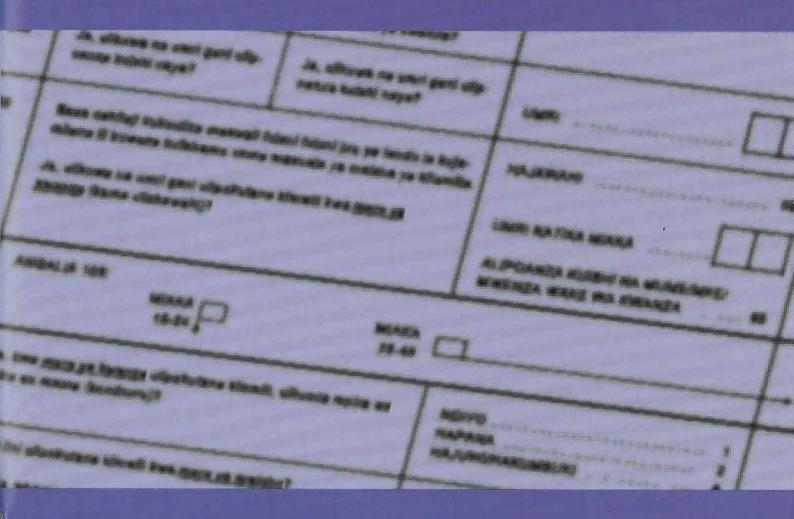


Comprehension of Questions in the Tanzania AIDS Indicator Survey



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PREFACE

This evaluation of several sections of the AIDS Indicator Survey (AIS) questionnaire was undertaken at the request of the USAID Mission in Tanzania as part of the process of preparing a questionnaire for a Demographic and Health Survey in Tanzania. The authors especially thank Said Aboud and Emilian Karugendo of the National Bureau of Statistics for their dedication and the technical skills they brought to the study. The authors also wish to thank the six AIS interviewers for their patience and perseverance during the workshop activities and the testing of the revised questionnaire.

CHAPTER 1 INTRODUCTION

This report documents the process and results of a rapid evaluation of respondents' comprehension of questions they were asked in the Tanzania HIV Indicator Survey (THIS), which was completed in March 2004 by the National Bureau of Statistics (NBS) of Tanzania with technical assistance from ORC Macro. The U.S. Agency for International Development (USAID) Mission in Tanzania requested that this evaluation study include information to guide the formulation of questions about sexual practices and HIV/AIDS in the Demographic and Health Survey (DHS) scheduled for 2004, as well as information on respondents' understanding of AIDS Indicator Survey (AIS) questions for use in future surveys. The area of greatest interest to the Mission was the questions on stigma associated with HIV/AIDS; however, feedback on other sections of the questionnaire was also desired.

Besides providing specific recommendations for the upcoming Tanzania DHS, the findings are relevant to all surveys that include these and similar HIV/AIDS questions. The findings are especially relevant to countries that use the AIDS module from MEASURE DHS (a project of ORC Macro) as part of their standard DHS questionnaire and countries that use the stand-alone AIDS Indicator Survey. Since the THIS was the first AIS questionnaire ever fielded, the findings from the evaluation study contribute to an understanding of how to strengthen, streamline, and improve the efficiency of the AIS questionnaire that will be used to create a baseline of knowledge and practice in the countries participating in the President's Emergency Plan for AIDS Relief (PEPFAR). In some countries, the baseline AIS survey will be followed by an interim survey and a final survey to measure outcomes of HIV/AIDS projects.

The constantly evolving knowledge about HIV/AIDS, coupled with rapid advances and changes in technology, treatment, and programs, requires questionnaires that collect information for evaluating HIV/AIDS programs to be flexible and to reflect the dynamic and changing nature of knowledge and programming in this field. The process of change usually takes place by means of adding new questions, but it should also include reassessment of standard questions. To ensure that timely and valid information for AIDS indicators is collected as cost-efficiently as possible, it is critical that both new and existing questions be assessed from time to time, to find out how questions have been understood by respondents and how the responses are marked. At a minimum, many of the questions in the AIS are either relatively or completely new, so they need to be evaluated to ensure that they are functioning as intended.

The specific objectives of this study were to achieve the following goals:

- 1. Evaluate respondents' understanding of questions related to sexual activity (Qs.309-341) and HIV/AIDS (Qs.501-533) that appear in the THIS.
- 2. Provide recommendations for formulating Swahili questions for the USAID mission in Tanzania to be used in the AIDS module of the Tanzania DHS scheduled for 2004.
- 3. Provide more general recommendations for consideration by DHS for formulating English questions for the AIS and other surveys seeking similar information.
- 4. Develop and document a rapid-evaluation process that is easily replicable and can serve as a basis for a wider evaluation study.

CHAPTER 2 METHODOLOGY

This study sought to determine how respondents understood key questions and concepts related to sexual practices and HIV/AIDS contained in the THIS survey. Although the study is not a validation study in the traditional sense, it does provide information useful for the design of a larger validation study, and it provides a template for a successful process of rapid evaluation that can be used for the pretesting of questionnaires. The research determined how key questions were understood by respondents, compared that understanding with the original intent of the questions, and assessed the extent to which the understanding matched the intent.

In cases where questions were not understood, the basis of misunderstanding was examined. A lack of understanding of a question may come from many sources, such as 1) problems in the translation of terms, 2) questions that were ambiguous in the original English, 3) a misunderstanding of concepts in English, 4) use of terms and concepts unfamiliar to or of little relevance to respondents, or 5) requiring calculations or analyses that are difficult to make in the context of a survey interview. In this report, we make recommendations for modifying the questions to minimize misunderstanding. In some cases, we also recommend making changes in the coding categories.

To strengthen and confirm the conclusions, data were triangulated by means of a three-step data collection process: 1) the observations of field teams conducting interviews; 2) a workshop with interviewers and other key survey staff; and 3) a test of a revised questionnaire that was based on the findings of the first two steps. The overall study was guided by the following research questions.

2.1 Research Questions

1. Are there any differences in the Kiswahili and English questions as formulated? In cases where differences are found, are they of any importance in the interpretation of the results?

This question constituted a quick check on the translation in an attempt to identify the choices that translators made during the translation process. For some questions, the meaning in the original English may have been ambiguous; in such cases, the translators would have made a choice in language that reflected their judgment about the possible meanings. It is instructive to examine translators' options and the rationale for the choices made.

2. Are there problems in understanding some questions?

We assumed that respondents would understand most questions with little difficulty, but we also expected certain questions to pose problems for respondents.

3. Where problems exist, what is the cause of the misunderstanding?

There are many reasons that some questions might not be easily understood. The original English or the Kiswahili may have been ambiguous, or the question may have invoked concepts unfamiliar to the respondents. For example, Q. 317A reads *In this relationship, do you feel you can say* No *to having sex when you do not feel like it?* The term *this relationship* refers to the connection between the respondent and the person with whom the respondent last had sex—an abstract concept—whether that person was a spouse or a casual acquaintance. However, since the concepts in the question derive from American discourse on sexual relations, they may have been understood in ways other than intended. Problematic

expressions include *relationship*, *feel you can say* No, *having sex*, and *when you do not feel like it*. Each of those terms or concepts presents its own challenges for both translation and comprehension.

In examining the possibilities for understanding the questions, we expected to find one of the following results:

- a. The question was understood just as it was intended
- b. The question was understood only partially
- c. The question was heard as quite a different question, and thus the answers obtained relate to another question altogether
- d. The question was not understood at all.

4. How can problematic questions be modified?

Questions can effectively be modified by completing two exercises: 1) accurately identifying the origin of the problem and 2) finding out how interviewers asked the problematic questions in the field so that the questions would be understood.

5. How does the common understanding of a question compare with the intent of researchers?

We assumed that in most cases, the common understanding of a question fits the original intent. For a few questions, it might be necessary to develop a local equivalent to the series of concepts so as to elicit the information sought. In some cases, the way a question was understood differed only a little from what was expected, so that only slight revisions will be needed.

6. Given the local understanding of question X, how should the answers obtained in the survey be interpreted?

This assessment question will be asked only about survey questions that were found to have been understood in an unanticipated way. The presentation of results contains comments about the analysis of certain questions that were (according to the interviewers) widely misunderstood in the survey.

7. How can questions about stigma and discrimination be formulated to fit with the common experiences of discrimination of those with HIV? Or those with AIDS?

This issue received a great deal of attention during the workshop, and changes were suggested for the Tanzania DHS. A separate section of the report is devoted to the challenges of measuring stigma. That section offers solutions and modified questions based on the THIS experience. It presents the experience of the USAID stigma and discrimination indicators working group (S&DIWG) and describes the initial phase of the stigma indicators study being conducted in Tanzania (with support from the S&DIWG) by the International Center for Research on Women (ICRW), Muhimbili University College of the Health Sciences (MUCHS), and the Synergy Project [http://www.synergyaids.com/about.htm].

2.2 Evaluation Activities

To answer the questions above, and to confirm the findings, a three-phase field process was undertaken. It consisted of observation of survey interviews, a workshop with interviewers, and a pilot test of a revised THIS questionnaire.

2.2.1 Observation of Field Teams

Laura Nyblade, who speaks Swahili fluently, spent 3 days in March 2004 observing a field team conducting interviews in three communities in the Dar es Salaam area. She observed a total of 11 interviews, nine with women and two with men. Notes were taken on a) which questions caused difficulties in eliciting useful answers; b) kinds of problems that arose; and c) how the interviewers dealt with the problems. The kinds of problems observed included not only questions that had to be repeated or rephrased before a respondent understood them, but also answers that clearly showed a respondent understanding a question differently from its original intent. Discussions were held with interviewers about the problems they had encountered and solutions that they had used to correct problems with the questions.

