



QUALITATIVE RESEARCH TOOLKIT

A guide to support networks of people living with HIV in conducting qualitative research for the People Living with HIV Stigma Index



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INTRODUCTION

Purpose of this toolkit

The People Living with HIV Stigma Index 2.0 is a research process used to gather evidence on how stigma and discrimination impact on the lives of people living with HIV. It involves networks of people living with HIV using a fixed questionnaire to collect quantitative data.

To enrich the evidence that they gather, networks implementing the Stigma Index are also strongly encouraged to undertake qualitative research. This allows them to dig a bit deeper to better understand people's opinions and the personal stories behind the statistics.

This toolkit is designed to support the qualitative research process, in particular to:

- provide guidance for networks of people living with HIV on how to carry out qualitative research as part of their Stigma Index implementation, including practical tools to use in-country;
- ensure that any qualitative research is well-designed, uses rigorous methods, and follows ethical principles;
- ensure that the qualitative research complements the main questionnaire by digging deeper into key areas and priority issues;
- provide guidance to the national networks of people living with HIV to use the findings from their qualitative research for advocacy at country-level.

The toolkit has three main parts:

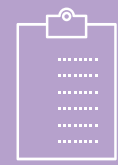
Part 1 provides information and guidance on conducting qualitative research for the Stigma Index.



Part 2 focuses on using qualitative data for advocacy and using it to complement the quantitative data collected.



Part 3 includes templates and sample tools for use during the preparation and implementation of the qualitative research.



About us

The Stigma Index is coordinated by an international partnership of two networks of people living with HIV – the International Community of Women Living with HIV/AIDS (ICW), the Global Network of People Living with HIV/AIDS (GNP+) – and the Joint United Nations Programme on HIV/AIDS (UNAIDS), with support from John Hopkins University. The International Partnership provides technical assistance to networks of people living with HIV that are implementing the Stigma Index.



The People Living with HIV Stigma Index 2.0 explained

The People Living with HIV Stigma Index 2.0 documents how stigma and discrimination impact on the lives of people living with HIV within a country. It was developed to provide much-needed data and evidence to advocate for the rights of people living with HIV.

It is a unique research project that empowers the people and communities most affected by the HIV epidemic, reflecting and supporting the GIPA principle – the Greater Involvement of People living with HIV and AIDS. It was designed to be used by and for people living with HIV so that networks led by people living with HIV are empowered to carry out the whole research

implementation process. The lead network can be any network led by people living with HIV, for example, a network of women, young people or transgender people.

A standard Stigma Index questionnaire is used to gather statistical evidence on the various experiences of people living with HIV within a particular community or country regarding HIV-related stigma and discrimination.

Each research team uses the same standardised questionnaire making it possible to compare the situation of people living with HIV across different countries relating to specific issues, such as access to HIV testing and treatment. Many countries have implemented the Stigma Index more than once enabling them to measure change over time, including whether the situation has worsened or improved.

STIGMA AND DISCRIMINATION DEFINITIONS

HIV-related stigma is when someone, for example a family member, employer, doctor, or someone you know from work or church, views you in a negative way or holds unfair or negative beliefs about you based on your HIV status. Self-stigma is when you have these negatives views about yourself.

Discrimination is when someone treats you unfairly based on those negative views and beliefs.

Intersectional stigma and discrimination are the stigma and discrimination experienced by people living with HIV because of other aspects of their lives or identity for example, their gender. The Stigma Index questionnaire includes specific questions to capture the intersecting layers of stigma and discrimination faced by sex workers, lesbian, bisexual, gay, transgender and intersex people, and people who use drugs.



WHAT'S THE DIFFERENCE BETWEEN QUANTITATIVE AND QUALITATIVE RESEARCH?

Different research methods can be used to answer different kinds of questions.



Quantitative research deals with numbers and statistics so, for example, it can tell us how many people experience discrimination in a certain type of setting. This is important because it gives a general picture of the levels and types of stigma and discrimination faced by people living with HIV in a certain geographical area. What it does not do is answer some of the questions about “why?”.



Qualitative research is useful to understand opinions, experiences and why people act in certain ways. This approach makes it possible to dig deeper into the issues around stigma and discrimination and

understand the stories behind people’s experiences. It gives more insight into the participants’ perspective and makes it possible to explore how social processes, institutions and relationships work.

Qualitative research for the Stigma Index

In the case of the Stigma Index, qualitative research can be useful to:

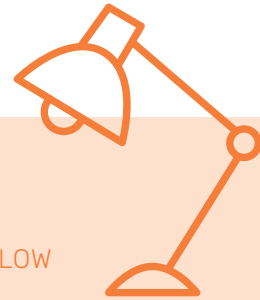
- tell the stories, and highlight in more detail, the experiences of key population or other marginalised population groups;
- gain in-depth information about people’s knowledge, beliefs and views;
- explore context-specific issues and reveal the challenges facing people from populations that do not have specific questions aimed at them in the standardised questionnaire;
- describe variations, relationships, individual experiences, and group norms;
- help improve understanding around intersectional stigma and discrimination;
- shape the development and implementation of national policies to protect the rights of people living with HIV;
- support advocacy for programmes that include interventions to reduce HIV-related stigma and discrimination.

Importance of a “mixed-method” approach

Research teams implementing the Stigma Index are strongly encouraged to use a “mixed-method approach” – in other words, to carry out both qualitative and quantitative research.

The Stigma Index quantitative survey can tell us about where stigma and discrimination exist and who is affected but it tells us little about personal experiences of stigma. In-depth interviews and focus group discussions can provide this missing information and give insights into personal stories of lived stigma and discrimination. Together, the two types of research combine to give a more complete picture of the experiences of people living with HIV in a country. For example, findings from the Stigma Index quantitative questionnaire can show how many people living with HIV have been excluded from family activities because of their HIV status, and qualitative research can explore the impact this exclusion has had on the individual.

On page 6, see an example from Zimbabwe where a mixed-method approach was used to better understand the reasons for low uptake of HIV services.



USING A MIXED-METHOD APPROACH IN ZIMBABWE TO BETTER UNDERSTAND THE LOW UPTAKE OF HIV SERVICES

In 2018, Zimbabwe National Network of People Living with HIV (ZNNP+) and Zimbabwe Young Positives (ZY+) teamed up to conduct community-led monitoring of HIV services using the Community Treatment Observatory (CTO) Model. The CTO model is a mechanism that systematically and routinely collects and analyses both qualitative and quantitative data and has been specifically designed for communities to collect and analyse health data to ensure accountability and to drive change (ITPC, 2019). ZNNP+ and ZY+ conducted 24 focus group discussions and 180 in-depth interviews and observations, focusing on issues such as ART performance and stockouts, viral load uptake services, access to treatment and access to prevention services.

