USAID
FROM THE AMERICAN PEOPLE

WORKING REPORT MEASURING HIV STIGMA: RESULTS OF A FIELD TEST IN TANZANIA

JUNE 2005

This publication was produced for review by the United States Agency for International Development. It was prepared by the Tanzania Stigma-Indicators Field Test Group on behalf of Social & Scientific Systems, Inc., under The Synergy Project through Contract HRN-C-00-99-00005-00.

Acknowledgments

This work and the resulting report were facilitated through the contributions of numerous individuals and members of the study communities.

We give special thanks to all the respondents who so willingly shared their time and insight with us on such a sensitive topic. Without them, this work would not have been possible.

The project teams in Tanzania—field, data entry, and administrative—require particular recognition. Their hard work, diligence, and dedication ensured the success of this project. Thanks go to Jeremia Willison Matiko, Field Coordinator; Elizabeth Semwaiko, Field Enumerator; Fabiola Upendo and Happiness Manase, Data Entry Clerks; Zawadi Shomari, Lucy Francis, Irene Lema, Gloria Karungula, Isack Abdiel, Katikirro Mujaya, and Temina Abeid, Interviewers.

We are grateful for the support and direction from many institutions and individuals, both in Washington and in Tanzania. In particular, the core members of the USAID Stigma and Discrimination Indicator Working Group (S&DIWG): Cameron Wolf and Billy Pick (USAID), Julie Pulerwitz (Horizons), and Lane Porter (POLICY Project).

This work would not have been possible without the funding and support of USAID and the Synergy CTO, Neen Alrutz.

A special thanks also goes to Jennifer Ramsey at ICRW for her administrative support in pulling this report together. We are particularly grateful for her calm, efficient, and unflappable demeanor, despite the extensive number of tables and daunting length of this report.

We would also like to thank the Synergy editors for undertaking the final editing and formatting.

ICRW
International Center for
Research On Women

THE SYNERGY PROJECT

WORKING REPORT MEASURING HIV STIGMA: RESULTS OF A FIELD TEST IN TANZANIA

Measuring the Results of HIV Stigma Field Test in Tanzania is the result of collaborative efforts among the Tanzania Stigma-Indicators Field Test Group, which includes the following individuals and organizations:

- Laura Nyblade and Kerry MacQuarrie, International Center for Research on Women
- Fausta Phillip, Gideon Kwesigabo, Jessie Mbwambo, and John Ndega, Muhimbili University College of Health Sciences
- Charles Katende and Elaine Yuan, The Synergy Project/Social & Scientific Systems, Inc.
- Lisanne Brown and Anne Stangl, MEASURE Evaluation/Tulane University

CONTENTS

INDEX OF TABLES

INDEX OF FIGURES

ACRONYMS AND ABBREVIATIONS

AIS	AIDS Indicator Surveys (Macro International)
Blue Book	USAID Expanded Response Guide to Core Indicators for Monitoring and Reporting on HIV/AIDS Programs
DHS	Demographic Health Surveys (Macro International)
ICRW	International Center for Research on Women
MTCT	mother-to-child transmission
MUCHS	Muhimbili University College of Health Sciences
PLHA	person/people living with HIV/AIDS
PMTCT	prevention of mother-to-child-transmission
S&DIWG	Stigma and Discrimination Indicator Working Group
SHARAN	Society for Service to Urban Poverty

1. BACKGROUND

SECTION 1.1: RATIONALE

Stigma and discrimination pose critical obstacles to stemming the HIV/AIDS epidemic. Increasingly, programs are addressing this problem, and it is thus essential to monitor and evaluate those efforts. There are currently no standard indicators to measure stigma and discrimination in developing-country contexts. As a part of its guidance to measure the effectiveness of an expanded response to the HIV/AIDS epidemic, the United States Agency for International Development (USAID) pressed for stigma indicators to be included as core indicators. The USAID Stigma and Discrimination Indicator Working Group (S&DIWG) was formed to address this gap, and, more specifically, to contribute to the monitoring and evaluation of USAID's expanded response to the HIV/AIDS epidemic. Based on the best suggestions from program experts and researchers grappling with stigma at the time, members of the S&DIWG proposed a set of indicators for the USAID expanded response in May 2002. These proposed indicators were subsequently included in the January 2003 edition of USAID's *Expanded Response Guide to Core Indicators for Monitoring and Reporting on HIV/AIDS Programs* (commonly referred to as the "Blue Book"). In February 2004, the S&DIWG reviewed these indicators in a daylong workshop with experts working in the arena of stigma and issued a series of recommendations to make the indicators more specific and measurable. While these efforts, particularly the February 2004 revised indicators, represent improvements in stigma indicators, they remained untested until now.

The demand for stigma indicators has continued to increase, particularly from USAID global missions and their partner agencies. Implementing agencies and donors need tested indicators by which they can reliably assess stigma in a given setting and measure progress in reducing it. In response to this need, USAID funded this first step, i.e., *field-testing and validation of an initial set of stigma indicators* at one site in Tanzania. This project builds expressly on the findings of the International Center for Research on Women (ICRW) and its partners in a multi-country study on stigma (Nyblade et al. 2003), and on the Horizons and POLICY Project work on stigma. The specific aim of this project is to examine, test, and validate selected stigma indicators from the Blue Book and the 2004 S&DIWG workshop. The results of this effort are found in this working report.

SECTION 1.2: PARTNERS

This study was conducted by a core group of S&DIWG members and their institutions. This activity was specifically implemented by ICRW, The Synergy Project/Social & Scientific Systems, Inc., and the Department of Psychiatry at Muhimbili University College of the Health Sciences (MUCHS) in Tanzania, with technical support from MEASURE Evaluation/Tulane University. The larger membership of the S&DIWG, in particular the Horizons Program, The POLICY Project, and USAID, served as an advisory group.

SECTION 1.3: DEFINITIONS

The standard point of departure for defining stigma is Erving Goffman's classic study on stigma related to mental illness, physical deformities, and what were perceived to be socially deviant behaviors (Goffman 1963). Goffman describes stigma as "an attribute that is deeply discrediting" and results in the reduction of a person or group "from a whole and usual person to a tainted, discounted one." He goes on to note that by regarding "others" negatively, an individual or group confirms its own "normalcy" and legitimizes its devaluation of the "other."

Expanding on Goffman's work, Link and Phelan describe stigma as a dynamic process occurring within the context of power (2001). This process has four distinct steps. The first three steps seek to divide the "tainted" from the "usual" people by distinguishing and labeling differences, associating negative attributes with those differences, and separating "us" from "them." Gilmore and Sommerville describe these three steps in the process as allowing the others ("them") to be perceived as non-persons (1994). This allows the "us" to distance themselves from the negative attributes of the "others," to justify treating the "others" in negative ways that would be unacceptable if they were one of "us," and to prevent "us" from being treated in the same negative manner. These steps culminate in the fourth and final step in Link and Phelan's process—status loss and discrimination for the stigmatized. Thus, the ultimate effect of stigma, as noted by Goffman, is the reduction of the life chances of the stigmatized through discriminatory actions (1963).

In keeping with Goffman, and Link and Phelan, therefore, we do not conceptualize discrimination as separate from stigma, but as the end result of the process of stigma—in effect, "enacted" stigma. We define discrimination (or enacted stigma) as the negative acts that result from stigma and that serve to devalue and reduce the life chances of the stigmatized. A somewhat different definition of the word discrimination may be used by the legal or human rights communities in their work on HIV-related discrimination (Carael et al. 2000).

Goffman notes that the stigmatized often accept the norms and values that label them as having negative differences (1963). As a result, stigmatized individuals or groups may accept that they "deserve" to be treated poorly and unequally, making resistance to stigma and resulting discrimination even more difficult. This phenomenon is often termed "internalized stigma" (also sometimes termed "self-stigma"). Research shows that this internal stigma manifests in many ways, including self-hatred, self-isolation, and shame (Crandall 1991; Alonzo and Reynolds 1995; Lee et al. 2002). Compound stigma (also referred to as multiple stigma) is HIV stigma that is layered on top of preexisting stigmas, frequently toward homosexuals, commercial sex workers, injecting drug users, women, and youth (Herek and Capitanio 1993; Herek et al. 2002; Boer and Emons 2004; Brown et al. 2004; Kalichman and Simbayi 2004; Nyblade 2004).

SECTION 1.4: STIGMA'S MAIN DOMAINS

Based on existing work, especially that of ICRW and its partners, Horizons, The POLICY Project, and other participants in the S&DIWG's February 2004 meeting, the following domains were selected as the key areas for which indicators (and accompanying questions) are needed to enable comprehensive measure of stigma.

- Fear of casual transmission and refusal of casual contact with people living with HIV/AIDS (PLHA)
- Values: shame, blame, and judgment
- Enacted stigma (discrimination)
- Disclosure

From existing work, it is clear that there are two essential “causes” of HIV stigma: the continued fear of casual transmission, which stems in large part from a lack of depth in knowledge; and the moral dimension of stigma that justifies stigma through judgment, shame, and blame (Nyblade et al. 2003). These two domains indicate what programs will need to change if reduction of stigma is desired. Having a separate measure for each domain is necessary to determine if programs have more success in changing one domain than other. A composite measure, on the other hand, may lead to faulty conclusions about what is or is not happening as a result of a specific program. For example, if a program is working to reduce stigma by improving knowledge of transmission and reducing fear of casual transmission, but is not working to change the other key underlying cause—values shame, blame, and judgment—a composite measure of stigma may indicate that the program is having little impact on stigma overall, when, in fact, it is having impact on the portion of stigma that is driven by fear. However, use of more detailed indicators may signal whether the program has an impact on the one domain of stigma that it is trying to change, rather than the other.

In addition to these two domains, disclosure is an important area to measure, because it is a critical link between stigma and its negative effects on programs. Stigma impedes disclosure, which in turn affects prevention, care, support, and treatment. The extent of disclosure is often thought to be a good proxy measure for stigma or a measure of the “stigma” climate. Enacted stigma (discrimination) is very critical, yet thus far we have had no measures for it at the population level and very little measurement of it among PLHA.

SECTION 1.5: EXISTING MEASURES OF STIGMA

The largest problem with measuring stigma and discrimination in the developing-country context is the fact that there are very few tested and validated measures from which we can develop indicators. A review conducted as a part of this study identified a number of stigma measures that were commonly collected and also identified many gaps (Nyblade 2004).

The review revealed that most studies of stigma in the general population measured HIV/AIDS knowledge through questions on modes of transmission (correct and incorrect), prevention, and, in some cases, disease progression (Herek and Capitanio 1993; Herek et al. 2002; Boer and Emons 2004; Brown et al. 2004; Kalichman and Simbayi 2004). These studies also included some form of an indirect question to measure fear of casual transmission of HIV.

Studies that examined responsibility and blame[1] assessed the degree to which respondents felt that PLHA were responsible for contracting HIV and, therefore, had themselves to blame for being infected. Typical questions in the shame domain assessed agreement with statements such as “PLHA should be ashamed of themselves.” A few studies also included items on guilt. A related construct that was sometimes included is the belief that PLHA are being punished by God for their sins (Blendon and Donelan 1988; Dubbert et al. 1994; Crandall and Moriarty 1995; Fawole et al. 1999; Fife and Wright 2000; Boer and Emons 2004).

---

[1] Sometimes referred to as *victim blaming*

Other studies among the general population sought to measure negative feelings or emotional reactions to PLHA. Those that went beyond emotional reactions to behaviors assessed respondents' willingness to interact with PLHA. This was done most commonly, however, through hypothetical questions. Finally, some studies examined respondents' support for coercive measures toward PLHA such as quarantine, denial of entry into a country, mandatory reporting of status, and routine or regular testing of people at risk for contracting HIV (Snell et al. 1991; Herek and Capitanio 1993; Porter 1993; Green 1995; Johnson 1995; Herek and Capitanio 1997; Herek et al. 2002; Boer and Emons 2004; Kalichman and Simbayi 2004; Morrison 2004).

Studies assessing stigma related to PLHA fall broadly into three main categories of measurement: perceived stigma; experienced stigma; and internalized stigma. Measurement of internalized stigma, the last category, focused on how external stigma led to internal stigma in the form of negative self-image. In the first category, studies assessed how PLHA respondents perceive their partners, friends, family, and community might react to PLHA (Berger et al. 2001; Derlega et al. 2002; Clark et al. 2003; Preston et al. 2004; Swendeman et al. 2004). These studies either inquired about perceptions of attitudes—what others would think, or how supportive or unsupportive they would be of a person with HIV—or fear of behaviors—what PLHA thought would happen if others knew about the respondent's HIV status. Examples include losing friends, family rejection, being blamed, being avoided, or others[1] being uncomfortable around the respondent.

Only a few studies were found that had quantitative measures of the actual stigma PLHA experienced (Fife and Wright 2000; Berger et al. 2001; Asia Pacific Network of People Living With HIV/AIDS 2004; Swendeman et al. 2004). These studies measured enacted stigma (discrimination) in the form of denial of rights to health, education, and employment. They also measured exclusion by family and community (e.g., a person's refusal to eat with the respondent, or keeping children away from the respondent), loss of respect, and physical and verbal abuse or violence (e.g., ridicule toward the respondent, harassment, threats of violence, or assaults).

SECTION 1.6: CHALLENGES TO MEASURING STIGMA INDICATORS

Key challenges remain for any effort to measure stigma. An overarching challenge to measuring HIV stigma, especially relevant to evaluating whether programs and policies reduce stigma over time, is measuring an increase in HIV stigma that is not necessarily a 'true' increase, but rather a reporting increase due to improved awareness and recognition of HIV stigma. Other common challenges are:

- Sample selectivity and bias (particularly with studies among PLHA)
- Ambiguity of survey questions, and the meaning of indicators derived from them
- Collection of data about actual, rather than hypothetical, enacted stigma
- Refinement of existing measures at the general-population level

---

- Covering of all key domains of stigma, and expanding the contexts from which HIV stigma data is collected

The main challenge for measuring stigma among PLHA is sample selectivity. The only way to ethically contact PLHA for a survey is with a request for participation through networks of PLHA, service organizations, and health care providers, which precludes the possibility of obtaining a random sample of all people living with HIV. As a result, any data collected from PLHA may present biased results, as the data will be from a very select group of PLHA. PLHA participating in any study will: (a) have to know they are HIV-positive; and (b) belong to an association or be in search of social or health services from selected organizations that necessitates some level of public disclosure of HIV status. Those who fear or have experienced the most HIV stigma may be the least likely to have been tested or, if tested and positive, to participate in a group or seek services. Because this study also recruited PLHA respondents via networks of PLHA, it too suffers from this limitation.

Current measures of stigma focusing on HIV/AIDS knowledge, fear of casual transmission, or social distancing often suffer from ambiguity and the inability to specify the underlying cause (motive) for the action. Furthermore, many of the questions present hypothetical situations that may not accurately reflect how people might really act in a given situation. Consider the typical question, “Would you be willing to share food with a person with HIV/AIDS?” Ambiguity arises from the use of the words “share food,” as we do not know how the respondent interprets this term. Does it mean sitting at the same table, eating from the same plate, using utensils that might have been used by a PLHA, or perhaps even eating food the PLHA has prepared?

The interpretation often given to such a question is that a negative response indicates the presence of stigma driven by inadequate knowledge and/or fear of casual transmission of HIV. Yet, while this is a plausible explanation, we cannot know for sure. Partaking of food or drink together, whether in the home, bar, or tea/coffee house, is an important social activity in many cultures. Refusing to eat with a PLHA may not necessarily be about fear of casual transmission of HIV, but may be instead a form of social censure because the person is assumed to have contracted HIV through “immoral behavior.” Understanding the specific reason a person engages in a particular stigmatizing behavior is especially critical to developing effective programs to reduce stigma and may signal a different programmatic approach, depending on whether the cause is fear of casual transmission or negative judgments about PLHA. This study responds to the challenge of ambiguity in wording and underlying motives by refining the wording of questions, asking similar questions in different ways, and asking open-ended, follow-up *why* questions.

No studies attempting to measure actual occurrences of enacted stigma at the general population were found in the literature review conducted by Nyblade (Nyblade 2004). This is not surprising given the inherent challenges in doing this. The very presence of stigma means that asking any survey questions about a respondent’s HIV status is unethical, removing the possibility of asking respondents whether they themselves have experienced HIV stigma, except for in surveys with PLHA. Additionally, a direct question asking the respondent if they themselves have engaged in stigmatizing behavior toward someone else is likely to suffer from a socially desirable, as opposed to truthful, response, particularly as programs to reduce stigma grow and more people become aware of stigma as inappropriate or socially undesirable behavior. This is also the case for hypothetical questions about stigma. While it is not surprising that there are no studies measuring enacted stigma at the general population level, the same review found surprisingly few that measure the actual experience of stigma among PLHA (Fife and Wright 2000; Berger et al. 2001; Asia Pacific Network of People Living With HIV/AIDS 2004; Swendeman et al. 2004). This study seeks to overcome this gap by investigating the occurrence of enacted stigma among three population groups: general community members, PLHA, and health care providers.

A recent study of the causes, forms, and consequences of HIV stigma in Africa untangled the complexities of stigma and identified discrete domains (Nyblade et al. 2003). Most studies of stigma measure only one or a few domains of stigma and not all of them. In addition, the more comprehensive studies reviewed by Nyblade were usually conducted in small samples, or with very narrow groups of respondents (e.g., undergraduate students in the United States), while studies with larger, more representative samples only asked a few, often ambiguous, questions related to stigma (Nyblade 2004). Two aspects of HIV stigma stand out as lacking measurement at the population level: enacted stigma and compound stigma (HIV stigma that is layered on top of pre-existing stigmas, frequently toward homosexuals, commercial sex workers, injecting drug users, women, and youth). This study undertakes a far more comprehensive investigation of stigma by including indicators in numerous domains among a broad sample of the general population and two specific populations (PLHA and health care providers).

2. METHODS

As described in the previous section, HIV-related stigma is a complex construct with multiple dimensions. Therefore, a set of items or questions (as opposed to a single one) is tested to try to capture the complexity of each key dimension. Based on the existing literature and data, we measured items in four key domains: fear of casual transmission and avoidance of casual contact with PLHA; values and attitudes, including shame, blame, and judgment; the experience of stigma and discrimination (enacted stigma); and disclosure of HIV status. The first two domains are latent, or not directly observable, while the last two are manifest or observable.

Scales were developed and tested to measure the two latent domains, while an index and single-item indicators were tested for the manifest domains. Developing scales or indices is important when a single item or question may not capture the complexity of the phenomena. A scale composed of several items offers greater validity and precision when measuring an underlying, unobservable, or latent construct. Where we cannot measure the construct directly (e.g., stigma due to attitudes and values), we assess the relationships between a set of items that we believe reflect the latent or unobservable variable, such as responses to a series of attitudinal or value statements that we expect reflect HIV-related stigma (Spector 1992; DeVellis 2003; Netemeyer et al. 2003).

The complexity of stigma also indicates the need to develop indicators to measure stigma with specific groups. While some indicators may work across multiple sub-groups of the population, others will be critical to only one or a few groups, or will need to be measured in different ways for different groups. For example, although enacted stigma is an important indicator across all groups within a population, it will be measured differently among PLHA as opposed to the general population. Additionally, some indicators may be more important for women as opposed to men if, for example, one gender experiences different forms of stigma than the other. Similarly, there are added dimensions among health care providers (e.g., work-related exposure) as compared to the general population that need to be measured, along with indicators such as fear of casual transmission of HIV. The scope of this project allowed us to focus on three groups: community/general population, people living with HIV and AIDS, and health care providers. Across all groups, a “good” indicator is one that is:

- **Valid:** an accurate measure of a behavior, practice, or task
- **Reliable:** consistently measurable, in the same way, by different observers
- **Precise:** operationally defined in clear terms
- **Independent:** non-directional and unidimensional, depicting a specific, definite value at one point in time
- **Measurable:** quantifiable, using available tools and methods
- **Timely:** provides a measurement at time intervals relevant and appropriate in terms of program goals and activities
- **Programmatically important:** linked to a public health impact or to achieving the objectives that are needed for impact

The focus of this project is to test and evaluate the indicators proposed by the S&DIWG and the Blue Book for each of four key domains, with a focus on evaluating reliability and validity of indicators that are programmatically important, timely, independent, and measurable.

Reliability is a statistical measure of the reproducibility of a survey instrument. As no measure is perfectly reliable, there is always some possibility of measurement error. When assessing the quality of a data set, one usually begins with an examination of the reliability characteristics of the measurement instrument, using three different techniques: test–re-test, alternate form, and internal consistency.

Test–re-test reliability examines the correlation in responses to the same questions, asked of the same respondent, by the same interviewer, at different points in time. The scope of this project does not allow for assessment of standard test–re-test reliability, as it did not allow for interviewers to return to the field a second time to ask the same questions. A selected few questions were asked twice within the same questionnaire/ interview, and the responses to these are compared for reliability. Certain limitations of this comparison should be noted: (1) the time elapsed between repeat questions is relatively brief (i.e., respondents are likely to remember what they answered before and question why the question is being repeated) and, (2) to ensure some “distance” between questions, repeat questions were posed at the end of the interview, when respondents often suffer from fatigue.

Inter-rater reliability examines the consistency of responses to a single question that is assessed twice with the same respondent but by different interviewers. The scope of this project did not allow for inter-rater reliability measurement.

Internal reliability examines how highly inter-correlated items within a scale are to each other. The more highly correlated, the higher the reliability of the scale. We assess internal reliability for the two latent domains (fear/refusal of contact and attitudes/values). Internal reliability was assessed using *Cronbach's Alpha*.[2]

Reliability examines to which degree items are measuring the same construct (e.g., stigma caused by attitudes and values), as opposed to *validity*, which focuses on whether the underlying variable (HIV stigma due to attitudes and values) is the true cause of the co-variation between the items being assessed (i.e., whether an item or scale is measuring what it is supposed to measure, such as HIV stigma related to attitudes and values). It is possible to have a reliable scale (all items measuring the same construct–items highly correlated) that is not necessarily valid (e.g., scale is measuring a different construct from the one intended). Validity is typically inferred from all or one of the following: content, criterion, or construct validity.

Content validity relates to the extent to which an item, or specific set of items, truly reflect the content of a particular domain. In particular, content validity focuses on the manner in which items are chosen or the scale is constructed. Content validity is typically assured by choosing items that are supported by existing data and by having experts review items. The choice of items for this project was based on existing data, in particular the collective work and expertise of the members of the S&DIWG and the questionnaires developed by a small group of experts.

Criterion-related validity, sometimes referred to as *predictive validity*, is an assessment of an item or scale (typically by correlation coefficient) against an existing criterion or gold standard. Given the nascent nature of measurement of HIV-related stigma, there is no gold standard against which to compare our data and indicators. We hope our work contributes to the development of such a gold standard.

Construct validity examines the extent to which a given measure behaves in the manner expected, given theory, hypotheses, and experience vis-à-vis other variables. In particular, it is the relationship between the item or scale being evaluated and other known/established variables in the expected direction and magnitude. For example, we might expect that a scale of fear of casual transmission of HIV will be related to knowledge about how HIV is or is not transmitted. We might expect that individuals with incomplete or incorrect knowledge of HIV will be more fearful of casual transmission of HIV than individuals with complete, correct knowledge of HIV transmission. For each of the four domains, where possible, we will detail and then examine the construct validity of the individual items or scales we are testing by examining the expected relationships of the indicator against other variables.

---

[2] Coefficient of reliability (consistency) measuring how well a set of items measures a single unidimensional latent construct

3. PROCESS

SECTION 3.1: QUESTIONNAIRE DESIGN

The process the study team undertook began with the design of three separate questionnaires: community/population, PLHA, and health care provider. The community questionnaire was designed first, and common elements, where appropriate, were integrated into the PLHA and provider questionnaires. The process of development for all three questionnaires was to develop an outline of key domains and issues that should be covered, review existing instruments, and then develop individual questions based on the existing instruments and identified domains. The project team worked collectively on this process. They also ensured that all the proposed stigma indicators were measured and that all AIDS Indicator Survey[3] stigma questions were included in the community survey.

Once a final draft of the English version was complete and agreed upon, it was translated into Kiswahili. The first round of pre-testing of the Kiswahili version was done with the trainees during training. Revisions were made based on their input. This version was then pre-tested. For the community questionnaire, pre-testing was done in Kawe ward, Kinondoni district, Dar-es-Salaam (some distance from our study community), and changes were made accordingly. Once a final version of a questionnaire was ready, a revised English version was produced, based on the final Kiswahili.

SECTION 3.2: SAMPLING

SECTION 3.2.1: COMMUNITY SURVEY IN KIMARA WARD, KINONDONI DISTRICT

Kimara Ward was selected as the site for the community sample for two reasons: to allow comparison with previously collected qualitative data on stigma, and because of a planned community stigma-reduction intervention by Kimara Peer Educators and Training Trust. An important element of testing indicators is examining how they perform over time and around an actual intervention. The hope was that a second phase of funding would allow additional testing of the indicators by conducting a follow-up survey at the end of the community stigma-reduction intervention in Kimara. Therefore, sample size estimates were based on estimating differences between two proportions, with proportion one being the proportion anticipated at the present time (the baseline), and proportion two the proportion one might anticipate in a cross-sectional survey after one year of stigma-reduction activities in the community. The following parameters were used to determine the estimated sample size: power, 80%; confidence level, 95%; ratio of first to second survey, 1:1; possible detectable differences between the two samples, 5%; and estimates of the outcome variable, 20–25%. Based on these parameters, a sample size of 1,134 was calculated.

Probability sampling methods were employed to obtain the study population. In particular, the cluster-sampling technique, with probability proportional to size method, was adopted. The administrative structure was used as the sampling frame. Administratively, a district comprises divisions, wards, streets, balozis[4] (formally 10 cell units), and households. To

---

[3] AIDS Indicator Surveys (AIS) are being conducted by Macro International, with U.S. government funding, in countries participating in the President's Emergency Plan for AIDS Relief.

[4] Balozis are the smallest unit of the government administrative system.

obtain the study population in Kimara ward, the streets in the ward were listed together with the corresponding balozis. All five streets in Kimara ward were included in the study. From the listed 288 balozis, an effective sampling interval of three was applied to obtain the 100 clusters (balozis) required for the study. A cluster was defined as one balozi—a group of approximately 10 households. The number of clusters obtained from one street was proportional to the size of the street (i.e., streets with larger populations contributed more balozis than those with a smaller population).

For each balozi selected, the respective households were listed, and six households were randomly selected. From each selected household, one male and one female aged 16 years or older were randomly selected for participation in the study. To obtain accurate information, an enumerator, working with the research assistants, updated each level in the sampling frame before selection was done.

A total of 1,196 respondents were selected for participation in the study, and 978 participated fully by responding to the administered questionnaire. The remaining 218 could not participate due to the following reasons: non-eligibility (105), could not be found after three strategic visits (82), moved (6), dead (2). The remaining 23 persons declined to participate. The response rate for the community survey was therefore 978/1083 = 90.3%.

SECTION 3.2.2: PEOPLE LIVING WITH HIV/AIDS SURVEY

The questionnaire for PLHA was administered to a purposively selected sample of 218 people living in/around Dar-es-Salaam district. Respondents were recruited into the study via one of several organizations with a membership or clientele of people living with HIV/AIDS: Service Health and Development for People Living Positively with HIV/AIDS, Mbagala Dispensary, Mbagala Kizuiani, and the Magomeni-TAYOPA (Tanzania Young People Living with AIDS) counseling centers.

An initial sample size of 100 was determined to fall within the minimum required size on which statistical tests could be meaningfully conducted and within the maximum that the study resources could support. However, the majority of the first 100 respondents, recruited from the first organization, were women. Therefore, a second wave of recruitment and data collection was needed, made up of greater numbers of male respondents, to ensure equal numbers of men and women respondents. Data collection resumed 3–4 months later, after the recruiting strategy was modified to enroll more men. At the final tally, 103 women and 115 men participated in the study.

SECTION 3.2.3: HEALTH CARE PROVIDERS SURVEY

A sample of 100 respondents was drawn for the health care providers survey from three locations: Muhimbili National Hospital, Mwananyamala District Hospital, and the Kimara Government Dispensary. A sample size of 100 was determined to fall within the minimum required size on which statistical tests could be meaningfully conducted and within the maximum that the study resources could support.

Muhimbili National Hospital is a referral and teaching hospital. It provides services to patients referred from lower level health facilities from across the country. It has a capacity of 1,000 beds, with 1,254 health care providers of which 105 are doctors (52 medical specialists, 53 medical officers), and 1,149 are nurses (281 registered nurses, 300 enrolled nurses, 568 health attendants).

To select respondents, a list of all health care facility workers was obtained from the administration of Muhimbili National Hospital. Administrative staff was excluded from the sampling frame. The rest of the staff (doctors, nurses, and attendants) were then stratified by cadre, and random samples were drawn from each cadre, using a systematic sampling approach, after working out the sampling interval. Out of the 105 doctors, every other third was sampled. For nurses and attendants (1,717), every 30th was sampled. Out of the 78 persons selected, 44 participated in the study by responding to the questionnaire. Three of the remaining 34 declined to participate; 18 could not be reached after three attempts; and 13 were ineligible (e.g., not clinical staff) despite being listed otherwise.

Mwananyamala Hospital is the Kinondoni District (municipal) hospital with the mandate to deliver and monitor health services for the district, attend referrals from lower level facilities, and refer difficult cases to higher level facilities. Hospital facilities provide outpatient and inpatient services with a capacity of 162 beds, attended by 168 health care providers, including two medical specialists, 16 assistant medical officers, 13 clinical officers, and 136 nurses and clinical service supportive staff.

A list of all doctors/clinical officers, nurses, and attendants (168) was obtained from the administration of Mwananyamala Hospital. All doctors/clinical officers (32) were included in the study. Of the nurses/attendants, every third was selected for participation in the study, for a total of 45 individuals. Out of the 77 selected staff, 42 participated fully by responding to the questionnaire. The remaining 35 were not available due to being on holiday, in training, sick, or off duty.

Kimara dispensary is a government health facility for Kimara ward, providing services for about 70,000 people. It has 16 health care providers (five clinical officers, one nurse officer, two nurse midwives, two public health nurses, four nurse attendants, and two maternal and child health attendants). The dispensary offers outpatient services only, including maternal and child health and antenatal care, as well as family planning. It has a maternity room for uncomplicated deliveries (provided with one delivery bed and one examination bed) and an observation room (two beds; 12-hour observation maximum). For the Kimara Government Dispensary, 14 of 16 employees were available[5] and interviewed as a part of the study.

SECTION 3.3: DATA COLLECTION

Training of the data collection team was conducted at the premises of Kimara Peer Educators and Health Promoters Trust Fund, Kimara Ward, Kinondoni District, Dar-es-Salaam. The research team involved 13 interviewers (four males and nine females). Training lasted for two weeks and covered the following topics: (1) understanding HIV-related stigma based on the results of the multi-country research study, (2) the study objectives, (3) the research instrument, (4) data collection procedures, and (5) data editing and consistency checks in the questionnaire. Participants studied the questionnaire section by section and question-by-question, referring to the interviewers manual as needed. Brainstorming, paired group

---

[5] Two providers were absent during interviews: one was away at a training course, and one was sick.

discussions, and role-playing were used to facilitate understanding of the concepts of HIV stigma and discrimination and of the questions employed in the research instruments. Both the data manager and the data entry clerks participated in the training to gain an understanding of the data collection instruments, which facilitated the data entry process.

A pilot test took place over two days during the second week of training. Two "streets" (mitaa) of Kawe ward in Kinondoni district were selected for this exercise. A pilot area far from Kimara was selected to avoid contamination with the study area. Interviewers randomly selected one male and one female present at the time each household was visited.

When the full study was mounted, arrangements were made to ensure that the randomly selected individuals were visited and interviewed. To facilitate this activity, members of the research team were allocated to the local administrator, who led them through the selected households. Upon selection of the study participants, interviews were conducted in private after informed consent was obtained. Informed consent was obtained orally and confirmed in writing by the interviewer. If the selected respondent was not available at the time, appointments (callbacks) were scheduled for future strategic visits. A person was declared "nonrespondent" if he/she could not be found after three strategic visits.

SECTION 3.4: DATA MANAGEMENT

Questionnaires were checked for errors, consistencies, and gaps in the field by the field supervisor. The questionnaires were also edited in the office by the office data editor/manager before data entry. Three data entry screens were developed (to correspond with the field questionnaires), using Epi Info Version 6.04. Before data entry, each questionnaire was given a unique ID to facilitate data cleaning later in the process. Each dataset was entered twice by two data entry clerks, checked for errors and inconsistencies, cleaned, and validated. Coding of open-ended questions and merging of files (e.g., questionnaire sections originally entered separately or data from the two waves of PLHA data collection) was executed after data was exported from Epi Info to SPSS.

SECTION 3.5: ORGANIZATION OF FINDINGS

The findings section is organized first by the population surveyed (community members, health care providers, and PLHA) and then by key stigma domains appropriate for the particular population. For each domain, we present existing and new indicators that were tested, questions asked to collect data relevant to the indicator, and basic frequencies for those questions. We then present further analysis of individual items, indexes, or scales, focused on reliability and validity testing, where appropriate. Each section closes with our recommendations for indicators and associated data collection questions/items for that particular domain, based on this population. These are made based on the results of the analysis and taking into consideration programmatic relevance and importance.

Conclusions and specific guidance for measuring the recommended indicators (e.g., as single indicators, scales, or indices) are summarized in table format in the conclusion section that follows. We provide recommendations for indicators at two levels (*Essential* and *Expanded*) to accommodate the varying needs, interests, and resources of different organizations for data collection. The first level comprises what we term *Essential-level indicators*—the minimum set of indicators recommended for each domain. We then provide a set of recommendations for *Expanded-level indicators* for those wishing to collect more comprehensive stigma evaluation data. A revised set of questionnaires that reflect lessons learned about which survey questions worked well and which did not can be found in Appendix C.

These recommendations are the first step in a process of indicator testing and validating that must include studies at additional sites. This is a working document describing the initial findings from this first field test and aimed at generating feedback, discussion, and a basis on which to move forward in further developing, refining, and testing HIV-stigma indicators.

4. COMMUNITY/POPULATION

As described in the Background section, a random sample survey was conducted among 978 respondents in Kimara Ward, Kindononi district, Tanzania. Table 1 presents the background socio-demographic characteristics of the sample.

Table 1. Background Characteristics of Community Sample

Background characteristics	**Percent**
Sex	
Female	53.3
Male	46.7
Age	
15–24	27.1
25–34	28.1
35–44	22.5
>44	27.1
Education	
No formal	7.5
Primary	58.7
Post-primary	25.5
University	8.4

Table 1. Background Characteristics of Community Sample (continued)

Background characteristics	Percent
Marital Status	
Married or cohabiting	61.3
Divorced	3.5
Widowed	4.7
Never married	30.5
Religion	
Catholic	36.2
Muslim	35.7
Lutheran	15.1
Anglican	4.7
Tanzania Assemblies of God	4.3
Seventh Day Adventist	1.9
Pentecostal	1.4
Other	0.5
None	0.1

Two key limitations need to be taken into consideration regarding the community sample. The first is that some of the questions were completely new and were being asked for the first time in a quantitative manner. Therefore, we had no prior experience to draw on to guide the formulation of these questions and no existing findings to use as a gold standard for comparison. The second limitation is the potential for *social desirability bias*. Many of these questions, particularly those that deal with hypothetical actions or attitudes, risk this kind of bias, as respondents may provide answers that reflect what they think are “correct” or “desirable” responses rather than their own true feelings or beliefs.

We now turn to an examination of indicators within the four specific domains: (1) fear of “casual” transmission of HIV and refusal of contact with PLHA; (2) shame, blame, and judgment; (3) enacted stigma; and (4) disclosure.

SECTION 4.1: FEAR OF “CASUAL”[6] TRANSMISSION OF HIV AND REFUSAL OF CONTACT WITH PLHA

While the focus in this area, as reflected in the existing indicators presented in Table 7, has been on measuring willingness to interact with PLHA, we have chosen to label this domain ***fear of “casual” transmission and refusal of contact with PLHA***. The label acknowledges a key underlying cause of refusal of “casual” contact with PLHA, namely the fear of contracting HIV from PLHA through non-invasive contact that includes no risk of HIV transmission.[7] From a program standpoint, in addition to measuring actual behavior (refusal of contact with PLHA), it is important to understand and measure the underlying cause of that behavior. Several studies (Nyblade et al. 2003; Hong et al. 2004; Ogden and Nyblade 2005) show that fear of contracting HIV through casual transmission is a key driving factor for the stigmatizing behavior of refusing “casual” contact with PLHA. They also argue that, to reduce stigma related to fear, programs need to analyze and address the specific fears people hold. Therefore, we present first the existing indicators and then a new proposed indicator on fear of transmission. For each indicator, we present the questions/items[8] used in the questionnaire to collect the data related to it, their basic frequencies, and, where appropriate, their reliability and construct analysis. Finally, we offer recommendations on prioritization of the indicators in each domain, questions to use in collecting the appropriate information, and future steps for further indicator testing and development.

Existing Indicator

Table 2 presents the existing indicator, including its original formulation from the Blue Book (USAID 2003) and a modified version proposed at the February 2004 S&DIWG workshop. To collect data for existing indicators, we used standard questions (see Table 2) found in many large-scale surveys that include modules on HIV and AIDS, such as Macro International’s Demographic and Health Surveys (DHS).

There are several limitations to these standard questions. The first is that they measure a hypothetical situation rather than actual behavior. The second is that the responses are likely to suffer from social desirability bias. Respondents are likely to say they would not engage in this type of behavior (even if they do) because they know that it is socially unacceptable (not desirable) to refuse contact with PLHA. As stigma-reduction campaigns become more widespread, these questions are more likely to suffer from this type of bias. The third is that it is not clear what some of these questions—particularly the ones about buying food, providing care, or allowing teachers with HIV to teach—are actually measuring.

---

[6] “Casual” contact means contact that carries no risk of HIV transmission, such as touching a person living with HIV or an object he/she has handled (i.e., contact that involves no invasive transfer of body fluids).

[7] See Ogden and Nyblade (2005) for a detailed discussion of these particular fears, including how they drive stigma and why they continue to exist despite education campaigns.

[8] The survey terns *question* and *item* are used interchangeably throughout this document.

Table 2. Fear of casual contact: Existing indicators, items, and frequencies

Existing Selected Indicators	Questions in survey corresponding to indicator(s) (n=978 if not stated)	Response Category	Percent
1. Percent of people who would refuse casual contact with a person living with HIV/AIDS (Blue Book) 2. Percent of people who would not have casual contact with a PLHA because they are worried about contagion (S&DIWG)	**In a market of several food vendors, would you buy food from a PLHA or person suspected of HIV/AIDS**	Yes	88.7
		No	11.3
	If no, why? (n=111)	Fear of being infected	86.5
		Do not trust his/her condition	13.5
	In your household, would you share utensils with a PLHA or a person suspected of having HIV/AIDS?	Yes	89.3
		No	10.7
	If no, why? (n=105)	Fear of being infected	89.5
		Do not trust his/her condition	7.6
		Other reasons	2.9
	Would you buy fresh vegetables from a shopkeeper or vendor if you knew that this person has the AIDS virus?	Yes	92.2
		No	7.2
		Not sure	0.6
	If no, why? (n=70)	Fear of being infected	84.3
		Do not trust his/her condition	15.7

Table 2. Fear of casual contact: Existing indicators, items, and frequencies (continued)

Existing Selected Indicators	Questions in survey corresponding to indicator(s) (n=978 if not stated)	Response Category	Percent
	If a relative of yours is infected with HIV/AIDS, would you be willing to care for her or him in the household?	Yes	98.3
		No	0.8
		Not sure/Depends	0.9
	If yes, what help would you give? (n=960)	Balanced diet	63.3
		Treatment and drugs	36.9
		Counseling	8.2
		Compassion and support	59.0
1. Percent of people who would refuse casual contact with a person living with HIV/AIDS (Blue Book) 2. Percent of people who would not have casual contact with a PLHA because they are worried about contagion (S&DIWG)	**If a male teacher has the AIDS virus but is not sick, should he continue teaching at the school?**	Yes	94.9
		No	4.2
		Depends	0.3
		Don’t know	0.6
	If a *female* teacher has the AIDS virus but is not sick, should she continue teaching at the school?	Yes	95.4
		No	4.0
		Depends	0.5
		Don’t know	0.1

For example, in an evaluation of some of these questions on the Tanzania HIV/AIDS Indicator survey, Yoder and Nyblade found that the response to the questions on buying food changed if a distinction was made as to whether the person was exhibiting physical signs of AIDS (Yoder and Nyblade 2004). In a pre-test of a revised questionnaire, the number of respondents answering they would not buy food from a PLHA increased significantly if it was specified that the person had physical signs/symptoms of AIDS. This same evaluation also found that respondents understood the question about teachers in a manner that was different from the original intent. Specifically, respondents understood the question to be asking about what was occurring in the community or what was allowed by the government, as opposed to what they themselves believed.

These limitations aside, we evaluated these questions to assess how well they worked in terms of variability and validity. Our ability to assess reliability on single items is limited because (1) they are not part of a scale, so we cannot assess internal consistency, and (2) the scope of the project did not allow us to assess for standard test–re-test or inter-rater reliability.

In examining variability, a question is judged to perform satisfactorily if it elicits variation in responses. If all or most respondents give the same answer to a question, then the usefulness of the question to detect differences is limited. Examining Table 2, the questions on providing care to a relative with HIV and allowing teachers with HIV to teach show little variability. Over 94% of respondents answer YES to these questions. The two questions on buying food from an HIV-positive vendor and sharing utensils within a household with a PLHA have slightly more, but still relatively low, variability, with 88–90% of respondents saying they would buy food or share utensils.

Construct validity was assessed by examining the relationship of items measuring avoidance of casual contact with PLHA with the construct variables (levels of HIV transmission, prevention and in-depth knowledge, and general education levels). Based on existing data and conceptual knowledge about HIV stigma, we expect that the more education or HIV knowledge a respondent has, the less likely he/she will be to refuse casual contact with a PLHA. We also examined the relationships between refusal of casual contact with PLHA and responses to a question asking whether certain avoidance behaviors toward PLHA are justified. We expected that respondents who refuse casual contact would be more likely to state that this type of behavior is justified. Given the number of relationships tested, we present (see Table 3) only selected results from this analysis.[9]

All of the relationships tested behaved in the expected direction, with statistical significance at the $p<=0.05$ level. Respondents with more education or HIV knowledge are less likely to report that they would refuse casual contact with PLHA (see Table 3), whereas respondents reporting that they would not engage in casual contact with PLHA are more likely to state that this type of avoidance behavior is justified.

