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Subject: Stigma and Discrimination

Posted by [alstangl](#) on Thu, 27 Mar 2014 20:39:08 GMT

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#### RECOMMENDATIONS TO REVISE WORDING OF EXISTING QUESTION:

ICRW, on behalf of the Global Stigma and Discrimination Indicator Working Group (GSDIWG), suggests a slight adaptation to the wording for question 932 in the HIV module. The current version of the question is, 'Would you buy fresh vegetables from a shopkeeper or vendor if you knew that this person had the AIDS virus?' We suggest the following wording for 932:

'Would you buy fresh vegetables from a shopkeeper or vendor if you knew that this person had HIV?' (Yes, No, It depends, Don't know/Not sure)

Rationale for change: Technically, AIDS is not a virus, HIV is. Thus, using the terminology 'AIDS virus' is technically incorrect and could foster confusion and misunderstanding of the difference between HIV and AIDS, resulting in poor quality data. In addition, the term 'AIDS virus' is stigmatizing, as it infers that people living with HIV will all progress to AIDS. The 'AIDS virus' language can also foster stigma by directly linking HIV and AIDS in respondent's minds. Given the negative association of AIDS with a long, debilitating death, the term often inspires fear, which is a key driver of stigma towards people living with HIV. In 2011, UNAIDS recommended that HIV and AIDS not be linked directly and that the term most specific and appropriate to a given situation be used in its Terminology Guidelines (See:

[http://www.unaids.org/en/media/unaids/contentassets/document/s/document/2011/20111009\\_UNAIDS\\_Terminology\\_Guidelines\\_MidtermAdditions\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/document/s/document/2011/20111009_UNAIDS_Terminology_Guidelines_MidtermAdditions_en.pdf)). Moving forward, the outdated 'AIDS virus' terminology should be replaced with 'HIV'.

Note: We strongly recommend the replacement of the 'AIDS virus' phrase with 'HIV' in all other questions where it currently appears in the HIV module, including questions: 902, 903, 904, 905, 906, 907, 914, 915, 916, 921, 922, 924, 926 and 930.

Other information in support of the revised wording of Q 932: The new wording of question 932 was approved by the UNAIDS Monitoring and Evaluation Reference Group in December 2013. Responses to question 932 and a new question proposed below will be used to construct a new indicator assessing discriminatory attitudes. This indicator has been added to the core set of indicators for Global AIDS Response Progress Reporting and all UN member countries will need to report it beginning in 2014. The discriminatory attitudes indicator will also be included in the annual Human Rights Report prepared by the US State Department beginning in 2014.

#### RECOMMENDATIONS FOR DELETING QUESTIONS:

Question 933, asking whether a respondent would prefer to keep a family's member's HIV status a secret, was determined to be an unreliable and invalid measure based on the field test. The question is not capturing what was originally intended (e.g. in many cases, people disagreeing with this statement are doing so to 'protect other members of the community from infection', as opposed to 'supporting their family members to be open about their status'), thus previous data collected using this question should not be used as a measure of HIV stigma in analyses, nor should it be included in the construction of the previously termed 'accepting attitudes' indicator.

Question 934 asking about willingness to care for a relative with HIV, was also determined to be

an unreliable measure, as men and women understand the term 'care for' differently. For men, 'care' is often viewed as providing financial support for clinic visits, medicines, etc. Whereas for women, 'care' is typically defined as having direct contact with ill family members (e.g. feeding, changing soiled sheets/clothing, cooking for, etc.) Given the different interpretations of this question by gender, data from this question are not useful for comparisons across gender. Also, given the increase in access to ARVs, it is less common to have relatives dying of AIDS in the household.

Question 935, asking whether teachers living with HIV should be allowed to continue teaching, had near universal agreement in the Rwanda pilot and many other DHS surveys for other African countries. It is therefore no longer a good measure of change in attitudes over time.

In addition, we propose that question 908 be removed. Question 908 is supposed to be a measure of in-depth knowledge of PMTCT. The GSDIWG attempted to use this question as a construct validity variable in the analyses of the new stigma indicators. Whereas individuals with correct knowledge typically hold less stigmatizing attitudes, this association was not observed consistently across the different stigma measures assessed. This was in contrast to the association between correct knowledge and less stigmatizing attitudes observed for all of the other knowledge questions (questions 902-907), indicating that question 908 is likely not a good measure of in-depth knowledge of HIV as originally intended. In addition, question 910 already provides an assessment of in-depth knowledge of PMTCT, so question 908 is not needed.

