

policy

June 2015

MEASURING HIV STIGMA AND DISCRIMINATION AMONG HEALTH FACILITY STAFF

Standardized Brief
Questionnaire

User Guide

This publication was prepared by Aparna Jain, Dara Carr, and Laura Nyblade.

.....
Suggested citation: Jain, A., D. Carr, and L. Nyblade. 2015. *Measuring HIV Stigma and Discrimination Among Health Facility Staff: Standardized Brief Questionnaire User Guide*. Washington, DC: Futures Group, Health Policy Project.

ISBN: 978-1-59560-094-3

The Health Policy Project is a five-year cooperative agreement funded by the U.S. Agency for International Development under Agreement No. AID-OAA-A-10-00067, beginning September 30, 2010. The project's HIV activities are supported by the U.S. President's Emergency Plan for AIDS Relief (PEPFAR). HPP is implemented by Futures Group, in collaboration with Plan International USA, Avenir Health (formerly Futures Institute), Partners in Population and Development, Africa Regional Office (PPD ARO), Population Reference Bureau (PRB), RTI International, and the White Ribbon Alliance for Safe Motherhood (WRA).

The information provided in this document is not official U.S. Government information and does not necessarily represent the views or positions of the U.S. Agency for International Development.

.....

Measuring HIV Stigma and Discrimination Among Health Facility Staff

Standardized Brief Questionnaire
User Guide



CONTENTS

Purpose	1
Questionnaire Development	2
Questionnaire Implementation	3
Measuring HIV Stigma and Discrimination in Health Facilities: Standardized Brief Questionnaire	6
Appendix A: Facility Administrator Questionnaire	14
Appendix B: Example Informed Consent Statement	15



Purpose

The purpose of this manual is to offer guidance in administering a standardized HIV-related stigma and discrimination (S&D) questionnaire in healthcare settings. The manual provides a short history of the development of this questionnaire; the rationale for measuring S&D in health facilities; a description of the questionnaire sections; practical steps and guidance for questionnaire implementation, including procedures to help ensure ethical data collection and the anonymity of respondents; and counsel on analysis.

This manual is intended for use by program managers, facility managers, researchers, and others interested in exploring, assessing, and reducing HIV-related S&D in healthcare settings. One of the first steps in developing interventions to reduce S&D is to understand the views and behaviors of health facility staff toward people living with HIV (PLHIV).

This questionnaire can be used

- To obtain data to inform the development of tailored S&D-reduction interventions;
- As a baseline for program monitoring and evaluation to assess the effect of intervention activities on reducing HIV S&D; and
- As a monitoring tool to assess levels of S&D over time.

This questionnaire is designed to be administered among all levels and types of staff, including clinical and medical staff (e.g., doctors and nurses), administrative staff, and support staff (e.g., cleaners and security guards). Data should be collected from all staff levels, not just doctors and nurses, because a patient living with HIV or other stigmatized groups, such as key populations, can experience S&D at every level of contact within a healthcare facility. By including a broad range of staff in the data collection process and subsequent S&D-reduction programming, S&D can be addressed across an entire health facility.

DEFINITIONS

Stigma: A social process of devaluing persons, beginning with marking or labeling someone's differences, then attributing negative connotations or values to those differences; this process leads to distancing and separation of the person, culminating in discrimination.

Anticipated stigma: Real or imagined fears of societal attitudes and behaviors (e.g., of family members, the community, healthcare professionals) if HIV or other stigmatized behavior (e.g., drug use) is disclosed.

Experienced stigma: Forms of stigmatizing behaviors or discrimination not typically actionable under law and experienced by people living with HIV or individuals associated with HIV, such as family members or healthcare providers.

Perceived stigma: The perception of how people in one's community feel and react toward people living with HIV.

Secondary stigma: Stigma experienced by individuals associated with people living with HIV (e.g., family, partners, friends, healthcare professionals).

Internalized stigma: Acceptance by the self that the external stigma is true and justified—that is, acceptance of society's judgment of oneself as being of a "lesser status." Internalized stigma can manifest itself as low self-esteem and sense of worth, self-blame, and self-isolation/withdrawal.

Compound/layered stigma: Experience of multiple stigmas—for example, in addition to HIV stigma, stigma toward men who have sex with men, transgender individuals, migrants, poor women, and people who use drugs.

Observed stigma: Forms of stigma witnessed by an individual (e.g., a nurse gossiping about a client's HIV status, as seen by a lab technician).

Discrimination: Unfair and unjust treatment of an individual on the basis of a real or perceived status or attribute (e.g., HIV status or association with HIV-positive individuals). Discrimination typically is actionable under law.

Questionnaire Development

An international team of researchers developed and tested this questionnaire to ensure that it is broadly applicable across diverse settings and produces data that provide practical guidance for action. The comprehensive development process began with a content development workshop, at which a group of international experts working with HIV-related S&D in healthcare settings convened to review and prioritize all existing questions and measurements available in this area. Based on this review, participants in the workshop produced a questionnaire that was pilot-tested in six sites in diverse settings: China, Dominica, Egypt, Kenya, Puerto Rico, and St. Kitts & Nevis. Once the questionnaires were administered, another workshop was held to review the data results and field-testing experiences across countries, and assess each question's potential for inclusion in a brief questionnaire. This exercise resulted in two brief versions of the field-tested questionnaire: the Measuring HIV Stigma and Discrimination Among Health Facility Staff: Standardized Brief Questionnaire (<http://www.healthpolicyproject.com/index.cfm?id=StigmaPackage>) and The Measuring HIV Stigma and Discrimination Among Health Facility Staff: Indicator Monitoring Tool (<http://www.healthpolicyproject.com/index.cfm?id=StigmaPackage>). The monitoring tool is a much shorter version of the standardized questionnaire; it includes only the eight questions needed to capture the six health facility indicators approved by the UNAIDS Monitoring and Evaluation Reference Group (see pages 15 and 16 for more details about these indicators). For more information and details about the process of developing, field testing, and finalizing the questionnaire, please see Nyblade, et al. (2013) at (<http://www.jiasociety.org/index.php/jias/article/view/18718>).

