interviewees to ask questions as they go along so that they learn from the interview process. Also, they will be able – if they wish – to do a self-assessment at the end of the questionnaire. Finally, the interviewees will have the opportunity to discuss issues of concern to them and will receive support in the form of information on referral services.

#### THE TEAM LEADERS, DATA CAPTURERS AND DATA ANALYSTS

Other people that will form part of the research team and help in supervising and managing the administration of the questionnaires are team leaders, data capturers and data analysts.

The **team leaders** will provide leadership and supervision support for the teams of interviewers by, for example, assisting in the training of interviewers, deciding on an appropriate sample of interviewees who are people living with HIV, providing guidance about the place in which interviews ought to occur, doing quality checks on each of the completed questionnaires, confirming which case studies ought to be recorded, ensuring that appropriate ethical standards are maintained during

the research process, and ensuring that appropriate follow-up and referral support is provided to all interviewees.

The **data capturers** will be responsible for taking each of the questionnaires that the interviewers have completed and entering the original data from each questionnaire into EPI-Info (the software package that this project has chosen to use to enter, manage and analyse all the data that are obtained from the questionnaires).

The **data analysts** will be responsible for reviewing the data that have been obtained from the questionnaires and the case studies and, using EPI-Info and more qualitative research techniques, analysing the data. They will then write up their interpretation of the data, along with their recommendation, which the research team will review. Collectively the team will decide on how best to use the findings of the People Living with HIV Stigma Index to promote the rights of people living with HIV within a country or, along with other networks, on an international level.

#### SEE ...

APPENDIX 10:

#### **An overview of the implementation process**

Appendix 10 provides an overview of how the implementation process is envisaged in a national context. It provides an illustration of the step-by-step approach one would take to implement the index in the field.

# PART 2

## THE APPROACH – A SURVEY CONDUCTED BY AND FOR PEOPLE LIVING WITH HIV

### WHY ARE PEOPLE LIVING WITH HIV AT THE HEART OF THIS RESEARCH PROCESS?

The People Living with HIV Stigma Index is not intended to be an abstract academic exercise that is done “to” our community. It is intended to embrace a participatory spirit for all those involved. People living with HIV will be at the centre of the process as interviewers and interviewees and as drivers of how the information is collected, analysed and used.

Ideally, the interviewer and interviewee will sit side by side, and the interviewee will be able to fill in the questionnaire with help from the interviewer, or both the interviewee and the interviewer can work together in filling in the questionnaire. The current questionnaire is not designed to be completed by interviewees on their own, although it is possible to complete the questionnaire in small groups if desired (see also Part 5 of the user guide).

We call this shared filling in of the questionnaire “side-by-side interviewing”. This is because the people who developed it suggested that the interviewer should sit beside the interviewee so that they could fill in the questionnaire together. This suggestion was made as a reaction to “face-to-face interviewing” (normal in survey work) where the interviewer faces the interviewee and the interviewee cannot see the questionnaire; the interviewee just provides information without being in control of how it is written down – a very disempowering experience.

The important thing to bear in mind here is that the People Living with HIV

Stigma Index is not designed merely to collect information for the index – although this is the main objective – but also to be part of a process of empowerment for the interviewees and interviewers. The process will be overseen by the key stakeholders (the networks of people living with HIV, the International Planned Parenthood Federation and UNAIDS) and should also contribute to the work of the local implementing organizations such as outreach to new members, capacity building and defining issues for advocacy or actions to be taken. It should not undermine their other work as a traditional survey might do. For these reasons, it is important that all interviewers should be aware of the philosophy of the People Living with HIV Stigma Index and should do their best to follow it. Some key points for the interviewer to remember are listed here.

- Make sure that the interviewee is fully informed of what the survey is about.
- Share the process of filling in the questionnaire with the interviewee (either or both of you can write down their responses to the questions). Make sure you explain any difficult concepts and provide definitions of words that you feel are needed as you go along.
- Remember that as the interviewer, you and the interviewee beside you have equal power. We are trying in this research process to introduce a spirit of equality and treat everyone with the utmost respect. Provide information and answer any questions that the interviewee asks to the best of your ability, but don't lecture the interviewee.

The process of implementing the index is intended to be an empowering one for people living with HIV, their networks and local communities.

“Try to reduce the power imbalance between yourself and the interviewee by sitting alongside the interviewee, and sharing information about some of the more difficult concepts with the interviewee.”

RESEARCHER, PILOT WORKSHOP,  
SOUTH AFRICA

You and the interviewee beside you have equal power.

- Always remember to thank interviewees for their participation at the end of the interview, and ensure that they are referred to the appropriate local organization if they require specific support after the interview.

### SEE ...

APPENDIX 11:

#### **A model three-day interviewer training programme**

In late 2006, in order to prepare interviewers who are people living with HIV to pilot the draft version of the People Living with HIV Stigma Index questionnaire in their home countries, GNP+, ICW, IPPF and UNAIDS trained representatives from local networks of people living with HIV in Kenya, Trinidad and Tobago, India and Lesotho.

Discussing experiences of having been a part of an interview or having conducted interviews themselves, reviewing the content of the questionnaire in detail and practising some basic interviewing skills formed an essential preparatory step for the interviewers to be able to gather the rich data that they did.

We have reproduced the framework of this training programme so that it can be adapted for regional trainings in 2008, national trainings and/or in other local contexts.

# PART 3

## ETHICAL ISSUES – INFORMED CONSENT AND CONFIDENTIALITY

### WHY WORRY ABOUT INFORMED CONSENT AND CONFIDENTIALITY?

The People Living with HIV Stigma Index, like other studies that collect data from people, must observe certain standards with regard to ethical issues and data protection. In each country where this survey is carried out, those responsible for conducting the study should make sure that it conforms to that country's ethical and data protection requirements. This user guide does not replace such requirements, but it provides some general guidance relating to ethical research that should be followed in all contexts in which the People Living with HIV Stigma Index is being conducted.

Two issues are of particular importance: informed consent and confidentiality.

### INFORMED CONSENT

#### What is informed consent?

The principle of informed consent means that each interviewee must be asked to consent to the collection and processing of their personal data after being fully informed about the nature of the study, who is involved in it, how the data will be processed and stored, and what the data will be used for.

The interviewer must explain to the interviewee that they are free to refuse to be interviewed, to withdraw from the interview at any time, or to refuse to fill in a particular question or set of questions.

The People Living with HIV Stigma Index will use an information sheet (Appendix 2) and informed consent form (Appendix 3) with each

interviewee. These must be translated into the appropriate local languages. The informed consent form does not require the written consent of the interviewee because this might be an unnecessary deterrent. Instead, the interviewer must sign the form recording that explicit verbal consent has been given.

The interviewer must ensure that the interviewee has provided their informed consent on the basis of the information sheet and informed consent form before starting the interview. It is particularly important to do so in this study because the data to be collected are of a personal nature and also focus on sensitive issues (like sexual relationships and instances of discrimination). If the interviewee does not freely give their consent, the interviewer should not sign the informed consent form and should end the interview.

It is difficult to obtain real informed consent from children or from those with disabilities that limit understanding or communication. Therefore, this study will only interview people of 16 years or above, and will avoid interviewing those with mental disabilities that impair the ability to give real, informed consent.

Care must be taken to ensure that interviewees are not pressured into giving informed consent. Informed consent must be given of the interviewee's own free will (voluntarily). Particular care should be taken when interviewing detained people (prisoners or people in drug rehabilitation centres) as their circumstances may make it difficult for them to refuse to participate in the study and, given different circumstances, might prefer not to be interviewed.

The People Living with HIV Stigma Index, like other studies that collect data from people, must observe certain standards with regard to ethical issues and data protection.

“Get informed consent before the interview starts and make certain that the interviewee would genuinely like to be a part of the process – and is not just saying ‘yes’ because s/he feels pressurised to do so.”

RESEARCHER, PILOT WORKSHOP, SOUTH AFRICA

The questionnaire used in the survey has been designed to help ensure confidentiality.

“I think there will be challenges around cross-gender interviewing (like when a man interviews a woman) which we need to be observant about when we conduct the actual interviews. It will be important in these situations to create a climate of trust, openness and respect.”

RESEARCHER, PILOT WORKSHOP,  
SOUTH AFRICA

## SEE ...

### APPENDICES 2 AND 3: Providing information and obtaining consent

A generic information sheet (Appendix 2) and an informed consent form (Appendix 3) have been prepared for people living with HIV who participate as interviewees in the People Living with HIV Stigma Index.

## CONFIDENTIALITY

### What is confidentiality?

Confidentiality is concerned with the issue of who has the right to access data provided by the participants of a research study. When conducting research, one should always ensure that appropriate measures are put in place so as to make absolutely certain that the information participants have disclosed and their identity are kept in confidence.

Every effort must be made to ensure that the data collected by the People Living with HIV Stigma Index are kept confidential (i.e. secret). This means that the person responsible for the study in each country (for example, the team leader) must put in place measures to ensure confidentiality. Any breaches of confidentiality could lead to stigmatization, loss of employment or access to services, media exposure, physical violence, etc. Every effort must be made, therefore, to avoid such things happening.

The questionnaire used in the survey has been designed to help ensure confidentiality. For example, instead of writing the name of the interviewee on it, there is space for a unique identifying code to be written in the top right-hand corner of each page of the questionnaire (see Part 5 of the user guide). The important thing to remember about this is that one should never write the names of interviewees on their questionnaires.

The interviewer will, however, keep a list of names and the contact details of all those they have interviewed. Beside each name, the interviewer will put in

the interviewee's unique identifying code. It is necessary to write up such a list and keep the list until the end of the research process in case there is a need to check information or contact an interviewee for a specific reason (see the “Interviewee contact list and questionnaire codes”, Appendix 4).

This list acts as a key. In other words, anyone in possession of the list and the questionnaires would have access to personal and sensitive data from the interviewees. Therefore, the list, informed consent forms and questionnaires should be kept in a safe and secure place, such as in a locked cupboard or filing cabinet. The informed consent forms and the list with the names and codes of interviewees should be kept separately. They should be destroyed as soon as they are no longer needed (i.e. after all the information has been entered into a database, the process of data cleaning and checking has been completed, and the report has been written up and accepted as a completed product).

Importantly, the only people who may see the list containing the contact details and codes of all interviewees, the informed consent forms and the completed questionnaires are the interviewers who collected the data and the team leader. Those responsible for data entry, cleaning and analysis should not have access to the list that contains the personal details of the interviewees – or for that matter the informed consent forms. Apart from the fact that their work is focused on the content of the questionnaires with there being little or no reason to know the identity of the interviewee, a lack of access to the identity of the interviewees for those responsible for data entry, cleaning and analysis further ensures the maintenance of confidentiality.

The use of a small group of HIV-positive interviewers is intended to help ensure confidentiality, as people living with HIV are generally best placed to know and understand the problems that might be caused by any leakage of information about their peers. However,

this assumption should be tested and worked through during the training process. In particular, the issue of creating an appropriate boundary between being in the interview process and other contact that the interviewer and interviewee might have as members of the same community should be explored and emphasized during training.

It may be necessary to bring in outside support (for example, a statistician) to conduct the sampling. If such people need to see the list of names, they should be asked to sign a confidentiality agreement. Alternatively, there are ways of disguising the personal data. For instance, the team leader could assign a number to each

person on the list and give this list of numbers to the statistician instead of the list of names.

### SEE ...

APPENDICES 4–9:

#### **Protecting the confidentiality of interviewees**

An example of the list that contains the name, contact details and unique identifying codes for all interviewees can be found in Appendix 4.

In addition, a number of confidentiality agreements have been developed that every member of the team implementing the People Living with HIV Stigma Index ought to sign. These can all be found in Appendices 5–9.

The use of a small group of HIV-positive interviewers is intended to help ensure confidentiality, as people living with HIV are generally best placed to know and understand the problems that might be caused by any leakage of information about their peers.

# PART 4

## SAMPLING – SOME GUIDELINES AND SUGGESTIONS

Although it is not possible to obtain a representative sample for the whole population of people living with HIV, it would be possible for a more narrowly defined population of people living with HIV such as people living with HIV who are members of a network.

### HOW DO YOU CHOOSE WHO SHOULD BE INTERVIEWED?

Developing a sampling strategy for a research study can be a complex task. When the team is ready to consider this, it is recommended that they contact the index coordinator at IPPF and seek their advice. In addition, advice could also be sought from a statistician within a local university or research institute.

### SAMPLING

There has been much debate about sampling for this index. Research studies such as these take a representative sample of the population of interest, with the aim of producing results that can be generalized for that population. When we talk about results being generalizable, we mean that information collected from a sub-section of a population (the representative sample) can be used to reach conclusions that apply to the population as a whole. This process is called **inference**.

The problem in our case is that it is not possible to take a representative sample of the whole population of people living with HIV. In order to take such a sample, we would need to use an objective method of selection where all members of the study population have a definable chance of being part of the sample (what is termed a **probability-based** method of selection). However, it is very difficult to take a representative sample of people living with HIV given that one does not have a complete list of all of those living with HIV (i.e. the whole population of interest). We are therefore left with two options...

### SAMPLING STRATEGY OPTION # 1: PURPOSIVE SAMPLING

The first option is that adopted by the Asia Pacific Network of People Living with HIV/AIDS.<sup>2</sup> This is what statisticians call **purposive sampling**. It is a respectable approach so long as its limitations are acknowledged. The Asia Pacific Network of People Living with HIV/AIDS report sets out its strategy clearly, arguing why the results should be taken seriously even though the study cannot claim to be based on a representative sample:

*The study sample contains a mix of positive people of different ages, sexuality and economic, social and educational backgrounds. The sample is not representative of the epidemiological profile of HIV infection in each country. Most people who are infected with HIV are not aware of it. People who are tested for HIV are a skewed sample of actual infections. They may represent, for example, higher numbers of migrant workers, women attending antenatal clinics or military personnel than in the general population because certain groups of people are more likely to be tested for HIV than others, with or without their consent. Of the people who do test HIV-positive, most keep their status secret for fear of the stigma and discrimination they may face if they reveal their status. Many do not access medical care and/or do not reveal their status to anybody, even their family.*

*The sample size was determined by the maximum number of positive people that interviewers could reach in each country at the time the study was conducted. Interviewers cast their nets widely from peer support groups, testing sites, hospitals and AIDS service organizations to capture the experiences of as many positive people as possible. Within each country, respondents were recruited from several regions.*

*The findings may not be representative. People interviewed may have suffered greater amounts of discrimination than others, or people who have no contact with AIDS organizations may have experienced more discrimination and been silenced to a greater extent*

<sup>2</sup> Asia Pacific Network of People Living with HIV/AIDS (2004). *AIDS Discrimination in Asia*. Bangkok: Asia Pacific Network of People Living with HIV/AIDS.



and are harder to reach. Nevertheless, because of the large sample size, it can be assumed that the findings reflect the experiences of thousands of people living with HIV in the region.<sup>3</sup>

### SAMPLING STRATEGY OPTION # 2: PROBABILITY-BASED SAMPLING OF DEFINED POPULATIONS

Although it is not possible to obtain a representative sample for the whole population of people living with HIV, it would be possible for a more narrowly defined population of people living with HIV such as people living with HIV who are members of a network. For such groups, assuming that they have lists of members, it should be possible to draw a sample using a probability-based method.<sup>4</sup>

Thus, for example, you could draw a representative sample of members of the International Community of Women Living with HIV/AIDS (ICW). When presenting the findings, it would need to be clear that they were based on a sample of members of ICW. It would also be wise to acknowledge that members of this network are probably more aware of some of the issues than the average woman living with HIV – their experiences and opinions are valuable, just not necessarily representative of the entire group of women living with HIV.

It should, however, be possible to have a sampling strategy that combines the first and second options. For instance, you might decide to start by sampling from the lists of network members, providing results from groups with clearly defined populations. You might then want to move beyond this core to groups of people who can be contacted in other ways, for example, through outreach. The reason for doing this might be that you wanted to increase your sample size in a particular place or to include a wider range of experiences than those covered by particular networks (for example, if you had sampled only from ICW and the study teams wanted to expand coverage to men as well as women).

### THE SAMPLE SIZE

Finally, it is important to bear in mind the question of sample size. You need to take a sample that is large enough to capture the main features of the population as well as the divergence from the main features – or what is termed variability. But what is large enough? Or to put this more formally, **What sample size is required to ensure that the study results can be relied upon to make generalizations?**

This is a difficult question to answer because it depends on a number of factors, including how precise you want your findings to be and the variability of the study population with respect to the characteristics of interest. The sample size has nothing to do with the underlying size of the population of interest (a common myth). However, it does depend on whether you want to present results at the international (global) level only or compare different countries, or within a particular country whether you want to show national-level results or breakdowns for specific areas or groups of people.

