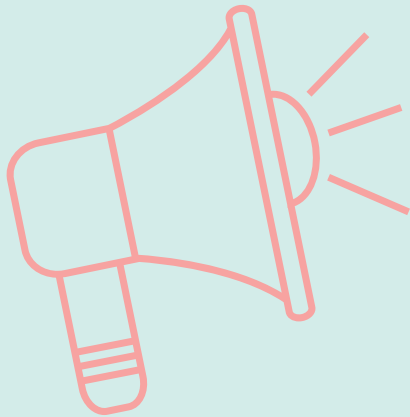


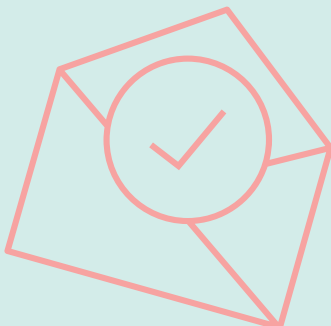
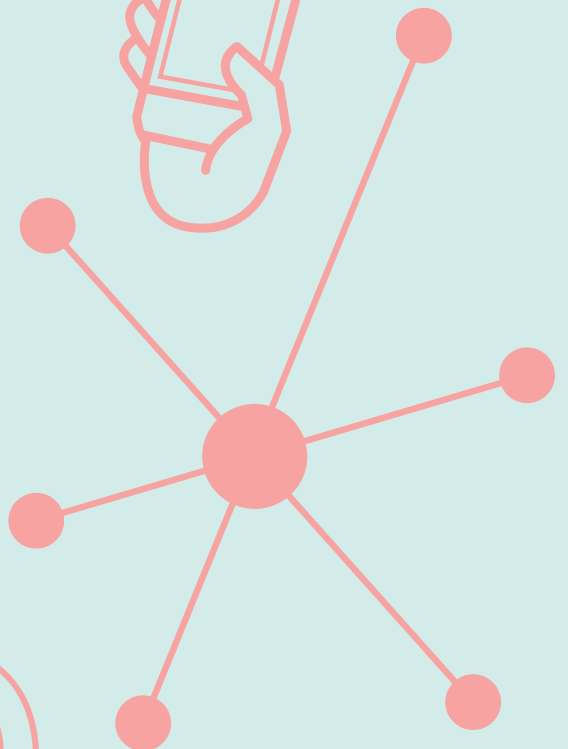
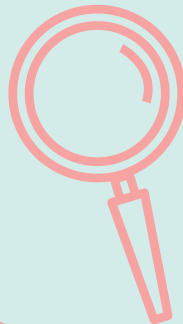


THE
PEOPLE
LIVING
WITH HIV
STIGMA
INDEX



IMPLEMENTATION GUIDELINES

A handbook to support networks of people living with HIV to conduct the People Living with HIV Stigma Index 2.0



Acknowledgements

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Design: Jane Shepherd

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Introduction

Who are these guidelines for?

These guidelines are designed to steer networks of people living with HIV (see box) through the process of implementing the People Living with HIV Stigma Index 2.0 in their communities. It provides the information needed to support them to use the Stigma Index to gather data on the stigma and discrimination experienced by people living with HIV in their country and to use that data to advocate for change.

About us

The Stigma Index is coordinated by an International Partnership of two global networks of people living with HIV – the International Community of Women Living with HIV (ICW) and the Global Network of People Living with HIV/AIDS (GNP+) – and the Joint United Nations Programme on HIV/AIDS (UNAIDS). 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 Stigma Index documents how stigma and discrimination impact the lives of people living with HIV within a country. It is a unique research project that empowers the people and communities most affected by the HIV epidemic. With the Stigma Index, the implementation is just

WHAT IS VERSION 2.0?

In 2018, the People Living with HIV Stigma Index 2.0 was launched to respond to shifts in the HIV epidemic and the global response. Throughout these Implementation Guidelines the latest Stigma Index 2.0 is referred to as simply, the Stigma Index.

as important as the actual results – the whole process should be guided by four key principles:

- 1. Capacity building** – The lead network is expected to guide the entire implementation process, but it is not left to do this on its own. It is encouraged to work in collaboration with partners in country (such as research institutes) and technical assistance is available at every step of the way from the International Partnership.
- 2. Accountability and ownership** – The Stigma Index centres around the GIPA principle, the Greater Involvement of People Living with HIV/AIDS. People living with HIV are not only the interviewers and the participants, but the entire research design and implementation process is led by and for people living with HIV. Local network(s) of people living with HIV decide for themselves if they would like to



PEOPLE LIVING WITH HIV TAKE THE LEAD

It is essential that the Stigma Index implementation is led by and for people living with HIV. The lead organisation throughout the entire process should be a network led by people living with HIV. This could be any network – including networks of women, young people or transgender people – that is led by people living with HIV in the country where the research is taking place. Throughout these guidelines they are referred to as the “lead network”. In some countries it may be appropriate to form a consortium of networks to implement the Stigma Index together.

conduct a Stigma Index in their country and the experiences and knowledge of people living with HIV are at the centre of the whole process.

- 3. Embracing equality and diversity** – Whichever network takes the lead, all those involved in the implementation process should pro-actively work to ensure gender equality and to embrace the diversity that exists among the whole community of people living with HIV.
- 4. Advocacy-oriented** – The data that is gathered through the Stigma Index enables a clear picture of stigma and discrimination to emerge. It also provides evidence for advocacy to shape policy and programmatic change and end HIV-related stigma and discrimination.

First developed in 2008, the Stigma Index has been implemented in more than 100 countries with over 100,000 people living with HIV participating in the process. At the heart of the Stigma Index research process is a standardised questionnaire that is used to measure stigma and discrimination experienced by people because of their HIV status.

The latest questionnaire (Stigma Index 2.0) has been expanded to enable a better understanding of how different groups of people living with HIV are affected by stigma and discrimination including key populations (see box). It now gathers data on the experiences of people who are marginalised because of their gender, gender identity, age, sexual orientation or involvement in sex work or drug use.



STIGMA AND HIV

Stigma and discrimination are some of the biggest barriers to tackling HIV.

The HIV epidemic is fuelled by myths and misinformation that in turn lead to stigma and discrimination. People who experience stigma or discrimination become increasingly marginalised and are less likely to access health services.

At the same time groups of people who are already discriminated against and marginalised by society are those most at risk of contracting HIV.

KEY POPULATIONS

The term “key populations” is used in these guidelines to refer to the following groups of people:¹

Gay men and other men who have sex with men – this includes men who self-identify as gay as well as men who do not, yet who have sex with other men.

Sex workers – people of any gender who regularly or occasionally consent to receive money or goods in exchange for sexual services.

Transgender people – anyone whose gender identity and expression are different to social expectations based on their sex at birth. This can include people who consider themselves to be male, female, gender non-conformist or elsewhere on the spectrum of gender identities.

People who use drugs – people who use psychoactive substances that are not medically approved. This includes people who have previously used drugs in this way.