2.2.2 Workshop

A 6-day workshop for six interviewers and personnel from National Bureau of Statistics (NBS) was held April 1-6, 2004, at MANTEP in Bagamoyo with four facilitators: Stanley Yoder of ORC Macro, Laura Nyblade of ICRW, and Said Aboud and Emilian Karugendo of NBS. A representative of the Tanzania Commission for AIDS (TACAIDS) and one from the Department of Statistical Methods and Standards of NBS also participated for 2 of the days.

The main objectives of the workshop were to find out which questions presented problems in the field, to discover how those questions had been asked or modified in the field, and to prepare a revised questionnaire based on the fieldwork experience of the previous 4 months. Group discussions focused on the approaches and methods that interviewers had used to deal with problematic questions. Only questions from section three (on sexual activities), section five (on HIV/AIDS and stigma), and section six (on other reproductive-health issues) were considered for revision. Special attention was paid to the questions on AIDS and stigma; three new questions on stigma were formulated for the test.

The facilitators of the workshop started with the assumption that the group should consider three versions of the questionnaire and examine their interrelationships:

- The original English version printed as a questionnaire
- The translation into Swahili printed as a questionnaire
- The way questions were actually asked in the field.

In a series of sequential exercises, the participants cumulatively constructed a knowledge base about the field experience. The first challenge was to help interviewers flag questions that respondents had not easily understood during the survey. The next tasks were 1) to identify the basis of misunderstanding in each case, 2) to isolate the problems inherent in specific questions, and 3) to determine how interviewers had been able to elicit answers by asking these questions in a slightly different way. Once the solutions had been recorded and the results typed up, there was a record of the way questions were actually asked in the field. Both group discussions involving everyone and small group discussions were used to carry out the exercises.

The specific activities of the workshop were as follows:

- Identify sections or questions that proved problematic in the field as judged from the way respondents reacted to the questions asked. On some questions, respondents 1) looked puzzled, 2) said they did not understand, or 3) asked for clarification. Requests for clarification were taken as an indication that respondents might have interpreted a question in a way the authors had not intended. On other survey questions, respondents answered in a way that showed they had not understood what was being asked.
- Consider each question identified as not understood and discuss the origin of the problem. Sometimes the translation was inaccurate or awkward; sometimes a word was not understood. In some cases, the question was simply too long; in other cases, the question was ambiguous in the original English. In the case of several of the questions, respondents did not realize the question was asking only for their opinion rather than for information on what was actually occurring in the community.
- Propose revisions in Swahili derived from the solutions found by interviewers in the field to questions that proved problematic. In most cases, the revisions or modifications involved 1) simplifying the problematic questions, 2) choosing terms that were likely to be more easily understood, and/or 3) rearranging or shortening the clauses of long questions.
- *Translate revised questions into English.* This task was relatively easy. Participants were able to complete it quickly, without referring to the original English.
- Decide which questions merit a revision in the original English. The revised questions in English were compared with the original version to determine whether the questions had been improved. In cases where the new version was simpler, more direct, or more precise than the original, a recommendation was made to modify the original English.
- Consider new stigma questions in Swahili, suitable for asking the general population, that relate to common experiences of stigma in Tanzanian society, and insert them into the questionnaire. The new questions were added near the end of the series of questions on stigma.
- Write up comments on each revised question that address the field experience, the exact change proposed in Swahili, and whether or not the original English should be modified. After the comments were written up by one facilitator (Yoder), they were examined by the other facilitators and the interviewers, who provided written comments about certain questions. The resulting text became the basis of the findings section of this report.

2.3 Pilot Test of Revised Questionnaire

The pilot test was set up to assess the new versions of the questions from the AIS. The revised questions were inserted into the original questionnaire, and the questionnaires were printed. Interviewers then spent 3 days in the field, interviewing and taking notes in the morning, and discussing what had been learned in the afternoons.

The pilot tests were conducted in three clusters in the Dar es Salaam area that were visited during the survey (THIS), but in households that had not been contacted for the survey. One of the supervisors from the THIS accompanied four interviewers to the field with a household listing used to select households to be visited. Each morning 12 interviews were conducted by four interviewers, for a total of 36 interviews.

Each afternoon the team met to discuss their experiences conducting interviews in the morning and to make slight adjustments to questions to be asked the next day.

The pilot test interviews were completed more quickly than those of the THIS survey because the respondents made few comments and asked few questions. The four interviewers agreed that the respondents understood the new questions better than those in the THIS and that the whole process went more smoothly and efficiently. This experience indicates that the correction of most of the questions that were not well understood in the THIS survey was successful. Only a few questions remained problematic.

CHAPTER 3 FINDINGS

This section is composed of two parts. The first part presents the questions from sections three, five, and six of the THIS (Swahili version) that needed amendments, the problems found with those questions, and a recommendation for how to improve the questions in Swahili. Changes are suggested for a few of the English questions. The findings are presented in the same form for each question. That is, for each question that appeared problematic, the text shows the following:

- Original English and original Swahili (translation)
- Experience from the field accounts of interviewers
- Field observation of a THIS team at work
- Changes made to the Swahili question
- Recommendation for changes to Swahili and English.

The experience in the field covered the accounts of problems that interviewers encountered while trying to get respondents to understand certain questions. Field observations came from the interviews that THIS teams observed in the field during the final weeks of the survey. The Changes section shows exactly what changes were made to the Swahili questions and the reasons for those changes. In most cases, the recommended improved Swahili question is presented along with, when needed, recommended changes to the English question. In the case of questions whose answers indicated respondents' understanding differing from what the writers intended, we note the difficulties they present for analyzing and interpreting the data.

The second part of the findings section focuses solely on the issue of HIV-related stigma and the measurement challenges that stigma presents. These challenges include: the difficulties of measuring stigma quantitatively, interviewers' experiences with stigma-related questions in the THIS, possible new stigma-related questions that were developed in the workshop, and a recommended set of indicators. The latter part of the findings section draws on formative research conducted by ICRW and partners¹ as well as on continuing USAID-funded work being done by ICRW, MUCHS, and the Synergy Project to test and validate indicators for stigma and discrimination.

3.1 Section 3 of the THIS Questionnaire

Q. 309

Original English: Now I need to ask you some questions about sexual activity in order to gain a better understanding of some family-life issues. How old were you when you first had sexual intercourse (if ever)?

Original Swahili: Sasa nahitaji kukuuliza maswali fulani fulani juu ya tendo la kujamiiana ili kuweza kufahamu vema masuala ya maisha ya kifamilia. Je, ulikuwa na umri gani ulipokutana kimwili kwa mara ya kwanza (kama ulishawahi)?

¹ Nyblade, L., R. Pande, S. Mathur, K. MacQuarrie, R. Kidd, H. Banteyerga et al. 2003. *Disentangling HIV stigma and AIDS in Ethiopia, Tanzania and Zambia*. Washington, D.C.: International Center for Research on Women.

Field experience: Many respondents thought they were being asked when it was that they had started having sex with their current partner, rather than when they first began having sex. The Swahili translation did not clearly convey the idea of "the [very] first time." Some respondents simply did not know how old they were at their first sexual encounter even if they were able to recall the year or the time; others were unable to remember the first time at all.

Field observations: This question often led to silence or long pauses on the part of the respondent, which in turn led to repetition of the question and then cajoling by the interviewer. For example: Everyone has to remember the first time they had sex, it is such a big event. Even I, such an old lady, remember that first time—It is nothing to be ashamed of; I remember my first time. If the interviewer was able to get a response, it was most often I don't remember [or don't know] how old I was. This response often led to a whole series of questions geared to helping the respondent arrive at an age: Were you still in school? What grade? Was it at a special occasion, or around a big event of some kind? Interestingly, more respondents remembered the year than the age at which they first had sex. Their recollection of the year often instigated a process of trying to figure out how old they were at the time, working backward from the year.

Many respondents initially answered *Don't know* or *I don't remember*, and then only after cajoling and much probing would they give or agree to an age. Therefore, perhaps *Don't know* or *Don't remember* should be added as codes.

The team also observed signs that respondents were not always understanding the expression *the very first time*, and therefore they were not including certain types of sexual activity in their response. For example, if the first time a respondent had sex was as a child, a preadolescent, or even an early teen—either as part of "playing" or "fooling around" to learn about sex—or if the sex was forced, respondents might not count such an experience as the first time they had had sex.

It should be noted that the questionnaire switches back and forth between different Swahili terms for sex. It uses primarily *kufanya ngono*, but occasionally *kujamiana* or *tendo la ndoa*. Most interviewers were reading whichever term was written in the questionnaire and then adding one of the other terms immediately afterward, to clarify or try to make sure the respondent had understood; if the interviewers had to repeat or rephrase the question, they would use a different term for sex than the one in the questionnaire.

Changes: In the original English question, the term "first" was underlined, to remind the interviewer to emphasize to the respondent the importance of thinking back to the first occasion of having had sex. However, underlining an English-equivalent word in Swahili does not necessarily convey the same emphasis as underlining in English. Therefore, we decided to add the word *kabisa* at the end of the question, to emphasize that the question is seeking information about the very first time. Also changed was the word for sex—from *kujamiana* to *kukutana kimwili*—because the latter is a more conversational, comfortable way to talk about the sex act. This change was made throughout the questionnaire to be consistent. Otherwise the Swahili question remains the same. Adding the word *kabisa* makes it clear that the event took place for the very first time in the respondent's life.