The qualitative measures used provided respondents the opportunity to express themselves in their own words, while providing the research team with an in-depth understanding of people’s views, thoughts and feelings. In addition, the interviews, focus group discussions and observing of verbal and non-verbal cues made it possible to probe, clarify where needed and dig deeper into certain topics and experiences. Complementing the numbers and statistics gathered by quantitative approaches, the qualitative data brought a human side and gave a voice to the challenges identified and was then used to emphasise these issues.

Tonderai Mwareka, ZNNP+

There are a number of benefits to combining the two methods:

- **Qualitative research** can help to interpret the quantitative data and to translate the findings from quantitative studies into specific recommendations.
- **Quantitative data** can test the “generalisability” of qualitative research – for example, whether findings from qualitative research can be applied to other groups or the wider population.
- The strengths of one method of data generation can compensate for the weaknesses of the other, together they increase the validity of the findings.
- The data from the two different research methods can be cross-checked. If there is any discrepancy between the two then this can be explored further to understand the differences.

PART 1: CONDUCTING QUALITATIVE RESEARCH

- 1. Principles**
- 2. Identifying priority issues**
- 3. Determining which method(s) to use**
- 4. Choosing the sample**
- 5. Developing the budget**
- 6. Setting up the research team**
- 7.1 In-Depth interviews**
- 7.2 Focus group discussions**
- 8. Analysing qualitative data**
- 9. Reporting**

1. PRINCIPLES

Throughout the qualitative research process, it is important to follow good practice and ensure that no one is harmed or put at risk. The welfare of participants and their right to self-determination should be the top priority. To achieve this the research process should be ethical and transparent and principles of informed consent, voluntary participation and confidentiality must be respected.

The research team should not only follow good practice but also take into consideration the local context and any challenges associated with it. The approach to the study will need to strike a balance between local issues and non-negotiable research principles.

It is important to follow this guide closely and to conduct the research in a way that is scientifically rigorous and ethically sound, then the research findings will be more credible and trusted.

Ethical approval

In many countries, qualitative and quantitative studies need approval from national and international ethics committees. Time must be allowed to obtain the relevant permission before the research process begins. It may also be necessary to get written permission from

relevant institutions or collaborators such as hospitals or community organisations. When qualitative research is being done alongside quantitative research all the details of both research approaches should be included in one Stigma Index research protocol, which should be submitted for ethical approval.

Informed consent

Participants must be given information about all aspects of the research, including the reasons behind the study, the methods, proposed outputs, and any potential risks. Participants can only give their informed consent to take part in the research if they have understood all this information. They can either give their consent in writing or, if that is not possible, they can give spoken consent.

The requirements for informed consent vary in different settings so you must check the situation in your country with your local ethics committee. You should also obtain specific consent to record the interview. There is a template for an [informed consent form](#) that you can download here. The template has been designed for the quantitative Stigma Index process, so you may need to adapt the text so that it is relevant to your qualitative research.

Confidentiality and data storage

The identity of participants needs to be protected from the start of the study. When recruiting participants, you should consider how much you

need to know about the participants before the selection process begins. Make sure that the data you collect cannot be linked to individuals so that the confidentiality of participants is guaranteed. Data should be kept private, and procedures need to be put in place to restrict who can access the data and in what circumstances.

Supporting participants

As participants are asked to share their personal experiences the interviews can be emotional and difficult. It is important to manage participant's expectations from the beginning and to clearly explain the research process and any support that is available for them. Participants should be given information on how and where to seek social and psychological support and, if possible, be referred to specific services. The study can offer small material or financial incentives to participants for their time. Participants should be thanked for their participation and the results of the study shared with them so they can see the impact of the research.

Quality assurance

Once in-depth interview or a focus group discussion is finished, the good practice is to ask participant(s) for feedback. Asking participants for feedback can identify bad choices, omissions, and strong points, and help you to improve your in-depth interview or focus group discussion technique. It is preferable to ask for anonymous written feedback so participants can freely

describe their experience in a confidential manner. The feedback does not have to follow evaluation forms standards, participants can write their feedback on a clear piece of paper – it is up to the organisation to choose their feedback mechanism.

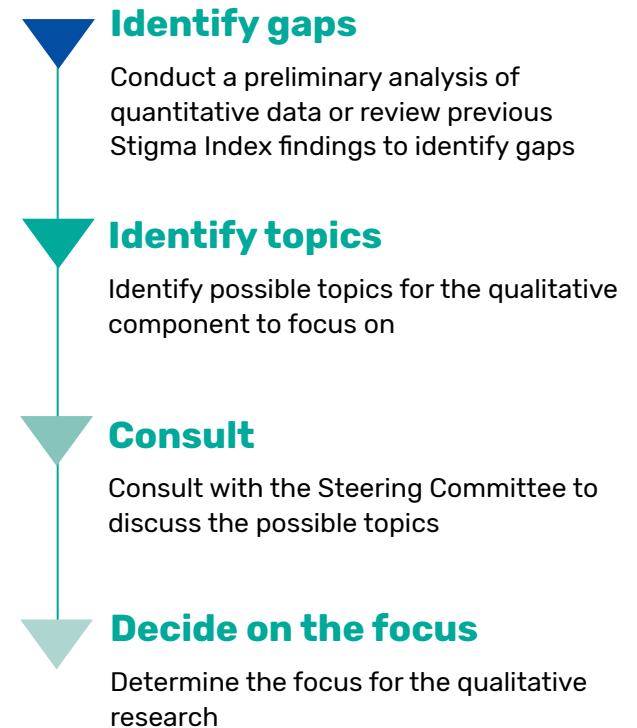


2. IDENTIFYING PRIORITY ISSUES

The questions in the standard Stigma Index questionnaire cover many different aspects of stigma and discrimination. For qualitative research, it is important to narrow down the focus to just a few of these key areas to make it possible to explore them in depth.

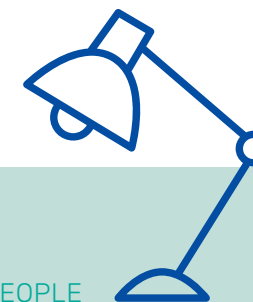
Qualitative research is often used to tell the stories of the people behind the numbers, so looking at the numbers is a good place to start when choosing what priority issues to focus on. Even if all the data has not yet been collected, it is a good idea to review the initial quantitative findings from the Stigma Index to identify gaps that may benefit from a more in-depth exploration using qualitative research. It is also worth exploring the findings from other research exploring HIV stigma, including previous Stigma Index studies.

A few potential topics for qualitative research should be presented to the Steering Committee for their input. The lead network can then share their feedback with the research partner and together they can decide on the focus for the qualitative research and start developing specific objectives and research questions. Once the focus is agreed, the best method for carrying out the research can be chosen – see section 3.



The priority issues that emerge will vary depending on the setting. The table below gives some examples.