#### RECOMMENDATIONS TO ADD NEW QUESTIONS:

ICRW on behalf of the GSDIWG, proposes 6 new questions to assess the key drivers and manifestations of stigma. These questions are the end result of a 3-year collaborative process supported by UNAIDS to develop and test new measures of stigma and discrimination for global reporting and to inform programmatic and policy efforts. The questions were developed and tested by a 16-member working group that was geographically diverse and had representation of affected communities, researchers and program implementers. All of the proposed questions were field-tested in a two-step process: cognitive interviews and a nationally representative pilot survey similar to a Demographic and Health Survey in Rwanda between June and August 2011. The goal of the field testing was to assess the reliability and validity of the measures prioritized by the GSDIWG.

The initial step in the field testing process was to pretest proposed survey questions using cognitive interviewing, a method that helps to reduce the risk of measurement error and allows researchers to identify and correct challenges in interpretation and comprehension of survey questions. Analysis of cognitive interviews with 24 people in Kigali, Rwanda in April 2011 confirmed that the 6 proposed questions assessed what the GSDIWG intended and were easily understood by respondents. 4,669 respondents aged 15 or older were available for inclusion in the analyses.

The question wording, details and rationale for the proposed additions are as follows:

1) DO YOU THINK CHILDREN LIVING WITH HIV SHOULD BE ABLE TO ATTEND SCHOOL WITH CHILDREN WHO ARE HIV NEGATIVE? (YES; NO; IT DEPENDS; DON'T KNOW/NOT SURE)

ICRW, on behalf of the GSDIWG, recommends the addition of 1 new question to assess

discriminatory attitudes.

a. What is the information needed?

A measure of progress towards reducing discriminatory attitudes, and support for discriminatory policies.

b. What questions will elicit this information?

New question: Do you think children living with HIV should be able to attend school with children who are HIV negative? (Yes; No; It depends; Don't know/not sure)

This question was field-tested in a nationally representative pilot survey similar to a DHS in Rwanda between June and August 2011. The goal of the field testing was to assess the reliability and validity of new measures of HIV-related stigma and discrimination developed by the GSIDIWG. Analysis of the cognitive interview data confirmed that the questions on buying vegetables from PLHIV and on allowing children with HIV to go to school were easily understood by respondents, and analysis of the field-tested measures demonstrated the reliability and validity of both of these questions.

c. How will the resulting information be used?

Discrimination is a human rights violation and is prohibited by international human rights law and most national constitutions. Discrimination in the context of HIV refers to unfair or unjust treatment (an act or an omission) of an individual based on his or her real or perceived HIV status. Discrimination exacerbates risks and deprives people of their rights and entitlements, fuelling the HIV epidemic.

This question, combined with question 932 (discussed above) will be used to construct an indicator of discriminatory attitudes, which may result in discriminatory actions, for global reporting in the GARPR. One item in this indicator measures the potential support by the respondents for discrimination that takes place at an institution while the other measures social distancing or behavioural expressions of prejudice. The composite indicator can be monitored as a measure of a key manifestation of HIV-related stigma and the potential for HIV-related discrimination within the general population. This indicator could provide further understanding and improve interventions in the area of HIV discrimination by: (1) showing change over time in the percentage of people with discriminatory attitudes, (2) allowing comparisons between national, provincial, state and more local administrations, and (3) pointing to priority areas for action.

Numerator: Number of respondents (aged 15-49 years) who respond "No" or "It depends" to any of the two questions.

Denominator: Number of all respondents aged 15-49 years who have heard of HIV

Calculation: Numerator / Denominator

Method of Measurement: Population-based surveys (Demographic and Health Survey, AIDS Indicator Survey, Multiple Indicator Cluster Survey or other representative survey)

This indicator is constructed from responses of respondents in a general population survey who have heard of HIV to the following set of prompted questions:

- Would you buy fresh vegetables from a shopkeeper or vendor if you knew that this person had HIV? (Yes; No; It depends; Don't know/ Not sure)
- Do you think children living with HIV should be able to attend school with children who are HIV negative? (Yes; No; It depends; Don't know/ Not sure)

Measurement Frequency: Every 3-5 years

Disaggregation: Responses for each of the individual questions (based on the same denominator) are required as well as the consolidated response for the composite indicator.