Recommendations: Use a revised Swahili question and change the English to approximate the modified Swahili question more closely. We think that this way of asking the question is easier to understand and to translate than underlining the word "first."

Revised Swahili Q. 309:

Sasa nahitaji kukuuliza maswali fulani juu ya tendo la kukutana kimwili ili kuweza kufahamu vema masuala ya maisha ya kifamilia.

Je, ulikuwa na umri gani ulipokutana kimwili kwa mara ya kwanza kabisa?

Revised English Q. 309:

Now I need to ask you some questions about sexual activity in order to get a better understanding of some family life issues. How old were you when you had sex for the very first time?

Q. 311

Original English: The <u>first</u> time you had sexual intercourse, was a condom used?

Original Swahili: Je, kwa <u>mara ya kwanza</u> ulipokutana kimwili, ulitumia mpira wa baba au mama (kondomu)?

Field experience: Interviewers found that respondents did not understand *mpira wa baba au mama* very well, but did understand the word *kondomu*, so the interviewers used the latter. Most people do not know what an *mpira wa mama* (female condom) is. Interviewers said that although men may claim to have used a condom the first time they had had sex, condom use at first intercourse was probably rare, because interviewers believe that men's first sexual experience was likely to have been forced on a girl, and thus no condom would have been used.

Field observations: Interviewers had been saying *kondomu* and then saying *mpira wa baba au mama* (male or female condom). *Kodomu* is a much more commonly used term for condom than *mpira* (rubber).

Changes: The Swahili question was changed to reflect what interviewers actually said. The Swahili was also changed to deal with the problem of asking women whether they had used a condom the last time they had had sex—when it was really the man who used the condom—by asking if either of the partners had used a condom.

Recommendation: The English question should be changed to deal with this problem and to avoid the terms for male and female condom, which many respondents do not understand.

Revised Swahili Q. 311:

Je, kwa mara ya kwanza ulipokutana kimwili, mmoja wenu alitumia kondomu [mpira wa baba au mama]?

Revised English Q. 311:

The first time you had sex, did either of you use a condom [male or female]?

Questions 313, 320, and 327, which ask the same question but ask them about additional partners, produced the same experience in the field as Q. 311 and received the same recommendation and modification. See Appendix A for the actual questions and recommended revised questions.

0.314

Original English: What was your relationship to the person with whom you last had sex?

Original Swahili: Je, ni nini uhusiano wako na mtu uliyekutana naye kimwili kwa mara ya mwisho?

Field experience: The word *uhusiano* (the translation of "relationship" in this question) refers mainly to blood relationships, so people were answering *No relationship*, except that he or she is my fiancée, or my friend, or my live-in partner, etc. Interviewers changed the way they asked the question to make it understood.

Field observations: This question always had to be repeated, and the meaning in this context of the use of the word *uhusiano* ("relationship") had to be explained. One respondent asked specifically: What do you mean by *uhusiano*? *Uhusiano* seems to be the problem word, both here and in the subsequent similar questions about additional partners. The use of the word *uhusiano* appears to make the question unclear. *Uhusiano* is usually used to ask about kinship or familial relationships, so it perplexes Swahili speakers to hear the term used in the context of a sexual partner. Alternatives heard were *ni nani kwako*, *yukoje kwako* (How is this person to you?) and *ukoje na huyu mtu?* (How are you with this person?). The interviewers also reported that they would sometimes say *uhusiano wa kimapenzi* (relationship of lovers), a phrase that helped them clarify the intent of the question for the respondent.

The same issues and observations occur again wherever the word *uhusiano* is used (Qs. 317A, 321, and 328).

Changes: Interviewers used the phrase *ni nani kwako* rather than the word *uhusiano* in an effort to be better understood by respondents.

Recommendation: Use the revised Swahili question; make no changes to the English questionnaire.

Revised Swahili Q. 314:

Je, ni nani kwako mtu uliyekutana naye kimwili kwa mara ya mwisho?

Qs. 321 and **328**, which ask the same question but about additional partners, have the same problems, and the same kind of modification is recommended. The revised Swahili **Q. 321** and **Q. 328** is *Je, mtu huyu ni nani kwako?*

Q. 317

Original English: Do you think he is at least 10 years older than you?

Original Swahili: Je, unafikiri anakuzidi kwa angalau miaka 10? (Do you think he is around 10 years older than you?)

Observation and field experience: There were no problems with the asking of this question, but rather with the content; the Swahili did not convey the meaning of the original English.

Changes: The Swahili translation did not accurately reflect the original English, so it was changed to be faithful to the English question. The original Swahili translates back into English as "Do you think he is around 10 years older than you?"

Recommendation: No changes to the English questionnaire.

Revised Swahili Q. 317:

Je, unafikiri anakuzidi kwa miaka 10 au zaidi?

The question is repeated in asking about additional partners. Therefore, the same modifications need to be made to Qs. 324 and 331. The exact questions are given in Appendix A.

Q. 317A

Original English: In this relationship, do you feel you can say no to having sex when you do not feel like it?

Original Swahili: Katika uhusiano huu, unahisi unaweza kusema hapana kufanya tendo la ngono ikiwa utakuwa hujisikii kufanya?

Field experience: As was the case with **Q. 314**, people understood *uhusiano* as referring to blood relatives. Some respondents may also have been confused by the abstract nature of the question.

Field observations: The same problems with the use of the word *uhusiano* occurred as discussed above. Furthermore, the interviewers had to keep repeating, rephrasing, and explaining the rest of the question, or the part about being able to refuse sex if the respondent did not feel like it. Rephrasing used by interviewers to clarify this part was *una huru kukataa?* (Do you have the freedom to refuse?) If repeating and rephrasing the question turned out to be unsuccessful, interviewers also used explanations to get respondents to understand: *For example, If you're not feeling well—say, you were sick—could you refuse this person sex?* One woman thought that the interviewer was asking about the last time she had had sex (the previous questions, 312–314, are specifically about the last time the respondent had had sex) and answered *No, I wasn't forced the last time I had sex*.

Changes: The question in Swahili was made more concrete by asking about "this person" instead of "this relationship," taking the word *No* out and replacing it by asking, "Can you refuse them sex if you don't feel like it?" The word *ngono* for sex (a less common term than several others) was replaced with the more familiar, more commonly used term *kukutana kimwili*.

Recommendation: Use the revised Swahili questionnaire and change the English question to make it more concrete.

Revised Swahili Q. 317A:

Kama mtu huyu anataka kukutana kimwili na wewe kwa mara nyingine; Je, unaweza kumkatalia ikiwa hujiskii?

(Codes) 1. Anaweza kukataa 2. Hawezi kukataa 3. Hajui

Revised English Q. 317A:

If this person wants to have sex with you again, can you refuse them if you don't feel like it?

(*Codes*) 1. Can refuse 2. Cannot refuse 3. Does not know

Q. 326

Original English: Other than these two people, have you had sex with anyone else in the last 12 months?

Original Swahili: Mbali na hawa watu wawili, je, umeshakutana kimwili na mtu mwingine yeyote katika kipindi cha miezi 12 iliyopita?

Field experience: When respondents were puzzled by the term *mbali ya*, interviewers changed the term to *zaidi ya* and were understood.

Field observations: It would be helpful to stress in this question that we are now asking about yet another partner, one beyond the two already reported on. It was not clear to some respondents that we were now asking about an additional (third) sex partner. Interviewers reported that when a respondent seemed to be confused or continued to report on the same partner, they would repeat the question but say *zaidi ya* to replace the term *mbali na* and add the word *uliyowataja* after *watu wawili*.

Changes: The term *mbali ya* was replaced by *zaidi ya*, and *ulionitajia* was added to be more specific about who was being referred to. The period of "past 12 months" was brought forward in the question, to focus the respondent on the period first, before asking whether the respondent had had sex with anyone else. Specifying the time period first seemed to make questions clearer to respondents.

Recommendation: Use the revised Swahili question, and change the English to make it more precise and more easily understood.

Revised Swahili Q. 326:

Zaidi ya hawa watu wawili ulionitajia; Je, katika kipindi cha miezi 12 iliyopita, umeshakutana kimwili na mtu mwingine yeyote?

Revised English Q. 326:

In addition to these two people you mentioned, in the past 12 months have you had sex with anyone else?

Q. 333

Original English: In total, how many different people have you had sex with in the last 12 months?

Original Swahili: Kwa jumla, ni watu tofauti wangapi umekutana nao kimwili katika miezi 12 iliyopita?

Field experience: Some respondents were confused by this question, thinking it was a question about frequency of sex with their partner. Others were not sure what was meant by the expression *kwa jumla* ("in all") at the beginning of the question. Many people were not sure what was meant by *watu tofauti* ("different people"). Interviewers discovered that it was better to begin the question with the time period, because when the time specification was at the end, respondents were giving the number of partners without limiting themselves to the 12-month period.

Field observations: This question usually led to a little bit of silence, with the interviewer repeating the question and emphasizing the number of <u>different</u> sexual partners during the prior 12 months.

Changes: The question now begins by specifying the time period, drops the term *kwa jumla*, and drops the word *tofauti*.

Recommendation: Adopt the revised Swahili question. Change the English to agree with the Swahili by putting the time period first.

Revised Swahili Q. 333:

Katika kipindi cha miezi 12 iliyopita; Je, ni watu wangapi umekutana nao kimwili?

Revised English Q. 333:

In the past 12 months, with how many people did you have sex?