Why measure HIV stigma and discrimination in healthcare settings?

HIV-related stigma and discrimination exist across multiple social settings, including the community, household, places of worship, and healthcare settings. Reducing S&D in healthcare settings is paramount because they are the first line of care, treatment, and support services that PLHIV can access to help them manage their response to HIV. The S&D that a person living with HIV (or suspected of living with HIV) may encounter at a health facility can influence his or her decision to return to the same facility for continued treatment or follow-up visits and lead to delays in seeking antiretroviral (ARV) treatment and other support services. Depending on the health facility and setting, HIV stigma can also prevent individuals from accessing voluntary testing services. Globally, research suggests that highly stigmatized groups, such as key populations, are much less likely to access HIV services, including treatment, despite their disproportionately high risk and burden of HIV. Reducing S&D in healthcare settings is crucial in removing barriers to accessing HIV prevention, care, and treatment services and improving the quality of those services. In addition to contravening the right to health, S&D in health facilities has the potential to fuel the spread of HIV.

Research has shown that S&D in healthcare facilities may occur in many different forms, including, but not limited to, the following: refusal to provide treatment services to a patient living with HIV; referral of a patient living with HIV to another provider or health facility; placement of a patient living with HIV at the end of a queue, irrespective of when she or he arrived at the facility; gossiping about the patient; disclosure of a patient's HIV status to colleagues/family members without consent; and the use of degrading language when interacting with PLHIV. Patients living with HIV often experience differential care that visibly marks them to others as living with HIV. For instance, a provider may use gloves during non-invasive procedures (like taking temperature or blood pressure) with patients living with HIV but not other patients. This excessive use of gloves has been linked to providers' fears of HIV transmission.

Staff who offer care to PLHIV also can experience S&D. Known as secondary stigma, staff may experience S&D from colleagues, friends, or family members due to their association with PLHIV. Measuring and reducing secondary stigma is important because it has the potential to impact the way services are offered. Staff who fear secondary stigma may try to avoid providing services to PLHIV or engage in more stigmatizing avoidance behaviors when providing care (e.g., double gloves, differential use of gloves). In addition, S&D in health facilities can impact health facility staff by discouraging them

from seeking HIV testing themselves or, if they are living with HIV, from disclosing their status or seeking treatment for themselves because of anticipation of S&D from their colleagues or supervisors if their status becomes known. Anticipated consequences of disclosure can include the loss of a job, denial of a promotion or participation in a training, or restriction from performing certain job-related activities.

Questionnaire Implementation

Implementing the questionnaire requires several steps, detailed below. This questionnaire can be implemented on its own, or parts of it can be incorporated as a module within other questionnaires—for example, in a broader survey on quality of care in a facility.

Guiding Principles

Consider the following guiding principles when implementing the HIV S&D questionnaire in healthcare settings:

- **Involve gatekeepers at health facilities:** In the healthcare setting, gatekeepers are influential individuals who will enable you to conduct your program and administer the questionnaire in a facility—for example, the facility administrator(s), heads of departments, or chiefs/heads/in-charge of various staff categories (e.g., doctors, nurses, support staff). To gain access to the staff who work in the facility and receive the necessary support to implement your questionnaire and intervention, you will need to engage and build relationships with them.
- **Health facilities are busy places:** The primary role of health facility staff is to provide services to patients; this often leaves very little time to complete a questionnaire. The goal is to cause as little disruption to their daily schedules as possible by making the questionnaire quick and convenient. Some ways to do this include working with the facility gatekeepers to identify a room where facility staff can complete the self-administered questionnaire at a time convenient for them. Make the room available all day for completing the questionnaire so staff can come whenever they are free, and offer lunch and tea/refreshments during the day. If respondents are unavailable to participate on a given day, then stay an additional day(s) until all respondents have had an opportunity to decide whether they would like to participate in the study.
- **Questionnaire completion is entirely voluntary:** Health facility staff may be concerned that their participation or refusal to participate in the questionnaire could lead to a demotion in job responsibilities, reduction in hours of work, or diminishment in another aspect of their current employment. It is important to emphasize respondents' potential concerns with the gatekeepers of the health facility; when gatekeepers inform staff about the questionnaire in their formal communications, they should provide information that alleviates staff concerns. You must also provide this information to staff via the informed consent statement.

Institutional Review Board

If you are collecting more than simple monitoring data, most studies will need to be approved by a local institutional review board (IRB). IRBs are charged with protecting the welfare and rights of study participants, and ensuring that the research is conducted in an ethical manner. IRBs review study protocols, informed consent forms, and questionnaires to ensure that the research does not unnecessarily harm study participants. Since this questionnaire does not include clinical research, the IRB approval process should be straightforward. Planning for the IRB review and allowing adequate time is important because some IRBs meet only periodically and may take a significant amount of time to complete their review. Depending on your country context, there may be one or more options for places to seek IRB approval, including a national IRB, a university IRB or ethics review board, or a similar entity of the Ministry of Health or national research institute in your country.