---

[9] For a detailed description of how knowledge was assessed, the categories that were created, and basic frequencies, see Appendix A. This appendix also includes Table A-2, which presents items and frequencies for the question on justification of behavior.

Table 3. Fear of casual contact: Percent of questions by knowledge

Type of HIV/AIDS Knowledge	**Willingness to interact with people living with HIV/AIDS:** In a market, would you buy food from a PLHA or person suspected of having HIV or AIDS?		
	No	**Yes**	**No. of respondents**
Transmission*			
Incorrect and some correct	15.8%	84.2%	449
Complete correct	7.6%	92.4%	529
Prevention*			
Incorrect and some correct	13.0%	87.0%	745
Complete correct	6.0%	94.0%	233
In-depth*			
0–2	20.8%	79.2%	231
3–7	8.4%	91.6%	747

*p = 0.000

For example, respondents who said they would not share utensils with PLHA were much more likely to state that assigning separate utensils in a household to PLHA was justified, compared to respondents who said they would share utensils with PLHA [60% vs. 7.9% (results not shown)]. We were not able to conduct construct testing on three questions (those related to giving care to a relative and allowing male/female teachers to teach). Lack of variability in responses means there were too few respondents in some categories to conduct meaningful statistical analysis.

Another way in which we tested the construct validity of these items was to ask an open-ended *why* question to those respondents who said that they would not buy food from, or share utensils with, PLHA. These open-ended responses were then examined and coded. The majority of respondents indicated that their refusal to interact with PLHA was linked to their fear of contracting HIV from this type of contact, indicating that the question is measuring the intended construct: stigma due to fear of transmission of HIV.

New indicator

As discussed above, these standard questions suffer from several limitations. In addition, particularly from a program standpoint, it is important to understand and measure the underlying fears more directly to know how to intervene. Therefore, drawing on the existing qualitative literature, we tested a new indicator for this domain focused on fear by including in the questionnaire multiple items on specific fears. Table 4 lists the items asked and the corresponding responses. The percent of respondents stating that they are worried about contracting HIV in a specific situation, or from a particular body fluid, varies for individual items from a low of 3.6% to a high of 30%. If we examine the set of items as a whole, 46.6 % of the respondents express the existence of at least one situation in which they feared casual transmission of HIV.

Because of the newness of this variable, we included a large range of items varying from specific body fluids to various common life situations described in the multi-country study. (Nyblade et al. 2003) Clearly, some of these items capture fear better than others, and some items duplicate each other, capturing the same “type” of fear. To reduce this list, we examined which items could be dropped without losing a large proportion of the overall number of respondents expressing fear. Table 5 presents the results of this analysis. For all analyses of this nature (also conducted for enacted stigma), we followed a general rule that items could be dropped from the index if, in doing so, we did not lose 10% or more of those answering in the affirmative,[10] and if the item was not critical for other conceptual reasons or performed differently by gender. Following these criteria, a fear index can be reduced to a final set of five items (see bold italics in Table 5) to capture fear of casual transmission in this population.

---

[10] For this index, given that 46.6% of all respondents report at least one fear, we only dropped items that reduced the index by less than 4.66%.

Table 4. Fear of casual contact: New indicators, items, and frequencies

New Recommended Indicators	Questions in survey corresponding to indicator(s)	Percent (n = 978 if not stated)		
1. Percent of people expressing fear of contracting HIV from non-invasive contact with PLHA	**Please tell me if you have fear, do not have fear, or do not know in response to the following statements:**	**Have fear**	**Don't know**	**No fear**
	Fearful/Afraid that you could become infected with HIV if you are exposed to the saliva of a person with HIV or AIDS	30.0	11.1	58.9
	Fearful/Afraid that you could become infected with HIV if you are exposed to the sweat of a person with HIV or AIDS	13.9	12.5	73.6
	Fearful/Afraid that you could become infected with HIV if you are exposed to the excreta of someone with HIV or AIDS	21.0	14.0	65.0
	Fearful/Afraid that your child could become infected with HIV if they play with a child who has HIV or AIDS	15.4	4.0	80.6
	Fearful/Afraid to care for a person living with HIV or AIDS	12.4	2.5	85.1
	Fearful/Afraid that you could become infected with HIV if you eat food prepared by a person with HIV or AIDS	9.1	3.9	87.0
	Fearful/Afraid to touch a person living with HIV or AIDS	6.3	1.4	92.2
	Fearful/Afraid to sleep in the same room as someone who has HIV or AIDS	5.4	1.9	92.6
	Fearful/Afraid to share eating utensils with someone who has HIV or AIDS	13.8	3.1	83.1
	Fearful/Afraid to sit next to someone who is showing signs of AIDS	3.6	1.6	94.8
	Fearful/Afraid to sleep in the same bed as a person with HIV or AIDS	12.6	4.0	83.4
	Fearful/Afraid to share a toilet with a person living with HIV or AIDS	5.4	3.0	91.6

Table 5. Performance of fear of casual transmission index

Index—Number of items left	Item(s) included in scale/Items dropped: Question: Please tell me if you have fear, do not have fear, or do not know if you have fear in response to the following situations:	Percent reporting at least one fear of casual transmission[11]
12	1. Sit next to someone who is showing signs of AIDS 2. Sleep in same room as someone who has HIV or AIDS 3. Touch a person living with HIV or AIDS 4. Share toilet with a person living with HIV or AIDS 5. Eat food prepared by a person living with HIV or AIDS 6. Share eating utensils with PLHA 7. Sleep in same bed with someone who has HIV or AIDS 8. Care for a person living with HIV or AIDS 9. Child play with child who has HIV or AIDS 10. Be exposed to sweat 11. Be exposed to saliva 12. Be exposed to excreta	46.6
5	Drop: 1. Sit next to someone who is showing signs of AIDS 2. Sleep in same room as someone who has HIV or AIDS 3. Touch a person living with HIV or AIDS 4. Share toilet with a person living with HIV or AIDS 5. Eat food prepared by a person living with HIV or AIDS 6. Share eating utensils with PLHA 7. Sleep in same bed with someone who has HIV or AIDS	42.4
5	1. Care for a person living with HIV or AIDS 2. Child play with child who has HIV or AIDS 3. Be exposed to sweat 4. Be exposed to saliva 5. Be exposed to excreta	42.4

We also examined the individual items, various groupings of fear items, and the final 5-item index for construct validity. In particular, we examined how these fear items behaved in relationship to the construct variables discussed above: HIV knowledge, education, and

---

[11] Response categories: *Have fear*/*Don't know*/*No fear*, showing only those responses in *Have fear* category

justification of avoidance behavior. Table 6 presents selected results of this analysis. We examined the relationship of individual fear items, various groupings of the items, as well as the final 5-item index in relationship to the construct variables. All of the relationships tested behaved in the expected direction, with statistical significance at the p<=0.05 level.

Table 6. Fear of Casual Transmission: Percent of questions by knowledge

Type of HIV/AIDS Knowledge	Level of Fear (5-item index)		
	None	**At least one**	**No. of respondents**
Transmission*			
Incorrect and some correct	52.8%	47.2%	449
Complete correct	61.6%	38.4%	529
Prevention*			
Incorrect and some correct	55.2%	44.8%	745
Complete correct	65.2%	34.8%	233
In-depth*			
0–2	51.9%	48.1%	231
3–7	59.3%	40.7%	747

*p<= 0.05

Recommendations for measuring fear of casual transmission and refusal of contact with PLHA in a community sample

1. If only one indicator can be collected for this domain, we recommend the new indicator that focuses on the actual fears leading to refusal of contact, rather than the existing indicator on refusal of casual contact. We do so for the following reasons: The standard questions on willingness to have casual contact with PLHA perform well on construct validity, but they show little variability. We expect that as stigma-awareness campaigns become more widespread, this variability will become even lower due to social desirability bias. In addition, if we compare the three standard contact avoidance items (related to buying food & use of utensils) to the fear index, it is clear that asking about fears (which are not hypothetical and are less likely to suffer from social desirability) captures substantially more variability. Our reduced 5-item fear index indicates that 42.4% of respondents have at least one fear of transmission through casual contact. If we create an index of the 3 avoidance of casual contact questions, 16.3% of respondents indicate they would refuse at least one form of casual contact, while the highest number captured by any single question is 11% (as opposed to 30% for any single fear items).

2. One caveat to this recommendation is that this is a new item being measured for the first time, and this study was conducted in only one site. It is therefore important that

further testing be done, both within other contexts and to determine the best wording for the items. Further testing could help to ensure that there is no ambiguity in what the item is asking about[12] and that the respondent clearly understands that he/she is being asked about exposure to body fluids in a non-invasive manner.

3. It is also clear from recent work (Ogden and Nyblade 2005) that we need to develop additional items that measure the different kinds of fears around non-invasive blood contact, which has now been documented as an important cause of refusal to have casual contact with PLHA.
4. For those wishing to collect data on more than one indicator in this domain, we recommend adding the indicator on refusing contact with PLHA. The question about buying food from a food vendor in a market had slightly more variability than the other two, so we suggest that, if only one question can be used, it be this one. However, we also recommend that this question be modified into two parts, as per the recommendations of Yoder and Nyblade (2004); that is, to ask the question first, indicating that the PLHA has no visible signs or symptoms of AIDS, followed by: "What if the person had visible signs and symptoms?"
5. For those who can ask a more extensive set of items, we suggest expanding the number of fear items and individual questions on avoidance of PLHA collected.

For a full listing of tested indicators, our recommendations, and steps for collecting relevant data and compiling indicators, see the tables in the Conclusion and Summary Recommendations section.

SECTION 4.2: VALUES: SHAME, BLAME, AND JUDGMENT

Previous research found that shame, blame, and judgment are key underlying causes of HIV-related stigma (Horizons et al. 2003; Nyblade et al. 2003; POLICY Project 2003; Ogden and Nyblade 2005). They therefore constitute a key dimension of stigma toward people living with HIV/AIDS, such that people's stigmatizing attitudes are founded in their perceptions and beliefs about how HIV was contracted. Many associate HIV with behaviors perceived as being socially "unacceptable" or "deviant" and under the control of the individual—such as sex outside of marriage, sex with multiple partners, and injecting drug use—leading to assumptions about the "moral" character of PLHA. This in turn leads to shame and blame of those infected with HIV. Therefore, assessment of people's shame, blame, and judgmental attitudes is a domain essential to fully understanding HIV stigma, and such assessment provides one entry into measuring stigma related to HIV and AIDS.

Table 7 presents the two existing indicators (the first from the Blue Book [USAID 2003] and the second from the February 2004 meeting of the S&DIWG), items included to collect data for these indicators, and their frequencies. The two existing indicators comprehensively capture the key dimensions of this domain—shame, blame, and judgment. Therefore, we do not propose any new indicators, but we focus instead on field-testing appropriate

---

[12] For example, it is not clear what fear the item asking about willingness to care for PLHA is capturing, given the wide range of activities care can include.

questions/items to collect data for these indicators. Several existing commonly asked questions that have sometimes been interpreted as measuring this domain are not presented here because of both their limitations and the fact that they are presented elsewhere in this report. These include the questions on willingness to care for an infected family member; whether an infected teacher (male or female) should continue teaching; and whether HIV status should be kept secret. The latter is discussed in Section 4.3 on disclosure, and the first three have already been discussed in the previous section on fear (Section 4.1).

Therefore, the rest of this section examines the other, less common items tested for this domain. It begins with a discussion of the frequency distribution as the preliminary test for inclusion in further analysis and a look at a form of test–re-test reliability of two of the questions. Subsequent analyses use factor analysis to sort and group the items and to examine the joint reliability of a set of questions measuring an underlying construct factor—value-driven stigma. The results of the factor analysis are then used to recommend items to be included in constructing the two indicators.

As with other domains, there are some limitations to the data and analysis for this domain. First, many of the questions were experimental and thus developed in the absence of previously tested questions and experience with measuring this domain. Second, given the scope of the project and the number of domains tested, we were limited in the number of items we could ask per domain, and therefore had fewer items per subdomain for the factor analysis than are optimal. Third, we attempted to measure a range of items for this domain by including both negatively and positively framed items. In the end, all the positively framed items showed little variability and so were dropped, further restricting the number of items available for factor analysis. Fourth, with attitudinal questions of this nature, there is always the risk that the responses are influenced by social desirability bias. Finally, as with all the data presented in this report, we only tested the indicators in one site in one country—Tanzania—so the applicability of these results to other settings is unknown. Therefore, we recommend further testing of the indicators and items, including development of additional new items to reflect the domains of shame and blame, and possibly a third category of judgment.

New questions

Given the limitations of many of the commonly used questions, several new questions were added to focus specifically on the shame, blame, and judgment dimensions. Negative and positive attitudinal statements were read (see Table 7), and respondents were asked whether they agreed with, were neutral about, or disagreed with each statement. Both because attitudinal questions are known to suffer from social desirability bias, which can influence responses about personal attitudes, and because of a potential difference between own stigmatizing attitudes and perceptions of stigma in the community, we also asked respondents to indicate how they thought their community would respond to the same attitudinal statements. The questions about the community's response were meant to capture the respondent's perception of the prevalence of stigmatizing attitudes in the study population and to provide some comparison with individual responses.

We discuss the positively and negatively framed statements separately because the respective responses showed two different patterns. The responses to the positive attitudinal statements about own attitudes showed limited variability and very low levels of stigma (See Table 7). The majority of the respondents (>86%) agreed with all the statements, suggesting that either the questions were not properly capturing stigma or that stigma was very low. We believe that the former is true because of the evidence from other variables within the community data and from the PLHA and health care provider data sets, as well as that in the existing literature. There is also more variability in the responses to the positively framed statements when the respondent reports on the community attitudes, an indication that perhaps social desirability bias is one factor that may be driving the lack of variability in the responses to the individual attitude questions. Because of these shortcomings with the positively framed attitudinal statements, we do not present any further analysis on these statements. We focus the rest of this section on the results of the negatively framed attitudinal statements.

Unlike the results from the positively framed attitudinal statements, responses to the negatively framed attitudinal statements indicate that stigma related to shame, blame, and judgment does exist in the study population, as each negative attitudinal statement attracted some agreement from the respondents. For example, 22.7% of respondents agreed that they would be ashamed if a family member had AIDS, and 44% agreed that HIV was a punishment from God. These two statements, respectively, had the lowest and the highest percent of respondents agreeing to them. Generally, more respondents agreed with statements assessing blame and judgment than with statements assessing shamefulness.

It is interesting to note that the majority of the respondents disagreed with these negative attitudinal statements. When asked about how they thought most people in their community would respond to these same statements, however, the majority reported that most people in their community would agree with the negative attitudinal statements. Percent responses for how community members would respond to identical statements were consistently higher than personal responses. Two possible explanations for this difference are that individuals’ perceptions of the prevalence of stigma in their communities are much higher than actual prevalence, or that social desirability bias is pushing down the number of respondents willing to admit to holding stigmatizing attitudes.

Table 7. Shame, blame, and judgment: Existing indicators, items, and frequencies

Shame and Blame Indicators	Questions in survey corresponding to indicator(s)	Percent (n=978 if not stated)		
Negative attitudinal statements related to shame, blame, and judgment				
1. Percent of people who would feel shame if they associated with a person living with HIV/AIDS (Blue Book; recommended by S&DIWG)	**Do you agree/disagree with the following statements?**	**Agree**	**Neutral**	**Disagree**
	I would be ashamed if someone in my family had HIV/AIDS.	29.4	1.8	68.7
	I would feel ashamed if I were infected with HIV.	38.9	2.1	59.0
	People with HIV/AIDS should be ashamed of themselves.	35.2	2.8	62.1
	How do you think most people in your community would answer the following questions?	**Agree**	**Neutral**	**Disagree**
	I would be ashamed if someone in my family had HIV/AIDS.	48.3	22.1	29.7
	I would feel ashamed if I were infected with HIV.	53.2	21.7	24.9
	People with HIV/AIDS should be ashamed of themselves.	50.5	10.1	39.4
2. Percent of people who judge or blame persons living with HIV/AIDS for their illness (Blue Book; recommended by S&DIWG)	**Do you agree/disagree with the following statements?**	**Agree**	**Neutral**	**Disagree**
	It is the women prostitutes who spread HIV in our community.	37.1	4.5	58.4
	HIV/AIDS is a punishment for bad behavior.	38.9	4.4	56.7
	People with HIV/AIDS are promiscuous.	22.7	5.7	71.6
	HIV/AIDS is a punishment from God.	44.4	9.0	46.6
	How do you think most people in your community would answer the following questions?	**Agree**	**Neutral**	**Disagree**
	It is the women prostitutes who spread HIV in our community.	65.2	8.2	26.6
	HIV/AIDS is a punishment for bad behavior.	62.6	9.6	27.8
	People with HIV/AIDS are promiscuous.	59.5	8.2	32.3
	HIV/AIDS is a punishment from God.	64.2	11.7	24.1

Table 7. Shame, blame, and judgment: Existing indicators, items, and frequencies (continued)

Shame and Blame Indicators	Questions in survey corresponding to indicator(s)	Percent (n=978 if not stated)		
Positive attitudinal statements related to shame, blame, and judgment				
	Do you agree/disagree with the following statements?	**Agree**	**Neutral**	**Disagree**
	People who publicly disclose that they have HIV/AIDS exhibit behavior that should be copied.	86.6	3.0	10.4
	People with HIV/AIDS deserve sympathy.	96.2	1.0	2.8
	I would attend a social event with someone know to have HIV.	92.8	1.1	6.0
	People with HIV/AIDS should be treated the same as people without HIV/AIDS.	95.3	.8	3.9
	People with HIV/AIDS should be allowed to fully participate in social events in our community.	94.3	.8	4.9
	I would invite a person with HIV/AIDS to a social event.	93.3	.9	5.8
	How do you think most people in your community would answer the following questions?	**Agree**	**Neutral**	**Disagree**
	People who publicly disclose that they have HIV/AIDS exhibit behavior that should be copied.	75.1	8.9	16.1
	People with HIV/AIDS deserve sympathy.	77.9	8.8	13.3
	I would attend a social event with someone know to have HIV.	69.3	12.2	18.5
	People with HIV/AIDS should be treated the same as people without HIV/AIDS.	72.5	9.2	18.3
	People with HIV/AIDS should be allowed to fully participate in social events in our community.	69.9	10.2	19.8
	I would invite a person with HIV/AIDS to a social event.	72.5	9.2	18.3

Test–re-test reliability

Reliability of shame and blame/judgment was assessed in two ways: internal reliability with Cronbach's Alpha—to be discussed next in the factor analysis section—and a modified test–re-test reliability of a few of the questions.

Because two of the questions on stigmatizing attitudes related to shame were asked in more than one section of the questionnaire, we can test consistency in respondents' answers to these questions. While this is not as rigorous as standard test–re-test reliability, it does provide some indication of the reliability of the question over a short time period (20–40 minutes) within a given interview. As shown in Table 8, the percent that agreed they would feel ashamed if they became infected with HIV was 38.9% and 35.5%, respectively, in the first and second responses to the same question. The corresponding result with regard to agreeing that people with AIDS should be ashamed of themselves was 35.2% and 31.2%. If we examine more closely the responses in which disagreement occurred, 17.7% of the respondents provided contradictory responses between the first and second time the question was asked. While less than 20% of the respondents provided inconsistent answers, this figure is higher than the inconsistent answers for other questions we also tested in this manner (see Section 4.3 on enacted stigma). This difference is not surprising, however, because the other questions dealt with a specific concrete event—reporting knowing someone who had experienced a specific form of enacted stigma—whereas these questions deal with attitudes.

Table 8. Test–re-test reliability: Percent disagreement of shame questions asked twice

Questions–	**Question asked first time (Q1) Percent agreed (n=978)[13]**	**Question asked second time (Q2) Percent agreed (n=978)**	**Percent Disagreement Q1=NO Q2=YES**	**Percent Disagreement Q1=YES Q2=NO**	**Total percent of responses in disagreement**
I would feel ashamed if I were infected with HIV.	38.9%	35.5%	7.0%	10.7%	17.7%
People with HIV/AIDS should be ashamed of themselves.	35.2%	31.2%	6.0%	10.4%	16.5%

---

[13] Neutral responses (*Don't know/no opinion*) in Q1 in Q2 were excluded in measuring number of disagreement.

The difference may also be due to the relative placement of the questions in the questionnaire and the manner in which they were asked. The first question in each pair was asked as part of a series of statements (*Please tell me if you agree/disagree or are neutral to the following statements*) that included a range of items about both positive and negative statements. This series of statements came early in the questionnaire, before any other sensitive or specific questions on enacted stigma had been asked. The second time, the question was asked at the very end of the questionnaire as a stand-alone question with the same wording (*Do you agree or disagree with the following statement?*), but the response categories were slightly different (*agree/disagree/don't know/no opinion*). By the end of the questionnaire, the respondent had been asked numerous questions pertaining directly to stigma, which may have influenced how he or she responded to the attitudinal questions the second time around. Note that the percentage of respondents agreeing with the negative statements is lower the second time the question is asked, and that more of those in disagreement fall into the *Yes* category the first time and *No* the second time. Overall, less than 20% of responses in disagreement show consistency over these two questions, suggesting that the negative attitudinal statements are generally reliable.

Factor analysis and internal consistency reliability

The preceding sections examined the new items for performance on variability and test–re-test reliability. Factor analysis was then used to assess the reliability of the items measuring this latent domain (values–shame and blame). The following steps were taken. Factor analysis was first conducted, using the principal-components factor-extraction method, on the selected set of items to identify factors and factor loadings. Only factor loadings of 0.40 or higher were considered for inclusion on a given factor. Once the number of factors was determined, promax rotation was performed on the factor loadings to ease interpretation. Internal reliability testing was then conducted separately for each factor by calculating Chronbach's Alpha. Based on the results of this testing, items were selected for inclusion on a scale, which was then interpreted and named based on the loadings.

The initial factor analysis included all 13 items (six positively and seven negatively framed attitudinal statements). The initial analysis results identified three factors; the negative attitudinal items divided across two factors, and all the positive attitudinal items grouped into one factor. The analysis was repeated without the positive attitudinal items, which were dropped because the frequency distribution for these items showed little variability in response (most people who answered agreed to them), and they exclusively constituted a separate factor.

The results of the analysis of the remaining seven items show that the items grouped onto two different factors: (1) shame and (2) blame and judgment. The factor loading of the items to the respective factors did not significantly change from that observed in the initial 13 item analysis. The factor loading remained good for each factor.[14] Table 9 presents the factor loadings of each item on the respective group factors.

---

[14] A loading above 0.7 is considered good, and one above 0.4 is satisfactory, showing that the variable strongly accounts for the underlying factor (Pett et al. 2003)

Table 9. Factor Loadings: Shame and blame/judgment items

Stigmatizing attitude statement	***Rotated factor loading***	**Shame**	**Blame and Judgment**
		1	**2**
I would feel ashamed if I were infected with HV/AIDS (S1).	0.884	▪	
I would be ashamed if someone in my family had HIV/AIDS (S2).	0.879	▪	
People with HIV/AIDS should be ashamed of themselves (S3).	0.777	▪	
People with HIV are promiscuous (B1).	0.844		▪
It is women prostitutes who spread HIV/AIDS in the community (B2).	0.824		▪
HIV/AIDS is a punishment from God (B3).	0.562		▪
HIV/AIDS is a punishment for bad behavior (B4).	0.482		▪

Table 10 presents the internal reliability of the items that loaded on to each factor. The three shame items explain 80% of the variance of shame-related stigma in this domain, while the four blame items explain 70% of the variance in blame/judgment-related stigma. The internal reliability results for each factor are within acceptable ranges,[15] with better results for the shame factor. The higher reliability of the shame factor is most likely due to a set of statements that more directly echo the theme of the factor—shamefulness—than the statements for blame and judgment. Although reliability of α=0.7 is acceptable, we would ideally like a higher score for the blame/judgment factor. Therefore, more work is needed in testing different phrasing for existing items or new items to capture blame and judgment. It is also notable that when limited to three items, B1, B2, and B4, the blame items still had a relatively high internal reliability (α -0.685), suggesting that in situations in which the number of items needs to be restricted, these three items would also provide a good set for measuring blame and judgment.

---

[15] Internal reliability of α ≥ 0.8 is considered very good; α ≥ 0.6 is satisfactory.

Table 10. Shame and blame factors: Internal consistency of items (Cronbach's Alpha)

Reliability results of stigmatizing attitudes

Factor	N	Coefficient α
1-Shame	3	0.797
2-Blame	4	0.700

Based on the factor loading and the internal reliability results, the three shame items and the four blame and judgment items provide robust measures for the shame and blame indicators, respectively. The results show that both indicators, reflecting two dimensions (shame and blame/judgment) that underlie the domain of value-related stigma, are needed to measure value-driven stigma. The findings also indicate that at least three items are needed for each indicator to adequately capture the underlying construct of shame and blame/judgment. When possible, four items should be used to measure blame/judgment.

Performance of composite indicator on study population

Mindful of the resource constraints faced in data collection for many programs and surveys, we further examined the performance of each of the composite indicators to explore the sensitivity of using a different number of items in a set and whether fewer items might still capture the indicator adequately.

Table 11 shows the frequencies that these indicators would capture if 1, 2, 3, or 4 (only for blame) items are used. The order in which the items are examined is based on the results of the factor analysis, with item 1 being the item that loaded most strongly, and so forth. It is notable that the 3-item indicators, based on "agree with at least one of the three negative attitudes," have substantially high values. Furthermore, the frequency distribution difference between the 2-element indicator and the 3-element indicators supports the factor analysis results of the need to use at least 3 elements to construct each of the indicators. If only one or two items are used to measure shame or blame/judgment, we would be under-reporting the level of these stigmatizing attitudes in this population.

Table 11. Number of respondents agreeing to stigmatizing statements by number of items in index

Number of elements constituting an indicator	Shame Indicator	Percent agreeing with at least one item	Blame and judgment Indicator	Percent agreeing with at least one item
1	S1	38.9%	B1	22.7%
2	S1, S2	42.7%	B1, B2	41.9%
3	S1, S2, S3	50.4%	B1, B2, B3	60.8%
4			B1, B2, B3, B4	65.7%

S1—I would feel ashamed if I were infected with HV/AIDS.

S2—I would be ashamed if someone in my family had HIV/AIDS.

S3—People with HIV/AIDS should be ashamed of themselves.

B1—People with HIV are promiscuous.

B2—It is women prostitutes who spread HIV/AIDS in the community.

B3—HIV/AIDS is a punishment from God.

B4—HIV/AIDS is a punishment for bad behavior.

Triangulating information between the composite indicator and the individuals' perceptions about their community

As noted earlier in this section, there was a marked difference between the percent of respondents agreeing with the stigmatizing statements and what they reported about community stigmatizing views. If we analyze the individual items separately (own vs. perception of community response), either individuals perceive a much higher level of stigma in the community than actually exists, relative to what would be measured based solely on self-reports of their own attitudes, or individuals are under-reporting their own stigmatizing views (social desirability bias). Given the nature of these statements, it is possible that respondents who hold negative attitudes refrain from reporting agreement with all the negative statements (because they know it is not socially desirable to stigmatize), but still do report agreement with at least one. Table 12 presents, for the final items selected for the shame and blame/judgment indicators, individual responses to these items, perceptions of community response, and the results of combining the 3 (shame) and 4 (blame and judgment) items into a composite variable–percent of respondents who answer affirmatively to at least one of these items for each indicator.

Table 12. A comparison between individual responses to individual items on views of community responses, and a composite 3-element indicator of respondent's individual responses

	Percent agreed	Percent thought community would agree
SHAME		
I/They would feel ashamed if I/they were infected with HIV.	38.9%	53.2%
I/They would feel ashamed if a member of my/their family were infected with HIV.	29.4%	48.3%
People with HIV/AIDS should be ashamed of themselves.	35.2%	50.5%
Percent of respondents who agree with at least one stigmatizing "shame" statement	**50.4%**	
BLAME AND JUDGMENT		
It is women prostitutes who spread HIV in our community.	37.1%	65.2%
People with HIV/AIDS are promiscuous.	22.7%	59.5%
HIV/AIDS is a punishment from God.	44.4%	64.2%
HIV/AIDS is a punishment for bad behavior.	38.9%	62.6%
Percent of respondents who agree with at least one stigmatizing "blame and judgment" statement	**65.7%**	

The comparison shown in Table 12 reveals an interesting pattern. For both shame and blame/judgment, the composite indicator was close to the respondents' perceptions of "community stigma," measured by whether the respondents thought the community agreed to any one of the negatively framed attitudinal items. Examined this way, a composite indicator depicts individual stigma to be as high as what one would conclude, based on the respondent's perception of prevalence of any one stigmatizing attitude in the community. This pattern, which was similar for both indicators, warrants further exploration and testing in different settings to establish whether combining at least three attitudinal items that score high on internal reliability consistently produces results similar to those obtained from respondents' perceptions about community attitudes.

Construct validity

Construct validity was assessed by examining the magnitude and direction of association between a negative attitude statement variable and variables expected to be associated with this domain of stigma. The variables hypothesized to be associated with stigma include education, knowledge of HIV and AIDS (prevention, transmission, in-depth), and proximity to PLHA. We also considered, but did not use, gender and religiosity as construct variables, because the direction of the relationships between gender and religiosity and this domain of stigma is unclear.

We expected that having more knowledge about HIV and higher levels of education would lead, in general, to a better understanding of how HIV is and is not transmitted (and thus fewer assumptions about how PLHA got infected) and the realization that everyone is at risk (and thus lower levels of stigma in the form of shame and blame). Proximity, that is, a personal relationship to a PLHA, was also expected to be associated with less negative attitudes. A review article of stigma-reduction interventions (Brown et al. 2004) notes that interventions that included firsthand interaction with PLHA were the most successful in reducing stigma.

Table 13 presents the results of the construct analysis for shame and blame/judgment composite indicators. The correlations between each of the composite indicators and the construct variables (education, in-depth knowledge about HIV, and proximity to PLHA) were strongly significant in the expected direction, indicating that these composite indicators are measuring the intended constructs of shame and blame/judgment related to HIV and AIDS and are valid measures of stigma. In addition, we tested each of the individual negatively framed statements against the construct variables (results not shown here), and they were all strongly associated ($p \leq 0.05$) in the expected direction.

Table 13. Percent agreeing to at least one attitudinal statement for shame and blame/judgment indicators, by construct validity variables

Construct Validity Variables	Percent agreed to at least one of the three statements related to shame	Percent agreed to at least one of the four statements related to blame and judgment
Education*		
No formal education (n=73)	63.0%	82.2%
Primary school (n=574)	52.8%	64.3%
Form 4/post-primary (n=249)	44.6%	46.6%
Form 5–6/university (n=82)	40.2%	40.2%
In-depth knowledge of HIV/AIDS*		
0–2 (n=231)	58.0%	67.1%
3–7 (n=747)	48.1%	56.6%
Proximity to PLHA*		
Don't know anybody who died of AIDS (n=372)	58.1%	64.2%
Personally know someone who died of AIDS (n=606)	45.7%	55.9%

* $p<0.05$

Recommendations for measuring shame and blame and judgment in a community sample

1. The results of the analysis of questions/items tested for collecting data in the domain of value-related stigma (shame, blame/judgment) indicate that the two existing indicators, one reflecting shame and the other reflecting blame/judgment, are both

needed to adequately capture this domain. It is possible that a third category is needed to capture judgment (see health provider analysis).

2. The commonly used questions (e.g., willingness to care for a relative with HIV) have substantial limitations and did not perform well in terms of variability. As such, we do not recommend these questions.

3. We tested positively framed attitudinal statements toward PLHA, as well as negatively framed ones, that were more specific to the two indicators. We also asked questions about the respondent's views of community attitudes on the same items. In light of the differences between own and perceptions of community attitudes, we recommend that both be included. The positively framed attitudinal questions showed little variability and are therefore not recommended.

4. The results of the factor analysis and reliability and construct validity testing, however, showed that a series of negative attitudinal statements provides a good, reliable, and valid measure of the shame and blame/judgment dimension of stigma. Three shame and four blame/judgment negative attitudinal statements were identified as particularly good sources of information for constructing indicator variables that measure (1) shame and (2) blame and judgment of PLHA.

5. The three items for shame (*I would be ashamed if I were infected with HIV*; *People with HIV are promiscuous*; and *People with HIV should be ashamed of themselves*) and the four for blame/judgment (*It is women prostitutes who spread HIV in the community*; *People with HIV are promiscuous*; *HIV is a punishment for bad behavior* and *HIV is a punishment from God*) need to be used together to adequately capture the stigma in the dimensions of shame and blame. In case fewer items are needed, three items, excluding the last item, would also produce reasonable results for measuring blame/judgment. For each of the two indicators, if only one or two items are used, a substantial loss in number of people reporting these attitudes occurs in this population and may result in substantial under-reporting of the actual level of value-driven stigmatizing attitudes.

6. The statements used in this study originated from findings of qualitative research in the study community (Nyblade et al. 2003). The statements used in this study are relevant for many communities with similar types and stages of the HIV epidemic. We recommend, however, that the statements be field-tested in other developing countries with generalized epidemics. In other settings with markedly different experiences with the HIV epidemic, new items may be required. The strategy of constructing the indicator in such cases should include at least two steps: first, identification of context-relevant statements, and second, use of a combination of at least three statements to construct an indicator variable.

For a full listing of indicators tested, our recommendations, and guidance on collecting the relevant data and compiling the indicators, see the tables in the conclusion and summary recommendations part of the report (Section 7).

SECTION 4.3: ENACTED STIGMA

As described in the background section, measuring enacted stigma at the general population/community level presents some difficult challenges. The first challenge is that it is not ethical to ask respondents selected through random sampling if they have ever personally experienced enacted HIV stigma, as this would entail them revealing their HIV sero-status. Therefore, a direct measure of personal experience of HIV stigma is not feasible for a general survey population (though it is possible and recommended for a sample of PLHA). The second challenge is that a question asking respondents if they themselves have engaged in stigmatizing behavior toward a person living with or suspected of having HIV is likely to suffer from severe social desirability bias and therefore be under-reported, particularly as stigma-reduction programs expand.

Despite these challenges, we felt it was important to explore other possible means to measure enacted stigma within the general population. This was done by asking respondents about what they observe happening around them (*Do you personally know someone who has had X* [a particular form of stigma, e.g., losing a job] *happen to them in the past 12 months because of their HIV status*?; see Table 14 for exact wording and list of items asked). While this type of question will not yield a measure of personal experience of stigma, it may still provide important information by measuring observed enacted stigma. Capturing this aspect of enacted stigma is important, as witnessing enacted stigma may play a role in individual decisions to seek testing, treatment, and other services or to disclose a positive sero-status.

While by no means perfect, this approach may also give some indication of the overall level of enacted stigma present in the population. Two important limitations should be noted, however. First, many forms of stigma (e.g., being fired, losing a promotion) may not be visible to most people in the general population. Second, we cannot determine if respondents reporting observing enacted stigma are all reporting on the same well-known cases (e.g., in the media), or on different cases of enacted stigma. To address this issue, the S&DIWG proposed that respondents be asked if they *personally* know of someone who in the *past 12 months* experienced a particular form of enacted stigma. The hope is that the emphasis on “personally knowing” a person and providing a specific time-frame will help reduce the potential problem of different respondents reporting on the same person/same case of enacted stigma. In addition, because the sample is random, with only two respondents per household and only a few households in a given community, we expect that the number of respondents reporting the same cases of enacted stigma will be reduced.

Table 14 presents the existing indicators, the corresponding items asked, and their frequencies. It also includes a list of additional items that were added to the questionnaire to test the forms of stigma documented in the literature (Bond et al. 2003; Nyblade et al. 2003; Banteyerga et al. 2004; Mbwambo et al. 2004) but not captured by the two existing indicators proposed by the S&DIWG. We focus our discussion in the rest of this section on the first two indicators. The third and last indicator presented in the table—the percentage of people who support discrimination toward PLHA—is not explored in any depth due to a lack of variability.

As this is the first time these types of items/questions have been asked about enacted stigma, we included a fairly extensive list of them. The dilemma posed by the results is that, while no individual item has more than 11% of respondents indicating that they personally know someone who has experienced that item in the past 12 months, 29.8% of respondents know at least one person who has experienced a form of stigma in the past 12 months. The challenge then becomes how to reduce this list of items without losing important information about enacted stigma.

Table 14. Enacted Stigma: Existing indicators, items, and frequencies

Existing Selected Indicators	Questions in survey corresponding to indicator(s)	Percent (n=978 if not stated)
1. Percent of people who personally know someone who has been refused services in the past 1 year because they were known to, or suspected of having HIV or AIDS (S&DIWG)	**Do you know someone in the past year that has had the following happen to him or her because of HIV or AIDS?**	**Yes**
	Lost housing or not been able to rent housing	0.9
	Denied religious rites/services like marriage, communion, burial, singing in choir, prayers/Not allowed to go to church/mosque	1.1
	Given poorer quality health services (for example, having to wait longer for medical care, being passed from provider to provider, not given medicines, treatment, surgery)	2.0
2. Percent of people who personally know someone who has been socially isolated because of HIV status or perceived status (high prevalence) (S&DIWG)	Excluded from a social gathering (wedding, funeral, party, community association or group)	6.7
	No longer visited, or visited less by family and friends	3.8
	Visitors increase to “check them out”	6.0
(Additional items tested for forms of stigma)	Lost customers to buy their produce/goods or lost a job	3.6
	Been denied promotion/further training	1.4
	Had property taken away because it is expected the person will die soon	3.8
	Abandoned by their spouse/partner	8.4
	Abandoned by their family/sent away to the village	11.3

Table 14. Enacted Stigma: Existing indicators, items, and frequencies (continued)

Existing Selected Indicators	**Questions in survey corresponding to indicator(s)**	**Percent** (n=978 if not stated)
(Additional items tested for forms of stigma)	Isolated within the household, for example, made to eat alone/made to use separate eating utensils/made to sleep in room alone	5.5
	Teased or sworn at	10.3
	Lost respect/standing within the family and/or community	4.6
	Gossiped about	10.5
	Given more care and support by family/neighbors/community	9.0
	Given special services (home-based care, medical treatment, material)	4.4
	Percent of people who know of at least one instance of the above 15 items	**29.8**

Table 14. Enacted Stigma: Existing indicators, items, and frequencies (continued)

Existing Selected Indicators	**Questions in survey corresponding to indicator(s)**	**Percent** (n=978 if not stated)			
3. Percent of people who support discrimination toward people living with HIV/AIDS (Blue Book)	**Society reacts and behaves in various ways toward PLHA or people suspected of having HIV. Please state whether you find the following reactions/behaviors as reasonable or not:**	**Reasonable**	**Not sure**	**Unreasonable**	**Depends**
	Divorce or leave a husband or partner because he has HIV	6.5	0.6	92.2	0.6
	Assigning separate hospital ward to PLHA	53.1	1.9	44.8	0.2
	Because of drug shortage, first priority given to non-HIV-infected patients	25.1	0.8	73.8	0.3
	No longer inviting a PLHA to social events, such as weddings	4.3	0.9	94.5	0.3
	Limiting people's participation in community activities because of their HIV status	3.3	0.9	95.1	0.7
	Not allowing a child to play with a child having HIV or AIDS	7.6	0.8	91.0	0.6
	In a household, assigning specific utensils for a PLHA	13.5	1.7	83.8	0.9
	Avoiding eating with a PLHA	8.7	1.7	89.1	0.5
	Avoiding using something touched by a PLHA	4.6	1.1	94.2	0.1
	Refusing to share a toilet with a PLHA	4.1	1.0	94.7	0.2
	Divorcing/leaving a wife/partner because she has HIV or AIDS	4.8	0.4	94.7	0.2
	Refusing to rent a room to a person with HIV and AIDS	2.8	1.3	95.7	0.2

Qualitative research by ICRW and its partners in Tanzania and two other countries identified four forms of stigma that occur in communities (Nyblade et al. 2003):

1. **Isolation:** This form includes two sub-forms, social and physical exclusion and violence. Social exclusion is characterized by reduction of daily social interactions, exclusion from family and community events, shunning or turning away by the public, and a breakdown in relationships (marital, familial, or friend). Physical exclusion occurs through isolation of the person with HIV/AIDS, separating sleeping quarters, marking and separating eating utensils, separating clothing and bed linens, no longer allowing the person to eat meals with the family, and even hiding an HIV-positive member of the family. Physical violence is the most acute example of isolation.
2. **Verbal stigma:** This form includes gossip, voyeurism, taunting, scolding, and being sworn at or called names. Voyeurism is a unique form of verbal stigma in which acquaintances visit the person with HIV or AIDS, but not out of concern for the PLHA or a desire to keep them company. Rather, visitors aim to observe how the person is faring to be able to report to others and generate gossip about the person's suspected HIV status (e.g., how sick the person may be and how he or she became infected with HIV).
3. **Loss of identity and role:** People with HIV are often stripped of their positions and roles in the community; this behavior arises from the belief that people living with HIV are or will imminently become incapacitated. Another important contributing factor is judgmental attitudes about how people are thought to have been infected with HIV. This form of stigma is marked by loss of power, respect, and the right to make decisions about their own lives.
4. **Loss of access to resources and livelihoods:** PLHA often lose access to resources such as housing; health care; educational, legal, financial, and other services; and a wide range of physical assets in the community. Loss of employment may include firing or restrictions in promotion or training opportunities. Livelihood options may also be restricted if vendors lose their customer base due to stigma.

As Table 15 shows, we grouped items according to these forms. We then began to drop items, based on the frequency of respondents reporting that they knew someone who had experienced that particular item, and following two basic rules: (1) the final set of items had to include at least one form from each of the groups, and (2) the items could not be dropped if they caused the index to drop more than 10% of the number of people who reported knowing at least one person experiencing stigma for the full set of 15 items.[16]

---

[16] For example, 29.8% of respondents reported knowing at least one person who had experienced one of the 15 items. Therefore, an item could not be dropped if it caused the index to fall by more than 2.98%, or below 26.82%.