Broad areas	Example question
Barriers and challenges accessing services	Are sex workers living with HIV experiencing any specific barriers and / or challenges to access healthcare service?
Behaviour criminalisation	How is criminalisation of drug use affecting access to HIV services for people who use drugs?
Intersectional stigma	What are the similarities / differences in the stigma and discrimination experienced by transgender people relating to their HIV status or their gender identity?
Internalised/self-stigma	How does self-stigma affect the ability of people living with HIV to access paid work?
Improving quality of life	How can reducing stigma and discrimination improve the quality of life of women living with HIV?
Experiences with stigma and discrimination in specific settings	How does HIV-related stigma and discrimination affect discordant couples / your workplace / your family?



QUALITATIVE RESEARCH FOCUSED ON YOUNG PEOPLE

In 2020, Zimbabwe Young Positives (ZY+) conducted a qualitative study into the factors that affect adherence to treatment among adolescents and young people living with HIV.

Through semi-structured in-depth interviews, 350 people living with HIV between the ages of 18 to 35 were interviewed over the phone. ART adherence is known to be a complex issue influenced by many factors so, it was important to use a method that made it possible to collect explanatory data.

The qualitative approach allowed the study team to build a relationship with the respondents so that they felt comfortable sharing their personal experiences, thoughts, and opinions on adhering to treatment. This approach helped researchers to identify the causes of poor adherence to ART. The research also revealed different attitudes towards treatment adherence and the reasons why some people tire of taking their medication. The findings are being used for advocacy purposes and will help to shape future studies.

3. DETERMINING WHICH METHOD(S) TO USE

The two most common methods used to conduct qualitative research for the Stigma Index are in-depth interviews and focus group discussions.

In-depth interviews

An interviewer gathers detailed information through a one-to-one conversation with a participant. In-depth interviews can be particularly useful in certain circumstances:

1. To help explain other data

For example, if the Stigma Index quantitative data shows that people over the age of 50 and living with HIV are less likely to go to hospital than other age groups, interviews can help to find out about their personal experiences and the reasons why they are avoiding healthcare facilities.

2. To identify questions for future research

For example, to prepare to develop a specific stigma survey for older people living with HIV it could be useful to hold individual interviews with a number of people in this age range first. If the interviews showed that many of them had highly stigmatising experiences at school, questions relating to school could be included in the survey.

Advantages	Disadvantages
In-depth interviews	
Learn about individual experiences, opinions and feelings.	The quality of the data depends on the skills of the interviewer.
Good for discussing sensitive topics in private.	Time consuming to conduct the interview and write up the notes.
Provides deeper insight into a person's experiences and opinions.	Difficult to analyse the data from lots of individual interviews and draw out common themes.
Allows time to explore topics in detail.	The data cannot be used as evidence of more general beliefs and behaviours because only a relatively small number of people will be interviewed.
Focus group discussions	
Can be used to understand group dynamics or social norms.	The quality of the data depends on the skill of the facilitator.
Subjects may come up that wouldn't arise in one-to-one interviews.	Some individuals may dominate the conversation.
A good way of quickly clarifying data with a group of people.	Does not allow much time for detailed discussion.
Produces data on a large number of opinions and / or experiences. Provides insights into how opinions are expressed, formed and discussed in groups.	Participants may be guided by the views of others in the group or reluctant to speak openly in front of them.
Can help to discover variety within the target population.	Takes time and effort to set up.

Focus group discussions

A group of normally 8–10 people are brought together and facilitated to have a conversation between them all. Focus groups can be a particularly good method to achieve certain aims:

1. To prompt conversations that may not arise easily in one-to-one interviews

Some people, particularly those from marginalised populations, may not feel comfortable talking about private subjects in an interview with someone they do not know. However, in a group setting with their peers they may open up more naturally. For example, women who use drugs and regularly attend group counselling sessions, may feel more comfortable talking in front of their peers rather than in an interview on their own.

2. To discover how much agreement there is on a specific topic

For example, the Stigma Index quantitative data may have shown that a high proportion of transgender people avoid visiting healthcare facilities. The research team may be aware that a lack of relevant identity documents can be a barrier to healthcare for the transgender community so a focus group discussion could be used to quickly find out from a number of transgender people the extent to which a lack of relevant identification is a problem for them.

4. CHOOSING THE SAMPLE

Once the purpose of the qualitative research is agreed and it is clear what questions the research is looking to answer, the next step is to identify the target population – who to question.

Determining target population

There should be a clear, logical connection between the target population and the objectives of the research. In some cases, there will be an obvious link. For example, if the research is designed to find out why people over the age of 50 and living with HIV are reluctant to visit hospitals, then the target population will be people living with HIV in that age group. However, if the research questions are relevant to the broader population of people living with HIV it may not be possible to narrow down the target population very much.

Usually, the target population is too large to study every member, so the research instead focuses on a sample of the population. A sample is a smaller, representative portion of the population that can be studied to draw conclusions about the whole target population.

The sample should reflect the characteristics and nature of the overall target population. It is important to consider if the sample includes:

- a range of ages
- gender diversity
- people from vulnerable groups (such as sex workers, gay men and other men who have sex with men, people who use drugs, incarcerated people, and transgender people)
- people from rural and urban areas

Sample size and saturation

The next decision is how many people to include in the sample. The aim is to have the smallest number of people possible to be able to draw some broad conclusions about the behaviour, opinions or experiences of the overall target population.

To decide how big the sample should be, it is useful to understand the idea of “saturation”. Saturation point is reached when any new information that is being collected is no longer significantly different to the data that has already been collected. When you reach saturation point you can stop collecting new data. Usually, it would take between 20–30 in-depth interviews to reach this point or 3–5 focus groups of 6–10 participants.¹ These figures are just given as a guide, the only way to know for sure is to analyse

1. van Rijnsoever, F. J. (2017). (I can't get no) saturation: a simulation and guidelines for sample sizes in qualitative research. *PLoS one*, 12(7), doi:10.1371/journal.pone.0181689.

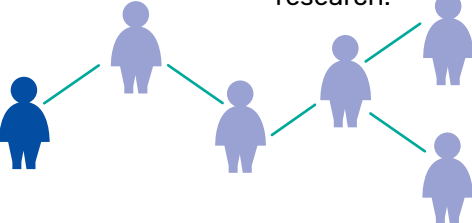
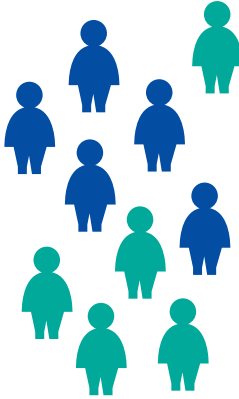
the data as it is collected, then it is possible to stop collecting data when you know saturation has been reached. Sometimes, it is not possible to reach saturation point before data collection needs to stop. Even if this happens the data can still be used, and the study successful.

Throughout the data collection process, it is useful to keep analysing the data as it is collected. The decision on when to stop data collection will not just be about saturation, other factors to consider include:

- Do you have good quality data?
- Do you have the money and resources to continue collecting data?
- Do you have the time to continue collecting data?
- Is the external environment safe enough to continue the research?