Informed Consent Procedures

You must consider and utilize informed consent procedures to ensure that you are implementing ethical research. Informed consent is a process that explains the study to the respondent, including providing information about the study purpose, potential consequences, or benefits of participation (for this questionnaire, there are minimal benefits or consequences attached to participation) and how you will uphold and maintain the anonymity and confidentiality of responses. Informed consent gives respondents the opportunity to voluntarily decide whether they would like to participate in the study and ensures they understand that participating or not participating in filling out the questionnaire will not affect their current job status. The informed consent statement should also tell respondents that they can refuse to answer any questions or stop the interview at any time and instruct the respondent to ask a data collector any questions they may have about the statement (see Appendix B a for sample consent form).

Upon completion of the questionnaire, respondents should be instructed to put it into an envelope, seal the envelope, and then drop it into a box. This is done to ensure the respondents' confidentiality and anonymity.

Two types of informed consent can be obtained from study participants: verbal and written. Which to use is a decision made depending on your context and the IRB's recommendations. Generally, verbal informed consent is recommended only when a respondent is not literate or when signing a consent form could put the respondent in danger. Therefore, for this questionnaire, apart from respondents who are not literate, signed informed consent is recommended. With written consent, the interviewer gives the respondent the consent form to read. The interviewer then goes over the consent form to ensure that the respondent has fully understood the meaning of informed consent, asking for and answering any questions the respondent may have, before asking the respondent to sign the form, which signifies that he or she understands the consent document and its contents, and is agreeing to participate in the study. The interviewer also signs the consent form to signify that he/she has administered the consent form. If a respondent does not agree to participate in the study, he or she will not sign the consent form. Respondents should receive a copy of the informed consent statement, along with the name and number of persons to contact if at any time they have any questions about the study. As the researcher, you are responsible for housing the signed informed consent statements in a secure, safe, and locked cabinet.

When a respondent needs verbal instead of written consent, the interviewer must find a witness who can be present during the reading of the consent form to the respondent and then sign the consent document. Once the interviewer has ensured that the respondent has fully understood the meaning of informed consent, the interviewer, witness, and respondent all sign the form to demonstrate that the consent statement was read to the respondent, signifying that he/she understands it and its contents, and is agreeing to participate in the study. If a respondent cannot sign, a thumbprint can also be used.

Informed consent templates can be found on the World Health Organization website at http://www.who.int/rpc/research_ethics/informed_consent/en/. An example standard informed consent form is provided in Appendix B.

Translate, Adapt, and Pilot-Test Questionnaire

Although this questionnaire has been tested in many different settings, and the questions selected have performed well across diverse contexts, we recommend that you review the questions to identify those that may need to be adapted to your context before implementing the questionnaire. Adaptation means the deliberate modification of a question, response categories, or layout to better fit the use of the questionnaire in a new population, language, social context, or mode of questionnaire administration.

It is important to translate the questionnaire and informed consent form into your language without changing the meaning of the questions. Ideally, questionnaires are translated into the local language and then back-translated into English. If you do not have the resources to do the back-translation, it is important that several other people review the translation before you pilot-test it. Sometimes it is useful to hold a short (half- to one-day) workshop with a few stakeholders to review the translation.

Pilot-testing is an important piece of the questionnaire adaptation; it is a practice or mock implementation with a few individuals to see how the questionnaire is working. During the pilot-test, you will learn whether respondents understand your adaptations and translations. First, you will need to determine who will participate in the pilot-test, how it will be conducted, and how you will obtain feedback about the questionnaire. Because the target population for your questionnaire is health facility staff, be sure to select staff for the pilot-test who will not be included in your study. For example, if you are planning to collect data only in certain facilities but not others, you could pilot-test the questionnaire in a facility you do not plan to include in your sample.

Some ways to pilot-test the questionnaire include the following:

- Ask pilot-testing participants to complete the questionnaire and note when they have had issues with any of the questions. Then hold sessions with individual participants or a joint meeting with all of them to discuss any problems that arose and ask for their suggestions for how to improve any problematic questions. Here are some sample questions to ask participants after they have gone through the questionnaire:
 - Were there any questions that were confusing or you did not understand? Why was the question unclear?
 - Were there any questions for which you had a response that was not among the response choices?
- Read the questions to your pilot-testing participants and watch for hesitation—then ask them to clarify why they hesitated. Also note when participants ask you for clarification or more information about a question they do not understand.

Once the pilot-test is completed, revise the questionnaire to account for any issues that need to be resolved. When the questionnaire has changed drastically or when you want to confirm that the adaptations are understandable, you may be warranted in conducting another pilot-test.

Questionnaire Administration Method

The questionnaire can be either self- or interviewer-administered. There are several reasons you might choose to implement the questionnaire as a self-administered one. First, respondents may feel more secure that their responses are confidential. This feeling may lead to more honest and truthful responses related to a highly sensitive topic area. In addition, this type of administration gives them the flexibility to complete the questionnaire on their own time (usually within the confines of a work day). In some settings, interviewer-administered questionnaires may be more appropriate, for example if some staff have low levels of literacy.