For example, one study in Tanzania sampled three key groups of interest to measure stigma related to HIV: general community members, health care providers, and people living with HIV. For the research, the study intended to gather 100 responses from people living with HIV “to fall within the minimum required size on which statistical tests could be meaningfully conducted and within the maximum that the study resources could support.”<sup>5</sup> In the end, to ensure gender balance in the sample size, they extended the survey to include 218 respondents since the majority of the first 100 respondents were women. In the Asia Pacific Network of People Living with HIV/AIDS study referred to earlier, there was a sample size of 764 (302 from India, 338 from Thailand, 82 from Philippines and 42 from Indonesia). These examples highlight that sample size will vary depending on the context and focus of each country study.

Some important things to remember for each individual study using the

You need to take a sample that is large enough to capture the main features of the population as well as the divergence from the main features – or what is termed variability.

3 Asia Pacific Network of People Living with HIV/AIDS (2004). *AIDS Discrimination in Asia*. P. 9. Bangkok: Asia Pacific Network of People Living with HIV/AIDS.

4 Random sampling is the best-known probability-based method, but others may be more appropriate for this sort of survey.

5 USAID (2005). *Working Report, Measuring HIV Stigma: Results of a Field Test in Tanzania*. P. 10. Washington: USAID.

Ultimately, you need to settle on the best and most feasible sampling strategy for your research.

People Living with HIV Stigma Index include:

- What is the minimum size required to meaningfully run statistical tests?
- What is the maximum size that the study resources can support?
- If balance is important for the study (e.g. gender), do you have an equal number of responses (e.g. from men and women)?
- Even if the study cannot be representative, do you have a sample that contains a mix of positive people

of different ages, sexuality and economic, social and educational backgrounds?

Ultimately, you need to settle on the best and most feasible sampling strategy for your research. The People Living with HIV Stigma Index coordinator at IPPF will be able to inform you about what other countries' teams have done and provide you with the necessary advice for your country.

A close-up, vertical photograph of a person's face, focusing on the eyes which are closed. The skin is a warm, brownish tone. The lighting is soft, highlighting the texture of the skin and the eyelashes. The overall mood is calm and contemplative.

WORKING  
WITH THE  
INDEX IN YOUR  
COMMUNITY

Training of interviewers is an essential part of the survey process. Without it, results will not be as reliable as they should be.

# PART 5

## PREPARING TO IMPLEMENT THE INDEX IN YOUR COMMUNITY

### WHAT ARE THE STEPS YOU NEED TO TAKE IN PRACTICE?

The questionnaire is the main tool for data collection by the People Living with HIV Stigma Index. However, the questionnaire-based interviews are in fact a small part of the entire research process. Before beginning to conduct the questionnaires, there needs to be a lot of preparation. This is the subject of this part of the user guide.

Before you read about the various activities that are required in preparation for the interviews, we would like to recommend that you first read the questionnaire. By doing that you will get a good sense of the various themes that are covered in the questionnaire and what questions, if you are an interviewer, you will be expected to ask an interviewee. You might also find it useful at this stage, while reading through the questionnaire, to make a note of any of the words, concepts or questions that you would like explained to you.

If some things do not appear clear to you at this stage, don't worry. Part 6 of this guide has been developed to help you understand the content of the questionnaire and its context in more detail.

### TRANSLATING THE QUESTIONNAIRE

Your first task when preparing to run the survey is to translate the questionnaire and accompanying documents from English into the language(s) in which the interviews will be conducted. It is essential that:

1. The translations for key concepts – such as stigma and discrimination –

are discussed and agreed upon in advance by the research team and members of the network(s) of people living with HIV collaborating on the project.

2. The questionnaire and other documents are “back-translated” into English by someone **other than the translator** to ensure that the meaning of each question is as close as possible to the original. If translations diverge across and within countries, the results will not be comparable.

Please note that it is **not** acceptable practice to translate on the spot from English into national or local languages while conducting an interview. This will produce variations not only across places, but from one interview to the next, making the findings extremely unreliable.

### TRAINING OF INTERVIEWERS

Training of interviewers is an essential part of the survey process. Without it, results will not be as reliable as they should be, and it will be difficult – if not impossible – to meet the capacity-building objectives of the survey or to adhere to its ethical principles. The Asia Pacific Network of People Living with HIV/AIDS report<sup>6</sup> notes that:

**Training was essential to strengthen the capacity of the positive people involved in data collection and was considered to be as important as the development of the data collection instrument. A three-day national training workshop was held for each data collection team (...) Day 1 dealt with the concepts of stigma, discrimination and human rights; it was conducted by a person with a legal background, in conjunction with the APN+ National Team Leader. Day 2 focused on training participants in**

<sup>6</sup> Asia Pacific Network of People Living with HIV/AIDS (2004). *AIDS Discrimination in Asia*. P. 10. Bangkok: Asia Pacific Network of People Living with HIV/AIDS.

interviewing techniques, particularly sensitizing interviewers on how to deal with potentially difficult emotional situations; it was facilitated by an academic with experience in qualitative data collection. Day 3 was devoted to interview practice, developing a referral system and the logistics of data collection. Training was rigorous in relation to the procedures and mechanisms to ensure confidentiality and was vital in ensuring the interviewers understood the ethical implications and psychological risks for the research participants.

Similarly, in training the interviewers who pilot tested the draft People Living with HIV Stigma Index in late 2006, a three-day training programme was developed. In reflecting on this event, IPPF and UNAIDS noted that:

- you must allow enough time to go through every section of the questionnaire plus the front page and the quality checks with the interviewers, so that every interviewer understands how to complete the questions and can ask for clarification;
- if the survey is being run in different countries and training is being done in-country, one “link” person should attend every training session to ensure that the interpretation of key issues and clarification of approaches to questions is consistent across countries; and
- the training provides an opportunity for those implementing the study (such as the GNP+, ICW, IPPF and UNAIDS) to discuss how the study can be coordinated with other initiatives and contribute to them.

### SEE ...

APPENDIX 11:

#### Template: three-day training programme for interviewers

See Appendix 11 for an outline of the agenda and content of this training programme, which could serve as a useful model for an interviewer training programme in any country.

## SETTING UP THE INTERVIEWS

The team leaders will need to decide on the best way to recruit interviewees and in what context or setting it would be best to interview people. Ideally, the team leader ought to put together a list of names and contact details of potential interviewees for the interviewers to contact. In some instances, this list may not be a full list at the beginning of the process. For example, you might decide to add to the core group of interviewees who appear on the list as you go along.

In terms of the setting or place in which the interview occurs, it is important that interviewees have privacy when responding to the questionnaire and also that they have the support of the interviewer throughout the process (following the side-by-side principle). The simplest way to achieve this is to agree to meet individual interviewees in private. However, you may want to have the option of interviewing people when they are in workshops or group meetings. This is appropriate as long as:

- there are enough interviewers to provide support; and
- the place where the interviews take place is organized in a way that allows people privacy when filling in the questionnaires. It is up to the workshop/group facilitators to create private spaces.

## PREPARING FOR POTENTIAL REFERRALS AND FOLLOW-UP ACTIVITIES

You may have noticed that the front page of the questionnaire has a section on referrals and follow-up. The idea here is not actually to provide a referral service following the interview – as this would probably be beyond the capacities and resources of most study teams – but to try to provide the interviewee with information about referral services if they need them. Often interviewers do this on an informal basis anyway, following their

It is important that interviewees have privacy when responding to the questionnaire and also that they have the support of the interviewer throughout the process.

In order to provide this referral and follow-up support, the team can develop a local resource list of organizations they feel could, collectively, meet most of the needs of people living with HIV.

“During the interview, it’s important to ask the interviewee if he/she is OK with the questions so far. Pay attention to all sensitive details and make notes of all of them. Also give suggestions where necessary, not advice – it’s important to know your boundaries as the interviewer.”

RESEARCHER, PILOT PHASE,  
TRINIDAD AND TOBAGO

instincts of solidarity and support for fellow human beings. This approach formalizes the process.

In order to provide this referral and follow-up support, the team can develop a local resource list of organizations they feel could, collectively, meet most of the needs of people living with HIV. For example:

- each interviewer could compile a list of appropriate contacts for his or her locality or community before beginning the interviews;
- you could share this information with the other interviewers in the team, and compile a (now very comprehensive) local resource list, with the names and contact details of organizations that can assist people living with HIV, to share with interviewees;
- during interviews, if the interviewee asks for advice, you should not provide such advice unless you are professionally qualified to do so. Instead, provide the interviewee with the local resource list; and
- if, during the interview, you are asked for a referral and you do not have the necessary contact on your list, you should agree to send it to the interviewee after the interview.

Again if, during the interview, you observe a need for medical, emotional or legal support of which the interviewee seems to be unaware, you have a duty to inform the interviewee if you believe that not to do so might endanger the interviewee’s future well-being. In such cases, you should provide the interviewee with the appropriate contacts from your local resource list if possible; and if not, you should send them after the interview.

In relation to referrals, it is important to keep a sensible balance with the onus on providing information and contacts for the interviewee to pursue rather than interviewers promising to make referrals themselves. However, not being prepared to provide information could put interviewers in an awkward position.

Also, the study teams might be seen as failing in their duty to the interviewees.

## PREPARING TO PROVIDE INTERVIEWEES WITH EXPLANATIONS AND DEFINITIONS AT THE START OF THE INTERVIEW

Whether filling in the questionnaire with each individual interviewee or as part of a small workshop or group meeting, an interviewer should begin by explaining what the survey is about and who is involved in it. You can use the information sheet (Appendix 2) for this purpose. It is also important at this stage to explain some basic concepts and definitions to the interviewees. It is suggested that you explain only a few key concepts to begin with, such as stigma, discrimination and rights, and provide the other key definitions (sourced from Appendix 1) as you go through the questionnaire. Otherwise, there will be too much information for interviewees to absorb all at once.

## GETTING FAMILIAR WITH THE UNIQUE IDENTIFYING CODE

As we mentioned above, to secure confidentiality the index questionnaires and informed consent forms will be identified by a unique identifying code (as opposed to the name of the interviewee). Each code should be made up in the following way:

1. a country code of two digits;
2. a network (of people living with HIV) code of two digits;
3. an interviewer code of two digits;
4. an interviewee code of two digits; and
5. the date on which the interview occurred, written in six digits (day/month/year).

1 Country code		2 Network (of people living with HIV) code		3 Interviewer code		4 Interviewee code		5 Date of interview					
U	K	P	P	2	3	0	5	2	1	0	2	0	8

For example:

The sample code above would represent:

1. an interview conducted in the United Kingdom (UK);
2. by the network "Positive People";
3. by the 23rd interviewer;
4. carrying out his or her fifth interview;
5. on 21 February 2008.

The format of the code will ensure that any questionnaire in any country, in any year, will have a different and unique questionnaire identification number. Interviewers must understand the purpose of the unique identifying code and how it works before going out interviewing.

After conducting an interview, interviewers should write the interviewee's unique identifying code:

- in the top right-hand corner of every page of the questionnaire (so that if pages get detached, they can be reunited with the rest of the questionnaire);

- next to the relevant name of that person on the list entitled "Interviewee contact list and questionnaire codes" (Appendix 4); and
- on the informed consent forms so that the team leader can check that informed consent has been obtained from every interviewee.

Interviewers should bear in mind that they should NOT:

- write interviewee names on the questionnaires or informed consent forms; or
- fill in the unique identifying code on the list of names until they have completed the interview.

On the next page is a checklist that the interviewers used when they pilot tested the draft People Living with HIV Stigma Index questionnaire. It might be helpful for local teams to consider and modify it to suit their context.

The format of the code will ensure that any questionnaire in any country, in any year, will have a different and unique questionnaire identification number.

"I saw how important body language was and what it conveys to someone else."

RESEARCHER, PILOT WORKSHOP, SOUTH AFRICA

“On the actual interview please make sure you have all the required documents to conduct the interview – consent forms, information sheet, referral list, questionnaire, receipt book, note pad, pen, pencil etc.”

RESEARCHER, PILOT PHASE,  
TRINIDAD AND TOBAGO

### CHECKLIST: PREPARING FOR AN INTERVIEW

1. Make an appointment with the interviewee and explain very briefly the purpose of the survey, the approach and process that the interview would take, and that the interview would include an honorarium.
2. Ensure that the agreed upon time to meet will allow for an optimal interview experience (two to three hours).
3. Book or arrange a suitable venue.
4. Plan for special requirements (e.g. child care, wheel chair access).
5. Arrange an honorarium that is equivalent to local practice (e.g. food or money).
6. Take:
  - two copies of the blank questionnaire (so that each person in the interview can have a copy – although only one would be completed during the interview process);
  - copies of the *Declaration of Commitment on HIV/AIDS* AND the national law, policy or set of guidelines that protects the rights of people living with HIV (that was selected by the network in your country to be included in Section 2D of the questionnaire);
  - pens and paper or a notebook;
  - a referral sheet (that has been developed for the local context);
  - an information sheet about the survey;
  - two consent forms (one which the interviewee will keep and the other which the interviewer will keep);
  - the People Living with HIV Stigma Index user guide; and
  - a piece of paper to record the interviewee’s details and unique identifying code (which will then be transferred onto the interviewer’s list of interviewee contact information and codes).



# PART 6

## THE QUESTIONNAIRE – BECOMING FAMILIAR WITH THE CONTENT

### WHAT ISSUES DO YOU TALK ABOUT IN THE INTERVIEW?

In this part of the user guide we will take you through each section of the questionnaire, highlighting important aspects of the content that you need to be aware of before you conduct an interview.

### THE OVERALL LAYOUT OF THE QUESTIONNAIRE

The questionnaire is divided into three sections, focusing on the following issues:

- SECTION 1** General information about the interviewee (and his or her household).
- SECTION 2** Indicators focusing on the reported experience over the last year of people living with HIV of HIV-related stigma and discrimination; internal stigma; the protection of the rights of people living with HIV through law, policy and/or practice; and effecting change.
- SECTION 3** Indicators focusing on instances of HIV-related stigma and/or discrimination over the last year specifically related to HIV testing, disclosure and the provision of health care.

Let us now look more closely at each of these three sections.

### THE FRONT PAGE

The front page carries important instructions for the interviewer to follow **before** starting the interview. These are:

1. Give the interviewee the information sheet and allow them time to read through it. If they cannot read, you must read it out to them.
2. Read the informed consent form to the interviewee and then complete two copies, one of which must be left with the interviewee for them to keep, and the other copy you keep.

If the interviewee does **not** give their consent, you should politely end the interview.

There is also a referrals and follow-up section and a quality control procedures panel which should be filled in by the interviewer **after** finishing the interview and, later, by other members of the survey team back in the office.

The information required on the front page is designed to be filled in by the interviewer and other members of the survey team, not by the interviewee.

The interviewer must, however, fill in the parts on the front page for which they are immediately responsible (i.e. the five questions relating to referrals and follow-up support) **before** ending the interview, as in doing so it may alert them to things that need to be clarified with the interviewee before they leave.

The team leader should keep an eye on Question 3 to make sure that any promises to interviewees to send information (or provide any other follow-up) are kept.

The team leader should make sure that any promises to interviewees to send information (or provide any other follow-up) are kept.

The skip pattern has been logically worked out by the designers of the questionnaire, and it is important that you become familiar with them and then follow the instructions carefully so as to take the interviewee logically through the questionnaire.

## GUIDANCE FOR SECTIONS 1–3

Sections 1–3 of the questionnaire should be filled in by the interviewer and interviewee together. You will need to provide explanations and definitions as you go along. If you are working in a small group or workshop situation, you may not be able to sit beside the interviewee all the time, but please ensure that there are enough trained interviewers to provide support to the interviewees as they go through the questionnaire. Otherwise, the reliability (or accuracy) of the responses will suffer.

- Most questions simply require one to tick one box alongside the response that seems most appropriate. However, in some cases there are other instructions, such as:
  - Tick one box **only**; and
  - Tick **at least** one box. You can tick more than one if appropriate.

Please follow these kinds of instructions carefully as they have been designed for each question and have implications for the data capturing and the analysis.

- **Use a black or blue ink pen** to fill in the questionnaire. Do not use pencil.
- **Tick all answers.** If you make a mistake, or an interviewee would like to change their initial response, do not try to rub it out or use a correction fluid. Just put an “X” (cross) through the wrong answer(s) and then tick the right one(s).