Table 15. Forms of stigma and their items

Modified forms of stigma	Item	Percent (n=978 if not stated)	Percent witnessing at least one item per group
1. Isolation (physical and social exclusion)	1. Excluded from a social gathering (wedding, funeral, party, community association group)	6.7	22.5
	2. Abandoned by spouse/partner	8.4	
	3. Abandoned by family/sent away to the village	11.3	
	4. No longer visited, or visited less by family and friends	3.8	
	5. Isolated in household (made to eat alone/ made to use separate eating utensils/ made to sleep alone in separate room)	5.5	
2. Verbal stigma (gossip, voyeurism, taunting)	**1. Visitors increased to "check out" how PLHA is doing**	6.0	18.9
	2. Teased, insulted, or sworn at	10.3	
	3. Gossiped about	10.5	
3. Loss of identity/role	1. Lost respect/standing within the family and/or community	4.6	5.5
	2. Denied religious rites/services (marriage, communion, burial, singing in choir, prayers)/Not allowed to go to church/mosque	1.1	
4. Loss of access to resources & livelihoods (housing, employment)	**1. Lost customers to buy produce/goods or lost a job**	3.6	9.4
	2. Denied promotion/further training	1.4	
	3. Lost housing or not able to rent housing	0.9	
	4. Given poorer quality health services (e.g., passed from provider to provider, not given medicines/treatment/surgery)	2.0	
	5. Had property taken away	3.8	
Percent reporting some form of stigma for all items			**29.8**

Table 16 presents the results of this analysis. The first column indicates the number of items in the index at that point, the second shows the item(s) dropped, and the third column shows the impact of dropping those items on capturing the total percent of people who reported knowing someone who has experienced stigma. Once 8 items remain, we are no longer able to drop items, as the total percent that reported knowing at least one person drops more than 10%.

Table 16. Performance of stigma analysis

Index—Number of items left	Item(s) included in scale/Items dropped	Percent reporting at least one fear of casual transmission
15	1. Excluded from a social gathering 2. Abandoned by spouse/partner 3. Abandoned by family/sent away to the village 4. No longer visited, or visited less by family and friends 5. Isolated in household 6. Visitors increased to “check out” how PLHA is doing 7. Teased, insulted, or sworn at 8. Gossiped about 9. Lost respect/standing within the family and/or community 10. Denied religious rites/services 11. Lost customers to buy produce/goods or lost a job 12. Denied promotion/further training 13. Lost housing or not able to rent housing 14. Given poorer quality health services 15. Had property taken away	29.8
11	Drop: 1. Given poor quality health services 2. Been denied promotion/further training 3. Not allowed/denied religious rights/services 4. Lost housing or not able to rent house	29.2
10	Drop: 1. No longer visited, or visited less by family and friends	28.8
9	Drop: 1. Visitors increase to “check them out”	28.0

Table 16. Performance of stigma analysis (continued)

Index—Number of items left	Item(s) included in scale/Items dropped	Percent reporting at least one fear of casual transmission
8	Drop: 1. Isolated in household	26.9
8 (kept 3 isolation items, 2 verbal stigma and loss of access to resources, 1 loss of identity/role)	1. Excluded from social gathering 2. Abandoned by spouse/partner 3. Abandoned by family/sent away to the village 4. Teased, insulted, or sworn at 5. Gossiped about 6. Lost respect/standing with the family and/or community 7. Lost customers to buy produce/goods or lost a job 8. Had property taken away	26.9

It should be noted that interpreting frequencies across the various forms of observed stigma should be done with caution. For example, the category of institutional discrimination [loss of access to resources] had the lowest number of respondents reporting knowledge of a person who had experienced such stigma, but this should not be interpreted to mean that this form of enacted stigma is less prevalent than others. Low frequencies for this form are not surprising, given that this form of stigma is less openly visible to the general public than other forms of stigma, such as social isolation or gossip. Unless respondents are closely involved with a PLHA, they are unlikely to know that the person has experienced stigma in the form of denial of health care, job promotion, etc.

Test–re-test reliability

The scope of the project did not allow for conducting standard test–re-test or inter-rater reliability. However, several of the questions were asked at two different points in the questionnaire[17], about 20–40 minutes apart, giving us some indication of the stability of the questions. Table 17 presents the results for those items that were asked twice. The first two columns present the percent of respondents answering *Yes* to each round of the question, while the next 2 columns present the number of respondents providing discordant answers (*No* to Q1 and *Yes* to Q2, or *Yes* to Q1 and *No* to Q2), and the percent of total responses that were in disagreement. The low number of total responses that are in disagreement indicates that the questions are reliable by this measure.

---

[17] Because the length of the questionnaire prohibited asking all items twice, priority was given to those included in the AIDS Indicator Survey (AIS).

Table 17. Test–re-test reliability: Percent disagreement of enacted stigma items asked twice

Question Item: Knowledge of person having been/had…	**Question asked first time (Q1): Percent responded *Yes* (n=978)**	**Question asked second time (Q2): Percent responded *Yes* (n=978)**	**Percent Disagreement Q1=*No* Q2=*Yes***	**Percent Disagreement Q1= *Yes* Q2= *No***	**Total percent of discordant responses**
Given poor health services	2.0%	1.6%	0.4%	0.8%	1.2%
Teased or sworn at	10.3%	9.6%	0.7%	1.4%	2.1%
Abandoned by spouse/partner	8.4%	8.2%	1.0%	1.2%	2.2%
Abandoned by family/sent away from village	11.3%	11.2%	0.9%	1.0%	1.9%
Visited no longer or visited less	3.8%	4.1%	0.8%	0.5%	1.3%
Visitors increase to “check them out”	6.0%	6.2%	1.1%	0.9%	2.0%
Property taken away	3.8%	4.1%	0.8%	0.5%	1.3%
Lost respect in family or community	4.6%	4.3%	0.9%	1.2%	2.1%
Isolated in household	5.5%	5.7%	0.5%	0.3%	0.8%

In addition to asking some of the specific enacted stigma items twice, a general question was also included: *Do people in your community behave differently toward people suspected of having HIV/AIDS or treat PLHA differently?* The respondents who answered *Yes* (39.3%) were then asked an open-ended follow-up question requesting examples of how PLHA are treated differently. All examples provided were of negative (i.e., stigmatizing) behavior, including isolation, harassment, loss of care and support, neglect, divorce, property loss, and gossip. While not an ideal comparison, given the negative/stigmatizing nature of the examples provided, it is possible to loosely compare the results of the general question (39.3% responding *Yes* [PLHA are treated differently]) to the percent of respondents who reported personally knowing at least one person who has experienced stigma in the past 12 months (29.8%). We would expect the latter to be somewhat lower, given the time-frame and specificity of the question with the 15 specific items, as opposed to the open-ended question.

Recommendations for measuring enacted stigma in a community sample

1. We do not recommend the original Blue Book enacted stigma indicator (*% of people who support discrimination toward people living with HIV/AIDS*; see indicator 3 in Table 14, as it is likely to suffer from strong social desirability bias. Only three items collected for this indicator showed much variability, and at least two of these items

could garner an affirmative response for reasons that do not necessarily indicate discrimination against PLHA. (For example, it can be argued that PLHA should be assigned separate hospital wards for their own benefit, to ensure they are not exposed to infectious diseases from other patients.)

2. Instead, we recommend collecting a set of items that ask about personal knowledge of someone who has experienced stigma in the past 12 months (see Table 14). The individual items tested demonstrated high reliability when asked more than once, and performed comparably to a general question about treatment of PLHA in the community. However, this is the first time these types of question have been tested, so further studies are needed at more sites to confirm this recommendation.

3. Based on our analysis, we recommend, as the *Essential* indicator for this domain, the 8-item index (see last row of Table 16). Based on the results of the analysis, this is the lowest number of items we recommend for this composite indicator. If time and resources allow, we recommend, for the expanded level of indicators, a composite that adds an additional 3 items to the 8-item index (rows 3–5 in Table 16) and/or the collection of all items to allow for 4 separate indicators, one for each form of stigma.

SECTION 4.4: DISCLOSURE OF HIV SERO-STATUS

Testing of indicators and corresponding questions for disclosure is included as a principal domain, as disclosure is closely linked to stigma and influences prevention, care, support and treatment. Measurement of disclosure at the population level has been limited in the past to hypothetical questions (e.g., *If you were positive, would you disclose your status*) because of the ongoing debate about whether or not it is acceptable to ask respondents in a randomly drawn sample whether a) they have been tested, b) whether they have disclosed their status, and c) for those who answer *No*, why they have not disclosed their status. Given that disclosure may serve as a good proxy measure of stigma, and considering the limitations of asking hypothetical questions to assess disclosure, we felt it was important to explore potential additional indicators and questions in this domain.

To further explore this domain, we examined the issue of disclosure from three different angles. First, we explored the possibility of asking respondents who had been tested if they had disclosed their status and to whom. After initial discussions and questionnaire pre-testing, it was decided that, in the Tanzanian context, it was acceptable to ask respondents (a) if they had been tested and (b) if they *had* been tested, had they disclosed their status to anyone (emphasizing for both questions that we do not want to know their test results). Second, we explored three permutations of a question about respondents' opinions on whether the status of PLHA should be kept secret or not. Finally, we explored questions seeking to measure how respondents are learning about PLHA's status.

1) Disclosure of status

Table 18 presents the one existing indicator for disclosure, the items asked, and their frequencies. As might be expected with a hypothetical question, there is little variability in the response to the question *Would you disclose your status*, with 92.6% of respondents indicating they would disclose their status to someone. Of those who responded that they would not disclose, we asked the open-ended question *Why would you not disclose?* The answers were then coded into the categories presented in Table 18.

Table 19 presents the new indicators we tested. The first one focuses on actual disclosure for those who have been tested. It should be noted that, of the 22% of respondents (215) who have been tested, 93.5% have disclosed their status to someone.

The lack of variability in responses for both the hypothetical and concrete version of the question raises the issue of the quality of the indicator. What we have learned from the PLHA data, as well as the follow-on questions in the population data, is that a general question about disclosure provides limited information useful to exploring stigma. This is because, both among PLHA and within this population sample (see Table 19), although almost everyone discloses to someone, most people only disclose to one or perhaps two people. Disclosure beyond a very small number of people is rare. Therefore, what will tell us more about the climate of stigma is not a general question on whether people disclose (hypothetical or concrete), but more specific ones on how widely people disclose (who they disclose to) and how long it takes them to disclose after learning their status (see Section 6.3).

2) Keeping HIV-positive status secret

The second type of question we explored in the domain of disclosure measures respondents' views on whether PLHA's sero-status should be kept secret or not. Some form of this question has been asked on some DHS surveys and is included in the AIS. This type of question poses some particular challenges related to ambiguity and wording (and hence translation). The first is that variations on this question in English use the terms *secret*, *private*, and *confidential*. Depending on how they were translated and then understood by respondents, these terms could be capturing the same or different information, particularly with respect to implications for analysis of the responses related to stigma. The second issue is that how a respondent replies to a question of this nature may depend on numerous factors, a principal one being who the PLHA is (e.g., family member or not) and from whom they are keeping their status secret or private (e.g., from family or the broader community). The third issue, which became apparent in the pre-test, was the need to specify in the question that the PLHA was yet to have visible signs and symptoms of HIV. Otherwise, a standard response to this type of question was a puzzled look and the answer that status could not be kept secret as everyone would know anyway (because of the signs).

We responded to these challenges by asking two questions that change the focus of who the PLHA is (general community member vs. own family member) and by specifying in each question that we are asking about a PLHA who had yet to show any outward signs of HIV (see Table 20). For these two questions, the term *secret* was used. We then included a third question to elicit information on whether respondents would encourage their own family members, who did not show visible signs of HIV, to be open to the community about their status.

Construct analysis

For construct analysis on these three questions, we examined how these questions related to knowing someone who is living with, or has died of, HIV/AIDS; having personally received disclosure of a PLHA's status; and personally knowing someone who had experienced at least one form of stigma in the past 12 months. None of the relationships were statistically significant, and only one was in the expected direction. We had expected that having personal knowledge of or contact with PLHA and personally knowing someone who had experienced stigma in the past 12 months would make a respondent more likely to answer that a positive sero-status should be kept secret. However, the opposite was true. People who knew of PLHA, or knew of PLHA who had experienced stigma, were slightly less likely (though the difference was not statistically significant) to say their status should be kept secret.

In addition, as part of the testing of what these questions measure, we asked respondents a follow-up question as to *why* they had responded *Yes* or *No*. A standard interpretation of the responses to the general question about keeping status secret or private has been that if stigma is low in the community, and therefore there are few negative ramifications to disclosure of a HIV-positive status, then more respondents will indicate that PLHA's status should be open. The majority of respondents did indicate that status should be open. However, the *why* responses indicate this response is not because stigma is low, but rather is more self-serving and may in fact be an indication of the presence of stigma. A majority of respondents felt PLHA should not keep their status secret so that others could protect themselves from the PLHA and/or because PLHA should be an example to, or teach, others about HIV. A fair proportion also indicated (particularly when asked about their own family members) that status should be open so that PLHA can access care, support, and services. Therefore, it is perhaps not surprising that we do not find the relationships we had expected between these questions and the construct variables.

Table 18. Disclosure: Existing indicators, items, and frequencies

Existing Selected Indicators	**Questions in survey corresponding to indicator(s)** **(n=978 if not stated)**	**Response category**	**Percent**
1. Percent of people who fear disclosing their HIV status because of negative reactions (Blue Book)	**If you personally found out that you were HIV-positive, would you tell anyone?**	Yes	92.6
		No	7.0
		Don’t know	0.4
	If *No* or *Don’t know*, why not?[18] (n=71)	**Response category**	**No. of respondents (in percent)**
		Fear of shame	36 (50.7)
		Fear of isolation	20 (28.2)
		Fear of discrimination	5 (7.0)
		Fear of being talked/gossiped about	15 (21.1)
		Fear of being stigmatized	9 (12.7)
		Fear of dissolution of partnership	5 (7.0)
		Fear of losing care/support	5 (7.0)
		No reason	14 (19.7)

---

[18] Open-ended question that was coded after questioning

Table 19. Disclosure: New indicator, items, and frequencies

New/Revised Indicators	Questions in survey corresponding to indicator(s) **(n=978 if not stated)**	Percent	
1. Percent of people who disclose their HIV status (added)	**Have you ever gone for an HIV test?**	Yes	22.1
		No	77.8
	Did you tell anyone the results of your test? (n=216)	Yes	93.5
		No	6.5

Table 20. Disclosure: New indicators, items, and frequencies

New/Revised Indicators (continued)	Questions in survey corresponding to indicator(s) (n=978 if not stated)	Response Category	Percent
2. Percent of people who think a person should be able to keep their HIV status private (added)	**If a person learns that he/she is infected with the virus that causes AIDS, should this information remain this person's secret or should this information be available to the community?**	Private	12.8
		Community	84.2
		Don't know	3.1
	If *kept private*, why?[19] (n=125)	Person would be isolated/neglected/avoided	66.4
		Personal problem	37.6
		People act differently toward person	33.6
		No one would care for person	18.4

---

[19] Multiple responses allowed

Table 20. Disclosure: New indicators, items, frequencies (continued)

New/Revised Indicators (continued)	Questions in survey corresponding to indicator(s) (n=978 if not stated)	Response Category	Percent
2. Percent of people who think a person should be able to keep their HIV status private (added) **(continued)**	**If *made available*, why?** (n=823)	PLHA threat to others/infect others	58.2
		PLHA needs care and support of the community	44.7
		PLHA should be example to/teach others	45.8
		PLHA should be isolated	1.3
3. Percent of people who would want a family member's HIV-positive status to be kept secret (added)	**If a member of your family contracted HIV/AIDS, would you want it to remain a secret?**	Remain a secret	11.7
		Be open	86.1
		Don't know	2.2
	If *kept secret*, why? (n=114)	Family member would be neglected, isolated, avoided	61.4
		Family member would not be allowed to be in public places	30.7
		Family member would be verbally abused/teased	28.9
		Family member would be blamed	21.1
	If *open*, why? (n=842)	Family member would be able to receive the care and support he/she needs	64.4
		Family member would be able to seek counseling	62.9
		Others can protect themselves	24.3

Table 20. Disclosure: New indicators, items, frequencies (continued)

New/Revised Indicators (continued)	Questions in survey corresponding to indicator(s) (n=978 if not stated)	Response Category	Percent
3. Percent of people who would want a family member's HIV-positive status to be kept secret (added)	**If a member of your family has HIV, but is not showing any symptoms/signs of AIDS, would you counsel/advise them to be open about their HIV status in the community?**	Yes	91.0
		No	7.3
		Depends	1.0
		Other	0.7

Test–re-test reliability

While the scope of the project did not provide the opportunity to examine reliability in a standard manner, we can compare these questions with each other to get some indication of how closely they measure the same concept. Table 21 shows the percent of disagreement on these questions. Some level of disagreement is to be expected, given the differences in phrasing and focus. Given that the percent of total cases in disagreement never goes above 10%, we believe that the questions are fairly reliable.

Table 21. Disagreement between similar questions about keeping HIV status secret

<table>
<tr><th>Q1: Percent responding <i>Secret</i></th><th>Q2: Percent responding <i>Secret</i></th><th>Percent disagreement
<i>Open</i> to Q1
<i>Secret</i> to Q2</th><th>Percent disagreement
<i>Secret</i> to Q1
<i>Open</i> to Q2</th><th>Total percent in disagreement</th></tr>
<tr><td colspan="5"><i>1. If a member of your family became infected with HIV and was not showing signs of AIDS, would you want it to remain secret or not?</i>
<i>2. If a person is infected with AIDS and has no signs, should his/her status be kept secret or made public?</i> <i>(n=943)</i></td></tr>
<tr><td>11.7%</td><td>13.1%</td><td>4.3%</td><td>2.9%</td><td>7.2%</td></tr>
<tr><td colspan="5"><i>1. If a member of your family got infected with HIV and was not showing signs of AIDS, would you advise them to disclose their status in the community?</i>
<i>2. If a person is infected with AIDS and has no signs, should his/her status be kept secret or made public?</i> <i>(n=938)</i></td></tr>
<tr><td>6.8%</td><td>13.0%</td><td>8.1%</td><td>1.9%</td><td>10.0%</td></tr>
<tr><td colspan="5"><i>1. If a member of your family got infected with HIV and was not showing signs of AIDS, would you advise them to disclose their status in the community?</i>
<i>2. If a member of your family got infected with HIV and was not showing signs of AIDS, would you want it to remain secret or not?</i> <i>(n=947)</i></td></tr>
<tr><td>7.0%</td><td>11.6%</td><td>5.8%</td><td>1.2%</td><td>7.0%</td></tr>
</table>

3) How respondents learn about PLHA’s sero-status

The third area we explored in the domain of disclosure was asking a series of questions about how respondents find out about a person’s HIV-positive status. Because these are new questions, we asked several, ranging from a general question about how people find out about someone’s status in the community to more specific questions for respondents who indicate knowing someone with HIV. We also ask respondents whether they have ever had anyone personally disclose their HIV status directly to them. Table 22 presents the indicators, questions, and basic frequencies.

Table 22. Disclosure: New indicators, items, and frequencies

New/Revised Indicators	Questions in survey corresponding to indicator(s) (n=978 if not stated)	Response category	Percent
4. Percent of people who have had someone they know personally disclose their HIV-positive status to them (added)	**Are there people you personally know who have either disclosed their HIV-positive status directly to you or publicly? For example, a family member, friend, neighbor, church member, work colleague?**	Yes	8.1
		No	91.9
	How many do you know? (n=79)	1-3	77.2
		4-10	10.1
		10 or more	12.7
	Do any of those people live in the community? (n=79)	Yes	30.4
		No	69.6
	In your community, in what way do people know if someone has HIV?	Self-disclosure	28.0
		General rumors/gossip	44.2
		Family of PLHA	37.3
		Friends/neighbors of PLHA	47.5
		Health center/health center worker	23.7
		Person looks ill/showing symptoms	92.1
	Is there anyone in the community that you know of who has HIV but has yet to show signs and symptoms of AIDS?	Yes	10.5
		No	89.5

Table 22. Disclosure: New indicators, items, and frequencies (continued)

New/Revised Indicators	**Questions in survey corresponding to indicator(s)** (**n=978 if not stated)**	**Response category**	**Percent**
4. Percent of people who have had someone they know personally disclose their HIV-positive status to them (added)	**Which of the following have been ways through which you got information that someone in your community is infected with HIV?** (n=103)	Self-disclosure	21.4
		Family member of PLHA	37.9
		Community member	62.1
		General gossip/rumors	69.9
		Clinic	8.7
	Do you personally know someone who has died of AIDS?	Yes	62.2
		No	37.8
	How did you find out? (n=608)	Self-disclosure	28.0
		Family member of deceased	44.2
		Community member	37.3
		General rumors/gossip	47.5
		Clinic	23.7
		Person showing signs/symptoms	92.1

What is striking to note is how few people say *disclosure by PLHA themselves* is the way people learn about someone's HIV status in the community (6.3%) and how few respondents have had someone personally disclose their HIV positive status to them (8.1%). Given that these two percentages are similar, and that the percent of disagreement between them is only 7.2% (analysis not shown), despite the different wording, the items appear to be reasonably reliable. Similarly, if we compare the percentage of respondents who said they learned about a PLHA's status through direct disclosure with that of respondents reporting direct disclosure, only 11.7% answered *Yes* to the first question and *No* to the second. It is also interesting to note that visible signs and symptoms, as well as general gossip or through another person (family, friend, neighbor), are the most common ways to find out about a PLHA's status.

Recommendations for measuring disclosure in a community sample

This is a domain that had not been previously explored in depth, so many of the indicators and questions tested were completely new. Further testing is therefore recommended. This is also a domain in which item wording is particularly critical. In addition, the appropriateness and feasibility of questions may vary by context. From our initial experience in measuring this domain, we have learned several important lessons. First, questions that are asking about a respondent's personal opinion (which often include the word *should* in the question, e.g., *Should HIV sero-status be open or not*) will obtain more accurate information if they begin with "*In your personal opinion...*"[20] Second, questions about family members with HIV appeared to be too sensitive to garner reliable data. Last, it is important, when asking about disclosure, either by the respondent or to the respondent, to specify whether you want them to include people who have died. Given those caveats:

1. We do <u>not</u> recommend using any general indicator (hypothetical or concrete) about willingness to disclose status, or even actual disclosure of status. Evidence indicates that practically everyone who is HIV-positive eventually discloses his/her status to at least one person. What *are* useful and more important to capture in terms of gauging stigma are the extent of disclosure (who and how widely) and the length of time from learning HIV status to disclosure to specific persons. If it is contextually appropriate to ask such questions, then we recommend these as Essential indicators (see Table 49).

2. We also recommend *percent of respondents who report having a PLHA personally disclose to them* as an Essential indicator. In the current study, we asked about this in terms of whether it ever happened. In future studies, however, a time period should be specified in such questions (e.g., …*in the last 12 months*).

3. At the Expanded level, we recommend the addition of a general question asking how people in the community learn about a PLHA's status. For more in-depth treatment of this domain, we recommend exploring different levels of how people learn about a person's HIV status.

4. We hesitate to recommend the questions on whether HIV status should be open or private, because the interpretation of what responses mean about stigma can go in opposite directions. These types of questions should only be asked if they are followed with a *why* question for both the *Yes* and *No* answers.

---

[20] See Yoder and Nyblade (2004) for more detail on this wording issue and how it affects responses.

5. HEALTH CARE PROVIDERS

In February 2004, seven indicators were proposed by the S&DIWG to measure HIV/AIDS-related stigma and discrimination among health care providers, including three at the facility level and four at the provider level. These indicators, along with the six existing indicators in the USAID Blue Book (2003), were field-tested with 100 health care providers at three health facilities in Tanzania. A combination of univariate and bivariate statistics and factor analyses techniques were used to determine whether these indicators, and the items measured to calculate them, provide valid and reliable measures of the four domains of HIV stigma: (1) fear of “casual” transmission of HIV and refusal of contact with PLHA, (2) shame and blame of PLHA, (3) HIV sero-status disclosure, and (4) actual acts of discrimination (enacted stigma). Table 50 (see the Conclusion section) lists each of the indicators tested and provides the rationale for the recommendations made. Table 53 presents our indicator recommendations and the proposed method for calculating each indicator.

As noted in the introduction, a sample of health care workers, excluding administrative staff, were selected from three levels of health facilities in Dar-es-Salaam, including a dispensary (Kimara), a district hospital (Mwananyamala), and a national hospital (Muhimbili). Section 3.2 provides a more detailed description of these facilities. Table 23 shows the socio-demographic characteristics of the 100 providers interviewed.

Table 23. Background characteristics of health care provider sample

Background characteristics	Percent
Sex	
Female	71.0
Male	29.0
Age	
15–24	1.0
25–34	10.0
35–44	45.0
>44	44.0
Education	
Less than Standard VII/VIII	1.0
Completed Standard VII/VIII	53.0
Form IV	25.0
Form VI	21.0

Table 23. Background characteristics of health care provider sample (continued)

Background characteristics	Percent
Pre-service Training	
Degree/advanced diploma	24.0
Diploma	17.0
Certificate	39.0
Short course/less than 1 year	20.0
Work Designation	
Medical specialist	10.0
General practitioner	8.0
Clinical officer (medical assistant)	11.0
Nurse officer	11.0
Enrolled nurse midwife (trained nurse)	21.0
Nurse assistant	18.0
Health attendant (nurse auxiliary)	15.0
Lab assistant	4.0
Other	20.0
Marital Status	
Married or cohabiting	83.0
Divorced	4.0
Widowed	6.0
Never married	7.0
Religion	
Catholic	36.0
Muslim	32.0
Lutheran	18.0
Anglican	9.0
Tanzania Assemblies of God	0.0
Seventh Day Adventist	1.0
Pentecostal	2.0
Other	2.0

As with the other study populations, there are some important limitations to the health care provider analysis. First, many of the questions posed to the health care providers were experimental and thus developed in the absence of previously tested questions and experience with this study population. Therefore, even if items were developed by experts with knowledge of the context in which health care providers work, it is possible that some of the measures will not work well. Second, some of the questions surrounding fears and attitudes are influenced by social desirability bias. Third, because of the potential work-related exposure to HIV, it can be difficult to disentangle what actions are driven by fear-related stigma (and therefore stigma) as opposed to justified fear that is not stigma (e.g., invasive procedure in high HIV-prevalence settings where gloves are not available). Fourth, the sample size for this population was small, which limited our ability to identify statistical differences by construct validity variables, if they existed, and to validate the indicators recommended. Finally, as with all the data presented in this report, we only tested the indicators in one site in one country—Tanzania—so it is not known if these results are applicable in other settings. Therefore, we recommend further testing of the indicators and items. For example, it would be useful to include the items tested in larger health facility surveys that are being planned for the future.

Methods

Factor analysis was used to assess the reliability of items in the two latent domains (fear of “casual” transmission of HIV/refusal of contact with PLHA, and values—shame and blame) and to create scales where appropriate. For those items in which factor analysis was appropriate, the following steps were taken to test item reliability and refine the scales. Factor analysis was first conducted, using the principal-components factor-extraction method, on the selected set of items to identify factors and factor loadings. Only factor loadings of 0.40 or higher were considered for inclusion on a given factor. Once the number of factors was determined, promax rotation was performed on the factor loadings to ease interpretation. Internal reliability testing was then conducted separately for each factor by calculating Chronbach’s Alpha. Based on the results of this testing, items were selected for inclusion on a scale, which was then interpreted and named based on the loadings. For the purposes of this analysis, after the scales of a particular construct were refined, each scale was scored individually and then standardized to ease comparison across scales. For all of the scales created, lower mean scores reflect more stigmatizing responses.

For the latent domains, indicator validation was conducted by examining the relationship of items, indices, or scales with selected socio-demographic and construct validity variables (see Table 31). The observed direction and magnitude of these relationships was then assessed based on existing conceptual knowledge about HIV-related stigma. Statistical tests performed included chi-square tests for categorical items and t-tests and analysis of variance for comparing mean scores across groups. While significance tests were conducted for all relationships examined, only a few significant differences were detected. This is likely due to the small number of health care providers interviewed. In cases in which no significant differences were detected, the trends in percentages or means across groups were examined to assess validity.

Construct validity variables

Education level

Pre-service training

In-depth knowledge of HIV (knows all three of the following):

- The risk of HIV transmission following needle-prick or sharps injuries is small (approximately 1 in 300).
- The risk of HIV transmission following a splash of blood to non-intact skin or mucus membrane is very small (approximately 1 in 1000).
- Standard sterilization procedures are sufficient when sterilizing instruments used on an HIV-positive patient

Personally know a health care worker/colleague who has died of AIDS

Know someone who has personally disclosed his/her HIV status to you

Ever been tested for HIV

Willing to disclose HIV status if found to be positive

Socio-demographic factors

Both conceptual and empirical knowledge suggest that those with more education are less likely to hold stigmatizing attitudes. Therefore, education and pre-service training were used to test construct validity.

HIV knowledge, proximity to PLHA, and HIV-testing experience

Lack of correct knowledge about the routes of HIV transmission is also commonly linked with stigmatizing attitudes. To assess knowledge of HIV among health care providers, a number of indicators were tested, ranging from general knowledge of HIV transmission to very specific questions about the rate of transmission after certain types of exposure typically encountered in medical settings. Bivariate analyses demonstrated that the health care providers interviewed had a high level of general knowledge. Therefore, only those items measuring knowledge related to risk of transmission in medical settings had sufficient variance for this analysis. For validation purposes, a dichotomous indicator for in-depth knowledge was created based on provider responses to the three questions with the most variance (see Table 31). Only those who provided correct responses to all three questions were considered to have in-depth knowledge.

Two of the validation indicators related to proximity to PLHA: (1) *know a health care provider/colleague who died of AIDS* and (2) *personally disclosed to by a PLHA*. It was expected that health care providers reporting greater proximity to PLHA would hold less stigmatizing attitudes. The final validation indicators selected related to HIV testing and disclosure. Providers were asked if they had ever been tested for HIV and if they would disclose their status if found to be HIV-positive.

Findings

The remainder of the section presents the results of the health care provider analysis according to the four stigma domains described in the Introduction section. A table is included at the beginning of each domain, including the existing indicators, the items asked in the questionnaire corresponding to each indicator, and the frequency of those items in the study population. The table is followed by results of the reliability and validity testing conducted for these indicators. Each domain section concludes with recommendations on indicators and measurement.

SECTION 5.1: FEAR OF "CASUAL"[21] TRANSMISSION OF HIV AND REFUSAL OF CONTACT WITH PLHA (INCLUDING WILLINGNESS TO CONDUCT MEDICAL PROCEDURES ON PLHA)

While no existing indicators are recommended in this domain for health care providers, we felt that it is important to understand and measure any fear of HIV transmission providers may feel while caring for PLHA. This kind of fear, driven by poor knowledge of HIV, may be a key underlying factor driving some forms of stigma within the health care setting that can be addressed programmatically. To assess the level and types of fear among health care providers, two types of questions were asked: (1) existing hypothetical scenarios (e.g., *Would you buy fresh vegetables from a HIV-positive shopkeeper*, etc.) that have been used in a number of surveys among community members, and (2) a series of items about specific fears (e.g., the response of health care providers when confronted with various situations, including casual contact with and performance of various medical procedures on PLHA).

The hypothetical scenario questions showed little variability and, as discussed above (in the Community section) suffer from several limitations. Therefore, they are not recommended or dealt with in this section.

New Indicators

To assess specific fears among health care providers, three new indicators and corresponding items were tested. The first indicator assesses fear of transmission and is similar to the one tested among community members (see Section 4.1). However, extra items were added to test fears during various types of contact that might occur with PLHA in the health care setting. The second indicator assesses providers' willingness to conduct non-invasive and invasive procedures on PLHA. The third and final new indicator in this domain measures fear of transmission if gloves are not worn while providing a range of invasive and non-invasive procedures on PLHA. This indicator was included because the inappropriate (e.g., double gloves) or unnecessary use of gloves (e.g., for non-invasive procedures) is a stigmatizing act in health care settings reported by PLHA. At the same time, in many developing country contexts, surgical gloves are not always available for procedures where they are necessary. As social desirability bias would affect any direct question to providers about their own [inappropriate] use of gloves, we attempted to capture this issue by including a set of items on risk in this domain, as well as a question in the enacted stigma domain on observations of other health care providers engaging in this behavior (see Table 35).

---

[21] By *casual contact* we mean contact that carries no risk of HIV transmission, such as touching a person living with HIV or an object they have handled. This type of contact involves no invasive transfer of body fluids.

Table 24 presents the frequencies of the items tested for each of the three indicators in this domain. The items show acceptable variance, though some of these items work better than others. Given that all of these items measure attitudes and have more than two response categories, factor analysis was conducted to identify the most appropriate items to measure each indicator and to assess their internal reliability. The items on gloves tested in this domain did not work and therefore are not discussed further. However, the item on observation of inappropriate use of gloves is discussed in the enacted stigma section.

Table 24. Fear of casual contact: New indicators, items, and frequencies

New Indicators	Questions in survey corresponding to indicator(s)	Percent (n=100 if not stated)		
1. Percent of people working in institutions/facilities (e.g., managers, health care workers) who fear: (a) providing invasive medical care to patients with HIV/AIDS (b) contact with non-blood bodily fluids of patients with HIV/AIDS (c) casual contact with PLHA	**In response to the following situations, please tell me if you have fear of HIV transmission, have no fear of HIV transmission, or do not know:**	**Have fear**	**Don't Know**	**No Fear**
	Conducting surgery or suturing on a person living with HIV or AIDS	25.0	1.0	74.0
	Removing used needle from a syringe after attending a person with HIV or AIDS	17.0	1.0	82.0
	Taking blood samples from a person with HIV or AIDS	15.0	1.0	84.0
	Giving an injection to a person living with HIV or AIDS	14.0	1.0	85.0
	Dressing the wounds of a person living with HIV or AIDS	13.0	2.0	85.0
	Putting in a drip on someone who is showing signs of AIDS	11.0	1.0	88.0
	Touching the saliva of a person with HIV or AIDS	17.0	0.0	83.0
	Touching the excreta of a person with HIV or AIDS	14.0	2.0	84.0
	Touching the sweat of a person with HIV or AIDS	8.0	1.0	91.0
	Caring for a person living with HIV or AIDS	18.0	1.0	81.0
	Your child plays with a child who has HIV or AIDS	9.0	0.0	91.0
	Sharing eating utensils with a person living with HIV or AIDS	3.0	0.0	97.0

Table 24. Fear of casual contact: New indicators, items, and frequencies (continued)

New Indicators	Questions in survey corresponding to indicator(s)	Percent (n=100 if not stated)			
2. Percent of people working in institutions/facilities (e.g., managers, health care workers) who: (a) are uncomfortable working with and treating PLHA (b) perceive work-related HIV exposure to be high (c) report negative attitudes toward PLHA	**I'm going to read you several statements, and I want you to tell me whether you strongly agree, agree, disagree, or strongly disagree:**	**Strongly agree**	**Agree**	**Disagree**	**Strongly disagree**
	People who are infected with HIV should **not** be treated in the same place as other patients in order to protect other patients from infection.	1.0	1.0	42.0	56.0
	You are comfortable providing health services to clients who are HIV-positive.	31.0	66.0	3.0	0.0
	You are comfortable performing surgical or invasive procedures on clients whose HIV status is unknown.	27.0	49.0	24.0	0.0
	You are comfortable sharing a bathroom with a colleague who is HIV-infected.	29.0	65.0	6.0	0.0
	You are comfortable assisting or being assisted by a colleague who is HIV-infected.	31.0	69.0	0.0	0.0
	You avoid touching clients who you know or suspect have HIV for fear of becoming infected.	2.0	2.0	53.0	43.0
	You are at high risk of becoming infected with HIV working in the health facility.	12.0	41.0	31.0	16.0
	Most HIV-positive health care workers get infected at work.	5.0	29.0	48.0	18.0

Table 24. Fear of casual contact: New indicators, items, and frequencies (continued)

New Indicators	Questions in survey corresponding to indicator(s)	Percent (n=100 if not stated)			
2. Percent of people working in institutions/facilities (e.g., managers, health care workers) who: (a) are uncomfortable working with and treating PLHA (b) perceive work-related HIV exposure to be high (c) report negative attitudes toward PLHA	**I'm going to read you several statements, and I want you to tell me whether you strongly agree, agree, disagree or strongly disagree:**	**Strongly agree**	**Agree**	**Disagree**	**Strongly disagree**
	The most frequent mode of contracting HIV among health care workers is through work-related exposure.	9.0	37.0	38.0	16.0
	It is required to wear latex gloves whenever performing any task related to examining a patient who may be HIV-positive.	5.0	36.0	37.0	22.0
	Health care providers have a right to know HIV status of all patients.	9.0	48.0	27.0	16.0
	People infected with HIV are generally to blame for becoming infected.	1.0	1.0	55.0	43.0
	Clients who are sex workers deserve to receive the same level and quality of care as other clients.	30.0	66.0	4.0	0.0
	Providing health care services to people infected with HIV is a waste of resources since they will soon die.	1.0	1.0	39.0	59.0
	Clients who have sexual relations with people of the same sex deserve to receive the same level and quality of health care as other clients.	26.0	61.0	7.0	6.0

Table 24. Fear of casual contact: New indicators, items, and frequencies (continued)

New Indicators	Questions in survey corresponding to indicator(s)	Percent (n=100 if not stated)			
3. Percent of people working in institutions/facilities (e.g., managers, health care workers) who perceive risk of HIV infection if gloves are not used while performing: (a) non-invasive, potential fluid contact procedures (b) non-invasive, no fluid contact procedures (c) invasive procedures	**Please tell me how you rank the following activities in terms of risk for transmission of HIV if performed without using latex gloves. Is the risk for transmission high, medium, low, or there is no risk at all?**	**High risk**	**Medium risk**	**Low risk**	**No risk at all**
	Giving an injection	12.0	11.0	15.0	62.0
	Taking blood pressure	5.0	1.0	1.0	93.0
	Delivering a baby	99.0	0.0	1.0	0.0
	Listening to the chest	0.0	1.0	0.0	99.0
	Taking temperature	0.0	2.0	0.0	98.0
	Surgery	98.0	0.0	2.0	0.0
	Changing bed pans	31.0	15.0	29.0	25.0
	Changing patient's beddings	20.0	15.0	32.0	33.0
	Wound dressing	72.0	19.0	6.0	3.0
	Taking blood samples	61.0	17.0	5.0	17.0
	Percent of respondents expressing at least one fear	61.7			

Factor analysis and internal reliability of new indicators for fear of HIV transmission and willingness to treat PLHA

Fear of HIV transmission while caring for PLHA

Table 25 presents the results of factor analysis conducted on the fear variables designed to measure fear of HIV transmission during various types of contact and medical procedures with PLHA listed in Table 24. Three factors emerged from this analysis: (1) fear of HIV transmission during invasive medical procedures with potential blood contact, (2) fear of HIV transmission during contact with non-blood bodily fluids, and (3) fear of casual contact with PLHA.

Table 25. Factor loadings: Fear of HIV transmission while caring for PLHA items

			Factor: Fear of HIV transmission…		
			Providing invasive medical care to patients with HIV/AIDS	**Contact with non-blood bodily fluids of patients with HIV/AIDS**	**Casual contact with PLHA**
Variable	***Indicator***	***Rotated factor loading***	1	2	3
	In response to the following situations, please tell me if you have fear of HIV transmission, no fear of HIV transmission, or do not know:				
1	Giving an injection to a person living with HIV or AIDS	0.92276	▪		
2	Caring for a person with HIV or AIDS	0.88657	▪		
3	Dressing the wounds of a person living with HIV or AIDS	0.86225	▪		
4	Conducting surgery or suturing on a person with HIV or AIDS	0.86682	▪		
5	Putting a drip in someone who is showing signs of AIDS	0.74655	▪		
6	Touching the sweat of a person with HIV or AIDS	0.91991		▪	
7	Touching the saliva of a person with HIV or AIDS	0.78777		▪	
8	Touching the excreta of a person with HIV or AIDS	0.43908		▪	
9	Your child play with a child who has HIV or AIDS	0.37426			▪
10	Sharing eating utensils with a person living with HIV or AIDS	0.89274			▪

Table 26 shows the reliability of the items that loaded onto each factor. Five items, explaining 92% of the variance in providers' fear of HIV transmission while providing invasive medical care to PLHA, loaded onto factor one. The second factor contains two items and explains 72% of the variance of provider fears about contact with non-blood bodily fluids. Factor 3 is composed of two items measuring casual contact with PLHA. These items only explain 23% of the variance, suggesting that (a) these items are not good measures of casual contact, or (b) health care providers' fears of casual contact is minimal and therefore not worth measuring, most likely because they have more knowledge about modes of transmission than community members and therefore do not fear casual contact of PLHA. This last factor is therefore not recommended and was dropped from any further analysis.

Table 26. Fear of HIV transmission while caring for PLHA: Internal consistency of items (Cronbach's Alpha)

Factor	N (items)	Coefficient α
1	5	0.9153
2	2	0.7177
3	2	0.2325

After identifying the factors and their corresponding items, we then constructed two indicators to assess the percentage of health care providers who feared one or more item per factor. Each item was recoded into a dichotomous variable (*fear* vs. *no fear/don't know*). A sum variable was then created from the group of items and then recoded into a dichotomous variable (*fear none* vs. *fear one or more items*). Table 27 presents the results of this analysis. These percentages concur with the findings from the reliability testing, such that it does not seem appropriate to measure fear of casual transmission among health care providers (data not shown). Therefore, we recommend measuring two indicators: fear of invasive procedures and fear of contact with non-blood bodily fluids.

Table 27. Fear of HIV transmission among health care providers: New indicators, items, and frequencies

New Indicators	Questions in survey corresponding to indicator(s)	Percent (n=100 if not stated)		
1. Percent of people working in institutions/facilities (e.g., managers, health care workers) who fear providing invasive medical care to patients with HIV/AIDS	**Do you agree or disagree with the following statements:**			
	Fear providing invasive medical care	**Have fear**	**Don't know**	**No fear**
	Giving an injection to a person living with HIV or AIDS	14.0	1.0	85.0
	Caring for a person with HIV or AIDS	18.0	1.0	81.0
	Dressing the wounds of a person living with HIV or AIDS	13.0	2.0	85.0
	Conducting surgery or suturing on a person with HIV or AIDS	25.0	1.0	74.0
	Putting a drip in someone who is showing signs of AIDS	11.0	1.0	88.0
	Percentage feared one or more items: 26.0			
2. Percent of people working in institutions/facilities (e.g., managers, health care workers) who fear contact with non-blood bodily fluids of patients with HIV/AIDS	*Fear contact with non-blood bodily fluids*	**Have fear**	**Don't know**	**No fear**
	Touching the sweat of a person with HIV or AIDS	8.0	1.0	91.0
	Touching the saliva of a person with HIV or AIDS	17.0	0.0	83.0
	Percent feared one or more items: 18.0			

Willingness To conduct medical procedures on PLHA

Another important aspect of HIV stigma among health care workers is their willingness to treat PLHA, as this can directly affect the availability and quality of care for PLHA. Sixteen items were tested to measure this construct, of which 10 are included in the proposed scales. One item (*you are at high risk of becoming infected with HIV working in the health facility*) was excluded from the analysis as it loaded poorly (<0.40) on all three factors. Table 28 presents the 15 items left, the factor loadings, and a description of the three factors that emerged from these items. The items are ordered from highest to lowest loading per factor. Three factors were identified: (1) comfort working with and caring for PLHA, (2) perceptions of work-related exposure to HIV, and (3) attitudes toward PLHA.