Where to Complete the Questionnaire

Work with facility gatekeepers to identify two or more private rooms where staff can complete the questionnaires. Use the first room for staff to read the informed consent form (or have it read to them if literacy is low), and the second or additional rooms for completing the questionnaire. Potential respondents who decide not to complete the questionnaire thus can leave the data collection area more privately than if the informed consent forms are administered in the same room as the questionnaire. If you are using an interviewer-administered questionnaire, you might need more than two rooms if you want to conduct self and interviewer-administered interviews simultaneously. As mentioned above, health facilities are busy places, so all staff might not be available to complete the questionnaire at the requested time. By having a designated room for the questionnaire, staff can swing by as their schedules allow. How long you should plan to be at the facility will depend on how many interviews you are collecting at that facility; at a minimum, plan for at least two days in case some staff are unavailable on a given day so they will have another day to complete the questionnaire. You can offer staff lunch and/or refreshments and tea throughout the day.

You should plan to have one or two data collection team members present in the room throughout the day. The data collectors will carry out the informed consent process, explain the questionnaire to respondents, answer any questions that may arise as respondents are completing the questionnaire, or administer the questionnaire when needed. The data collectors will also be responsible for collecting and safeguarding the questionnaires. They should pay close attention to any specific issues or questions that come up repeatedly as this will inform particular areas of the questionnaire that need to be stressed and reviewed with future respondents.

Interviewer Training for Improved Data Quality

You should plan to hold a training of all data collectors involved in the study. The purpose of the training is to provide an overview of HIV S&D and the study objectives, an in-depth review of the questionnaire, and an orientation on how to conduct research using the highest ethical standards and rules to uphold the confidentiality of respondents and data. The training can include an opportunity for data collectors to complete the self-administered questionnaire themselves to increase their understanding of the questionnaire's flow and skip patterns. If the interview is interviewer-administered, then data collectors should practice their interviewing skills through mock interviews and role plays. To facilitate the training and serve as a reference guide for the data collection team, a study manual of operations should be developed. An outline of a study manual is available in Appendix C.

To ensure that respondents do not accidentally skip questions, data collectors should remind them at the outset to double check their completed questionnaires and make sure they have answered every question. Data collectors also can remind respondents to review the questionnaire for completeness before they seal it in the envelope.

Measuring HIV Stigma and Discrimination in Health Facilities: Standardized Brief Questionnaire

This questionnaire was deliberately designed to capture immediately actionable causes of HIV-related S&D, as well as their manifestations (discrimination). The key areas or domains identified by existing research as important and subsequently collected in this questionnaire include the following:

Immediately Actionable Causes

1. Fear of HIV infection
2. Attitudes (stereotypes and prejudice)
3. Institutional-level facilitators and barriers (facility policy)

Manifestations (discrimination)

4. Self-reported use of unnecessary infection control measures
5. Observed discrimination
6. Secondary stigma that is either anticipated or experienced by health facility staff
7. Unwillingness to work alongside a health facility colleague living with HIV

In addition, the questionnaire starts with a brief background section that collects limited demographic information, as well as job duty and facility-related information.

Table 1 provides an overview of the questionnaire by key area, topic, questionnaire section, and question number. More detail on each topic is provided below.

Table 1: Question Type, by Questionnaire Section and Question Number

KEY AREA	TOPIC	QUESTIONNAIRE SECTION	QUESTION NUMBER
Background	Demographic	Section 1: Background information	Questions 1–2
	Job duties and facility-related information	Section 1: Background information	Questions 4–7
Immediately Actionable Causes	Fear of HIV infection	Section 2: Infection control	Question 8
	Health facility policies	Section 4: Health facility policies	Questions 14–17
	Attitudes toward PLHIV & key populations	Section 5: Opinions about PLHIV & willingness to care for key populations	Questions 18–22
Discrimination	Self-reported use of extra infection precautions	Section 2: Infection control	Question 9
	Observed	Section 3: Health facility environment	Questions 10–11
	Secondary stigma	Section 3: Health facility environment	Question 12
	Willingness to work alongside a colleague living with HIV	Section 3: Health facility environment	Question 13
Module: Stigma toward pregnant women living with HIV among facility staff who care for pregnant women	Fear	Module 1	Question 23
	Opinions	Module 1	Question 25
	Observed	Module 1	Question 24

Background—Questions 1–7

This section contains both standard respondent questions about age and gender and questions related to current job, trainings received, and years working at the facility. Depending on the goals of your project, the background section can be expanded to include additional questions.

The questionnaire does not ask respondents about where they work (location), as this information can be collected through a questionnaire ID number prefilled by an interviewer or survey administrator (see Tip box—Constructing an ID number). This approach is preferable because it keeps the questionnaire shorter and ensures consistency in classifying facilities.

For the training question (Question 7), you should offer some guidance and instructions to the respondents on the types of trainings you are interested in knowing about. For example, are you interested in on-the-job training (in-service) and/or pre-service training (e.g., was stigma included in their formal education to become a nurse or doctor)?