1. All definitions are taken from UNAIDS (2015) Terminology Guide 2015 or INPUD (2019) Drug Users’ Terminology: Community Quick Reference Guide.

Each time the same standardised questionnaire is used 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, for which groups of people, and in what settings.

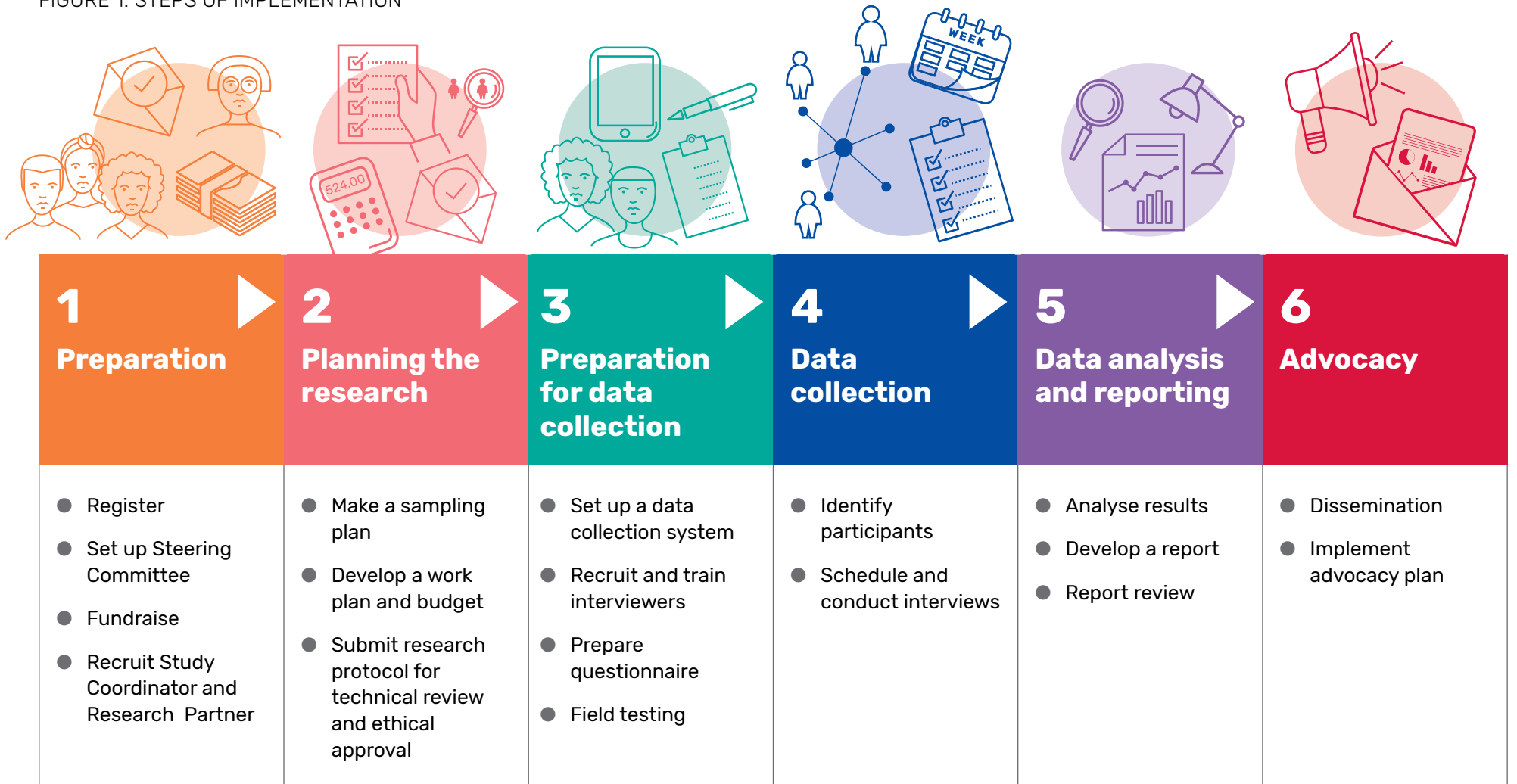
Once the Stigma Index has been implemented within a country, the findings can then be combined and compared with other surveys that explore HIV-related stigma and discrimination from different perspectives, such as health care providers or the general community. Together they increase our shared understanding of these issues.

The six phases of implementation

These implementation guidelines are divided into six main sections, each focused on a separate phase of the implementation process – preparation, research protocol development, preparation for data collection, data collection, data analysis and reporting, and advocacy. See Figure 1.

It is important to read through all the guidelines before beginning any of the processes. The guidelines run through each phase in the order they are most likely to be completed but it is possible to work on several steps at the same time, or to follow a slightly different order. Also, some of the steps towards the end of the guidelines need to be kept in mind at the beginning of the process to make sure they are included in the workplan and budget. For example, some idea of the advocacy strategy is needed to be able to include it in the budget and ensure that there is enough money to pay for this essential part of the process.

FIGURE 1. STEPS OF IMPLEMENTATION



PHASE 1: PREPARATION

1.1 Register

1.2 Seek support

1.3 Consult with key stakeholders and partners

1.4 Develop a work plan and fundraise

1.5 Set up a Steering Committee

1.6 Recruit a Country Coordinator

1.7 Recruit a Research Partner



A key principle of the Stigma Index is that the planning and implementation is led and owned by local people living with HIV, so it is important that each step in the preparation phase is carried out by the lead network. This does not mean that they work entirely on their own, they can draw on expertise from consultants and will have access to advice and technical support throughout the process. The lead network must involve networks of women living with HIV and young people living with HIV where these exist in the country and are strongly advised to also work with other key population networks.

1.1 Register

To begin the implementation process, a [People Living with HIV Stigma Index 2.0 intake form](#) needs to be completed and emailed to plhivstigmaindex@gnpplus.net. The form is available on the Stigma Index website. It is essential to complete this first step to be able to access all the available tools and support and to ensure the final report is recognised as officially part of the Stigma Index.

Attached to the intake form is a list of “non-negotiable principles” that any network wishing to implement the Stigma Index is expected to follow. This includes ensuring that the implementation is led by people living with HIV and using the standard questionnaire for the research. The full list of non-negotiable principles can be found [here](#).

Finally, the lead network will also need to sign a [Data Sharing and Usage Agreement](#) at this stage.

1.2 Seek support

The International Partnership provides technical assistance for the Stigma Index during the planning and implementation process.