Table 28. Factor loadings: Willingness to treat PLHA items

			Factor		
			Comfort around PLHA	**Work-related HIV exposure**	**Attitudes toward PLHA**
Variable	***Indicator***	***Rotated factor loadings***	1	2	3
1	Comfortable assisting or being assisted by a colleague who is HIV-infected	0.96250	▪		
2	Comfortable performing surgical or invasive procedure on clients whose HIV status is unknown	0.93416	▪		
3	Comfortable in providing health services to clients who are HIV-positive	0.91354	▪		
4	Comfortable sharing a bathroom with a colleague who is HIV-infected	0.88592	▪		
5	Clients who are sex workers deserve to receive the same level and quality of health care as other clients	0.75194	▪		
6	You avoid touching clients' clothing and belongings known or suspected to have HIV for fear of becoming HIV-infected.	0.63951	▪		
7	It is required to wear latex gloves whenever performing **any** task related to examining a patient who may be HIV-positive.	0.49589	▪		
8	You avoid touching clients known or suspected to have HIV for fear of becoming infected	0.41798	▪		

Table 28. Factor loadings: Willingness to treat PLHA items (continued)

			Factor		
			Comfort around PLHA	**Work-related HIV exposure**	**Attitudes toward PLHA**
Variable	***Indicator***	***Rotated factor loadings***	1	2	3
9	Most frequent mode of contracting HIV among health care workers is through work-related exposure.	0.90487		▪	
10	Most HIV-positive health care workers get infected at work.	0.84205		▪	
11	Health care providers have a right to know HIV status of all patients.	0.57284		▪	
12	Providing health care services to people infected with HIV is a waste of resources since they will die soon anyway.	0.89886			▪
13	People infected with HIV are generally to blame for becoming infected.	0.78908			▪
14	People who are infected with HIV should **not** be treated in the same place as other patients in order to protect other patients from infection.	0.77504			▪
15	Clients who have sexual relations with people of the same sex deserve to receive the same level and quality of care as other clients	0.46191			▪

Table 29 presents the reliability of each scale. The remaining six items explain 94% of the variance in factor 1. In an effort to minimize the number of items in this index, items 5 and 6 in Table 29 were excluded from factor 1, which reduced the reliability to 0.93. As the reliability of the 4-item index is still very high, we recommend the smaller index as an essential measure if questionnaire space and time are limited. However, it would be best to collect all 6 items, as they may behave differently in different study populations and contexts. For those researchers or groups wishing to assess health care providers' willingness to treat PLHA, the 6-item index is recommended. Item 11 in Table 29 was excluded from factor 2, as it decreased the reliability of the items measuring perceptions of work-related exposure. The remaining two items explain 78% of the variance in factor 2. Finally, items 14 and 15 in Table 28 were excluded from the scale, as they decreased reliability of items measuring attitudes toward PLHA. The two items retained on factor 3 explain 84% of the variance.

Table 29. Willingness to treat PLHA: Internal consistency of items (Cronbach's Alpha)

Factor	N (items)	Coefficient α
1	6	0.9370
1	4	0.9293
2	2	0.7823
3	2	0.8441

To assess the performance of these factors in the study population, we assessed the percentage of providers who gave one or more stigmatizing responses to the items for each factor. As both positive and negative statements were asked, sometimes agreement indicated a stigmatizing response, and sometimes disagreement did. Items were recoded such that non-stigmatizing responses were given a value of zero, and stigmatizing responses were given a value of 1. Composite indicators were then created from these items and recoded into dichotomous variables (gave no stigmatizing responses vs. gave one or more stigmatizing responses). Table 30 presents the results of this analysis. Based on the percentage of providers who reported stigmatizing responses for each factor, it appears that only the first two factors provide enough variance to warrant including them in the indicator measure. Very few providers (2.0%) reported stigmatizing attitudes toward PLHA. Overall, positive items do not work well in either community or health care provider populations. This is likely due to social desirability bias.

Therefore, we recommend measuring two indicators: *uncomfortable working with and treating PLHA* and *perceive work-related HIV exposure to be high*.

Table 30. Willingness to provide medical care to PLHA: New indicators, items, and frequencies

New Indicators	Questions in survey corresponding to indicator(s)	Percent (n=100 if not stated)			
3. Percent of people working in institutions/facilities (e.g., managers, health care workers) who are uncomfortable working with and treating PLHA	**Do you agree or disagree with the following statements:**				
	Comfort working with and treating PLHA	**Strongly agree**	**Agree**	**Disagree**	**Strongly disagree**
	Comfortable assisting or being assisted by a colleague who is HIV- infected	31.0	69.0	0.0	0.0
	Comfortable performing surgical or invasive procedure on clients whose HIV status is unknown	27.0	49.0	24.0	0.0
	Comfortable to providing health services to clients who are HIV-positive	31.0	66.0	3.0	0.0
	Comfortable sharing a bathroom with a colleague who is HIV-infected	29.0	65.0	6.0	0.0
	Clients who are sex workers deserve to receive the same level and quality of health care as other clients	30.0	66.0	4.0	0.0
	You avoid touching clothing and belongings of clients known or suspected to have HIV for fear of becoming HIV-infected.	2.0	2.0	53.0	43.0
	Percent reporting one or more stigmatizing responses: 28.0				
4. Percent of people working in institutions/facilities (e.g., managers, health care workers) who perceive work-related HIV exposure to be high	*High work-related HIV exposure*				
	Most frequent mode of contracting HIV among health care workers is through work-related exposure.	9.0	37.0	38.0	16.0
	Most HIV-positive health care workers get infected at work.	5.0	29.0	48.0	18.0
	Percent reporting one or more stigmatizing responses: 53.0				

Construct validity

After reliability testing was completed and the factors were refined, scales were created for each factor with a mean of 10 and a standard deviation of 1 to allow for comparison between scales with different numbers of items. Construct validity was then assessed by comparing the mean score of each factor by the selected socio-demographic and construct validity variables. The results of this analysis are presented in Appendix B. For all indices presented, a lower mean score indicates a more stigmatizing response.

Overall, the relationship between the construct variable of knowledge and education and the sub-scales of fear-related stigma and willingness to treat were in the expected direction. Health care providers with incorrect in-depth knowledge of HIV transmission held more stigmatizing attitudes, while health care providers with in-depth knowledge were more willing to treat PLHA and less likely to fear non-invasive procedures with potential fluid contact.

It was expected that health care providers reporting greater proximity to PLHA would hold less stigmatizing attitudes. Interestingly, the opposite relationship was observed across most of the fear indicators tested. It is possible that proximity to PLHA affects health care providers differently than community members in general. For example, knowing a colleague who has died of AIDS could lead to heightened fear of work-related HIV exposure, which could in turn influence negative attitudes toward PLHA. This hypothesis is supported by the fact that most of the stigma indicators performed consistently across the proximity variables.

The proximity and HIV testing validation indicators performed contrary to what was expected for two indictors in particular: (1) fear of HIV transmission while caring for PLHA; and (2) willingness to conduct medical procedures on PLHA. This suggests that either proximity to PLHA and testing behavior influence health care providers differently than community members, or these indicators do not accurately measure the stigma constructs intended. It is our belief that the former is the case, as both indicators behaved as expected with regard to in-depth knowledge and willingness to disclose if HIV-positive. As mentioned previously, one explanation could be that knowing colleagues and patients with HIV increases anxiety about work-related exposure. This hypothesis is supported by the fact that perceptions of work-related exposure were high among health care providers, with 53% agreeing that they are at high risk of becoming infected with HIV at work and 47% reporting having been exposed at work. The relationship between HIV testing and stigmatizing attitudes could also be explained by a heightened fear of work-related exposure. For example, a health care provider who has tested HIV negative may be more worried about being exposed to PLHA than a provider who does not know his/her status.

Based on this analysis, we believe that the factors and items recommended are accurately capturing the constructs intended for this domain of stigma. However, it would be prudent to conduct further testing of these items with a larger sample of health care providers.

Recommendations for measuring fear of casual transmission of HIV by health care providers

1. We do not recommend using the existing general questions (e.g., *willingness to buy food from a PLHA*) that have been asked in population surveys for health care providers as they perform poorly and suffer from other limitations (see the Community section).

2. We do not recommend the indicator on risk of performing various tasks without gloves, as it did not perform well.
3. We do recommend that four of the new indicators be collected: two at the Essential level and two at the Expanded level (for those wishing for a more comprehensive understanding of health care provider fears that drive stigma).

Essential-level indicators

- Percent of people in institutions/facilities (e.g., managers, health care workers) who are uncomfortable working with and treating PLHA
- Percent of people in institutions/facilities (e.g., managers, health care workers) who perceive work-related HIV exposure to be high

Expanded-level indicators

- Percent of people working in institutions/facilities (e.g., managers, health care workers) who fear providing invasive medical care to patients with HIV/AIDS
- Percent of people working in institutions/facilities (e.g., managers, health care workers) who fear contact with non-blood bodily fluids of patients with HIV/AIDS

The summary tables in the Conclusion section provide a listing of all the indicators, rationale for recommendations, a list of items used to collect the appropriate data, and suggestions for aggregation of those items into an indicator.

SECTION 5.2: VALUES, SHAME, BLAME

When measuring HIV stigma among health care providers, it is also important to assess the shame and blame they feel toward people living with HIV and AIDS, as this is a main cause of stigma and discrimination. Table 31 lists the existing indicators (the same as those for the population sample) and corresponding items for measurement. The existing items to measure the shame and blame domain are the same as those tested among the community sample and are not specifically related to health care providers. Table 31 shows the frequency of each item tested. Based on the variances observed, it is clear that some of these items worked better than others at capturing provider attitudes.

Table 31. Values, shame, and blame: Existing indicators, items, and frequencies

Existing Indicators	Questions in survey corresponding to indicator(s)	Percent (n=100 if not stated)		
1. Percent of people who judge or blame persons living with HIV/AIDS for their illness (Blue Book & S&DIWG) 2. Percent of people who would feel shame if they associated with a person living with HIV/AIDS	**Do you agree or disagree with the following statements:**	**Agree**	**Neutral**	**Disagree**
	People who publicly disclose they have HIV/AIDS exhibit behavior that others should copy.	83.0	6.0	11.0
	It is the women prostitutes who spread HIV.	23.0	3.0	74.0
	People with HIV/AIDS deserve sympathy.	98.0	0.0	2.0
	HIV/AIDS is punishment for bad behavior.	9.0	4.0	87.0
	People with HIV/AIDS should be ashamed of themselves.	8.0	2.0	90.0
	I would attend a social event with someone known to have HIV/AIDS.	98.0	0.0	2.0
	People with HIV/AIDS should be treated the same as people without HIV/AIDS.	100.0	0.0	0.0
	I would be ashamed if someone in my family had HIV/AIDS.	9.0	3.0	88.0
	People with HIV should be allowed to fully participate in social events.	100.0	0.0	0.0
	People with HIV/AIDS are promiscuous.	4.0	0.0	96.0
	I would invite a person with HIV/AIDS to a social event.	98.0	0.0	2.0
	HIV is a punishment from God.	14.0	12.0	74.0
	I would feel ashamed if I were infected with HIV.	18.0	8.0	74.0
	Promiscuous men are the ones who spread HIV in our community.	31.0	4.0	65.0

Table 31. Values, shame and blame: Existing indicators, items and frequencies (continued)

Existing Indicators	Questions in survey corresponding to indicator(s)	Percent (n=100 if not stated)			
3. Percent of people who have positive attitudes toward the rights of people living with HIV/AIDS (S&DIWG)	**Society reacts and behaves in various ways toward PLHA or people suspected of having HIV. Please state whether you find the following reactions/behaviors reasonable or not:**	**Reasonable**	**Not sure**	**Unreasonable**	**Depends**
	Divorce or leave a husband or partner because he has HIV	0.0	0.0	100.0	0.0
	Assigning separate hospital ward to PLHA	18.0	0.0	82.0	0.0
	Because of drug shortage, first priority given to non-HIV-infected patients	2.0	0.0	98.0	0.0
	No longer inviting a PLHA to social events, like weddings	0.0	0.0	100.0	0.0
	Limiting people's participation in community activities because of their HIV status	0.0	0.0	100.0	0.0
	Not allowing a child to play with a child having HIV or AIDS	6.0	0.0	94.0	0.0
	In a household, assigning specific utensils for a PLHA	0.0	0.0	100.0	0.0
	Avoiding eating with a PLHA	0.0	0.0	100.0	0.0
	Avoiding using something touched by a PLHA	0.0	0.0	100.0	0.0
	Refusing to share a toilet with a PLHA	0.0	0.0	100.0	0.0
	Divorcing/leaving a spouse/partner because he/she has HIV or AIDS	0.0	0.0	100.0	0.0
	Refusing to rent a room to a person with HIV and AIDS	0.0	0.0	100.0	0.0

Factor analysis and internal reliability

To determine the internal reliability of these items and create appropriate indices to measure this domain, factor analysis was conducted on these items. As many of items had no variance, they were not included in the factor analysis. Table 32 presents the results of the factor analysis conducted for the shame and blame items. Three factors were identified: (1) Judgment of PLHA, (2) attitudes about blame, and (3) attitudes about shame .

Table 32. Factor loadings: Shame and blame items

			Factor		
			Judgment of PLHA	**Attitudes about blame**	**Attitudes about shame**
Variable	***Indicator***	***Rotated factor loadings***	1	2	3
1	HIV/AIDS is a punishment for bad behavior	-0.88155	▪		
2	People with HIV/AIDS should be ashamed of themselves	-0.67127	▪		
3	HIV is a punishment from God	-0.62516	▪		
4	It is the women prostitutes that spread HIV	0.86272		▪	
5	Promiscuous men are the ones who spread HIV in our community	0.83475		▪	
6	I would be ashamed if someone in my family had HIV/AIDS	0.81970			▪
7	I would feel ashamed if I were infected with HIV	0.77509			▪

Internal Reliability

Table 33 shows the internal reliability of the items that loaded on these factors. The first factor contains three items, which explains 59% of the variance of judgment toward PLHA. The coefficient α of the second factor is higher, indicating that the two items explain 70% of the variance of the blame construct. The third factor has two items that explain 61% of the variance of the aspect of shame. Because α of 0.60 or higher is generally considered satisfactory, further testing of the items is warranted and could enhance reliability.

Table 33. Shame and blame: Internal consistency of items (Cronbach's Alpha)

Factor	N (items)	Coefficient α
1	3	0.5882
2	2	0.6980
3	2	0.6072

To assess how well the three indicators worked among the health care providers in the study, the percentage of providers agreeing with one or more of the negative statements for each factor were calculated after dichotomous, composite variables were created. Table 34 presents the findings of this analysis.

Based on the results of the factor analysis described above and the performance of the three indicators in the study population, we recommend that only seven of the original questions be asked to assess the three components of values: judgment, blame, and shame among health care providers that emerged. However, it must be noted that, while the reliability reported for each of these components is acceptable, it is still relatively low. Therefore, additional items should be tested to improve the reliability and validity of this domain among health care providers. For example, it might be beneficial to ask specific questions about provider attitudes toward PLHA in health facilities (e.g., *PLHA attending health facilities should be ashamed of themselves*; *It's a waste of my time to provide care to PLHA in health facilities*, etc.).

Table 34. Values, shame, and blame: New indicators, items, and frequencies

New Indicators	Questions in survey corresponding to indicator(s)	Percent (n=100 if not stated)		
4. Percent of people working in institutions/facilities (e.g., managers, health care workers) who report judgment of PLHA	**Do you agree or disagree with the following statements:**	**Agree**	**Neutral**	**Disagree**
	Judgment			
	HIV is punishment for bad behavior.	9.0	4.0	87.0
	People with HIV/AIDS should be ashamed of themselves.	8.0	2.0	90.0
	HIV is a punishment from God.	14.0	12.0	74.0
	Percentage agreed with one or more negative statements	**21.0**		
5. Percent of people working in institutions/facilities (e.g., managers, health care workers) who report negative attitudes of blame toward PLHA	*Blame*			
	Promiscuous men are the ones who spread HIV in our community.	31.0	4.0	65.0
	It is the women prostitutes who spread HIV.	23.0	3.0	74.0
	Percentage agreed with one or more negative statements	**36.0**		
6. Percent of people working in institutions/facilities (e.g., managers, health care workers) who report negative attitudes of shame toward PLHA	*Shame*			
	I would feel ashamed if I were infected with HIV.	18.0	8.0	74.0
	I would be ashamed if someone in my family were infected with HIV.	9.0	3.0	88.0
	Percentage agreed with one or more negative statements	**21.0**		

Construct validity

The scales designed to measure morally based stigmatizing attitudes, such as shame and blame toward PLHA, behaved as expected across most of the validation indicators. Providers who had been personally disclosed to were less likely to report judgment of PLHA. Likewise, providers who were willing to disclose their sero-status, if HIV-positive, were less likely to report judgment of PLHA. Alternatively, providers who knew a colleague who had died of AIDS were more likely to blame PLHA for contracting HIV. This finding could be explained as a defense mechanism, such that health care providers are more likely to blame their infected colleagues to lessen their own fears of work-related exposure. This hypothesis is supported by the fact that providers' perception of work-related exposure was high (e.g., 66% agreed that *most HIV-positive health care workers get infected at work*; 53% agreed that they *are at high risk of becoming infected with HIV working in the health facility*; and 46% agreed that *the most frequent mode of contracting HIV among health care workers is through work-related exposure*).

Recommendations for measuring values, shame, and blame in health care providers

While the items tested did not perform as well as we would like, both reliability and construct validity testing suggest they will yield reliable and valid measures of this domain. Therefore, we recommend that:

1. The three new indicators are included at the Essential level of measurement for this domain among health care providers.

   <u>Essential-level indicators</u>

   - Percent of people working in institutions/facilities (e.g., managers, health care workers) who report judgment of PLHA
   - Percent of people working in institutions/facilities (e.g., managers, health care workers) who report negative attitudes of blame toward PLHA
   - Percent of people working in institutions/facilities (e.g., managers, health care workers) who report negative attitudes of shame toward PLHA

2. The new indicators should replace the two existing indicators regarding the percent of people who judge, blame, or shame PLHA.
3. As the indicator and items proposed to measure positive attitudes toward PLHA did not yield any variance, we do not recommend collecting this measure.

The summary tables in the Conclusion section provide a listing of all the indicators, rationale for recommendations, a list of items used to collect the appropriate data, and suggestions for aggregation of those items into an indicator.

SECTION 5.3: ENACTED STIGMA (DISCRIMINATION)

Although no indicators were specifically recommended by the S&DIWG to measure enacted stigma among health care providers, we felt that providers are in a unique position to provide information on the forms of discrimination common in health facilities. While we might expect some degree of under-reporting, due to social desirability bias, this type of measure should still provide important information. As such, we asked providers about the discrimination against HIV-positive patients they witnessed or observed in their facilities. Respondents were asked a series of questions about specific types of discrimination witnessed in the past 12 months, including: neglect, unnecessary referral, testing and disclosure without consent, verbal abuse, and differential treatment. Table 35 shows the frequency of these events. It is evident that the frequency of these events varies greatly, ranging from 1% to 43%. To develop a measure that appropriately captures the different types of stigma experienced by PLHA in health care facilities, the experiences were grouped into five categories (see Table 35), based on the similarity of the scenarios posed. Among providers who witnessed enacted stigma, the most common form was differential treatment/forced testing (53%). Overall, 59% of providers reported witnessing at least one form of discrimination toward an HIV-positive patient in the past year. Clearly, it is essential that we ask providers about the types of enacted stigma witnessed in their health care facilities.

Construction of index

We conducted additional analyses to minimize the number of items needed to measure the five categories of enacted stigma listed in Table 35. We followed the same procedure used to minimize the enacted stigma indices in the general population and among PLHA. For example, we observed the effect of dropping items with the lowest frequency from the five categories on the overall percentage of providers witnessing one or more types of enacted stigma. We then determined the minimum items necessary to arrive close to the percentage of those reporting stigma with the original 15-item scale (59.0%). Table 36 presents the results of this analysis.

As these items measure witnessed enacted stigma as opposed to personally experienced enacted stigma, we did not examine differences by gender. In addition, the majority of health care providers surveyed were women. The analysis was carried out as follows: During the first round of minimization, the item with the lowest frequency in each category was dropped. This led to a 10-item scale that resulted in the same prevalence of enacted stigma witnessed as the 15-item scale (59.0%). In the next round of minimization, the two items with the lowest frequency in each category were dropped. For categories with only two items to begin with, we included the remaining item in the overall scale. The resulting 7-item scale decreased the prevalence of enacted stigma observed by 1 percentage point (58.0%). In the next minimization exercise, only one item with the highest frequency was retained for each category. With this 5-item index, the prevalence of enacted stigma witnessed dropped to 56.0%.

Table 35. Forms of stigma and their items

Indicators	Modified Forms of Stigma	Item	Percent (n=100)	Percent who saw or observed at least one item per group
1. Percent of people working in institutions/facilities (e.g., managers, health care workers) who personally know patients who were [*fill in type of discrimination*] because they were known or suspected to have HIV/AIDS (a) neglected (b) treated differently (c) denied care (d) verbally abused (e) tested for HIV/sero-status disclosed without consent	1. Neglect	Because of HIV/AIDS, a client having to wait longer to be attended to because a provider did not want to treat them	3.0	8.0
		Not having bed pans or bed clothes changed as needed/as often for patients with HIV compared to other patients	2.0	
		Receiving less care/attention than other patients	7.0	
	2. Differential treatment/ forced to test	Requiring some clients to be tested for HIV before care was given	8.0	53.0
		Requiring some clients to be tested for HIV before scheduling surgery	30.0	
		Using latex gloves for performing non-invasive exams on clients suspected of having HIV	22.0	
		Extra precautions being taken in the sterilization of instruments used on HIV-positive patients	43.0	
	3. Denied care/ unnecessary referral	A client being denied treatment because they were known or suspected to have HIV	1.0	15.0
		A client being unnecessarily referred on to another provider or another facility because the provider did not want to treat him/her	5.0	
		Because a patient is HIV-positive, a senior health care provider pushed the client to a junior provider	11.0	
		Because a patient is HIV-positive, a junior health care provider pushed the client to a senior health care provider	4.0	
	4. HIV testing & disclosure without consent	Testing a client for HIV without their consent	19.0	21.0
		Disclosing a client's HIV status to their family without the client's consent	8.0	

Table 35. Forms of stigma and their items (continued)

Indicators	Modified Forms of Stigma	Item	Percent (n=100)	Percent who saw or observed at least one item per group
	5. Verbal abuse/gossip	Health care providers gossiping about a client’s HIV status	16.0	18.0
		Scolding or blaming of a client for having HIV infection	6.0	
Percent reporting at least one form of stigma across all areas			**59.0**	

Table 36. Performance of Witnessed Enacted Stigma Indices

Number of items in index	Item(s) included in scale/Items dropped	Percent who saw or observed one or more types of enacted stigma in the last year
15	1. Because of HIV/AIDS, a client having to wait longer to be attended to because a provider did not want to treat him/her 2. Not having bed pans or bed clothes changed as needed/as often for patients with HIV compared to other patients 3. Receiving less care/attention than other patients 4. Requiring some clients to be tested for HIV before care was given 5. Requiring some clients to be tested for HIV before scheduling surgery 6. Using latex gloves for performing non-invasive exams on clients suspected of having HIV 7. Extra precautions being taken in the sterilization of instruments used on HIV positive patients 8. A client being denied treatment because they were known or suspected to have HIV 9. A client being unnecessarily referred on to another provider or another facility because the provider did not want to treat him/her 10. Because a patient is HIV-positive, a senior health care provider pushed the client to a junior health care provider 11. Because a patient is HIV-positive, a junior health care provider pushed the client to a senior health care provider 12. Testing a client for HIV without their consent 13. Disclosing a client’s HIV status to their family without the client’s consent 14. Health care providers gossiping about a client’s HIV status 15. Scolding or blaming of a client for having HIV infection	59.0
10	Drop: 1. Not having bed pans or bed clothes changed as needed/as often for patients with HIV compared to other patients 2. Requiring some clients to be tested for HIV before care was given 3. A client being denied treatment because they were known or suspected to have HIV 4. Disclosing a client’s HIV status to their family without the client’s consent 5. Scolding or blaming of a client for having HIV infection	59.0

Table 36. Performance of Witnessed Enacted Stigma Indices (continued)

Number of items in index	Item(s) included in scale/Items dropped	Percent who saw or observed one or more types of enacted stigma in the last year
7	Drop: 1. Because of HIV/AIDS, a client having to wait longer to be attended to because a provider did not want to treat him/her 2. Using latex gloves for performing non-invasive exams on clients suspected of having HIV 3. Because a patient is HIV-positive, a junior health care provider pushed the client to a senior health care provider	58.0
5	Drop: 1. Requiring some clients to be tested for HIV before scheduling surgery 2. A client being unnecessarily referred on to another provider or another facility because the provider did not want to treat him/her	56.0
7 (kept 3 differential treatment items, and 1 of all other items)	1. Receiving less care/attention than other patients 2. Extra precautions being taken in the sterilization of instruments used on HIV-positive patients 3. Requiring some clients to be tested for HIV before scheduling surgery 4. Using latex gloves for perform non-invasive exams on clients suspected of having HIV 5. Because a patient is HIV-positive, a senior health care provider pushed the client to a junior health care provider 6. Testing a client for HIV without their consent 7. Health care providers gossiping about a client's HIV status	59.0
6 (kept 2 differential treatment items, and 1 of all other items)	1. Receiving less care/attention than other patients 2. Extra precautions being taken in the sterilization of instruments used on HIV-positive patients 3. Requiring some clients to be tested for HIV before scheduling surgery 4. Because a patient is HIV-positive, a senior health care provider pushed the client to a junior health care provider 5. Testing a client for HIV without their consent 6. Health care providers gossiping about a client's HIV status	58.0

Given that the most common form of enacted stigma witnessed was differential treatment/ unnecessary referral (see Table 35), we decided to conduct initial analyses to see what would happen if we kept more than one item for this category. We first created a 7-item index, including the 3 items in the differential treatment category with the highest frequencies and the individual item with the highest frequency for all other categories. As suspected, the 7-item scale performed identically to the 15-item scale, achieving 59.0% prevalence of enacted stigma witnessed. For the final 6-item scale tested, we kept the two items with the highest frequency in the differential treatment category and the individual item with the highest frequency for all other categories. This scale resulted in a 1% drop in prevalence of enacted stigma witnessed (58.0%). Therefore, we recommend that the 7-item scale (with 3 items measuring differential treatment) be adopted to measure this domain among health care providers.

Recommendations

Based on the analysis of items tested to measure enacted stigma among PLHA in health facilities, we recommend that:

1. A new indicator measuring overall observed prevalence of enacted stigma witnessed in the past 12 months be adopted at the Essential level. To measure the overall observed prevalence, we recommend that the 7-item index, including 3 items from the differential treatment category, be measured among health care providers.
2. In addition, to the overall index, it would also be beneficial to report the levels of the specific types of discrimination witnessed, for programmatic purposes (e.g., *neglected*, *treated differently*, *denied care*, *verbally abused*, *tested for HIV/sero-status*, *disclosed without consent*).
3. We also recommend that, when feasible, follow-on questions be added after each of the enacted stigma items to ascertain the frequency of occurrence of the various types of stigma identified.
4. In addition, it would be good to know if the provider did anything after witnessing the specific type of stigma, and if so, what he/she did.

The summary tables in the Conclusion section provide a listing of all the indicators, rationale for recommendation, a list of items used to collect the appropriate data, and suggestions for aggregation of those items into an indicator.

SECTION 5.4: DISCLOSURE OF POSITIVE HIV SERO-STATUS

Personal attitudes and behaviors surrounding disclosure of HIV-positive sero-status can provide important information about personal perceptions of HIV stigma. As such, a number of questions were included in the health care provider questionnaire, including hypothetical questions about personal willingness to disclose and questions about personal HIV testing behavior and subsequent disclosure. In addition to the existing indicator for this domain, three new indicators were tested.

Existing indicator

Table 37 presents the frequency of the items tested to measure the existing indicator for this domain. Among health care providers, as in the population sample, there was little variance in response to the hypothetical question about willingness to disclose if found to be HIV-positive.

Among those who would not disclose, common reasons included: fear of shame, fear of gossip, and fear of losing care and support.

Table 37. Disclosure: Existing indicator, items, and frequencies

Existing Indicator (Source)	Questions in survey corresponding to indicator(s)	Percent (n=100 if not stated)		
		Yes	**No**	**Don't know**
1. Percent of people working in institutions/facilities (e.g., manager, health care workers) who fear disclosing their HIV status because of negative reactions (Blue Book)	**If you personally found out that you were HIV-positive, would you tell anyone?**	88.0	11.0	1.0

New indicators

Asking about actual testing and disclosure was more informative than the hypothetical questions (see Table 38). Of those tested, 20% did not tell anyone their results. However, we do not know if their result was positive or negative. It could be that those who did not disclose were predominantly HIV-negative or vice versa. It is interesting to note the much higher rate of testing in the health care provider sample relative to the population sample. This could be attributed to a number of factors, in particular easier access to testing and more knowledge about treatment options, as well as access to them.

As in the population sample, a series of questions were asked about whether or not a person should keep their HIV-positive sero-status a secret. The answers to these provided some interesting information and worked better (in the expected direction) with health care providers than among the general population. Several of the reasons given that people should keep their status secret suggest an assumption that disclosure will lead to some form of discrimination. For example, in response to the question about whether a family member's status should be kept secret or not, all of the reasons given for keeping it a secret were related to stigma (e.g., the family member will be blamed, isolated, neglected, etc.) Alternatively, the most common reasons given for sharing one's HIV status were positive (e.g., family member will be able to receive care and support and seek counseling.) However, 25% of providers said PLHA should share their status so they don't infect more people. One potential explanation for this could be that health care providers may be more aware of the benefits of disclosing a HIV-positive sero-status (e.g., care and treatment options such as antiretroviral drugs, prevention of mother-to-child transmission, etc.) than those in the general population. They also may feel that these benefits outweigh the potential stigma and discrimination that PLHA may be exposed to following disclosure. To ensure that a statement that a family member's HIV status should remain a secret represents the fear or perception of stigma, we recommend that this question always be followed by a *why* question.

The final new indicator tested how health care providers typically learn about a patient's HIV-positive sero-status. Respondents were first asked, in general, about how they learn about PLHA in their community. Subsequent questions included specific ones about the providers' work colleagues and patients. It should be noted that, for all of these questions, general rumors/ gossip was the most common source reported. For the question pertaining to learning patients' HIV status, however, 44% reported learning from the infected person themselves. Also of interest is the fact that reports of self-disclosure (being told by an infected person about his/her HIV-positive status) are higher among health care providers than among the general population. One explanation for this could be that PLHA may feel more comfortable disclosing their HIV-positive status to health care providers, given the perceived trust a client has in his/her health care provider. The PLHA may also recognize that being open about his/her sero-status may improve the care and treatment he/she receives, or help ensure that appropriate care is given. Another alternative is that PLHA assume that their health care provider already suspects he/she is HIV-positive, given signs and symptoms. However, the fact that 44% of providers reported self-disclosure among PLHA who were not showing visible signs and symptoms seems to negate this hypothesis.

It was not possible to conduct test–re-test or inter-item reliability for the disclosure items, as none of the questions were repeated. In addition, as most of the questions asked about concrete events, it was not necessary to test the construct validity. However, we do observe a general reliability based on the consistent responses across the different measures.

Table 38. Disclosure: New indicators, items, and frequencies

New Indicators	Questions in survey corresponding to indicator(s)		Percent (n=100 if not stated)			
1. Percent of people who disclose their HIV status (added)	**Have you ever gone for an HIV test?**		**Yes**	**No**	**Don't know**	
			63.0	37.0	0.0	
	Did you tell anyone the results of your test?		**n=63**			
			Yes	**No**		
			81.0	19.1		
			n=51			
	Who did you tell?	**Family member**	**Other relative**	**Partner**	**Friend**	**Work colleague**
		19.6	3.9	74.5	17.7	13.3
2. Percent of people who think a person should be able to keep their HIV status private (added)	**If a person learns that he/she is HIV positive but not showing signs/symptoms, should this information remain this person's secret or should this information be available to the community?**		**Personal secret**	**Family secret**	**Community**	**Don't know**
			35.0	26.0	35.0	4.0
	If kept personal secret, why?		**n=35**			
	Personal/private issue		77.1			
	Person would be treated differently		31.4			
	Person would be isolated/neglect or avoided		25.7			
	If let other people know, why?		**n=35**			
	So person cannot infect others		82.9			
	So person can get care and support from the community		74.3			
	So person can encourage others to do the same		31.4			

Table 38. Disclosure: New indicators, items and frequencies (continued)

New Indicators	Questions in survey corresponding to indicator(s)	Percent (n=100 if not stated)			
3. Percent of people who would want a family member's HIV-positive status to be kept secret (added)	**If a member of your family contracted HIV/AIDS, would you want it to remain a secret?**	**Personal secret**	**Family secret**	**Be open**	**Don't know**
		31.0	29.0	36.0	4.0
	If kept a family secret, why?	**n=29**			
	Family member would be…				
	Blamed	17.2			
	Have difficulty finding care and support	6.9			
	Isolated/neglected/avoided	34.5			
	Verbally abused	13.8			
	Not allowed in public places	27.6			
	People would avoid entire family	17.2			
	People would blame entire family	10.3			
	People would stop interacting with entire family	13.8			
	If would let other people know, why?	**n=36**			
	Family member would be able to receive care and support	88.9			
	Family member would be able to seek counseling	75.0			
	So person doesn't infect others	25.0			
	If a member of your family has HIV, but is not showing any symptoms/signs of AIDS, would you counsel/advise them to be open about their HIV status in the community?	**Yes**	**No**	**Depends**	**Other**
		66.0	29.0	4.0	1.0

Table 38. Disclosure: New indicators, items and frequencies (continued)

New Indicators	Questions in survey corresponding to indicator(s)				Percent (n=100 if not stated)			
4. Percent of people working in institutions/facilities (e.g., managers, health care workers) who learned about a patient's status through unofficial channels during the past year	**In a health facility, how does someone's HIV status become known to other people?**	**Infected person**	**General rumors/ gossip**	**Person's family**	**Facility/health care worker where person tested**	**Other**		
		19.0	46.0	6.0	27.0	3.0		
	Is there anyone you know in the health facility who has HIV but has yet to show signs and symptoms of AIDS?				**Yes**	**No**		
					23.0	77.0		
	How did you know that he/she has HIV infection?				**n=23**			
		Infected person	**General rumors/ gossip**	**Person's family**	**Community member**	**Health care provider where person tested**	**Read from hospital file**	**Other**
		43.5	47.8	13.0	26.1	21.7	17.4	21.7
	Do you know of a health worker colleague who has died of AIDS?				**Yes**	**No**		
					51.0	49.0		
	Which of the following have been ways through which you learned that the person died of AIDS?				**n=51**			
		Deceased told me before died	**General rumors/ gossip**	**Person's family**	**Community member**	**Announced at funeral**	**Person had obvious signs and symptoms**	
		19.6	49.0	9.8	19.6	3.9	94.1	
	Do you know of a health worker colleague who has HIV or AIDS?				**Yes**	**No**	**Don't know**	
					26.0	71.0	3.0	

Table 38. Disclosure: New indicators, items and frequencies (continued)

New Indicators	Questions in survey corresponding to indicator(s)				Percent (n=100 if not stated)	
4. Percent of people working in institutions/facilities (e.g., managers, health care workers) who learned about a patient's status through unofficial channels during the past year	**How did you know has HIV or AIDS?**				**n=26**	
		Infected person	**General rumors/ gossip**	**Person's family**	**Someone else**	**Other**
		46.2	53.9	11.5	26.9	26.9

Recommendations

1. As in the community and PLHA samples, findings indicated that neither a general indicator on willingness to disclose nor a more concrete one on actual disclosure provided much information. Therefore, we do not recommend such a general indicator.
2. However, if it is contextually possible to ask, use of an indicator on personal disclosure that asks about specific aspects of disclosure (e.g., *How many people did you disclose to? To whom did you disclose? How long did you wait between finding out your results and disclosing to someone?*) is recommended at the Expanded level. However, these specific questions are sensitive and should be asked with care (e.g., be sure to precede each question with “I don’t want to know your status …”).
3. Based on the analysis of indicators and items to measure disclosure, we recommend that only one of the new indicators—percent of people working in institutions/facilities (e.g., managers, health care workers) who have personally learned about a patient’s HIV status through unofficial channels (e.g., gossip) in the past year—be included at the Essential level.
4. However, because the other new indicators tested provided interesting information on the views and actions of health care providers, we are recommending that they (the ones relating to whether PLHA’s status should be kept secret) be collected for those wishing to have a more in-depth understanding of this domain. However, these must be followed by a *why* question to ensure that the indicator can be interpreted as indicating stigma.

SECTION 5.5: AWARENESS OF LAWS AND POLICIES TO PROTECT PLHA FROM STIGMA AND DISCRIMINATION

In addition to assessing the four domains of stigma among health care providers, it is also important to assess both the existence and awareness of policies and laws within health care institutions to protect the rights of PLHA and prevent discrimination. It is also important to measure provider willingness to report discrimination toward PLHA. Two existing indicators and one new indicator were tested among our study population to assess this area (see Tables 39 and 40). In addition to these indicators, the Blue Book recommends two indicators at the national level related to policies and discrimination within health care settings. As the scope of this project did not allow for an assessment of all health care institutions nationally, we do not report on these but do recommend that such assessments be collected.

Existing Indicators

The items asked to measure the existing indicators had good variance among the health care provider population. It is evident that many of the providers are not aware of either national policies and laws or facility-level policies. Of those who reported being aware of policies at their health facility (15 people), 40% stated that these policies were not enforced. It is clear that awareness of anti-discrimination policies needs to be increased among health care providers, so that health facilities can enforce these policies. It will be important to measure these items over time to see if providers’ awareness increases. Therefore, it is recommended that both of these indicators and their corresponding items continue to be asked among health care provider populations. It is not necessary to ask whether withholding services from PLHA is a violation of the client's human rights, as almost all of the providers interviewed stated that it was.

New indicator

In addition to assessing providers' awareness of laws and policies, it is also important to measure willingness to report discrimination if witnessed. Anti-discrimination policies will only be useful if health care providers are willing to report discrimination. In this analysis, only 30% of the 60 providers who reported witnessing some form of discrimination against PLHA in their health facility were willing to report it to a higher authority. Clearly, we need to measure such willingness over time, as we would expect an increase. However, we recommend testing additional questions to assess provider willingness to better understand their responses. In addition, only those providers who reported hearing or witnessing one of the types of enacted stigma mentioned were asked this question. It is possible that providers may not have perceived some of the items we asked about to be types of stigma and therefore may not have deemed it necessary to report them to a higher authority.

Reliability

It was not possible to assess test–re-test reliability for the knowledge of laws and policies indicators, because none of the questions were repeated in the questionnaire. In addition, as the existing indicators and items ask about concrete events, it was not necessary to assess construct validity.

Construct validity

However, the new indicator recommended asked about provider willingness. We were therefore able to assess the construct validity of this item by comparing it with the selected socio-demographic and construct validity variables. Given the small number of providers who responded to this question (n=60), only one significant difference in willingness was identified. Health care providers who were unwilling to report discrimination against PLHA were significantly more likely to have incorrect in-depth knowledge. As this finding concurs with our hypothesized relationship between in-depth knowledge and stigma, it appears that this item is accurately measuring the intended construct. Although not significantly different, the direction of a number of other relationships was as expected. For example, those who knew a colleague who died of AIDS and those who had been tested for HIV reported higher willingness to report discrimination.

Table 39. Anti-discrimination laws and policies: Existing indicators, items, and frequencies

Existing Indicators (Source)	Questions in survey corresponding to indicator(s)	Percent (n=100 if not stated)		
1. Percent of people working in institutions/facilities (e.g., managers, health care workers) who are aware of policies guaranteeing access/rights to PLHA (S&DIWG)	**Do you know of any national policies against HIV/AIDS stigma and discrimination in Tanzania?**	**Yes**	**No**	
		31.0	69.0	
	Do you know of any laws against HIV/AIDS discrimination that exist in Tanzania?	**Yes**	**No**	
		23.0	77.0	
	Are you aware of any policies to protect PLHA at your health facility?	**Yes**	**No**	
		16.0	84.0	
2. Number or percent of institutions/facilities enforcing policies guaranteeing access/rights and providing recourse (S&DIWG)	**Are these policies enforced?**	**n=15**		
		Yes	**No**	**Don't know**
		53.3	40.0	6.7
	Is withholding health services from a client suspected or known to be HIV-positive a violation of the client's human rights?	**Yes**	**No**	
		98.0	2.0	

Table 40. Anti-discrimination laws and policies: New indicator, items, and frequencies

New Indicator	Questions in survey corresponding to indicator(s)	Percent (n=60)	
1. Percent of people working in institutions or facilities (e.g. managers, health care workers) willing to report discrimination against PLHA	**If you ever saw any of the above happening to a client because he/she has HIV/AIDS, would you be willing to report to higher authority?**	**Yes**	**No**
		30.0	70.0

Recommendations

Based on the results of the analysis of the indicators and items tested to measure awareness of anti-discrimination laws and policies, we recommend that all of the indicators tested be included in the Essential set of indicators to assess this domain.

Essential-level Indicators

- Percent of people in institutions/facilities (e.g., managers, health care workers) who are aware of policies guaranteeing access/rights to PLHA
- Percent of people in institutions or facilities (e.g. managers, health care workers) willing to report discrimination against PLHA

6. PEOPLE LIVING WITH HIV/AIDS

Sample

As previously mentioned, the PLHA questionnaire was administered to a purposively selected sample of 218 people (103 women and 115 men) known to have HIV and living in/around Dar-es-Salaam district (see Table 41). Because respondents were invited to participate through counseling centers or organizations providing other services for PLHA, this sample is not likely to be completely representative of PLHA living in Dar-es-Salaam district. In addition, all participants have tested and know their HIV-positive status, which is also not representative of people living in a high-prevalence setting but with low testing rates. This is also a principally urban sample of PLHA, so respondents' experiences with stigma may differ markedly from those of PLHA in rural areas.

