

Recommendations for Measuring Awareness of Policies and Laws among PLHA

1. It is important to understand not only whether people are aware of policies and laws dealing with HIV-related stigma and discrimination but also what they know and whether it is correct. However, the open-ended questions we used (*What do the [policies/laws] say?*) did not capture anything other than vague awareness of the contents of policies and laws. It may be worth considering revising the follow-up question to include a series of pre-coded response options. The question could first be administered without prompting and then with prompting for those responses. The pre-coded responses, of course, would vary according to the existence of any relevant policies or laws in that setting. We suggest an Expanded indicator for PLHA who are aware of anti-discrimination policies and laws.
2. In a setting where awareness of policies and laws is low, asking questions about means of redress and sources of support only of those who know about the existence of anti-discrimination laws results in few respondents answering the question. These questions should be asked of the full sample, as some people who have low awareness of the law may still be aware of places to go for support or redress. We propose several Expanded indicators in this area: (1) percent of PLHA who have been referred to places of support for stigma and discrimination; (2) percent of PLHA who know a source of assistances/support; (3) and percent of PLHA who have confronted or challenged stigma.

7. CONCLUSIONS AND SUMMARY RECOMMENDATIONS

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

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

For example, measuring enacted stigma with PLHA captures the actual experience of the respondent, whereas measuring enacted stigma in a general population survey is more complicated (see Section 6.2) and provides a measure of observed stigma by the respondent

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Level of Recommendation	Indicator	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
<i>Community-level: Fear of casual contact and refusal of contact with PLHA</i>			
Essential	Percent of people expressing fear of contracting HIV from non-invasive contact with PLHA	<p>Please tell me if you have fear, do not have fear, or do not know in response to the following statements:</p> <ol style="list-style-type: none"> 1. You could become infected with HIV if you are exposed to the saliva of a PLHA. 2. You could become infected with HIV if you are exposed to the sweat of a PLHA. 3. You could become infected with HIV if you are exposed to the excreta of PLHA. 4. Your child could become infected with HIV if they play with a child who has HIV or AIDS. 5. To care for PLHA 	<p>Numerator: No. of respondents reporting at least 1 fear of casual transmission</p> <p>Denominator: No. of respondents</p> <p><i>Note: Respondents should only appear once in the numerator; if they answer Yes to more than one fear, they should only be counted 1 time.</i></p>
Expanded	<p>Percent of people who would refuse casual contact with a PLHA who was not exhibiting signs of AIDS</p> <p>Percent of people who would refuse casual contact with a PLHA who was not exhibiting signs of AIDS</p>	<p>1a. In a market of several food vendors, would you buy food from a PLHA or person suspected of HIV/AIDS who was not visibly sick?</p> <p>1b. And what if they were visibly sick?</p>	<p>Numerator: No. of respondents answering no they would not buy food</p> <p>Denominator: No. of respondents</p> <p>Numerator: No. of respondents answering no they would not buy food</p> <p>Denominator: No. of respondents</p>

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

Level of Recommendation	Indicator	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
<i>Community-level: Fear of casual contact and refusal of contact with PLHA</i>			
Expanded	<p>Percentage of people expressing fear of contracting HIV from non-invasive contact with PLHA</p> <p>If it is possible to include additional items in a survey, we recommend including these items and/or other items that reflect common daily interaction situations within the target population.</p>	<p>Please tell me if you have fear, do not have fear, or do not know in response to the following statements:</p> <ol style="list-style-type: none"> 1. You could become infected with HIV if you eat food prepared by PLHA. 2. To touch a PLHA 3. To sleep in the same room as PLHA 4. To share eating utensils with PLHA 5. To sit next to someone who is showing signs of AIDS 6. To sleep in the same bed as PLHA 7. To share a toilet with PLHA 	<p>Numerator: No. of respondents reporting at least 1 fear of casual transmission</p> <p>Denominator: No. of respondents</p> <p><i>Note: Respondents should only appear once in the numerator; if they answer Yes to more than one fear, they will only be counted 1 time.</i></p>
<i>Community-level: Shame and blame/judgment</i>			
Essential	Percent of people who judge or blame persons living with HIV/AIDS for their illness	<p>Do you agree/disagree with the following statement:</p> <ol style="list-style-type: none"> 1. HIV is a punishment from God. 2. HIV/AIDS is a punishment for bad behavior 3. It is women prostitutes who spread HIV in the community. 4. People with HIV are promiscuous. 	<p>Numerator: No. of respondents agreed with at least one statement</p> <p>Denominator: No. of respondents</p>