Q. 334

Original English: In the last 12 months, did you have sex with a prostitute?

Original Swahili: Katika kipindi cha miezi 12 iliyopita, umewahi kukutana kimwili na malaya?

Field experience: The word for "prostitute" in Swahili is *malaya*, a term that is highly pejorative. (Furthermore, prostitution is illegal in Tanzania.) Since few people will admit having gone to visit a *malaya*, the workshop group was unanimous in saying that that question was not a useful one. An earlier DHS in Tanzania had asked about taking money for sex, and the group decided to return to that formulation.

Changes: Two new questions have replaced the one used in the THIS, so that there is now one question for men and another for women. In the THIS, women were not asked about taking money for sex.

Recommendation: Both the Swahili and the English questionnaires should return to the earlier version with its gender-specific subquestions, as presented below.

Revised Swahili and English Q. 334:

MALE:

Katika kipindi cha miezi 12 iliyopita; Je, umewahi kumlipa yeyote kwa ajili ya kukutana naye kimwili?

Did you ever pay anyone for sex during the last 12 months?

FEMALE:

Katika kipindi cha miezi 12 iliyopita; Je, umewahi kulipwa na mwanamme yeyote kwa ajili ya kukutana naye kimwili?

Were you ever paid by a man for sex during the past 12 months?

Q. 334A

Original English: The last time you had sex with a prostitute, did you use a condom?

Original Swahili: Mara ya mwisho ulipo jamiiana na malaya, ulitumia mpira (kondomu)?

Field experience: Same as for Q. 334.

Changes: The word *malaya* is replaced by "that person" (*mtu huyo*), to avoid the use of the term for prostitute.

Recommendation: No changes were recommended by the group, although to be consistent with **Q. 334,** the English should be changed to say "that person" rather than "prostitute." As in the previous questions dealing with condoms, the word *kondomu* is substituted for *mpira*, and the question then becomes, "Did either of you use a condom?" Per **Q. 334,** both men and women would be asked this detail if they answered *Yes* to **Q. 334.**

Revised Swahili Q. 334A:

Kwa mara ya mwisho ulipokutana kimwili na mtu huyo; Je, mmoja wenu alitumia kondomu (mpira wa baba au mama)?

Revised English Q. 334A:

The last time you had sex with that person, did either of you use a condom (male or female)?

Q. 335

Original English: In the past 12 months, has anyone forced you to have sex when you did not want to?

Original Swahili: Katika miezi 12 iliyopita, umewahi kulazimishwa na yeyote kujamiiana naye wakati ambapo wewe hukutaka kujamiiana?

Field experience: This question proved problematic, because women did not think of their husbands when they answered the question, partly because they thought the term *na yeyote* excluded husbands. Many women said, "I don't go outside my husband," meaning "I don't have sex with anyone besides my husband." The original question in Swahili required a great deal of explanation.

Field observations: It is not clear whether the respondent is including the primary partner in answering this question. Interviewers thought probably not, for two reasons: 1) It is considered the husband's right to have sex (even if his wife doesn't want to), so the idea of rape/forced sex existing within marriage is an alien concept and would probably not enter into a married woman's response. This question could be clarified by adding the phrase "including your husband/partner." 2) The use of the word *yeyote* seems to compound the misunderstanding. *Yeyote* in this context seems to imply a man other than one's husband/primary partner. Interviewers noted that some women would ask for clarification, asking, *What if the man didn't succeed, in the end, with the rape? Does that still count?* Two cases were observed in which the respondent asked such questions.

Analysis note: In interpreting these data, note that the usual female respondent is probably not thinking of her husband or primary partner when she hears this question. Therefore, any interpretation of the data should include that caveat. If in fact they did consider a primary partner when answering this question, the number of women who reported having experienced forced sex during the prior 12 months might well be higher than was recorded.

Changes: The term *na yeyote* was dropped, and the phrasing was slightly modified. The sentence in brackets was added to specify that the question does include husbands. The revised question now begins with the time period (12 months), a position that field experience indicates helps respondents understand the question better.

Recommendation: Adopt revised Swahili questions. Change the English question to begin with the time period and to include husbands.

Revised Swahili Q. 335:

Katika kipindi cha miezi 12 iliyopita, umewahi kulazimishwa kukutana kimwili ambapo wakati wewe hukutaka? (Swali linawahusu hata mume wako.)

Revised English Q. 335:

In the past 12 months, have you ever been forced to have sex when you did not want to? (Question includes your husband.)

Q. 336

Original English: In total, how many different people have you had sex with in your lifetime?

Original Swahili: Kwa jumla, ni watu wangapi tofauti tofauti umejamiiana nao katika maisha yako hadi sasa?

Field experience: Many people did not understand this question. First they were confused by the term *kwa jumla*. Then they were not sure what was meant by *tofauti tofauti*. The problem stems partly from a too-literal translation into Swahili.

Field observations: Asking this question often resulted in immediate silence, leading the interviewer to repeat the question, and in some cases, rephrase it. Respondents did not always seem to understand that the question was asking for the *total number* of sexual partners starting with the very first one up until the interview. Some respondents asked, "You want *all*?"

Discussions with the interviewers suggested that the root of the problem might be the time in the respondent's life at which sex began to count or be meaningful. Interviewers reported that some people simply do not count sex as "real" if it happened before adulthood. Thus, acts of sexual intercourse that were part of playing and experimentation before adulthood—whether forced or not—would not be counted.

Changes: The sentence now begins with the time period ("During your lifetime until now"), and the words *tofauti tofauti* were dropped.

Recommendation: Adopt the revised Swahili question. Change the English question to fit the Swahili version.

Revised Swahili Q. 336:

Katika maisha yako hadi sasa; Je, ni watu wangapi umeshakutana nao kimwili?

Revised English Q. 336:

In your entire lifetime, how many people have you had sex with?

Q. 337

Original English: Do you know of a place where a person can get condoms?

Original Swahili: Je, unafahamu mahali ambapo mtu anaweza kupata mpira wa baba au mama (kondomu)?

Field experience: Since condom use in Tanzania is highly stigmatized, the interviewers expected most people to say *No* to this question. Respondents want to avoid admitting that they know of any place where condoms may be obtained, fearing that people around them will assume that their knowing that much about condoms means they have had many sexual partners. Some respondents at first replied, "I don't know, because I don't use them," but when probed, in fact admitted knowing where condoms could be obtained. Therefore, we believe that the answers to this question that are collected from the THIS will not reflect Tanzanian respondents' actual degree of knowledge about where to get condoms.

Field observations: Although this appears to be a straightforward question, it seemed to cause much discomfort, hesitation, and immediate *No* answers, particularly among the younger unmarried respondents. In several interviews, the interviewer quickly added, "I don't want to know if you use them, or even if you don't use them; we just want to know where they can be gotten in this community."

Analysis note: Because of the sensitive nature of this issue and the direct nature of the question asked, many respondents may have answered *No* to it even though they probably did know where to find condoms locally. Therefore, responses to this question are probably an undercount of the true number of people who know where to get condoms.

Changes: First, the question has been changed so that it is no longer personal, to preclude the stigma associated with condom use. Second, the question has been changed from a Yes/No format to directly asking *where* condoms might be obtained, to prevent losing information from respondents who easily say *No* and thus sidestep the question of place. Third, this question (**Q. 337**) has been combined with **Q. 338.** That is, the coded answers now in **Q. 338** have become the answers to **Q. 337**, with the additional code of *Hakuna* ("There is no place").

Recommendation: The English questionnaire should be changed to follow the new formulation in Swahili.

Probe: Ikiwa ni hospitali, kituo cha afya, au kliniki, au sehemu nyingine yoyote. Andika jina la mahali. Dadisi kutambua aina ya umiliki wa mahali hapo kisha zungushia sehemu inayohusika.

Additional Probe: Kuna sehemu nyingine yoyote? (Any other place?)

Revised Swahili Q. 337:

Kama mtu anahitaji kondomu; Je, atapata wapi?

Probe: Kuna sehemu nyingine yoyote?

Revised English Q. 337:

If someone needs a condom, where will they get it?

Probe: Any other place?

3.2 Section 5 of Questionnaire

Q. 502

Original English: Can people reduce their chances of getting the AIDS virus by having just one sex partner, who is not infected and who has no other partners?

Original Swahili: Je, watu wanaweza kupunguza uwezekano wao wa kuambukizwa virusi vya UKIMWI kwa kuwa na mpenzi mmoja ambaye hajaambukizwa na ambaye hana wapenzi wengine?

Field experience: Respondents did not understand this question, partly because it was so long. Quite a few respondents began to answer before the question had been completely posed, after the first clause. People who in Section 3 had stated they had had many sexual partners appeared to be embarrassed by this question, judging from their facial expressions, and they paused for a long time before answering. Others wondered whether they had been selected for this question because they were thought to be HIV positive, since the question came immediately after **Q. 501**, which asked whether they had ever heard of AIDS. Nearly always, the question had to be repeated several times to elicit an answer.

Field observations: The question had to be repeated several times, and several respondents flatly said that they did not understand the question or that they were confused. There seemed to be two problems: the length of the question and its construction. By the time the interviewer has finished reading this question, it seems, the respondent has forgotten the first part of the question, at which point the question no longer makes sense. Interviewers confirmed that observation. There also might be a problem rooted in the reality of daily life, particularly women's lives, for there is no way to be sure that one's partner is faithful or that one's partner is not infected. One woman respondent, for example, first looked puzzled and then answered the question by saying, "You can't know whether or not your partner is being faithful."