Table 41. Background characteristics of PLHA sample

	Female (n=103)	Male (n=115)	Total (n=218)
Age			
15–24	7.8%	14.8%	11.5%
25–34	22.3%	30.4%	26.6%
35–44	52.4%	33.9%	42.7%
>44	17.5%	20.9%	19.3%
Education			
No formal education	8.7%	2.6%	5.5%
Primary (Standard 1–7)	62.1%	67.0%	64.7%
Post-primary/Form 4	28.2%	21.7%	24.8%
University/Form 5–6	1.0%	8.7%	5.0%

Table 41. Background characteristics of PLHA sample (continued)

	Female (n=103)	Male (n=115)	Total (n=218)
Marital Status			
Married/cohabiting	16.5%	35.7%	26.6%
Divorced	16.5%	7.8%	11.9%
Widowed	50.5%	22.6%	35.8%
Unmarried	16.5%	33.9%	25.7%
Length of Time Knowing HIV Status (mean = 5 years)			
Less than 1 year	10.7%	20.9%	16.1%
1–5 years	45.6%	47.8%	46.8%
6–10 years	30.1%	20.9%	25.2%
11–15 years	9.7%	6.1%	7.8%
More than 15 years	3.9%	4.3%	4.1%

This section focuses on the following dimensions: enacted stigma, disclosure, internal stigma, and awareness of policy, laws, and means of redress. Less attention is paid to the fear of transmission and refusal of contact and the shame, blame, and judgment dimensions in this sample.

SECTION 6.1: FEAR OF TRANSMISSION, REFUSAL OF CONTACT, AND SHAME, BLAME, AND JUDGMENT

The questionnaire among PLHA included general HIV/AIDS knowledge questions and a very few in-depth knowledge questions. It did not include questions about respondents’ fears, as people living with HIV, of transmitting the virus to others, or questions about actions they may have taken to prevent transmission, such as avoidance, isolation, and refusal of contact behaviors. Therefore, there was little, if any, data to contribute to a discussion of fear of transmission or refusal of contact in this sample.

The PLHA respondents were asked a nearly identical set of questions related to community attitudes about values, shame, and blame as found in the community questionnaire. Like the community questionnaire, these questions were worded as follows: *Society and people react to PLHA in different ways. Please tell me whether the following statements are true or not true with regard to people in the community you live in: “Most people in my community think that …”* and *“Most people in my community behave in the following ways: …”.*

This set of questions did not work well in this sample. It seems that the issues—particularly on the items about the most shameful and judgmental attitudes—may have been too personal to the respondents. The data generated by these questions were not stable and are difficult to interpret with much confidence. We are far more confident of the way these questions performed when asked of the community sample about respondents' own attitudes and about respondents' perceptions of community attitudes.

Recommendations for measuring fear of transmission, refusal of contact, and shame, blame, and judgment among PLHA

1. At the Expanded level, ask more questions about in-depth knowledge that are more pertinent to people living with HIV. Some suggestions include questions about details of mother-to-child transmission; sero-discordance; co-infection and re-infection; CD-4 counts and viral loads; opportunistic infections; and/or healthy living, longevity, and capabilities while living with HIV.
2. Develop new questions to ask about PLHA fears of transmitting HIV to others and actions that they have taken to avoid it (also at the Expanded level).
3. Rely on general population data (e.g., data from the community survey) to assess stigmatizing attitudes related to shame, blame, and judgment in the community, rather than data from a PLHA sample.

SECTION 6.2: ENACTED STIGMA

To gather data on enacted stigma, the questionnaire administered to PLHA included questions about respondents' fear and experience of 17 items representative of four main forms of enacted stigma, as described by qualitative research in Tanzania. Table 42 presents the two existing indicators for this domain, items grouped by main form of enacted stigma, frequencies for these items (fear and experience), and percent of respondents experiencing at least one item for each form. Included in the questionnaire were questions about whether PLHA *ever* experienced stigma and whether (and how frequently) they experienced it *in the last year*. In nearly every case, those who reported ever experiencing an item also reported experiencing it one or more times in the last year. For that reason, our focus is on the experience of stigma in the last year.

More than half (56%) of PLHA had experienced at least one stigmatizing incident in the last year (see Table 42). Most respondents who experienced stigma experienced more than one item of stigma (data not shown). A quarter of respondents (24.3%) experienced 1–3 items, and just under 7% experienced 10–13 items. No one experienced all 17 items of stigma that we inquired about. Of the forms of stigma, verbal stigma is the most prevalent, with 45% of PLHA reporting they experienced at least 1 of the 3 items in this form. Isolation follows closely, with 43% experiencing at least one of its 7 items. Of the two sub-forms, social exclusion occurred more, with 36% experiencing 1 of 4 items and 33.5% experiencing 1 of 3 physical exclusion items. Most PLHA who experienced isolation experienced both social and physical exclusion.

At different points of the questionnaire, respondents were asked both whether they feared experiencing a given item and whether they actually experienced it. As seen in Table 42, the pattern for fear of stigma roughly follows that of the experience of stigma. That is to say that PLHA fear most the types of stigma that were most commonly experienced, such as being gossiped about and teased, and they fear least the types of stigma that occur infrequently, like physical assault and being denied religious rites. This indicates that people living with HIV are well aware of the type and degree of stigma that occurs in their environment (i.e., fear of stigma is neither overly heightened nor unduly downplayed). Fear exceeds actual experience, as can be expected, but the levels of fear and actual experience are close to one another. In only a few instances was this not the case, both of which pertained to verbal stigma (gossip and teasing).

In addition to stigmatizing experiences, PLHA were asked about two positive responses they may have experienced: (1) receipt of more care and support from family, neighbors, or the community, and (2) receipt of any special services (home-based care, medical treatment, material support). Results showed that 22% reported being given more care and support by family, neighbors, or the community, and 15% reported being given special services. Another section of the questionnaire probed deeper into stigmatizing experiences in health care settings.

In nearly every case, those who reported ever experiencing an item also reported experiencing it one or more times in the last year. For that reason, this study focused on the experience of stigma in the last year.

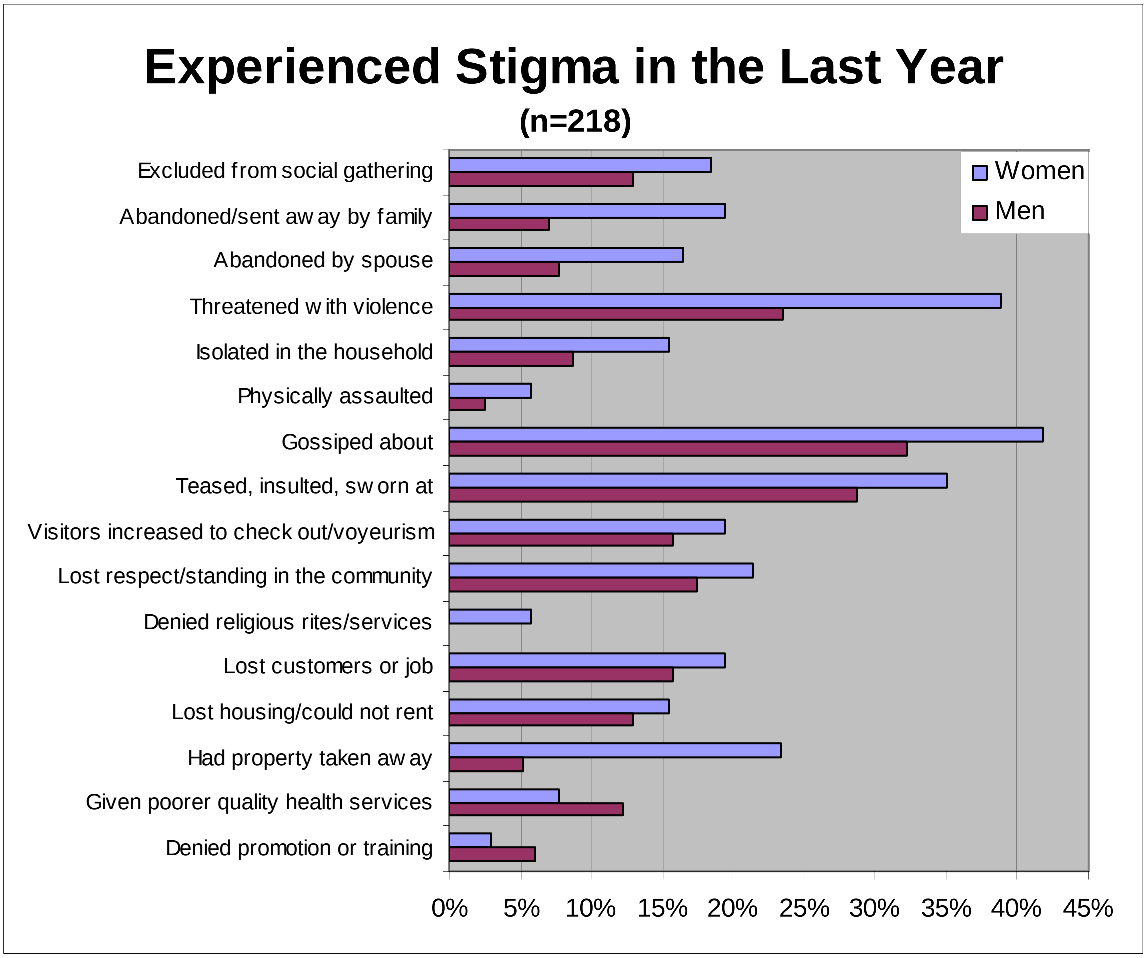
Table 42. Enacted stigma: Existing indicators, items, and frequencies

Existing Selected Indicators	Form of Stigma	Item	Percent fearing	Percent experiencing (n=218)	Percent experiencing at least 1 Item
1. Percent of PLHA reporting fear of stigma and discrimination in the past 12 months (Blue Book) 2. Percent of PLHA reporting experiencing stigma or discrimination ever, and in the past 12 months (Blue Book)	1. Isolation (physical exclusion, social exclusion)	1. Excluded from a social gathering (wedding, funeral, party, community association group)	20.6	16.1	43
		2. Abandoned by your spouse/partner	11.4	11.9	
		3. Abandoned by your family/sent away to the village	20.6	12.8	
		4. No longer visited, or visited less by family and friends	15.3	21.1	
		5. Isolated in your household (made to eat alone/made to use separate eating utensils/made to sleep alone in your own room)	16.5	12.4	
		6. Physically assaulted (e.g., hit, kicked, punched)	9.1	4.1	
		7. Threatened with violence	N/A	30.7	
	2. Verbal stigma (gossip, taunting, voyeurism)	**1. Visitors increase to “check out” how you are doing**	**22.9**	**18.3**	**45**
		2. Teased, insulted, or sworn at	26.6	32.1	
		3. Gossiped about	35.3	37.6	
	3. Loss of identity/role	1. Lose respect/standing within the family and/or community	23.0	19.3	21
		2. Denied religious rites/services (marriage, communion, burial, singing in choir, prayers)/Not allowed to go to church/mosque	7.8	2.8	
	4. Loss of access to resources and livelihoods (housing, employment)	**1. Lost customers to buy produce/goods or lost a job**	**21.6**	**17.9**	**43**
		2. Denied promotion/further training	**8.3**	**5.0**	
		3. Lose housing or not be able to rent housing	19.7	14.2	
		4. Given poorer quality health services (e.g., passed from provider to provider, not given medicines, treatment, surgery)	**12.4**	**10.1**	
		5. Have property taken away	16.1	14.2	
Percent experiencing at least one of the above items				**56.0**	

Gender Differences in the Experience of Stigma

There are also marked differences in the experience of stigma by gender.[22] In nearly every instance, women experienced each form of stigma more often than men, in some cases much more (see Figure 1). Women were threatened with violence, abandoned by a spouse or family, and had property taken away far more often than did men. They also experienced noticeably more verbal stigma. In only two situations did men experience more stigma than women: men more often were denied a promotion or training opportunities and were given poorer quality health services.

Figure 1. Percent who experienced stigma in last year



Several possible reasons may explain these differences. Men may outnumber women in the formal employment sector, and women may therefore simply not have the same opportunity as men to be denied promotions or training opportunities in that setting. Regarding health services, it may similarly be that men access health services to a greater degree than do women and therefore are at greater risk of experiencing stigma in health care settings. Alternately, it may be that health

---

[22] This sample showed a significant difference between men and women in the length of time since learning about HIV status (women knowing status longer). Therefore, we compared experiences of men and women, controlling for length of time knowing HIV status. The overall finding, that women experience more stigma than men, continues to hold while controlling for length of knowing status.

services are primarily geared toward women’s health issues and staffed with female health care providers, who, being women, may maintain harsher judgmental attitudes toward men who have HIV as compared to women who have HIV. Or it could be a reflection of men’s higher expectations for care: the level of care may be equally good or poor for women and men, but men may be more vocal when care does not meet their expectations. None of these hypotheses have been tested in this study.

Enacted Stigma Index

As in the population sample, a much higher proportion of PLHA have experienced at least one form of enacted stigma (56%) than would be indicated by only examining the data from any one individual enacted stigma item (highest for an individual item is 35%). Therefore, we conducted an analysis to determine if any items could be dropped without losing a significant number of PLHA reporting that they have experienced at least one form of stigma. The first step in creating an index for experienced stigma was to categorize questionnaire items according to the four forms of stigma described and presented earlier (see Table 42): (1) isolation (physical and social), (2) verbal stigma, (3) loss of identity and role, and (4) loss of access to resources and livelihoods (sometimes referred to as institutional stigma).

Analysis was then conducted to determine the minimum number of items possible while still arriving close to the overall level of stigma (56%). Since there is a [sometimes sizable] difference according to gender as to the extent of stigma experienced, attention was paid to how the elimination of any given item affected the ability of the index to capture the level of stigma in the full sample as well as among women and men separately. These were the two criteria (overall level and levels by gender) used to determine if an index performed satisfactorily. A drop of 10% or greater of the total amount (5.6% in this case) was considered unsatisfactory performance.

For each form of stigma, the item with the highest frequency was retained. Next, each of the other items in that form was compared to that highest frequency item to determine which ones contributed the most new cases (i.e., did not experience A, but did experience B). The items that contributed the fewest new cases were eliminated. This step was repeated until the index no longer performed satisfactorily.

The complete Enacted Stigma Index, including all 17 items, shows that 56% of the full sample, 63.1% of women and 49.6% of men, experienced some stigma (Table 43). For each form of stigma, the item recording the highest frequency was retained as the core of the index:

- No longer visited/visited less by family and friends (isolation/social exclusion)
- Threatened with violence (isolation/physical exclusion)
- Gossiped about (verbal stigma)
- Lost respect/standing with family or community (loss of identity/role)
- Lost customers or job (loss of resources/livelihood)

Table 43. Performance of Enacted Stigma Indices

Number of items in index	Items included in scale/Item(s) dropped	Percent experiencing at least one instance of stigma in last year		
		Female	Male	Total
17	1. Excluded from a social gathering 2. Abandoned by your spouse/partner 3. Abandoned by your family/sent away to the village 4. No longer visited, or visited less by family and friends 5. Isolated in your household 6. Physically assaulted 7. Threatened with violence 8. Visitors increase to “check out” how you are doing 9. Teased, insulted, or sworn at 10. Gossiped about 11. Lose respect/standing within the family and/or community 12. Denied religious rites/services/Not allowed to go to church/mosque 13. Lose customers to buy produce/goods or lose a job 14. Denied promotion/further training 15. Lose housing or not be able to rent housing 16. Given poorer quality health services 17. Have property taken away	63.1	49.6	56
14	Drop: 1. Been abandoned by your family/sent away from family 2. Had visitors increase to “check out” how you are doing 3. Been denied promotion/further training	63.1	49.6	56
12	Drop: 1. Been given poorer quality health services (e.g., been passed from provider to provider, not given medicines, treatment, surgery) 2. Been physically assaulted (e.g., hit, kicked, punched)	63.1	49.6	56

Table 43. Performance of Enacted Stigma Indices (continued)

Number of items in index	Items included in scale/Item(s) dropped	Percent experiencing at least one instance of stigma in last year		
		Female	Male	Total
9	Drop: 1. Been excluded from a social gathering (wedding, funeral, party, community association group) 2. Lost housing or not been able to rent housing 3. Isolated in the household	63.1	48.7	55.5
7	Drop: 1. Been teased, insulted, or sworn at 2. Been denied religious rites/services (marriage, communion, burial, singing in choir, prayers)/Not allowed to go to church/mosque	60.2	46.1	52.8
6	Drop: 1. Been abandoned by spouse/partner	54.4	44.3	49.1
5	Drop: 1. Had property taken away	53.4	43.5	48.2
5 (kept 2 isolation items, one of the others)	1. No longer visited, or visited less by family and friends 2. Threatened with violence 3. Gossiped about 4. Lose respect/standing within the family and/or community 5. Lose customers to buy produce/goods or lose a job	53.4	43.5	48.2

An item garnering the highest frequency was retained for each sub-form of isolation: social and physical exclusion. Although most people who experienced physical exclusion experienced social exclusion as well and, therefore, physical exclusion items are unlikely to contribute many new cases, earlier qualitative research indicates that both sub-forms are important and discrete components of the isolation form of stigma. There was, then, a compelling conceptual basis for including both items.

With the elimination of the lowest contributing three items (abandonment by family, voyeuristic visits, denial of promotion/training), the resulting 14-item index remained unchanged at 56%, as did a reduction to 12 items (see Table 43). Once the index was reduced to 9 items, the index dropped slightly to 55.5%. The decrease in the level of stigma measured among men was small (less than 1%), and there was no decrease in the level of stigma measured among women. In addition to the core items, this 9-item index includes abandonment by spouse/partner; teased, insulted, sworn at; denied religious rites; and property taken away. The fact that three of these items (abandonment, denial of rites, and property taken away) are experienced predominantly by women and that the fourth, teasing and insults, is experienced by many PLHA, male or female, most likely accounts for the favorable performance of this index for both men and women.

Eliminating the next two items that contribute the fewest new cases causes the index to fall further to 52.8%, but the decrease (3.2%) is still within the 5.6% margin that defines an acceptably performing index. There is now a 2.9% drop in the level of stigma measured for women and a 3.5% drop for men. Eliminating the next single item that contributed the fewest new cases, abandonment by spouse or partner, causes a more precipitous drop. This 6-item index measures stigma at 49% rather than at 56% and is slightly below the 50.4% level for good performance. Of greater concern, however, is that it captures far less of the stigma experienced by women than by men. The level of stigma among women drops by 8.7%, as compared to a drop of 5.3% among men, because it is disproportionately women who experience spousal/partner abandonment (16.5% compared to 7.8%).

The 5-item core index, the most minimalist one possible to retain one item in each form of stigma, introduces even further distortions in both the overall level of stigma captured and the level of stigma captured among women and men.

Toward Reliability: Comparing Similar Questions

Some items were asked about in more than one question as a way to test reliability of some of the items. These questions were not repeated in identical fashion, which would allow a rigorous test–re-test reliability analysis. Rather, they asked about similar aspects of stigmatizing experiences in slightly different ways, or of a slightly different subset of the sample, allowing us to compare and contrast data yielded from variations of a question. Items in the isolation and loss of access to resources/livelihoods can be compared in this manner.

Isolation

There are three places in the questionnaire where a respondent could report experiencing two different items related to isolation—having been divorced or abandoned and social or physical isolation. The first place is where these items are asked about directly or prompted (e.g., *Have you experienced X in the past 12 months because of your HIV status*?). There are then two additional points in the questionnaires where respondents can report they have experienced these items in response to an open-ended or unprompted question.

1) Respondents are asked if they have disclosed their HIV status to anyone. Those who respond that they have (n=178) are then asked whether the way in which people behaved toward them changed after they disclosed. For those who report that the way people treated them changed after disclosure (n=66), an open-ended question follows (e.g., *How did things change?*). The responses were then coded, with 9% indicating divorce or abandonment, and 54.5% indicating isolation. This compares to the 10% of respondents (those who had disclosed; n=178) who reported, when asked the direct (prompted) question, that they had been divorced

or abandoned, and 21.3% who reported being isolated in their household or excluded from a social event.

2) Similarly, respondents who reported that they had exhibited signs/symptoms of HIV/AIDS (n=123) were also asked if the way people treated them changed once those signs appeared, and then how things changed. Of those who indicated things changed (n=59), 10% reported divorce or abandonment and 47.5% reported isolation in response to the unprompted/open-ended question (e.g., *How did things change?*). This compares to the 14.6% of respondents (n=123) who reported, when asked a direct question, that they have experienced divorce or abandonment, and 31.7% who reported being isolated in their household or excluded from a social event.

A comparison of the responses elicited from these questions is displayed in Table 44. Other items either did not occur in the unprompted question or the wording was too different between the unprompted and prompted versions to warrant comparison.

Table 44. Enacted Stigma—Isolation: Frequency comparison of similar questions

Item	Percent respondents who disclosed		Percent respondents who had signs	
	Unprompted (n=66)	**Prompted** (n=178)	**Unprompted** (n=59)	**Prompted** (n=123)
Divorced/ abandoned	9	10	10	14.6
Isolated*	54.5	21.3*	47.5	31.7*

* *Responding* Yes *to either:* Have you been isolated in your household because of your HIV status in the last year? *or* Have you been excluded from a social gathering because of your HIV status in the last year?

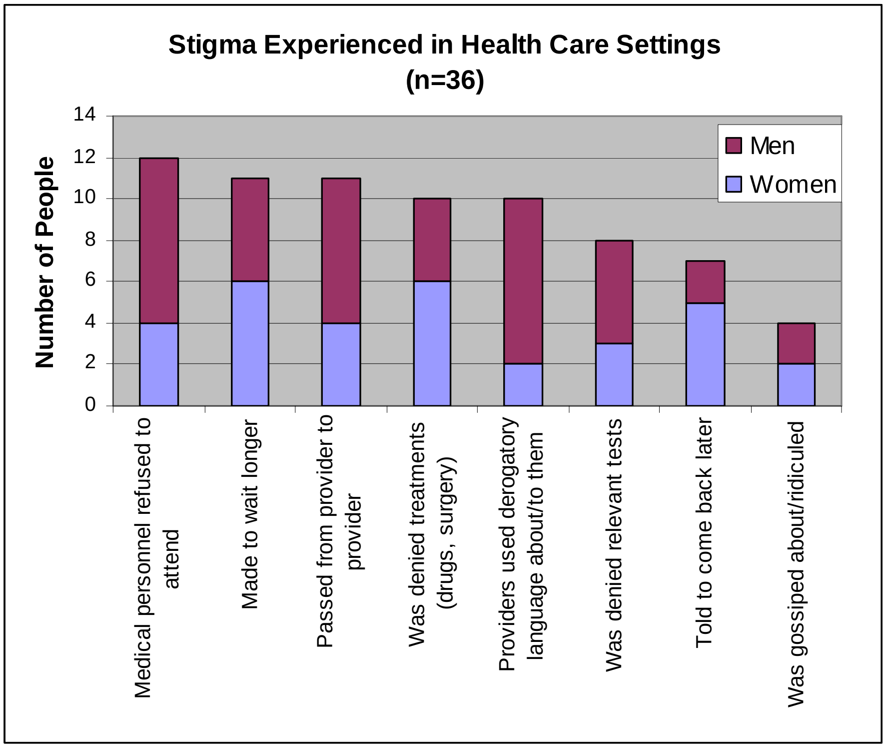
Responses to both prompted and unprompted questions about being abandoned by a spouse or partner were very comparable. These questions may have yielded such consistent data in part because divorce and abandonment are tangible, concrete items. As can be seen in Table 44, the responses about isolation are not at all consistent. They vary by as much as 22.2% between unprompted and prompted questions. This implies that there are other forms of isolation experienced by PLHA that are not captured by the phrasing *excluded from a social gathering (wedding, funeral, party, community association, group)* and *isolated in the household, made to eat alone/made to use separate eating utensils/made to sleep alone in own room*, which was used in the prompted questions. Respondents may have been reporting isolation that occurred in places other than the household or about situations other than those examples listed in our prompted questions. This indicates a need to include additional items related to isolation in the enacted stigma index.

Loss of access to resources/livelihoods

In response to an open-ended question about how PLHA may be treated in the community (n=185), 23% mentioned loss of job or housing, which is precisely the percent of the full sample that reported experiencing one or both of these losses. Other than questions about care, no other items were included that could be used for comparison of the experience of the enacted stigma forms of lost access to resources and livelihoods.

The items relating to loss of care provide the most data for comparison because (a) a section of the questionnaire dealt explicitly with stigma in health care settings (3 items about services denied, 3 items about delays, 2 items about verbal stigma), and (b) 1 of 17 items asking about all forms of enacted stigma was specifically about experiencing stigma within health care settings. In answer to this question, 10% of PLHA reported ever receiving poorer quality health care because of their HIV status, compared to 16.5% of people who say they were ever treated differently in a health care setting because of their HIV status (in response to questions in the more in-depth section on health care settings—see Figure 2). No single example, however, was experienced by more than 12 individuals.

Figure 2. Percent who experienced stigma in health care settings



Some items about stigma in health care settings were asked in both the PLHA sample (36 PLHA who sought health care and were treated differently) and the health care provider sample, albeit with slightly different wording in some cases (see Table 45). In nearly all similar items, PLHA reported experiencing the stigmatizing item more than health care providers reported witnessing it. The biggest differences occurred regarding denial of treatment and being made to wait.

Table 45. Health Care: Frequency comparison of similar questions

Item	Percent PLHA experiencing item (n=36)	Percent provider witnessing item (n=100)
Denied treatment (provider) **Denied relevant treatments (PLHA)**	27.7	1
Made to wait longer	30.5	3
Referred to another facility		5
Pushed from senior to junior provider		11
Passed from provider to provider	30.5	
Gossiped about (HIV-status provider)	11	16
Being scolded/blamed for having HIV (provider) **Used derogatory language (PLHA)**	27.7	6

Recommendations for Measuring Enacted Stigma in PLHA

1. Experienced stigma and fear of stigma followed the same pattern, and the questions worked well in both cases. However, experienced stigma is a more concrete set of indicators. It is also likely to be more sensitive to change due to interventions. Changes in fear of stigma may lag behind changes in experienced stigma, as fears may not be allayed until observed stigma has decreased for some time. For these reasons, it would be preferable to measure experienced stigma over fear of stigma if both sets of indicators cannot be collected. Experienced stigma is recommended as an Essential indicator, while fear of stigma is recommended as an Expanded one.

2. Because most items of stigma were experienced in the last year, it makes more sense to measure stigma experienced *in the last year* for the above-mentioned Essential indicator rather than stigma *ever experienced*, with the exception of particularly severe stigma items. By measuring stigma experienced in a given time period, such as one year, we are likely to have an indicator that is sensitive to changes from stigma reduction interventions. For more severe forms of stigma (e.g., physical assault, loss of job) and one-time events (e.g., abandonment), which occur with less frequency, it is essential to inquire about stigma *ever experienced* as well as experienced in the last year, as these items may be otherwise missed if data are collected only for the last year.

3. It is also worthwhile measuring how often respondents experienced stigma in the last year as an Expanded level of information. A decrease in how often stigma is experienced in a year is an indication of intervention effectiveness that would be overlooked if respondents were asked only whether or not that item was experienced in the last year. We asked about frequency both in relation to fear of stigma and experienced stigma, using different ways to categorize the response. The three categories—never, sometimes, and often—that were used to capture frequency of feared stigma should be sufficient and can be applied with modest sample sizes. More categories may run the risk of small numbers in some categories.

4. Since most people experience more than one item in the stigma index, it is also worthwhile to create a count variable that measures how many people experience only 1 item, how many experience 2–3 items, and how many experience many stigma items. A reduction in how many items a person experienced in the last year in spite of no changes in the percentage of people experiencing some stigma would indicate a measure of intervention effectiveness that would otherwise be overlooked. This recommendation is being made at the Expanded level.
5. It is essential that data be disaggregated by gender, because the experience of stigma clearly differs for men and women. Such disaggregation can uncover whether one gender experiences more stigma overall (as is the case with women in our sample), as well as whether there are some forms of stigma that are experienced predominantly by one gender (as is the case with abandonment by spouse in our sample). These items are likely to vary by setting.
6. When creating an index to summarize how much stigma is occurring, the 12-item index performs well, as it captures the full extent of stigma in the sample and has no distortions by gender. For this reason, we are recommending the use of the 12-item index as the Expanded index. The 7-item index is acceptable as the Essential index, as it performs within the 10% rule. However, it does not capture all stigma occurring in the sample, and there are some distortions in the stigma measured among women and men. Furthermore, as it does not save much time or effort to drop 5 items, the Expanded index should be considered whenever possible. This 12-item index includes:
   a. No longer visited/visited less by family and friends (isolation/social exclusion)
   b. Been abandoned by your spouse/partner (isolation/social exclusion)
   c. Been excluded from a social gathering (isolation/social exclusion)
   d. Threatened with violence (isolation/physical exclusion)
   e. Isolated in the household (isolation/physical exclusion)
   f. Gossiped about (verbal stigma)
   g. Lost respect/standing with family or community (loss of identity/role)
   h. Been denied religious rites/services (loss of identity/role)
   i. Lost customers or job (loss of resources/livelihood)
   j. Lost housing/not able to rent (loss of resources/livelihood)
   k. Had property taken away (loss of resources/livelihood)
7. The enacted stigma index is a first effort at measuring in index form the level of stigma in a population of PLHA. All 17 items should be collected, and the recommended 12-item index should be tested in other settings (and disaggregated by gender), as variations in prevalence of the different forms are likely to occur in different places.

8. We recommend collecting all 17 items separately, even if only 12 items are included in the summary index. This is because some severe forms (e.g., physical assault) may have low frequencies and contribute little to a summary index, but it is still critical to know about them.
9. One form of stigma that was not especially well measured was the loss of identity/role form. There are only two items in this form, one of which was experienced by very few people. It is suggested, therefore, to introduce new items in this form. Qualitative methods may be useful in developing potential items that could then be evaluated in a quantitative instrument. There may also be other forms that would benefit from additional items that would be relevant in some settings.
10. The high frequencies of the unprompted question about isolation, as compared to 22.5% of the sample who reported actually being isolated or excluded from a social gathering in the household, indicates that this specific item did not capture all types of isolation. We recommend asking open-ended questions about *physical isolation* experienced by PLHA and creating more specific physical exclusion items from those responses. We combined several examples at once. Consider separating *isolated in household* from *made to eat along/use separate utensils* and *made to sleep alone in own room*. Similarly, additional examples of exclusion from social gatherings could be provided.

SECTION 6.3: DISCLOSURE

Disclosure is an important issue to investigate because it is often suggested as a proxy indicator for stigma. Yet there is much to learn about how best to measure disclosure and how disclosure indicators are, in fact, related to a range of stigma indicators. In the PLHA sample, we asked respondents whether they have disclosed their HIV status, to whom they disclosed it, and whether they intend to disclose it in the future (Table 46). We also asked how long it took before respondents shared their HIV status and whether their HIV status was disclosed to someone without their consent.

Eight out of 10 PLHA in our sample have told someone outside the context of this survey that they are HIV-positive. It is important to keep in mind, however, that respondents, by and large, have known about their HIV status for a considerable amount of time. Approximately 85% have known their HIV status for more than a year; the mean is five years with a range of 16 days to 22.5 years. This means that most respondents have had ample opportunity to disclose their status to another person, so an 81.7% disclosure rate is not entirely surprising.

Table 46. Disclosure: Existing indicator, items, and frequencies

Existing Selected Indicators	Questions in survey corresponding to indicator(s)	Percent (n=218 if not stated)		
1. Percent of persons living with HIV/AIDS who have disclosed their sero-status to anyone (Blue Book)	**Have you told anyone about your HIV status?**	**Yes**		**No**
		81.7		18.3
2. Percent of PLHA who have disclosed their sero-status to various key people (Working Group)	**[For those who say they have disclosed:] Who have you told? [Followed by:] How soon after learning your status did you tell X of your status?**	(n=178)		
		Yes (%)	**Mean**	**Range**
	Partner [of those who have a spouse/partner and have told someone (n=66)	50	2yrs 11 mos	1 day–11yrs
	Mother	24.7	1 yr 10 mos	0 days–15yrs 7 mos
	Father	18.5	1 yr 9mos	1 day–10 yrs
	Sister	27.5	2 yrs 9mos	1 day–13 yrs 7mos
	Brother	27.5	2 yrs 4mos	1 day–16 yrs 1mo
	Children	10.1	3 yrs 10 mos	1 day–12 yrs 10 mos
	Other relative	24.2	1 yr 11mos	1 day–9 yrs 5 mos
	Friend	14.0	1 yr 4 mos	0 day–10 yrs.
	Neighbor	2.8	1 yr 11mos	2 days–9yrs 5 mos
	Health care provider	0.6	10 days	–
	Religious leader	1.1	3 yrs	16 days–6 yrs
	Public disclosure	2.2	4 yrs 2mos	1yr 6mos–9yrs 5mos

Table 46. Disclosure: Existing indicator, items, and frequencies (continued)

Existing Selected Indicators	Questions in survey corresponding to indicator(s)	Percent (n=218 if not stated)	
4. Percent of persons living with HIV/AIDS who would be willing to disclose sero-status (Blue Book)	Do you intend to disclose your HIV status to anyone [else]? [Followed by:] Who will you tell? [list] (data not shown; small numbers)	**Yes**	**No**
		60.6	39.4
5. Percent of people whose HIV status has been disclosed without their consent (S&DIWG)	Has your HIV status ever been revealed without your consent? [Followed by:] Who revealed your status without your consent? (data not shown; small numbers)	**Yes**	**No**
		23.4	76.6

What this apparent high level of disclosure disguises, however, is that disclosure is quite limited in terms of who and how many people PLHA disclose to and how long it takes for that disclosure to take place. Table 46 illustrates that there is a wide variation in the length of time before someone discloses their status, with much disclosure coming well after the one-year mark. Comparing sex-disaggregated means (data not shown), women take longer than men to tell people, particularly family members, about being HIV-positive. Of those with a current partner or spouse (n=66), it took women an average of 4 years and 3 months to tell their partner they had HIV, as compared to 2 years and 5 months for men. The point that disclosure evolves slowly over time is reiterated by the high percentage of respondents (60.6%) who indicated that they intend to disclose to someone [else] in future but had not yet done so.

Of those who have told someone about being HIV-positive (n=178), 47.8% have only told one person and another 30.3% have told only two people. Wider disclosure is much more rare. Only 2.2% of those telling anyone about their HIV status have disclosed it publicly. As seen in Table 46, disclosure is limited to one or two key people, namely a partner, sibling, mother, or other close relative. Half of those who currently have a partner or spouse (n=66) have told their partner about their HIV status. Considerably more men (24) have told their partner about having HIV than women (9). More women than men have disclosed to only two or fewer people (87.3% compared to 74.8%), whereas more men than women have disclosed widely (25.2% vs. 12.7%) or publicly (2.5% vs. 2%). This is not surprising, given what we know about women’s greater vulnerabilities.

Although respondents desire to limit who knows their HIV status and when, they are not always able to control whether their HIV status is disclosed. About a quarter of those living with HIV had their HIV status disclosed without their consent. This was somewhat more the case for women (25.2%) than for men (21.7%). Of the cases where HIV status was disclosed without the respondent’s consent (n=51), other relatives (35.3%), mothers (15.7%), and friends (15.7%) were most frequently the ones to disclose someone’s HIV status. In another 15.7% of cases, respondents did not know who it was that had disclosed their status.

Recommendations for Measuring Disclosure among PLHA

1. The summary indicator recommended in the Blue Book (*% of PLHA who have disclosed to someone*) does not work well because it masks limited disclosure, making it appear as if disclosure is more prevalent. We strongly recommend for Essential indicators asking to whom PLHA have disclosed and how much time passed before disclosure took place. This would allow people to assess how widely PLHA have disclosed (i.e., how many people: none, 1, 2–3, many, publicly) as well as who are the key people to whom HIV status is disclosed.

2. We also recommend that, at the Expanded level, a question be included that asks about disclosure against consent, as the question *Who did you tell*? may not capture how many people know one’s HIV status, and disclosure without consent is an important element of the poor treatment and lack of control that PLHA may experience. This indicator, however, can only capture instances of such disclosure that PLHA are aware of.

SECTION 6.4: INTERNAL STIGMA

Internal stigma (also referred to as self-stigma) is defined as the internalization of stigma that people with HIV/AIDS encounter in the wider community and is marked by acceptance of the stigma they face: negative self-image; feelings of shame, self-blame, and guilt, often leading to voluntary withdrawal and isolation from relationships and activities. The S&DIWG proposed an indicator for internal stigma that attempts to measure PLHA withdrawal (see Table 47). In this study, we probed about self-withdrawal and negative self-image. We did not investigate acceptance of stigmatizing beliefs and actions.

We also inquired about life aspirations that people living with HIV/AIDS had abandoned, because earlier qualitative work indicated this was an important theme. That slightly more than 50% reported giving up on at least one life goal confirms this is an important element to investigate. We did not, however, investigate which life goals were most often given up.

Table 47. Internal Stigma: Existing indicator, items, and frequencies

Existing Selected Indicators	Questions in survey corresponding to indicator(s)	Percent (n=218 if not stated)	
		Yes	**No**
1. Percent of PLHA who, in the past X time period, chose not to access [or excluded themselves from] health care, education opportunities, support, or friendships (S&DIWG)	**Have you ever done things or behaved in a way to try to avoid people knowing your status?** **[Followed by:] What kinds of things have you done to avoid people knowing your status?**	28.9	71.1
	Have you ever avoided or withdrawn from applying for school, further training, or a scholarship because of your HIV status? **[Followed by:] Why did you choose not to pursue this opportunity? (data not shown)**	4.1	95.9
	In the past 12 months, have you ever found yourself avoiding or isolating yourself from your friends or family because of your HIV status? [Followed by:] What made you avoid or isolate yourself from friends and family? (data not shown)	12.8	87.2
	Please tell me a little about how you feel or think about by being HIV positive [code the following]:		
	A. Shameful	13.8	86.2
	B. Guilty	11.9	88.1
	C. Blame myself	31.7	68.3
	D. Blame relatives	1.4	98.6
	Sometimes people have negative feelings. Do you ever have negative feelings, such as blue mood, despair, anxiety, depression? **[Followed by:] In the past 12 months, how often have you had these negative feelings? (data not shown)**	56.9	43.1
	Are there any life goals or hopes you had that have changed because of your HIV status (e.g., sex, marriage, childbearing, study/job application, etc.)? **[Followed by:] Why did you choose not to pursue this opportunity? (data not shown)**	50.9	49.1

We also asked about self-withdrawal or isolation in separate questions for withdrawal from educational opportunities and relationships with family and friends.[23] Neither of these questions resulted in high numbers of respondents reporting self-withdrawal, and, among the few who did report self-withdrawal, it was unclear how much of it was due to internal stigma. Most of those who withdrew from educational opportunities cited health concerns as the reason. Only one response (*because of thinking "you are smaller"*) seemed to pertain to internal stigma. Among the 28 people who reported distancing themselves from family and friends, respondents mentioned fear of stigma (e.g., *fear of being isolated* [14]; *fear of being gossiped about/fingers pointed* [9]; *I was easily recognized* [5]). It seems that an overarching problem with questions about self-withdrawal is attributing the action to internalization of stigma as opposed to fear of stigma or constraints imposed by health problems.

Of concern are the considerable numbers of people that report experiencing negative feelings. Of those who reported experiencing such negative feelings in the last year (124), 57% reported experiencing them sometimes, and 24% often. Regardless of how long the respondent knew she or he had HIV, an equal proportion of people reported experiencing negative feelings sometimes or often, demonstrating that experiencing negative emotions is sustained over the course of living with HIV. In spite of alarming figures, however, it is again difficult to ascertain whether responses to this question reflect internal stigma or something else. Therefore, we also coded responses specifically about shame, guilt, and self-blame to a question about feelings about living with HIV. All of these emotions did occur in our sample. Self-blame was the most frequently reported feeling, with nearly one-third of all respondents reporting it.

Recommendations for Measuring Internal Stigma Among PLHA

1. We recommend collecting data as an Essential indicator about which specific aspirations are foregone due to one's HIV-positive status. Our question provides several examples. It would be worthwhile separating out these aspirations and asking these, and perhaps others, individually. Suggestions include: sex, marriage, and childbearing; travel; job applications/promotions; education/training; and other goals.

2. We also suggest that it is essential to ask specifically about feelings of self-blame, shame, and guilt and not just "negative feelings." These items are more clearly related to internal stigma, whereas "negative feelings" may be related to a broader issue of quality of life. It is also possible to ask about other feelings of self-hatred and low self-esteem. Some work developing items and scales for measuring self-esteem has been done as a part of quality of life studies, and it may be useful to borrow from this body of work and explore those elements most related to internal stigma. Measuring these items may be accomplished through a question, like the one we used, as to whether or not these feelings were experienced (*Yes*/*No*), or through a Likert-type (attitude-measuring) scale, using response option words such as *a lot*, *somewhat*, and *not at all*.

---

[23] Respondents were also asked whether they had delayed or foregone health services, but these questions were asked related to fear of and desire to avoid stigma (e.g., *Have you ever avoided or delayed seeking health care because you were afraid of service providers' attitudes toward you as a person with HIV?*)

3. One area we did not investigate is the extent to which people living with HIV were accepting of the stigmatizing actions they may be exposed to. It would be worthwhile to ask whether respondents feel that stigmatizing actions are justified; we therefore propose this as an Essential indicator. This could be accomplished with a question listing all the items we found occurring in the sample (see the Enacted Stigma section) beginning with the words, “*Do you believe it is reasonable, unreasonable, or neither reasonable nor unreasonable that* […] .”

SECTION 6.5: AWARENESS OF STIGMA AND POLICY AND LAW

In this sample, awareness of anti-stigma and discrimination policies and laws was rather modest (see Table 48). About a quarter of respondents were aware of national policies against HIV stigma and discrimination, but they were only described in rather broad terms, in response to an open-ended follow-up question. Of the 55 people who knew of national HIV policies, nearly half reported that the policy says “We should isolate or discriminate against people with HIV/AIDS,” and nearly half say the policy says “We should not stigmatize people with HIV/AIDS.” Seven people could not recall what was in the policy. Similarly, 23 of the 24 people who knew of laws against discrimination reported that the law says “All human beings are equal.” The remaining person could not remember what was in the law. Data from these open-ended questions indicate that people living with HIV are not aware of the specific rights and protections afforded them in laws and policies. Legal and rights literacy is an area that could stand improvement among this sample.

It is more heartening, however, to see that more than half of those who had pre- or post-test counseling (n=197) received discussions on stigma and discrimination and were referred to a source of support for dealing with stigma and discrimination. Similarly, of the few who knew about anti-discrimination laws (n=24), a sizable number (17) knew of a means or an organization to go to for help. Seven of the 17 had actually made use of some means of resolution in the last year. Of the full sample of 218 PLHA, 15.6% had confronted someone who was stigmatizing or discriminating against them or another person. In spite of the low awareness of laws and policies, people are aware of sources of support and redress for stigma and discrimination and seem to be willing to use them.