This includes support with:

- Initial planning
- Research protocol development
- Ethical approval
- Training of interviewers
- Data collection and data storage
- Data analysis
- Report development
- Advocacy planning

The International Partnership can be contacted by email at plhivstigmaindex@gnpplus.net

1.3 Consult with key stakeholders and partners

The lead network must consult with key stakeholders and potential technical and financial partners in the local area, region, or country where the research will take place, to introduce the Stigma Index research study and:

- Clarify the roles that each partner can play in the process.
- Develop a set of shared principles for the implementation partners and Steering Committee. The principles should be collectively discussed and agreed upon and should include things like inclusivity, transparency, power sharing, consensus driven decision-making, and equity. It may also be useful to make a commitment to self-reflection or self-transformation around pre-existing biases to ensure that the Stigma Index process does not reinforce harmful norms around gender, race, ethnicity, religion or membership in a key population. Developing an agreed set of principles or even a Memorandum of Understanding between partners will ensure that everyone can engage equitably in the process.

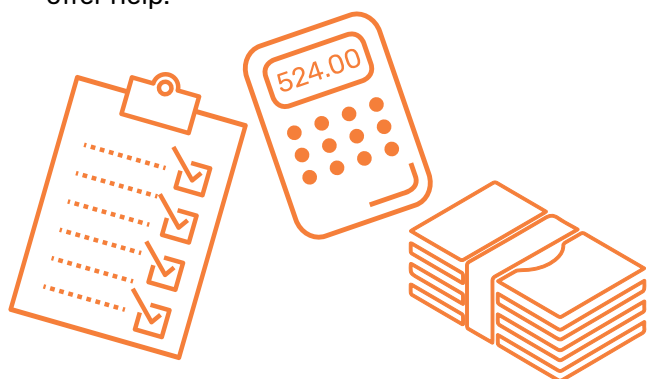
- Discuss what resources are available for the research and how to access any additional resources that are needed. Ensure that all partners are supported to play an effective role in the implementation.
- Agree to timelines and a mechanism to keep key stakeholders and partners informed about the progress of the research.

1.4 Develop a work plan and fundraise

Funding is needed to cover the costs of the implementation process. The lead network will need to work with the Steering Committee to identify possible funders and put together funding applications. A good funding application should be based on a detailed workplan and budget. The work plan should include each of the steps in the research process and specific dates for when they will happen, and the budget should also be detailed including the costs for every stage. In order to develop these plans, at least some of the planning process will have to begin, for example steps 2.1 (deciding on the geographical scope of the study) and 2.2 (making a sampling plan).

Any funding applications may need to be based on a draft workplan and budget. Once funds are secured, the lead network can begin work, as different stages of the process are completed, such as finalising the sampling plan, it may then be necessary to go back and revise the work plan and budget.

Templates for both the workplan and budget are available from the International Partnership and the UNAIDS country office may also be able to offer help.



The budget should cover every part of the implementation process:

- Training
- Research
- Data analysis
- Report writing
- Dissemination
- Advocacy

Once funding has been secured, systems should be put in place to make sure that the funds are managed well and can be accounted for transparently.

1.5 Set up a Steering Committee

It is important to include a wide range of stakeholders to ensure they support and engage with the Stigma Index process and findings. The Steering Committee will help to formalise partnerships with national stakeholders and to make sure that the national authorities who implement the AIDS response in country are positively engaged.

The following groups should be invited to join the Steering Committee: networks of young people living with HIV, networks of women living with HIV, key population networks, networks of people living with HIV, UNAIDS, National AIDS commissions, research organisations, legal and human rights groups, and local community-based organisations that provide services to people living with HIV. It is important to ensure that networks of key populations, young people living with HIV and women living with HIV are encouraged and supported to engage in the Stigma Index leadership as they are often underfunded at country level.

The main role of the Steering Committee is to make sure that the Stigma Index is implemented correctly and to ensure that the evidence gathered is used to advocate for improved

policies, programmes, and practices. There is a [Terms of Reference](#) available to guide the Steering Committee in its work.

1.6 Recruit a Country Coordinator

A Country Coordinator should be appointed to lead the implementation process and liaise with the Steering Committee. The Coordinator should be someone from a network of people living with HIV who can build a good working relationship with key stakeholders to encourage them to follow principles of accountability, transparency and mutual respect. There is more information on their role in the [Country Coordinator Terms of Reference](#). It is important to ensure that the selection process for the Coordinator is transparent, accounts for gender and other biases, and encourages young people, women and people from key populations to apply and be considered for the role.

1.7 Recruit a Research Partner

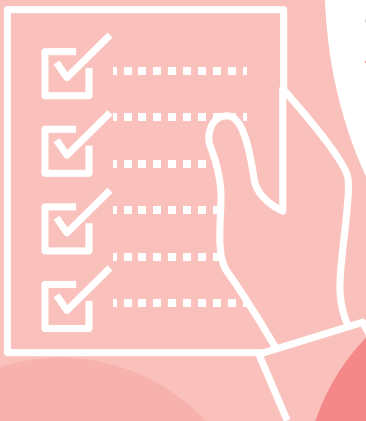
This is an important role. A Research Partner is needed to give support on all the technical aspects of the research process. Whether it is an individual researcher or someone from a university or research institute, ideally, they should have experience of working with communities and developing inclusive research processes that reflect gender equality and engaging key populations. The Research Partner should support the lead network to build its capacity and develop research skills. For more information, see the [Research Partner Terms of Reference](#).



COLLABORATIVE WORKING

The lead network should work with all the partners in country to develop a shared set of principles to guide their work together. This could include guidelines on issues such as transparent power sharing and consensus driven decision-making. Throughout these guidelines the lead network and key partners (including the Country Coordinator and Research Partner) are referred to as the country team.