Sampling strategy and recruitment

If the target population is large and diverse, it is important that the sample also represents the same diversity. Participants will need to be selected “purposefully” to achieve this. In other words, participants representing a range of individuals from all key populations offering different perspectives and experiences should be included in the sample. There are several ways this can be done. The table here outlines two of the most common.

Type	Definition	When best to use	Limitations
 <p>Snowball sampling</p>	<p>A few participants ask people they know (that meet the sampling strategy criteria / characteristics) to also participate in the research.</p>	<ul style="list-style-type: none"> ● The target population is hard to find. ● Vulnerable populations are reluctant to identify themselves to strangers. 	<p>Participants recruited are likely to have the same characteristics as the participants that recruited them which can lead to a non-representative sample if systems are not in place to address this.</p>
 <p>Quota sampling</p>	<p>Participants are selected because of specific characteristics, like gender identity or HIV status. A sample is made of a set number of people with certain traits. For example, at least five participants who are trans and five who are sex workers.</p>	<p>Ideal when the study aims to investigate the experiences of a specific key population group.</p>	<p>The sampling is not random so it may not represent the target population as a whole.</p>

Once the priorities have been decided, research method chosen, and sampling strategy agreed it is important to obtain the relevant permissions – see information on ethical approval in section 1. Once ethical approval has been granted participants can be recruited.

First you should identify the characteristics that the participants must have to be able to contribute to the research. You need to be confident that you can find enough people that meet your criteria. Work with key contacts from the target group to help you recruit participants. you will need to explain what the research is about and the kind of questions that will be asked and give them details of when and where the focus group or interview will take place. Providing the informed consent forms can help recruit participants as they include much of this information.

5. DEVELOPING THE BUDGET

Budget development will be partly guided by the sample size and the chosen method. When preparing the budget, bear in mind that apart from the usual venue hire and refreshments, you may also need to provide incentives to encourage people to participate such as a meal voucher, supermarket coupon or other discount. Participants should also have the costs of travelling to and from the interview venue reimbursed.

Do not forget to include any costs related to the data analysis in the budget, particularly if this is being done by a consultant and not the lead network implementing the Stigma Index. The Stigma Index [workplan and budget guide](#) can be downloaded here.

Resource mobilisation and fundraising can either happen at the same time as the development of the research methodology or afterwards – it is up to the lead network to decide depending on their local context.



6. SETTING UP THE RESEARCH TEAM

A well-trained team is needed to either conduct the in-depth interviews or facilitate the focus group discussions. Section 7 below outlines the different roles. All members of the research team need to be trained on their role in the qualitative research process before the in-depth interviews or focus group discussions are held.

When recruiting people to the research team it is important to consider their characteristics, in particular their:

- gender
- membership of a key population
- languages spoken
- age
- ethnicity

In some studies, members of the research team will need to speak the local language and understand cultural context. For this reason, it might be preferable to recruit people who come from the country or area where research is taking place. It is also important to choose people who will be trusted by the study group and who will be able to create a relaxed environment where



participants feel comfortable speaking freely. For instance, you may want a female facilitator to lead a focus group for women or you may choose a sex worker to conduct in-depth interviews with other sex workers.

Environment for data collection

It is important to find a time and place for the interviews / focus groups that allows participants to relax and feel safe and comfortable. You should also consider whether the target population has any specific needs and be sure there are no barriers preventing people from taking part, for example, you may need to provide childcare. Consider the daily lives of participants – you may need to adjust timing of the interviews to fit people's work routines and timetables. For example, some people may prefer to meet at night to make it easier to come and go without being seen. Section 7 has further information about practicalities and the set-up of the interview space.



“The quality and skills of interviewers are of utmost importance when conducting qualitative research. In addition to communication skills and knowledge about HIV, it is extremely important for the interviewer to have strong interviewing skills and an understanding of research indicators. For any qualitative research led and conducted by the community, we need to invest more in the quality of the data collectors, especially because there isn't any standard questionnaire for interviewers when doing qualitative interviews, so the quality of the data we expect to collect will depend a lot on the interviewers.”

Dong Do Dang, VNP+, Viet Nam

7.1 IN-DEPTH INTERVIEWS

In-depth interviews provide an opportunity to build a relationship of trust between the participant and the interviewer. Each interview should take the shape of a conversation. It does not always need to be fully structured, but the interviewer should still follow the interview guide.

Preparing for the interviews

This table shows the three types of interviews you can choose from. Your choice will depend on the aim of the research. When researching a new topic or trying to gain an in-depth understanding of the topic, a less structured approach is best. To understand people’s experiences of lived stigma and discrimination, we recommend using semi-structured interviews as this allows for some level of comparison, but also leaves room to probe more deeply and to hear about an individual’s experiences.

Developing an interview guide

Once the type of interview is chosen, an interview guide should be written to help the interviewer organise their thoughts and keep the interview on track. The guide should include a header to record essential information including the date,

Type	Description	Advantages	Disadvantages
Structured interview	Questions are fixed, pre-determined and asked in the same order.	<ul style="list-style-type: none"> ● Comparable data ● Less time consuming 	<p>Provides less freedom to explore experiences in depth</p> <p>Does not allow people to speak freely as they would in a more natural setting</p>
Semi-structured interview	There is a list of questions to cover, but there is flexibility to rephrase them to suit the understanding and vocabulary of the respondent.	Similar data can be gathered from all respondents	As above
Unstructured/narrative/in-depth interview	The interviewer has a broad topic guide with a list of questions and subjects to cover but the conversation is guided by the priorities of the respondent.	Useful to draw out the views and priorities of respondents	<ul style="list-style-type: none"> ● Time consuming ● Risk of “drifting away” from the main topic

time, location, interviewer name, and interviewee name. The interview questions can follow this section, with enough space in between them for the interviewer to take notes. These questions may vary depending on the stakeholder or type of interview being conducted. At the end there should be a section with closing comments to prompt the interviewer to thank the participant for their time and to provide follow-up information if necessary. An in-depth interview guide is available to provide further guidance, see page 28.

The interview guide should be translated into local languages if necessary. Any translated documents should be tested to make sure they are accurate and effective.

Conducting the interview

The success of in-depth interviews depends on the interviewer building a relationship with the participant that allows them to speak frankly and feel safe and secure. The interviewer should create a comfortable environment where the participant can open up about their lived experiences. The interviewer will need to be aware of the participants feelings and if necessary, adapt to different emotions. Interviewers should also be encouraged to share their own experiences to make participants feel at ease and encourage

the participant to speak up. Interviewers should always use non-judgemental language, avoid technical language or jargon and adapt their body language to the conversation so that participants fully understand the that questions asked and are able to respond.

Practicalities

A safe and private location should be chosen for the interviews. Somewhere that is not associated with HIV and where participants can be protected from onlookers and passers-by. If the budget allows, it may help if interviews are held in a location away from the participant's home village or city.

The venue will need toilet facilities and a separate room for the interview with two comfortable chairs, a table and some refreshments for the participant. The interviewer should have either a voice recorder or a notebook and a pen to take notes during the interview. Immediately following the interview is the best time for the interviewer to summarise the key data, while the interview is still fresh in their mind. Some of the information provided during interviews may need to be verified and it is useful to have the participant's contact details in case there are any future queries.