Given your program and contextual setting, additional training topic areas may be added to (or removed from) the provided list. For example, you may be interested in exploring participation in trainings on topics such as HIV prevention and treatment, prevention of mother-to-child transmission, or gender sensitivity, in addition to those listed in the questionnaire. Data on this training question are useful in building evidence-based interventions. Data will inform you as to how many staff have participated in a specific training and allow you to determine whether to offer a training as part of your intervention. This question is also valuable in evaluating your intervention if trainings were a part of it; in this case, you can measure whether the training had an influence on reducing HIV S&D. To do this, you will need to add a timeframe for the endline questionnaire so as to track when the trainings you are evaluating were conducted. Here is an example of a revised version of Question 7: In the past 12 months, have you received training in the following subjects? (Then list the training topics/subjects that your intervention has covered and you are trying to assess.)

Note that two versions are provided for Question 6, which captures HIV-positive patient load. This is to allow for implementation of this questionnaire in diverse HIV prevalence settings. Low-prevalence settings are defined as those in which HIV prevalence is less than 1 percent; high-settings are places in which HIV prevalence is greater than 1 percent. The difference between the low- and high-HIV prevalence setting in Question 6 is in the timeframe. In high-prevalence settings, the suggested timeframe in which to measure HIV-positive patient load is a typical week; a longer timeframe is recommended for low-HIV prevalence settings—typically, you would measure patient load in the past 12 months. A longer timeframe is recommended in low-prevalence settings to increase the likelihood that staff will have seen several patients living with HIV.

TIP: CONSTRUCTING AN ID NUMBER

To help facilitate efficient and anonymous data collection, you will need to create an ID number. Facility location (urban/rural) and type (hospital/health center/health post, etc.) were not included as questions in the survey because this information can be captured through an ID number. Here is an example of how to construct an ID number. This method could vary, depending on the specific information you want to collect about the facility. This example is of a six-digit ID number that collects basic information about the site and leads to a unique identifier for each respondent:

- The first number signifies the type of facility (e.g., 1=regional hospital, 2=district hospital, 3=health center, 4=health post, etc.).
- The second number identifies whether the facility is located in a (1) rural, (2) peri-urban, or (3) urban area.
- The third and fourth numbers identify the facility where the survey is implemented (you will need to list all of the facilities where the survey will take place and assign a number to each one).
- The fifth and sixth numbers are the unique ID for the respondent. This number begins at 1 (marked down as “01”) and is a count of all the respondents interviewed.

From the ID below, we know that this interview took place at a district hospital (2) in an urban area (3) at facility #5 (05), and the unique ID for this respondent is 32.

2 3 0 5 3 2

Fear of HIV Infection—Question 8

This question measures HIV infection worry among health facility staff when performing certain work-related activities—both non-invasive procedures (with no risk of infection) and invasive procedures (with some risk of infection). This worry can lead to both differential and unnecessary use of protective measures that visibly mark patients living with HIV (such as double gloves or physical isolation), thereby stigmatizing the patient and potentially disclosing his/her HIV status to other facility staff and other patients. Fear of HIV infection in the work setting continues to be prevalent among health facility staff, so understanding the specific fears will allow you to develop more effective programs that address HIV transmission concerns and thus reduce stigmatizing-avoidance behaviors. Deepening knowledge of HIV transmission and prevention is necessary to offer high-quality services in a non-stigmatizing environment.

Because the four items in this question are presented in increasing levels of procedure invasiveness and include at least one situation to which most respondents will relate, this indicator will capture fear of HIV transmission among the majority of respondents. The question gives *touching the clothing of a patient living with HIV* as the least invasive procedure and *drew blood from a patient living with HIV* as the most invasive.

Note that there is a “not applicable” response category for Question 8 for respondents who feel that their duties do not include the specific job responsibility being explored. For example, a cleaner would be expected to answer *not applicable* to the question asking about worry when drawing blood from a patient living with HIV. (See *Data Management and Analysis Tips* for analysis guidelines of *not applicable*, *don't know*, missing, and skip-patterned questions.)

Attitudes (stereotypes and prejudices)—Questions 18–22

An important cause of HIV S&D in healthcare settings is the attitudes of health facility staff toward people living with HIV. Measuring stereotypes and prejudices toward PLHIV and key populations is important because attitudes may affect how a provider consciously or unconsciously treats patients, which healthcare options are offered to patients, and which individuals are offered testing (and when), leading to inaccurate risk assessment.

The questions are designed to understand the attitudes of health facility staff toward PLHIV (Question 18); pregnant women living with HIV (Question 19); and key populations, including people who use drugs (Question 20), men who have sex with men (Question 21), and sex workers (Question 22). Note that you can add additional key population groups by repeating the series of questions designed for key populations. For example, if you are interested in exploring healthcare staff attitudes toward migrants, follow the Question 22 series and create new questions (23a and 23b) by replacing the term “migrants” with “sex workers.”

RESPONSE BIAS

Response bias occurs when a respondent answers survey questions in a way they think the researcher/interviewers desires, even if the true beliefs and behaviors are the opposite. Questions that assess an individual's attitudes often are challenged by response bias. This questionnaire has been designed to minimize response bias.

At the time of data collection, one way to reduce response bias is to maintain the privacy and confidentiality of all participants. This method includes ensuring that they can voluntarily decide to skip questions and decide whether to complete the questionnaire, offering a private space for them to complete it, and not collecting any identifying information about the participant on the questionnaire.

Discrimination and Secondary Stigma—Questions 9–12

These questions are spread throughout the questionnaire and focus on three aspects of discrimination in health facilities. The first two relate to discrimination toward patients, and the last is as experienced or anticipated by healthcare staff: (1) self-reported use of unnecessary precautions with PLHIV, (2) observed discriminatory behavior, (3) secondary stigma, and (4) willingness to work alongside a colleague living with HIV.