For example, let’s say that the interviewee answers Section 2A, Question 1a as “A few times”, and then, when she gets to Question 2a she thinks, “Actually, it has been my decision not to attend these social gatherings and not because others have excluded me from them – so I want to correct my answer to Question 1a to ‘Never’”. In this case, just go back to Section 2A, Question 1a and put a cross in “A few times” and a tick in “Never”. Then continue

answering Question 2a. In some sections you will find what is termed a “**skip pattern**” where you are asked to skip onto the next question or leave out some of the sequential questions if you responded to an initial question in a specific way. The skip pattern has been logically worked out by the designers of the questionnaire, and it is important that you become familiar with them and then follow the instructions carefully so as to take the interviewee logically through the questionnaire. You will find an example of such a skip pattern in Section 2D (Rights, laws and policies), starting at Question 4a.

- **Every question in Sections 1–3 should be answered.** There should be an appropriate box to tick for every possible answer in each question – even if it is “Not applicable” or “Don’t know” or “Not sure”. You might need to reassure an interviewee that these kinds of responses are perfectly acceptable as people tend to think that a response that is more neutral or uncertain is less desirable than a definitive and/or positive response.

The **only exception** to the rule that every question should be answered is **if the interviewee decides they do not wish to answer it**. Such cases should be summarized under Point 1 on the quality checks page (the last page of the questionnaire). You should note down the section and question numbers and the comment “interviewee preferred not to answer”.

- The interviewer should **make sure that the interviewee has seen all possible answers to a question** before deciding which box to tick. Otherwise, they may tick the wrong box and only realize later on that there was an option which better reflected their experience. If the interviewee cannot read, the interviewer will need to be

particularly careful to read out all the possible answers before ticking a box. You may need to repeat the options. Do not rush this process. Remember, your job is to provide excellent support to the interviewee.

### DETAILED GUIDANCE ON SOME QUESTIONS IN SECTIONS 1–3

We would now like to provide you with guidance on how to deal with particular questions in the questionnaire. Please note that there are some complex concepts and words in some of the

questions, which we have attempted to define in Appendix 1 of this guide.

Remember that the interviewer, before starting to interview people living with HIV, should be familiar with all the words and concepts – and of course the questions – that are contained within this questionnaire. They should also have the user guide with them in each interview so that they can have Appendix 1 at hand if they need to explain one of the more difficult concepts and words to an interviewee.

The interviewer, should be familiar with all the words and concepts that are contained within the questionnaire.

SECTION 1	
Question 2 <b>AGE</b>	In some cases an interviewee might be uncertain of or not know their exact age. If this is the case, we suggest that the interviewer ask the interviewee to estimate his or her age and then decide which would be the most appropriate age range to tick for this question.
Question 4 <b>RELATIONSHIP STATUS</b>	The possible choices of answers to this question have been carefully selected to be inclusive and remain relevant for people in same-sex relationships and heterosexual relationships. Interviewees should be encouraged to select the answer that most closely reflects their current situation. For instance, an interviewee might be single because their partner or spouse has recently died. In such a case, the interviewee should tick “Widow/widower” as opposed to “Single”. The same rule would apply to “Divorced/separated”.
Question 6 <b>SEXUALLY ACTIVE</b>	Remember to refer to Appendix 1 (key definitions and concepts) to make sure you are familiar with how we have defined <b>sexually active</b> in this questionnaire. Please bear in mind that although the interviewee might not have described themselves to be in a relationship (in the previous two questions), they still could be sexually active.
Question 7 <b>CATEGORIES</b>	This question attempts to ascertain the interviewee’s current or past association with a specific group, which in itself might be considered by society as different or “other” – and, in some cases, deviant or morally wrong. The interviewee’s membership or association with this group might very well be underlying or contributing to their experience of HIV-related stigma and discrimination. We have also asked if the interviewee belonged to one of these categories in the past because we believe that even if someone is no longer, for example, a sex worker, the community might still stigmatize them for having been a sex worker in the past. In other words, so long as someone is seen as having belonged to a particular group – even if they are no longer a member of that group now – the attitude of the community towards that person might still reflect their past membership of a particular group rather than their current situation. Interviewers will have to exercise some judgement here in recording an appropriate response to this question. For instance, an interviewee is unlikely to consider themselves to be part of the category of men who had sex with men if they had one, brief sexual encounter with another man and they have not been sexually involved with a man again. In instances where there is some doubt as to whether a person belongs to a particular category, we suggest that the interviewer and interviewee consider to what extent other people in the community might see them to be part of that category, given that the categorization has relevance to how other people might stigmatize and

	discriminate against someone if they were seen to belong to one of these categories. See Appendix 1 (key definitions and concepts) to make sure you are familiar with our definitions of the categories covered in this question.
Question 8 <b>PHYSICAL DISABILITY</b>	<p>In this question, we are trying to identify people with disabilities in the more traditional sense of the word, for example, people who are blind, deaf, etc. General ill health resulting from being HIV-positive does not apply in this instance.</p> <p>See Appendix 1 (key definitions and concepts) to make sure you are familiar with our definition of <b>physical disability</b> for this questionnaire.</p>
Question 10 <b>EMPLOYMENT STATUS</b>	<p>The aim of this question is to understand the employment status of the interviewee. Some interviewees may want to tick more than one box. For example, an interviewee may be formally employed for three days a week and would then tick “In part-time employment (as an employee)”. They may, however, also be doing odd jobs on other days and thus it would also be appropriate to tick “Doing casual or part-time work (self-employed)”.</p> <p>Please note that:</p> <ul style="list-style-type: none"> <li>• the self-employed option includes informal and/or manual labour-type activity; and</li> <li>• we have not included in this list a category for household activities such as cleaning, cooking or looking after children or the elderly. While we recognize these as important aspects of work, we are in fact wanting to find out at this point whether the interviewee works <b>outside of the home</b>.</li> </ul>
Question 12 <b>AIDS ORPHAN</b>	Remember to refer to Appendix 1 (key definitions and concepts) to make sure you are familiar with how we have defined <b>AIDS orphan</b> in this questionnaire.
Question 14 <b>HOUSEHOLD INCOME</b>	<p><b>For the interviewee</b></p> <p>In this question, the interviewee is being asked to estimate the average monthly income of their household over the last 12 months. This amount should be written down in the local currency of the interviewee. The monthly income should include the total income in money, <b>plus</b> any in-kind payments for which a money value can easily be estimated.</p> <p>We are interested in an estimate, so do not worry about small amounts that cannot easily be counted; just round these off to the closest multiple of 10, for example. It is important to write a single figure in the box – not a range of figures (for example, write down “20,000 pesos” rather than “15–25,000 pesos”).</p> <p>Please be aware that interviewees might be hesitant or reluctant to provide the interviewer with information about their income. Generally it is considered to be difficult to get accurate information on income through surveys like this one. This occurs for a range of reasons. For example, tax collection might be an issue in a country and interviewees might be reluctant to share what they earn out of a fear that, once recorded, their income will come under investigation.</p> <p>Many people also feel that what they earn is a private matter and would not feel comfortable sharing this information with someone that they did not know. Others might struggle to talk about their income as it might be very low and/or intermittent, and they might find it difficult to work out what an average amount is for a month.</p> <p>The interviewer should reassure the interviewee that this, as with other information in the questionnaire, will be kept confidential. However, if the interviewer feels that this particular issue might be causing the interviewee too much anxiety, they might sensitively suggest that they proceed to the next question.</p> <p><b>For the data capturer</b></p> <p>Firstly, multiply the amount given by the interviewee by 12 to calculate their annual household income in local currency.</p> <p>Secondly, note the date that the interview was conducted. This can be found on the top right corner of each page of the questionnaire in the unique questionnaire code. The date forms the last six blocks of the code using the format day/month/year.</p> <p>Using a website that provides historical information on exchange rates (an example of such a website we recommend is <a href="http://www.exchangerate.com">www.exchangerate.com</a>), go to “past exchange</p>

rates". When you are within that facility on the website, enter the currency that has been used in the interview, the year and month of the interview, and the currency you are converting to (US dollars). The site will then provide you with a list of exchange rates for each day of the month and year you selected. Select the rate of exchange for the day of the interview. For the purposes of comparison, all currency data provided in these questionnaires should be converted into US dollars.

Using a calculator, multiply the annual amount in local currency with the exchange rate in US dollars.

On the questionnaire write down:

- annual income in local currency (top line);
- exchange rate that you used (middle line); and
- annual income in US dollars (bottom line).

#### For the data analyst

The purpose of this question is to get a sense of the socioeconomic status of the interviewees and, in households with a low income, to assess their level of poverty.

The most commonly used definition of global poverty is the concept of a dollar a day that was developed by the World Bank. The concept tries to identify an amount of money required to buy the most basic necessities – food, clothing, housing – and satisfy sociocultural needs.

At present, people are considered to live below the poverty line if their household income is US\$2 a day or less per person, and they are considered to be in extreme poverty if their household income is US\$1 per person per day or less. This mostly applies to low-income countries. More developed countries have a higher poverty line – for example, in 2005 the poverty line for single individuals in the United States was set at US\$26.19 a day.

## SECTION 2

### Section 2A PERCEIVED CAUSES OF STIGMA AND DISCRIMINATION

Please note that the questions in Section 2A focus on the interviewee's **perceptions** of the causes of stigma and discrimination. The causes do not have to be objectively verified as it is more about what the interviewee **perceives** or **feels** happens rather than what actually happens.

Please also note that in questions 4–7 we are progressively differentiating between the interviewee being:

- talked or gossiped about;
- being confronted and verbally insulted, harassed and/or threatened;
- being harassed and/or threatened physically; and
- being attacked or assaulted.

Remember to refer to Appendix 1 (key definitions and concepts) to make sure you are familiar with how we have defined **stigma**, **internal stigma** and **discrimination** in this questionnaire.

### Section 2B ACCESS TO WORK AND SERVICES

As in the previous section, we are trying to ascertain whether the interviewee **perceives** that their access to work (and in some cases the access of members of their household) and to basic services such as health and education has been limited or reduced because of their HIV-positive status.

Given that we are not interviewing the interviewee's neighbours or landlord, work colleagues or the school teachers, principals or health workers that they have interacted with, we will not be able to find out whether any of the incidents that were perceived by the interviewee to be discriminatory because of their HIV-positive status were in fact a result of their status or not. Thus it is the interviewee's perceptions, feelings and interpretation of their experience that count in this instance.

### Section 2C INTERNAL STIGMA

Remember to refer to Appendix 1 (key definitions and concepts) to make sure you are familiar with how we have defined **internal stigma** in this questionnaire. Questions 2, 3 and 4 are simple yes/no questions, but the concept is less simple. These questions are

about fear. The idea behind asking these questions is not whether the interviewee has experienced tangible or obvious forms of stigma or discrimination, but rather that they have **anticipated** or **feared** what other people **might** do or think, and this might very well have changed the way they behaved or felt, or caused them anxiety.

For example, when someone is HIV-positive they might decide not to go to the local health clinic or hospital to seek medical care or counselling advice because they anticipate and/or fear that they will have to disclose their HIV-positive status – even if the disclosure of their HIV status is not required or they are unlikely to be asked about their HIV status.

In Question 3, we have distinguished between increasing levels of verbal and physical intimidation and abuse. Given that you might be asked by the interviewees to distinguish between the various terms, we offer the following explanations:

- gossip – to talk about someone else’s personal or private affairs – generally when they are not present;
- insult – to say something or act in a manner that deliberately is intended to be rude, insensitive and offensive to the person that the insult is directed at;
- harass – to repeatedly annoy or provoke or hassle someone;
- threaten – to intimidate or give a warning that something dangerous will happen; and
- assault – a violent attack or show of force that is intended to frighten and/or hurt the person it is directed at.

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Section 2D  
RIGHTS, LAWS AND  
POLICIES

Question 1a refers to an international agreement from 2001 called the *Declaration of Commitment on HIV/AIDS*.

In the *Declaration of Commitment on HIV/AIDS*, governments affirmed that the realization of human rights and fundamental freedoms for all is essential to reduce vulnerability to HIV, and that respect for the rights of people living with HIV drives an effective response.

The full text of the *Declaration of Commitment on HIV/AIDS* is available at [www.ohchr.org/english/law/hiv.htm](http://www.ohchr.org/english/law/hiv.htm). We recommend that interviewers take a copy of the *Declaration of Commitment on HIV/AIDS* to each interview. Depending on the circumstances, the interviewers may want to show and/or provide the interviewee with a copy. If a copy of the *Declaration of Commitment on HIV/AIDS* is not going to be given to the interviewee, we would advise that the interviewer then tells the interviewee how and where they can obtain a copy themselves.

Question 2a refers to a national law or guideline that protects the rights of people living with HIV. The networks of people living with HIV operating in the participating country should reach consensus on which national law or guideline they believe protects the rights of people living with HIV and should be included in this question.

Once a national law/policy or set of guidelines has been selected, its name should be inserted into Question 2a.

As with the international *Declaration of Commitment on HIV/AIDS*, we recommend that interviewers take a copy of the national law, policy or set of guidelines with them to the interview so as to share it with the interviewee. While the index is a tool to gather information together about the experiences of people living with HIV, it is also intended to be an empowering process. Sharing information about the rights of people living with HIV and the international and national commitments that have been made to protect such rights is an important part of the index process. It is for this reason we recommend that such information be made available for all interviewees.

Remember to refer to Appendix 1 (key definitions and concepts) to make sure you are familiar with how we have defined **legal redress** in this questionnaire.

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Section 2E  
EFFECTING CHANGE

This section focuses on action or what one does in order to bring about positive change. Question 4 specifically provides interviewees with an opportunity to describe some action that they might have taken in attempting to resolve or challenge an incident of HIV-related stigma and discrimination.

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Interviewees are asked to explain in detail firstly what the issue was about, secondly whether others provided assistance (and if so, who they were), and thirdly what they did to resolve the issue. Interviewees should be encouraged to provide as much detail about the incident as possible as this will provide a richness to the data and assist in the analysis process. If the interviewees prefer, they can write their answers to this question; or the interviewer must listen carefully and record the details in as much detail as possible.

The interviewer should note that it is important not to make interviewees feel uncomfortable or bad if it is clear that they are not active in effecting change. If this is the case and you feel it appropriate, you might at the end of the interview provide the interviewee with the contact details of a local organization or network of people living with HIV that they might want to contact and get involved in.

Question 5b provides a space for interviewees to identify the type of support they have given to another person or people living with HIV. This could be emotional support, which includes the provision of counselling, giving hope, sharing and listening to personal stories; physical support, which includes providing someone with money, making a meal for someone, doing housework for someone, accessing medication and condoms for someone; and/or referral, which includes helping someone access a grant or a support group, or referring someone to a treatment clinic or a home-based care organization.

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### SECTION 3

#### Section 3B DISCLOSURE and CONFIDENTIALITY

Question 1, which relates to disclosure and confidentiality, has a more complex set of possible responses. It is thus important that you make the interviewee familiar with the **range of possible responses** they can give to this part of the questionnaire. Some things which you need to be observant of in relation to this question:

- If the categories of people (listed in the first column of the table) have not been told about the interviewee's HIV-positive status, tick "They don't know my HIV status".
- If the interviewee does not associate, interact with or know one of the categories of people (listed in the first column of the table), for example, a teacher, they should tick "Not applicable".
- Interviewees are permitted to tick more than one box in each line **only** if the answer is different for different individuals. For example, the interviewee might have told one health worker directly about their HIV-positive status at, for example, the local hospital, while another health worker at that same facility might have been told about the interviewee's HIV-positive status from someone else (without the interviewee's consent).

In Question 6 the interviewees are asked to consider the **most common** or **frequent reaction** that the different groups or categories of people had toward them on finding out they were HIV-positive. Possible responses range from "Very discriminatory" to "Very supportive".

However, unlike in Question 1, the interviewee is only able to tick **one box** in each line. This could be problematic if some groups/categories had different attitudes. For example, some co-workers could have been very supportive while others were very discriminatory. What we want to try and have the interviewee describe, however, is the **most common** or **frequent** attitude that members of each group or category of people had when finding out they were HIV-positive.

If the interviewee does not associate or interact with any one of these groups, a "Not applicable" choice can then be made.

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#### Section 3D HAVING CHILDREN

Section 3D relates to the interviewee's experience of having children. Questions 1–4 can be completed by both male and female interviewees and Questions 6 and 7 by female interviewees.

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Section 3E  
**PROBLEMS and  
 CHALLENGES**

Interviewers should ask each of the interviewees all four questions, and allow them to verbally respond to the question. The interviewer needs to listen well and capture the experience of the interviewee in writing. If the interviewees prefer, they can also write details of their response to this question. If necessary, the interviewer can continue writing their note on the back of the questionnaire or on a separate piece of paper. If the latter is done, the interviewee code should be written on the additional pages and then stapled onto the body of the questionnaire.

In relation to question 1 (testing/diagnosis), interviewees should be encouraged to provide information about both their first HIV test as well as other testing experiences such as CD4 count tests, viral load tests, as well as testing relating to opportunistic infections.