7.2 FOCUS GROUP DISCUSSIONS

Preparing the focus group guide

Each focus group involves gathering a group of people together to discuss certain issues, with guidance from a facilitator. A focus group guide needs to be developed for each focus group. These guides should list the questions or issues to be explored and organise the topics into a structure for the facilitator to follow. The questions should be open-ended and non-leading so that they encourage conversation.

Some tips for developing topic guides:

- Start the discussion with an introduction where you assure participants of confidentiality and remind them about the aims of the research, length of the focus group and arrangements for data storage.
- You may want to introduce an ice-breaker exercise so that participants meet each other.
- If one person is dominating a discussion, you might want to break the pattern using phrases like these:
 - Has anyone else had this experience?
 - Thank you for contributing. Do other people feel as strongly?

The guides should be translated into local languages if necessary and the translation tested for accuracy. A focus group discussion guide is available to support you, see page 30.

Setting up the research team

Each focus group will need a facilitator and a note taker who may also record the discussion, if necessary, make sure the equipment is working, meet and greet participants and organise refreshments. Sometimes these roles may be shared between more than one person.

It is important to choose the right facilitator to moderate focus group discussions, someone with the following characteristics:

- Excellent interpersonal skills to run discussions
- Ability to inspire confidence in others
- A good judge and interpreter of group dynamics
- Empathetic but not judgemental
- Ability to make participants feel respected
- Ability to keep the discussion focused without driving it

Conducting the focus group discussions

Each focus group should include between 6 and 10 participants and last for approximately 1-2 hours. If the focus group is going to be recorded, all recording equipment (video or audio) should be

checked in advance and permission needs to be obtained from participants. This can be done using the [informed consent form](#).

Usually, the discussion begins with the facilitator explaining the purpose of the focus group and any ground rules. The facilitator should then follow the focus group guide and bring up different topics. At the end of the discussion, the facilitator should thank everyone for participating and ask for closing statements. The note taker is responsible for keeping detailed notes, including recording what individuals say and any important non-verbal gestures.

Practicalities

The research team will need to prepare the venue. This includes setting up the furniture in a way that makes sure there are no barriers to communication and everyone can see each other, perhaps in a circle. They may also need to provide some refreshments and if possible, a secure, outside space for people who want to smoke. You may need to buy some specific equipment such as recording equipment, flip charts and markers and any materials needed for the icebreaker or other exercises.

As outlined in section 6, the venue must be secure, making it possible to respect participants' confidentiality. You should be sure to record all the participants' contact details in case you have any future queries.

8. ANALYSING QUALITATIVE DATA

Although qualitative studies usually have a small sample size that may not represent the general population, the data they generate can still lead to deeper understanding and give useful insight into particular parts of the populations, such as different key populations.

In qualitative research, analysis should happen throughout the data collection process so that the research team can see what themes are emerging and assess when saturation point is reached and the study can be completed (see section 4). By continually analysing the data it is possible to see new theories emerge, suggest collecting new data or refine the topic guide.

After each interview or focus group, the interviewer / note taker should write up some general reflections, the main topics discussed and any new topics that came up. They should also write up the interview / discussion either as a word-for-word (verbatim) transcript, field notes, and / or a simplified summary. For verbatim transcripts, every element of language should be noted – breaks, hesitations, and figures of speech specific to the participant(s) – so that the transcript is accurate. To protect participants'

confidentiality, transcripts and field notes must not contain any names, just the codes or references.

The aim is to then analyse the data collected in the interviews and focus groups by grouping the participants' experiences, opinions and feelings into themes. This type of thematic analysis is ideal for the Stigma Index, as it organises data into themes and sub-themes following a pre-agreed framework making it possible to identify any issues that commonly emerge in interviews / discussions. How the framework is created will depend on what data is already available. For example, there may be data from a previous Stigma Index, other studies, scientific articles, publications etc. that can give an idea of the types of themes that are likely to emerge. Although it is not essential, conducting some form of a literature review of this data is a helpful starting point. Having a pre-agreed framework also makes it easier to check whether the themes that emerge during the interviews / discussions match the themes that are described in the literature review, and whether there are any areas missing.

As the data is collected, and patterns of key themes emerge, it is useful to translate the themes into codes, making it possible to measure how often themes and patterns occur. This analysis can be done using Word or Excel or using specialist analysis software such as ATLAS.ti or NVivo.



There are three stages to the thematic analysis:

1. Initial coding: This involves changing the raw data into codes by giving labels to parts of the text that reflect key ideas. It is a repetitive process where the researcher repeatedly marks up the text to refine the coding.

A list of codes related to the research question is developed before data collection begins – this list of codes can come from the literature review. In the example in the table, these codes are used:

Code 1: Fear of stigma

Code 2: Parental acceptance

Code 3: Parental rejection

Code 4: Lack of financial resources

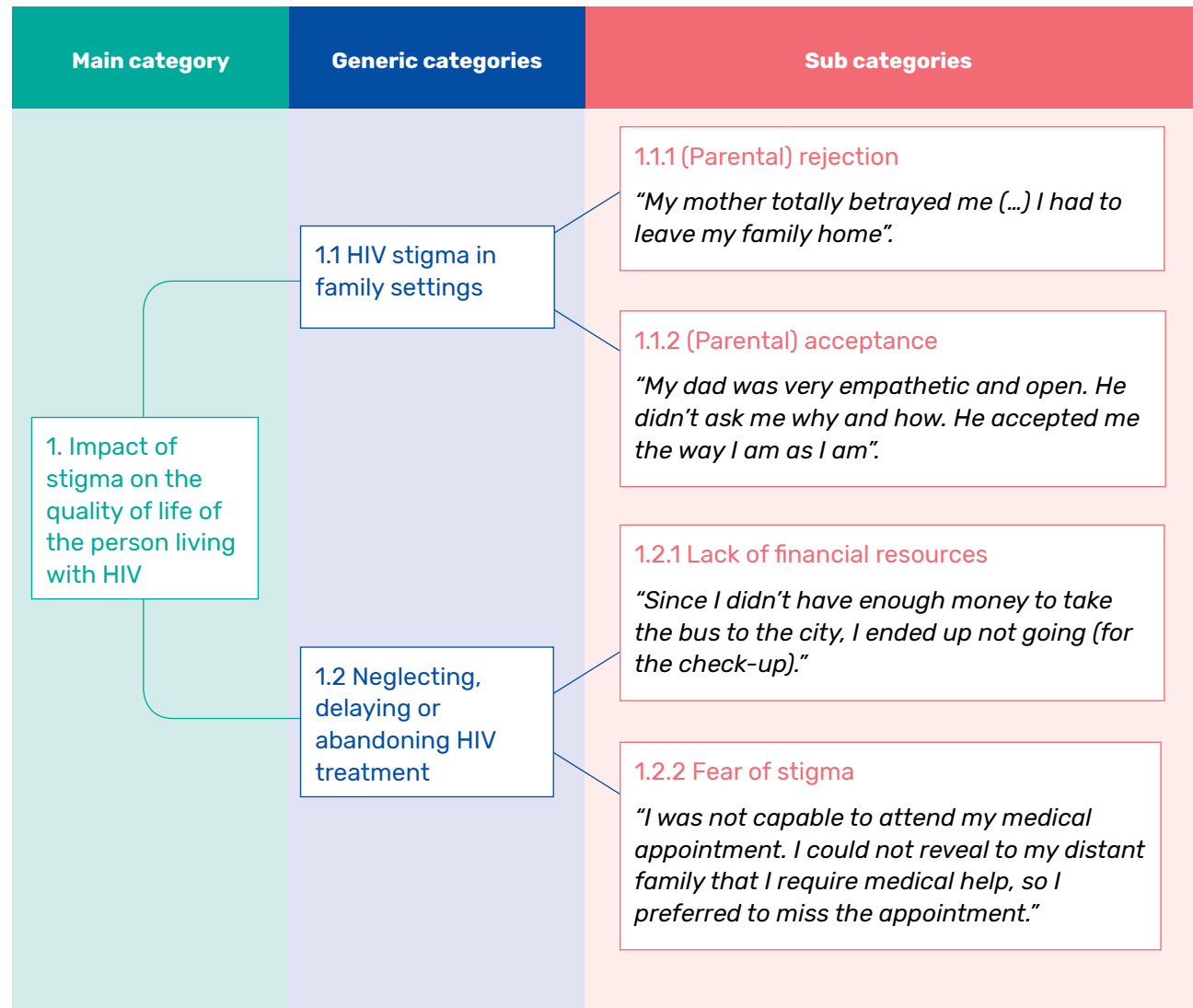
The table shows two examples of how codes could be applied.