1. **Self-reported use of unnecessary precautions with PLHIV (Question 9):** The use of unnecessary or excessive precautions when providing care or services to a patient living with HIV in a healthcare setting is a manifestation of the fear of HIV infection in routine job responsibilities. These types of behaviors include avoiding physical contact and wearing double gloves, among others. The use of such extra precautions may be noticeable to others in the healthcare setting, including other patients and health facility staff, which could lead to disclosure of the status of a patient living with HIV without her or his consent. Note that this set of questions includes a *not applicable* response for respondents who do not interact with patients or perform tasks that would, for example, not require the use of gloves. (See *Data Management and Analysis Tips* for guidance on the *not applicable* responses.)
2. **Observed discriminatory behavior (Questions 10 and 11):** The observed discriminatory behavior questions begin with a filter question, asking respondents to report whether they have seen a PLHIV in their health facility in the *past 12 months*. Respondents who have seen PLHIV move to the observed discriminatory behavior questions, whereas all other respondents skip to the next question. (See *Data Management and Analysis Tips* for guidance on skip patterns.) Respondents who have not seen an HIV-positive patient in their facility skip this question because they will not have had an opportunity to observe discrimination toward patients living with HIV.

OBSERVED STIGMA RESPONSES

If the observed stigma questions yield low responses in low-prevalence settings, it may be because the “opportunity” to observe stigmatizing behaviors is limited, given that few patients living with HIV are seeking services at that health facility.

The observed discriminatory behavior questions do not ask health facility staff directly if they themselves have engaged in specific stigmatizing behaviors because previous research has shown that staff often know which types of behaviors are acceptable and which are not, and may provide the socially desirable response, whether or not they have actually engaged in the behavior. However, asking facility staff about what they have observed provides a more accurate measure because staff are more comfortable reporting what they see happening (including what they themselves may have done). Thus, the questions ask whether staff have observed the discriminatory behaviors in their health facility in the past 12 months, rather than whether they themselves have engaged in them.

The reason for asking about observation in the past 12 months (as opposed to ever) is twofold. The first is that you are asking respondents to report on actions they have observed in the past; this can introduce recall bias. Limiting the timeframe can help with this challenge. Second, if you are collecting data to evaluate stigma-reduction efforts, you will need to restrict the observation period to the length of your intervention or the period over which you want to evaluate change. If this time period is shorter than a year, you may want to adjust the timeframe on this question accordingly (e.g., six months).

In addition to providing a proxy measure for discrimination in a health facility, observed stigma is also an important issue to measure because individuals often are influenced by what they see happening around them. For example, observing stigma in a health facility may lead staff to avoid HIV testing themselves (or if found positive, to avoid seeking treatment) for fear that they will be treated in the same way they observe their colleagues behaving toward HIV-positive patients. Perceptions of stigma can also influence discriminatory behaviors—if staff perceive that a stigmatizing health facility environment is acceptable or the norm, it can shape the way they themselves interact with and offer services to HIV-positive patients.

3. **Secondary stigma (Question 12):** Because providers may anticipate or experience stigma due to their association with and care of patients living with HIV, it is important to measure this domain so as to design S&D intervention programs that specifically address secondary stigma. Two versions of the secondary stigma questions are offered; one for high- and one for low-HIV prevalence settings. In low-prevalence settings, the likelihood that health facility staff regularly provide services to HIV-positive patients is low. Thus, the question for low-HIV prevalence settings is presented as a hypothetical and asks how worried health facility staff would be if specific instances of secondary stigma happened to them. This question is important to ask in low-prevalence settings because anticipated secondary stigma can affect staff behaviors toward patients living with HIV. In high-prevalence settings, the question simply asks whether the respondent has experienced different forms of secondary stigma.
4. **Willingness to work alongside a colleague living with HIV (Question 13):** In addition to examining S&D in a health facility with respect to patients, it is also important to gauge how welcoming a health facility is toward health facility staff living with HIV. Staff who observe or perceive that colleagues are stigmatizing PLHIV may be hesitant to seek testing and/or seek the HIV treatment they need for fear that this might disclose their HIV status. This question measures such a climate by asking respondents' opinions about how hesitant they think health facility staff in their facility are to work alongside a co-worker living with HIV, regardless of their duties.

Institutional-level Facilitators and Barriers—Questions 14–17

This section of the questionnaire collects data on institutional factors that can help to reduce HIV-related S&D and also support health facility staff in offering safe and welcoming services to patients living with HIV and key populations affected by HIV. Some causes of stigma at the institutional level can include the absence of (1) anti-discrimination policies and guidelines related to the treatment of patients living with HIV and; (2) standards of practice and supplies that support the protection of health facility staff from the risk of HIV infection. In facilities where such policies do exist, stigma can occur if the policies and guidelines are unknown to staff or are not enforced.

Module: HIV S&D Toward HIV-positive Pregnant Women—Questions 23–25

The purpose of this module is to focus on stigma toward a particularly vulnerable group—pregnant women living with HIV. HIV-related S&D can be a barrier to pregnant women living with HIV who are seeking prevention of mother-to-child transmission services and treatment for their own health. As with the main body of the questionnaire, this module captures actionable causes of HIV S&D (fear of HIV transmission and opinions about HIV-positive pregnant women) and observed discriminatory practices. It is intended to be completed only by service providers who work with pregnant women in antenatal care, prevention of mother-to-child transmission of HIV, or in labor and delivery rooms and postpartum care. Clear instructions to respondents are included in the questionnaire, indicating that only staff who work with pregnant women should complete this module. You should emphasize this fact when introducing the questionnaire to respondents.