#### Explanation of Numerator

Those who have never heard of HIV and AIDS should be excluded from the numerator and denominator. Participants who respond "Don't Know/Not sure" and those who refuse to answer should also be excluded from the analyses.

d. What is the priority of suggested additions compared with what is already in the questionnaires?

Based on the results of the Rwanda field test, the GSDIWG recommends the removal of 3 of the 4 questions that have been used to assess discriminatory attitudes in past Demographic and Health Surveys, including questions 933, 934 and 935. The GSDIWG also recommends the removal of question 908 (see above for rationale).

e. If suggesting more than one addition, what is the priority among the suggested additions?

The new question is a high priority as countries will need data from this question to construct the core GARPR indicator on discriminatory attitudes.

f. Should the additional data be collected in all countries, or only in selected types of countries (e.g., countries with a particular type of program, countries with prevalence of a particular infection >5% or 10%)?

The new measure is applicable in both high and low HIV prevalence settings, in both high and low income countries, and are relevant across a wide cultural range.

2) DO YOU FEAR THAT YOU COULD CONTRACT HIV IF YOU COME INTO CONTACT WITH THE SALIVA OF A PERSON LIVING WITH HIV? (YES; NO; DON'T KNOW/NOT SURE; NOT APPLICABLE)

a. What is the information needed?

A measure of progress towards reducing fear of HIV transmission through casual contact with a person living with HIV, a key driver of HIV-related stigma.

b. What questions will elicit this information?

Do you fear that you could contract HIV if you come into contact with the saliva of a person living with HIV? (Yes; No; Don't know/Not sure; Not applicable)

In the Rwanda field test, fear of HIV infection through casual (non-invasive) contact with a person living with HIV was assessed with two questions, that is, respondents were asked if they feared contracting HIV from contact with the sweat of a PLHIV and the saliva of a PLHIV. Analysis of cognitive interviews with 24 people in Kigali confirmed that the questions assessing individuals' fear of infection were easily understood by respondents and were capturing what was intended.

4,669 respondents aged 15 or older were available for inclusion in the analyses. Compared to women, a higher proportion of men reported fear of infection through casual contact with a PLHIV. 23% and 19% of women feared contact with saliva and sweat, respectively. Whereas 29% of men feared contact with saliva and 25% of men feared contact with sweat. For both questions, significant associations in the expected direction were observed for all of the socio-demographic and construct validity variables, regardless of gender. For example, older respondents and those

with less education, less wealth, incomplete knowledge and those who never tested for HIV expressed more fear.

The fear questions asking about contact with the sweat and saliva of PLHIV were highly correlated (0.67). Therefore, the GSDIWG recommended that only the saliva question be asked in future population-based surveys, as agreement was higher allowing more room to assess change over time. Both variables were valid based on the construct validity assessments.

c. How will the resulting information be used?

Fear of infection has been identified as an important driver of HIV-related stigma in a number of settings. Contact with saliva has consistently been found to be a source of fear among the general population in multiple contexts (e.g. previous ICRW studies in Tanzania (2005) and Vietnam (2009), among others). This fear persists in many contexts, even when HIV knowledge is relatively high. The persistence of this unjustified fear of contact with saliva continues to drive the stigmatization process, and manifests in avoidance behaviours, such as not wanting to share meals, or having separate dishes and cutlery for people living with HIV within the household. These actions can then foster internalised stigma and feelings of shame among people living with HIV, which have been linked with poor adherence to treatment and engagement in HIV care and support services.