Table 48. Awareness of Policy and Law: Existing indicators, items, and frequencies

Existing Selected Indicators	Questions in survey corresponding to indicator(s)	Percent (n=218 if not stated)	
1. Number of people living with HIV/AIDS who have been referred to stigma-reduction activities (e.g., support groups for PLHA) (Blue Book)	**[Of those who had pre- or post-test counseling:] Did the counselor discuss with you anything about stigma and discrimination during any of the pre- or post-counseling sessions?**	**n=197**	
		Yes	**No**
		59.9	40.1
	Were you referred to any group or place where you could get support to help you deal with stigma and discrimination?	51.8	48.2
2. Percent of persons living with HIV/AIDS aware of anti-discrimination policies (Blue Book) 3. Percent of PLHA who are aware of their human rights (right to health, right to association) (S&DIWG) 4. Percent of PLHA who are aware of their HIV-related rights (S&DIWG)	**Do you know of any national policies against HIV stigma and discrimination in Tanzania? [Followed by:] What does the policy say? (data not shown)**	25.2	74.8
	Do you know of any laws against discrimination that exist in Tanzania? [Followed by:] What do the laws say? (data not shown)	11	89
5. Percent of PLHA who are aware of and how to access systems of redress (S&DIWG)	**[Of those who know laws:] Do you know of any ways, or organizations, that you can go to for help with using the anti-discrimination laws if you experience stigma or discrimination? [Followed by:] What ways do you know or what organizations would you go to for help? (data not shown)**	**n=24**	
		70.8 (17)	29.2 (7)
6. Percent of PLHA who have experienced discrimination and who have also accessed the remedies/system (S&DIWG)	**[Of those who knew of organizations to go to for help:]**	**n=17**	
	In the past 12 months, have you sought help from one of these organizations to resolve an issue of discrimination? [Followed by:] How was the issue resolved? What happened? (data not shown)	41.2 (7)	58.8 (10)
7. Percent of PLHA that report complaints that in turn are acted upon (S&DIWG)	**In the past 12 months, have you confronted or challenged someone who was stigmatizing or discriminating against you, or another person? [Followed by:] What did you do or say to this person? (data not shown)**	15.6	84.4

Recommendations for Measuring Awareness of Policies and Laws among PLHA

1. It is important to understand not only whether people are aware of policies and laws dealing with HIV-related stigma and discrimination but also what they know and whether it is correct. However, the open-ended questions we used (*What do the [policies/laws] say?*) did not capture anything other than vague awareness of the contents of policies and laws. It may be worth considering revising the follow-up question to include a series of pre-coded response options. The question could first be administered without prompting and then with prompting for those responses. The pre-coded responses, of course, would vary according to the existence of any relevant policies or laws in that setting. We suggest an Expanded indicator for PLHA who are aware of anti-discrimination policies and laws.

2. In a setting where awareness of policies and laws is low, asking questions about means of redress and sources of support only of those who know about the existence of anti-discrimination laws results in few respondents answering the question. These questions should be asked of the full sample, as some people who have low awareness of the law may still be aware of places to go for support or redress. We propose several Expanded indicators in this area: (1) percent of PLHA who have been referred to places of support for stigma and discrimination; (2) percent of PLHA who know a source of assistances/support; (3) and percent of PLHA who have confronted or challenged stigma.

7. CONCLUSIONS AND SUMMARY RECOMMENDATIONS

This field-testing of an initial set of indicators and associated data collection questions in one site in Tanzania is a much anticipated initial step, but it is just the first step in the longer process of testing and refining HIV stigma indicators that work well over time and across different contexts. The findings and recommendations presented in this report are a solid foundation on which to progress toward the ultimate goal of a set of fully tested (reliable and valid), refined stigma indicators. To reach this goal, further testing needs to be conducted in contexts that vary both in terms of cultural and socioeconomic factors (including urban vs. rural settings), as well as in type and length of experience with the HIV and AIDS epidemic and political response to it.

As recommendations for indicators and their rationale have been presented in each of the individual sections above, this final section will only include a brief discussion of some of the study’s overarching conclusions and a set of summary tables. Based on existing work (Horizons 2003; Nyblade et al. 2003; POLICY Project 2003; Hadjipateras 2004; Hong et al. 2004; Pulerwitz et al. 2004; Ogden and Nyblade 2005) and the data from this study, it is clear that, at minimum, several indicators are needed to capture the full complexity of the issue and to provide an accurate assessment of HIV-related stigma. We recommend, as a general guideline, that at least one indicator (and in some cases more; see Tables 52–54) be collected in each of the four main domains of stigma used in this report: fear of casual contact with PLHA; values, shame, and blame/judgment; enacted stigma (discrimination); and disclosure. The exact nature of these indicators, their interpretation, and their relative importance will vary slightly according to type of population.

For example, measuring enacted stigma with PLHA captures the actual experience of the respondent, whereas measuring enacted stigma in a general population survey is more complicated (see Section 6.2) and provides a measure of observed stigma by the respondent (i.e., what they see happening to others in their community) rather than their own personal experience of stigma. It is not surprising then that the level of *experienced* enacted stigma measured in the PLHA sample is much higher than the *observed* enacted stigma measured in the community sample. An example of another slight difference comes in the domain of fear of casual transmission and avoidance of casual contact. When measuring this domain with health care providers, additional items need to be added to the general ones asked of the community to capture their unique or additional issues related to work exposure.

To conclude this final section, we present two sets of tables that summarize the specific recommendations presented in each individual section. The first set of tables (49–51) lists all the indicators tested (by population and domain), whether the findings of this study support recommending them or not, and the rationale for that conclusion. The second set of tables (52–54) presents only the indicators that this study recommends. For each of these, we specify two levels of recommendations—Essential and Expanded—to reflect the varying needs of different organizations, as well as resources available for data collection. Essential indicators are those that the findings from this project indicate as a minimum to be collected in each population tested: community, health care providers, and PLHA. Expanded indicators are indicators that performed well and we feel add important information about stigma, and so are recommended where resources and interest allow collecting them.

We also present in Tables 52–54 the questions/items used in the Tanzania questionnaire to collect data for each recommended indicator. It should be noted that this was the first time many of these questions had been asked. While the items and phrasing worked in this urban Tanzanian sample, it is critical that they also be tested in other contexts where additional or different questions or phrasings may be more appropriate.

We also make recommendations for how to aggregate the information collected for indicators where more than one question/item is collected. There are many possible ways to aggregate information and, ideally, testing should occur to determine the best form of aggregation for each indicator. The scope of this project and the nascent field of quantitative measurement of stigma (e.g., no existing standards could be found on which to base our recommendations) limited our ability to conduct this next level of testing of the indicators. Therefore, at this stage we recommend the simplest aggregation for most indicators. Where an indicator is the aggregation of multiple questions/items, we recommend that a response be entered into the numerator if a respondent answers in the affirmative to at least one of the items (see Tables 52–54).

Table 49. Indicators tested at the community level: Source, recommendations, and rationale

Indicator	Source	Recommend (Yes/No)	Rationale
Community-level: Fear of casual contact and refusal of contact with PLHA			
Percent of people who would refuse casual contact with PLHA	Blue Book	No	The questions used to collect data for these indicators are limited due to several factors, including their being hypothetical and ambiguous and their potential for social desirability bias. Therefore, their use is only recommended with several caveats (see text and Table 52).
Percent of people who would not have casual contact with PLHA because they are worried about contagion	S&DIWG	Yes—Expanded	
Percent of people expressing fear of contracting HIV from non-invasive contact with PLHA	Added	Yes—Essential	Asking about fears captures more variability and elicits responses less likely to suffer from social desirability bias. It also provides more programmatic relevant information by indicating the specific fears that need to be addressed to reduce the behavior of refusing casual contact with PLHA.
Community-level: Shame, blame, judgment			
Percent of people who judge or blame PLHA for their illness	Blue Book, S&DIWG	Yes—Essential	The indicator measures a distinct aspect (blame/judgment) that underlies value-based stigma. When measured using four items, the indicator efficiently captures the stigma aspects related to blame.
Percent of people who would feel shame if they associated with a PLHA	S&DIWG	Yes—Essential	The indicator measures a distinct aspect (shame) that underlies value-based stigma. When measured using three items, the indicator efficiently captures the stigma aspects related to shamefulness.
Community-level: Enacted stigma (discrimination)			
Percent of people who personally know someone who has experienced any form of stigma in the past 1 year because they were known to, or suspected of having, HIV or AIDS	Composite—Added	Yes—Essential	The composite measure for observed enacted stigma at the population level worked well and captures important information. For many, it will not be possible to measure each of the 4 domains of stigma separately. Therefore, we offer one composite measure (see Table 52). It is important to measure at least one form of stigma from each of the 4 domains, as some domains may be more prevalent or more visible (hence reported on more), while the impact of others (even if less frequently reported) may be stronger.
Percent of people who personally know someone who has been refused services in the past 1 year because they were known to, or suspected of having HIV or AIDS	S&DIWG	Yes—Expanded (modified)	This form of stigma is less visible to the general public, so the responses generated as to its occurrence on a population survey are likely to be an underestimate of actual occurrences. We recommend either not measuring it at the population level (measuring it at the PLHA level instead) or expanding the number of items included. See modified version in Table 52 for details.

Table 49. Indicators tested at the community level: Source, recommendations, and rationale (continued)

Indicator	Source	Recommend (Yes/No)	Rationale
Community-level: Enacted stigma (discrimination)			
Percent of people who personally know someone who has been socially isolated in the past 1 year because of HIV status or perceived status (high prevalence)	S&DIWG	Yes—Expanded (modified)	We recommend expanding this indicator to include abandonment, divorce, and physical isolation (see modified version below).
Percent of people who personally know someone who has been isolated in the past 1 year because of HIV status or perceived status	Modified	Yes—Expanded	For programmatic purposes, collecting items for each of the 4 domains can provide valuable information, as some forms of stigma may respond more or less to different interventions. This particular domain was a common one, both in previous qualitative work and in this survey. As measured, it includes social and physical isolation, including abandonment by family or partner and divorce.
Percent of people who personally know someone who has experienced verbal stigma in the past 1 year because of HIV status or perceived status (high prevalence)	Modified	Yes—Expanded	Stigma in the form of verbal abuse through gossip, teasing, taunting, insults, or cursing/swearing was one of the most common forms reported in both qualitative studies and in this survey.
Percent of people who personally know someone who has experienced a negative effect on their identity in the past 1 year because of HIV status or perceived status (high prevalence)	Modified	Yes—Expanded	Identity loss in the form of losing respect or standing, both within the family and the community, was a less common but very damaging form of stigma reported in the qualitative data and at a relatively moderate level in the survey, hence we recommend retaining at least one item in this category.
Percent of people who personally know someone who has experienced loss of access to resources in the past 1 year because they were known to, or suspected of having HIV or AIDS	Modified	Yes—expanded	Although this is an important area to measure, our experience is that few respondents report knowing anyone. This is not surprising given that this type of enacted stigma is not widely visible to the public. We recommend expanding the existing indicator to include livelihood-related enacted stigma such as loss of customers, loss of employment, and denial of promotion or further training opportunities.
Percent of people who support discrimination toward PLHA	Blue Book	No	This is likely to suffer from strong social desirability bias. Most items had low variability, and some suffered ambiguity.

Table 49. Indicators tested at the community level: Source, recommendations, and rationale (continued)

Indicator	Source	Recommend (Yes/No)	Rationale
Community-level: Disclosure			
Percent of people who fear disclosing their HIV status because of negative reactions	Blue Book	No	The question is hypothetical in nature and has little variability. With over 90% saying they would disclose to someone, too few cases remain for collection of data on fear of disclosure.
Percent of persons tested for HIV who have disclosed their status to someone	Added	No	Few respondents are tested (<25%), and of these most have disclosed to at least one person, leaving too few cases on which to collect relevant information for this indicator.
Percent of persons tested for HIV who have disclosed their status beyond a trusted few individuals* (*more than 3 people, including one non-family member)	Added	Yes—Expanded (if context allows)	Both the population data and the data from PLHA indicated that most everyone discloses to at least one person (at some point in time). Therefore, for disclosure to be a useful proxy measure for stigma, more detailed information needs to be collected on both the extent of disclosure (who is disclosed to) and the length of time between learning status and disclosure to specific individuals.
Percent of persons* who have disclosed their HIV sero-status to their primary sexual partner. (*currently in a partnership and who have been tested for HIV)	Added	Yes—Essential (if context allows)	
Percent of persons* who have disclosed their HIV sero-status to their primary sexual partner within 6 months of learning their status (*currently in partnership and who have been tested for HIV)	Added	Yes—Expanded (if context allows)	
Percent of people who think a person should be able to keep their HIV status private	Added	No	Not recommended because of the inconclusive construct analysis results and the finding that the interpretation of what responses mean about stigma can go in opposite directions. These types of questions should only be asked if they are followed with a *Why* question for both the *Yes* and *No* answers.
Percent of people who would want a family member's HIV-positive status to be kept secret	Added	No	
Percent of people who have had someone they know personally disclose their HIV-positive status to them	Added	Yes—Essential	In some contexts, it will be too sensitive to ask respondents of a population survey if they have been tested for HIV, and then to whom they have disclosed and how long it took. Therefore, it is important to get a more general, indirect measure of "openness" in the community. These indicators are two possible options for collecting this kind of indirect measure of disclosure, and they appeared to work well.
Percent of people who report that, in their community, the main way people find out about a person's HIV status is through self-disclosure by the PLHA.	Added	Yes—Expanded	

Table 50. Indicators tested at the health care provider level: Source, recommendations, and rationale

Indicator	Source	Recommend (Yes/No)	Rationale
Provider-level: Fear of casual transmission of HIV and refusal of contact with PLHA			
Percent of people who would refuse casual contact with a person living with HIV/AIDS	Blue Book	No	Need an indicator more specific to health care providers; replace with fear of HIV transmission during medical care scale.
Percent of people who would not have casual contact with a PLHA because they are worried about contagion	S&DIWG	No	Need an indicator more specific to health care providers; replace with fear of HIV transmission during medical care scale.
Percent of people working in institutions/facilities (e.g., managers, health care workers) who fear: (a) providing invasive medical care on patients with HIV/AIDS (b) contact with non-blood bodily fluids of patients with HIV/AIDS (c) casual contact with PLHA	New	Yes—Expanded	Indicator more specific to type of contact with PLHA typical among health care providers; not necessary to ask providers about fear of casual contact, as none of these items performed well in the study population.
Percent of people working in institutions/facilities (e.g., managers, health care workers) who fear transmission of HIV if gloves are not used while performing: (a) non-invasive procedures with potential fluid contact (b) non-invasive procedures with no fluid contact (c) invasive procedures	New	No	None of the three factors performed well in the study population. It is also unclear if the items are measuring stigma.
Percent of people working in institutions/facilities (e.g., managers, health care workers) who: (a) are uncomfortable working with or treating PLHA (b) perceive work-related HIV exposure to be high (c) report negative attitudes toward PLHA	New	Yes—Essential	Necessary to assess willingness to treat PLHA. Only the first two factors performed well, therefore not recommended as collecting option (c).

Table 50. Indicators tested at the health care provider level: Source, recommendations, and rationale (continued)

Indicator	Source	Recommend (Yes/No)	Rationale
Provider-level: Values, shame, and blame			
Percent of people who judge or blame persons living with HIV/AIDS for their illness	Blue Book and S&DIWG	No	Needs to be specific to health care providers; replace with shame/blame indicators.
Percent of people who would feel shame if they associated with a person living with HIV/AIDS	Blue Book and S&DIWG	No	Needs to be specific to health care providers; replace with shame/blame indicators.
Percent of people working in institutions/facilities (e.g., managers, health care workers) who report: (a) negative attitudes/judgment of PLHA (b) negative attitudes/blame toward PLHA (c) negative attitudes/shame toward PLHA	New	Yes—Essential	Good variance on shame and blame items included in scales. Indices valid and moderately reliable. Gives good indication of basis for discrimination.
Percent of people who have positive attitudes toward the rights of people living with HIV/AIDS	S&DIWG	No	Very little variance.
Provider-level: Enacted Stigma			
Percent of people in institutions/facilities (e.g., managers, health care workers) who personally know patients who were [*fill in from list below*] in the past 12 months because they were known or suspected to have HIV/AIDS: (a) neglected (b) treated differently (c) denied care (d) verbally abused (e) tested for HIV/sero-status disclosed without consent	New	Yes—Essential	Good variance on these items; it's also good to know which types of stigma are more common when planning anti-stigma campaigns and programs.

Table 50. Indicators tested at the health care provider level: Source, recommendations, and rationale (continued)

Indicator	Source	Recommend (Yes/No)	Rationale
Provider-level: Enacted Stigma			
Percent of people working in institutions/facilities (e.g., managers, health care workers) who personally know patients who were discriminated against in the past 12 months because they were known or suspected to have HIV/AIDS (composite score of the next indicator).	New	Yes—Essential	Good variance; provides an estimate of the overall prevalence of enacted stigma in health facilities.
Provider-level: Disclosure			
Percent of people who fear disclosing their HIV status because of negative reactions	Blue Book	No	Not much variance.
Percent of people who disclose their sero-status	New	No	Good variance, but not necessarily appropriate for providers.
Percent of people in institutions/facilities (e.g., managers, health care workers) who learned about a patient's HIV status through unofficial channels during the past year	New	Yes—Essential	Gossip was frequently reported as a means of learning about a patient's HIV status. Such information provides a good indication of HIV stigma in the health facility.
Percent of people who think a person should be able to keep their HIV status private	New	Yes—Expanded	Provides interesting information on provider perceptions of HIV stigma. Has to include a follow-up *why* question.
Percent of people who would want a family member's HIV-positive status to be kept secret	New	Yes—Expanded	Provides interesting information on provider perceptions of HIV stigma. Has to include a follow-up *why* question.
Provider-level: Anti-discrimination policies			
Number of health facilities that have policies to protect against discrimination by protecting client rights and providing recourse	S&DIWG	Yes—Essential	While not tested in this analysis, this information is needed to calculate the next indicator regarding percentage of facilities that enforce policies.
Number or percent of institutions/facilities enforcing policies guaranteeing access/rights and providing recourse	S&DIWG	Yes—Essential	Much variance reported among providers who knew of policies.

Table 50. Indicators tested at the health care provider level: Source, recommendations, and rationale (continued)

Indicator	Source	Recommend (Yes/No)	Rationale
Provider-level: Anti-discrimination policies			
Percent of people working in institutions/facilities (e.g., managers, health care workers) who are aware of policies guaranteeing access/rights to PLHA	S&DIWG	Yes—Essential	Small percentage aware of policies—need to measure change in awareness over time.
Percent of people working in institutions or facilities (e.g., managers, health care workers) willing to report discrimination against PLHA	New	Yes—Essential	Only a small percentage of providers were willing to report acts of discrimination; policies will only be useful if providers are willing to report.

Table 51. Indicators tested at the PLHA level: Source, recommendations, and rationale

Indicator	Source	Recommend (Yes/No)	Rationale
PLHA-level: Enacted stigma			
Percent of PLHA reporting fear of stigma and discrimination in the past 12 months	Blue Book	Yes—Expanded (modified)	Questions about fear of stigma work well, yielding data that follows the same pattern as experiences of stigma. These data should be collected in addition to, not in place of, data on the experience of stigma. We recommend separate indicators for each of the types of stigma listed, rather than a composite variable, as fear of some types of stigma, particularly more severe types, may lag behind decreasing experiences of that type of stigma.
Percent of PLHA reporting experiencing stigma or discrimination in the past 12 months	Blue Book (Modified to exclude ever and focus on last 1 year)	Yes—Essential	Experienced stigma is a stable summary indicator based on a concrete set of indicators (index). Keeping it time-bound (e.g., 12 months) makes the indicator more sensitive to change induced by stigma reduction interventions. We recommend an overall composite indicator and a composite indicator for each form of stigma, as well as separate indicators for each item.
Percent of PLHA who have been socially isolated in the past 1 year because of HIV status	S&DIWG	Yes—Expanded	At the program level, in addition to the composite indicator, it is important to gather data on the main forms of stigma and the individual items that make up these forms, as some forms may be more or less responsive to any given intervention. The separate items for this form may include: *excluded from social gathering*, *abandonment by spouse/partner*, *abandonment by family*, and *no longer visited or visited less by family and friends*.
Percent of PLHA who have been physically isolated in the past 1 year because of HIV status	Modified	Yes—Expanded	At the program level, in addition to the composite indicator, it is important to gather data on the main forms of stigma and the individual items that make up these forms, as some forms may be more or less responsive to any given intervention. The separate items for this form may include: *isolated in household*, *physically assaulted*, and *threatened with violence*. Additional items should be tested for isolation in household.

Table 51. Indicators tested at the PLHA level: Source, recommendations, and rationale (continued)

Indicator	Source	Recommend (Yes/No)	Rationale
Percent of PLHA who have experienced verbal stigma in the past 1 year because of HIV status	Modified	Yes—Expanded	At the program level, in addition to the composite indicator, it is important to gather data on the main forms of stigma and the individual items that make up these forms, as some forms may be more or less responsive to any given intervention. The separate items for this form may include: voyeurism (visitors increasing to "check out" PLHA); teasing, insulting, and being sworn at or gossiped about.
Percent of PLHA who have experienced a negative effect on their identity in the past 1 year because of HIV status	Modified	Yes—Expanded	At the program level, in addition to the composite indicator, it is important to gather data on the main forms of stigma and the individual items that make up these forms, as some forms may be more or less responsive to any given intervention. The separate items for this form may include: *lost respect within family/community* and *denied religious rites/services*. Additional items should be tested for this form.
Percent of PLHA who have lost access to resources in the past 1 year because of HIV status	Modified	Yes—Expanded	At the program level, in addition to the composite indicator, it is important to gather data on the main forms of stigma and the individual items that make up these forms, as some forms may be more or less responsive to any given intervention. The separate items for this form may include: *lost customers/job*, *denied promotion/training*, *lost housing*, *had property taken away*.
How many times in X period of time have each type of stigma happened in the past 1 year because of HIV status	S&DIWG	Yes—Expanded	Decrease in frequency of stigma is important to capture (as it may be a sign of program effectiveness) and may be overlooked if respondents are only asked if the type of stigma occurred.
PLHA-level: Disclosure			
Percent of persons living with HIV/AIDS who have disclosed their sero-status to someone	Blue Book	No	Most people have disclosed their HIV-positive status, but to a limited number of people. This indicator masks such limited disclosure, making it appear as if disclosure is more prevalent than it is. It is more important to know how widespread, whether key people are disclosed to, and how timely disclosure is.

Table 51. Indicators tested at the PLHA level: Source, recommendations and rationale (continued)

Indicator	Source	Recommend (Yes/No)	Rationale
PLHA-level: Disclosure			
Percent of PLHA who have disclosed their status beyond a few trusted individuals* (*more than 3 people, including one non-family member)	Modified	Yes—Essential	This allows people to assess how widely PLHA have disclosed.
Percent of PLHA* who have disclosed their HIV sero-status to their primary sexual partner (*currently in partnership)	Added	Yes—Essential	A partner is a key person for whom disclosure is important to know about. Disclosure to partner is particularly of interest for prevention of transmission, especially in high-prevalence settings in which sexual transmission is the main route of transmission.
Percent of PLHA* who have disclosed their HIV sero-status to their primary sexual partner within 6 months of learning their sero-status (*currently in a partnership)	Added	Yes—Expanded	This indicator signifies not only whether disclosure happens with a key person but also how much time passes before disclosure.
Percent of persons living with HIV/AIDS who would be willing to disclose sero-status	Blue Book	No	This is a hypothetical indicator and does not accurately reflect actual disclosure, as almost all people plan on telling at least one [more] person, but there is no way to know if such disclosure does take place or how long before it does.
Percent of people whose HIV status has been disclosed without their consent	S&DIWG	Yes—Essential	This is an important element of stigmatizing treatment and lack of control over decisions about disclosure that PLHA experience.
PLHA-level: Internal stigma			
Percent of PLHA who in the past *X* time period, chose not to access (or exclude themselves from) health care, education opportunities, support, or friendships due to their HIV-positive status	S&DIWG	Yes—Essential	Abandoning aspirations/life goals is an important and measurable manifestation of internal stigma. Questions should elicit which specific aspirations are foregone, perhaps in categories, as well as what the motivation is for abandoning it, to separate out internal stigma from other reasons.
Percent of PLHA with negative self-perception, feelings of shame or guilt due to their HIV-positive status	S&DIWG	Yes—Essential	The specific feelings of self-blame, shame, and guilt are the second important aspect of internal stigma. Specific feelings can be more clearly related to internal stigma, whereas responses indicating “negative feelings” are too ambiguous and may be related to broader issues related to quality of life rather than internal stigma.

Table 51. Indicators tested at the PLHA level: Source, recommendations, and rationale (continued)

Indicator	Source	Recommend (Yes/No)	Rationale
PLHA-level: Internal stigma			
Percent of PLHA reporting that stigmatizing actions are reasonable	Added	Yes—Essential	Acceptance of stigmatizing actions is the third aspect of internal stigma and could be easily collected in a series of questions such as that for experience of stigma.
PLHA-level: Stigma policy/reduction awareness			
Percent of PLHA who have been referred to places of support for stigma and discrimination	Blue Book	Yes—Essential	Awareness of resources to enlist in coping with stigma is important to understand alongside the prevalence of stigma.
Percent of PLHA aware of anti-discrimination policies and laws	Blue Book	Yes—Essential	It is important to measure the prevalence of knowledge of governmental policies. This will likely reflect the effectiveness and growing number of interventions.
Percent of PLHA who know a source of assistance if stigma is experienced	Modified	Yes—Expanded	Awareness of resources to enlist in coping with stigma is important to understand alongside the prevalence of stigma.
Percent of PLHA who have confronted or challenged someone stigmatizing the respondent	Modified	Yes—Expanded	Use of means to seek redress or confronting stigma is an indication of stigma losing acceptance, even if the occurrence of stigma does not decrease right away.

Table 52. Recommended indicators at the community level (numerator/denominator): Questions, aggregation

Level of Recommendation	Indicator	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
Community-level: Fear of casual contact and refusal of contact with PLHA			
Essential	Percent of people expressing fear of contracting HIV from non-invasive contact with PLHA	Please tell me if you have fear, do not have fear, or do not know in response to the following statements: 1. You could become infected with HIV if you are exposed to the saliva of a PLHA. 2. You could become infected with HIV if you are exposed to the sweat of a PLHA. 3. You could become infected with HIV if you are exposed to the excreta of PLHA. 4. Your child could become infected with HIV if they play with a child who has HIV or AIDS. 5. To care for PLHA	Numerator: No. of respondents reporting at least 1 fear of casual transmission Denominator: No. of respondents *Note: Respondents should only appear once in the numerator; if they answer* Yes *to more than one fear, they should only be counted 1 time.*
Expanded	Percent of people who would refuse casual contact with a PLHA who was not exhibiting signs of AIDS Percent of people who would refuse casual contact with a PLHA who was not exhibiting signs of AIDS	1a. In a market of several food vendors, would you buy food from a PLHA or person suspected of HIV/AIDS who was not visibly sick? 1b. And what if they were visibly sick?	Numerator: No. of respondents answering no they would not buy food Denominator: No. of respondents Numerator: No. of respondents answering no they would not buy food Denominator: No. of respondents

Table 52. Recommended indicators at the community level (numerator/denominator): Questions, aggregation (continued)

Level of Recommendation	Indicator	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
Community-level: Fear of casual contact and refusal of contact with PLHA			
Expanded	Percentage of people expressing fear of contracting HIV from non-invasive contact with PLHA If it is possible to include additional items in a survey, we recommend including these items and/or other items that reflect common daily interaction situations within the target population.	Please tell me if you have fear, do not have fear, or do not know in response to the following statements: 1. You could become infected with HIV if you eat food prepared by PLHA. 2. To touch a PLHA 3. To sleep in the same room as PLHA 4. To share eating utensils with PLHA 5. To sit next to someone who is showing signs of AIDS 6. To sleep in the same bed as PLHA 7. To share a toilet with PLHA	Numerator: No. of respondents reporting at least 1 fear of casual transmission Denominator: No. of respondents *Note: Respondents should only appear once in the numerator; if they answer* Yes *to more than one fear, they will only be counted 1 time.*
Community-level: Shame and blame/judgment			
Essential	Percent of people who judge or blame persons living with HIV/AIDS for their illness	Do you agree/disagree with the following statement: 1. HIV is a punishment from God. 2. HIV/AIDS is a punishment for bad behavior 3. It is women prostitutes who spread HIV in the community. 4. People with HIV are promiscuous.	Numerator: No. of respondents agreed with at least one statement Denominator: No. of respondents

Table 52. Recommended indicators at the community level (numerator/denominator): Questions, aggregation (continued)

Level of Recommendation	Indicator	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
Essential	Percent of people who would feel shame if they associated with a PLHA	Do you agree/disagree with the following statement: 1. I would be ashamed if I were infected with HIV. 2. I would be ashamed if someone in my family had HIV/AIDS. 3. People with HIV should be ashamed of themselves.	Numerator: No. of respondents agreed with at least one statement Denominator: No. of respondents
Community-level: Enacted stigma (discrimination)			
Essential	Aggregated enacted stigma indicator: Percentage of people who personally know someone who has experienced enacted stigma in the past 1 year because they were known or suspected to have HIV or AIDS	Do you know someone in the past year that has had the following happen to them because of HIV or AIDS? 1. Excluded from a social gathering 2. Lost customers to buy their produce/goods or lost a job 3. Had property taken away 4. Abandoned by their spouse/partner 5. Abandoned by their family/sent away to the village 6. Teased or sworn at 7. Lost respect/standing within the family and/or community 8. Gossiped about	Numerator: No. of respondents reporting knowing at least 1 person who has experienced enacted stigma in the past one year Denominator: No. of respondents *Note: Respondents should only appear once in the numerator, so if they answer* Yes *to knowing more than one person who has experienced a given form of enacted stigma, or multiple people who have experienced multiple forms of stigma, they should only be counted 1 time in the numerator.*

Table 52. Recommended indicators at the community level (numerator/denominator): Questions, aggregation (continued)

Level of Recommendation	Indicator	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
Expanded	Percentage of people who personally know someone who has experienced enacted stigma in the past 1 year because they were known or suspected to have HIV or AIDS	Do you know someone in the past year that has had the following happen to them because of HIV or AIDS? 1. Excluded from a social gathering 2. Lost customers to buy their produce/goods or lost a job 3. Had property taken away 4. Abandoned by their spouse/partner 5. Abandoned by their family/sent away to the village 6. Teased or sworn at 7. Lost respect/standing within the family and/or community 8. Gossiped about 9. No longer visited, or visited less by family and friends 10. Visitors increase to "check them out" 11. Isolated within the household	Numerator: No. of respondents reporting knowing at least 1 person who has experienced enacted stigma in the past one year Denominator: No. of respondents *Note: Respondents should only appear once in the numerator, so if they answer* Yes *to knowing more than one person who has experienced a given form of enacted stigma, or multiple people who have experienced multiple forms of stigma, they should only be counted 1 time in the numerator.*
Expanded	For an in-depth look at enacted stigma, we recommend collecting all 4 of the indicators that are recommended in Table 15.	See Table 15 in Section 4.3 for the individual items we collected for each domain. Additional items may be collected as appropriate for the target population	(same as above)

Table 52. Recommended indicators at the community level (numerator/denominator): Questions, aggregation (continued)

Level of Recommendation	Indicator	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
Community-level: Disclosure			
Essential	Percentage of people who have had someone they personally know disclose their HIV-positive status to them	1. Are there people you personally know who have either disclosed their HIV-positive status directly to you or publicly in the last 12 months? For example a family member, friend, neighbor, church member, work colleague?	Numerator: No. of people answering *Yes* Denominator: total no. of respondents
Essential (where contextually possible)	1. Percentage of persons tested for HIV who have disclosed their status beyond a trusted few individuals 2. Percentage of persons tested for HIV in relationship that have disclosed their status to their primary sexual partner. 3. Percentage of persons tested for HIV in relationship who have disclosed their status to their primary sexual partner within 6 months of learning their status	1. How many people have you disclosed your status to? 2. How soon after learning your HIV status did you disclose your status to these specific people?	1. Numerator: No. of respondents who have disclose to >3 people Denominator: No. of respondents who have been tested for HIV 2. Numerator: No. of respondents who have disclosed to their primary sexual partner Denominator: No. of respondents who have been tested for HIV and are currently in relationship 3. Numerator: No. of respondents who disclosed status to their primary sexual partner within 6 months of learning their status Denominator: No. of respondents who have been tested for HIV and are currently in relationship

Table 52. Recommended indicators at the community level (numerator/denominator): Questions, aggregation (continued)

Level of Recommendation	Indicator	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
Expanded	Percent of persons reporting that self-disclosure by PLHA is a primary way that people in the community find out about a person's HIV status	In your community, what is the primary way people know if someone has HIV? 1. The infected person discloses his/her status 2. From general rumors/gossip 3. From the HIV-positive person's family 4. From the HIV-positive person's employer 5. From the HIV-positive person's friends/neighbors 6. From the health center/health care worker where the person got tested 7. The person looks ill and has lost a lot of weight 8. Other (specify)	Numerator: No. of people reporting self-disclosure is primary mode Denominator: Total no. of respondents
Expanded	Percent of persons reporting that self-disclosure is the way they learned about a person's HIV-positive status —PLHA who is community member and still living —PLHA who is family member and still living —Deceased PLHA, community member —Deceased PLHA, family member	1a. Is there anyone in the community that you know of who has HIV but has yet to show signs and symptoms of AIDS? If *Yes*, 1b. Which of the following have been ways through which you got information that someone in your community is infected with HIV? (see items above) 2. Do you personally know someone who has died of AIDS? How did you find out?	

Table 53. Recommended indicators at the health care provider level (numerator/denominator): Questions, aggregation

Level of Recommendation	Indicator (Numerator/Denominator)	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
Provider-level: Fear of casual transmission of HIV and refusal of contact with PLHA			
Essential	Percent of people working in institutions/facilities (e.g., managers, health care workers) who: (a) Are uncomfortable working with or treating PLHA; and (b) Perceive work-related HIV exposure to be high.	**Do you strongly agree, agree, disagree or strongly disagree with each statement:** 1. Comfortable assisting or being assisted by a colleague who is HIV infected 2. Comfortable performing surgical or invasive procedure on clients whose HIV status is unknown 3. Comfortable to providing health services to clients who are HIV-positive 4. Comfortable sharing a bathroom with a colleague who is HIV-infected 5. Clients who are sex workers deserve to receive the same level and quality of health care as other clients 6. You avoid touching clients' clothing and belongings known or suspected have HIV for fear of becoming HIV-infected. 7. Most frequent mode of contracting HIV among health care workers is through work-related exposure 8. Most HIV-positive health care workers get infected at work	Numerator: No. of respondent gave one or more stigmatizing response Denominator: No. of respondents *Note: Use the following items to calculate each category:* *(a) Are uncomfortable working with and treating PLHA (item 1–6);* *(b) Perceive work-related HIV exposure to be high (item 7–8)*

Table 53. Recommended indicators at the health care provider level (numerator/denominator): Questions, aggregation (continued)

Level of Recommendation	Indicator (Numerator/Denominator)	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
Expanded	Percent of people working in institutions/facilities (e.g., managers, health care workers) who fear (a) providing invasive medical care on patients with HIV/AIDS and (b) contact with non-blood bodily fluids of patients with HIV/AIDS	In response to the following situations, please indicate if you have fear of HIV transmission, do not have fear of HIV transmission, or do not know if you have fear of HIV transmission: 1. Giving an injection to a person living with HIV or AIDS 2. Caring for a person with HIV or AIDS 3. Dressing the wounds of a person living with HIV or AIDS 4. Conducting surgery or suturing on a person with HIV or AIDS 5. Putting a drip in someone who is showing signs of AIDS 6. Touching the sweat of a person with HIV or AIDS 7. Touching the saliva of a person with HIV or AIDS	Numerator: No. of respondent feared one or more situations Denominator: No. of respondents *Note: Use the following items to calculate each category:* *(a) providing invasive medical care on PLHA (items 1–5);* *(b) contact with non-blood bodily fluids of PLHA (items 6–7)*
Provider-level: Values, shame, blame			
Essential	Percent of people working in institutions/facilities (e.g., managers, health care workers) who report (a) Judgment (b) Blame (c) Shame	Do you agree or disagree with the following statements: 1. HIV is punishment for bad behavior. 2. People with HIV should be ashamed of themselves. 3. HIV is a punishment from God. 4. Promiscuous men are the ones that spread HIV in our community. 5. It is the women prostitutes who spread HIV. 6. I would feel ashamed if I was infected with HIV. 7. I would feel ashamed if someone in my family was infected with HIV.	Numerator: No. of respondents who agreed with one or more negative statements Denominator: No. of respondents *Note: Use the following items to calculate each category:* *(a) judgment (items 1–3)* *(b) blame (items 4–5)* *(c) shame (items 6–7*)

Table 53. Recommended indicators at the health care provider level (numerator/denominator): Questions, aggregation (continued)

Level of Recommendation	Indicator (Numerator/Denominator)	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
Provider-level: Enacted Stigma			
Essential	*Specific Indicator* Percent of people in institutions/facilities (e.g., managers, health care workers) who personally know patients who were [fill in type of discrimination] in the past 12 months because they were known or suspected to have HIV/AIDS: (a) neglected (b) treated differently (c) denied care (d) verbally abused (e) tested for HIV or had sero-status disclosed without consent *Aggregate indicator* Percent of people working in institutions/facilities (e.g., managers, health care workers) who personally know patients who were discriminated against in the past 12 months because they were known or suspected to have HIV/AIDS (composite score of the next indicator).	In the past 12 months, have you seen or observed the following happen in this health facility because a client was known or suspected of having HIV/AIDS? 1. Receiving less care/attention than other patients 2. Extra precautions being taken in the sterilization of instruments used on HIV positive patients 3. Requiring some clients to be tested for HIV before scheduling surgery 4. Using latex gloves for performing non-invasive exams on clients suspected of having HIV 5. Because a patient is HIV positive, a senior health care provider pushed the client to a junior provider 6. Testing a client for HIV without their consent 7. Health care providers gossiping about a client's HIV status	Numerator: No. of respondent observed one or more types of stigma Denominator: No. of respondents *Note: Use the following items to calculate the categories:* *(a) neglected (item 1)* *(b) treated differently (items 2-4)* *(c) denied care (item 5)* *(d) verbally abused (item 6)* *(e) verbal abuse/gossip (item 7)* To calculate the aggregate indicator, create a composite variable from the 7 items and report the percentage of providers observing one or more types of discrimination against PLHA in the past year.