TIP: COLLECT DATA FROM FACILITY ADMINISTRATOR

When possible, triangulating the data through a facility administrator questionnaire will provide knowledge of whether written guidelines are in place, which helps with analysis of this particular question. For example, a research team could ask a facility administrator whether there are written guidelines to protect patients living with HIV from discrimination. If the answer is yes, ask the facility administrator to show them to the research team. An administrator interview guide is available in Appendix A.

Data Management and Analysis Tips

Depending on your research expertise, or that of your organization, you may want to consider partnering with a research firm or university group to help with data management and analysis. Questionnaires will need to be entered into a customized database created to reflect the structure and content of the questionnaire, which then allows the data to be tabulated.

There are a few issues to consider as you analyze the data.

Not applicable (Questions 8, 9, 23): Respondents who choose *not applicable* (N/A) as their response should be excluded from the analysis for that particular question because the respondent feels the question does not apply to him/her and thus has not provided a response. For instance, say the questionnaire is implemented among 100 healthcare facility staff, and in Question 9, the responses yield 50 *yes*, 35 *no*, and 15 *not applicable* responses. The percentage of respondents who avoid physical contact is 50/85, or 58.8 percent, not 50/100, or 50 percent. Those who responded *not applicable* are excluded from the denominator in the analysis of this question (so the denominator becomes 85 instead of 100).

Don't know (Questions 10, 15, 17): That a respondent does not know the answer to a specific question is important information; it should be reported as *don't know* and included in the analysis of the question. For example, in Question 17, if the respondent reports that he/she does not know if the health facility has written guidelines to protect patients living with HIV from discrimination, it is useful information for programming. For this reason, in reporting the responses, *don't know* responses would be counted as part of the denominator. For example, in Question 17, *don't know* is one of the potential response categories, along with *yes* and *no*. Building on the example above, of the 100 respondents interviewed, if 20 report *yes*, 55 report *no*, and 25 report *don't know*, the corresponding percentages would be 20 percent (20/100) *yes*, 55 percent (55/100) *no*, and 25 percent (25/100) *don't know*. (Note: unlike the *not applicable* example, *don't know* is a legitimate response here and so is included in the denominator.)

Missing data: Even when there is no answer provided to a question, the missing data should be included in the question's analysis. For example, in Question 18a, staying with a sample of 100, if the responses are 15 *strongly agree*, 35 *agree*, 25 *disagree*, 20 *strongly disagree*, and 5 *missing*, you would keep the 5 missing responses in the denominator, so the percentages are constructed are out of 100, and note that 5 responses, or 5 percent of the sample, had missing responses. Missing data can also give you important information. For example, if many respondents do not answer a question, this fact may tell you something about the sensitivity of the question and/or that respondents know the socially desirable response and choose to skip it because their own response differs. For example, we have found a significantly larger proportion of missing responses in some countries relative to others for the module Question 25d—*It can be appropriate to sterilize a woman living with HIV, even if it is not her choice*—indicating that perhaps more respondents agree with this statement than the *yes* responses would indicate.

TIP ON MISSING DATA

Missing data may indicate refusal to answer the question, so you may want to consider this when analyzing the responses. If certain questions have more missing responses than others, this may be an indication that the question is more susceptible to response bias.

Skip-patterned questions: Questions 10, 20, 21, and 22 contain skip patterns. A skip pattern occurs with a question that elicits a conditional response pertaining only to certain respondents. For example, in Question 10, respondents who have seen a patient living with HIV in the past 12 months go on to answer Question 11. Those who have not seen a patient living with HIV skip Question 11 and move to Question 12. For the analysis, respondents who skip Question 10 should be recorded as *not applicable* and excluded from the denominator when calculating percentages for Question 11. (Follow the example for *not applicable* above.)

Constructing Indicators

For more guidance on how to construct indicators from some of the questions asked in this questionnaire, visit the UN indicator registry, a repository of indicators used to track the AIDS epidemic and national, regional, and global responses. There are six health facility indicators (see hyperlinks below) that have been approved by the UNAIDS Monitoring and Evaluation Reference Group (MERG); they are constructed from the questions included in the Measuring HIV Stigma and Discrimination Among Health Facility Staff: Monitoring Tool for Global Indicators, a much shorter version of the Measuring HIV Stigma and Discrimination Among Health Facility Staff: Standardized Brief Questionnaire.