PHASE 2: PLANNING THE RESEARCH



2.1 Decide on the areas to study

2.2 Develop a sampling plan

2.3 Decide on data collection method

2.4 Adding country-specific questions

2.5 Consider conducting qualitative research

2.6 Submit protocol for technical review

2.7 Ethical review

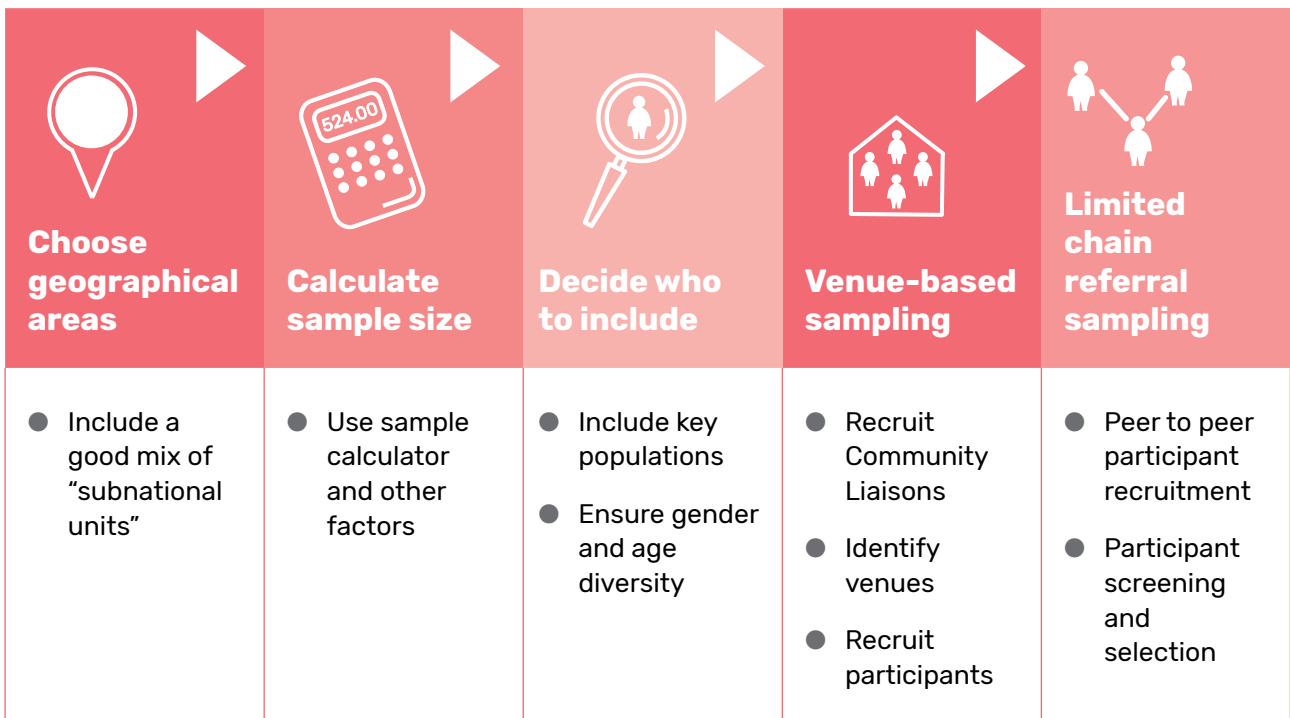
A research protocol has to be developed - this is a complete description of the research. It acts as a guide for everyone involved in the study to follow throughout the process and it is used to help monitor the progress and results of the research. There is a [Research Protocol Template](#) available to help. The template outlines the key sections that must be included in the protocol and gives guidance to ensure that the research follows the standardised Stigma Index methodology. However, the template is just a guide, the research protocol should be designed to meet the requirements of the national ethics committee.

WHAT IS "STANDARDISED" METHODOLOGY?

The Stigma Index uses a "standardised methodology", with an agreed set of standard methods and principles that must be followed by any country that implements it.

Using the standardised methodology strengthens the overall quality of the Stigma Index programme and allows comparisons to be made within the same country across time and across different settings.

FIGURE 2. PLANNING THE RESEARCH



2.1 Decide on the areas to study

Each country has “Subnational Administrative Units” (SNU) – this is the name for the units that provide health care. They may be provinces, districts, regions, or other geographical areas. The research protocol should explain in detail which SNUs are included in the study and why they have been selected.

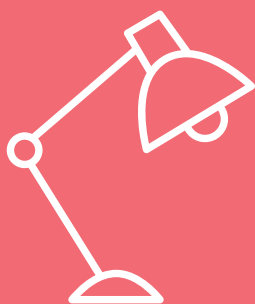
- If possible, the SNUs selected for the study should include more than half the total population of people living with HIV in the country. However not all those people will be interviewed, just a sample from each SNU will be asked to participate. If data is not available to show where people living with HIV live, then the study should instead include SNUs that cover 50% of the total adult population. This information is usually available from the latest census. A good mix of SNUs should be included in the study, so, for example, even if most of the population is based in urban areas,

the study should still include at least one SNU that covers more rural populations. It is also important to think about the nature of the HIV epidemic and which communities are most vulnerable. It is useful to consider areas with:

- the highest burden of HIV
- existing community structures for people living with HIV and key populations
- previous stigma data for comparison
- focused HIV prevention and treatment programmes
- higher than average numbers of people from key populations or migrants

2.2 Develop a sampling plan

A sampling strategy outlines the number and type of people to interview. Developing the plan can be quite complicated but the Research Partner will be able to give valuable guidance and the



CASE STUDY: VIET NAM

The Viet Nam Network of People Living with HIV (VNP+) began implementing the Stigma Index for the third time in 2020. Due to changes in the HIV epidemic and responses in Viet Nam over time, they decided when they were developing the research protocol to add two provinces that were not included in previous studies. Unlike the other provinces, these two do not benefit from large project-funded interventions, so their inclusion will make it possible for VNP+ to get a broader picture of stigma and discrimination across settings with different levels of donor support.

As recommended, they have based their sample size on the proportion of participants in the last Stigma Index who reported avoiding healthcare due to anticipated stigma. They have also used data that is available on the distribution of new HIV infections among key populations in Viet Nam to help decide how many people to interview in each province. By doing this, they hope to get a thorough understanding of the intersecting layers of stigma and discrimination experienced by key populations.

International Partnership (plhivstigmaindex@gnpplus.net) can also offer advice. In some cases, researchers from a local university or research institute may be brought on to the country team to help with this stage.

Decide on the sample size

To support networks to work out how many people to interview, there is an online Stigma Index sample size calculator. The calculator and guidance on how to use it, are available [here](#).

The calculator uses data from a previous Stigma Index to calculate appropriate sample sizes. In places where there has not been a previous Stigma Index, global and regional estimates from the UNAIDS data hub can be used instead or the International Partnership can suggest what data to use.

The calculator is a helpful tool but there are always several possible sample sizes. The country team can decide on the most suitable sample size for their implementation by using the calculator and considering other factors such as resource availability, human capacity, time frame for the implementation etc. Once the country team has decided on the sample size, they should inform the International Partnership who will then check that it is appropriate.

Who to include

Everyone who takes part in the study (the “study population”) must be living with HIV. Research shows that, across all settings, key populations consistently experience a disproportionate burden of HIV, so the following groups must be included in the sample:

- Gay men and other men who have sex with men
- Sex workers of all genders
- Transgender people
- People who use drugs of all genders

It is important that there is gender and age diversity among the study participants. Women and young people living with HIV must be well represented and depending on the country context other vulnerable populations should be included in the sample such as migrants and people who were incarcerated.² It is a good idea to include definitions of the key populations in the study as well as any other vulnerable populations that the team has decided to prioritise so that everyone in the country team has a shared understanding of exactly who is eligible to participate (see the box on page 6).

To be **included** in the study, participants must be:

- ✓ 18 years of age or older (or the age of majority in your country)
- ✓ Aware that they are living with HIV for at least 12 months
- ✓ Able to speak one of the languages being used for the questionnaire
- ✓ Able to provide informed consent, i.e., understand all elements of the study

People **cannot be included** in the study if they:

- ✗ Have already participated in the current study
- ✗ If they are not living with HIV, even if they are from a key population.