Question	Response	Code
1. Has anything prevented you from seeking HIV treatment? If so, what?	Person A. <i>Once, we had a distant family staying with us for a week. As I am the head of the family, I was not capable to attend my medical appointment. I could not reveal to my distant family that I require medical help, so I preferred to miss the appointment. I was too scared my distant family would gossip about me and cause me trouble with other family members.</i>	1. [Fear of stigma]
	Person B. <i>There was a period of my life when I didn't have enough money to support myself. I was already on ARVs, but my doctor asked me to come for the check-up. Since I didn't have enough money to take the bus to the city, I ended up not going. Luckily, the pharmacist in our village knows me and agreed to give me my medication without the prescription so I could continue the treatment. Once I found additional source of income, I was able to see my doctor.</i>	4. [Lack of financial resources]
2. What have been your experiences with disclosing your HIV status to family members?	Person A. <i>I am a single child; thus, I was really scared to come out to my dad. I was really scared of rejection and loneliness. Thank God, my dad was very empathetic and open. He didn't ask me why and how. He accepted me the way I am as I am his only child and he doesn't want to lose me. I felt so relieved.</i>	3. [Parental acceptance]
	Person B. <i>I come from a traditional family in a rural area. I have never thought about revealing my HIV status to my family; however, I have been blackmailed by a nurse in my health facility that if I do not tell my family about my HIV status, she would do so. I didn't have anything to lose at this point. I approached my mum, as I hoped she would be understandable and accept me as I am, but I was wrong. My mum totally betrayed me and ran to my father to tell him that I brought shame on the whole family. My parents always associated HIV infection with prohibited activities. In the end, I had to leave my family home.</i>	2. [Parental rejection]

2. Categorisation: Codes are classified into sub-themes, themes, and general categories making it possible to connect the codes, find patterns, and interpret the data. Each of the codes should be named, it is also useful to provide a definition and description of the code so it is easy to assign text to the code.

The diagram shows an example of categorisation.

3. Coding: As new data is added from later interviews / discussions, the established codes may need to be adapted – the system needs to be flexible so that new categories and sub-categories can be included and any categories that overlap or where there is duplication can be removed. The key headings from your coding scheme may be used to form the sections of your report.



9. REPORTING

Once the data has been collected and analysed the findings need to be written up. Remember, the research team will also have the quantitative data from the Stigma Index research. The findings from both sets of data should be combined to make up the final Stigma Index report.

The methodology section of the report should explain the reason for using a mixed-method approach and describe both the qualitative and quantitative methodologies that were followed. It should also include the reasons for choosing the themes for the focus group discussions and the in-depth interviews. The section of the report that analyses the findings should include analysis of both sets of data – quantitative and qualitative. If possible, both should be analysed together under each different themes. For data that requires specific attention (for instance if the qualitative study had a specific focus on a certain population or region) a separate section can be added to the report.

The results section should begin with the quantitative findings from the main Stigma Index tool – the questionnaire – and then present the qualitative findings. The qualitative results section should describe the themes and trends that came out of the qualitative research. Quotes from the qualitative research can be used to illustrate the findings but it is important that these quotes never contain any information that could potentially reveal the identity of a participant. You may want to use a quote to provide a concrete example of a theme that came up many times or alternatively, to highlight unique experiences, emphasising that while most people have a certain experience, it is not the same for everyone.

The report should finish with a recommendations section, to provide concrete recommendations based on the evidence gathered by the study. This is critical so that the evidence you have gathered can be used to advocate for improved practices, policies or laws and to reduce stigma and discrimination.

Click here to download a [final report template](#).



PART 2: USING QUALITATIVE DATA FOR ADVOCACY

About the process

Presenting the findings

Briefing papers

Face-to-face testimonies

Broadcast media

Opinion-editorial articles

Social media

About the process

Qualitative data can be a powerful advocacy tool, providing vital context and illustrating the lived experience of people living with HIV in a way that can deepen our understanding of experiences of stigma and discrimination. Quotes and stories lift the data off the page, making the links with real people. Good qualitative data gained from in-depth interviews and focus group discussions strengthens the Stigma Index findings and creates added opportunities to inform, educate and persuade key audiences from government officials to healthcare providers.

To make the most of the qualitative data, an advocacy strategy should be drawn up with clear advocacy goals and target audiences. Your advocacy strategy will need to focus on the recommendations that you make in the report summarising the findings from both the quantitative and qualitative Stigma Index research. You may not have the time and resources to actively campaign on all the recommendations so you will need to decide where to focus your energies and think about what change you can realistically hope to achieve. See adjacent graphic for the key steps to follow – an [advocacy toolkit](#) is available to download with more detail to guide you through this process.



Review

What needs to change?



Convene

What are the most urgent issues to address?

Who are your partners and allies?



Map

What are the key opportunities, targets and goals?



Plan

What are the key dates, activities and costs?

