Recommendations

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

Essential-level Indicators

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

6. PEOPLE LIVING WITH HIV/AIDS

Sample

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

Table 41. Background characteristics of PLHA sample

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

Table 41. Background characteristics of PLHA sample (continued)

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

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

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

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

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

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

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

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

SECTION 6.2: ENACTED STIGMA

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

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

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

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

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

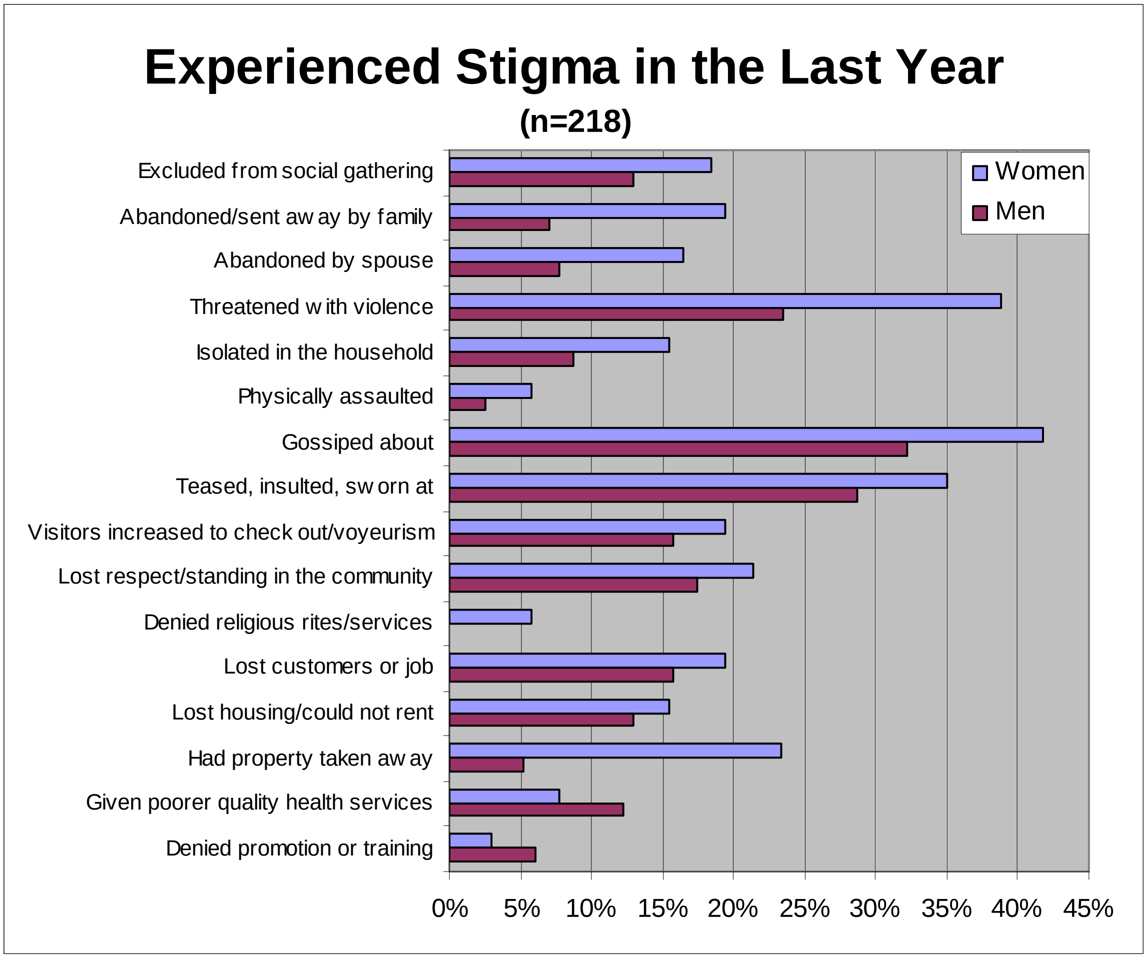
Table 42. Enacted stigma: Existing indicators, items, and frequencies

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

Gender Differences in the Experience of Stigma

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

Figure 1. Percent who experienced stigma in last year



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

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

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

Enacted Stigma Index

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

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

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

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

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

Table 43. Performance of Enacted Stigma Indices

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

Table 43. Performance of Enacted Stigma Indices (continued)