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At the end of the interview, establish whether the interviewee needs referral information and, if so, give them a copy of the list that the research team has developed of local organizations that can assist those living with HIV.

### CHECKLIST: DURING THE INTERVIEW

1. Greet and welcome the interviewee and introduce yourself.
2. Give them a copy of the information sheet and read this through with them, answering any questions they might have about the People Living with HIV Stigma Index and the interview process.
3. Give the interviewee a copy of the informed consent form and read this through with them, answering any additional questions they might have. If they agree to be interviewed, you will then need to sign two copies of the consent form (for verbal consent). If the interviewee feels comfortable enough giving their written consent, you and the interviewee will need to sign the two copies of the consent form. In either case, give the interviewee one of the signed copies of the consent form, and keep the other copy in a safe place with your other documents. (If, as is sometimes the case, the interviewee decides not to participate in the survey, thank them politely for considering to be interviewed and end the discussion.)
4. Start the interview.
5. At the end of the interview, establish whether the interviewee needs referral information and, if so, give them a copy of the list that the research team has developed of local organizations that can assist those living with HIV.
6. Thank the interviewee for their participation in the survey.
7. If you think the interviewee could be followed up as a case study at a later date, explain why you think you would like to interview them again for the purposes of a case study and agree on a suitable time, date and place to meet for this second interview.
8. Complete the referral and follow-up section on the front page of the questionnaire so that you can confirm any of the follow-up arrangements that are required.
9. Provide the interviewee with an honorarium.
10. End the interview and bid the interviewee farewell.
11. Spend some time alone reflecting on the interview that you have just conducted: review the notes that you took during the interview, make sure that you recorded all the details that you wanted to and add to your notes if necessary. Write down anything that you feel you need to discuss or need advice about from your team leader.



## GUIDANCE FOR THE QUALITY CHECK SECTION

The last page of the questionnaire contains the quality checks section, which is designed to be filled in by the interviewer and checked by the team leader. The interviewer must fill in the parts for which they are responsible before handing the completed questionnaire over to the team leader for review.

The reason for including this section is that many surveys suffer from poor filling in of questionnaires, which means that there are gaps in the information or the answers are unreliable. For instance, the Asia Pacific Network of People Living with HIV/AIDS report<sup>7</sup> notes the problem of “inaccurate or careless completion of the questionnaire” in some cases. It is a pity to spend a lot of time and effort on training people and running a survey, only to end up with a poor quality data set. For this reason, the quality checks section is very important.

The way that this section works is as follows.

- Questions 1–4 ask the interviewer to check that everything has been fully completed. For Sections 1–3 of the questionnaire, if answers are missing, reasons must be given. This is in order to make sure that answers are only missing if the interviewee did not wish to answer the questions – not because of a mistake. It is of course our hope that interviewees will answer all the questions, although they should not be pressured to answer questions against their will.
- Questions 5–7 are intended to help the interviewer think about the **consistency** and **credibility** of the answers.
- Please note that some of the responses are “Yes/No” and others only allow for “Yes” as a response. The latter is for cases where no is **not an option**. For example, in point 7 the reasons for any inconsistencies must be checked – it is not an option for the interviewer to fail to check

them. Similarly, it is obligatory to complete the front page and write the code on each page, so the “No” response is not an option.

Once an interviewer is satisfied that the questionnaire is as complete and accurate as possible – which the quality checks section helps to verify – and has completed the referrals and follow-up section on the front page, they can sign and date the quality control procedures panel at the bottom of the front page. By signing this panel, the interviewer is stating that their job is complete. People should only sign when they are sure that they have completed their task properly and in full.

## GUIDANCE ABOUT THE ISSUE OF CASE STUDIES

You may have noticed on the front page of the questionnaire that there was mention of another interview with the interviewee if they were considered to be a potential candidate for a case study. The idea behind this second interview is that if the interviewee appeared to be an interesting case, the interviewer would ask if they could return for a more in-depth qualitative interview and, if possible, agree on a time then and there. In this case, the interviewer would tick “Yes” in answer to Question 4 in the referrals and follow-up section on the front page and record the time and date in Question 5; otherwise, the interviewer would just tick “No” for Question 4.

This is an optional part of the process and it is not essential for the construction of the People Living with HIV Stigma Index, but it is considered helpful in providing illustrations of the problems and challenges encountered by people living with HIV on a daily basis. However, the case studies are not only intended to record the struggles and difficulties that people living with HIV face but also their positive experiences – for example, the way in which a family member has supported the process of their disclosing their HIV-positive status, or how they have

The case studies are not only intended to record the struggles and difficulties that people living with HIV face but also their positive experiences.

“Always ensure that you do not judge the interviewee or their responses.”

RESEARCHER, PILOT WORKSHOP, SOUTH AFRICA

<sup>7</sup> Asia Pacific Network of People Living with HIV/AIDS (2004). *AIDS Discrimination in Asia*. Bangkok: Asia Pacific Network of People Living with HIV/AIDS.

The team leader will be responsible for putting the informed consent forms and the list containing the names, contact details and unique identifying codes of all those who you have interviewed in a secure place that has been arranged for these documents.

challenged an instance of HIV-related stigma and/or discrimination, or how community members or a network of people living with HIV have advocated for better services for people living with HIV.

Case studies can be a powerful advocacy tool and will serve to complement the quantitative data collected by the index. However, they are not easy to do and usually require experienced qualitative researchers to carry out the interviewing. If case studies are going to be conducted, interviewers will need to be specifically trained to conduct an interview using a more qualitative approach to interviewing – something that is different to the approach that they have followed when facilitating the completion of the questionnaire with interviewees.

If the team does decide to do case studies, as a team you will also need to decide what kinds of issues or experiences of people living with HIV you particularly want to capture through the use of the case studies. This will depend on the priorities of the study team and may vary among networks. Once you have decided on this, you will need to identify which questions in the questionnaire ought to be flagged or highlighted given that they will alert interviewers when potential information for a case study comes up in an interview.

You will also need to alert the interviewers to what you want to explore in greater depth in the case studies and which responses they ought to pay particular attention to in terms of identifying potential material for a follow-up case study. For instance, if the study team is interested in cases of sexual manipulation, interviewers could be asked to keep an eye on responses to Question 10 in Section 2A, which will provide an indication of this. If the interviewee indicates that they have suffered psychological pressure or manipulation by their spouse or sex partner in response to this question, the

interviewer could ask whether this is something they would be willing to talk more about and, if so, explore the possibility of a case study. Such probing needs to be handled very carefully, and the manner in which this is sensitively explored with the interviewee ought to be covered during the interviewer training process.

Here are some examples of issues (and the corresponding questions) that members of the pilot project thought would be interesting to explore further through case studies:

- Questions in Section 2A deal with an interviewee's experience of being **verbally insulted, harassed and/or threatened**. Even though this is a more subtle form of stigma and not as obvious as a physical assault, it has a significant impact that would be important for this research to explore in greater depth through a case study.
- Alternatively, questions in Section 2B would allow one to identify incidents where a person living with HIV has been more obviously discriminated against in relation to **accessing employment, education and/or basic health services**.
- Question 4b in Section 2D focuses on whether people living with HIV have tried to get **legal redress** for an abuse of their rights. If they have tried, whether the matter has been resolved, is still in process or has not been responded to appropriately, the process of seeking protection from the law could provide us with important information on what the experiences of people living with HIV are in this area.
- Questions 1 and 4 in Section 2E focus on how an interviewee has tried to educate and/or challenge and resolve an incident of HIV-related stigma and discrimination. In some instances they would have received support and assistance from others. Such stories could provide excellent examples of how people living with HIV have **managed to effect change** within a

relationship, their household or within the broader community.

- Question 6 in Section 3B focuses on the **process of disclosure** and whether this has been an empowering process or not. Learning how other people living with HIV

have managed the process of disclosure and – where this has been an empowering process – what lessons could be learnt from this could be a valuable theme to follow in a series of case studies.

#### CHECKLIST: AFTER THE INTERVIEW

1. Transfer the details of the interviewee onto your list containing the names, contact details and unique identifying codes of interviewees.
2. Develop a unique identifying code for the interviewee and write down this code alongside their details on the list and also on the top of all of the pages of their completed questionnaire and their informed consent form.
3. Arrange to meet your team leader to discuss the interview and hand over all the necessary documents from the interview.
4. The team leader will be responsible for putting the informed consent forms and the list containing the names, contact details and unique identifying codes of all those who you have interviewed in a secure place that has been arranged for these documents.
5. The team leader will also be responsible for putting all the completed questionnaires in a (separate) safe place that has been arranged to store all the completed questionnaires from the survey.

“My principal advice is for the interviewer to relax and take his time through the process of posing interview questions and to also be friendly to the interviewee.”

RESEARCHER,  
PILOT PHASE, LESOTHO



A close-up photograph of two people's hair. On the left, there is a long, straight, brown ponytail. On the right, there is dark, wavy hair. The background is a plain, light grey color. The text 'USING THE EVIDENCE FOR ADVOCACY' is overlaid in white, bold, sans-serif font in the center of the image.

# USING THE EVIDENCE FOR ADVOCACY

# PART 7

## WORKING WITH THE DATA – ISSUES RELATED TO THE MANAGEMENT, ANALYSIS AND REPORTING OF DATA

The quality checks section on the last page of the questionnaire should help the team leader to check that the interviewer is doing a good job.

### WHAT HAPPENS TO ALL THE INFORMATION YOU COLLECT?

#### CHECKING THE QUESTIONNAIRES

As soon as questionnaires come back to the office, they should be checked by the team leader. The quality checks section on the last page of the questionnaire should help the team leader to check that the interviewer is doing a good job and to query any work that does not seem to be satisfactory. The team leader should sign the quality control procedures panel at the bottom of the front page if – and only if – they are satisfied with the questionnaire. By doing so, they are “certifying” the quality of the interviewer’s work. If it is not satisfactory, the team leader will probably have to ask the interviewer to visit the interviewee again to fill in missing information or check inconsistent answers. This adds to the cost of the study in terms of both time and money. If interviewers are being paid for their work, no extra funds should be provided for such follow-up visits to correct mistakes, as this would provide the wrong incentives.

#### STORING THE QUESTIONNAIRES

As soon as the questionnaires have been checked by the team leader, they should be archived (i.e. stored in an organized manner). Because of the need to ensure confidentiality, the questionnaires should be kept in a locked filing cabinet or cupboard (to which only the team leader has the key) and destroyed as soon as they are no longer needed (i.e. all information has been entered into a

database, the process of data cleaning and checking has been completed, and the report has been written up and accepted as a completed product). It is critical that similar protective mechanisms are put in place to maintain the confidentiality of the data on the computer as well.

The same applies to the informed consent forms and the list containing the interviewee contact details and questionnaire codes, as outlined in Appendix 4). Both of these documents should be stored in a separate place – preferably not in the same office as the questionnaires.

#### DATA ENTRY AND ANALYSIS PROCEDURE

Once all the necessary data have been collected, the next stage in the research process is to collate (in other words, to summarize) the data so that the research team can begin to compare and contrast the various responses that the interviewees provided during their interviews.

This is the stage in the research process when one begins to look for recurring themes across the study sample and tries to understand, interpret and analyse why the data look the way they do. It is through this final analytical process that the research team will be able to produce a report that documents the key results and findings from the People Living with HIV Stigma Index and, on this basis, make some recommendations for the future.

Before all this can happen, two people called data capturers need to enter the raw data or original responses and narratives from each of the questionnaires into a computer-based

programme called EPI-Info so that all the information can then be analysed. The People Living with HIV Stigma Index has been designed to be used with EPI-Info. The research team, in their preparations, will thus need the help of two data capturers who are familiar with this particular statistical package or, if the data capturers are not familiar with EPI-Info, they will need to have the capacity to learn how to use it very efficiently and competently in a short amount of time.

When planning the actual data entry process, it is important to bear in mind the following steps that will need to be taken in order to get the raw data collated.

#### 1. INSTALL THE STATISTICAL PROGRAMME ON A COMPUTER

EPI-Info is a free software package that contains statistical facilities for developing a questionnaire; customizing the data entry process; entering the data; and analysing the data. EPI-Info can be downloaded from the Centres for Disease Control and Prevention (CDC) website: [www.cdc.gov/EpiInfo](http://www.cdc.gov/EpiInfo)

There are a number of versions available, but the latest version is EPI-Info™ Version 3.4.3. EPI-Info is designed for users who only have basic computer skills and gives step-by-step instructions to complete the basic tasks. If you are using EPI-Info for the first time, it is strongly advised that you download the user manual from [www.glitc.org/epicenter/publications/tools/Epi\\_Info\\_Beginners\\_Manual.pdf](http://www.glitc.org/epicenter/publications/tools/Epi_Info_Beginners_Manual.pdf)

#### 2. CREATE A DATABASE FOR THE QUESTIONNAIRE IN EPI-INFO

Using EPI-Info, use the “Make View” component to create the questionnaire. You will create fields or type questions onto the screen to be filled in later when you do the data entry. In essence, you are creating a database that will then store the data from the questionnaire.

#### 3. ENTER THE DATA

When entering the data, use the “Enter Data” component of EPI-Info. Entered

data are stored in the database. Data from each questionnaire should be entered twice into two separate databases (“double data entry”). The two data entry people (“Data entry 1” and “Data entry 2”) must enter all data from the questionnaire correctly and independently – i.e. without help from the other person – and sign the quality control procedures panel at the bottom of the front page of the questionnaire to say that they have done so. The two databases should then be compared to identify any inconsistencies. These should be checked against the original questionnaires and corrected in the databases.

When planning the data entry process, consideration should be given to the amount of time needed to complete this task. From our experience, it takes approximately 20 minutes to enter the data from each questionnaire. Additional time will need to be set aside to do the necessary currency conversions in Section 1, Question 13.

#### 4. ANALYSE THE DATA

This component allows you to access the data from your data tables to perform the analysis. In terms of analysis, EPI-Info will be able to produce lists, frequencies, cross tabulations and many other statistical tasks that will assist you to extract useful findings.

The analysis process can help you:

- describe the experiences of the whole data set;
- make comparisons across groups; and
- verify data.

For example, Section 1 of the questionnaire describes the interviewees in terms of their age, gender, education, employment status and household income. When this information is compared to the responses in Sections 2 and 3 (which focus more on interviewees’ experiences of stigma and discrimination, and their experiences of HIV testing, disclosure and access to services), interesting associations (or relationships) might emerge, for example, between the educational level

When planning the data entry process, consideration should be given to the amount of time needed to complete this task.

It can also help the research team compare answers between different questions to help verify (or confirm) that the data provided by interviewees are consistent or reliable across themes in the questionnaire.

and income of interviewees, the nature of a relationship they are in and their access to services. A programme like EPI-Info can assist one in exploring associations and relationships like these and helps one manage a big data set.

It can also help the research team compare answers between different questions to help verify (or confirm) that the data provided by interviewees are consistent or reliable across themes in the questionnaire. As an example, in Section 1, Question 9 (the interviewee's employment status), Question 12 (whether they live in an urban or rural area), Question 13 (what the average income of the household is per month) and Question 14 (whether the household ever runs out of money to buy food or not) can be looked at as a group of questions. When one puts all the responses of one interviewee together, we would expect to be able to build a picture in our mind of the life or lifestyle of that person.

For example, we would expect that someone who is in full-time employment to (most likely) live in an urban area (as there is improved access

to employment) and have a relatively comfortable household income. This person is never likely to run out of money for food. Another interviewee may be doing part-time or casual work and really struggle to consistently provide an income for their household. In this instance, they may be more vulnerable to not having enough money to pay for basic resources like food.

Lastly, it is important to bear in mind in relation to the analysis of the data that Sections 2 and 3 of the questionnaire are predominantly based on a set of indicators related to HIV-related stigma and discrimination that were developed at a UNAIDS meeting in August 2005.<sup>8</sup> Participants at this meeting suggested that each indicator (such as the percentage of people living with HIV that report experiences of HIV-related discrimination, or the percentage of people living with HIV that report experience of protection through law, policy and practice in relation to HIV-related discrimination) and each question within each indicator receives an equal weight in the analysis process.

<sup>8</sup> UNAIDS (2005). *Meeting on Development of Index on Human Rights, Stigma and Discrimination by and for People Living with HIV: Report of the Meeting*. Geneva, Switzerland; 22–23 August 2005.



# PART 8

## COMMUNICATING THE FINDINGS AND NEXT STEPS

### HOW DO YOU COMMUNICATE THE OUTCOMES OF THE RESEARCH?

Now you have come this far, it is important to think about how to make the most of the findings and who to tell about the outcomes of the research. In order for the index to be useful – that is, for the perspectives of people living with HIV to inform policy and programme responses to address stigma and discrimination related to HIV – people need to know about the findings and analysis of the research.