Table 53. Recommended indicators at the health care provider level (numerator/denominator): Questions, aggregation (continued)

Level of Recommendation	**Indicator (Numerator/Denominator)**	**Data Collection Questions**	**How to aggregate to get indicator Numerator/Denominator**
Provider-level: Disclosure			
Essential	Percent of people in institutions/facilities (e.g., managers, health care workers) who learned about a patient's HIV status through unofficial channels during the past year	Is there anyone you know in the health facility who has HIV, but has not yet shown signs and symptoms of AIDS? How did you know that he/she has HIV infection? Do you know of a health worker/colleague who has HIV or AIDS? How did you know he/she has HIV or AIDS? 1. The infected person told me her/himself 2. Family member of infected person told me 3. Community member told me 4. General gossip/rumors 5. From health care provider where the person tested 6. Read from his/her hospital file 7. Other	Numerator: No. of respondent who mentioned unofficial channels* Denominator: No. of respondents who knew HIV status of a person in their health facility (*in any way other than via the PLHA themselves or due to medical necessity)
Expanded	Percent of people who think a person should be able to keep their HIV status private	If a person learns that he/she is infected with the virus that causes AIDS, should this information remain this person's secret of should this information be available to the community? If kept secret, why? If let other people now, why?	Numerator: No. of respondents who thought a person's HIV status should be kept secret Denominator: No. of respondents *Note: It is important to ask the follow-up* Why *questions to ensure capture of stigmatizing responses.*

Table 53. Recommended indicators at the health care provider level (numerator/denominator): Questions, aggregation (continued)

Level of Recommendation	Indicator (Numerator/Denominator)	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
Expanded	Percent of people who would want a family member's HIV-positive status to be kept secret	If a member of your family contracted HIV/AIDS, would you want it to remain a secret? If kept secret, why? If would let others know, why?	Numerator: No. of respondent thought a family member's HIV status should be kept private Denominator: No. of respondents *Note: It is important to ask the follow-up* Why *questions to ensure capture of stigmatizing responses.*
Provider-level: Anti-discrimination policies			
Essential	Percent of people working in institutions/facilities (e.g., managers, health care workers) who are aware of policies guaranteeing access/rights to PLHA	Are you aware of any policies to protect PLHA at your health facility?	Numerator: No. of people aware of policies to protect PLHA in a particular institution/facility Denominator: No. of people working in the institution facility
Essential	Number or percent of institutions/facilities enforcing policies guaranteeing access/rights and providing recourse	Are these policies enforced?	Numerator: No. of facilities that enforced policies Denominator: No. of facilities

Table 53. Recommended indicators at the health care provider level (numerator/denominator): Questions, aggregation (continued)

Level of Recommendation	**Indicator (Numerator/Denominator)**	**Data Collection Questions**	**How to aggregate to get indicator Numerator/Denominator**
Essential	Percent of people working in institutions or facilities (e.g., managers, health care workers) willing to report discrimination against PLHA	If you ever saw any of the above (types of enacted stigma) happening to a client because he/she is a PLHA, would you be willing to report it to a higher authority?	Numerator: No. of people working in particular institution/facility Denominator: No. of people working in that institution/facility *Note: Rather than asking, in general, whether people working in institutions/facilities are willing to report discrimination, it would be more beneficial to report whether providers are willing to report specific types of discrimination. Therefore, we recommend asking about willingness to report the specific types of stigma and discrimination seen or observed by the health care providers. In this case, the denominator would be total number of people who saw or observed that particular type of discrimination.*

Table 54. Recommended indicators at the PLHA level (numerator/denominator): Questions, aggregation

Level of Recommendation	Indicator	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
PLHA-level: Enacted Stigma			
Essential	Percentage of PLHA who experienced enacted stigma in last year	In the last year, have you [fill in from list below] because of your HIV status? 1. Been excluded from a social gathering 2. Been abandoned by your spouse/partner 3. Been isolated in your household 4. No longer visited or visited less by family and friends 5. Been teased, insulted, or sworn at 6. Lost customers to buy produce/goods or lost a job 7. Lost housing or not been able to rent housing 8. Been denied religious rites/services 9. Had property taken away 10. Been gossiped about 11. Lost respect/standing within the family and/or community 12. Been threatened with violence	Numerator: No. of respondents reporting experiencing at least 1 item Denominator: No. of respondents *Note: Respondents should only appear once in the numerator, so if they answer* Yes *to more than one item they are only counted 1 time.*

Table 54. Recommended indicators at the PLHA level (numerator/denominator): Questions, aggregation (continued)

Level of Recommendation	Indicator	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
Expanded	Percentage of PLHA who experienced enacted stigma in last year	In the last year, have you [fill in from list below] because of your HIV status? 1. Been excluded from a social gathering 2. Been abandoned by your spouse/partner 3. Been isolated in your household 4. No longer visited or visited less by family and friends 5. Been teased, insulted, or sworn at 6. Lost customers to buy produce/goods or lost a job 7. Lost housing or not been able to rent housing 8. Been denied religious rites/services 9. Had property taken away 10. Been gossiped about 11. Lost respect/standing within the family and/or community 12. Been threatened with violence 13. Been given poorer quality health services 14. Been physically assaulted 15. Been denied promotion/further training 16. Visitors increased to “check out” how you are doing 17. Abandoned by your family/sent away to the village	(same as above)

Table 54. Recommended indicators at the PLHA level (numerator/denominator): Questions, aggregation (continued)

Level of Recommendation	Indicator	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
Expanded	Percentage of PLHA who feared enacted stigma in last year	In the last year, have you feared [fill in from list below] because of your HIV status? 1. Been excluded from a social gathering 2. Been abandoned by your spouse/partner 3. Been isolated in your household 4. No longer visited or visited less by family and friends 5. Been teased, insulted, or sworn at 6. Lost customers to buy produce/goods or lost a job 7. Lost housing or not been able to rent housing 8. Been denied religious rites/services 9. Had property taken away 10. Been gossiped about 11. Lost respect/standing within the family and/or community 12. Been threatened with violence 13. Been given poorer quality health services 14. Been physically assaulted 15. Been denied promotion/further training 16. Visitors increased to “check out” how you are doing 17. Abandoned by your family/sent away to the village	(same as above)

Table 54. Recommended indicators at the PLHA level (numerator/denominator): Questions, aggregation (continued)

Level of Recommendation	Indicator	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
Expanded	Percent of PLHA who have been socially isolated in the past 1 year because of HIV status	In the last year, have you [*fill in from list below*] because of your HIV status? 1. Been excluded from a social gathering 2. Been abandoned by your spouse/partner 3. No longer visited or visited less by family and friends 4. Abandoned by your family/sent away to the village	(same as above)
Expanded	Percent of PLHA who have been physically isolated in the past 1 year because of their HIV status	In the last year, have you [*fill in from list below*] because of your HIV status? 1. Been isolated in your household 2. Been threatened with violence 3. Been physically assaulted 4. Other new item re physical isolation?	(same as above)
Expanded	Percent of PLHA who have experienced verbal stigma in the past 1 year because of their HIV status	In the last year, have you [*fill in from list below*] because of your HIV status? 1. Been teased, insulted, or sworn at 2. Been gossiped about 3. Visitors increased to “check out” how you are doing	(same as above)
Expanded	Percent of PLHA who have experienced a negative effect on their identity in the past 1 year because of their HIV status	In the last year, have you [*fill in from list below*] because of your HIV status? 1. Been denied religious rites/services 2. Lost respect/standing within the family and/or community 3. Other new item re: loss of identity?	(same as above)

Table 54. Recommended indicators at the PLHA level (numerator/denominator): Questions, aggregation (continued)

Level of Recommendation	Indicator	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
Expanded	Percent of PLHA who have lost access to resources in the past 1 year because of HIV status	In the last year, have you [*fill in from list below*] because of your HIV status? 1. Lost customers to buy produce/goods or lost a job 2. Lost housing or not been able to rent housing 3. Had property taken away 4. Been given poorer quality health services 5. Been denied promotion/further training	(same as above)
Expanded	How many times in *X* period of time have each type of stigma happened in the past 1 year because of HIV status?	In the last year, have you [*fill in from list below*] because of your HIV status? 1. Been excluded from a social gathering 2. Been abandoned by your spouse/partner 3. Been isolated in your household 4. No longer visited or visited less by family and friends 5. Been teased, insulted, or sworn at 6. Lost customers to buy produce/goods or lost a job 7. Lost housing or not been able to rent housing 8. Been denied religious rites/services 9. Had property taken away 10. Been gossiped about 11. Lost respect/standing within the family and/or community 12. Been threatened with violence 13. Been given poorer quality health services 14. Been physically assaulted 15. Been denied promotion/further training 16. Visitors increased to "check out" how you are doing 17. Abandoned by your family/sent away to the village	Numerator: No. of respondents who experienced 1 type of stigma Numerator: No. of respondents who experienced 2–3 types of stigma Numerator: No. of respondents who experienced 4–6 types of stigma Numerator: No. of respondents who experienced 7 or more types of stigma Denominator: No. of respondents

Table 54. Recommended indicators at the PLHA level (numerator/denominator): Questions, aggregation (continued)

Level of Recommendation	Indicator	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
Expanded	Frequency with which PLHA experience stigma	In the last year, how often have you [*fill in from list below*] because of your HIV status? 1. Been excluded from a social gathering 2. Been abandoned by your spouse/partner 3. Been isolated in your household 4. No longer visited or visited less by family and friends 5. Been teased, insulted, or sworn at 6. Lost customers to buy produce/goods or lost a job 7. Lost housing or not been able to rent housing 8. Been denied religious rites/services 9. Had property taken away 10. Been gossiped about 11. Lost respect/standing within the family and/or community 12. Been threatened with violence 13. Been given poorer quality health services 14. Been physically assaulted 15. Been denied promotion/further training 16. Visitors increased to "check out" how you are doing 17. Abandoned by your family/sent away to the village	Response categories: *Never* *Sometimes* *Often*

Table 54. Recommended indicators at the PLHA level (numerator/denominator): Questions, aggregation (continued)

Level of Recommendation	Indicator	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
PLHA-level: Disclosure			
Essential	Percent of PLHA who have disclosed their status beyond a few trusted individuals* (*more than 5 people, including one non-family member)	1. Have you told anyone about your HIV status? 2. Who have you told?	Numerator: No. of respondents who have disclosed to more than 3 people Denominator: No. of respondents
Essential	Percent of PLHA who have disclosed their HIV sero-status to their primary sexual partner	Who have you told?	Numerator: No. of respondents who currently have a partner and who have disclosed their sero-status to him/her Denominator: No. of respondents who currently have a partner
Expanded	Percent of PLHA who have disclosed their HIV sero-status to their primary sexual partner within 6 months of knowing their sero-status	1. Who have you told? 2. How soon after learning your status did you tell (full name of person) of your status?	Numerator: No. of respondents who currently have a partner and who have disclosed their sero-status to him/her within 6 months of learning their sero-status Denominator: No. of respondents who currently have a partner
Essential	Percent of PLHA whose HIV status has been disclosed without their consent	Has your HIV status ever been revealed without your consent?	Numerator: No. of respondents answering *Yes* Denominator: No. of respondents

Table 54. Recommended indicators at the PLHA level (numerator/denominator): Questions, aggregation (continued)

Level of Recommendation	**Indicator**	**Data Collection Questions**	**How to aggregate to get indicator Numerator/Denominator**
PLHA-level: Internal stigma			
Essential	Percent of PLHA who withdraw themselves or abandon life aspirations	In the last [*X* period], have you ever avoided or withdrawn from [fill in from list below] because of your HIV status? 1. Applying for school, further training or a scholarship 2. Promotion or job opportunity 3. Travel 4. Seeking health care 5. Relationships with friends or relatives 6. Having a sexual relationship, getting married, or having a child Why? *Note: Select only those who report internal stigma (not feeling worthy, pointless, etc.) rather than fear of stigma or other reasons.*	Numerator: No. of respondents reporting at least 1 item Denominator: No. of respondents *Note: Respondents should only appear once in the numerator, so if they answer* Yes *to more than one item they are only counted 1 time.*
Essential	Percent of PLHA with feelings of shame, guilt, self-blame	In the last year, have you felt [*fill in from list below*] because of your HIV status: 1. shame 2. guilt 3. self-blame	Numerator: No. of respondents reporting experiencing at least 1 item Denominator: No. of respondents *Note: Respondents should only appear once in the numerator; if they answer* Yes *to more than one item, they are only counted 1 time.*

Table 54. Recommended indicators at the PLHA level (numerator/denominator): Questions, aggregation (continued)

Level of Recommendation	Indicator	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
PLHA-level: Stigma policy/reduction awareness			
Expanded	Percent of people living with HIV/AIDS who have been referred to places of support for stigma and discrimination	1. During pre or post-test counseling, did you discuss stigma and discrimination? 2. Were you referred to any group or place where you could get support to help you deal with stigma and discrimination?	Numerator: No. of respondents who reported being referred to an organization Denominator: No. of respondents who discussed stigma during counseling
Expanded (where relevant policies and laws exist)	Percent of persons living with HIV/AIDS aware of anti-discrimination policies and laws	1. Are you aware of any policies dealing with stigma and discrimination? 2. What do they say? (pre-coded responses) 3. Are you aware of any laws dealing with stigma and discrimination? 4. What do they say? (pre-coded responses)	Numerator: No. of respondents correctly reporting content of laws & policies Denominator: No. of respondents
Expanded	Percent of PLHA who know a source of assistance if stigma is experienced	1. Do you know of any resources, including organizations, where you can get help in using anti-discrimination laws if you experience stigma or discrimination? 2. What resources do you know of or which organizations would you go to for help?	Numerator: No. of respondents who report at least one place for support coping with stigma and discrimination Denominator: No. of respondents
Expanded	Percent of PLHA who have confronted or challenged someone stigmatizing the respondent	In the last year, have you confronted or challenged someone who was stigmatizing or discriminating against you or another person?	Numerator: No. of respondents who experienced stigma and confronted, educated, or reported (or other response) the person in the last year Denominator: No. of respondents who experienced stigma in the last year

REFERENCES

Alonzo, AA, and NR Reynolds. 1995. Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. Social Science and Medicine 41(3): 303-315.

Asia Pacific Network of People Living with HIV/AIDS (APN+). 2004. AIDS discrimination in Asia. Bangkok: APN+

Banteyerga, H, A Kidanu, L Nyblade, K MacQuarrie, and R Pande. 2004. "Yichalaliko" (It Can Be Done)! Exploring HIV and AIDS stigma and related discrimination in Ethiopia: Causes, manifestations, consequences, and coping mechanisms. Addis Ababa: Miz Hasab Research Center.

Berger, B, CE Ferrans, and FR Lashly. 2001. Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. Research in Nursing and Health 24(6): 518-529.

Blendon, RJ, and K Donelan. 1988. Discrimination against people with AIDS: The public's perspective. New England Journal of Medicine 19(15): 1022-6.

Boer, H, and PAA Emons. 2004. Accurate and inaccurate HIV transmission beliefs, stigmatizing and HIV protection motivation in northern Thailand. AIDS CARE 16(2): 167-176.

Bond, V, L Chilikwela, S Clay, T Kafuma, L Nyblade, and N Bettega. 2003. "Kanayaka" (The light is on): Understanding HIV and AIDS related stigma in urban and rural Zambia. Lusaka: Zambart Project and Kara Counselling and Training Trust (KCTT).

Brown, L, F Yokota, Y Sawadogo, and A Afable. 2004. Stigma measurement in Africa: A comparative analysis of DHS and BSS Surveys (forthcoming working paper for MEASURE Evaluation).

Carael, M, L Curran, E Gacad, E Gnaore, R Harding, BM Mandofia, M Stahlhofer, S Timberlake, M Ummel, and T Murphy. 2000. Protocol for the identification of discrimination against people living with HIV. Geneva: Joint United Nations Programme on HIV/AIDS.

Clark, HJ, G Linder, L Armistead, and BJ Austin. 2003. Stigma, disclosure, and psychological functioning among HIV-infected and non-infected African-American Women. Women & Health 38(4): 57-71.

Crandall, CS. 1991. Multiple stigma and AIDS: Illness stigma and attitudes toward homosexuals and IV drug users in AIDS-related stigmatization. Journal of Community & Applied Social Psychology 1(2): 165-172.

Crandall, CS and D Moriarty. 1995. Physical illness stigma and social rejection. British Journal of Social Psychology 34: 67-83.

Derlega, VJ, BA Winstead, K Greene, J Servoich, and WN Elwood. 2002. Perceived HIV-related stigma and HIV disclosure to relationship partners after finding out about the seropositive diagnosis. Journal of Health Psychology 7(4): 415-432.

DeVellis, RF. 2003. Scale development: Theory and applications. Applied Social Research Methods Series. Bickman, L and DJ Rog. Thousand Oaks, Calif.: SAGE Publications, Inc.

Dubbert, PM, JK Kemppainen, and D White-Taylor. 1994. Development of a measure of willingness to provide nursing care to AIDS patients. Nurse Administration Quarterly 18: 16-21.

Fawole, I, M Asuzu, S.O. Oduntan and W. R. Brieger. 1999. A school-based AIDS education programme for secondary school students in Nigeria: A review of effectiveness. Health Education Research 14(5): 675-83.

Fife, BL and ER Wright. 2000. The dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer. Journal of Health and Social Behavior 41(1): 50-67.

Gilmore, N and MA Somerville. 1994. Stigmatization, scapegoating, and discrimination in sexually transmitted diseases: Overcoming "them" and "us". Social Science and Medicine 39(9): 1339-1358.

Goffman, E. 1963. Stigma: Notes on the management of spoiled identity. New York: Simon & Schuster Inc.

Green, G. 1995. Attitudes toward people with HIV: Are they as stigmatizing as people with HIV perceive them to be? Social Science and Medicine 41(4): 557-568.

Hadjipateras, A. 2004. Unravelling the dynamics of HIV/AIDS-related stigma and discrimination: The role of community-based research. Research Report Series 1. Nairobi: Agency for Co-operation and Research in Development (ACORD).

Herek, G, J Capitanio, and KF Widaman. 2002. HIV-related stigma and knowledge in the United States: Prevalence and trends, 1991-1999. American Journal of Public Health 92(3): 371-377.

Herek, GM and JP Capitanio. 1993. Public reactions to AIDS in the United States: A second decade of stigma. American Journal of Public Health 83(4): 574-577.

Herek, GM and JP Capitanio. 1997. AIDS stigma and contact with persons with AIDS: Effects of direct and vicarious contact. Journal of Applied Social Psychology 27(1): 1-36.

Hong, KT, NT Van Anh, and J Ogden. 2004. Because this is the disease of the century: Understanding HIV and AIDS-related stigma and discrimination in Vietnam. Hanoi and Washington: Institute for Social Development Studies/ICRW.

Horizons. 2003. HIV/AIDS workplace programs. Mobilizing managers, crafting policies, educating workers. Washington: Population Council.

Horizons/Population Council, Society for Service to Urban Poverty. 2003. The PLHA-friendly achievement checklist: A self-assessment tool for hospitals and other medical institutions caring for people living with HIV/AIDS (PLHA). New Delhi and Washington: Horizons/SHARAN.

Johnson, SD. 1995. Model of factors related to tendencies to discriminate against people with AIDS. Psychological Reports 76(2): 563-572.

Kalichman, SC and L Simbayi. 2004. Traditional beliefs about the cause of AIDS and AIDS-related stigma in South Africa. AIDS CARE 16(5): 572-580.

Lee, RS, A Kochman, and KJ Sikkema. 2002. Internalized stigma among people living with HIV-AIDS. AIDS and Behavior 6(4): 309-319.

Link, B and J Phelan. 2001. On stigma and its public health implications. Stigma and Global Health: Developing a Research Agenda. Washington: National Institutes of Health.

Mbwambo, J, GP Kilonzo, P Kopoka, and L Nyblade. 2004. Understanding HIV and AIDS-related stigma and resulting discrimination in Tanzania. Dar-es-Salaam: MUCHS.

Morrison, K. 2004. Mo Kexteya: Reduction of Stigma and Discrimination related to HIV/AIDS in Mexico. Mexico City: POLICY Project, National Institute of Public Health of Mexico, the Mexican Network of PLHAs, Colectivo Sol, LetraS, FRENPAVIH, Empresa Medilex, CENSIDA.

Netemeyer, RG, WO Bearden, and S Sharma. 2003. Scaling Procedures: Issues and Applications. Thousand Oaks, Calif.: SAGE Publications, Inc.

Nyblade, L. 2004. Measuring HIV stigma: existing knowledge, gaps, challenges, and moving forward. Research Workshop on Health-related Stigma and Discrimination. Soesterberg: The Netherlands.

Nyblade, L, R Pande, S Mathur, K MacQuarrie, R Kidd, H Banteyerga, A Kidanu, G Kilonzo, J Mbwambo, and V Bond. 2003. Disentangling HIV and AIDS Stigma in Ethiopia, Tanzania and Zambia. Washington: ICRW.

Ogden, J and L Nyblade. 2005. Common at Its Core: HIV-Related Stigma Across Contexts. Washington: ICRW.

Pett, M, N Lackey, and J Sullivan (2003). Making sense of Factor Analysis: The use of factor analysis for instrument development in health care research. Sage Publications. Thousand Oaks, California.

POLICY Project. 2003. Siyam'Kela: Measuring HIV/AIDS Related Stigma. Cape Town, South Africa: USAID; POLICY Project/South Africa; Centre for the Study of AIDS at the University of Pretoria; Chief Directorate: HIV, AIDS & TB, Department of Health.

POLICY Project, ICRW, Horizons, MEASURE/Evaluation. 2004. HIV/AIDS-related Stigma and Discrimination Indicators Development Workshop Report.

Porter, SB. 1993. Public Knowledge and Attitudes about AIDS among Adults in Calcutta, India. AIDS Care 5(2): 169-76.

Preston, DB, AR D'Augelli, CD Kassab, RE Cain, FW Schulze, and MT Starks. 2004. The Influence of Stigma on the Sexual Risk Behavior of Rural Men Who Have Sex with Men. AIDS Education and Prevention 16(4): 291-303.

Pulerwitz, J, S Lippman, MS Setubal, M Chinaglia, C Takae-Ogura, J Van Dam and J Diaz. 2004. Measuring and Addressing HIV/AIDS Stigma Among Truckers in Brazil. XV International AIDS Conference, Bangkok, Thailand. Abstract: WEOrD1254.

Snell, WEJ, PD Finney, and L Godwin. 1991. Stereotypes about AIDS. Contemporary Social Psychology 15.

Spector, PE. 1992. Summated Rating Scale Construction: An Introduction. Quantitative Applications in the Social Sciences. Lewis-Beck, MS. Newbury Park, Calif.: SAGE Publications, Inc.

Swendeman, D, MJ Rotheram-Borus, S Comulada, and RE Weiss. 2004. Experienced and perceived HIV-related stigma among young people living with HIV: Implications for preventative and supportive interventions. Washington: American Public Health Association Annual Meeting [Abstract #92208]

USAID. 2003. Expanded Response Guide to Core Indicators for Monitoring and Reporting on HIV/AIDS Programs. Washington: USAID.

Yoder, S and L Nyblade. 2004. Comprehension of questions in the Tanzania AIDS Indicator Survey. Calverton, Md.: Macro International.

APPENDICES

APPENDIX A: HIV AND AIDS KNOWLEDGE

Multiple questions were collected on HIV and AIDS knowledge in the community survey because of the relationship between knowledge and stigma and were used to test construct validity for the stigma indicators, in particular for the domain of fear of casual transmission and avoidance of casual contact with PLHA. In particular, information was collected on transmission and prevention, as well as a series of questions probing for knowledge beyond standard transmission and prevention. From this series of questions, we created three composite variables for transmission, prevention and in-depth knowledge. Table A-1 presents the overall frequencies for each composite variable. The details of items in each composite variable are described below.

Table A-1. Overall frequency for each composite variable

HIV/AIDS Knowledge Category		
	Incorrect and Some Correct	**Complete Correct**
Transmission Knowledge	45.9%	54.1%
Prevention Knowledge	76.2%	23.8%
In-depth Knowledge	**Correct on 0–2 items**	**Correct on 3–7 items**
	23.6%	76.4%

<u>HIV Transmission</u>

Transmission was assessed through the general question (answers unprompted): “Please tell me all the ways you know of that HIV can be transmitted.” Interviewers recorded the unprompted answers on to a set of pre-coded responses. Because few respondents in the pre-test mentioned transmission from mother to child (MTCT) to the general, unprompted question, we also asked the closed-ended question: “Can the virus that causes AIDS be transmitted from a mother to her baby?” We then categorized the unprompted responses to the general transmission question into the correct and incorrect modes listed below and combined them with the direct question on MTCT. Answers coded in the other ways category (less than 1% of all responses) were not included in the composite variable.

Correct modes contains three categories:

1. Unprotected sex, sex with prostitutes, and sex with multiple partners
2. Blood transfusion, sharing injections, sharing razors/blades, and injecting illegal drugs
3. Mother-to-child transmission and/or answered *yes* to the closed-ended question regarding MTCT

Incorrect modes mentioned included: kissing, mosquito bites, share toilets, road accidents, sweat, and saliva.

Respondents who answered at least one item in each category (and did not mention any incorrect modes) were grouped into a category labeled as “complete correct,” and all the others were grouped as “incorrect and some correct,” which included the “don’t know” responses.

Prevention Knowledge:

Prevention knowledge was assessed by the general question (unprompted responses):

“How can people protect themselves from getting HIV?” Answers were recorded by the interviewer to a set of coded responses. Similar to the transmission composite variable, we divided the answers into correct and incorrect modes (listed below). Answers coded into the other ways category (less than 1% of all responses) were not included in the composite variable.

Correct modes contains three categories:

1. Abstain from sex, be faithful to one uninfected partner, and use condoms.
2. Limit number of sexual partners, avoid sex with prostitutes, avoid sex with persons who have sex with many partners, avoid sex with homosexuals, and avoid injecting drug users.
3. Avoid blood transfusion, sharing injections, sharing razors/blades, injecting illegal drugs.

Incorrect modes included: avoid kissing, mosquito bites, sex with younger girls, and use protection methods from traditional healer.

Respondents who answered at least one item in each of the correct knowledge categories (and gave no incorrect answers) were grouped as “complete correct,” and all the others were grouped as “incorrect and some correct,” which included the “don’t know” responses.

In-depth Knowledge:

The composite variable for in-depth knowledge included the seven questions that performed best out of larger set of questions, based on examining frequencies and variability. We then created a 7-likert composite score for in-depth knowledge, with 7 being the highest and 0 being the lowest scores. The specific questions and their frequencies are listed in Table A-2.

Table A-2. In-depth knowledge composite variable: Questions used and frequencies

No.	In-depth Question	Frequency Distribution (%)	Note: Respondents scored as having complete knowledge
1	Is there a difference between HIV and AIDS?	Yes: 59.1% No: 28.7% Don't know: 12.2%	Respondents answering "Yes"
2	In your opinion, when can the virus that causes AIDS be transmitted from a mother to her baby? (Recorded all possible responses given)	During pregnancy: 52.0% During delivery: 76.5% During breastfeeding: 79.4% Other: 0.4%	Respondents who mentioned all three paths
3	In your opinion, if a mother has HIV, would the virus always be passed on to the baby?	Yes: 56.5% No: 23.4% Sometimes/rarely: 3.8% Depends: 0.5% Don't know and 'missing': 15.7%	Respondents answering "No" or "Depends"
4	Can a healthy looking person have HIV?	Yes: 95.9% No: 1.4% Don't know: 2.7%	Respondents answering "Yes"
5	Is there a cure for AIDS?	Yes: 1.7% No: 96.8% Don't know: 1.4%	Respondents answering "No"
6	Do you know of treatment that can prolong the life of PLHA? If yes, what treatment*? (Recorded all possible responses applied)	Yes: 54.7% No: 45.3% **(n=535, answered 'yes' in above question)** Local herbs: 1.9% Prophylaxis: 7.9% Faith healing/prayer: 1.5% ARV: 72.9% Lishe bora: 37.4% Other: 3.5%	Respondents answering "Yes" and who at least mentioned ARV treatment
7	In a married couple, is it possible for one person to have HIV and the other one not to have HIV?	Yes: 71.6% No: 21.3% Don't know: 7.2%	Respondents answering "Yes "

APPENDIX B: HEALTH CARE PROVIDERS

The following tables present the results of the construct validity analysis conducted for the latent stigma variables. Table B-1 presents the indicators by selected socio-demographic variables, and Table B-2 presents the indicators by selected construct validity variables. The “willingness to report discrimination” indicator was dichotomous; therefore, cross tabulations are presented with the socio-demographic variables. Chi-square tests of significance were performed to identify any statistical differences present. The remaining indicators are made up of several indices created by using factor analysis. These indices were all standardized to have a mean of 10 to ease comparisons. For all indices, a lower mean score represents a more stigmatizing response. To assess statistical difference, t-tests were performed for dichotomous construct validity variables, and f-tests were performed for those with more than two response categories. All significant associations are shaded in gray.

Table B-1. Validation of health care provider latent stigma indicators by socio-demographic variables

Indicator	Education			Pre-service training	
	Std vii/viii	**Form iv**	**Form vi**	**Dipl.**	**Cert.**
(Number of respondents per category)					
	(34)	(13)	(13)	(22)	(38)
Percent who responded ‘no’					
Willingness to report discrimination against PLHA	64.7	69.2	84.6	72.7	68.4
(Number of respondents per category)					
	(54)	(25)	(21)	(41)	(59)
Fear of HIV transmission while caring for PLHA	**Mean Score**				
Providing invasive medical care	10.0	10.1	10.0	10.2	9.9
Contact with non-blood bodily fluids	9.9	10.1	10.3	10.2	9.9
Willingness to conduct medical procedures on PLHA	**Mean Score**				
Comfort around PLHA	9.7**	10.5**	10.2**	10.3**	9.8**
Work-related exposure	9.9*	10.4*	9.8*	10.1	9.9
Attitudes toward PLHA	9.8**	10.3**	10.3**	10.4**	9.7**
Hold morally based discriminatory attitudes toward PLHA	**Mean** Score				
General shame of PLHA	9.7**	10.4**	10.3**	10.3**	9.8**
Attitudes about blame	10.0	10.1	10.0	10.1	9.9
Personal shame of PLHA	9.9	10.2	10.1	10.1	9.9

Note: Chi-square tests of significance were conducted for willingness to report discrimination indicator. For stigma indices, t-tests of significance were conducted for dichotomous variables; f-tests were conducted for variables with multiple response categories. *<.10 **<0.05 ***<0.01

Table B-2. Validation of health care provider latent stigma indicators by in-depth knowledge, proximity, HIV testing, and disclosure

Indicator	In-depth knowledge		Know colleague who died of AIDS		Personally disclosed to by PLHA		Ever been tested		Willing to disclose if HIV+	
	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes
	(Number of respondents per category)									
	(44)	(16)	(22)	(38)	(44)	(16)	(17)	(43)	(8)	(52)
	Percent who responded 'no'									
Willingness to report discrimination against PLHA	81.8**	37.5**	68.2	71.1	70.1	68.8	64.7	72.1	87.5	67.3
	(Number of respondents per category)									
	(66)	(34)	(49)	(51)	(74)	(26)	(37)	(63)	(12)	(88)
Fear of HIV transmission while caring for PLHA	Mean Score									
Providing invasive medical care	9.9	10.2	10.0	10.0	10.1	9.8	10.0	10.0	8.7***	10.2***
Contact with non-blood bodily fluids	9.9*	10.3*	10.2	9.9	10.1**	9.7**	10.0	10.0	9.6	10.1
Willingness to conduct medical procedures on PLHA	Mean Score									
Comfort around PLHA	9.7***	10.6***	10.2	9.8	10.2**	9.5**	10.4**	9.8**	9.9	10.0
Work-related exposure	9.7***	10.5***	9.8	10.2	10.1	9.8	10.3**	9.9**	9.1***	10.1***
Attitudes toward PLHA	9.8***	10.5***	10.1	9.9	10.1	9.9	10.2*	9.9*	10.1	10.0
Hold morally-based discriminatory attitudes toward PLHA	Mean Score									
General shame of PLHA	10.0	10.1	10.1	10.0	9.9**	10.4**	9.8	10.1	9.9	10.0
Attitudes about blame	9.9	10.2	10.2*	9.8*	10.1	9.9	10.1	9.9	9.7	10.0
Personal shame of PLHA	9.9	10.2	9.9	10.1	10.0	10.0	10.2	9.9	8.8***	10.2***

Note: Chi-square tests of significance were conducted for willingness to report discrimination indicator. For stigma indices, t-tests of significance were conducted for dichotomous variables; f-tests were conducted for variables with multiple response categories. T-tests of significance were performed to determine if means were significantly different. ***<0.001 **<0.05 *<.

APPENDIX C: RECOMMENDED QUESTIONNAIRES

This appendix includes revised questionnaires based on the learning of the studies. As such, they do not include the full set of questions asked. Individual questions that did not perform well or were included as additional checks for other questions are not presented in these questionnaires in order to provide a better and shorter questionnaire than was originally used.

APPENDIX C-1: TANZANIA STIGMA INDICATOR AND COMMUNITY BASELINE-INDIVIDUAL QUESTIONNAIRE

INTRODUCTION

INFORMED CONSENT – Read, agreed, signed, approved

SECTION 1: Respondent and Household Characteristics

No.	Questions and filters	Coding categories		Skip
101	[RECORD INTERVIEW START TIME]	Hour	[__|__]	
		Minutes	[__|__]	
102	[RECORD SEX OF RESPONDENT]	Female	1	
		Male	2	
103	How old are you? [RECORD AGE OF RESPONDENT]	Age in years	[__|__]	
		Don’t know	98	
104	Have you ever attended school? If so, what is the highest level of school you attended: Primary, middle, secondary, or higher? [RECORD RESPONSE]	None	1	
		Madrasa	2	
		Less than Primary 7	3	
		Competed Primary 7	4	
		Form 1-4/post primary tertiary	5	
		Form 5-6/post form 4 tertiary	6	
		University/post secondary tertiary institutions	7	
105	What is your marital status? [RECORD RESPONSE. IF “2-4” SKIP TO Q106]	Married/cohabiting	1	
		Divorced	2	
		Widowed	3	Go to 106
		Never married	4	
105a	Do you presently have a partner/lover? [RECORD RESPONSE]	Yes	1	
		No	2	
106	What is your employment status? [RECORD RESPONSE]	Unemployed	0	
		Petty business	1	
		Civil servant	2	
		Businessperson	3	
		Self-employed	4	
		Peasant	5	
		Other (Specify)_____________	95	

SECTION 1: Respondent and Household Characteristics (continued)

No.	Questions and filters	Coding categories		Skip
107	What is your religion?	Catholic	1	
		Tanzania Assemblies of God	2	
	[IF REPLY IS “CHRISTIAN,” ASK “WHAT DENOMINATION?”]	Pentecostal	3	
		Seventh Day Adventist	4	
		Lutheran	5	
		Anglican	6	
		Muslim	7	
		Traditional beliefs	8	
		None	9	
		Other(Specify)______________	95	
108	I would now like to ask you some questions about your household. Does your household have:		No Yes	
		Electricity	0 1	
		Radio	0 1	
		Television	0 1	
	[READ OUT EACH ITEM AND CIRCLE “0” FOR NO AND “1” FOR YES.]	Land line telephone or cell phone	0 1	
		Bicycle	0 1	
		Fridge	0 1	
	[DO NOT LEAVE ANY LINE BLANK]	Car	0 1	
109	Type of house roof	Thatch/palm	1	
		Corrugated iron sheet	2	
	[OBSERVE/RECORD ROOF TYPE]	Tiles/slate/cemented	3	
		Other (specify)______________	95	
110	What kind of toilet facility does your household use?	Flush toilet	1	
		Pit toilet	2	
	[RECORD RESPONSE. IF “3” SKIP TO Q112]	No facility	3➔	Go to 112
111	Do you share toilet facility with another household?	No	0	
	[RECORD RESPONSE]	Yes	1	

SECTION 1: Respondent and Household Characteristics (continued)

No.	Questions and filters	Coding categories		Skip
112	What is the main source of drinking water for members of your households? [RECORD RESPONSE. IF RESPONDENT SAYS THAT HOUSEHOLD WATER IS PURCHASED, ASK WHERE THAT WATER COMES FROM]	Piped into residence/yard	1	
		Public tap	2	
		Well in residence/yard	3	
		Public well	4	
		Spring	5	
		River/stream	6	
		Pond/lake	7	
		Bottled water	8	
		Water tanker or water seller	9	
113	Have you ever heard the word ‘kunyanyapa’ (stigma)?	No	0➔	Go to 201
		Yes	1	
114	What does this word mean?			
115	Please give me some examples of stigma. [PROBE: Any other examples?]			

SECTION 2: Knowledge of HIV

[START WITH INTRODUCTION] Now, I would like to talk with you about HIV and AIDS

No.	Questions and filters	Coding categories		Skip
201	Is there a difference between HIV and AIDS?	No	0➔	Go to 202
		Yes	1	
		Don't know	98➔	Go to 202
202	In your opinion, if a mother has HIV, would the virus always be passed on to the baby? [IF “DEPENDS,” ASK “ON WHAT?” AND RECORD ANSWER IN OPEN SPACE]	No	1	
		Yes	2	
		Sometimes/rarely	3	
		Don’t know	98	
		Depends___________________	90	

SECTION 2: Knowledge of HIV (continued)

No.	Questions and filters	Coding categories		Skip
203	Please tell me all the ways you know of that HIV can be transmitted	Unprotected sex/sex without condom	A	
		Sharing injections	B	
		Blood transfusions	C	
	PROBE: Any other ways?	Mother-to-child transmission	D	
		Injecting drug use	E	
	[CIRCLE ALL THAT APPLY—DO NOT READ OUT THE ANSWERS]	Sex with prostitutes	F	
		Sex with multiple partners	G	
		Kissing	H	
		Mosquito bites	I	
		Sharing razors/blades	J	
		Sharing food/drink/eating utensils	K	
		Sharing toilets	L	
		Road accidents	M	
		Sweat	N	
		Saliva	O	
		Don’t know	98	
		Other (specify)_________________	95	
204	How can people protect themselves from getting HIV?	Abstain from sex	A	
		Use condoms	B	
		Be faithful to one uninfected partner	C	
	[CHECK ALL THAT APPLY]	Limit number of sexual partners	D	
		Avoid sex with prostitutes	E	
		Avoid sex with persons who have sex with many partners	F	
		Avoid sex with homosexuals	G	
		Avoid sex with injecting drug users	H	
		Avoid sharing razors/blades	I	
		Avoid sharing needles	J	
		Avoid injections	K	
		Avoid kissing	L	
		Avoid mosquito bites	M	
		Avoid blood transfusions	N	
		Avoid sex with younger girls	O	
		Obtain protection methods from traditional healer	P	
		Don’t know	98	
		Other (specify)______________	95	

SECTION 2: Knowledge of HIV (continued)

No.	Questions and filters	Coding categories		Skip
204a	Can someone prevent getting HIV by abstaining from sex?	Yes No Don't know	0 1 98	
204b	Can someone prevent getting HIV by remaining faithful to a faithful partner?	Yes No Don't know	0 1 98	
204c	Can someone prevent getting HIV by always using condoms correctly?	Yes No Don't know	0 1 98	
205	Can the virus that causes AIDS be transmitted from a mother to her baby? [IF DEPENDS, ASK "ON WHAT?" AND RECORD ANSWER IN OPEN SPACE]	No Yes Depends____________________ Don't know	0➔ 1 90➔ 98	Go to 206 Go to 206
205a	In your opinion, when can the virus that causes AIDS be transmitted from a mother to her baby? Can the virus be transmitted during— [CIRCLE ALL RESPONSES GIVEN]	 During pregnancy…………….. During delivery………………. During breastfeeding………. Other (specify)___ ____________	Yes No 0 1 0 1 0 1 0 1	
206	Can a healthy looking person have HIV? [IF DEPENDS, ASK "ON WHAT?" AND RECORD ANSWER IN OPEN SPACE]	No Yes Don't know Depends____________________ Other (specify)________________	0 1 98 90 95	
207	Is there a cure for AIDS?	No Yes Don't know/not sure	0 ➔ 1 98➔	Go to 208 Go to 208
207a	If there is a cure, what kind is it? [CHECK ALL THAT APPLY]	A. Modern medicine B. Traditional medicine C. Faith healing/prayer Other (specify)_______________	A B C 95	
208	Do you know of treatment that can prolong the life of a PLHA?	No Yes	0➔ 1	Go to 209

SECTION 2: Knowledge of HIV (continued)

No.	Questions and filters	Coding categories		Skip
208a	If yes, what treatment? [CHECK ALL THAT APPLY]	Local herbs Treatment for opportunistic infection Faith healing/prayer ARV Good nutrition Other (specify)__________________	A B C D E 95	
209	In a married couple, is it possible for one person to have HIV and the other one not to have HIV?	No Yes Don't know	0 1 95	
210	Please tell me if you are worried/have fear, or not worried about contracting HIV, in response to the following statements:			
210.1	Being exposed to the saliva of a person with HIV or AIDS	Have fear Do not have fear	1 2	
210.2	Being exposed to the excreta of a person with HIV or AIDS	Have fear Do not have fear	1 2	
210.3	Being exposed to the sweat of a person with HIV or AIDS	Have fear Do not have fear	1 2	
210.4	Your child could become infected with HIV if they play with a child who has HIV or AIDS	Have fear Do not have fear	1 2	
210.5	Caring for a person living with HIV or AIDS	Have fear Do not have fear	1 2	
211	In a market of several food vendors, would you buy food from a PLHA but not showing signs/symptoms?	No Yes	0➔ 1	Go to 301
211b	And what about if they were showing signs/symptoms?	Will still buy Will not buy	1 2	

Section 3: Shame and Blame

Note: Statements below were tailored specific to this epidemic and proven to work well. We recommend that these statements be field-tested in other developing countries with a generalized epidemic, and new items may need to be used.

No.	Questions and filters	Coding categories		Skip
301	Do you agree/disagree with the following statements:			
301.1	It is the women prostitutes that spread HIV in our community	Agree Disagree	1 2	
301.2	People with HIV/AIDS should be ashamed of themselves	Agree Disagree	1 2	
301.3	I would be ashamed if someone in my family had HIV/AIDS	Agree Disagree	1 2	
301.4	People with HIV/AIDS are promiscuous	Agree Disagree	1 2	
301.5	Promiscuous men are the ones who spread HIV in our community	Agree Disagree	1 2	
301.6	Promiscuous women are the ones who spread HIV in our community	Agree Disagree	1 2	
301.7	HIV is a punishment from God	Agree Disagree	1 2	
301.8	I would feel ashamed if I was infected with HIV	Agree Disagree	1 2	
301.9	HIV is a punishment for bad behavior	Agree Disagree	1 2	
301.10	People with HIV/AIDS are to blame for bringing the disease to the community	Agree Disagree	1 2	
302	How do you think most people in your community would answer the following questions:			
302.1	It is the women prostitutes that spread HIV in our community	Agree Disagree	1 2	
302.2	People with HIV/AIDS should be ashamed of themselves	Agree Disagree	1 2	
302.3	I would be ashamed if someone in my family had HIV/AIDS	Agree Disagree	1 2	
302.4	People with HIV/AIDS are promiscuous	Agree Disagree	1 2	
302.5	Promiscuous men are the ones who spread HIV in our community	Agree Disagree	1 2	

Part 3: Shame and Blame (continued)

No.	Questions and filters	Coding categories		Skip
302.6	Promiscuous women are the ones who spread HIV in our community	Agree Disagree	1 2	
302.7	HIV is a punishment from God.	Agree Disagree	1 2	
302.8	I would feel ashamed if I was infected with HIV	Agree Disagree	1 2	
302.9	HIV is a punishment for bad behavior	Agree Disagree	1 2	
302.10	People with HIV/AIDS are to blame for bringing the disease to the community	Agree Disagree	1 2	

Section 4: Enacted Stigma Questions—Primary Stigma

No.	Questions and filters	Coding categories		Skip
401	Do people in your community toward people suspected of having HIV/AIDS or treat PLHA differently?	No Yes Don’t know	0 1 98	
402	Do you personally know someone who in the last 12 months has had the following happen to them because they were known to have, or suspected of having, HIV or AIDS?			
402.1	Excluded from a social gathering (wedding, funeral, party, community association group)	Yes No How many PLHA? ___	1 0 No.	
402.2	Treated differently/shunned at a social gathering	Yes No How many PLHA? ___	1 0 No.	
402.3	Abandoned by their spouse/partner	Yes No How many PLHA? ___	1 0 No.	
402.4	Abandoned by their family/sent away-to the village	Yes No How many PLHA? ___	1 0 No.	

Section 4: Enacted Stigma Questions—Primary Stigma (continued)

No.	Questions and filters	Coding categories		Skip
402.5	Isolated in household e.g., Made to eat alone/Made to use separate eating utensils/Made to sleep alone in own room	Yes No How many PLHA? ___	1 0 No.	
402.6	No longer visited, or visited less by family and friends	Yes No How many PLHA? ___	1 0 No.	
402.7	Visitors increased to “check them out”	Yes No How many PLHA? ___	1 0 No.	
402.8	Teased, insulted, or sworn at	Yes No How many PLHA? ___	1 0 No.	
402.9	Lost customers to buy their produce/goods or lost a job	Yes No How many PLHA? ___	1 0 No.	
402.10	Been denied promotion/further training	Yes No How many PLHA? ___	1 0 No.	
402.11	Lost housing or not been able to rent housing	Yes No How many PLHA? ___	1 0 No.	
402.12	Not allowed/denied religious rites/services (marriage, communion, burial, singing in choir, prayers)/Not allowed to go to church/mosque	Yes No How many PLHA? ___	1 0 No.	
402.13	Given poorer quality health services, for example: being passed from provider to provider, not given medicines, denied treatment	Yes No How many PLHA? ___	1 0 No.	
402.14	Had property (land, household goods, etc) taken away	Yes No How many PLHA? ___	1 0 No.	
402.15	Lost respect/standing within the family and/or community	Yes No How many PLHA? ___	1 0 No.	

Section 4: Enacted Stigma Questions—Primary Stigma (continued)

No.	Questions and filters	Coding categories		Skip
402.16	Gossiped about	Yes	1	
		No	0	
		How many PLHA? ___	No.	
402.17	Physically assaulted (i.e., hit, kicked, punched)	Yes	1	
		No	0	
		How many PLHA? ___	No.	