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

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

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

Level of Recommendation	Indicator	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
Expanded	Percentage of people who personally know someone who has experienced enacted stigma in the past 1 year because they were known or suspected to have HIV or AIDS	<p>Do you know someone in the past year that has had the following happen to them because of HIV or AIDS?</p> <ol style="list-style-type: none"> 1. Excluded from a social gathering 2. Lost customers to buy their produce/goods or lost a job 3. Had property taken away 4. Abandoned by their spouse/partner 5. Abandoned by their family/sent away to the village 6. Teased or sworn at 7. Lost respect/standing within the family and/or community 8. Gossiped about 9. No longer visited, or visited less by family and friends 10. Visitors increase to “check them out” 11. Isolated within the household 	<p>Numerator: No. of respondents reporting knowing at least 1 person who has experienced enacted stigma in the past one year</p> <p>Denominator: No. of respondents</p> <p><i>Note: Respondents should only appear once in the numerator, so if they answer Yes to knowing more than one person who has experienced a given form of enacted stigma, or multiple people who have experienced multiple forms of stigma, they should only be counted 1 time in the numerator.</i></p>
Expanded	For an in-depth look at enacted stigma, we recommend collecting all 4 of the indicators that are recommended in Table 15.	See Table 15 in Section 4.3 for the individual items we collected for each domain. Additional items may be collected as appropriate for the target population	(same as above)

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

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

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

Level of Recommendation	Indicator	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
Expanded	Percent of persons reporting that self-disclosure by PLHA is a primary way that people in the community find out about a person's HIV status	<p>In your community, what is the primary way people know if someone has HIV?</p> <ol style="list-style-type: none"> 1. The infected person discloses his/her status 2. From general rumors/gossip 3. From the HIV-positive person's family 4. From the HIV-positive person's employer 5. From the HIV-positive person's friends/neighbors 6. From the health center/health care worker where the person got tested 7. The person looks ill and has lost a lot of weight 8. Other (specify) 	<p>Numerator: No. of people reporting self-disclosure is primary mode</p> <p>Denominator: Total no. of respondents</p>
Expanded	<p>Percent of persons reporting that self-disclosure is the way they learned about a person's HIV-positive status</p> <ul style="list-style-type: none"> —PLHA who is community member and still living —PLHA who is family member and still living —Deceased PLHA, community member —Deceased PLHA, family member 	<p>1a. Is there anyone in the community that you know of who has HIV but has yet to show signs and symptoms of AIDS? If Yes,</p> <p>1b. Which of the following have been ways through which you got information that someone in your community is infected with HIV? (see items above)</p> <p>2. Do you personally know someone who has died of AIDS? How did you find out?</p>	

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

Level of Recommendation	Indicator (Numerator/Denominator)	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
<i>Provider-level: Fear of casual transmission of HIV and refusal of contact with PLHA</i>			
Essential	<p>Percent of people working in institutions/facilities (e.g., managers, health care workers) who:</p> <p>(a) Are uncomfortable working with or treating PLHA; and</p> <p>(b) Perceive work-related HIV exposure to be high.</p>	<p>Do you strongly agree, agree, disagree or strongly disagree with each statement:</p> <ol style="list-style-type: none"> 1. Comfortable assisting or being assisted by a colleague who is HIV infected 2. Comfortable performing surgical or invasive procedure on clients whose HIV status is unknown 3. Comfortable to providing health services to clients who are HIV-positive 4. Comfortable sharing a bathroom with a colleague who is HIV-infected 5. Clients who are sex workers deserve to receive the same level and quality of health care as other clients 6. You avoid touching clients' clothing and belongings known or suspected have HIV for fear of becoming HIV-infected. 7. Most frequent mode of contracting HIV among health care workers is through work-related exposure 8. Most HIV-positive health care workers get infected at work 	<p>Numerator: No. of respondent gave one or more stigmatizing response</p> <p>Denominator: No. of respondents</p> <p><i>Note: Use the following items to calculate each category:</i></p> <p>(a) <i>Are uncomfortable working with and treating PLHA (item 1–6);</i></p> <p>(b) <i>Perceive work-related HIV exposure to be high (item 7–8)</i></p>