First of all, the research team should ideally present their findings to local networks of people living with HIV that were key partners in the research process. Many of the interviewees will be interested to hear about how their individual experiences compare with the bigger picture. Following this initial process of feedback, the research team should consider the best way to record and share the overall findings with a wider audience.

Some things to consider when thinking about communicating findings from your research include:

- What are the key findings from the research? Who should know about them?
- What is the best way to communicate the findings? For example is a report the best way, or would a meeting be more effective? If a report is the best way, who should write it? Who will read it? And what language, tone, style will be most appropriate?
- If you decide a meeting is the best way to communicate the findings, who should you invite? Is a group

discussion appropriate; or would a one-to-one meeting be better? And where is the best place to hold the meeting so that everyone can engage in the discussion?

- Be creative. When communicating the research findings try to think of a way that will be effective, accurate and also attention grabbing.

IPPF, UNAIDS, GNP+ and ICW will be consolidating the research findings to share with key stakeholders and decision-makers working or living within the communities in which the survey was conducted. In this way, the experiences of people living with HIV within the country or within specific communities will be highlighted and contribute to informing locally relevant policy and practice to address stigma and discrimination.

Systems are being developed to store data collected that is coordinated by IPPF, UNAIDS, GNP+ and ICW. However we also hope that the People Living with HIV Stigma Index questionnaire, user guide and accompanying training tools will be taken up beyond the scope of the partnership. Please adapt and adopt these resources according to your needs – **let us know if you like, we would be interested to hear about your experiences.**

### ADVOCACY IN ACTION

The networks of people living with HIV that have been an integral part of the development of this survey hope that the study – either in its own right or through linkages with other activities (for example, in workshops) – will provide opportunities for people living with HIV to involve themselves more

Many of the interviewees will be interested to hear about how their individual experiences compare with the bigger picture. Following this initial process of feedback, the research team should consider the best way to record and share the overall findings with a wider audience.

We hope that the process as much as the outcomes of this research will support people living with HIV.

fully with their organizations at a local level. This involvement could take the form of participation in the survey itself, outreach to non-members, helping to define new issues for possible organizational or individual advocacy, capacity building and refinement of existing operational priorities.

To what extent actions result from the implementation of the People Living with HIV Stigma Index in a country or community will depend on the capacity of each network and local implementing

organization to make good use of the study both in terms of its process and its findings. We hope that the process as much as the outcomes of this research will support people living with HIV. If successful, the evidence gathered will contribute to informing more effective policy and programmatic responses to address stigma and discrimination related to HIV.

**We wish you the best in implementing the People Living with HIV Stigma Index in your community.**

# APPENDICES



## APPENDIX 1 KEY DEFINITIONS AND CONCEPTS

<b>Blame</b>	To blame someone is to suggest that they are responsible for something wrong; to find fault with them; to accuse them.
<b>Coercion</b>	The application of force to restrain or prevent someone from doing something, or to force or intimidate them to do something.
<b>Confidential</b>	To keep information private or secret. Ensuring confidentiality implies making sure that information is kept private or secret and is not shared or made known to others. Confidentiality is often associated with a feeling of trust, or the belief that if you tell someone something private or secret he/she will not share this information with others without your permission.
<b>Consent</b>	Voluntary agreement or permission. Written consent means giving permission in writing and oral consent means giving spoken permission.
<b>Constructive discussion</b>	A discussion which is helpful and productive, in contrast with one which has the effect of destroying or undermining a person.
<b>Discrimination</b>	<p>Discrimination involves treating someone in a different and unjust, unfair or prejudicial manner, often on the basis of their belonging, or being perceived to belong, to a particular group. It is often viewed as the end result of the process of stigmatization. In other words, when stigma is acted upon (sometimes called “enacted stigma”), the result is discrimination.</p> <p>“Discrimination consists of actions or omissions that are derived from stigma and directed towards those individuals who are stigmatized.” For example, HIV-related discrimination occurs when someone is treated differently (and to their disadvantage) because they are known to be living with HIV, suspected of being HIV-positive, or closely associated with people living with HIV (such as their partner or a member of their household).</p> <p>Discrimination occurs at many different levels. It can occur within a family or community setting. For example, when people:</p> <ul style="list-style-type: none"> <li>• avoid people living with HIV or do not allow them to use the same eating utensils as other members of the household; or</li> <li>• reject people living with HIV by not allowing them entry or membership into a group, or by not being willing to be associated with them.</li> </ul> <p>It can also occur within an institutional setting, for example, when:</p> <ul style="list-style-type: none"> <li>• people living with HIV are segregated from other patients in a health facility or denied access to health care services or medical insurance because they are HIV-positive;</li> <li>• when a supervisor does not uphold the rights of a positive person and discloses their HIV-positive status without their consent to work colleagues; or</li> <li>• HIV-affected children are denied entry into school.</li> </ul> <p>Discrimination can also occur at a national level, when it is sanctioned or legitimized through laws and policies. Such examples include:</p> <ul style="list-style-type: none"> <li>• refusing a person living with HIV entry into a country because of their HIV positive status;</li> <li>• prohibiting people living with HIV from certain occupations and types of employment; or</li> <li>• the compulsory screening and testing of individuals or groups for HIV.</li> </ul> <p>Discrimination against people living with HIV, or those thought to be infected, is a violation of their human rights and is something that the legal system in a country can address.</p>

<b>Empowering</b>	Something is empowering when it helps a person have greater control over their own life. It is often associated with increased confidence and a sense of strength. A person who is empowered feels they have the power to meet their own needs and can put their skills and energy to use in their community and act on the issues they feel are important.
<b>Exclude</b>	To leave out or keep out; to not include.
<b>Family planning</b>	The conscious effort of couples or individuals to plan for and attain their desired number of children and to regulate the spacing and timing of their births. Family planning is achieved through contraception and through the treatment of involuntary infertility.
<b>Guilt</b>	When a person feels bad about having done something they believe they should not have done (or experiences similar feelings when thinking about something they have not done but believe they should have done).
<b>Household</b>	A group of people who live in the same place (a house or other dwelling place), sharing space and resources; they are often – but not necessarily – members of the same family.
<b>Index</b>	In this context, index refers to a collection of information (data) organized in a way which allows us to reach overall conclusions about particular issues and to measure differences between the situation in different places and/or how a situation has changed over time. The People Living with HIV Stigma Index, for example, will give a measure of how much HIV-related stigma and discrimination there is at a certain point in time, in a certain community. Once we have this point of reference, we believe it will be possible to survey people from the same community in the future and get a sense of whether HIV-related stigma and discrimination is increasing or decreasing in the community.
<b>Indicator</b>	A measure that tells us the presence or absence of something. An indicator can help us determine, for example, whether or not a project has achieved its purpose over time.
<b>Indigenous group</b>	A group of people who have a longstanding historical association with a particular region or part of a region – in many cases, before the region was colonized by others. Often the group has maintained customs or traditions over many generations and see themselves as part of a distinct community with special bonds of kinship, language and culture. Examples of indigenous peoples are the San of the Kalahari desert in Southern Africa, the indigenous peoples of the Americas (often referred to as Native Americans or First Peoples), the Ngunnawal and Eora peoples in Australia and the Maori in New Zealand.
<b>Informed consent</b>	<p>Voluntary agreement or permission that is given with full knowledge of what is involved (e.g. risks and benefits). For example, if someone decides that they want to take an HIV test and they receive comprehensive and understandable information about the test from a counsellor, following which they consent to take an HIV test, this would be called giving informed consent.</p> <p>Similarly, if you are an interviewer administering this questionnaire and you provide a potential interviewee with a comprehensive account of what it will involve to respond to the questionnaire, following which the potential interviewee then says they would like to participate in the survey, the interviewee is then indicating that they are informed and that their participation in the survey is voluntary.</p>

<b>Injecting drug user (IDU)</b>	There are several ways of using drugs, and one way is through injecting. In HIV work, the term “injecting drug use” describes the behaviour of someone who injects drugs. Injecting drug users face the same sex-related risks of HIV as other people, and those who share contaminated drug injecting equipment (such as a needle or a syringe) are at an additional risk of acquiring HIV through the use of contaminated drug equipment.
<b>Internal stigma</b>	<p>Internal stigma, also referred to as “felt” stigma or “self-stigmatization”, is used to describe the way a person living with HIV feels about themselves and specifically if they feel a sense of shame about being HIV-positive. Internal stigma can lead to low self-esteem, a sense of worthlessness and depression.</p> <p>Internal stigma can also result in a person living with HIV withdrawing from social and intimate contact, or excluding themselves from accessing services and opportunities out of a fear of having their status revealed or being discriminated against because of their HIV-positive status.</p> <p>See page 47 for a definition of “stigma”.</p>
<b>Internally displaced person</b>	A person who is forced to move from their home (for example, because of a conflict situation, a natural disaster or because they and their family or community is being discriminated against or threatened) and settle in another area. Like refugees, they are forced to flee from their original home but in this case they stay within the borders of their country of origin.
<b>Law/legislation</b>	A set of rules or norms of conduct which define how people must behave. Law is normally administered through a system of courts, in which lawyers argue cases before judges.
<b>Legal redress</b>	“Setting right” a wrong done to someone and possibly compensating them for the loss resulting from this wrong. Legal redress implies doing this through the courts, a human rights commission or similar forum. It may involve having a lawyer or advocate represent the person who was wronged and using the law to argue that the wrong be addressed in some way.
<b>Men who have sex with men (MSM)</b>	This is a term that refers to the behaviour of men who have sex with other men. It is a term that recognizes that some men who have sex with men also have sex with female partners and that men who have sex with other men may not necessarily identify as “gay”, “homosexual” or “bisexual” – all of which are examples of categories of sexual orientation and identity. Men who have sex with men often face a double stigma because they are marginalized for their sexual behaviour and seen as part of a group that is associated with being at particular risk for HIV infection.
<b>Network of people living with HIV</b>	A network of people living with HIV is a group, association or an affiliation of HIV-positive individuals who unite together for a common purpose.
<b>Orphan</b>	A child, under 18 years of age, who has lost both parents through death. While not all children become orphaned as a result of their parents dying of AIDS, in many communities where the prevalence of HIV is high, it is likely that many of the orphans have lost one or both of their parents to AIDS.
<b>People living with HIV support group</b>	A people living with HIV support group is a group of HIV-positive people who meet to give each other support, given that they share a common experience – that of living

with HIV. A people living with HIV support group may also be involved in HIV-related advocacy work.

<b>Physical disability</b>	A partial or total loss of a bodily function or part of a body. It includes sensory impairments such as being deaf, hearing impaired, or visually impaired.
<b>Policy/policies</b>	A plan or course of action adopted and pursued by government or, by extension, an official in a decision-making position.
<b>Programme</b>	A collection of projects working towards a common and broader goal.
<b>Project</b>	A series of activities with a common objective, usually small in size and engaging in a unique activity with clear start and end points. Often the smallest operational unit of a programme.
<b>Quarantine</b>	Keeping people in isolation from the rest of the community on the basis that they have a contagious disease.
<b>Refugee/asylum seeker</b>	Those who are forced to cross international borders because of conflict or political instability that causes them to fear being persecuted because of their race, religion, nationality, membership in a particular social group or their political opinion.
<b>Rights</b>	<p>A right is something to which one has a just claim or entitlement. Rights exist at local, national and international levels.</p> <p>Human rights are those rights that one has because one is a human being. These include the rights to life, privacy, freedom of expression, freedom of association, an adequate standard of living, education and health. Human rights are founded on the dignity and worth of each person. People are entitled to enjoy their rights regardless of their race, colour, sex, language, religion, political or other opinion, national or social origin, or other status. (Many governments have defined “other status” to also include HIV status.)</p> <p>Human rights are legally guaranteed by human rights law, which exists to protect individuals and groups from actions that interfere with their freedom and dignity, and promote access to the things that help people realize their rights. Human rights law exists at the international level (e.g. treaties and covenants) and at the national level (e.g. constitution, bill of rights, domestic laws).</p>
<b>Self-esteem</b>	How you value or respect yourself. For example, when we refer to someone as having low self-esteem it means that that person does not value themselves or have confidence in their ability or the contribution they can make generally.
<b>Sex worker</b>	The term sex worker is used to describe either a man or a woman who engages in sexual activity for payment.
<b>Sexual and reproductive health services</b>	<p>Sexual and reproductive health services are health care and counselling services that contribute to sexual and reproductive health and well-being, through preventing and solving sexual and reproductive health problems.</p> <p>Sexual and reproductive health services include information about sexual and reproductive issues; access to safe, effective, affordable and acceptable methods of family planning; care for pregnancy and childbirth; care and counselling related to sexually transmitted infections, including HIV; and services to prevent and solve sexual and reproductive health problems.</p>



<b>Sexual rejection</b>	A negative response; the refusal by a sexual partner to engage in any form of sexual activity.
<b>Sexuality</b>	The expression of sexual sensation and related intimacy between human beings, as well as the expression of identity through sex.
<b>Sexually active</b>	There is not one, all-encompassing definition for the term sexually active. For some people, being sexually active means vaginal or anal sex, for others it means oral sex and for others it might simply mean kissing and touching their partner.
<b>Shame</b>	A feeling of dishonour, disgrace or condemnation. To be ashamed of oneself refers to one having this feeling of shame.
<b>Stigma</b>	<p>A sign of disgrace or shame. It originates from the ancient practice of branding or marking someone who was thought to be “morally flawed” or to have behaved badly and therefore ought to be avoided by other members of society.</p> <p>Stigma is often described as a process of devaluation. In other words, if one is stigmatized one is discredited, seen as a disgrace and/or perceived to have less value or worth in the eyes of others.</p> <p>HIV-related stigma often builds upon and reinforces other existing prejudices, such as those related to gender, sexuality and race. For example, the stigma associated with HIV is often based upon the association of HIV and AIDS with already marginalized and stigmatized behaviours, such as sex work, drug use and same-sex and transgender sexual practices.</p> <p>HIV-related stigma affects those living with HIV and – through association – those who they are associated with, such as their partner or spouse, their children and the other members of their household.</p> <p>See also “internal stigma”, described on page 45.</p>
<b>Traditional or complementary medicine</b>	Medical skills and practices traditionally used within societies, which were developed to maintain health and treat illness before the era of modern (or what is often termed “western”) medicine. Traditional medicine is seen as providing an alternative or complementary set of health care practices that are not always found in the main health care system.
<b>Transgender</b>	Transgender is an umbrella term that includes transsexuals and transvestites. A transsexual is someone who may be born biologically male, yet has a female gender identity or be born a female and yet define themselves as a man. A transvestite is a man who likes to wear female clothes and adopt traditionally female characteristics.
<b>Treatment literacy</b>	<p>Treatment literacy is knowledge about treatment and how it works. When people have this knowledge, they can make informed choices about their own treatment options: whether to begin taking treatment, when to begin treatment, what treatment options are available to them, side effects of treatment, strategies to stay on treatment (adherence) and what to do when staying on treatment becomes difficult.</p> <p>Treatment literacy is also important for people providing care to people living with HIV – it enables them to support others on treatment. Information resources, support groups and training programmes are all ways of promoting treatment literacy.</p>

## APPENDIX 2 INFORMATION SHEET

### THE PEOPLE LIVING WITH HIV STIGMA INDEX

Note to interviewers: this information sheet is designed for the interviewees to take away as a summary of the project if they are interested. Take some spare copies with you to the interview. However it is best not to read through the whole information sheet in the interview itself, as much of this information is covered in other parts of the interview process (for example in the informed consent form).

This information sheet tells you about a questionnaire that has been developed to find out more about the experiences of people living with HIV, particularly their experiences of stigma and discrimination.

Each questionnaire that is administered forms part of a larger survey conducted in a country that aims to document the extent of stigma and discrimination experienced by people living with HIV in that particular country. The questionnaire, together with the idea of conducting such a survey, was developed by the Global Network of People Living with HIV (GNP+) and the International Community of Women Living with HIV/AIDS (ICW), with financial and management support from the International Planned Parenthood Federation (IPPF) and the Joint United Nations Programme on HIV/AIDS (UNAIDS).

### THE PURPOSE AND NATURE OF THE PEOPLE LIVING WITH HIV STIGMA INDEX SURVEY

The People Living with HIV Stigma Index survey was created to find out more about the experiences of people living with HIV, especially experiences of stigma or discrimination. There are a number of organizations campaigning against stigma and discrimination and fighting for the human rights of people living with HIV. It is hoped that this survey will one day provide information that will help these efforts.

In order to collect such information (i.e. on what HIV-positive people are experiencing, specifically in relation to stigma and discrimination), the questionnaires and survey will be administered and managed by organizations or networks of people living with HIV in a country. The information that is collected from the questionnaires will then be put together and presented in a way that presents a general picture of the experiences of people living with HIV in that country. It is **not** information about individual experiences of stigma and/or discrimination. For example, in documenting the results of the survey, information will be presented in the report on “What percentage of people living with HIV experienced discrimination last year”, as opposed to presenting information on your own, personal experiences of stigma and discrimination.