This indicator measures the irrational fear of contracting HIV through casual, or non-invasive, contact with a person living with HIV; it focuses on the root cause of the fear (i.e. fear of saliva) that many people attach to ubiquitous actions (i.e. sharing utensils or a glass of water, sneezing, and kissing) conducted with or in the presence of people living with HIV. Assessing the underlying fear of saliva is more useful than assessing situations in which people may fear infection, because these situations vary across settings, making comparisons difficult. This indicator can be used to assess the impact of programmatic interventions that attempt to increase knowledge of how HIV is and is not transmitted and to reduce stigmatizing and discriminatory behaviors due to fear. The indicator can also be used to measure progress over time and influence programming and funding decisions. This indicator should be measured alongside the GARPR indicator on correct knowledge of HIV transmission, as the knowledge indicator includes a measure of myth rejection related to HIV transmission (Can a person get HIV by sharing food with someone who is infected?).

Numerator: Number of respondents (aged 15-49 years) who respond "Yes" to the question

Denominator: Number of all respondents aged 15-49 years who have heard of HIV

Calculation: Numerator / Denominator

Method of Measurement: Population-based surveys (Demographic and Health Survey, AIDS Indicator Survey, Multiple Indicator Cluster Survey or other representative survey)

This indicator is constructed from responses of respondents in a general population survey who have heard of HIV to the following prompted question:

- Do you fear that you could contract HIV if you come into contact with the saliva of a person living with HIV? (Yes; No; Don't know/Not sure; Not applicable)

Measurement Frequency: Every 3-5 years

Disaggregation: The indicator should be reported broken down by:

Sex: Male; Female

Age group: 15-19 years; 20-24 years; 25-49 years

## Explanation of Numerator

Those who have never heard of HIV and AIDS should be excluded from the numerator and denominator. Participants who respond "Don't Know/Not sure" and those who refuse to answer should also be excluded from the analyses. Participants who respond "Not Applicable" should also be excluded from analyses, as they may be living with HIV and thus would not fear infection.

d. What is the priority of suggested additions compared with what is already in the questionnaires?

The proposed addition would replace one of the 3 questions being proposed for deletion. As noted above, the GSDIWG proposes that Questions 933, 934 and 935 be removed and replaced with the new questions. In addition, we propose that question 908 be removed (see above).

e. If suggesting more than one addition, what is the priority among the suggested additions?

As the proposed fear question would be the only question in the HIV module that could assess a key driver of the stigmatization process, the GSDIWG places a high priority on this addition. Also, the indicator constructed from this question was recently approved by the UNAIDS MERG and has been included in the Global Indicator Registry. UNAIDS is recommending that countries collect this important information to inform evidence-based programmatic responses.

f. Should the additional data be collected in all countries, or only in selected types of countries (e.g., countries with a particular type of program, countries with prevalence of a particular infection >5% or 10%)?

This measure is applicable in both high and low HIV prevalence settings, in both high and low income countries, and is relevant across a wide cultural range.

3) IN YOUR OPINION, ARE PEOPLE HESITANT TO TAKE AN HIV TEST DUE TO FEAR OF PEOPLE'S REACTION IF THE TEST RESULT IS POSITIVE FOR HIV? (YES; NO; IT DEPENDS; DON'T KNOW/NOT SURE)

a. What is the information needed?

A measure of progress towards reducing a common manifestation of HIV-related stigma that may interfere with HIV prevention, care and treatment efforts- the anticipated impact of stigma on the uptake of HIV testing.

b. What questions will elicit this information?

In your opinion, are people hesitant to take an HIV test due to fear of people's reaction if the test result is positive for HIV? (Yes; No; It depends; Don't know/ Not sure)

Analysis of the cognitive interview data confirmed that this question on anticipated stigma was easily understood and provided feedback that resulted in reformulation. The question was originally framed as asking whether respondents had personally hesitated to test for HIV- this appeared to be difficult to answer for those respondents who revealed that they were living with HIV, as well as for those who had never contemplated having an HIV test. This resulted in the re-framing of the question to a hypothetical effect of HIV stigma on decisions to test for HIV for the survey field-testing. Analysis of the field-tested measure demonstrated the reliability and validity of this question on anticipated stigma.

c. How will the resulting information be used?

This is one of four questions in a proposed composite indicator measuring the negative influence of HIV-related stigma in the population- a sound indicator, recently approved by the UNAIDS MERG, of the existence of stigma manifestations that may interfere with HIV prevention, care and treatment efforts. The indicator includes a measure of the anticipated impact of stigma on the uptake of HIV testing, two measures of perceived stigma within the community and one measure of personal feelings of shame associated with HIV infection.

