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.

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[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)	**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
2. Percent of people who would not have casual contact with a PLHA because they are worried about contagion (S&DIWG)	**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.

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[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.

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[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

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[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

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[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%

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[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.

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[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.

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[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]

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[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.

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[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)

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[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

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[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

Q1: Percent responding *Secret*	**Q2: Percent responding *Secret***	**Percent disagreement** ***Open* to Q1 *Secret* to Q2**	**Percent disagreement** ***Secret* to Q1 *Open* to Q2**	**Total percent in disagreement**
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? ***2. If a person is infected with AIDS and has no signs, should his/her status be kept secret or made public?*** *(n=943)*				
11.7%	13.1%	4.3%	2.9%	7.2%
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? ***2. If a person is infected with AIDS and has no signs, should his/her status be kept secret or made public?*** *(n=938)*				
6.8%	13.0%	8.1%	1.9%	10.0%
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? ***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?*** *(n=947)*				
7.0%	11.6%	5.8%	1.2%	7.0%

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.

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