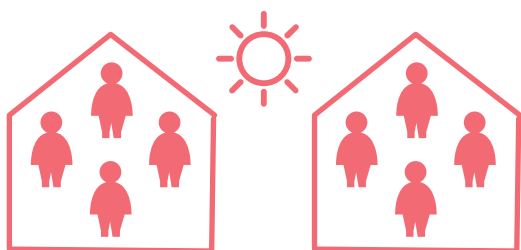
2. For ethics reasons, we do not encourage the inclusion of people who are currently incarcerated. Information about stigma and discrimination in prisons and closed settings can be shared by those previously incarcerated and recently released.

Sampling strategies

Once the geographical area and sample size for the study are fixed, a sampling strategy needs to be chosen to find study participants. A combination of two approaches is recommended - venue-based sampling and limited chain referral sampling.

Venue-based sampling

This method focuses on reaching participants in the places and at the times where they gather. Participants are recruited at sites that people living with HIV are likely to visit including treatment facilities, community centres, association/network offices, etc. This approach can be combined with proportional sampling - also known as probability proportional to size (PPS) - which ensures that the number of participants recruited at any specific venue is proportional to the total number of people who visit that venue.



Recruit Community Liaisons - Community Liaisons are recruited to help identify the venues where interviews will take place and to recruit people living with HIV to participate in the research. It is important that the Community Liaisons have a good relationship with networks of people living with HIV and key population networks. They should be chosen based on their knowledge and experience of working with diverse groups of people living with HIV. They will need to help build connections with the national networks for people living with HIV, women living with HIV, young people living with HIV, key populations and other relevant non-governmental organisations (e.g., community outreach workers working in HIV prevention, sexual health or adolescent health).

IMPORTANT CONSIDERATIONS

- At least 25% of the sample must be made up of people living with HIV from key populations.
- Depending on the number of possible venues and the country setting, approximately three-quarters of participants should be recruited using venue-based sampling and about one-quarter using the limited chain referral sampling approach.
- As participants are enrolled into the study, regular checks should be made to be sure that the sample is diverse. If needed the sampling strategy can be adjusted to increase recruitment of populations that are underrepresented. This could involve changing the types of venues used for venue-based enrolment or identifying people with access to specific populations to recruit participants using limited-chain referral enrolment
- The International Partnership can give advice on sampling during the protocol development and as interviews begin.

Venue identification - It is important to choose venues that are visited by the populations to be interviewed. Most countries have data showing which venues are attended by people living with HIV and/or key populations. This data can be used to create a database of venues. With support from the Community Liaison and their local knowledge of community-based support and treatment facilities, the database can be updated to make sure it only includes venues that are currently visited by people living with HIV and key populations who are eligible to participate in the study. It may also be possible to identify new or additional venues to add to the database.

Venues that are not related to healthcare should also be included in this approach, for example

popular meeting places (hot spots) and drop-in centres. In some settings, for example more social gatherings at clubs or community centres or venues where people living with HIV are in the minority, it may be necessary to ask the owner / manager / social gatekeeper to help to identify and recruit participants.

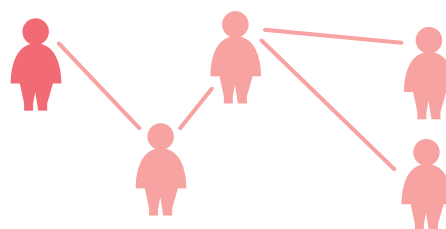
Participant recruitment – When interviewers arrive at the venue, they will have a set number of interviews that they need to complete. They will directly approach potential participants according to a pre-set plan (for example, every third person waiting in line) to assess whether they are interested and eligible to take part in the research. The interviews can be conducted then and there, or alternatively recruited participants may be invited to attend their interview at an agreed place on a later date. Before the interview takes place, the study staff should explain the study and ask if the person would like to participate. If they agree, the interviewer must obtain informed consent before holding the interview. See the [Informed Consent template](#).

During the interviewer training, the country team will explore appropriate and confidential ways to approach potential participants in their setting.

Limited chain referral sampling

Limited chain referral sampling method is used to recruit participants for the study who are less likely to be reached using the venue-based approach, such as people who are not receiving HIV care or members of certain key populations. The country team will decide in advance which populations to prioritise. This method relies on people sharing information about the research project with people they know. People who have participated in the study themselves or people who are well connected to the communities the study is trying to reach are selected. They are given three to six cards with contact details for the project and asked to give them to people they know who are living with HIV, available for interview and who belong to the priority target populations, such as people not in care or members of specific key populations. As the cards

are only distributed to people who they know privacy issues are minimised. Over the course of the study, the characteristics of people who are interviewed should be tracked so that this method can be used to recruit people from any groups that are underrepresented.



The cards give the study office and contact phone number but not the eligibility criteria or the focus of the study. The study coordinator then screens all the people who get in touch and selects who to interview. When the study staff talk to a potential participant for the first time, they explain the study and ask if they would like to participate. If they agree, the interviewer must obtain informed consent before holding the interview.

2.3 Decide on data collection method

All data entry is done by the interviewers and/or team leaders in collaboration with the Research Partner. Specific systems must be put in place and explained in advance.

The country team will have to decide whether to use a paper-based or digital data collection method, or a combination of the two. The chosen method should be described in the research protocol.

Digital data collection using tablets is recommended. The International Partnership provides access to a digital platform called REDCap that is used for the data collection process and as a database (see step 3.1 for more information). The data can be entered on to the system as it is collected making it quick and easy to analyse at any point. The country team can choose to collect data with a different platform, but the dataset must still be uploaded to REDCap

later as this is the global database that holds all the data for the Stigma Index.

Although digital data collection is advised, the country team can choose paper-based data collection instead. In this case, after each interview the answers to the questionnaire have to be entered into the REDCap database via the internet. The REDCap platform can then be used to create a database which can be downloaded in different formats for analysis.

2.4 Adding country-specific questions

It may be useful to ask extra questions to find out more about issues that are relevant to the local setting. These questions could collect more information about intersectional experiences of stigma or discrimination, for example exploring gendered aspects of stigma and discrimination or specific aspects of discrimination and stigma experienced by members of key populations. If any questions are added to the questionnaire, they must be in line with the overall objectives of the Stigma Index. Local networks and the Steering Committee should be consulted and if they agree then the additional questions must be sent to the International Partnership for approval. It is important to know that the standard questions **cannot be removed or changed in any way** and the order of the questions needs to remain the same. If any extra questions are added, they must be in a separate section, at the end of the standard questionnaire.

2.5 Consider conducting qualitative research

The Stigma Index questionnaire is used to conduct quantitative research. This means it measures numbers and statistics, so, for example, it can tell us how many people in the study report discrimination in a certain type of setting. This is really useful 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.

To get a deeper understanding of the context, perspectives, and impact of stigma on people, qualitative research can be useful. This approach makes it possible to dig a bit deeper into the issues around stigma and discrimination and understand the stories behind people's experiences. A combination of both quantitative and qualitative research gives a more in-depth understanding of the lived experiences of people living with HIV. There is a [toolkit](#) available to help guide organisations wanting to conduct qualitative research as part of the Stigma Index implementation in their country.