The indicator could provide further understanding and improve interventions in the area of reducing stigma by: (1) showing change over time in the level of stigma manifestations that may interfere with HIV prevention, care and treatment efforts, (2) allowing comparisons between national, provincial, state and more local administrations, and (3) pointing to priority areas for action.

Numerator: Number of respondents (aged 15-49 years) who respond in the affirmative (Yes/Agree/It depends) to at least one of the four questions.

Denominator: Number of all respondents aged 15-49 years who have heard of HIV

Calculation: Numerator / Denominator

Method of Measurement: Population-based surveys (Demographic and Health Survey, AIDS Indicator Survey, Multiple Indicator Cluster Survey or other representative survey)

This indicator is constructed from responses of respondents in a general population survey who have heard of HIV to the following set of prompted questions:

- In your opinion, are people hesitant to take an HIV test due to fear of people's reaction if the test result is positive for HIV? (Yes; No; Don't Know/Not Sure)
- Do people talk badly about people living with or thought to be living with HIV? (Yes; No; It Depends; Don't Know/Not Sure)
- Do people living with or thought to be living with HIV lose respect or standing? (Yes; No; It Depends; Don't Know/Not Sure)
- Do you agree or disagree with the following statement: I would be ashamed if someone in my family had HIV (Agree; Disagree; Don't Know/No Opinion)

Measurement Frequency: Every 3-5 years

Disaggregation: Responses for each of the individual questions (based on the same denominator) are required as well as the consolidated response for the composite indicator.

Individual questions and composite indicator should be reported broken down by:

Sex: Male; Female

Age group: 15-19 years; 20-24 years; 25-49 years

#### Explanation of Numerator

Those who have never heard of HIV and AIDS should be excluded from the numerator and denominator. Participants who respond "Don't Know/Not sure" and those who refuse to answer any of the four questions should also be excluded from the analyses.

This measure captures a key dimension of stigma that is relevant at program, national and global levels. Understanding the level of social hostility faced by PLHIV is important to understanding the behaviors of PLHIV and those at risk of contracting HIV. Data collected on this indicator will provide policymakers at both the global and national levels with a clearer indication of the level

and importance of key manifestations of stigma in the general population, including anticipated stigma, perceived stigma and shame in a diverse range of settings, thereby assisting in prioritizing efforts to address stigma and combating HIV more effectively.

d. What is the priority of suggested additions compared with what is already in the questionnaires?

The proposed addition would replace one of the 4 questions being proposed for deletion. As noted above, the GSIDIWG proposes that Questions 933, 934 and 935 be removed and replaced with the new questions. In addition, we propose that question 908 be removed (see above).

e. If suggesting more than one addition, what is the priority among the suggested additions?

There are 3 manifestations of stigma that are particularly important to assess among the general population: perceived stigma, anticipated stigma and shame. The proposed question would be the only question in the HIV module that could assess anticipated stigma (i.e. concern about being stigmatized if HIV+, which poses a major barrier to uptake of testing, care and treatment). Also, this question is one of four that is used to calculate an indicator assessing the manifestations of stigma, recently approved by the UNAIDS MERG. The new manifestations indicator has been included in the Global Indicator Registry and UNAIDS is recommending that countries collect this important information to inform evidence-based programmatic responses.

f. Should the additional data be collected in all countries, or only in selected types of countries (e.g., countries with a particular type of program, countries with prevalence of a particular infection >5% or 10%)?

The new measure is applicable in both high and low HIV prevalence settings, in both high and low income countries, and are relevant across a wide cultural range.

4) DO PEOPLE TALK BADLY ABOUT PEOPLE LIVING WITH OR THOUGHT TO BE LIVING WITH HIV? (YES; NO; IT DEPENDS; DON'T KNOW/NOT SURE)

a. What is the information needed?

A measure of progress towards reducing a common manifestation of HIV-related stigma- perceived community stigma.

b. What questions will elicit this information?

Do people talk badly about people living with or thought to be living with HIV? (Yes; No; It Depends; Don't know/Not sure)

c. How will the resulting information be used?

