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Subject: Suggested questions for HIV module  
Posted by [alstangl](#) on Thu, 14 Mar 2019 18:55:21 GMT  
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Researchers and policy makers alike agree that it is important to assess HIV stigma to ensure that national governments can appropriately address this structural driver of HIV. The DHS currently has 7 questions asked of people who have heard of HIV in the standard module, 6 of which were added to the survey in 2015. These questions assess fear of HIV infection, anticipated stigma, perceived stigma and discriminatory attitudes. As members of the Global Stigma and Discrimination Working Group that suggested these questions, we do not recommend any changes to these 7 questions at this time. It would be prudent to collect these measures for another 5-year period to allow time for cross-country analyses to determine if the items remain valid, reliable and useful.

We would like to recommend that new questions be added to capture internalized and experienced stigma among people living with HIV. As a co-investigator of the stigma ancillary study nested within the HPTN 071 PopART trial, Dr. Stangl and colleagues developed a series parallel measures to capture stigma among three populations: people living with HIV (PLHIV), community members and health workers. These questions were based on the 7 DHS stigma questions, as well as the PLHIV Stigma Index Survey 2.0 (GNP+, 2018) and a global tool to assess stigma in health care facilities (Nyblade et al 2013). We found the measures to be valid and reliable (publication under review). We also found that it was feasible to ask members of the general population who were being recruited for the study to share their HIV status, and if positive, respond to a brief set of measures assessing internalized and experienced stigma. For example at baseline, of the 38,961 participants enrolled in the Population Cohort in South Africa and Zambia, 4,225 self-reported that they were living with HIV and 4,073 of these participants has a lab confirmed HIV positive test result. We did not experience any negative repercussions by asking about HIV status. It would greatly advance our understanding of the prevalence of stigma internalized and experienced by PLHIV if we were able to collect measures of stigma in a population-based, random survey such as the DHS. Currently, these measures are typically collected in small studies or studies that use convenience or snowball sampling, and are therefore subject to bias and not necessarily representative of PLHIV more broadly.

Here are the questions that we recommend adding that were used in the HPTN 071 PopART stigma sub-study. While two of these questions were formulated for a 4- point likert scale (i.e. internalized stigma items), we have suggested using a dichotomous response category for the DHS. We would recommend adding the HIV status screening question directly before the current stigma questions, such that anyone who self-reports that they are living with HIV would be skipped from the general population measures and only be asked the items about internalized and experienced stigma. Hopefully, this would eliminate any time burden by adding the proposed questions.

#### Screening questions

[For those who respond that they have tested for HIV]

If you feel comfortable, would you mind telling me what the result of your last HIV test was? or the last test from which you received results? (HIV-negative; HIV-positive; Not comfortable/Don't know)

Have you disclosed your HIV status to anyone, except to me for the purpose of this study?  
(Yes;No)

### Internalized stigma

I would now like to ask you a few questions about your experiences living with HIV. Please remember this interview and your responses are private and confidential. Do you have any questions before we begin? Please tell me whether you agree or disagree with the following statements. (Response categories: Agree; Disagree)

I have felt ashamed because of my HIV status (Strongly agree; Agree; Disagree; Strongly Disagree)

I think less of myself because of my HIV status (Strongly agree; Agree; Disagree; Strongly Disagree)

### Experienced stigma

Please tell us how often the following things have happened to you, or whether you think they have happened to you, because of your HIV status in the last 12 months? (Response categories: Never; Once; A few times; Often; Not applicable because no-one knows my status)

People have talked badly about me because of my HIV status

Someone else disclosed my HIV status without my permission

I have been verbally insulted, harassed and/or threatened because of my HIV status

I have been physically assaulted because of my HIV status

Healthcare workers talked badly about me because of my HIV status

Healthcare workers verbally abused me (yelled, scolded, name called) because of my HIV status  
(This item is from the PLHIV Stigma Index 2.0; the wording has been changed slightly to match the formatting of and response categories of the PopART questions)

Please feel free to reach out with questions.

Respectfully,  
Anne Stangl (astangl@icrw.org)  
Laura Nyblade (lnyblade@rti.org)

Subject: Re: Suggested questions for HIV module  
Posted by [mcarras5@jhu.edu](mailto:mcarras5@jhu.edu) on Thu, 14 Mar 2019 19:12:35 GMT  
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I support these suggestions. A population level index on internalized stigma is badly needed to help inform current PEPFAR programs. As we strive to reach 90-90-90 it is of the essence to measure internalized stigma of PLHIV at the population level.

Maria A. Carrasco

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Subject: Re: Suggested questions for HIV module  
Posted by [Lynn Van Lith](#) on Fri, 15 Mar 2019 19:28:01 GMT  
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I concur with the suggested additional stigma-related questions.

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Subject: Re: Suggested questions for HIV module  
Posted by [danzhalim](#) on Fri, 15 Mar 2019 20:20:33 GMT  
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This comment is made on behalf of the Gender Group at The World Bank.

In addition to the proposed suggestions regarding stigma surrounding HIV, we would also like to propose the following question in the Man's Questionnaire:

Do you think husbands can rightfully divorce his wife if the wife is tested positive for HIV?

This question potentially measures the consequence of being found out with HIV.

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Subject: Re: Suggested questions for HIV module  
Posted by [jmturan](#) on Fri, 15 Mar 2019 21:31:38 GMT  
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I support the addition of these items. Assessment of HIV-related stigma is crucial for understanding progress on the 90-90-90 goals, and global efforts to eliminate stigma and discrimination.

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