Interviewers suggested a slight rewording of part of **Q. 502:** *Mpenzi moja mwaaminifu asieambukizwa* (One faithful partner who is not infected).

Changes: The order of the clauses in the question was rearranged so that the condition being asked about comes first, then the question itself. Interviewers found that this arrangement made the question easier to understand. However, even after it was revised for the pilot test, the question remained difficult for some respondents to understand.

Recommendation: Adopt the revised Swahili question, but work on the question further. No changes should be made to the English question.

Revised Swahili Q. 502:

Kwa kuwa na mpenzi mmoja tu, ambae hajaambukizwa, na hana wapenzi wengine, je, watu wanaweza kupunguza uwezekano wao wa kuambukizwa virusi vya UKIMWI?

O. 503

Original English: Can people get the AIDS virus from mosquito bites?

Original Swahili: Je, watu wanaweza kuambukizwa UKIMWI kwa kuumwa na mbu?

Field experience: Respondents had no problems with this question.

Changes: The words *virusi vya* were added to the Swahili, to more accurately convey the meaning of the question in English as well as what is known biologically.

Recommendations: Adopt slight rewording in the Swahili question. No changes are needed to the English question.

Revised Swahili Q. 503:

Je, watu wanaweza kuambukizwa virusi vya UKIMWI kwa kuumwa wa mbu?

(Can people be infected with the AIDS virus through mosquito bites?)

Q. 504

Original English: Can people reduce their chances of getting the AIDS virus by using a condom every time they have sex?

Original Swahili: Je, watu wanaweza kupunguza uwezekano wa kuambukizwa virusi vya UKIMWI kwa kutumia mpira wa baba au mama kila mara wafanyapo tendo la ngono?

Field experience: The long length of the question in Swahili made it hard for respondents to remember the beginning by the time the interviewers reached the end of asking the question.

Field observations: Same as for **Q. 502.** The question had to be repeated several times, and several respondents simply said they did not understand the question or that they were confused. There seemed to be two problems: the length of the question and its construction. By the time the interviewer finished reading the question, the respondent might have forgotten what the first part of the question was, at which point the question no longer made sense. Interviewers confirmed that observation.

Changes: The order of the clauses was changed so that the condition or situation being described came first, and the question followed. The word *kondomu* replaces *mpira wa baba au mama* (for reasons mentioned earlier). The word *tendo* (act) replaces *mara* (time), so as to emphasize an act more than a time. The word *ngono* for sex is replaced by *kukutana kimwili*, per previous discussion on terms for sex in Swahili.

Recommendation: Adopt the revised Swahili question, and revise the English question to make it more precise.

Revised Swahili Q. 504:

Kwa kutumia kondomu, [mpira wa baba au mama] kwa kila tendo la kukutana kimwili; Je, watu wanaweza kupunguza uwezekano wao wa kuambukizwa virusi vya UKIMWI?

Revised English Q. 504:

By using condoms [male or female] each time they have sex, can people reduce their chances of being infected with the AIDS virus?

O. 505

Original English: Can people get the AIDS virus by sharing food with a person who has AIDS?

Original Swahili: Je, watu wanaweza kuambukizwa virusi vya UKIMWI kwa kula pamoja na mgonjwa wa UKIMWI?

Field experience: No major problems were experienced in asking this question, although some people asked what was meant by "eating together" [kula pamoja].

Field observations: Respondents answered this question easily, but workshop participants wondered how they interpreted "eating together" The section on stigma indicators discusses this topic further.

Analysis note: Because we do not know how respondents understood or interpreted "eating together," it is difficult to know what the answers to this question are measuring.

Changes: To reduce the ambiguity in the question, replace the term *pamoja* (together) with the words *kwenye sahani moja* (from one plate).

Recommendation: Adopt the revised Swahili question. Change the English question to make it unambiguous (the meaning of "sharing food" should be made explicit).

Revised Swahili Q. 505:

Je, watu wanaweza kuambukizwa virusi vya UKIMWI kwa kula kwenye sahani moja na mgonjwa wa UKIMWI?

Revised English Q. 505:

Can people be infected with the AIDS virus by eating from the same plate as someone who is sick with AIDS?

Q. 506

Original English: Can people reduce their chance of getting the AIDS virus by not having sex at all?

Original Swahili: Je, watu wanaweza kupunguza uwezekano wa kuambukizwa virusi vya UKIMWI kwa kutofanya tendo la ngono kabisa?

Field experience: The phrasing *kutofanya tendo la ngono kabisa* was poorly understood. Some people said they could not imagine not engaging in sex, so they had trouble answering the question.

Field observations: Same as **Qs. 502** and **504.** The question had to be repeated several times, and several respondents said they did not understand the question or were confused. There seemed to be two problems with this question: its length and its construction. This is another example of the difficulties of a long question. By the time the interviewer had finished reading the question, it seems, the respondent had forgotten what the first part of the question was. Interviewers confirmed this observation. As with **Q. 502,** respondents also seemed to find it difficult to understand the question because the notion of giving up having sex was inconceivable to them. One woman answered this question by saying, "We Swahili, it is not possible for us to stop sex completely." Rewording suggested by interviewers: *Je, kwa kutofanya tendo la ndoa, mtu anaweza kupunguza uwezekano wa kuambukizwa virusi vya UKIMWI?* (By stopping sex completely, can a person reduce their risk of being infected with the AIDS virus?)

Changes: The order of the phrasing of the question was changed to present the condition to be imagined—*kuacha kabisa kukutana kimwili*—before asking the question. As per earlier discussion, the term *ngono* was replaced by *kukutana kimwili*.

Recommendation: Adopt the revised Swahili question and revise the English question to convey the action of stopping sex altogether. The English question assumes that people are having sex, since respondents are asked to consider what they could do in order to reduce their chances of infection.

Revised Swahili Q. 506:

Kwa kuacha kabisa kukutana kimwili; Je, watu wanaweza kupunguza uwezekano wa kuambukizwa virusi vya UKIMWI?

Revised English Q. 506:

Can people reduce their chances of being infected with the AIDS virus if they stop having sex altogether?

Q. 508

Original English: Is there anything (else) a person can do to avoid or reduce the chances of getting AIDS or the virus that causes AIDS?

Original Swahili: Je, kuna kitu chochote kile ambacho mtu anaweza kufanya ili kuepuka au kupunguza uwezekano wa kupata UKIMWI au virusi vinavyosababisha UKIMWI?

Field experience: The response of "Nothing, he will just die," was often heard from respondents who understood the question as asking what a person would do if he or she became infected with HIV, or what they themselves would do if infected, rather than what they could do to reduce the chances of becoming infected. Some respondents said, "There is nothing to do if I become infected." It then took much probing to obtain answers to **Q. 509.** Furthermore, the Swahili question was rather long.

Field observations: This question often had to be repeated, and in some cases it elicited the response of "No, because there is no treatment or cure." Something about this question leads to confusion between prevention on the one hand and treatment or cure on the other. Several respondents sought clarification because they were not sure what was being asked. One respondent asked, "If already infected, or not infected?" Interviewers suggested combining **Qs. 508-509** and rewording the new **Qs. 508/509** as *Mtu anaweza kufanya nini ilikujikinga au kupunguza uwezekano wakuambukizwa virusi vya UKIMWI?* (What can a person do to prevent or reduce the chances of becoming infected by the AIDS virus?)

It would be interesting to revisit the rationale for the sequencing of this first set of questions in section five. One wonders whether asking **Qs. 502-508** before **Q. 509** biases the answers to **Q. 509**. The Swahili translation does not include the "(else)" that the English does.

Analysis note: This question has several aspects that need to be considered. Since the English version asks "Anything else?"—referring to the previous set of questions, which ask about condom use, faithfulness, and abstinence—but the Swahili version does not, there might be confusion in the analysis process when someone totals the responses for this series of questions rather than considering **Q. 509** as a stand-alone question.

Changes: Questions **508** and **509** have been combined. The introductory phrase *kuna chochote kile ambacho* has been dropped and the word *nini* has been added. The effect of the change is to ask respondents *what* they can do rather than *whether* they can do anything at all.

Recommendation: Adopt the revised Swahili and English questions. The original English question asked whether there was anything (else) a person could do to avoid or reduce the chances of HIV infection. Respondents generally did not understand the question as its authors intended. The question should be changed, and the answer codes to **Q. 509** will be used to respond to **Q. 508.** That means that **Q. 509** can be dropped.

Revised Swahili Qs. 508 and 509:

Mtu anaweza kufanya nini ili kuepuka au kupunguza kupata maambukizi ya virusi vya UKIMWI?

Revised English Qs. 508 and 509:

What can a person do in order to avoid or reduce the chances of being infected by the AIDS virus?

Q. 512

Original English: Can the virus that causes AIDS be transmitted from mother to a child:

During pregnancy? During delivery? By breastfeeding?

Original Swahili: Je, inawezekana mtoto akaambukizwa virusi vinavyosababisha UKIMWI kutoka kwa mama yake:

Wakati wa ujauzito? Wakati wa kujifungua? Kwa kumnyoyesha?

Field experience: Interviewers in the field did not repeat this question as written, since it seemed redundant to repeat the entire question for each option or to say "from the mother" when asking about transmission to offspring in utero, during delivery, and while breastfeeding.

Changes: The word *vinavyosababisha* is replaced by *vya*, and the end of the original Swahili question—*kutoka kwa mama yake*—is dropped.

Recommendation: Adopt the revised Swahili question and change the English question.