Presenting the findings

Findings from qualitative research can be presented in many different ways for advocacy purposes. The advocacy strategy should outline how the data will be used with each audience and provide a plan to ensure that the key messages reach their targets and have the greatest possible impact. Decisions on how to present the qualitative data will depend on the country context. Below are a few examples:

Briefing papers

Specific findings from the Stigma Index can be used to develop a briefing paper that is designed to influence policy on a particular issue. For example, it could be about a key population (sex workers, young people etc.), certain geographical settings (a particular health facility or a city or region) or specific issue (such as experiences of forced sterilisation). A briefing paper could present research findings as evidence, outline how existing policies or regulations apply to the issue and make recommendations on what can be done to improve the situation. Quantitative data is important to show the extent of the problem and qualitative data can



be used to add in quotes or short examples that illustrate the impact on real people's lives.

Face-to-face testimonies

It is always really powerful to hear about stigma and discrimination directly from the people affected by it. Many people do not want to talk in public about their experiences for all kinds of reasons, however, some people are comfortable sharing their experiences. If any of the research participants are willing to talk publicly then you could ask them to participate in some of your advocacy events – such as face-to-face lobbying meetings, or public community meetings. Their contribution can have a big impact, but it is very important that they are given clear information in advance about who they will be speaking to and what their role will be so that they know exactly what to expect.

Broadcast media

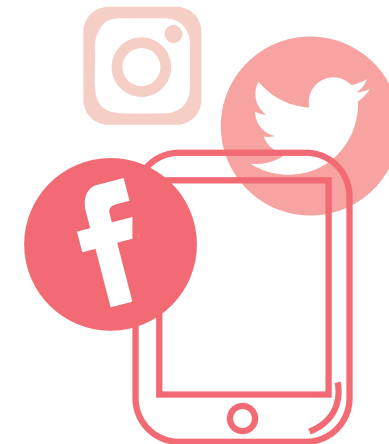
Personal testimonies can be a very useful way of increasing media attention – this again can help to ensure your findings and recommendations are heard more widely. The participants' experiences of stigma and discrimination can be shared through videos, television spots, radio programmes etc.

Opinion-editorial article

Networks of people living with HIV can use examples from the qualitative research as the basis for articles that they write and try to place with the media – in a newspaper, magazine, journal or online. This is a useful way of reaching out to a broader audience about HIV-related issues.

Social media

Most networks of people living with HIV have their own communication channels (Facebook page, Twitter account, website, blogs etc.). Mini case studies, quotes and examples from the qualitative research can be shared through these channels to raise awareness of the issues and to make the case for policy and programme change.





CONCLUSION

We hope this toolkit provides networks led by people living with HIV with the knowledge and confidence needed to complete qualitative research into stigma and discrimination in their country. We strongly believe that the People Living with HIV Stigma Index benefits from a “mixed method” approach with both quantitative and qualitative research undertaken so that the findings contribute not just data but a greater understanding of the lived experiences of people living with HIV.

The research process has been designed to empower communities of people living with HIV and we hope the research findings will be used to make policies and programmes more effective at eliminating the stigma and discrimination experienced by people living with HIV in all their diversity.



PART 3: TEMPLATES AND TOOLS

- A. [Workplan and budget guide](#)
- B. [Template: Informed consent form \(quantitative\)](#) – can be adapted to fit the qualitative research needs
- C. In-depth interview guide
- D. Focus group discussion guide
- E. [Final report template](#)
- F. [Advocacy toolkit](#)

C. IN-DEPTH INTERVIEW GUIDE

This guide to in-depth interviews is designed for researchers studying the stigma and discrimination experienced by people living with HIV in their everyday lives. It should be adapted to local circumstances and priorities.



Introduction

At the beginning, make sure you discuss each of these areas with the participant:

- Thank them for participating.
- Explain what the interview will involve. Let them know that you have some set questions to ask and give them an idea of how long the interview will last.
- Explain the context. This interview is part of a larger Stigma Index study where a number of people living with HIV have responded to a questionnaire about their experiences of living with HIV within family, community and health settings as well as disclosure and stigma experienced for reasons other than HIV status.
- Outline why you are conducting in-depth interviews.
- Tell them why you will be recording the interview.
- Reassure them that their responses will be confidential and explain that anything they say will only be used anonymously.
- Give them an opportunity to ask questions.
- Make sure you obtain their informed consent before you begin.

Here is an example of what you can say;

“Hello and thank you for taking the time to take part in this research project. My name is _____ and I would like to talk to you about your experiences as someone living with HIV.

This interview should take _____ mins/ hours and will be recorded. This is to make sure that I don't miss any of your thoughts and comments. I will also be taking notes while you speak, please don't think I'm not paying attention to you.

Your participation in this study and everything you tell me today will be kept confidential. Any information you give me will only be shared with the other researchers on this project and all information will be anonymised, so that your name and any defining characteristics are removed. You don't have to tell me anything you don't want to or that makes you uncomfortable and you can end the interview at any time.

Do you have any questions about what we will be doing today before we continue?

Do you agree to participate in this interview?”

If they agree to participate, you then ask them to sign a consent form.

Questions

- Don't ask more than 15 questions
- Try to encourage the participant to share facts with you not just their opinions.
- Use probing or follow up questions to gather more information and encourage the conversation to flow.
- If possible, use open-ended questions (ones where participants cannot simply answer yes or no).

The actual questions you ask will depend on your research question. These are examples of questions relating to the impact of HIV stigma on access to care:

- Can you explain to me what you understand as stigma? What does it mean to you?
- Have you ever visited a health facility / hospital / or doctor of any kind to receive HIV-related services or information?
- Can you describe your last visit to me? Did you go to a government clinic, health centre or hospital or a private doctor or clinic?
- Have you ever felt you experienced stigma in a healthcare setting because of your HIV status? Could you describe what happened?

- During your visits to health facilities, do you feel comfortable enough to ask questions? Is there enough privacy? Could you describe what makes you feel that way?
- What about your mental health? Can you think of a time when stigma has stopped you accessing mental health services?
- Do you know someone else living with HIV who has experienced stigma in a health facility that stopped them from seeking treatment or care? Can you share their experience with me, while respecting their privacy, so do not tell me their name?
- What would you like to see changed in HIV services, laws or policies to remove HIV-related stigma in healthcare settings?
- Can you think of any way that stigma has had a positive impact on your day-to-day life?

Closing

- Ask them if they have any additional or final thoughts they would like to share.
- Tell them what will happen now with the information they have given.
- Thank them again for participating.

Here's an example of how you can end the interview.

“Thank you again for taking the time to speak with me today. Is there anything else you'd like to add about your experiences living with HIV? Do you have any other questions about the research?”

I'll be going over the information you have given me during this interview and submitting a report to my organisation in the coming months. I would be happy to send you a copy of the finished project, if you'd like.

Thank you for sharing your experiences with me today.”

Expenses and follow up

A list of referral services should be available for participants so that they know where they can get additional support locally (whether that is social, psychological, financial etc.).

If the participant has had to travel to the venue for the interview their travel costs should be reimbursed. They can also be given a token of some sort to thank them for their time, for example a voucher, supermarket discount or some other coupon. This is not essential and will depend on the budget available and the local context.