2.6 Submit protocol for technical review

The draft research protocol must be submitted for technical review by the International Partnership and experts at John Hopkins University. There are a minimum of two rounds of review to ensure that the research protocol complies with the standard methodology.

2.7 Ethical review

As the study collects personal information about individuals, the country team needs to apply for ethical approval, this is often done by the Research Partner. After the technical review process has been completed, but before any data is collected, the research protocol will need to be submitted to the national ethical review board or equivalent body. It is important to check when and how frequently the review board gathers so that this schedule can be taken into account when drafting a timeline for the research process. The application will usually involve submitting various other relevant documents alongside the research protocol, such as an informed consent form, [information sheet](#) etc.

PHASE 3: PREPARATION FOR DATA COLLECTION



3.1 Set up a data collection system

3.2 Translate the questionnaire

3.3 Recruit interviewers

3.4 Train the interviewers

3.5 Referral and follow-up

3.6 Prepare interview venues

3.7 Field testing



3.1 Set up a data collection system

The country team need to set-up a data collection system (paper-based or digital) including arranging a secure way to transport data from the field and a safe place where the data (including the participant's contact details and the code list) can be stored.

To collect data electronically, the REDCap mobile app is available from the Stigma Index secretariat for free. With REDCap, data can be collected offline (without an internet connection) using a tablet or mobile device. It can then be uploaded onto the secure REDCap server when an internet connection is available. The app makes it easy to store and synchronise the data and is available in many languages including English, French and Russian. It can be used on Android 4.3 or later (for mobile phones and tablets) or iOS 6.0 or later (for iPhone 4 and up and iPad 2 and up). [A training guide](#) on using REDCap for digital data collection is available.



3.2 Translate the questionnaire

The questionnaire, information sheet and consent forms will need to be translated into the local language(s). It is essential that:

- The translations for key concepts - including stigma and discrimination - are discussed and agreed upon in advance by the country team and the network(s) of people living with HIV involved in the project. There needs to be a shared understanding of these terms among the interviewers.
- The questionnaire and other documents are then “back-translated” into English by someone other than the translator to be sure that the meaning of each question is as close to the original as possible. This is important so that results can be compared across and within countries.

Before arranging for a questionnaire to be translated, it is important to check with the International Partnership if the questionnaire is already available in that language.

Interviewers should not translate on the spot from English into national or local languages while they are conducting an interview. This can lead to different variations of the questions from one interview to the next, making the findings unreliable. For the same reason, interpreters cannot be used. Having an interpreter sit in during an interview is a risk to the confidentiality of the participant and the overall setting.

3.3 Recruit interviewers

The lead network should recruit interviewers. They must all be people openly living with HIV and there should be diversity among the team, including people from key populations, young people and women. They must be 18 years or older, fluent in the dominant language of the area and prepared to participate in the interviewer training.

3.4 Train the interviewers

The interviewers (and others involved in the interview process) will need to be trained to conduct the interviews and understand the background and overall goals of the Stigma Index. The lead network should run the training with support from the Research Partner. Training is not just important to make sure that the results from the survey are reliable, but it is also one of the overall objectives of the stigma index – capacity-building. The training should take place over at least three days to allow enough time to teach the interviewers practical skills and give them an opportunity to make sure they understand the key concepts related to the Stigma Index. The International Partnership can give feedback and guidance on any training plans. There is interviewer training guidance [here](#).

The lead network must work with the whole country team to agree the roles and responsibilities that each team member will play in the research process. Everyone who is involved in the research, individuals and any service providers, will also need to sign a [confidentiality agreement](#).

3.5 Referral and follow-up

The questionnaire includes a section on referrals and follow-up. A formal referral service following the interview is not advised – it would be a lot of extra work for the country team. However, interviewers often want to offer support to the people they interview, so this section of the questionnaire formalises the process a little and gives them some information about agencies or resources that they may find useful.

Before starting any interviews, the lead network should develop a list of local organisations they feel could meet the needs of people living with HIV. This may include psychosocial, medical, or other similar services.

- Each interviewer can make a list of appropriate contacts for their area before beginning the interviews. These can then be combined to

make a detailed local resource list with the names and contact details of organisations that can support people living with HIV.

- If a participant asks for advice during the interview, the interviewer should give the local resource list. They should not provide advice themselves unless they are professionally qualified to do so.
- If the interviewer is asked for a referral and they do not have the relevant contact on the list, they should agree to provide the information after the interview. Somebody within the team will need to be responsible for following up in these cases – the team leader may be the best person to do this. It is important to check with the participant that they are happy to be contacted with the referral information.

The interviewers have a responsibility to the person they are interviewing. If the participant seems to need medical, emotional or legal support (even if they are not aware of this themselves) the interviewer has a duty to suggest they seek help, particularly if the participant's wellbeing is at risk. During the training process, interviewers will need to be shown what to look out for during the interviews and how to deal with any concerns. In these cases, the interviewer should follow the process recommended above, providing contacts from the local resource list if possible and if not, providing details after the interview or getting permission for the team leader to follow-up. With all referrals, once information and contacts have been given to the participant, it is up to them to follow-up.

3.6 Prepare interview venues

The team leaders will need to decide on the best location for the interviews. It is important that there is privacy for the participants and that they feel supported by the interviewer throughout the process. The interviewer should put the participant at ease. It may help if they avoid sitting opposite the participant and instead are more informal, sitting close enough for the conversation to flow freely. Sitting side by side may allow the

participant to see their answers being recorded. This can be helpful for building trust by showing the participant that only their answers are being entered and there are no separate comments that the interviewer is entering without their knowledge.

It is important to be flexible about the venue to make participants feel comfortable and to encourage them to take part. Some people might want to be interviewed at a place they know where they receive medical or other care, such as a drop-in centre or community centre. Others might prefer a location that is only known to the interviewer and participant.

Depending on the setting, it may be simpler to have a fixed site for the interviews (and ask participants to come to the site) or to conduct interviews at the recruitment venues themselves. Certain venues may be more suitable, especially if they have separate and closed spaces where the interviews can be held in private.

3.7 Field testing

The country team should field test the questionnaire and other data collection systems. This is a trial run where interviewers carry out practice interviews to make sure the process works. After the field tests, the interviewers should come together to share their experiences and resolve any difficulties they may have faced. The research process may need to be adapted, for example, procedures may need to be clarified or some questions may need to be rephrased to make them easier to understand.