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

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

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

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

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

Toward Reliability: Comparing Similar Questions

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

Isolation

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

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

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

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

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

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

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

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

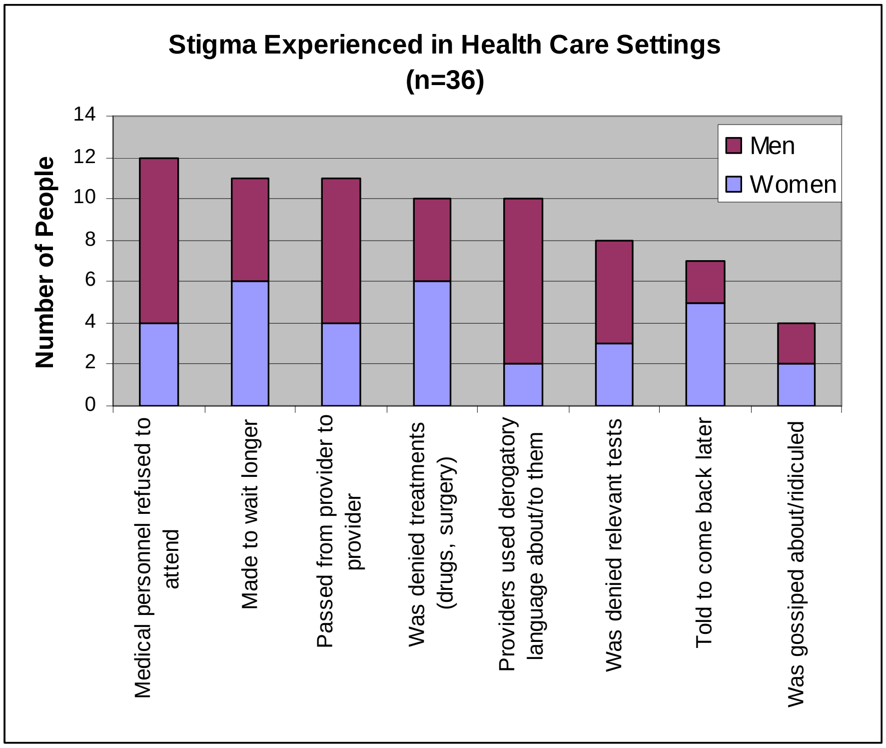
Responses to both prompted and unprompted questions about being abandoned by a spouse or partner were very comparable. These questions may have yielded such consistent data in part because divorce and abandonment are tangible, concrete items. As can be seen in Table 44, the responses about isolation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

Loss of access to resources/livelihoods

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

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

Figure 2. Percent who experienced stigma in health care settings



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

Table 45. Health Care: Frequency comparison of similar questions

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

Recommendations for Measuring Enacted Stigma in PLHA

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

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

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

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

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

SECTION 6.3: DISCLOSURE

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

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

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

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

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

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

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

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

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

Recommendations for Measuring Disclosure among PLHA

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

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

SECTION 6.4: INTERNAL STIGMA

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

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

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

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

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

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

Recommendations for Measuring Internal Stigma Among PLHA

1. We recommend collecting data as an Essential indicator about which specific aspirations are foregone due to one's HIV-positive status. Our question provides several examples. It would be worthwhile separating out these aspirations and asking these, and perhaps others, individually. Suggestions include: sex, marriage, and childbearing; travel; job applications/promotions; education/training; and other goals.
2. We also suggest that it is essential to ask specifically about feelings of self-blame, shame, and guilt and not just "negative feelings." These items are more clearly related to internal stigma, whereas "negative feelings" may be related to a broader issue of quality of life. It is also possible to ask about other feelings of self-hatred and low self-esteem. Some work developing items and scales for measuring self-esteem has been done as a part of quality of life studies, and it may be useful to borrow from this body of work and explore those elements most related to internal stigma. Measuring these items may be accomplished through a question, like the one we used, as to whether or not these feelings were experienced (*Yes*/*No*), or through a Likert-type (attitude-measuring) scale, using response option words such as *a lot*, *somewhat*, and *not at all*.

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

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

SECTION 6.5: AWARENESS OF STIGMA AND POLICY AND LAW

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

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

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

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

Recommendations for Measuring Awareness of Policies and Laws among PLHA

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

7. CONCLUSIONS AND SUMMARY RECOMMENDATIONS

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

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

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