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

Level of Recommendation	Indicator (Numerator/Denominator)	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
Expanded	<p>Percent of people working in institutions/facilities (e.g., managers, health care workers) who fear</p> <p>(a) providing invasive medical care on patients with HIV/AIDS and</p> <p>(b) contact with non-blood bodily fluids of patients with HIV/AIDS</p>	<p>In response to the following situations, please indicate if you have fear of HIV transmission, do not have fear of HIV transmission, or do not know if you have fear of HIV transmission:</p> <ol style="list-style-type: none"> 1. Giving an injection to a person living with HIV or AIDS 2. Caring for a person with HIV or AIDS 3. Dressing the wounds of a person living with HIV or AIDS 4. Conducting surgery or suturing on a person with HIV or AIDS 5. Putting a drip in someone who is showing signs of AIDS 6. Touching the sweat of a person with HIV or AIDS 7. Touching the saliva of a person with HIV or AIDS 	<p>Numerator: No. of respondent feared one or more situations</p> <p>Denominator: No. of respondents</p> <p><i>Note: Use the following items to calculate each category:</i></p> <p>(a) providing invasive medical care on PLHA (items 1–5);</p> <p>(b) contact with non-blood bodily fluids of PLHA (items 6–7)</p>
<i>Provider-level: Values, shame, blame</i>			
Essential	<p>Percent of people working in institutions/facilities (e.g., managers, health care workers) who report</p> <p>(a) Judgment</p> <p>(b) Blame</p> <p>(c) Shame</p>	<p>Do you agree or disagree with the following statements:</p> <ol style="list-style-type: none"> 1. HIV is punishment for bad behavior. 2. People with HIV should be ashamed of themselves. 3. HIV is a punishment from God. 4. Promiscuous men are the ones that spread HIV in our community. 5. It is the women prostitutes who spread HIV. 6. I would feel ashamed if I was infected with HIV. 7. I would feel ashamed if someone in my family was infected with HIV. 	<p>Numerator: No. of respondents who agreed with one or more negative statements</p> <p>Denominator: No. of respondents</p> <p><i>Note: Use the following items to calculate each category:</i></p> <p>(a) judgment (items 1–3)</p> <p>(b) blame (items 4–5)</p> <p>(c) shame (items 6–7)</p>

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

Level of Recommendation	Indicator (Numerator/Denominator)	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
<i>Provider-level: Enacted Stigma</i>			
Essential	<p><i>Specific Indicator</i></p> <p>Percent of people in institutions/facilities (e.g., managers, health care workers) who personally know patients who were [fill in type of discrimination] in the past 12 months because they were known or suspected to have HIV/AIDS:</p> <ul style="list-style-type: none"> (a) neglected (b) treated differently (c) denied care (d) verbally abused (e) tested for HIV or had sero-status disclosed without consent <p><i>Aggregate indicator</i></p> <p>Percent of people working in institutions/facilities (e.g., managers, health care workers) who personally know patients who were discriminated against in the past 12 months because they were known or suspected to have HIV/AIDS (composite score of the next indicator).</p>	<p>In the past 12 months, have you seen or observed the following happen in this health facility because a client was known or suspected of having HIV/AIDS?</p> <ol style="list-style-type: none"> 1. Receiving less care/attention than other patients 2. Extra precautions being taken in the sterilization of instruments used on HIV positive patients 3. Requiring some clients to be tested for HIV before scheduling surgery 4. Using latex gloves for performing non-invasive exams on clients suspected of having HIV 5. Because a patient is HIV positive, a senior health care provider pushed the client to a junior provider 6. Testing a client for HIV without their consent 7. Health care providers gossiping about a client's HIV status 	<p>Numerator: No. of respondent observed one or more types of stigma</p> <p>Denominator: No. of respondents</p> <p><i>Note: Use the following items to calculate the categories:</i></p> <ul style="list-style-type: none"> (a) neglected (item 1) (b) treated differently (items 2-4) (c) denied care (item 5) (d) verbally abused (item 6) (e) verbal abuse/gossip (item 7) <p>To calculate the aggregate indicator, create a composite variable from the 7 items and report the percentage of providers observing one or more types of discrimination against PLHA in the past year.</p>