Ultimately, the main aim of this project is to broaden the understanding of stigma and discrimination faced by people living with HIV in different countries, and to be able to find out if there have been changes over a period of time. The organizations involved in this project intend to use the information as a national and global advocacy tool to fight for the human rights for people living with HIV.

### PROCEDURES AND PROCESSES INVOLVED IN PARTICIPATING

I would like to make clear that your participation in this project is entirely voluntary. It is your choice whether to participate or not. If you choose to participate, you are also free to not answer any of the questions, and you can also decide to stop participating in the interview at any time that you wish.

In terms of process, if you choose to participate in the survey, we will complete a questionnaire that asks you questions about your social environment, work, access to health services, knowledge about your rights, HIV testing and treatment. Please feel free to ask to see the questionnaire at this stage if you would like to take a more detailed look at the questions.

If you participate in the survey, we will fill in the questionnaire together. You can write down the answers and I will help explain anything that is not clear to you. Or, if you prefer, I can fill it in for you while you sit beside me checking that I am ticking the right boxes and recording your responses correctly.

We believe that stories sometimes help people better understand what other people experience. If you participate in the survey and at some point in the interview you describe an experience that I would like to include in the survey report, I will stop and ask for your permission to do so. I may also request an additional interview with you in order to record your story and your experience so it can then be written up as a case study. You should always feel free to say no. If you tell me that I have your permission to include a particular experience you have had in the report, I will not use your name, and I will not include any personal information that would allow someone to identify you. The story will be completely anonymous.

Lastly, before we begin to conduct an interview and administer the questionnaire, we need to obtain informed, verbal consent from all potential survey participants. This ensures that all those agreeing to participate in the survey are voluntarily willing to participate and that they have obtained all the information they needed in order to make an informed choice about their participation.

## CONFIDENTIALITY AND POTENTIAL RISKS OF PARTICIPATING IN THE SURVEY

This project is taking every possible step to ensure confidentiality, i.e. to prevent any personal information from being known to people outside the research team. We know that breaches of confidentiality could lead to problems for interviewees, so we have put in place measures to avoid this from happening. For example, we do not write the name of the interviewee (i.e. the person being interviewed who is providing us with information about their experiences of living with HIV) on the questionnaire, and we do not write down anything that would allow someone to link the completed questionnaire to the interviewee. All questionnaires and other forms used in this project will be stored in a locked cabinet or cupboard. These data will be destroyed as soon as they are no longer needed (i.e. once they are stored electronically in a suitably secure place).

Nevertheless, in all studies like this there is a very small risk that a breach of confidentiality could take place. If this were to happen, your HIV status or other personal information might become known to someone who does not already know your HIV status. As a result, it is possible that you could face stigmatizing treatment from someone. In the most extreme situations, you might experience discrimination in your workplace, loss of access to services, media exposure or physical violence. While this is a very small risk, it is our duty to warn you of this.

## DISCOMFORT THAT YOU MIGHT EXPERIENCE AS A PARTICIPANT

The questionnaire asks personal questions that may make you feel uncomfortable at times, and it may bring up topics that are difficult to talk about. We do not wish for this to happen. We want you to know that you do not have to answer any question or take part in the interview if you feel the questions are too personal or if talking about them makes you uncomfortable. If you find you feel uncomfortable at any point during the interview, you can decide to pause or stop the interview at this time – it is completely up to you to decide this and to indicate to me, as the interviewer, that you wish to pause or stop the interview process.

Sometimes people want to explore certain issues and experiences in more depth after the interview. In case you need psychological or physical support, such as counselling or legal assistance or advice concerning educational, health or social support, we have developed a list of professional support services in our community. I will be happy to share this information with you.

## POTENTIAL BENEFITS FOR YOU AND THE COMMUNITY IN RELATION TO YOUR PARTICIPATION

We hope that the process of going through the questionnaire is an interesting one for you as it might cover some issues that you may not have thought about in detail. We also hope that you will learn from the interview process and from any discussions which may arise from it. However it is hoped that, through you and other people living with HIV participating in this project, we will be able to produce rich and valuable information that will assist both our national and global efforts to reduce HIV-related stigma and discrimination and ultimately improve the lives of all people living with HIV.

## APPENDIX 3 INFORMED CONSENT FORM



To be completed by the interviewee and the interviewer.

My name is   
 [INSERT the name of the interviewer.]

I am administering a questionnaire about the experiences of people living with HIV, particularly the experiences of stigma and discrimination they may have had.

I have provided you with an information sheet that describes the purpose of this questionnaire and how the information collected from this questionnaire will form part of a larger survey that is being conducted in this country to document some of the experiences of people living with HIV. The information sheet also outlined what types of information you will be asked, how we will keep this information confidential and the potential risks involved in your participating in this survey.

Before we begin the questionnaire, I would like to make sure that you are voluntarily willing to participate in this survey and that you have obtained all the information that you need in order to make an informed choice about your participation.

This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. You do not have to decide today whether or not you will respond to this questionnaire. Before you make a decision, you can talk to anyone you feel comfortable with about the questionnaire and/or the survey.

Please feel free to also contact the project team leader if you have any questions or concerns about this questionnaire or the survey. These are the contact details for the team leader:

Name

Contact details

[INSERT the name of the team leader plus appropriate contact details such as their telephone number(s), email address and their physical address.]

If, however, you choose to respond to this questionnaire and thus participate in the survey, I will ask you some questions about some of your experiences as a person living with HIV, in particular those related to the experiences of stigma or discrimination you may have had. I expect that the interview will take between two and three hours.

Before asking you whether or not you would like to be a participant, I would like you to know that:

1. Your participation in this survey is entirely voluntary. It is your choice whether to participate or not.
2. You are free to not answer any of the questions in the questionnaire.
3. You may stop participating in the interview at any time that you wish.

The information collected in this interview will be kept strictly confidential. To help ensure confidentiality, I will not write your name on the questionnaire or this form, and I will not write down particular details that would allow you to be identified.

If you would like to know more about the measures that we are taking to protect confidentiality, please ask me to provide you with these details.

Your participation will include my providing you with a list of services that are available in our community, including health care, social support and legal services.

Do you consent to participating in the interview?

Yes  1

No  2

If **NO**: Thank you for your time.

If **YES**: Thank you for agreeing to take part in this project.

By saying yes, that means that you have read the information on the information sheet, or it has been read to you. You have had the opportunity to ask questions related to the questionnaire and the People Living with HIV Stigma Index survey and any questions you have asked have been answered to your satisfaction. You consent voluntarily to be a participant in this project and you understand that you have the right to end the interview at any time.

If you agree, I will now sign this form to confirm that your consent has been obtained.

Signature/initials of interviewer

Date of interview

Your verbal consent is all that is needed to go ahead with the interview. If you feel comfortable enough doing so, however, you can also sign your name or initials below to indicate that you have consented in writing to participating in this interview.

However, please remember that verbal consent is all that is needed. You do not have to provide us with written consent, but you can if you would like to.

**I have read the information on the information sheet, or it has been read to me. I have had the opportunity to ask questions related to the questionnaire and the People Living with HIV Stigma Index survey, and any questions I have asked have been answered to my satisfaction. I consent voluntarily to be a participant in this project and understand that I have the right to end the interview at any time.**

Signature/initials of interviewee

Date of interview

## APPENDIX 4 INTERVIEWEE CONTACT LIST AND QUESTIONNAIRE CODES

## VERY IMPORTANT

- Information on this list is to be kept **confidential**. The **only** people who ought to have access to information on this list are (a) the interviewer who collected the data and (b) the team leader.
- This list must be kept in a **locked**, secure place – **different** from the completed questionnaires so as to protect the identity of all interviewees and to maintain the confidentiality that has been entrusted to the research team.

UNIQUE IDENTIFYING CODE	NAME OF INTERVIEWEE	CONTACT DETAILS*

\* Contact details of each of the interviewees can include any of the following: their telephone number, their address or their email. If an interviewee feels uncomfortable providing any of this information they could provide the contact details of the people living with HIV network to which they belong.

## APPENDIX 5 CONFIDENTIALITY AGREEMENT: INTERVIEWER

I, [REDACTED], an interviewer administering the People Living with HIV Stigma Index survey in [REDACTED] *[INSERT the name of the country in which the study is being conducted]*, agree to the following:

- (a) I will take all possible steps to protect the confidentiality of the information I receive during the interviews I conduct. This means that I will not disclose any personally identifying information to anyone, unless:
  - i. explicitly instructed to do so by the participant in the pilot/study; or
  - ii. compelled to disclose specific information under a court order of a competent court.
- (b) I will not record any personally identifying information on the questionnaire.
- (c) I will keep the "key" (contact list and questionnaire code) in a secure location (e.g. under lock and key), and stored separately from the questionnaires.
- (d) Any information stored electronically will be on a password-protected system where I have sole access or in a password-protected file.
- (e) Following the data entry and verification process, and upon instruction from the project leader with the [REDACTED] *[INSERT name of the organization managing the survey]*, I will destroy all completed questionnaires and the "key". I will retain a contact list for the purpose of sharing results of the study with participants expressing interest in receiving such information.

INTERVIEWER:

Signature:

Name (printed):

Date:

Place (city, country):

PROJECT LEADER OR WITNESS:

Signature:

Name (printed):

Date:

Place (city, country):

## APPENDIX 6 CONFIDENTIALITY AGREEMENT: INTERPRETER

I, , an interpreter assisting with the delivery of the People Living with HIV Stigma Index survey in  *[INSERT the name of the country in which the study is being conducted]*, agree to the following:

- (a) I will protect the confidentiality of the information that is shared during the interviews in which I assist. This means that I will not disclose any information that arises during the interview to anyone, either verbally or in writing, outside of the interview setting.
- (b) I will protect the identity of all people participating in the People Living with HIV Stigma Index survey. I will do nothing that discloses the identity of someone who is or has been associated with the project.

INTERPRETER:

Signature:

Name (printed):

Date:

Place (city, country):

PROJECT LEADER OR ANOTHER WITNESS:

Signature:

Name (printed):

Date:

Place (city, country):

## APPENDIX 7 CONFIDENTIALITY AGREEMENT: TEAM LEADER

I, , a team leader responsible for overseeing and supporting the delivery of the People Living with HIV Stigma Index survey in  *[INSERT the name of the country in which the study is being conducted]*, agree to the following:

- (a) I will take all possible steps to protect the confidentiality of the information that is under my care. This means that I will not disclose any personally identifying information to anyone, either verbally or in writing, unless:
  - i. explicitly instructed to do so by a participant in the pilot/study; or
  - ii. compelled to disclose specific information under a court order of a competent court.
- (b) I will take all possible steps to protect the confidentiality of employee/volunteer information in accordance with local laws and regulations.
- (c) Any information stored electronically will be on a password-protected system or in a password-protected file, and I will ensure that only project employees/volunteers who need access to this information have the necessary password.
- (d) I will instruct interviewers administering the People Living with HIV Stigma Index survey to keep the “key” (contact list and questionnaire code) in a secure location (e.g. under lock and key), and stored separately from the questionnaires.
- (e) Following the data entry and verification process, I will destroy all completed questionnaires and the “key”. I will instruct interviewers to do the same. I will retain a contact list for the purpose of sharing results of the study with participants expressing interest in receiving such information.
- (f) I will protect the identity of all people participating in the People Living with HIV Stigma Index survey. I will do nothing that discloses the identity of someone who is or has been associated with the project.
- (g) I am responsible for ensuring that appropriate ethical standards are maintained in this project. As part of the training that is provided to interviewers administering the People Living with HIV Stigma Index survey, I will instruct them not to record any personally identifying information on the questionnaire. I will remove (or make illegible) any personally identifying information that I observe when reviewing completed questionnaires (e.g. while doing quality checks).

TEAM LEADER:

Signature:

Name (printed):

Date:

Place (city, country):

WITNESS:

Signature:

Name (printed):

Date:

Place (city, country):



## APPENDIX 8 CONFIDENTIALITY AGREEMENT: DATA CLERK

I, , a data clerk assisting with the People Living with HIV Stigma Index survey project in  [INSERT the name of the country in which the study is being conducted], agree to the following:

- (a) I will take all possible steps to protect the confidentiality of the information that I handle. This means that if personally identifying information is made known to me, I will not disclose it – either verbally or in writing – to anyone. I will do nothing that discloses the identity of someone who is or has been associated with the project.
- (b) I will not enter any information into the electronic storage system that could be personally identifying. If I have doubts about whether or not information recorded on the questionnaire could be personally identifying, I will consult with the team leader. I understand that personally identifying information is to be removed from the paper questionnaire or made illegible (e.g. blacked out with a pen or marker).
- (c) I will use computer equipment in accordance with the instructions provided to me by the team leader. I will keep the password or access code for computer equipment and files in a safe place, and I will not disclose this information to anyone unless explicitly instructed by the team leader.
- (d) Back up copies of the data – whether on disk, electronic storage devices (e.g. “flash drives” or memory sticks) or in hard copy – will be stored in a secure location, in accordance with the instructions of the team leader.

DATA CLERK:

Signature:

Name (printed):

Date:

Place (city, country):

PROJECT LEADER OR ANOTHER WITNESS:

Signature:

Name (printed):

Date:

Place (city, country):

## APPENDIX 9 CONFIDENTIALITY AGREEMENT: DATA ANALYST

I, , a data analyst assisting with the People Living with HIV Stigma Index survey project in  [INSERT the name of the country in which the study is being conducted], agree to the following:

- (a) I will take all possible steps to protect the confidentiality of the information that I handle. This means that if personally identifying information is made known to me during the course of the project, I will not disclose it – either verbally or in writing – to anyone. I will do nothing that discloses the identity of someone who is or has been associated with the project.
- (b) I will use computer equipment and data in accordance with the instructions provided to me by the team leader. I will keep the password or access code for computer equipment and files in a safe place, and I will not disclose this information to anyone unless explicitly instructed by the team leader.

DATA CLERK:

Signature:

Name (printed):

Date:

Place (city, country):

PROJECT LEADER OR ANOTHER WITNESS:

Signature:

Name (printed):

Date:

Place (city, country):

## APPENDIX 10 TEMPLATE: KEY STEPS IN THE LOCAL IMPLEMENTATION PROCESS

STEPS	TASK	TIMELINE
1.	Seek guidance from the People Living with HIV Stigma Index <b>coordinator</b> at the International Planned Parenthood Federation.	
2.	<p>Introduce the People Living with HIV Stigma Index research study to <b>key stakeholders</b> and partners (the people living with HIV network and organizations) in the local site, region or country.</p> <ul style="list-style-type: none"> <li>• Discuss how the research results from the People Living with HIV Stigma Index can support local advocacy and other activities.</li> <li>• Clarify the role that the key stakeholders and partners can play in the research process.</li> <li>• Discuss what resources are available for the research and how any necessary additional resources can be mobilized.</li> <li>• Discuss a possible dissemination strategy for the results, including sharing results with the study participants and the wider community.</li> <li>• Agree to timelines and a mechanism whereby key stakeholders and partners can be kept informed about the progress of the research.</li> </ul> <p>Consider setting up an <b>advisory committee</b> to include various stakeholders and partners in addition to people living with HIV networks and organizations (e.g. UNAIDS partnership or monitoring and evaluation officers, International Planned Parenthood Federation representatives, representative from local community-based organizations that are providing services to people living with HIV, legal and human rights groups, etc).</p>	
3.	Decide on the <b>sampling frame and sample size</b> .	
4.	<p>If an <b>ethical review</b> is necessary for this type of research study in the country, prepare a research protocol and submit it to the relevant authority for ethical review.</p> <p>Consider approaching a local university or research institution that has done similar research to be a partner on the project and to assist with obtaining ethical approval for the study.</p>	
5.	<p><b>Recruit</b> a team leader, interviewers who are people living with HIV, data capturers, data analysts.</p> <p>It might also be necessary to secure some part-time financial and administrative support.</p>	
6.	<p><b>Clarify the different roles and responsibilities</b> the various team members will play in the research process.</p> <p>Have each team member and service provider sign a <b>confidentiality agreement</b> (Appendices 5–9).</p>	
7.	Establish an appropriate <b>system to manage the financial and administrative aspects</b> of the research process.	
8.	In consultation with members of the local people living with HIV network/advisory group members, decide which <b>national law, policy or set of guidelines</b> that upholds the rights of people living with HIV would be the most appropriate to include in Section 2D of the questionnaire.	
9.	In consultation with members of the local people living with HIV network/advisory group members, develop a <b>list of local organizations</b> that interviewees can be referred to should they require further support.	