Revised Swahili Q. 512:

Inawezekana mtoto akaambukizwa na virusi vya UKIMWI:

Wakati wa ujauzito? Wakati wa kujifungua? Kwa kumnyoyesha?

Revised English Q. 512:

Is it possible for a child to be infected by the AIDS virus:

During pregnancy? During delivery? By breastfeeding?

O. 512B

Original English: What can a mother who is infected with the AIDS virus do to reduce the chances of passing the virus to her child in her breast milk?

Original Swahili: Je, mama aliyeambukizwa virusi vya UKIMWI anaweza kufanya nini ili kupunguza uwezekano wa kumuambukiza mtoto wake kupitia katika njia ya kumnyonyesha?

Field experience: This question was not well understood in the field. Many mothers said that if a mother is infected, her child will also be infected, a response showing that they did not understand the question in the way it was intended. Those mothers simply could not imagine that a child would not be infected if the mother was HIV positive. Furthermore, interviewers found that this was a leading question because of the way it ends: *njia ya kumnyonyesha* (through breastfeeding)?

Field observations: This question had to be repeated several times, and even then, often explained. The construction of the sentence seemed to lead to confusion rather than understanding. An additional code, "Nothing you can do," is needed. The question also seems to lead the respondent to say "Stop breastfeeding." Interviewers suggested a possible way to rephrase by asking *Kama mama aliyeathirika amepata mtoto—utamshauri vipi?* (If a mother who has HIV has a baby, how would you advise her?) Or *Iwapo mama ana virusi vya UKIMWI anaponyonyesha, anaweza kufanya nini ili asimwambukiza mtoto?* (If a mother has HIV while breastfeeding, what can she do in order not to transmit HIV to the baby?).

Changes: The question has been rewritten with *aliyejifungua* (who has delivered) replacing *njia* ya kumnyonyesha (through breastfeeding). A followup has been added, Kuna kingine chochote? (Anything else?) A code for exclusive breastfeeding is added, as well as one for "Nothing can be done."

Recommendation: Adopt the revised Swahili question, and change the English version to avoid creating a leading question. In most places, it is assumed that a woman who has just given birth will breastfeed her child. Therefore, asking the question this way will elicit the information sought without leading the respondent to the specific answer of "stop breastfeeding."

Another way to present possibilities in a useful manner is to evaluate the series of questions (512-513) together and consider reorganizing them. Since there are steps that can be taken at each stage—pregnancy, delivery, and breastfeeding—to reduce the risk of vertical transmission, this series of questions (512-513) could be reworked to ask respondents who say *Yes* to transmission at each stage whether there is anything that can be done to lower the risk of transmission at that stage. For example, if a respondent says, "Yes, HIV can be transmitted during pregnancy," the interviewer could immediately ask something like "Is there anything that can be done during pregnancy to reduce risk of transmission?"

Revised Swahili Q. 512B:

Je, mama aliyejifungua akiwa na virusi vya UKIMWI, anaweza kufanya nini ili kupunguza uwezekano wa kumuambukiza mtoto wake?

Revised English Q. 512B:

What can a mother who has just given birth and is infected with the AIDS virus do in order to reduce the chances of infecting her child?

Questions 514, 514A, 515, 515A, 517, and 517A are discussed in the section dealing with questions about HIV stigma and discrimination, which begins on page 30.

Q. 518B (In the revised order of questions, this would become Q. 518D)

Original English: Do you think your chances of getting AIDS are small, moderate, great, or no risk at all?

Original Swahili: Je, unadhani nafasi yako kupata UKIMWI, ni ndogo, ya wastani, ni kubwa au haiwezekani kabisa?

Field experience: Many women asked, "Are you asking about me or about the actions of my husband?" Or they said, "On my side there is no chance I will become infected, but my husband is not faithful at all." Some men said, "You can be sure of yourself 100 percent, but not with your wife; it's her secret." In their minds, thinking about their own actions, their risk assessment would be one thing, but if they considered the actions of their spouse or partner, it might be quite different. The interviewers responded, "No. We are thinking of your own actions only, not those of your partner." Thus we were not sure of what we were getting, since some respondents asked the question but others did not. Some interviewers explained the intent of the question, but others probably did not. So we do not know the basis on which respondents answered the question in this survey.

Field observations: Some respondents said that they could not give an answer because one cannot know what one's partner is doing. For example, one female respondent said, "For me? Not possible, but I can't say what my husband is doing." That response led to the interviewer's probing, "What about your own risk," implying that the respondent should consider her/his behavior alone. That added question elicited an answer. Somehow we need to include a question (or two) about risk based on the respondent's own behavior, and another question about risk based on the partner's behavior, in order to obtain a clearer image of respondents' perceived level of risk of contracting HIV.

Analysis note: Because of the difficulties described above, it is difficult to know just what the information collected in this question signifies. Some respondents (especially women) may have been responding about what they think their risk is solely on the basis of their own behavior, whereas others might have been considering their perceived risk in relation to their primary partner as well. Perhaps the respondents who responded solely on the basis of their own behavior would have given a different answer if they took into account the risk they might incur from their partner's sexual behavior.

Changes: The original question was changed slightly, and a second question was added. The change to the original question was adding the phrase *wewe mwenyewe* (you yourself) after *nafasi yako* (your risk).

Recommendation: Adopt the revised Swahili question and change the English question. A second question, given below, should be added to capture the respondent's perceived risk relation to a partner's sexual behavior.

Revised Swahili Q. 518B:

Je, unadhani nafasi yako wewe mwenyewe ya kupata UKIMWI ni ndogo, ya wastani, ni kubwa au haiwezekani kabisa?

Revised English Q. 518B:

Do you think your own chances of getting AIDS are low, average, high, or no risk at all?

Additional Recommended Question:

Ukitilia maanani mahusiano yako na mwenzi wako; Je, unadhani nafasi yako ya kupata UKIMWI ni ndogo, ya wastani, ni kubwa au haiwezekani kabisa

Reflecting on your relationship with your partner, do you think your own chances of getting AIDS are low, average, high, or no risk at all?

Q. 521

Original English: Now I would like to ask some questions about your last birth. Did you see anyone for antenatal care during that pregnancy?

Original Swahili: Sasa ningependa nikuulize baadhi ya maswali kuhusiana na uzazi wako wa mara ya mwisho. Je, ulimuona yeyote kwa ajili ya huduma kwa wajawazito wakati wa ujauzito huo?

Field experience: Many respondents found the phrase *kumona yeyote* (see anyone) confusing.

Changes: Replaced *ulimuona yeyote kwa ajili ya* (see anyone for...) with *ulipata* (got).

Recommendation: Adopt the revised Swahili question. No change to the English question.

Revised Swahili Q. 521:

Sasa ningependa nikuulize baadhi ya maswali kuhusiana na uzazi wako wa mara ya mwisho. Je, ulipata huduma ya wajawazito wakati wa ujauzito huo?

Q. 526

Original English: Where was the test done?

[If source is hospital, health center, or clinic, write the name of the place. Probe to identify the type of source and circle the appropriate code.]

Original Swahili: Vipimo hivyo vilifanyika wapi?

Probe: Ikiwa ni hospitali, kituo cha afya, au kliniki, andika jina la mahali. Dadisi kutambua aina ya umiliki wa mahali hapo kisha zungushia sehemu inayohusika.

Field experience: Sometimes respondents had gone to a place that was not listed in the probe, one that was neither a hospital nor a clinic [kituo cha afya . . . kliniki].

Changes: Added to the interviewer's instructions was the phrase *au sehemu nyingine yoyote* (or any other place). Then another probing question was added.

Recommendation: Adopt the revised Swahili question. No change to the English question.

Revised Swahili Q. 526:

Vipimo hivyo vilifanyika wapi?

Probe: Ikiwa ni hospitali, kituo cha afya, au kliniki, au sehemu nyingine yoyote. Andika jina la mahali. Dadisi kutambua aina ya umiliki wa mahali hapo kisha zungushia sehemu inayohusika.

Additional Probe: Kuna sehemu nyingine yoyote? (Any other place?)

Q. 533

Original English: There are many reasons why people do not get tested for HIV. Can you tell me why you have not been tested?

Original Swahili: Kuna sababu nyingi zinazowafanya watu kutopima virusi. Je, unaweza kuniambia ni kwa nini hujapima?

Field experience: Some people said, "No, I can't tell you." Others were thinking of the many possible reasons in general in trying to answer and thus were not thinking of their own reasons.

Field observations: A great deal of hesitation on this question was found. The phrase *unaweza kuniambia* (can you tell me) seems to be problematic—leading to responses like "I can't tell you"—which led the interviewer to explain further, along the line of "We are looking to understand the reason why you have not been tested." In several cases, this question seemed to put respondents on the defensive and to make them feel they had to justify not having been tested. The question clearly led to discomfort. One respondent answered, "I don't have a reason." One young woman responded that she had not had an HIV test because her parents did not allow her to move about on her own. To record a wider range of answers, some additional codes may be needed here, such as "Too far"; "Would have to ask permission to go" (the latter might apply to teenagers or wives). Also, either there should be a code for "Don't know where to go" here, or a skip over this question from **Q. 532** for the respondents who had already said that they did not know where they could go to get tested.

Changes: The phrase *unaweza kuniambia* was dropped, and the question became: *Je, wewe una sababu gani?*

Recommendation: Adopt the revised Swahili question. No change, apart from additional codes, is recommended for the English question.

Revised Swahili Q. 533:

Kuna sababu nyingi zinazowafanya watu kutopima virusi. Je, wewe una sababu gani?

(There are many reasons why people do not get tested for the AIDS virus. And what is your reason?)