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

Level of Recommendation	Indicator (Numerator/Denominator)	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
<i>Provider-level: Disclosure</i>			
Essential	Percent of people in institutions/facilities (e.g., managers, health care workers) who learned about a patient's HIV status through unofficial channels during the past year	<p>Is there anyone you know in the health facility who has HIV, but has not yet shown signs and symptoms of AIDS?</p> <p>How did you know that he/she has HIV infection?</p> <p>Do you know of a health worker/colleague who has HIV or AIDS?</p> <p>How did you know he/she has HIV or AIDS?</p> <ol style="list-style-type: none"> 1. The infected person told me her/himself 2. Family member of infected person told me 3. Community member told me 4. General gossip/rumors 5. From health care provider where the person tested 6. Read from his/her hospital file 7. Other 	<p>Numerator: No. of respondent who mentioned unofficial channels*</p> <p>Denominator: No. of respondents who knew HIV status of a person in their health facility</p> <p>(*in any way other than via the PLHA themselves or due to medical necessity)</p>
Expanded	Percent of people who think a person should be able to keep their HIV status private	<p>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?</p> <p>If kept secret, why?</p> <p>If let other people now, why?</p>	<p>Numerator: No. of respondents who thought a person's HIV status should be kept secret</p> <p>Denominator: No. of respondents</p> <p><i>Note: It is important to ask the follow-up Why questions to ensure capture of stigmatizing responses.</i></p>

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

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

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

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

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

Level of Recommendation	Indicator	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
<i>PLHA-level: Enacted Stigma</i>			
Essential	Percentage of PLHA who experienced enacted stigma in last year	<p>In the last year, have you [fill in from list below] because of your HIV status?</p> <ol style="list-style-type: none"> 1. Been excluded from a social gathering 2. Been abandoned by your spouse/partner 3. Been isolated in your household 4. No longer visited or visited less by family and friends 5. Been teased, insulted, or sworn at 6. Lost customers to buy produce/goods or lost a job 7. Lost housing or not been able to rent housing 8. Been denied religious rites/services 9. Had property taken away 10. Been gossiped about 11. Lost respect/standing within the family and/or community 12. Been threatened with violence 	<p>Numerator: No. of respondents reporting experiencing at least 1 item</p> <p>Denominator: No. of respondents</p> <p><i>Note: Respondents should only appear once in the numerator, so if they answer Yes to more than one item they are only counted 1 time.</i></p>

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

Level of Recommendation	Indicator	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
Expanded	Percentage of PLHA who experienced enacted stigma in last year	<p>In the last year, have you [fill in from list below] because of your HIV status?</p> <ol style="list-style-type: none"> 1. Been excluded from a social gathering 2. Been abandoned by your spouse/partner 3. Been isolated in your household 4. No longer visited or visited less by family and friends 5. Been teased, insulted, or sworn at 6. Lost customers to buy produce/goods or lost a job 7. Lost housing or not been able to rent housing 8. Been denied religious rites/services 9. Had property taken away 10. Been gossiped about 11. Lost respect/standing within the family and/or community 12. Been threatened with violence 13. Been given poorer quality health services 14. Been physically assaulted 15. Been denied promotion/further training 16. Visitors increased to “check out” how you are doing 17. Abandoned by your family/sent away to the village 	(same as above)