STEPS	TASK	TIMELINE
10.	<p>Arrange that the questionnaire, information sheet and consent forms are <b>translated</b> into the local language(s).</p> <p>Have the translated documents checked for quality by having another translator review them.</p>	
11.	<p>Arrange a <b>suitable venue</b> in which the interviews can be conducted.</p> <p>Establish a <b>safe place</b> for the data and the interviewee contact and code list to be stored.</p>	
12.	<p><b>Train</b> a group of interviewers, who are people living with HIV, to be able to conduct the interviews.</p>	
13.	<p>Set up regular <b>supervision meetings</b> between the team leader and/or supervisors and interviewers.</p>	
14.	<p>Agree, based on local custom and practice, what an appropriate <b>honorarium</b> would be for interviewees (e.g. cash, a food parcel, t-shirt and/or with the provision of a meal and transport money).</p>	
15.	<p>Ensure that there are a <b>sufficient number of copies</b> of the questionnaire, the information sheet, the informed consent forms and the referral list for the interviews.</p> <p>In addition, copies of the <i>Declaration of Commitment on HIV/AIDS</i> and the national law, policy or set of guidelines that protects the rights of people living with HIV (selected by the network to be included in the questionnaire) should also be made available for all interviews.</p> <p>Ensure that the necessary stationery, refreshments and honoraria are available for each interview.</p>	
16.	<p>Introduce the People Living with HIV Stigma Index to potential interviewees and <b>set up the interviews</b>.</p>	
17.	<p><b>Conduct the interviews</b>.</p>	
18.	<p>Set up and conduct <b>case study</b> interviews with the chosen interviewees.</p>	
19.	<p>In consultation with the People Living with HIV Stigma Index coordinator at the International Planned Parenthood Federation, <b>enter the data</b> from the questionnaires into Epi-Info.</p>	
20.	<p>In consultation with the People Living with HIV Stigma Index coordinator at the International Planned Parenthood Federation, <b>analyse</b> the results and write up the case studies.</p>	
21.	<p><b>Present</b> the results of the research to the research team, members of the local people living with HIV network/advisory group members for their comment and feedback.</p>	
22.	<p>Agree on how to operationalize the <b>dissemination strategy</b> and the different ways of <b>taking action</b> following the study results.</p>	

## APPENDIX 11 TEMPLATE: THREE-DAY TRAINING PROGRAMME FOR INTERVIEWERS

### OBJECTIVES OF THE TRAINING PROGRAMME

The training aims to be fun. By working through the People Living with HIV Stigma Index in an interactive and engaging way, the training aims to provide a supportive space where people can reflect on their own experiences and learn from their peers.

The training specifically aims to provide participants with:

- an understanding of the history, rationale and the partners involved in the People Living with HIV Stigma Index;
- an opportunity to consolidate their own understanding of the key concepts associated with HIV-related stigma and discrimination, and to reflect on some of their own experiences of these;
- a thorough understanding of the content of the questionnaire, and the associated forms and agreements that are administered as part of the interview process;
- the skills to conduct and record interviews with people living with HIV in their community using appropriate research methods; and
- guidance as to how one would reflect on the data that have been gathered during the interview process and be able to access the necessary support from the team leader.

### OVERVIEW OF THE THREE-DAY TRAINING PROGRAMME

<b>DAY 1</b>	<b>AGENDA</b>
	Opening, welcome and introductions
	Review of the objectives and the programme, the expectations of the participants and the logistical arrangements
	History and background of the People Living with HIV Stigma Index
	<b>MORNING TEA</b>
	Consolidation of theory: HIV-related stigma and discrimination
	<b>LUNCH</b>
	Reflections on participants' previous research experience
	Putting people living with HIV at the centre of the research process
	Getting to know the user guide: issues around informed consent and confidentiality
	<b>AFTERNOON TEA</b>
	Getting to know the user guide: issues around sampling
	Accessing the interviewees
	Questions, homework, wrap-up and closure of the first day
<b>DAY 2</b>	<b>AGENDA</b>
	Reflection on Day 1
	Getting to know the user guide: key definitions and concepts
	Becoming familiar with the content of the People Living with HIV Stigma Index questionnaire
	<b>MORNING TEA</b>
	Previous session continued
	Input: some basic skills required for conducting interviews
	Practice round # 1: role play
	Paired feedback and discussion on experiences
	<b>LUNCH</b>
	Practice round # 2: reversal role play
	Paired feedback and discussion on experiences
	Plenary discussion on lessons learnt
	<b>AFTERNOON TEA</b>
	Practice round # 3: reflections on note-taking
	Role play: administering the information sheet and consent form
	Questions, wrap-up and closure of the second day

DAY 3	AGENDA
	Reflection on Day 2
	Conducting interviews: some very practical things to consider
	The issue of case studies
	MORNING TEA
	Mapping out the research journey: what do we do next?
	LUNCH
	Confirmation of all the follow-up steps and agreements made during the training programme
	Evaluation of training programme
	Wrap-up and closure

## A FACILITATOR'S GUIDE TO THE TRAINING PROGRAMME

The notes provided in this section are intended to provide the facilitator(s) of a local interviewer training programme with some broad ideas about what one could do when preparing and training people to conduct the interviews that form the basis of the People Living with HIV Stigma Index. The ideas and guidelines contained over the next few pages are not intended to be exhaustive, and facilitators are thus encouraged to adapt and modify the agenda and the programme that has been documented in this appendix.

This training programme template is based on the experiences of the team that facilitated the People Living with HIV Stigma Index pilot training programme held in Johannesburg, South Africa in 2006.

## PRACTICAL THINGS THAT NEED TO BE ARRANGED BEFOREHAND

### PARTICIPANT FILES AND RESOURCES

Each participant ought to be given, at the minimum, a file containing the following information:

- the objectives and agenda for the three-day training programme;
- a copy of the People Living with HIV Stigma Index questionnaire, the user guide and the accompanying Appendixes (1–11);
- basic literature and resources on HIV-related stigma and discrimination (see the resource ideas listed opposite);
- a copy of the *Declaration of Commitment on HIV/AIDS* (2001), and a copy of the national law, policy or set of guidelines that protects the rights of people living with HIV, and that the people living with HIV network has chosen to include in the People Living with HIV Stigma Index questionnaire (Section 2D, question 2A); and
- an evaluation form for participants to complete at the end of the training.

### GUEST SPEAKERS

It would also be important to arrange that:

- a representative from a partner organization or people living with HIV network opens the event and welcomes participants to the training programme; and
- that someone (either the facilitator or invited guest speakers) provides comprehensive input on (a) HIV-related stigma and discrimination and (b) interviewing techniques.

### TRAINING RESOURCES

In the People Living with HIV Stigma Index pilot training programme, the facilitators used worksheets, which outlined the key questions they asked participants in the small group and plenary discussions. The idea behind this was that participants could then record their and others' responses to these questions and be provided with a space to record some of the ideas that might assist them in the forthcoming interview process.

Worksheets like these, plus any handouts from the input sessions (described above), would need to be prepared beforehand and included in the files for all participants.

## RESOURCES WE FOUND USEFUL ON HIV-RELATED STIGMA AND DISCRIMINATION AND RELATED ISSUES

The following is a list of useful resources, some of which would be important to make accessible and share with the participants at the training:

- *HIV/AIDS Stigma Resource Pack*. Produced by the Siyam'kela Project, South Africa. Copies available from The Center for the Study of AIDS, University of Pretoria, South Africa. Website: [www.csa.za.org](http://www.csa.za.org) Email: [csa@up.ac.za](mailto:csa@up.ac.za)
- *Understanding and Challenging HIV Stigma: Toolkit for Action* (September 2003). Developed by Ross Kidd and Sue Clay for The CHANGE Project and The International Center for Research on Women. Copies available from The CHANGE Project, Academy of Educational Development, Washington, DC. Website: [www.changeproject.org](http://www.changeproject.org) Email: [changeinfo@aed.org](mailto:changeinfo@aed.org)
- *World AIDS Campaign 2003. A Conceptual Framework and Basis for Action: HIV/AIDS Stigma and Discrimination* (June 2003). Prepared for UNAIDS by Peter Aggleton and Richard Parker. Available from the UNAIDS website: [www.unaids.org](http://www.unaids.org)
- *HIV-related Stigma, Discrimination and Human Rights Violations: Case Studies of Successful Programmes*. UNAIDS Best Practice Collection (April 2005). Available from the UNAIDS website: [www.unaids.org](http://www.unaids.org)
- *The Greater Involvement of People Living with HIV* (March 2007). This UNAIDS Policy Brief is available from the UNAIDS website: [www.unaids.org](http://www.unaids.org)
- A series of publications on various aspects of HIV-related stigma and discrimination, produced by the POLICY Project in January 2006 and available from its website at [www.policyproject.com](http://www.policyproject.com):
  - *A Closer Look: The Internalization of Stigma Related to HIV*. Prepared by Pierre Brouard and Caroline Wills.
  - *Can We Measure HIV/AIDS-related Stigma and Discrimination? Current Knowledge About Quantifying Stigma in Developing Countries*. Prepared by Laura Nyblade and Kerry MacQuarrie.
  - *Breaking the Cycle: Stigma, Discrimination, Internal Stigma and HIV*. Prepared by Ken Morrison.
  - *Breaking Through: Profiles of Individuals Challenging HIV-related Stigma and Promoting Human Rights Around the World*.

## DAY 1: OUTLINE OF CONTENT AND PROCESS FOR SOME OF THE KEY SESSIONS

### CONSOLIDATION OF THEORY: HIV-RELATED STIGMA AND DISCRIMINATION

TIME: 2 hours

PURPOSE: The purpose of this session is to ensure that the participants, who will be interviewing other people living with HIV about their experiences of HIV-related stigma and discrimination, have a thorough understanding of these two key concepts.

PROCESS: Input is provided on:

- the definition of and relationship between the concepts of stigma and discrimination;
- examples, illustrations and stories about both concepts;
- why HIV-related stigma and discrimination develops, and how it relates to other forms of stigma and discrimination (such as those based on gender, sexuality and race); and
- what impact stigma and discrimination has on those infected and affected (including an explanation of the concept of internal stigma).

Participants are asked, in small groups, to:

- recall their own experiences of HIV-related stigma and discrimination, how they felt about such incidents, and what they did about them; and
- consider what people living with HIV, people living with HIV networks, the general community and governments can do about HIV-related stigma and discrimination.

Following plenary feedback, participants are asked to:

- raise any further questions they have about the issue of HIV-related stigma and discrimination and that they think might be important to clarify in preparation for conducting the interviews.

### REFLECTIONS ON PARTICIPANTS' PREVIOUS RESEARCH EXPERIENCE

#### Putting people living with HIV at the centre of the research process

TIME: 1 hour

PURPOSE: The purpose of this session is to allow participants to reflect on their own experience of being a participant in a research study.

The intention is to have the participants recall and/or imagine what it feels like to be an interviewee and how they can ensure that the People Living with HIV Stigma Index process is a respectful and supportive one for interviewees who are people living with HIV.

PROCESS: Participants are asked, in small groups, to:

- recall their own experiences of being an interviewee or participant in a research study and to think about:
  - what they were asked/had to do;
  - what it felt like being part of the study;
  - what they liked about the interview process; and
  - what they did not like about it.

Following plenary feedback, participants are asked to:

- consider what they think the important things are (both in terms of ethical practice/principles and logistics) to remember in the way they:
  - request interviews;



- 
- conduct interviews;
  - record and maintain records of the interviews; and
  - how they can ensure that the interview process is inclusive and supportive of people living with HIV.

Guidance is then provided by the facilitator on how to facilitate an inclusive, supportive and ethically sound interview process by having, for example:

- the interviewer and interviewee sitting side by side (as opposed to opposite one another as a traditional interview would be conducted);
- the interviewee filling in the questionnaire with help from the interviewer, or vice versa (in other words, a shared filling-in process);
- the interviewer explaining any difficult concepts and providing definitions as the interview proceeds;
- the interviewer providing information and answering any questions the interviewee might have to the best of their ability, without lecturing the interviewee;
- all interviewees being treated with respect, observing utmost confidentiality and obtaining their consent to be interviewed prior to starting the interview; and
- the interviewer thanking the interviewee for their participation at the end of the interview and, importantly, referring the interviewee for further support or information, if so required or requested.

The facilitator can also make reference to the People Living with HIV Stigma Index user guide (Part 2) and the Greater Involvement of People Living with HIV Principle.

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#### GETTING TO KNOW THE USER GUIDE

##### How do we ensure that there is informed consent and confidentiality?

TIME: 1 hour

PURPOSE: The purpose of this session is to ensure that participants are familiar with the definition, purpose and importance of these two concepts and how they have been included in the People Living with HIV Stigma Index.

PROCESS: Participants are asked, in plenary:

- to explain what each concept means; and
- why they are important issues to consider in a research process.

The facilitator, in plenary:

- ensures that there is a collective understanding of these two concepts;
  - provides additional input on the two concepts; and
  - by working with the user guide, explains how these two concepts have been incorporated into the People Living with HIV Stigma Index research process and how they can practically be put into practice in the interviews.
- 

The table on the following page can be used by the facilitator as they guide participants through the explanations.

	INFORMED CONSENT	CONFIDENTIALITY
<b>Definition</b>	Part 3: Ethical issues (user guide)	Part 3: Ethical issues (user guide)
<b>What has been developed to support this?</b>	Appendix 2: information sheet	Unique ID code for each interviewee
<b>How do we practically apply this in the field?</b>	Appendix 3: consent form Read through each and discuss with participants when and how they would actually use Appendices 2 and 3 in the interviews.	Appendix 4: a list on which the names and contact details of all the interviewees is kept. Illustrate to participants: <ul style="list-style-type: none"> <li>• how they would make up the unique identification code for each interviewee (by using examples from the group of participants and different scenarios); and</li> <li>• how they would write up and keep the list of interviewee information securely and separately from the questionnaires.</li> </ul>

#### GETTING TO KNOW THE USER GUIDE:

- Our sampling strategy – how should we select those to be interviewed?
- How do we access our interviewees once we have decided on who we ought to interview?

TIME: 1 hour

PURPOSE: The purpose of this session is to ensure that participants are familiar with the definition, purpose and importance of sampling and, based on this, how they would go about recruiting interviewees into the People Living with HIV Stigma Index study.

PROCESS: Participants are asked, in plenary:

- to explain what they understand by the term “sampling”; and
- why it is an important issue to consider in the process of research.

The facilitator, in plenary:

- ensures that there is a collective understanding of the term;
- provides additional input on the issue (for example, by discussing the advantages and disadvantages of different types of sampling methods, and what sampling method and sample size have been chosen for the People Living with HIV Stigma Index in that country); and
- working with the user guide, explains what this will mean practically for the interviewers before they recruit participants into the study.

The following table can be used by the facilitator as they guide the participants through the above explanation.

#### SAMPLING STRATEGY

<b>Definition</b>	Part 4: Sampling (user guide)
<b>What has been developed to support this?</b>	Part 4: Sampling (user guide)
<b>How do we practically apply this in the field?</b>	Issues to discuss here include: <ul style="list-style-type: none"> <li>• how to find potential interviewees in the most appropriate and sensitive way;</li> <li>• how to contact them (for example, phone, visit, approach at a meeting);</li> <li>• what they will say to a potential interviewee when they are asked whether they would be interested in participating in the People Living with HIV Stigma Index study; and</li> <li>• what they will do after this if the potential interviewee declines or accepts the invitation to participate in the study (e.g. how they will set up the interview time and venue and make other arrangements, etc).</li> </ul>

**DAY # 1: HOMEWORK TASK**

- Read the People Living with HIV Stigma Index questionnaire
- Read Appendix 1: Key definitions and concepts

TIME: 2 hours

PURPOSE: The purpose of this homework task session is to prepare participants for the content of the morning sessions on Day 2. It is anticipated that having read the questionnaire and Appendix 1 before the sessions, participants will be able to bring their own questions to the session and be able to participate in a more engaging way with the content of the sessions.

**DAY 2: OUTLINE OF CONTENT AND PROCESS FOR SOME OF THE KEY SESSIONS****THE WORD GAME: AN ICE-BREAKER TO START THE DAY**

TIME: 20 minutes

PURPOSE: The purpose of this exercise is to make sure participants are familiar with – and can explain to others – the meaning of the key concepts contained in the People Living with HIV Stigma Index questionnaire.

**FACILITATOR PREPARATION:**

- Create a card ( $\frac{1}{4}$  of the size of an A4 piece of paper) for each of the words in Appendix 1. These are referred to as “word cards” in this exercise.
- Place all the word cards in a box or some form of container like a tin and have each participant take a couple of the word cards. Have each participant take a number of cards so that the cards are divided equally among the participants.
- Have participants take their allocated number of word cards as they enter the training room on Day 2.
- Get a soft ball (or make one yourself by squashing up newspaper and binding it together with a piece of string or sticky tape).