D. FOCUS GROUP DISCUSSION GUIDE

This discussion guide is designed to help you run a focus group discussion with people living with HIV to discover more about their views and experiences of HIV-related stigma and discrimination in their day-to-day lives.

Introduction

- Introduce yourself (the facilitator) and the note taker and explain your roles. The facilitator guides the conversation, and the note taker will write down what is said.
- Explain the context. This focus group discussion is part of a larger Stigma Index study where a number of people living with HIV have responded to a questionnaire about their experiences of living with HIV within family, community and health settings as well as disclosure and stigma experienced for reasons other than HIV status.
- Then introduce the specific topic for this focus group and explain why the participants were selected.

Language

For the purpose of the focus group discussion, it is important that everyone has a shared understanding of the different concepts that will be discussed so take time to explain the meaning of the different terms:

- **HIV-related stigma** is when someone, for example a family member, employer, doctor, or someone you know from work or church, views you in a negative way or holds unfair or negative beliefs about you based on your HIV status.
- **Discrimination** is when someone treats you unfairly based on their negative views and beliefs.
- **Intersectional stigma and discrimination** are the stigma and discrimination experienced by people living with HIV because of other aspects of their lives or identity for example, people who are marginalised because of their gender, gender identity, age, sexual orientation or involvement in sex work or drug use.
- **(HIV) Internalised stigma** is when a person living with HIV has negative feelings or thoughts about their HIV status. For example, internalised stigma can lead to thoughts such as: "I am ashamed of my HIV status", "I sometimes feel guilty / worthless because I am HIV-positive".

Expectations and setting

Run through any practicalities and your expectations for the session.

- Tell participants that you will be recording the session and explain why.
- Ask participants to turn cell phones off or put them on silent mode.
- Explain that there will be a refreshment break halfway through when participants will have the opportunity to make a quick phone call, go to the bathroom, etc.
- Encourage participants to ensure that only one person speaks at any time.
- Ask everyone to be respectful and listen even to those they disagree with.
- Make clear that there are no right and wrong answers, only different points of view.
- Explain to participants that they can leave the room at any time if they feel uncomfortable.
- Ensure everyone has given their informed consent before you begin.

Starting the group discussion

Here is an example of how you could begin the focus group discussion:

“Hello everyone and welcome to our session. Thank you for taking the time to join us to talk about your experiences living with HIV. My name is _____ and assisting me is _____. We're both with _____ [your local organisation]. We are here to gather some information from local people about your day-to-day lives living with HIV. We'd like to know about what hardships you may face, how it's affected your relationships with friends and family, and how you've been able to access healthcare and cope with your diagnosis, among other things.

You were invited because you indicated in our screening process that you are diagnosed with HIV, you have experiences that we are keen to learn about, and you all live in this region.

There are no wrong answers so please feel free to share your point of view even if it differs from what others have said. Keep in mind that we're just as interested in negative comments, sometimes they can be the most helpful to learn from. If, at any time you feel uncomfortable you can leave the room.

You've probably noticed the recording device. We're recording the session so we don't miss any of your comments. People often say very helpful things in these discussions and we can't write fast enough to get them all down. If you want, during this discussion you can use an initial or a fictional name instead of your real name. I can assure you that we will guarantee complete confidentiality. We will never use any names in our report. Where we do use quotes from the discussion they will be anonymised.

Does anyone have any questions, or are you happy for us to begin? Let's find out some more about each other by going around the table. Tell us your name and an interesting thing about yourself.”

Asking questions

- Try to use open-ended questions (ones where participants cannot answer yes or no).
- Ask questions that require the participant to think back to a time in their life or a specific event.
- Try to encourage the participants to share facts not just opinions.
- Use probing or follow up questions to gather more information and prompt further discussion.
- Don't ask more than 15 questions.



The actual questions you ask will depend on the exact focus of your research. Here are a few example questions for a FGD studying people's experiences accessing care:

- Could any of you describe a time that you felt stigma because of your HIV status in a healthcare setting? What about the rest of you, do you have any similar experiences you would like to share? Are there any of you that have never experienced stigma because of your HIV status in the healthcare settings?
- Are there any specific measures in place at your health centre to protect your privacy and put you at ease? For example, do you feel comfortable enough to ask questions? Does anyone have a different experience?
- What about your mental health? Can you think of a time when stigma prevented you accessing mental health services? Can someone else share their experience?
- Do you know of someone else living with HIV who has experienced stigma in a health facility that stopped them seeking treatment or care? Can everyone share one story about one of their peers? Do remember to respect their privacy so don't tell us their name.
- What would you like to see changed in HIV services, laws or policies to remove HIV-related stigma in healthcare settings?
- Has anyone had an experience where stigma has had a positive impact on your day-to-day life? Can you describe it to us?

Closing

- Thank everyone for their time and participation.
- Ask for any additional thoughts and comments.
- Tell them what will be done with the information.

Example of closing words:

“Thank you again for taking the time to speak with me today. Is there anything else you'd like to add about your experiences living with HIV? Do you have any other questions about the research?”

I'll be going over the information you have given me during this interview and submitting a report to my organisation in the coming months. I would be happy to send you a copy of the finished project, if you'd like.

Thank you for again for sharing your experiences.”

Expenses and follow up

A list of referral services should be available for participants so that they know where they can get additional support locally (whether that is social, psychological, financial etc.).

REFERENCES

Balard F, Kivits J, Schrecker C, Voléry I. (2016) L'analyse qualitative en santé in *Les recherches qualitatives en santé*. Armand Colin.

Caitlin K. *Qualitative Methods*. June 2012. [PowerPoint slides].

Durand MA, Chantler T. (2014) *Principles of Social Research*. Open University Press.

Family Health International (2005) Module 3: In-Depth Interviews in *Qualitative Research Methods: A Data Collector's Field Guide*. Available from: <https://www.fhi360.org/sites/default/files/media/documents/Qualitative%20Research%20Methods%20-%20A%20Data%20Collector%27s%20Field%20Guide.pdf>

ITPC (2019) *The Community Treatment Observatory (CTO) Model Explained: How communities can collect and analyze health data to ensure accountability and drive change*. Available from: <https://itpcglobal.org/wp-content/uploads/2019/02/ITPC-CTO-Model-Full-Eng.pdf>

Martínez-Mesa et al. (2016). Sampling: How to Select Participants in my Research Study? *An Bras Dermatol*. 2016 May-Jun; 91(3): 326-330. doi: 10.1590/abd1806-4841.20165254.

Owczarzak J. *Qualitative Research Methods for Implementation Science*. [PowerPoint slides].

Silva S. and Fraga S. (2012) Qualitative Research in Epidemiology in *Epidemiology - Current Perspectives on Research and Practice*. doi:10.5772/32986.

van Rijnsoever FJ. (2017) (I can't get no) saturation: a simulation and guidelines for sample sizes in qualitative research. *PloS one*, 12(7), doi:10.1371/journal.pone.0181689.



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