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

Level of Recommendation	Indicator	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
Expanded	Percentage of PLHA who feared enacted stigma in last year	<p>In the last year, have you feared [fill in from list below] because of your HIV status?</p> <ol style="list-style-type: none"> 1. Been excluded from a social gathering 2. Been abandoned by your spouse/partner 3. Been isolated in your household 4. No longer visited or visited less by family and friends 5. Been teased, insulted, or sworn at 6. Lost customers to buy produce/goods or lost a job 7. Lost housing or not been able to rent housing 8. Been denied religious rites/services 9. Had property taken away 10. Been gossiped about 11. Lost respect/standing within the family and/or community 12. Been threatened with violence 13. Been given poorer quality health services 14. Been physically assaulted 15. Been denied promotion/further training 16. Visitors increased to “check out” how you are doing 17. Abandoned by your family/sent away to the village 	(same as above)

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

Level of Recommendation	Indicator	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
Expanded	Percent of PLHA who have been socially isolated in the past 1 year because of HIV status	<p>In the last year, have you [<i>fill in from list below</i>] because of your HIV status?</p> <ol style="list-style-type: none"> 1. Been excluded from a social gathering 2. Been abandoned by your spouse/partner 3. No longer visited or visited less by family and friends 4. Abandoned by your family/sent away to the village 	(same as above)
Expanded	Percent of PLHA who have been physically isolated in the past 1 year because of their HIV status	<p>In the last year, have you [<i>fill in from list below</i>] because of your HIV status?</p> <ol style="list-style-type: none"> 1. Been isolated in your household 2. Been threatened with violence 3. Been physically assaulted 4. Other new item re physical isolation? 	(same as above)
Expanded	Percent of PLHA who have experienced verbal stigma in the past 1 year because of their HIV status	<p>In the last year, have you [<i>fill in from list below</i>] because of your HIV status?</p> <ol style="list-style-type: none"> 1. Been teased, insulted, or sworn at 2. Been gossiped about 3. Visitors increased to “check out” how you are doing 	(same as above)
Expanded	Percent of PLHA who have experienced a negative effect on their identity in the past 1 year because of their HIV status	<p>In the last year, have you [<i>fill in from list below</i>] because of your HIV status?</p> <ol style="list-style-type: none"> 1. Been denied religious rites/services 2. Lost respect/standing within the family and/or community 3. Other new item re: loss of identity? 	(same as above)

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

Level of Recommendation	Indicator	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
Expanded	Percent of PLHA who have lost access to resources in the past 1 year because of HIV status	<p>In the last year, have you [<i>fill in from list below</i>] because of your HIV status?</p> <ol style="list-style-type: none"> 1. Lost customers to buy produce/goods or lost a job 2. Lost housing or not been able to rent housing 3. Had property taken away 4. Been given poorer quality health services 5. Been denied promotion/further training 	(same as above)
Expanded	How many times in X period of time have each type of stigma happened in the past 1 year because of HIV status?	<p>In the last year, have you [<i>fill in from list below</i>] because of your HIV status?</p> <ol style="list-style-type: none"> 1. Been excluded from a social gathering 2. Been abandoned by your spouse/partner 3. Been isolated in your household 4. No longer visited or visited less by family and friends 5. Been teased, insulted, or sworn at 6. Lost customers to buy produce/goods or lost a job 7. Lost housing or not been able to rent housing 8. Been denied religious rites/services 9. Had property taken away 10. Been gossiped about 11. Lost respect/standing within the family and/or community 12. Been threatened with violence 13. Been given poorer quality health services 14. Been physically assaulted 15. Been denied promotion/further training 16. Visitors increased to “check out” how you are doing 17. Abandoned by your family/sent away to the village 	<p>Numerator: No. of respondents who experienced 1 type of stigma</p> <p>Numerator: No. of respondents who experienced 2–3 types of stigma</p> <p>Numerator: No. of respondents who experienced 4–6 types of stigma</p> <p>Numerator: No. of respondents who experienced 7 or more types of stigma</p> <p>Denominator: No. of respondents</p>