See 3c for further explanation.

d. What is the priority of suggested additions compared with what is already in the questionnaires?

The proposed addition would replace one of the 4 questions being proposed for deletion. As noted above, the GSIDIWG proposes that Questions 933, 934 and 935 be removed and replaced with the new questions. In addition, we propose that question 908 be removed (see above).

e. If suggesting more than one addition, what is the priority among the suggested additions?



There are 3 manifestations of stigma that are particularly important to assess among the general population: perceived stigma, anticipated stigma and shame. The proposed question would be one of two that could assess perceived stigma (the perception of the level of stigma in a community, which influences HIV-related health seeking behavior). We are proposing two questions to assess perceived stigma, as the representatives from affected communities on the GSDIWG specifically noted that loss of respect/standing and being talked badly about were two of the most common and highly damaging manifestations of stigma, based on a large PLHIV consultation and pilot survey of manifestations questions among PLHIV. While we recommend that both questions be included in the revised HIV module, the GSDIWG places higher priority on the 'lose respect and standing' question.

However, this question is one of four that is used to calculate an indicator assessing the manifestations of stigma, recently approved by the UNAIDS MERG. The new manifestations indicator has been included in the Global Indicator Registry and UNAIDS is recommending that countries collect this important information to inform evidence-based programmatic responses. Therefore the GSDIWG places a high priority on the addition of this question.

f. Should the additional data be collected in all countries, or only in selected types of countries (e.g., countries with a particular type of program, countries with prevalence of a particular infection >5% or 10%)?

The new measure is applicable in both high and low HIV prevalence settings, in both high and low income countries, and are relevant across a wide cultural range.

5) DO PEOPLE LIVING WITH OR THOUGHT TO BE LIVING WITH HIV LOSE RESPECT OR STANDING? (YES; NO; IT DEPENDS; DON'T KNOW/NOT SURE)

a. What is the information needed?

A measure of progress towards reducing a common manifestation of HIV-related stigma-perceived community stigma.

b. What questions will elicit this information?

Do people living with or thought to be living with HIV lose respect or standing? (Yes; No; It depends; Don't know/Not sure)

c. How will the resulting information be used?

See 3c for further information.

d. What is the priority of suggested additions compared with what is already in the questionnaires?

The proposed addition would replace one of the 4 questions being proposed for deletion. As noted above, the GSDIWG proposes that Questions 933, 934 and 935 be removed and replaced with the new questions. In addition, we propose that question 908 be removed (see above).

e. If suggesting more than one addition, what is the priority among the suggested additions?

As noted above in 3e, there are 3 manifestations of stigma that are particularly important to assess among the general population: perceived stigma, anticipated stigma and shame. The proposed question would be one of two that could assess perceived stigma (the perception of the

level of stigma in a community, which influences HIV-related health seeking behavior). We are proposing two questions to assess perceived stigma, as the representatives from affected communities on the GSDIWG specifically noted that loss of respect/standing and being talked badly about were two of the most common and highly damaging manifestations of stigma, based on a large PLHIV consultation and pilot survey of manifestations questions among PLHIV. While we recommend that both questions be included in the revised HIV module, the GSDIWG places higher priority on the 'lose respect and standing' question.

In addition, this question is one of four that is used to calculate an indicator assessing the manifestations of stigma, recently approved by the UNAIDS MERG. The new manifestations indicator has been included in the Global Indicator Registry and UNAIDS is recommending that countries collect this important information to inform evidence-based programmatic responses. Therefore the GSDIWG places a high priority on the addition of this question.

f. Should the additional data be collected in all countries, or only in selected types of countries (e.g., countries with a particular type of program, countries with prevalence of a particular infection >5% or 10%)?

The new measure is applicable in both high and low HIV prevalence settings, in both high and low income countries, and are relevant across a wide cultural range.

6) DO YOU AGREE OR DISAGREE WITH THE FOLLOWING STATEMENT: I WOULD BE ASHAMED IF SOMEONE IN MY FAMILY HAD HIV (AGREE; DISAGREE; DON'T KNOW/NO OPINION)

a. What is the information needed?

A measure of progress towards reducing a common manifestation of HIV-related stigma- shame.

2b What questions will elicit this information?