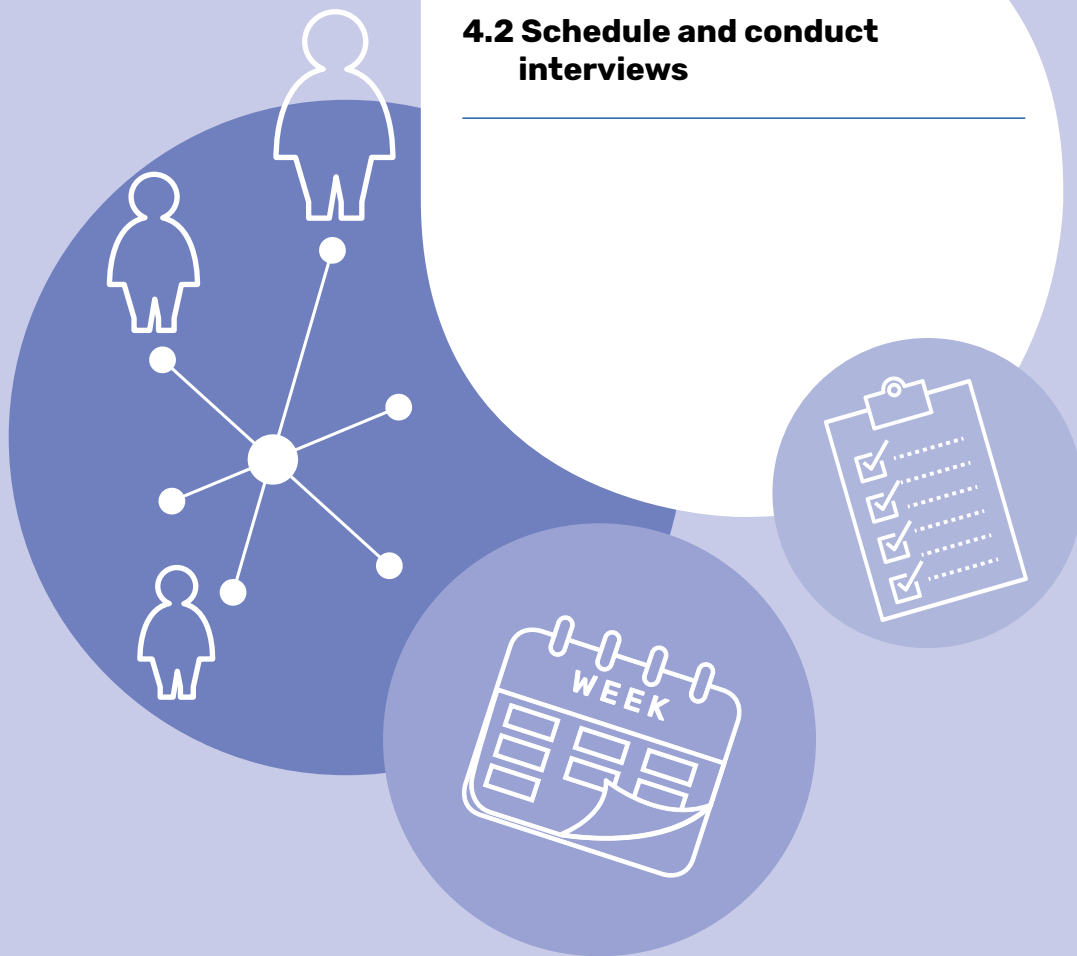
PUTTING SAFETY FIRST

The health and, safety of everyone involved in the research process – interviewers and participants – must be a top priority. The team leader should be careful when selecting venues for interviews to make sure that security can be guaranteed. They should also think about every other step of the process to consider any safety or confidentiality concerns – whether that is the risk of participants being identified, the way the interview is conducted or the method of data collection. Safety planning also includes respecting any health regulations that are currently in force in the country and considering the individual needs of each person involved.

PHASE 4: DATA COLLECTION

4.1 Identify participants

4.2 Schedule and conduct interviews



4.1 Identify participants

The team leaders will need to follow the sampling plan to recruit and select participants.

4.2 Schedule and conduct interviews

It is best if the interviewers book interviews in advance. This way there is less chance of losing potential participants if, for example, people come to a drop-in centre and there are long waiting times. However, some drop-in sampling can still be useful particularly to reach certain key groups.

The simplest way to maintain privacy is to hold individual interviews in private. There is also the option of interviewing some people in workshops or group meetings. This is appropriate as long as:

- There are enough interviewers to provide support; and
- The workshop/group facilitators are able to create private spaces for participants to answer the questionnaire.

Throughout the interviewing process, team leaders will need to regularly track the data to make sure that there is a good mix of participants. For example, it may become clear that very few people from a specific key population have been interviewed. If this happens, the sampling strategy will need to be adjusted so that extra efforts can be made to target the underrepresented populations. This could include conducting additional interviews in venues where the specific key populations are known to gather or simply giving more business cards to participants from that specific key population to hand out to their peers.

A detailed checklist with all the steps needed to prepare for and conduct each interview can be found [here](#). It is important to remember the country team may also be doing qualitative research as part of the study. This might include in-depth qualitative interviews with participants as well as focus group discussions. The [qualitative research toolkit](#) gives more guidance.

IMPORTANT CONSIDERATION

People from certain key populations or communities may not want to be interviewed by their peers. For example, in a pilot study in Senegal, some men who have sex with men preferred not to be interviewed by other men who have sex with men.

Some people might be 'out' about their sexual orientations, but not about their HIV status or the opposite. When participants are being recruited, it is best to ask them who they would feel most comfortable talking to and provide them with options.

PHASE 5: DATA ANALYSIS AND REPORTING



5.1 Analyse results

Once all the data from the research has been entered (both qualitative and quantitative), the country team can begin to analyse the results. This includes looking for recurring themes across the study sample and trying to understand and interpret the findings. The country team will need to use this analysis to produce a report with the key results from the Stigma Index and recommendations for the future.

Section A of the questionnaire asks participants questions about their age, gender identity, education, work status etc. Sections B-F focus more on their experiences of stigma and discrimination when accessing health services. If the answers to the two sections are compared some connections may appear, for example between someone's age and their access to services, or between their gender identity and experience of verbal or physical abuse.

It is important to be able to look at the data for specific groups. This 'disaggregated' data can tell us a lot about the diversity of the lives, experiences and needs of people living with HIV in a certain community or country. For example, it can provide important insights into the specific issues faced by young people, women, or gay men and other men who have sex with men, transgender people, sex workers or people who use drugs. Section G of the Stigma Index questionnaire focuses specifically on questions about intersectional experiences of stigma.

Conducting a specific gender analysis of the data is encouraged to ensure that the research report and policy recommendations accurately reflect the different experiences of women, including transgender people and gender-non conforming or non-binary people and women within key populations groups whose experiences of stigma and discrimination are intersectional.

The country team can also look at individual responses to compare answers between questions. For example, in Section A, some questions can be looked at together – question 9 (the participant's education level), question 10 (employment status) and question 11 (ability to meet basic needs). When you look at the responses from one participant, you can build up a picture of that person's life circumstances. For example, someone who has had university/tertiary education and works full-time is likely to be able to meet their basic needs, such as food and shelter. Another participant, with no formal education and doing casual or part-time work, is more likely to be unable to pay for basic needs.