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

Level of Recommendation	Indicator	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
Expanded	Frequency with which PLHA experience stigma	<p>In the last year, how often have you [<i>fill in from list below</i>] because of your HIV status?</p> <ol style="list-style-type: none"> 1. Been excluded from a social gathering 2. Been abandoned by your spouse/partner 3. Been isolated in your household 4. No longer visited or visited less by family and friends 5. Been teased, insulted, or sworn at 6. Lost customers to buy produce/goods or lost a job 7. Lost housing or not been able to rent housing 8. Been denied religious rites/services 9. Had property taken away 10. Been gossiped about 11. Lost respect/standing within the family and/or community 12. Been threatened with violence 13. Been given poorer quality health services 14. Been physically assaulted 15. Been denied promotion/further training 16. Visitors increased to “check out” how you are doing 17. Abandoned by your family/sent away to the village 	<p>Response categories:</p> <p><i>Never</i></p> <p><i>Sometimes</i></p> <p><i>Often</i></p>

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

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

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

Level of Recommendation	Indicator	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
<i>PLHA-level: Internal stigma</i>			
Essential	Percent of PLHA who withdraw themselves or abandon life aspirations	<p>In the last [X period], have you ever avoided or withdrawn from [fill in from list below] because of your HIV status?</p> <ol style="list-style-type: none"> 1. Applying for school, further training or a scholarship 2. Promotion or job opportunity 3. Travel 4. Seeking health care 5. Relationships with friends or relatives 6. Having a sexual relationship, getting married, or having a child <p>Why?</p> <p><i>Note: Select only those who report internal stigma (not feeling worthy, pointless, etc.) rather than fear of stigma or other reasons.</i></p>	<p>Numerator: No. of respondents reporting at least 1 item</p> <p>Denominator: No. of respondents</p> <p><i>Note: Respondents should only appear once in the numerator, so if they answer Yes to more than one item they are only counted 1 time.</i></p>
Essential	Percent of PLHA with feelings of shame, guilt, self-blame	<p>In the last year, have you felt [fill in from list below] because of your HIV status:</p> <ol style="list-style-type: none"> 1. shame 2. guilt 3. self-blame 	<p>Numerator: No. of respondents reporting experiencing at least 1 item</p> <p>Denominator: No. of respondents</p> <p><i>Note: Respondents should only appear once in the numerator; if they answer Yes to more than one item, they are only counted 1 time.</i></p>

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

Level of Recommendation	Indicator	Data Collection Questions	How to aggregate to get indicator Numerator/Denominator
<i>PLHA-level: Stigma policy/reduction awareness</i>			
Expanded	Percent of people living with HIV/AIDS who have been referred to places of support for stigma and discrimination	<ol style="list-style-type: none"> 1. During pre or post-test counseling, did you discuss stigma and discrimination? 2. Were you referred to any group or place where you could get support to help you deal with stigma and discrimination? 	<p>Numerator: No. of respondents who reported being referred to an organization</p> <p>Denominator: No. of respondents who discussed stigma during counseling</p>
Expanded (where relevant policies and laws exist)	Percent of persons living with HIV/AIDS aware of anti-discrimination policies and laws	<ol style="list-style-type: none"> 1. Are you aware of any policies dealing with stigma and discrimination? 2. What do they say? (pre-coded responses) 3. Are you aware of any laws dealing with stigma and discrimination? 4. What do they say? (pre-coded responses) 	<p>Numerator: No. of respondents correctly reporting content of laws & policies</p> <p>Denominator: No. of respondents</p>
Expanded	Percent of PLHA who know a source of assistance if stigma is experienced	<ol style="list-style-type: none"> 1. Do you know of any resources, including organizations, where you can get help in using anti-discrimination laws if you experience stigma or discrimination? 2. What resources do you know of or which organizations would you go to for help? 	<p>Numerator: No. of respondents who report at least one place for support coping with stigma and discrimination</p> <p>Denominator: No. of respondents</p>
Expanded	Percent of PLHA who have confronted or challenged someone stigmatizing the respondent	In the last year, have you confronted or challenged someone who was stigmatizing or discriminating against you or another person?	<p>Numerator: No. of respondents who experienced stigma and confronted, educated, or reported (or other response) the person in the last year</p> <p>Denominator: No. of respondents who experienced stigma in the last year</p>