Add codes:

Mbali sana. Hajui mahali pa kupimia. Atahitaji kuomba ruhusa. (It is very far away.) (I don't know where to go.) (Would have to ask permission.)

3.3 Section 6 of Questionnaire

Q. 602

Original English: Apart from AIDS, have you heard about other infections that can be transmitted through sexual contact?

Original Swahili: Mbali na UKIMWI, je, umeshawahi kusikia juu ya maambukizo ya aina nyingine yanayoweza kuenezwa kwa kujamiiana?

Field experience: Many respondents did not understand the word *maambukizo* (infection).

Field observation: Although this seems to be a straightforward question, it often had to be repeated. Something—in either the choice of words or structure of the sentence—is making this question confusing. Some interviewers rephrased the question to use the words *magonjwa ya zinaa* (common term for sexually transmitted infections [STIs] in Swahili) instead of the phrase *maambukizo ya aina nyingine yanayoweza kuenezwa kwa kujamiiana*.

Changes: The word *maambukizo* was replaced by *ya magonjwa* and the word *kujamiiana* was replaced by *kukutana kimwili*, per the earlier discussion on terms for sex in Swahili.

Recommendation: Adopt the revised Swahili question. No changes should be made to the English question.

Revised Swahili Q. 602:

Mbali na UKIMWI, je, umeshawahi kusikia juu ya majongwa ya aina nyingine yanayoweza kuenezwa kwa kukutana kimwili.

(Besides AIDS, have you heard about any other diseases that are transmitted through sexual intercourse?)

Q. 611

Original English: Husbands and wives do not always agree on everything. Please tell me if you think a wife is justified in refusing to have sex with her husband when she knows he has a disease that can be transmitted through sexual contact?

Original Swahili: Si wakati wote mke na mume hukubaliana katika kila kitu. Tafadhali nieleze ikiwa unafikiri ni halali mke kukataa kufanya ngono na mume wake wakati akijuwa mumewe ana ugonjwa unaoambukiza kwa kukutana kimwili?

Field experience: Respondents had a difficult time understanding this question. Interviewers struggled to find alternative ways to ask this question.

Field observations: This question was never understood on the first reading. If a female respondent answered quickly, it was understood as meaning "Can you refuse your husband sex?" Therefore, it often received an initial answer of *No*, and then, after more explanation from the interviewer about the meaning of the question, the answer changed to *Yes*. For example, in one interview the response of a young woman was "I don't have the right." Then the interviewer (this was the most skilled interviewer observed) explained that she wanted to know what she *thought*, rather than what she *could do*. The answer was then changed to *Yes*.

In all cases observed—whether because the answer was wrong, because of silence or bemusement, or because of a direct "I don't understand" response—the question was repeated several times and then often modified by means of probing questions such as, "For example, if your husband had an STI, could you refuse him sex?"

Use of this question as a probe to try to finally elicit an answer means that we do not know how many respondents actually answered **Q. 611** as intended—"Do women have the right to refuse sex?"—

and how many answered the question "Can you refuse your husband sex?" The more concrete question (the latter) seemed to be easily understood, and it is what the female respondents seem to understand even from the question in its original form.

A way to modify this question, and to gain important information, is to ask the direct question of what the respondent can or cannot do, and then ask the followup question "Do you think women should be able/have the right to...?" It would also be instructive to know how a woman thinks (or a man reports) he would respond if she refused him sex.

One young man responded with bemusement after several repetitions of the question by saying: "But the women wouldn't know..."

In discussions with the interviewers, and from previous work, we found that we cannot assume that HIV is part of respondents' thought process in this case, given that HIV is often thought of differently from other STIs (HIV is linked with the concepts of not curable, death as the outcome, highly stigmatized, little understanding of the possibility of discordancy between couples, and more). If what we want to know is whether a wife is able to refuse sex when she knows her husband has HIV, we might need to ask that question separately. Two complications with that approach arise, however: 1) few people have been tested, and 2) of those who have been tested, few disclose their status, so a wife probably does not know and can only suspect that her husband has HIV until the husband is very sick. Furthermore, because there is little understanding of discordancy, wives will assume that if their husbands are infected, they must also be, and vice versa. Whether wives/women have a right to refuse sex to a husband/partner on the basis of suspected STI(s) might also depend on whether the husband/partner is sick.

Analysis note: Per the above discussion, it is difficult to know what the information collected from this question is actually measuring. Is it measuring a respondent's opinion of a wife's right to refuse a husband sex? Is it measuring the respondent's ability to say *No* to a husband (or in the case of men, the ability of their wives to refuse them sex)? Since HIV is thought of differently from other STIs, this question also probably does not measure a woman's rights in relation to refusing an HIV-positive husband sex (particularly if he has no visible signs or symptoms of AIDS).

Changes: Replaced the phrase *tafadhali nieleze ikiwa unafikiri* with *Je.* Replaced *kufanya ngono* with *kukutana kimwili*. Replaced *mume wake* with *mumewe*.

Recommendation: Adopt the revised Swahili question. No changes to the English question.

This question still posed a challenge in the pilot testing. Although respondents were answering it more easily, it was not at all clear *how* they were understanding it and whether its intent was clear to them.

Revised Swahili Q. 611:

Si wakati wote mke na mume hukubaliana katika kila kitu. Je, ni halali mke kukataa kukutana kimwili na mumewe wakati akijuwa mumewe ana ugonjwa unaoambukiza kwa kukutana kimwili (kujamiiana)?

(Husbands and wives do not always agree on everything. Is it right for a wife to refuse sex with her husband if she knows he is suffering from an illness transmitted through sexual intercourse?)

O. 612

Original English: When a wife knows her husband has a disease that can be transmitted through sexual contact, is she justified in asking that they use a condom when they have sex?

Original Swahili: Wakati mke anajuwa kwamba mume wake ana ugonjwa unaoambukiza kwa kujamiiana, ni halali kumuomba watumie mpira (kondomu) wakati wa kujamiiana?

Field experience: The majority of women respondents understood the question. Some said, "Well, if he has an STI she will simply not have sex with him until he is treated and has recovered."

Field observations: This question also needed repeating, though it seemed a bit easier to understand than the previous one. However, the idea of asking about condom use within marriage seemed to be alien to the respondents and therefore difficult for them to answer. Two common-sense understandings seem to effect the results here. First, condoms are rarely used between marriage partners, so it was hard to conceptualize a question about condom use within marriage, no matter what the reason. Interviewers reported that many women said they could never ask for condom use. However, some answered that women could withhold sex until the husband had sought and completed treatment. Second, there is a general distrust of condoms in Tanzania. Interviewers reported that common responses were "I don't trust condoms" or "Condoms don't work." For respondents with such perspectives, this question seems irrelevant. One female respondent repeatedly asked, "Will condoms help?" The interviewer kept saying, "They could be used, so imagine that...."

Replacing this question with one about refusing sex until treatment has been sought and completed may be more appropriate and effective, in view of the low acceptability of condom use within marriage and sexual partnerships in most countries. If the question was asked specifically about HIV, rather than about STIs in general, a question concerning condoms might be more relevant. As per the discussion above, HIV probably does not enter into respondents' consideration in their answers to this question.

Changes: Replaced *mume wake* with *mumewe*; replaced *kuenea kwa kujamiiana* with *kwa kukutana kimwili*.

Recommendation: Adopt the revised Swahili question. No change should be made to the English question.

Revised Swahili Q. 612:

Wakati mke anajuwa kwamba mumewe ana ugonjwa unaoambukiza kwa kukutana kimwili; Je, ni halali kumuomba watumie kondomu (mpira wa baba au mama) wakati wa kukutana kimwili (kujamiiana)?

(When a wife knows that her husband is suffering from a disease transmitted through sexual intercourse, is it right to ask him to use a condom for sex?)

CHAPTER 4 MEASURING HIV-RELATED STIGMA

4.1 Introduction

Governments, donors, policymakers, and program implementers are increasingly recognizing the combined force of HIV-related stigma and discrimination as a key barrier that must be addressed if HIV/AIDS programs are to succeed. Along with this recognition has come funding for research to increase our understanding of the issue and more insight into where to find entry points for intervention, as well as new tools to support programming for stigma reduction. Although such efforts have led to recommendations and to tools that are now being adopted in Tanzania and across the region, the new programs must be evaluated to learn what works and what promising efforts should be scaled up. A critical part of this evaluation is to develop indicators—as well as corresponding questions and data collection methods at multiple levels to collect appropriate and accurate information to use in assessing the progress and impact of various programs and projects.

This section of the report describes 1) key dimensions of stigma that need to be captured to gain a balanced picture of stigma, 2) critical issues to take into consideration when formulating and asking questions about stigma on population-based surveys, 3) recommendations for key domains that need to be captured by these questions, and 4) specific suggestions for actual questions. Our recommendations for specific questions use the questions on stigma and discrimination included in the THIS as a starting point. As for other questions, we document the field experience with these questions and suggest modifications.

This section of the report draws not only on the THIS evaluation experience, but on the experience of ICRW and partners from a multicountry study on HIV stigma conducted from 2001 to 2003 in Ethiopia, Tanzania, Zambia, and Vietnam, the collective work of the USAID Stigma and Discrimination Indicators Working Group (SDIWG), and initial testing of survey indicators done by ICRW, MUCHS, and the Synergy indicators testing survey. It should be noted that the indicators testing currently being done by ICRW, the Synergy Project, and MUCHS is testing and validating stigma indicators at three levels: 1) population, 2) people living with HIV and AIDS (PLHA), and 3) health care providers. In the coming months, more information will become available on all three levels of indicators.