SECTION 5: Disclosure

No.	Questions and filters	Coding categories		Skip
501	In your community, in what way do people know if someone has HIV?	The infected person discloses his/her status	A	
		From general rumors/gossip	B	
		From the HIV+ person's family	C	
	[CHECK ALL THAT APPLY]	From the HIV+ person's friends/neighbors	D	
		From the health center/health worker where the person got tested	E	
		The person looks ill and has lost a lot of weight	F	
	What are some other ways?	Other (specify)__________________	G	
			95	
502	Is there anyone who is currently living in this community that you know of who has HIV, but has yet to show signs and symptoms of AIDS?	No	0	
		Yes	1	
502a	Which one of the following have been ways through which you got information that someone in your community is infected with HIV?		No Yes	
		The infected person told me herself/himself	0 1	
		Family member of infected person told me	0 1	
		Community member told me	0 1	
	[READ ALL OPTIONS, CIRCLE "YES" OR "NO" FOR EACH ONE]	General gossip/rumors	0 1	
		I heard it at the clinic	0 1	
		Other (specify)__________________	0 1	

SECTION 5: Disclosure (continued)

No.	Questions and filters	Coding categories		Skip
503	Would you recommend to a person who is living with HIV, but is not showing signs/symptoms of AIDS, to keep his/her status secret, tell only family members, or share this information with the community? [RECORD RESPONSE. IF “3” SKIP TO Q319B; IF “98” SKIP TO Q320]	Tell no one	1	
		Tell only family	2	
		Make available to the community	3→	Go to 503a
		Don’t know	98→	Go to 401
503a	If you recommend that HIV-positive status be kept private, why? [CHECK ALL THAT APPLY]	Personal problem	A	Go to 401
		People act differently toward a person with HIV	B	
		Person would be isolated/ neglected/avoided	C	
		No one would care for person	D	
		Other (specify) _________________	95	
504	Are there people you personally know who have either disclosed their HIV positive status directly to you or publicly?	Yes	1	
		No	0→	Go to 506
504a	If yes, how many do you know?		No.	

Section 6: Knowledge, Implementation, Use of Policies and Laws

No.	Questions and filters	Coding categories		Skip
601	Do you know of any national policies against HIV stigma and discrimination in Tanzania?	No	**0→**	**Go to 603**
		Yes	1	
602	What does the policy say?	[PRECODED RESPONSE CATEGORIES TO CORRESPOND WITH RELEVANT POLICY]		
603	Do you know of any laws against discrimination that exist in Tanzania?	No	**0→**	**Go to 701**
		Yes	1	
604	What do the laws say?	[PRECODED RESPONSE CATEGORIES TO CORRESPOND WITH RELEVANT LAWS]		

Section 7: Interview close

701	[RECORD TIME INTERVIEW ENDS]	Hour Minutes	[__|__] [__|__]	

APPENDIX C-2: TANZANIA STIGMA INDICATOR AND COMMUNITY BASELINE-HEALTH PROVIDER QUESTIONNAIRE

INTRODUCTION

INFORMED CONSENT – Read, agreed, signed, approved

SECTION 1: HP-level: Respondent and Household Characteristics

No.	Questions and filters	Coding categories		Skip
101	RECORD TIME INTERVIEW BEGINS	HOUR-------- MINUTES----------	[__|__] [__|__]	
102	Record sex of the respondent	Female Male	1 2	
103	How old are you? [PROBE: What month were you born? Therefore you have completed x years?]	Age in years Don't know	[__|__] 98	
104	Background level of education	Form iv Form vi Less than std vii/viii Completed std vii/viii	1 2 3 4	
105	What level of pre-service training did you complete?	Degree/Advanced diploma Diploma Certificate Short course/less than 1 yr Other------------------ (specify)	1 2 3 4 95	
106	Please tell me about your work here at this facility. What is your designation?	Medical specialist General Practitioner Clinical officer (medical assistant) Nurse officer Enrolled nurse midwife (trained nurse) Nurse Assistant Health attendant (nurse auxiliary) Other…………………….. (specify)	1 2 3 4 5 6 7 95	
107	How long have you been working here? CODE THE FINAL RESPONSE IN MONTHS [IF LESS THAN ONE MONTH, WRITE 00]	Months--------- Years-----------	[__|__] [__|__]	

SECTION 1: HP-level: Respondent and Household Characteristics (continued)

No.	Questions and filters	Coding categories		Skip
108	Have you received any in-service training?	No Yes	0→ 1	Go to 112
109	What kind of in-service training have you received?			
110	Have you received any in-service training specifically on HIV and AIDS?	No Yes	0→ 1	Go to 112
111	Please tell me about that training. What was it about? What topics did it cover?			
112	What is your marital status?	Married/cohabiting Divorced Widowed Never married/single	1→ 2 3 4	Go to 114
113	Do you presently have a partner/lover?	No Yes	0 1	
114	What is your religion? [IF THE RESPONSE IS CHRISTIAN-ASK WHAT DENOMINATION]	Catholic Tz Assemblies of God Pentecostal Seventh Day Adventist Lutheran Anglican Muslim Traditional beliefs None Other______________________ (Specify)	1 2 3 4 5 6 7 8 9→ 95	 Go to 201
115	How often do you attend religious activities?	More than once a week Once a week 1-3 times a month Rarely Never	1 2 3 4 5	

SECTION 2: HP-level: In-Depth Knowledge of HIV and AIDS

No.	Questions and filters	Coding categories		Skip
201	Can the HIV virus live in the open air (outside the human body)?	Yes	1	
		No	0	
		Depends	90	
		Don't know	98	
		Other	95	
202	It is required to wear latex gloves whenever performing ANY task related to examining a patient who may be HIV positive.	Strongly agree	1	
		Agree	2	
		Disagree	3	
		Strongly disagree	4	
203	The risk of HIV transmission following needle prick or sharps injuries is small, approximately 1 in 300.	True	1	
		False	0	
		Don't know	98	
204	The risk of HIV transmission following a splash of blood to non-intact skin or mucus membrane is very small, approximately 1 in 1,000.	True	1	
		False	0	
		Don't know	98	
205	Standard sterilization procedures are sufficient when sterilizing instruments used on an HIV-positive patient.	True	1	
		False	0	
		Don't know	98	
206	To prevent transmission of HIV and other blood-borne infections in the health care setting, staff should wear latex gloves for every client contact for any procedure, including taking vital signs.	True	1	
		False	0	
		Don't know	98	
207	Which body fluids have high enough concentrations of HIV to transmit the virus? [CIRCLE ALL RESPONSES GIVEN—DO NOT READ OUT THE OPTIONS]	Semen	A	
		Blood	B	
		Vaginal fluid	C	
		Breast milk	D	
		Other bodily fluids containing blood	E	
		Saliva	F	
		Sweat	G	
		Tears	H	
		Don't know	98	
		Other (specify)________________________	95	

SECTION 2: HP-level: In-Depth Knowledge of HIV and AIDS (continued)

No.	Questions and filters	Coding categories		Skip
208	Which body fluids do NOT have high enough concentrations of HIV to transmit the virus? [CIRCLE ALL RESPONSES GIVEN-DO NOT READ OUT THE OPTIONS]	Semen	A	
		Blood	B	
		Vaginal fluid	C	
		Breast milk	D	
		Other bodily fluids containing blood	E	
		Saliva	F	
		Sweat	G	
		Tears	H	
		Don’t know	98	
		Other (specify)________________________	95	

SECTION 3: HP-level: Fear of Casual Transmission of HIV and Refusal of Contact with PLHA

[START WITH INTRODUCTION] Now, I would like to talk with you about HIV and AIDS

No.	Questions and filters	Coding categories		Skip
301	In response to the following situations, please tell me if you have fear of HIV transmission, do not have fear of HIV transmission, or don’t know:			
301.1	Giving an injection to a person with HIV or AIDS	Have fear	1	
		Do not have fear	2	
		Don’t know	3	
301.2	Assisting the delivery of a woman with HIV or AIDS	Have fear	1	
		Do not have fear	2	
		Don’t know	3	
301.3	Dressing the wounds of a person living with HIV or AIDS	Have fear	1	
		Do not have fear	2	
		Don’t know	3	
301.4	Conducting surgery on or suturing a person with HIV or AIDS	Have fear	1	
		Do not have fear	2	
		Don’t know	3	
301.5	Putting a drip in someone who is showing signs of AIDS	Have fear	1	
		Do not have fear	2	
		Don’t know	3	

SECTION 3: HP-level: Fear of Casual Transmission of HIV and Refusal of Contact with PLHA (continued)

No.	Questions and filters	Coding categories		Skip
301.6	Touching the sweat of a person with HIV or AIDS	Have fear Do not have fear Don't know	1 2 3	
301.7	Touching the saliva of a person with HIV or AIDS	Have fear Do not have fear Don't know	1 2 3	
301.8	Drawing blood of a person with HIV or AIDS	Have fear Do not have fear Don't know	1 2 3	
301.9	Caring for a person living with HIV or AIDS	Have fear Do not have fear Don't know	1 2 3	
302	Now I am going to read you several statements, and I want you to tell me whether you strongly agree, agree, disagree or strongly disagree:			
302.1	Comfortable assisting or being assisted by a colleague who is HIV infected	Strongly agree Agree Disagree Strongly disagree	1 2 3 4	
302.2	Comfortable performing surgical or invasive procedure on clients whose HIV status is unknown	Strongly agree Agree Disagree Strongly disagree	1 2 3 4	
302.3	Comfortable providing health services to clients who are HIV-positive	Strongly agree Agree Disagree Strongly disagree	1 2 3 4	
302.4	Comfortable sharing a bathroom with a colleague who is HIV infected	Strongly agree Agree Disagree Strongly disagree	1 2 3 4	

SECTION 3: HP-level: Fear of Casual Transmission of HIV and Refusal of Contact with PLHA (continued)

[START WITH INTRODUCTION] Now, I would like to talk with you about HIV and AIDS

No.	Questions and filters	Coding categories		Skip
302.5	Most frequent mode of contracting HIV among health workers is through work-related exposure	Strongly agree Agree Disagree Strongly disagree	1 2 3 4	
302.6	Most HIV-positive health care workers get infected at work	Strongly agree Agree Disagree Strongly disagree	1 2 3 4	

SECTION 4: HP-level: Shame and Blame

No.	Questions and filters	Coding categories		Skip
401	Do you agree/disagree with the following statements:			
401.1	It is the women prostitutes that spread HIV in our community	Agree Disagree	1 2	
401.2	People with HIV/AIDS should be ashamed of themselves	Agree Disagree	1 2	
401.3	I would feel ashamed if someone in my family had HIV/AIDS	Agree Disagree	1 2	
401.4	Promiscuous men are the ones who spread HIV in our community	Agree Disagree	1 2	
401.5	Promiscuous women are the ones who spread HIV in our community	Agree Disagree	1 2	
401.6	HIV is a punishment from God	Agree Disagree	1 2	
401.7	I would feel ashamed if I was infected with HIV	Agree Disagree	1 2	
401.8	HIV is a punishment for bad behavior	Agree Disagree	1 2	
401.9	People with HIV/AIDS are to blame for bringing the disease to the community	Agree Disagree	1 2	

SECTION 4: HP-level: Shame and Blame (continued)

No.	Questions and filters	Coding categories		Skip
402	How do you think most health care providers in your clinic would answer the following questions:			
402.1	It is the women prostitutes that spread HIV in our community	Agree Disagree	1 2	
402.2	People with HIV/AIDS should be ashamed of themselves	Agree Disagree	1 2	
402.3	I would feel ashamed if someone in my family had HIV/AIDS	Agree Disagree	1 2	
402.4	Promiscuous men are the ones who spread HIV in our community	Agree Disagree	1 2	
402.5	Promiscuous women are the ones who spread HIV in our community	Agree Disagree	1 2	
402.6	HIV is a punishment from God	Agree Disagree	1 2	
402.7	I would feel ashamed if I was infected with HIV	Agree Disagree	1 2	
402.8	HIV is a punishment for bad behavior	Agree Disagree	1 2	
402.9	People with HIV/AIDS are to blame for bringing the disease to the community	Agree Disagree	1 2	

SECTION 5: HP-level: Enacted Stigma

No.	Questions and filters	Coding categories		Skip
501	In the past 12 months, have you seen or observed the following happen in this health care facility because a client was known or suspected of having HIV/AIDS? [READ SCENARIOS BELOW]			
501.1	Testing a client for HIV without their consent	Yes No	1 2	
501.2	Requiring some clients to be tested for HIV before scheduling surgery	Yes No	1 2	
501.3	Using latex gloves for performing noninvasive exams on clients suspected of HIV.	Yes No	1 2	
501.4	Extra precautions being taken in the sterilization of instruments used on HIV-positive patients.	Yes No	1 2	

SECTION 5: HP-level: Enacted Stigma (continued)

No.	**Questions and filters**	**Coding categories**		**Skip**
501.5	Health providers gossiping about a client's HIV status	Yes No	1 2	
501.6	Because a patient is HIV-positive a senior health provider pushing the client to a junior provider	Yes No	1 2	
501.7	Receiving less care/attention than other patients	Yes No	1 2	
502	[If yes], where does it occur?	Health facilities Household/family Community Workplace Places of worship Places of entertainment Others________________ (specify)	A B C D E F 95	
503	Have you ever heard the word 'unyanyapaa' (stigma)?	No Yes	0➔ 1	Go to 601
504	Does stigma occur in health facilities	No Yes Not sure Don't know	0➔ 1 2➔ 98➔	Go to 506 Go to 506 Go to 506
505	Please give me some examples of stigma in the health facility. [PROBE: Any other examples?]	1. 2. 3. 4.		
506	Does stigma occur outside health facilities	No Yes Not sure Don't know	0➔ 1 2➔ 98➔	Go to 601 Go to 601 Go to 601

SECTION 5: HP-level: Enacted Stigma (continued)

No.	Questions and filters	Coding categories		Skip
507	Please give me some examples of stigma that occur outside health facilities. [PROBE: Any other examples?]	-- -- -- ---		
508	If you ever saw any of the above (types of enacted stigma) happening to a client because s/he is a PLHA, would you be willing to report to higher authority?	Yes	0	
		No	1	
		Don't know	98	

SECTION 6: HP-level: Disclosure

No.	Questions and filters	Coding categories		Skip
601	If a person learns that he/she is HIV positive, but is not yet showing signs and symptoms of AIDS, should this fact remain a personal secret, a family secret, or should it be known to the community?	Be kept a personal secret	1➔	Go to 602.a
		Be kept a family secret	2➔	Go to 603
		Should be known to the community	3➔	Go to 602.b
		Don't know	98➔	
		Other (specify)________________	95➔	Go to 603
601.a	If it should be kept a personal secret, why? [CHECK ALL THAT APPLY]	It is a personal/private issue	A	
		Person would be treated differently	B	
		Person would be isolated/neglected/avoided	C	Go to 603
		Other (specify) ______________________	95	
601.b	If it should be known to the community, why? [CHECK ALL THAT APPLY]	S/He would not threat/infect others	A	
		S/He needs to be isolated	B	
		S/He should get care and support of the community	C	
		S/He to encourage others do the same	D	
		Other (specify) ______________________	95	

SECTION 6: HP-level: Disclosure (continued)

No.	Questions and filters	Coding categories		Skip
602	Is there anyone you know in this health facility who has HIV, but has yet to show signs and symptoms of AIDS?	Yes No	0 1	
602a	How did you find out that he/she is infected with HIV?		NO YES	
		The infected person told me her/himself	0 1	
		Family member of infected person told me	0 1	
		Community member told me	0 1	
		General gossip/rumors	0 1	
		From health care provider where the person tested	0 1	
		Read from his/her hospital file	0 1	
		Other (specify)_____________	0 1	
603	Are there people you personally know, but not as a patient, that have disclosed their HIV-positive status directly to you?	Yes No	0 1	

SECTION 7: Awareness of Laws and Policies to Protect PLHA from Stigma and Discrimination

No.	Questions and filters	Coding categories		Skip
701	Does the health facility have a policy to protect HIV positive patients from discrimination by protecting patients' rights and providing recourse? [INTERVIEWER SHOULD ASK TO SEE A COPY OF THE POLICY AND THEN FILL IN THE RESPONSE TO THIS QUESTION—SHOULD NOT ASK RESPONDENT THIS QUESTION]	Yes No	1 2	
702	Are you aware of any policies to protect PLHA at your health facility?	Yes	1	
		No	2➔	Go to 602
702a	Are these policies enforced?	Yes No Don't know	0 1 98	

Section 8: Interview Close

801	[RECORD TIME INTERVIEW ENDS]	Hour Minutes	[__|__] [__|__]	

THANK YOU FOR YOUR TIME AND COOPERATION

APPENDIX C-3: TANZANIA STIGMA INDICATOR PLHA QUESTIONNAIRE

INTRODUCTION

INFORMED CONSENT – Read, agreed, signed, approved

SECTION 1. Respondent and Household Characteristics

No.	Questions and filters	Coding categories		Skip
101	[RECORD TIME INTERVIEW BEGINS]	Hour Minutes	[__|__] [__|__]	
102	[RECORD SEX OF THE RESPONDENT]	Female Male	1 2	
103	How old are you? [RECORD AGE OF RESPONDENT]	Age in years Don't know	[__|__] 98	
104	Have you ever attended school? If so, what is the highest level of school you have attended? [RECORD RESPONSE]	None Madrasa Less than Primary 7 Completed Primary 7 Form 1–4/post-primary tertiary Form 5–6/post-Form 4 tertiary University/post-secondary tertiary	1 2 3 4 5 6 7	
105	What is your marital status? [RECORD RESPONSE. IF "2–4" SKIP TO Q106]	Married/cohabiting Divorced Widowed Never married	1 2 } 3 } 4 }	Go to 106
105a	Do you presently have a partner/ lover? [RECORD RESPONSE]	Yes No	1 0	
106	What is your employment status? [RECORD RESPONSE]	Unemployed Petty business Civil servant Businessperson Self-employed Peasant Other (specify) _______________	0 1 2 3 4 5 95	

SECTION 1. Respondent and Household Characteristics (continued)

No.	Questions and filters	Coding categories		Skip
107	What is your religion? [RECORD RESPONSE. IF REPLY IS “CHRISTIAN,” ASK “WHAT DENOMINATION?”]	Catholic	1	
		Tanzania Assemblies of God	2	
		Pentecostal	3	
		Seventh Day Adventist	4	
		Lutheran	5	
		Anglican	6	
		Muslim	7	
		Traditional beliefs	8	
		None	9	
		Other (specify) _______________	95	
108	I would now like to ask you some questions about your household. Does your household have ➔: [READ OUT EACH ITEM AND CIRCLE “0” FOR “NO” AND 1 FOR “YES.” DO NOT LEAVE ANY LINE BLANK]		No Yes	
		Electricity?	0 1	
		Radio?	0 1	
		Television?	0 1	
		Land line telephone or cell phone?	0 1	
		Bicycle?	0 1	
		Fridge?	0 1	
		Car?	0 1	
109	Type of house roof: [OBSERVE/RECORD ROOF TYPE]	Thatch/palm	1	
		Corrugated iron sheet	2	
		Tile/slate/cemented	3	
		Other (specify) _______________	95	
110	What kind of toilet facility does your household use? [RECORD RESPONSE. IF “3” SKIP TO Q112]	Flush toilet	1	
		Pit toilet	2	
		No facility	3 ➔	Go to 112
111	Do you share toilet facility with another household?	No	0	
		Yes	1	
112	What is the main source of drinking water for members of your household? [RECORD RESPONSE. IF RESPONDENT SAYS THAT HOUSEHOLD WATER IS PURCHASED, ASK “WHERE DOES THAT WATER COME FROM?”]	Piped into residence/yard	1	
		Public tap	2	
		Well (in residence/yard)	3	
		Public well	4	
		Spring	5	
		River/stream	6	
		Pond/lake	7	
		Bottled water	8	
		Water tanker or water seller	9	

SECTION 2: Knowledge and Misconceptions of HIV

[INTRODUCE THE SECTION:] Now I would like to talk with you about HIV and AIDS.

No.	Questions and filters	Coding categories		Skip
201	*[NOTE: General knowledge questions were subject to low variability in the sample. Therefore, we recommend the development of a new set of questions on specific, in-depth knowledge in the these areas: ➔]*	*[Mother-to-child transmission* *Sero-discordance* *Co-infection and re-infection* *CD-4 counts and viral loads* *Healthy living and longevity* *Capabilities (living with HIV)]*		
202	*[NOTE: We recommend the development of a new question about fear of transmitting HIV to others and possible actions to avoid it.]*			

SECTION 3: Testing and Disclosure

[INTRODUCE THE SECTION:] Now I would now like to ask you some questions about your experience with learning about and disclosing your HIV status.

No.	Questions and filters	Coding categories		Skip
301	How long have you known that you are HIV-positive? [RECORD RESPONSE]	Less than 1 year	1	
		1–5 years	2	
		6–10 years	3	
		10 years or more	4	
302	Do you remember when you received your HIV test results (month/year)? [RECORD MONTH/YEAR (IF KNOWN)]	Month	[__|__]	
		Year	[__|__]	
303	Why did you get tested? [CHECK ALL THAT APPLY]	Other illness	A	
		Partner illness/death	B	
		To prepare for marriage	C	
		Child illness/death	D	
		Health provider recommended	E	
		Just to know my sero-status	F	
		Decision of doctor/medical officer	G	
		Other (specify) _____________	95	

SECTION 3: Testing and Disclosure (continued)

No.	Questions and filters	Coding categories		Skip
304	Was the decision to be tested your own, or were you asked by someone else to be tested? [RECORD RESPONSE. IF “1” SKIP TO Q306]	Own/went by self/voluntary Mandatory test	1 ➔ 2	Go to 306
305	Who asked you to be tested? [CHECK ALL THAT APPLY]	Medical professional Partner Parents Religious leader Employer Scholarship/school Visa application Other (specify) ____________	A B C D E F G 95	
306	Was your informed consent taken before you were tested? [RECORD RESPONSE]	No Yes	0 1	
307	Where was the test conducted? Name of facility/place____________________ [WRITE FACILITY NAME ABOVE AND TO CODE/CLASSIFY RESPONSE, CHECK ALL THAT APPLY ➔]	Government/clinic/hospital Mission hospital/clinic Private hospital/clinic NGO-CBO VCT center Other (specify) ____________	1 2 3 4 5 95	
308	Did you receive counseling before or after your blood was taken for testing? [RECORD RESPONSE. IF REPLY IS “NO COUNSELING,” PROBE FURTHER: “WHAT ABOUT PRE-TEST OR POST-TEST COUNSELING?”]	No counseling Pre-test only Post-test only Pre-test and post-test	0 ➔ 1 2 3	Go to 312
309	At the time you were tested for HIV or were told your results, did any counselor discuss with you anything about stigma and discrimination? [RECORD RESPONSE]	No Yes	0 1	
310	Were you referred to any group or place where you could get support to help you deal with stigma and discrimination? [RECORD RESPONSE. IF “0”, SKIP TO Q312]	No Yes	0➔ 1	Go to 312

SECTION 3: Testing and Disclosure (continued)

No.	Questions and filters	Coding categories		Skip
311	[If yes] Which group(s)/place(s)? [WRITE DOWN ALL EXAMPLES GIVEN➔]	-- -- -- -- -- ----------------------------------		
312	Have you told anyone about your HIV sero-status? [RECORD REPONSE. IF “0” SKIP TO Q316]	No Yes	0➔ 1	Go to 316

No.	Questions and filters	Coding categories		
313	[If yes] Who have you told? [check all that apply] How soon after learning your status did you tell [person/organization]? [RECORD LENGTH OF TIME (DAYS, MONTHS, YEARS) FROM KNOWLEDGE OF STATUS TO DISCLOSURE TO PERSON/ORGANIZATION]			Time: test ➔disclosure DAYS/MONTHS/YRS
		Current partner	A	[ ] [ ] [ ]
		Previous partner	B	[ ] [ ] [ ]
		Mother	C	[ ] [ ] [ ]
	[PROBE FURTHER: “IS THERE ANYONE ELSE YOU HAVE TOLD?”]	Father	D	[ ] [ ] [ ]
		Sister	E	[ ] [ ] [ ]
		Brother	F	[ ] [ ] [ ]
	[REFER TO Q111. FOR THOSE WITH OPTIONS 2 OR 3, PROBE FURTHER: “YOU TOLD ME EARLIER THAT YOU ARE DIVORCED OR WIDOWED. DID YOU TELL YOUR PARTNER BEFORE S/HE PASSED AWAY OR YOU DIVORCED?”]	Other relative	G	[ ] [ ] [ ]
		Friend	H	[ ] [ ] [ ]
		Neighbor	I	[ ] [ ] [ ]
		Health provider/s	J	[ ] [ ] [ ]
		Religious leader	K	[ ] [ ] [ ]
		Public disclosure	L	[ ] [ ] [ ]
		Other_________ (specify)	95	

SECTION 3: Testing and Disclosure (continued)

No.	Questions and filters	Coding categories	Skip	
316	[If not] Why have you not told anyone about your status?	[Because:]		
	[CHECK ALL THAT APPLY]	They would tell someone else	A	
		I would be gossiped about/laughed at	B	
		It would become news around here	C	
		I would be physically isolated	D	
		I would be socially isolated	E	
		I would lose respect	F	
		I would lose job, housing, livelihood	G	
		It would be difficult to get medical services	H	
		I'd be treated differently at church/mosque	I	
		I would be afraid of being stigmatized	J	
		Private matter	K	
		Don't know	98	
		Other (specify) ______________________	95	
317	Have you ever done things or behaved in a way to try and prevent people from knowing your status? [RECORD RESPONSE. IF "0" SKIP TO Q318]	No	0→	Go to 318
		Yes	1	
317b	What kinds of things have you done to avoid people knowing your status? [WRITE DOWN ALL EXAMPLES GIVEN →]			
318	Has your HIV status ever been revealed without your consent? [RECORD RESPONSE. IF "0" SKIP TO Q319]	No	0→	Go to 319
		Yes	1	

SECTION 3: Testing and Disclosure (continued)

No.	Questions and filters	Coding categories		Skip
318a	Who revealed your status without your consent? [CHECK ALL THAT APPLY AND ASK: "ANYONE ELSE?"]	Partner	A	
		Mother	B	
		Father	C	
		Sister	D	
		Brother	E	
		Other relative	F	
		Friend	G	
		Neighbor	H	
		Health provider/s	I	
		Religious leader	J	
		Don't know	98	
		Other (specify) _________________	95	
319	Would you recommend to a person who is living with HIV, but is not showing signs/symptoms of AIDS, to keep his/her status secret, tell only family members, or share this information with the community? [RECORD RESPONSE. IF "3" SKIP TO Q319B; IF "98" SKIP TO Q320]	Tell no one	1	
		Tell only family	2	
		Make available to the community	3→	Go to 319b
		Don't know	98→	Go to 320
319a	If you recommend that HIV-positive status be kept private, why? [CHECK ALL THAT APPLY]	Personal problem	A	Go to 401
		People act differently toward a person with HIV	B	
		Person would be isolated/ neglected/avoided	C	
		No one would care for person	D	
		Other (specify) _________________	95	
319b	If you recommend that HIV-positive status be made available to the community, why? [CHECK ALL THAT APPLY]	To avoid community infection by PLHA	A	
		PLHA can encourage/teach others do the same	B	
		PLHA can create opportunity for care and support from community	C	
		To reduce discrimination/ stigma against PLHA	D	
		Other (specify) _________________	95	

SECTION 4: Community Attitudes Toward PLHA and Fear of Stigma and Discrimination

No.	Questions and filters	Coding categories		Skip
401	Do people behave differently toward people suspected of having HIV/AIDS or treat PLHA differently? [RECORD RESPONSE. IF “0” OR “98” SKIP TO Q402]	No Yes Don’t know	0➔ 1 98➔	Go to 402 Go to 402
401a	Can you give some examples of how people suspected of having HIV/AIDS might be treated differently? [WRITE DOWN ALL EXAMPLES GIVEN➔]			
402	In the last 12 months, have you been afraid that [read options from below] because of your HIV status?			
402.1	You would be excluded from a social gathering (wedding, funeral, party, community association group)	No Yes	0 1	
402.2	You would be treated differently/shunned at a social gathering	No Yes	0 1	
402.3	You would be abandoned by your spouse/partner	No Yes	0 1	
402.4	You would be abandoned by your family/sent away to the village	No Yes	0 1	
402.5	You would be isolated in your household (made to eat alone/made to use separate eating utensils/made to sleep alone in your own room)	No Yes	0 1	
402.6	You would no longer be visited or would be visited less by family and friends	No Yes	0 1	
402.7	Visitors would increase to “check out” how you are doing	No Yes	0 1	
402.8	You would be teased, insulted, or sworn at	No Yes	0 1	
402.9	You would lose customers to buy produce/goods or lose a job	No Yes	0 1	
402.10	You would be denied promotion/further training	No Yes	0 1	
402.11	You would lose housing or not be able to rent housing	No Yes	0 1	
402.12	You would be denied religious rites/services (marriage, communion, burial, singing in choir, prayers)/ Not allowed to go to church/mosque	No Yes	0 1	

SECTION 4: Community Attitudes Toward PLHA and Fear of Stigma and Discrimination (continued)

402.13	You would be given poorer quality health services (e.g., passed from provider to provider or not given medicines, treatment, surgery)	No Yes	0 1
402.14	You would have property taken away	No Yes	0 1
402.15	You would lose respect/standing within the family and/or community	No Yes	0 1
402.16	You would be gossiped about	No Yes	0 1
402.17	You would be physically assaulted (i.e., hit, kicked, or punched)	No Yes	0 1

SECTION 5: Enacted Stigma (Discrimination)

	501. Have you **ever** [read out options from list below] because of your HIV status? [RECORD RESPONSES BELOW]		502. **In the last year**, have you [read out options from list below left] because of your HIV status? **[If yes]** How often has this happened (never, sometimes, often)? [record responses below]
1	Been excluded from a social gathering (wedding, funeral, party, community association group)	0. No 1. Yes	0. Never 1. Sometimes 2. Often
2	Been treated differently/shunned at a social gathering	0. No 1. Yes	0. Never 1. Sometimes 2. Often
3	Been abandoned by your spouse/partner	0. No 1. Yes	0. Never 1. Sometimes 2. Often
4	Been abandoned by your family/sent away from family	0. No 1. Yes	0. Never 1. Sometimes 2. Often
5	Been isolated in the household (made to eat alone/made to use separate eating utensils/made to sleep alone in own room	0. No 1. Yes	0. Never 1. Sometimes 2. Often
6	Been no longer visited, or visited less by family and friends	0. No 1. Yes	0. Never 1. Sometimes 2. Often

SECTION 5: Enacted Stigma (Discrimination) (continued)

7	Had visitors increase to “check out” how you are doing	0. No 1. Yes	0. Never 1. Sometimes 2. Often
8	Been teased, insulted, or sworn at	0. No 1. Yes	0. Never 1. Sometimes 2. Often
9	Lost customers to buy your produce/goods or lost a job	0. No 1. Yes	0. Never 1. Sometimes 2. Often
10	Been denied promotion/further training	0. No 1. Yes	0. Never 1. Sometimes 2. Often
11	Lost housing or not been able to rent housing	0. No 1. Yes	0. Never 1. Sometimes 2. Often
12	Been denied religious rites/services (marriage, communion, burial, singing in choir, prayers)/ Not allowed to go to church/mosque	0. No 1. Yes	0. Never 1. Sometimes 2. Often
13	Been given poorer quality health services (e.g., been passed from provider to provider or not given medicines, treatment, surgery)	0. No 1. Yes	0. Never 1. Sometimes 2. Often
14	Had property (e.g., household property or land) taken away	0. No 1. Yes	0. Never 1. Sometimes 2. Often
15	Lost respect/standing within the family and/or community	0. No 1. Yes	0. Never 1. Sometimes 2. Often
16	Been gossiped about	0. No 1. Yes	0. Never 1. Sometimes 2. Often
17	Been physically assaulted (i.e. hit, kicked, or punched)	0. No 1. Yes	0. Never 1. Sometimes 2. Often

SECTION 5: Enacted Stigma (Discrimination) (continued)

18	Been threatened with violence	0. No 1. Yes	0. Never 1. Sometimes 2. Often
503	**[If “yes” to at least one question in Q502]** How did you know it was because of your HIV status? [WRITE DOWN ALL EXAMPLES GIVEN➔]		
504	**[If “yes” to at least one question in Q502]** How did you react to and cope with the stigma and discrimination you have just told me about? [WRITE DOWN ALL EXAMPLES GIVEN➔]		
505	Have you ever been given more care and support by family/ neighbors/community because of your HIV status? Please describe. [WRITE DOWN ALL EXAMPLES GIVEN➔]	0. No 1. Yes	
506	Have you ever been given special services (home based care, medical treatment, material) because of your HIV status? Please describe. [WRITE DOWN ALL EXAMPLES GIVEN➔]	0. No 1. Yes	

SECTION 6. Experiences of Stigma and Discrimination in Health Settings

No.	Questions and filters	Coding categories		Skip
601	How is your health in general? Would you say it is very poor, poor, neither poor nor good, good, or very good?	Very poor Poor Neither poor nor good Good Very good	1 2 3 4 5	
602	Have you ever had HIV/AIDS-related signs/symptoms (e.g., skin rash, loss of weight, herpes) visible in your physical appearance?	No Yes	0 1	
603	In the past 12 months, have you had any health concerns/worries that required medical attention?	No Yes	0➔ 1	Go to 605

SECTION 6. Experiences of Stigma and Discrimination in Health Settings (continued)

No.	Questions and filters	Coding categories		Skip
604	In the past 12 months, when you had health problems that required medical advice or treatment, who in your household had primary responsibility to facilitate your health care?	Spouse	1	
		Child	2	
		Parent	3	
		Sibling	4	
		Other relative	5	
		Other household member	6	
		No one in the household	7	
605	In the past 12 months, when you had these health concerns/worries, did you seek medical advice or treatment?	No	0 ➔	Go to 607
		Yes	1	
606	In the past 12 months, where did you seek medical advice/treatment? [CHECK ALL APPLY. PROBE FURTHER.]	Government health facility	A	
		Private health facility	B	
		NGO health facility	C	
		Pharmacy/drug Store	D	
		Traditional practitioner	E	
		Other (specify) _____________	95	
607	The last time you went for medical advice or treatment, did service providers at this place know your HIV status?	No	0	
		Yes	1	
		Not sure	2	
608	How would you rate the quality of services provided to you during your last visit to a medical facility?	Poor	1	
		Fair	2	
		Good	3	
609	In the **past 12 months**, have you had any of the following happen to you at a **health care facility** because of your HIV status? [READ OPTIONS BELOW AND RECORD EACH RESPONSE]			
609.1	Health provider refused to attend you	No	0	
		Yes	1	
609.2	You were discharged too early	No	0	
		Yes	1	
609.3	You had to wait longer to be attended	No	0	
		Yes	1	
609.4	You were being unnecessarily referred on to another provider in the same facility or referred to another facility	No	0	
		Yes	1	
609.5	You were told to come back later	No	0	
		Yes	1	

SECTION 6. Experiences of Stigma and Discrimination in Health Settings (continued)

No.	Questions and filters	Coding categories		Skip
609.6	You were being denied treatment—drugs, surgery—or relevant tests/investigations	No Yes	0 1	
609.7	You were tested for HIV without your informed consent?	No Yes	0 1	
609.8	You were required to be tested for HIV before care was given or surgery scheduled	No Yes	0 1	
609.9	Health provider used latex gloves for performing non-invasive exams on you or took extra precautions.	No Yes	0 1	
609.10	Health provider disclosed your HIV status to your family without your consent.	No Yes	0 1	
609.11	Health provider gossiped about your HIV status	No Yes	0 1	
609.12	Health provider used derogatory language or scolded or blamed you for having HIV	No Yes	0 1	
609.13	Your bed pans or bed clothes were not changed as needed/as often compared to other patients	No Yes	0 1	
609.14	You received less care/attention than other patients	No Yes	0 1	
610	In the past 12 months, was there any other way in which you were treated differently because of your HIV status? Please describe. [WRITE DOWN ALL EXAMPLES GIVEN➔]			
611	**[If “yes” to Q609–610]** How did you know it was because of your HIV status? [WRITE DOWN ALL EXAMPLES GIVEN➔]			
612	**[If “yes” to at least one question in 401]** How did you react to and cope with the stigma and discrimination you have just told me about? [WRITE DOWN ALL EXAMPLES GIVEN➔]			

SECTION 6. Experiences of Stigma and Discrimination in Health Settings (continued)

No.	Questions and filters	Coding categories		Skip
613	Have you ever avoided or delayed seeking health care treatment because you were afraid of service providers' attitudes toward you as a person with HIV? [RECORD RESPONSE]	No Yes	0 1	
614	Have you ever traveled to a clinic or hospital that is far away, instead of going to a nearby clinic/hospital, because of your HIV status?	No Yes	**0➔** 1	**Go to 616**
615	**[If "yes" to Q614]** Why did you choose to go to a clinic/hospital that is farther away?			
616	Have you ever paid for treatment when it was available for free, because of your HIV status?	No Yes	**0➔** 1	**Go to 618**
617	Why did you choose to pay rather than seek free treatment?			
618	How would you rate your ability to work? Would you say it is very poor, poor, neither poor nor good, good, or very good?	Very poor Poor Neither poor nor good Good Very good	1 2 3 4 5	
619	Has your HIV status affected your ability to work and support yourself and your family?	No Yes Not sure	**0 ➔** 1 **2 ➔**	Go to 621 Go to 621
620	**[If "yes" to Q619]** How has it been affected? [WRITE DOWN ALL EXAMPLES GIVEN➔]			
621	In the last 12 months, did you or your household receive support from any organizations to help you with basic <u>social and economic</u> needs (e.g., food, clothing, school fees)?	No Yes	**0 ➔** 1	**Go to 623**

SECTION 6. Experiences of Stigma and Discrimination in Health Settings (continued)

No.	Questions and filters	Coding categories		Skip
622	Which organization(s)? ________________________________ [WRITE FACILITY NAME ABOVE AND, TO CODE/CLASSIFY RESPONSE, CHECK ALL THAT APPLY ➔]	Government/local administration department Religious-based organization Other NGO Local/community club/society Private company Other (specify)_______________	A B C D E 95	
623	In the last 12 months, did you or your household receive support from any organizations to help you with basic medical care needs (e.g., home-based care, palliative care, medicine)?	No Yes Not sure	**0 ➔** 1 2	**Go to 624**
624	What organization was this? [CHECK ALL THAT APPLY]	Government/Local Administration dept. Religious Based Organization Other NGO Local/community club/society Private company Other (specify) ______________	A B C D E 95	
625	Are you a member of any social support group of people living with HIV/AIDS? **[If “yes”]** What group? [RECORD RESPONSE. IF “YES” WRITE DOWN NAME OF GROUP➔]	No Yes ____________________________ (Name of PLHA support group)	0 1	
626	Are there any major lifestyle or behavior changes you have made because of your HIV status?	No Yes	**0➔** 1	**Go to 701**
627	What lifestyle changes have you made? [WRITE DOWN ALL EXAMPLES GIVEN➔]			

SECTION 7: Internalized [Self] Stigma

No.	Questions and filters	Coding categories		Skip
701	Sometimes, having HIV changes what someone plans to do in his/her life. Would you please tell me if you have ever done any of the following because of your HIV status?			
701.1	Avoided or withdrawn from applying for school, further training, or scholarship	No Yes	0 1	
701.2	Not applied for a job or promotion	No Yes	0 1	
701.3	Avoided or isolated yourself from your friends or family	No Yes	0 1	
701.4	Decided not to get married or have a sexual partner	No Yes	0 1	
701.5	Decided not to have [more] children	No Yes	0 1	
701.6	Avoided travel to another country or another area of Tanzania	No Yes	0 1	
702	Are there any [other] life goals or hopes you had that have changed because of your HIV status? Please describe. [RECORD RESPONSE AND WRITE DOWN ALL EXAMPLES GIVEN➔]	No Yes -- -- -- -----------------	0 1	
703	**[If “yes” to at least one question in Q701–702]** Why did you choose not to pursue this opportunity? [WRITE DOWN ALL REASONS GIVEN➔]			
704	Please tell me a little about how you feel or think about being HIV-positive.			
705	Please tell me if you have **in the last 12 months** experienced any of the following feelings because of your HIV status: [CHECK ALL THAT APPLY]	Shame Guilt Blame myself/self-blame Blame others Low self-esteem Dislike myself	A B C D E F	

SECTION 7: Internalized [Self] Stigma (continued)

No.	Questions and filters	Coding categories		Skip
706	**[If "yes" to 705]** When you experience this, how do you react to and cope with such feelings?			
707	Are their people, groups, or organizations that you can go to for support and advice when you have such feelings? **[If "yes]** Who? [CHECK ALL THAT APPLY]	Spouse/partner	A	
		Parent	B	
		Sibling	C	
		Other relative	D	
		Friend	E	
		Group for PLHA (specify)________________	F	
		Church/mosque/religious organization	G	
		Other NGO		
		Other (specify)______________________	H	
			95	

Section 8: Knowledge, Implementation, Use of Policies and Laws

No.	Questions and filters	Coding categories		Skip
801	Do you know of any national policies against HIV stigma and discrimination in Tanzania?	No	**0➔**	**Go to 803**
		Yes	1	
802	What does the policy say? [PRECODED RESPONSE CATEGORIES TO CORRESPOND WITH RELEVANT POLICY]			
803	Do you know of any laws against discrimination that exist in Tanzania?	No	**0➔**	**Go to 805**
		Yes	1	
804	What do the laws say? [PRECODED RESPONSE CATEGORIES TO CORRESPOND WITH RELEVANT LAWS]			
805	Do you know of any ways, or organizations, that you can go to for help with if you experience stigma or discrimination?	No	**0➔**	**Go to 807**
		Yes	1	

Section 8: Knowledge, Implementation, Use of Policies and Laws (continued)

No.	Questions and filters	Coding categories		Skip
806	What ways do you know or what organizations would you go to for help?			
807	In the past 12 months, have you sought help from any organizations to resolve an issue of discrimination?	No Yes	**0➔** 1	**Go to 809**
808	How was the issue resolved? What happened?			
809	In the past 12 months, have you confronted or challenged someone who was stigmatizing or discriminating against you, or another person?	No Yes	**0➔** 1	**Go to 811**
810	What did you do or say to this person?			
811	In the past 12 months, have you participated in stigma reduction activities held by a support group?	0. No 1. Yes	**0➔** 1	**Go to 813**
812	What was your role in this group?			
813	Do you have comments or recommendations regarding HIV/AIDS?			

Section 9: Interview Close

901	[RECORD TIME INTERVIEW ENDS]	Hour Minutes	[__|__] [__|__]	