- 1079 Health Facility Staff: Institutional Policies (Tier 1)
- 1080 Health Facility Staff: Enforcement of Institutional Policies (Tier 2)
- 1081 Health Facility Staff: Fear of HIV Infection (Tier 1)
- 1082 Health Facility Staff: Attitudes and Opinions (Tier 1)
- 1083 Health Facility Staff: Observed Enacted Stigma (Tier 1 for High HIV Prevalence and Tier 2 for Low HIV or Concentrated Prevalence Settings)
- 1084 Health Facility Staff: Unnecessary Precautions and Measures (Tier 2)
- 1085 Health Facility Staff: Staff Needs and Support (Tier 2)

Appendix A: Facility Administrator Questionnaire

1. Are there standard precaution guidelines in place at this facility?
 Yes No (*skip to Question 3*)
2. May I see them?
 Observed Did not observe
3. Are there Standard Operating Procedures (SOPs) for care and treatment of people living with HIV in place at this facility?
 Yes No (*skip to Question 5*)
4. May I see them?
 Observed Did not observe
5. Are there written guidelines to protect people living with HIV from discrimination?
 Yes No (*skip to Question 8*)
6. May I see them?
 Observed Did not observe
7. How are the written guidelines to protect people living with HIV enforced/implemented?
8. What happens if a provider discriminates against a patient living with HIV at this facility?
9. Are informed consent protocols enforced when screening patients for HIV?
 Yes No (*End the interview*)
10. Please describe the protocols used.

Appendix B: Example Informed Consent Statement¹

CONSENT TO BE A RESEARCH SUBJECT: HEALTH FACILITY STAFF

Explanation of Procedures

You are being asked to participate in a study being conducted by researchers from [*insert institution name(s) and location(s)*]. The purpose of this consent form is to give you the information you will need to help you decide whether to be in the study. You may ask questions about the purpose of the research, what happens if you participate in the research, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When we have answered all your questions, you can decide whether you want to be in the study. We will give you a copy of this form for your records.

The purpose of this study is to explore reasons why some people who are living with HIV might not use healthcare services for treatment and care of their illness. The ultimate aim of this study is to learn how fears about HIV and AIDS might influence access to health services by patients living with HIV in [*insert region and country location*]. You are being asked to take part in this study because you are a health facility staff member who provides care to community members at a health facility in [*insert region and country location*].

You will be asked to fill out a questionnaire [*or be interviewed one-on-one by a trained interviewer*]. The questionnaire will ask you about HIV infection concerns at the health facility, observed HIV-related stigma in the work environment, health facility policies on stigma and discrimination, and opinions about persons living with HIV. We will also ask about your sociodemographic characteristics and experience as a health worker. The questionnaires will be completed in a designated room at your health facility or a nearby private and convenient location. Participation in the study will take about 20–30 minutes of your time. In total, about [*insert a number*] healthcare providers in [*insert region location*] will be interviewed in this way.

Risks and Discomforts

A potential risk includes social risks (e.g., risks to reputation) involved if the information you reveal about your HIV infection concerns, observed HIV-related stigma in the work environment, health facility policies on stigma and discrimination, and opinions about persons living with HIV were disclosed to others. To minimize such risks, we will not ask you for or record any personal identifying information, such as name, telephone number, or date of birth, for your participation in this study. Some interview questions may make you uncomfortable or upset, but you are free to decline to answer any questions you do not wish to answer, or stop the interview at any time.

You may refuse to answer any questions that you do not wish to answer. You can stop participating in the study at any time, and your employment will not be affected in any way. Also, the study researcher may stop you from taking part in this study at any time if he or she believes it is in your best interest, if you do not follow the study rules, or if the study is stopped. All of the information collected during the study will be kept strictly confidential. For more information about risks, please ask the interviewer.

Benefits

There will be no direct benefit to you from participating in this study beyond any psychological benefits possibly associated with sharing your insights and opinions. However, the information that you provide may help researchers to learn more about barriers to service use and develop interventions to reduce HIV stigma experienced by people living with HIV in [*insert country*].

1. From “Measuring HIV-related Stigma and Discrimination Among Workers in Healthcare Facilities in Kenya.” *Study Manual of Operations*. 2102. Study investigators: Janet M. Turan, Elizabeth A. Bukusi, and Zachary Kwena.

Alternatives

You are free to decline participation in the study and you can withdraw at any time. If you decide not to take part in this study, there will be no penalty to you.

Confidentiality

The information that we collect about you during this study will be kept private to the extent permitted by law. The compiled results of this survey will be shared with health officials at the recruiting sites and may be published for scientific purposes; however, your identity will not be revealed. The study sponsors, *[insert sponsor(s)]*, may review the research records.

Refusal or Withdrawal Without Penalty

Taking part in this study is your choice. There will be no penalty if you decide not to participate in the study. If you decide not to participate, you will not lose any benefits you otherwise are owed. You are free to withdraw from this research study at any time. Your choice to leave the study will not affect your relationship with your health facility.

Cost of Participation

There will be no cost to you due to participation in this research.

Payment for Participation in Research

You will be reimbursed in the amount of *[insert amount and how payment will be dispersed—cash, cell phone time voucher, etc.]* for your time or travel expenses related to your participation in this study.

Questions

If you have further questions or concerns about participating, please call our study staff at *[insert telephone number]*. You may also contact *[insert names, roles, and telephone numbers of individuals responsible for the implementation of the study. These may include the chair of the ethical review committee or study principal investigator or coordinator]*.

Legal Rights

You are not waiving any of your legal rights by signing this informed consent document.

SIGNATURES

Your signature below indicates that you agree to participate in this study. You will receive a copy of this signed document.

Signature of Participant

Date

Signature of Investigator

Date

Signature of Witness (if needed)

Date



For more information, contact:

Health Policy Project
Futures Group
1331 Pennsylvania Ave NW, Suite 600
Washington, DC 20004
Tel: (202) 775-9680
Fax: (202) 775-9694
Email: policyinfo@futuresgroup.com
www.healthpolicyproject.com