The Research Partner is likely to do most of the data analysis but the whole country team should still be involved. In particular, the lead network should certainly be involved in deciding what to look for in the data analysis and choosing which relationships and themes to explore and understanding how to interpret the results in their context.

5.2 Share the findings with key partners

The lead network should present their findings to the Steering Committee and any networks of people living with HIV that were key partners in the research process. It is also important to share the results with the people that participated in the interviews. The feedback from all those involved can be used to decide if any more data analysis is needed to explore themes further and include them in the final report. After these initial discussions, the country team should decide how best to record and share the overall study findings with a wider audience.

5.3 Develop the report

The lead network should write a full report on the research. As well as presenting the results, the report should draw conclusions from the findings and make recommendations. There is a [template](#) available to guide the report writing.

The draft report should be shared with the International Partnership and other partners for their review and feedback and to ensure that the Stigma Index quality standards are met. Then it can be revised, and their comments taken on board before the final report is produced.

All final country reports should be available in English but can also be available in other local languages. All the anonymised data and the final report should always be shared with the International Partnership.

PHASE 6: DISSEMINATION AND ADVOCACY



6.1 Share the report findings

6.2 Advocacy



6.1 Share the report findings

The country team will need to create a dissemination strategy before the report is launched, to outline how the report will be shared with different audiences. It is a good idea to launch the report and the main findings with an event or action to draw attention to it. The lead network and the Steering Committee should work together to make these plans.

Things to consider:

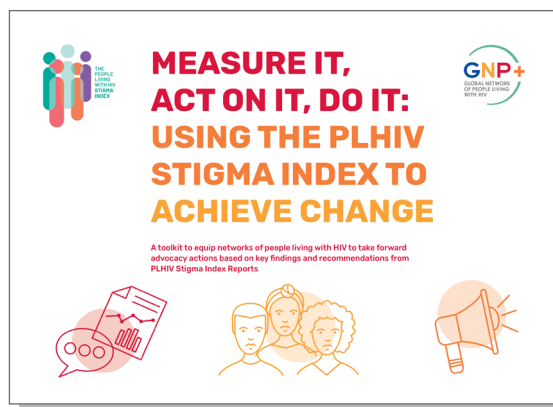
- What are the key findings from the research? Who should know about them?
- What is the best way to communicate the findings? There are many different possible approaches, from a publication like a leaflet to a high-profile meeting, infographics or even a video. The most effective approach will depend on the target audience and the country setting.
- If a physical product is being made (flyer, briefing paper, infographic, video etc.) who should make it? Who will read or watch it? What language, tone and style are most appropriate?
- If a meeting is being organised, who should be invited? Is a group discussion appropriate, or would a one-to-one meeting be better? Where is the best place to hold the meeting so that people engage in the discussion?
- Creativity can make a big difference. An effective strategy should really capture the audience's attention. There is no need to be limited to just one approach, the dissemination strategy could include producing a press release, holding a meeting and making a video.

Once the dissemination strategy is finalised, the report and findings can be shared as widely as possible.

6.2 Advocacy

This is an essential part of the Stigma Index. The aim of measuring stigma and discrimination is not just to understand the situation in a particular setting, it is also to inform and shape policies, practices and behaviour to remove stigma altogether.

The advocacy strategy involves longer-term strategic planning and thinking than the dissemination strategy. It should be led by the lead network with other relevant stakeholders involved throughout. An [advocacy toolkit](#) and a [gender advocacy toolkit](#) are available to help give guidance on what to include in an advocacy strategy.



Once the strategy is agreed, advocacy can begin. The data gathered through the Stigma Index can be used to inform advocacy demands and give them credibility. Change rarely happens quickly so it is important to be prepared to keep pushing for reforms over a long period of time.

The impact of any advocacy work should be shared with the International Partnership.



CASE STUDY: ZIMBABWE

When the Stigma Index was implemented in Zimbabwe in 2014, it revealed that some people were experiencing stigma and discrimination in religious settings. The leading network of people living with HIV, ZNNP+, were concerned by these findings so put together a programme of activities to try to improve the situation.

In partnership with SAFAIDS, they built stronger relationships with religious leaders and developed a framework to engage faith leaders in reducing stigma. Their training programme supported people living with HIV to act as focal points and to carry out sensitisation work in their communities. A short [video](#) is available showing how this work has changed lives.

Conclusion

The People Living with HIV Stigma Index 2.0 is the result of a long history of the self-empowerment of people living with HIV. It is designed to strengthen people living with HIV and their networks by building capacity in research project management, community organising, data literacy, and evidence-based advocacy. It creates opportunities for people living with HIV to become more involved with their organisations at a local and national level and to build and strengthen partnerships with key population networks, civil society organisations, research partners, ministries of health and other stakeholders. The Stigma Index process is also designed to reduce experienced and internalised stigma as people living with HIV self-organise and take a leading role in reducing the barriers to an effective HIV response.

The impact of advocacy is different in each country or community but together, our combined efforts help to make policies and programmes more effective at addressing HIV-related stigma and discrimination and beyond. We, as GNP+, ICW, and UNAIDS sincerely believe that both the process and the outcomes of this research improve the quality of life for all people living with HIV.



Annex 1: Implementation checklist

This checklist summarises the different steps involved in each phase of the Stigma Index implementation. The Country Coordinator should regularly update the checklist so that it can act as a reminder of what needs to be done and allow the country team to keep track of the process.

Phase 1: Preparation

- Complete the People Living with HIV Stigma Index 2.0 intake form and submit to the International Partnership
- Seek support from the International Partnership
- Consult with key stakeholders and partners
- Set up a Steering Committee
- Identify the Country Coordinator
- Appoint the Research Partner
- Develop a work plan and budget
- Conduct necessary fundraising

Phase 2: Planning the research

- Decide on the geographical areas to study
- Develop the sampling plan
- Recruit Community Liaisons
- Determine data collection method (paper-based or digital)
- Consider conducting qualitative research
- Submit protocol for technical review
- Submit the protocol for ethical review

Phase 3: Preparation for data collection

- Set up data collection system (paper-based or digital)
- Translate the questionnaire to predominant local language(s)
- Recruit interviewers
- Conduct training session for all those involved in conducting the interviews
- Prepare for referrals and follow-up
- Prepare interview venues
- Field test the questionnaire and data collection procedures

Phase 4: Data collection

- Identify and recruit participants
- Schedule and conduct interviews
- Regularly track the sample composition

Phase 5: Data analysis and reporting

- Analyse results (both qualitative and quantitative)
- Present results to the country team, local people living with HIV network(s), and the Steering Committee
- Gather comments and feedback
- Draft the report based on Stigma Index report template
- Circulate the report for peer review
- Revise and finalise report
- Share anonymised data and final report with the International Partnership

Phase 6: Dissemination and advocacy

- Develop a dissemination strategy and advocacy strategy
- Disseminate the report
- Implement the advocacy plan
- Share the impact of advocacy with the International Partnership





The People Living with HIV Stigma Index
www.stigmaindex.org