**PROCESS:**

- Participants are asked, individually:
- to spend 10 minutes reviewing the word cards they have been allocated and getting familiar with the definition of these words (as defined in Appendix 1).
- Participants are then asked, in plenary:
- to stand in a circle holding their collection of word cards. The facilitator starts the game by throwing the ball to a participant. When they catch the ball they have to tell the group about one of the words they have (saying what the word is and defining it);
  - when they are finished with the explanation, the participant then throws the ball to another participant and they too are required to define one of their words. The game proceeds in this same way for another 10 minutes or so;
  - all participants are encouraged to add to or to disagree with the definitions that participants give as the ball goes around and around the circle; and
  - given that there are a number of words in Appendix 1 and not all of them will have been defined by the end of this exercise, the facilitator can return to this exercise later in the day if they feel that the group needs some exercise. Alternatively, the game could be played as an ice-breaker on the morning of Day 3.

## BECOMING FAMILIAR WITH THE CONTENT OF THE PEOPLE LIVING WITH HIV STIGMA INDEX QUESTIONNAIRE

**TIME:** 2 hours (separated by morning tea)

**PURPOSE:** The purpose of this exercise is to provide participants with an opportunity to become familiar with the questionnaire.

**PROCESS:** In plenary:

- participants are asked to have the People Living with HIV Stigma Index questionnaire and the user guide (Part 6) open in front of them; guided by the facilitator, the group works through each section (starting with the cover sheet, proceeding through the different sections and ending with the quality control procedures);
- in working through these two documents, the facilitator should ensure that the participants understand the motivation behind each question, are familiar with the words that are used in the questionnaire and can appreciate the range of available response options; and
- the facilitator should encourage participants to raise questions and seek clarification when they are uncertain about the content or meaning of a specific question.

## INPUT: SOME BASIC SKILLS REQUIRED FOR CONDUCTING INTERVIEWS

### Practice rounds # 1 and # 2

**TIME:** 3 hours (separated by lunch)

**PURPOSE:** The purpose of this exercise is to provide participants with an opportunity, through a role play, to practise administering the questionnaire.

**PROCESS:** In plenary:

- participants are asked, "What are the key things that you think make an interview successful?";
- the facilitator, capturing the responses, then constructs a "good quality interview checklist" on the white board/flipchart that participants can then use as a guide in their role plays. An example of such a checklist has been illustrated opposite; and
- building on these ideas, input is then provided on the key skills and qualities that are required to conduct a good interview.

Participants are then asked, in pairs, to:

- role play the administration of the questionnaire. In the first round, one of the pair assumes the role of the interviewer and the other the interviewee;
- at the end of the first role play, participant pairs are asked to provide one another with feedback about what they observed, felt and noticed about the interview (from the different perspectives of the interviewer and interviewee). The participants are reminded about providing feedback in relation to the areas that the group outlined in their "good quality interview checklist";
- following this, the pair is then asked to reverse roles and conduct the second role play interview. They are asked to provide feedback in the same way as they did for the first role play; and
- it is suggested that the facilitator makes a judgement call about whether the participants ought to develop a character for the role play (when they are the interviewee) or to respond to the questions from their own perspective. In the pilot training programme, given that a significant level of trust had been built up among participants, some participants chose to respond as themselves and not in a role.

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In plenary:

- the participant pairs share some of their key observations and feelings about the role plays; and
- a discussion is held on the issues that participants, as interviewers, will need to be mindful of when they conduct the interviews in the field.

Importantly, if there are an uneven number of participants or representatives from the local people living with HIV network attending the training, they can be asked to be observers of the role plays. Their responsibility would be to discreetly observe a role play and to share their feedback with the participant pair at the end of each role play.

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#### EXAMPLE: A GOOD QUALITY INTERVIEW CHECKLIST

<b>THE DATA:</b>	<ul style="list-style-type: none"> <li>• are captured that relate to the focus of the research question or research issue; and</li> <li>• are recorded accurately and written down in a legible manner.</li> </ul>
<b>THE INTERVIEWEE:</b>	<ul style="list-style-type: none"> <li>• feels comfortable and supported, and is able to share their opinions and experiences in an environment which is non-judgemental; and</li> <li>• feels sufficiently informed and comfortable giving their consent to participate in the interview and the research study.</li> </ul>
<b>THE INTERVIEWER:</b>	<ul style="list-style-type: none"> <li>• explains the purpose of the study and obtains informed consent from the interviewee before the interview begins;</li> <li>• listens attentively, is empathetic and is sensitive to the interviewee's responses (such as their tone of voice, their body language and the questions they ask);</li> <li>• manages time so that the interview is not too rushed or too lengthy, which is then inconvenient for the interviewee;</li> <li>• provides accurate information in response to the interviewee's questions and refers them to access further support where necessary;</li> <li>• assures the interviewee that the information they share will be kept confidential;</li> <li>• compensates the interviewee for their time with an honorarium; and</li> <li>• reflects on the process and content of the interview after the interview.</li> </ul>
<b>THE VENUE:</b>	<ul style="list-style-type: none"> <li>• the seating arrangements are appropriate, for example, the interviewer and interviewee are able to sit side by side;</li> <li>• the interviewee feels physically comfortable and safe in the venue;</li> <li>• the venue does not place the interviewee at risk of further stigmatization or discrimination; and</li> <li>• the venue is private and there are no interruptions or disturbances during the process of the interview.</li> </ul>

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**REFLECTIONS ON NOTE-TAKING****Administering the information sheet and consent form****Practice round # 3**

**TIME:** 1 hour

**PURPOSE:** The purpose of this exercise is to provide participants with an opportunity to reflect on the task of record-keeping and to practise administering the information sheet and the consent form as they begin an interview.

**PROCESS:** Participants are asked, in their role play pairs, to:

- review their partner's notes and respond to the following questions:
  - Are their responses clearly written so that you could read them?
  - Have all the questions been filled in? If not, was an appropriate explanation provided for why these questions were not completed?
  - Was the quality check section (at the end of the questionnaire) completed?
  - What about the qualitative sections of the questionnaire: do you think that the responses were documented in sufficient detail?

In plenary, the facilitator:

- requests that participants share their reflections on their note-taking;
- provides additional input and advice on how to record the data accurately and in sufficient detail; and
- then asks for two volunteers to role play how they would start an interview and use the information sheet (Appendix 2) and the informed consent form (Appendix 3).

Following the role play, the volunteer pair is asked to provide one another with feedback, after which the other participants are asked to share their own observations of the last role play.

The facilitator wraps up the session by providing additional input on how to use these two forms to the benefit of the interviewee.

## DAY 3: OUTLINE OF CONTENT AND PROCESS FOR SOME OF THE KEY SESSIONS

### CONDUCTING INTERVIEWS: SOME VERY PRACTICAL ISSUES TO CONSIDER

**TIME:** 1 hour 30 minutes

**PURPOSE:** The purpose of this exercise is to provide participants with an opportunity to reflect on some of the issues that they will need to consider when conducting interviews in the field. Such issues include arranging and conducting interviews, providing follow-up or referral information to the interviewees and storing the data safely.

**PROCESS:** The facilitator asks the participants, in small groups, to brainstorm a list of things that they imagine can potentially go wrong during the different stages of the research process, like, for example, when:

- arranging interviews;
- conducting interviews;
- providing follow-up/referral information to the interviewees; and
- storing the data in a safe place.

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Examples of such problems could include:

- getting support from the other members of their organization for this research study;
- struggling to set up appointments with interviewees;
- interviewees not keeping their appointments;
- not being able to record the responses of the interviewees fast enough; and
- having to respond to difficult situations or questions in the interviews.

Once a list of difficult scenarios has been created by the small groups, the facilitator then ought to ask the small groups to share, in plenary, their difficult scenarios or problems. The facilitator ought to write up these scenarios on a flipchart or whiteboard.

The facilitator can then divide these scenarios up among the small groups asking that the small groups come up with solutions to these problems. The proposed solutions to the problems are then shared in plenary, with the facilitator adding in additional comments where appropriate.

Examples of such scenarios – specifically in relation to the interview process – and the proposed solutions to these problems are described below and on page 70.

Following this exercise, the facilitator then proceeds to outline the other practical things that interviewers need to consider when beginning the research process. These include:

- ensuring that a comprehensive list of referrals (including their contact details) has been developed for interviewees. Some guidance in relation to developing this list is suggested below and on page 70;
- ensuring that refreshments are purchased and available for interviewees;
- arranging transport reimbursement for interviewees;
- setting up a schedule to meet with their supervisor/team leader on a regular basis;
- ensuring that sufficient copies of the questionnaire, information sheets and informed consent forms have been copied and are easily available; and
- making sure that there is sufficient stationery to support the interview process.

Participants are referred to the People Living with HIV Stigma Index user guide (Part 5) for additional information and guidance on these types of practical matters.

The facilitator then provides input on the requirements for storing the data securely (see Parts 6 and 7 in the user guide).

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#### WHAT IS THE BEST THING TO DO WHEN A DIFFICULT SITUATION ARISES IN AN INTERVIEW?

##### Some examples and potential solutions

SCENARIOS	POSSIBLE SOLUTIONS
The interviewee <b>brings along a child</b> to the interview and is old enough to understand what their mother or father is saying in the interview. You are worried that it would not be appropriate for the interviewee to share their responses in front of the child.	<ul style="list-style-type: none"> <li>• When contacting the potential interviewee, find out about whether they would have to bring their child to the interview and organize good child care support.</li> <li>• Clarify whether the interviewee has disclosed their HIV status to their child and whether she feels comfortable talking in front of her child.</li> <li>• Possibly re-schedule the interview and then arrange child care for the next appointment, or get “emergency” child care on the spot (by asking someone you trust who is close by).</li> </ul>

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The interviewee comes to the interview **under the influence of alcohol and/or drugs** and is not sufficiently focused. You realize this at the start of the interview, or when you realize they are not able to concentrate very well (for example, they ask you to repeat the questions, they can't remember things that you consider to be quite basic such as their age or the members in their family, and they say things early on in the interview that then contradict their later responses).

- Make a judgement call and consider whether it is ethical to interview the interviewee or not (for example, if someone is not completely sober their judgement might be impaired in deciding whether they feel comfortable to participate in the interview or not – apart from the fact that they might not be able to concentrate and remember aspects of the responses that are required from them).
- Do not do the interview and re-schedule it for another date. If they are still drunk or high, terminate the requested interview process and find another interviewee.
- Try and support the interviewee by referring them to a drug counselling organization.

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The interviewee **wants to end the interview early**.

- Explore tactfully with the interviewee what their reasons are for wanting to leave early; if possible, provide a response to their concerns (if this is one of the reasons for the early termination of the interview); then reflect on your own skills as an interviewer and consult with your supervisor for guidance.

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The interviewee **does not come** to the scheduled interview.

- If the interviewee does not arrive, contact them (by telephone, if possible) and discuss with them what implications this has for the research process. Provide them with one more opportunity for a re-scheduling.

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The interviewee becomes **very emotional** and distressed during the course of the interview.

- Provide the interviewee with the space to express their emotions, reflect their feelings and try to "normalize" their emotions.
- Ask if it is OK to continue the interview, and if not, ask them to re-schedule the interview.
- Refer the interviewee on for support, and decide on how much follow-up is appropriate given your role as an interviewer.

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The interviewee **tells a long story**.

- Depending on the content of the story, it would be important to determine whether there are signs of suicidal thought and then immediately refer the interviewee on for counselling and guidance.
- If the story is a rambling one and disconnected to the People Living with HIV Stigma Index, re-focus the interviewee in a tactful way, reminding them of the focus of the research.
- Alternatively, listening is important as it builds up rapport, but this needs to be weighed against the cost of them returning home late – especially if they are using public transport.

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The interviewee **flirts with you** during the course of the interview.

- Establish clear boundaries in relation to your professional role as an interviewer (as opposed to a friend, family member or potential partner) from the beginning.
  - Ensure that you choose an interviewee that is beyond your circle of immediate friends, family members or past and present partners.
-



Below are some ideas to consider when compiling a referral list.

#### PROPOSED CONTENT AND GUIDANCE: IN-COUNTRY INFORMATION LIST ON REFERRAL SERVICES

- The name, address and contact numbers of the organizations should be provided – and where appropriate, the name of a contact person to speak to specifically in the organization.
- A local network, support group or organization that has a good database and good resources to refer people living with HIV to the relevant services are ideal to include in this list. Keep the list concise. Remember you are not being asked to develop a whole new database of HIV/AIDS services but rather to provide your interviewee with a good list of referrals which they can contact and through which they can then access the service they require – either directly or with the help of the listed organization.
- Examples of networks or organizations that refer or offer counselling and psychological, physical, medical, treatment and spiritual support to people living with HIV should be included in the list.
- Issue-specific organizations, such as those supporting injecting drug users, sex workers or the gay and lesbian community ought also to be included in this referral list.

#### THE ISSUE OF CASE STUDIES

TIME: 30 minutes

PURPOSE: The purpose of this session is to introduce participants to the concept of case studies and to inform them of how they ought to identify potential case study candidates.

PROCESS: In plenary, the facilitator:

- provides input on the rationale for case studies;
- clarifies with participants how they could identify potential candidates for the case studies; and
- clarifies any questions they might have about the case study scenarios.

Participants are referred to the People Living with HIV Stigma Index user guide (Part 7), which describes the case studies.

#### MAPPING OUT THE RESEARCH JOURNEY: WHAT DO WE DO NEXT?

TIME: 2 hours

PURPOSE: The purpose of this exercise is to provide participants with time to collectively map out and plan the different tasks and activities that they will need to perform in order to conduct the research in a systematic and rigorous way.

FACILITATOR PREPARATION:

The facilitator will need to prepare a worksheet so as to assist the participants to identify and plan what, how and when they will implement the research at a local level. Appendix 11 of the user guide (which provides a template of the key tasks that need to be considered at a local level) will assist in the development of this worksheet.

PROCESS: The facilitator requests that:

- participants work individually, in pairs or in small groups – whatever is appropriate for the group. For example, it might be appropriate for the team leader to work alone or in partnership with a representative from a local people living with HIV network and the participants who are going to be conducting the interviews (either with particular groups or in a particular geographical area) to work together.

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Once the planning task has been completed, the facilitator can ask that participants share in plenary some of the questions or concerns they have about the implementation of the research process within the community.

Alternatively, if time allows, participant groups could be paired and asked to share their plans with their colleagues. In this way the paired groups could double-check that all the necessary steps had been considered and were in a logical sequence, and provide one another with critical feedback on their plans.

It would be advisable that the facilitator (during the session or over lunch) reviews some of the plans that have been made by the small groups and develops a summary of the key steps that the group will collectively take following the training programme.

This overview can then be presented to the participants in plenary and the final follow-up tasks and responsibilities confirmed collectively.

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#### **PARTICIPANT EVALUATION: IDEAS FOR A QUESTIONNAIRE**

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A participant evaluation questionnaire focusing on the content, process and logistics associated with the training programme ought to be administered at the end of the training programme.

Here are some examples of questions that could be included in that questionnaire:

- What aspects of the workshop did you find most useful?
- What aspects of the workshop did you find not useful?
- How confident, on a scale of 1 (not confident at all) to 5 (very confident), do you feel about conducting interviews in your local area? Please explain your rating.
- What further support do you feel you still require in order to conduct interviews?
- What did you feel about the presentations and the facilitation?
- Do you have any other comments you would like to share with us?

Participants can also be asked to rate, on a scale of 1 (poor) to 5 (excellent), the efficiency of the logistics and administration associated with the event. Questions could be asked about:

- information received prior to the workshop about the purpose, content, logistics and preparation related to participation;
  - travel arrangements related to arriving and departing from the workshop;
  - accommodation during the workshop;
  - catering during the workshop; and
  - support provided related to any logistical problems faced during the workshop.
-



## THE PEOPLE LIVING WITH HIV STIGMA INDEX

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**THE PEOPLE LIVING WITH  
HIV STIGMA INDEX:  
BUILDING THE EVIDENCE  
BASE FOR UNDERSTANDING  
THE STIGMA AND  
DISCRIMINATION  
EXPERIENCED BY PEOPLE  
LIVING WITH HIV IN  
DIFFERENT COUNTRIES.**

**GET INVOLVED – SHARE  
THE INDEX WIDELY SO  
THAT IT CAN BE USED AS  
A LOCAL, NATIONAL AND  
GLOBAL ADVOCACY TOOL  
TO SUPPORT THE  
REALIZATION OF RIGHTS  
FOR PEOPLE LIVING WITH  
HIV EVERYWHERE.**



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