Do you agree or disagree with the following statement: I would be ashamed if someone in my family had HIV (Agree; Disagree; Don't know/No opinion)

c. How will the resulting information be used?

See 3c for further information.

d. What is the priority of suggested additions compared with what is already in the questionnaires?

The proposed addition would replace one of the 4 questions being proposed for deletion. As noted above, the GSDIWG proposes that Questions 933, 934 and 935 be removed and replaced with the new questions. In addition, we propose that question 908 be removed (see above).

e. If suggesting more than one addition, what is the priority among the suggested additions?

As noted above in 3e, there are 3 manifestations of stigma that are particularly important to assess among the general population: perceived stigma, anticipated stigma and shame. The proposed question would be the only one in the HIV module that could assess shame. Also, this question is one of four that is used to calculate an indicator assessing the manifestations of stigma, recently approved by the UNAIDS MERG. The new manifestations indicator has been included in the Global Indicator Registry and UNAIDS is recommending that countries collect this important information to inform evidence-based programmatic responses.

f. Should the additional data be collected in all countries, or only in selected types of countries (e.g., countries with a particular type of program, countries with prevalence of a particular infection >5% or 10%)?

The new measure is applicable in both high and low HIV prevalence settings, in both high and low income countries, and are relevant across a wide cultural range.

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## File Attachments

- 1) [8 1 Discriminatory Attitudes Indicator definition\\_from\\_GARPR\\_2014\\_2013\\_12\\_06.docx](#), downloaded 771 times
  - 2) [Indicator definition\\_fear of HIV infection.docx](#), downloaded 785 times
  - 3) [Indicator definition\\_negative manifestations stigma.docx](#), downloaded 770 times
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**Subject: Re: Stigma and Discrimination**

Posted by [UNAIDS\\_RAL](#) on Wed, 02 Apr 2014 17:09:13 GMT

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On behalf of the Human Rights Division of the Rights, Community, Gender and Prevention Department, UNAIDS Secretariat, we would like to support the recommendations submitted by the ICRW on behalf of the Global Stigma and Discrimination Working Group.

The new questions suggested as well as the minor adaptation of Q932 in the HIV module, are used to construct indicators measuring stigma and discrimination, that have been developed through a participatory and rigorous process initiated in 2009, and galvanized by the Political Declaration on HIV and AIDS adopted by the UN General Assembly in 2011 (available at [http://www.unaids.org/en/media/unaids/contentassets/document/s/document/2011/06/20110610\\_un\\_a-res-65-277\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/document/s/document/2011/06/20110610_un_a-res-65-277_en.pdf)), which explicitly endorsed elimination of stigma and discrimination as a key focus of the response to HIV (para 77-80). These commitments have translated into targets on reducing stigma and discrimination included in many HIV national strategic plans. UNAIDS Strategy also has as one of its pillars the aspirational Goal of Zero Discrimination. Indicators allowing to track progress towards achieving these results are imperative.

The process to develop these indicators on drivers and manifestations of stigma, and discriminatory attitudes in the general population, was envisioned and led by GNP+, ICRW, IPPF, Johns Hopkins School of Public Health, HPP and UNAIDS. As part of the process that has lasted throughout more than 4 years, an expert meeting and 2 stakeholder consultations were held, extensive work was carried out virtually, leading to over 1,000 questions on S&D across 3 populations reviewed, and 8 questions being finalized and field tested in Rwanda in 2011, in a Survey similar to a DHS with over 4000 respondents.

Seven of these questions were used to construct 3 indicators, submitted to the MERG Indicator

Review Panel in 2013. Following a comprehensive review of these indicators, it has been recommended that one is included in the core GARPR indicators, and 2 more indicators are included in the Indicator Registry (available at <http://www.indicatorregistry.org/?q=taxonomy/term/677>), with the recommendation that data be collected and submitted to authors for finalization of indicators. In order to ensure that this very important data is collected, we recommend that questions are included in the DHS questionnaire, as described by the ICRW.

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Subject: Re: Stigma and Discrimination  
Posted by [poteattc](#) on Fri, 04 Apr 2014 04:32:35 GMT  
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The Office of the U.S. Global AIDS Coordinator strongly supports the changes recommended by IRCW.

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