For the rest of this report, we will define discrimination as the endpoint of stigma (enacted stigma) and therefore will use the word *stigma* by itself. We are not addressing any questions or corresponding indicators that seek to collect data on the legal or policy aspects of stigma and discrimination.

4.2 Key Dimensions of Stigma

Measuring stigma at the population level in a standard survey poses numerous challenges because of the multidimensional nature of stigma; because it is intertwined with sensitive issues of sex, death, and

² Nyblade, L., R. Pande, S. Mathur, K. MacQuarrie, R. Kidd, H. Banteyerga et al. 2003. *Disentangling HIV stigma and AIDS in Ethiopia, Tanzania and Zambia*. Washington, D.C.: International Center for Research on Women.

³ Kidd, R. and S. Clay. 2004. *Understanding and Challenging HIV Stigma: Toolkit for Action:* Washington, D.C. CHANGE/AED and ICRW.

⁴ The other critical element is targeted evaluation research concerning types of stigma-reduction programs and intervention models, as well as studies examining the link between stigma reduction and uptake in Voluntary Counseling and Testing (VCT), prevention of mother-to-child transmission (PMTCT), antiretrovirals (ARVs,) disclosure for prevention, reduction in negative outcomes, and increase in support for people living with HIV and AIDS (PLHA).

⁵ For example, at the population level, with PLHA, and in institutional settings such as establishments for health and education.

inequity; and because of its variations across cultures and by context.⁶ Until recently, we had little data from developing countries to help us disentangle stigma to identify critical entry points for intervention and key aspects of the phenomenon to measure. However, we now have evidence that there are common core dimensions of stigma across diverse settings that can form a basis for establishing indicators of stigma. The multicountry study done by ICRW and partners indicates that we should be measuring underlying indicators of stigma, key manifestations of stigma, and a proxy of stigma, which is disclosure of HIV status.

The two underlying causes of stigma⁷ are as follows:

- Fear of casual transmission
- Moral judgments—shame and blame.

Common manifestations of stigma across contexts that reflect the above underlying causes include the following:

- Physical and social isolation or exclusion within the home and community (separate utensils, bedding, and sleeping areas; exclusion from social events)
- Verbal abuse (name calling, taunting, teasing, insults)
- Loss of property, from land to household goods
- Loss of, or inability to secure, housing
- Loss of relationships (divorce, abandonment)
- Violence
- Loss of respect and diminished standing in family and community
- Institutional stigma in various forms:
 - Differential care in healthcare settings
 - Loss of employment, promotions, or further training
 - Loss of educational opportunities.

In all three countries, the findings suggested that disclosure of HIV status (positive or negative) was an indirect (or proxy) measure of stigma. Although HIV testing is not widespread in most countries, it is rapidly becoming more available. People often cite stigma as a reason for not getting tested, and if they are tested, disclosing results to only a few trusted individuals. As the power of stigma drops, we would expect both the testing uptake and the actual disclosure of test results to increase. The measurement of actual disclosure is important not only for what it can tell us about stigma but also for

⁶ For example, stigma can vary according to age, setting (home, community, or an institution), intensity and length of the epidemic, or disease progression.

⁷ For more information, see Nyblade, L., R. Pande, S. Mathur, K. MacQuarrie, R. Kidd, H. Banteyerga et al. 2003. *Disentangling HIV stigma and AIDS in Ethiopia, Tanzania and Zambia*. Washington, D.C.: International Center for Research on Women.

what it can tell us about how possible it is for people who do get tested to use the knowledge of their sero status for prevention. (If one cannot share one's test results with one's sexual partner, negotiating safe sex is bound to be difficult.)

We recommend formulating a series of indicators and corresponding questions to measure key dimensions of stigma. Recommendations for such indicators and questions are presented below. However, before we turn to those, we need to discuss some challenges that must be dealt with as we measure stigma quantitatively, as well as some solutions to those challenges.

4.3 Challenges in Measuring Stigma

4.3.1 Asking Questions

Both ethical considerations and stigma itself make it unacceptable to ask randomly selected respondents in a population-based survey about their HIV status. This constraint rules out the possibility of asking a direct question about whether a respondent has experienced HIV-related stigma. And there is another roadblock: with a rise in programs focused on the reduction of stigma—which will heighten awareness of stigma and the public opinion that stigmatizing is undesirable behavior—the likelihood increases that survey respondents will give the desirable or "right" answer, regardless of their actual knowledge or behavior. Therefore, asking questions about a respondent's own stigmatizing behavior becomes even more problematic.

A possible solution to those two obstacles might to pose a hypothetical question such as "If you knew someone with HIV, would you...?" However, the likelihood of interviewers getting responses that respondents perceive as desired by the interviewer rather than accurate responses would remain high. Furthermore, we know from experience that hypothetical questions seldom work well for reflecting what will happen or what actually happens.

To overcome such difficulties, one option is to ask a question that does not put the respondent on the defensive. For example, interviewers could ask respondents whether they have observed stigma, or know of anyone who has experienced it, over a specified period of time.

This option, however, raises another problem: how to ensure that respondents are not all reporting on the same case of stigma (as in a case that has been highly publicized in the media). Although their responses in such a case might give us some sense of how many people are aware of the possibility or existence of stigma, they will not show us the actual levels of stigma within the population.

We could address this issue by asking a more specific question: "Do you personally know someone who has experienced a particular form of stigma in the past x period of time?" Although in a tight-knit community, the respondents might still all be reporting on a single widely known local case, the disadvantages of a random sample will be lessened by the fact that only a few people from any given community are interviewed. If a survey has the space and flexibility to do so, it could add a further control by asking for some specific characteristics about the stigmatized person whom the respondent reports knowing.

4.3.2 Specific Questions

In crafting questions that will accurately capture stigma, it is essential to pay attention to the complexity of the issue as well as potential ambiguities. Though clarity is always important in the design of survey questions, it is particularly critical to ensure that questions about stigma are clear, unambiguous, and tightly focused. Two questions from the THIS illustrate the problems that arise when ambiguities creep into questions and when the nuances of stigma are not taken into consideration.

1) Can people get the AIDS virus by sharing food with a person who has AIDS?

2) Would you buy fresh vegetables from a shopkeeper or vendor if you knew that the person had the AIDS virus?

The intent of those questions is to measure both knowledge about transmission of HIV—an important concept to measure, since we know that fear of casual (non-sexual) transmission of HIV leads directly to stigmatizing acts—and an actual stigmatizing act (refusing to buy goods from a PLHA) that may or may not be the result of misconceptions about transmission.

The ambiguities and nuances in these questions arise from "sharing food" and putting "shopkeeper" and "vendor" together in the same question.

In the first question, it is hard to know how respondents interpreted what "sharing food" means—sitting at the same table? eating from the same plate? eating food prepared by someone? Because we cannot know how respondents interpreted "sharing food," and therefore what question they were answering, analysis of these data becomes problematic. We know from multicountry data that it is important to pay attention to degrees of physical interaction—particularly in regard to food—because the fears of transmission from casual contact vary widely, and the level of fear will directly affect stigmatizing actions.

For example, the multicountry data document (at one extreme end) people refusing to even sit at a table with a PLHA, for any of several reasons: 1) extreme/irrational fear about how the virus may be transmitted; 2) fear that eating with a PLHA will cause others to assume they are also infected with HIV; 3) a display of social censure for the person's presumed actions, since PLHA are assumed to have contracted HIV via immoral behavior. The latter response to the presence of a PLHA is the most extreme form of discrimination found involving food, and may not be frequent. What is more common is fear of sharing the same utensils, not eating from the same plate, or not eating food prepared by PLHA. This fear extends not only to food cooked in the home but also to prepared food bought from street vendors or food sellers.

In the second question, the issues are also related to fears of casual transmission. The problem with asking about shopkeepers and vendors together is that they handle and package their goods in different ways. Shopkeepers are more likely to sell prepackaged goods or to handle food with a utensil rather than with bare hands. Vendors are more likely to have direct physical contact with the food—an important consideration for respondents in determining whether they would buy from a PLHA.

In both examples, a second nuance that is critical to how the respondent answers is whether the PLHA has visible signs and symptoms of AIDS. All of the practices—eating at the same table, from the same plate, with the same (even if washed) utensils; eating or buying food prepared or handled in some way by PLHA—may be affected by seeing or not seeing physical signs or symptoms of AIDS. People may be willing to give or receive food from a PLHA who shows no outward signs of illness, but unwilling to do so once symptoms appear. How a respondent interprets this question—or if they ask for clarification, how the interviewer responds—will determine the answer.

In the experience of the field teams, many respondents sought clarification on the signs of symptoms. In the pilot test of the modified questions, this nuance was addressed by including two separate questions: Would you buy food from a vendor who has HIV, but is not sick? What about if he/she were sick? In the answers to the first question, 30/36 (83.3 percent) of the respondents said *Yes*, they would buy, but the *Yes* response dropped to 21/36 (58.3 percent) if the PLHA was sick (a substantial difference). Details of the specifics of how to correct the above questions are provided in section 4.4.

4.3.3 Stigma and Care

Another nuance that is important to consider and poses a challenge is distinguishing between what is and what is not a stigma, particularly in the realm of care within a home or family. A question asked in many surveys: "If a relative of yours became sick with the virus that causes AIDS, would you be willing to care for her or him in your own household?" There are two issues to consider with this question. To begin with, this question suffers from the kinds of ambiguity discussed above: What does "care" mean? How close a relative? Second, social norms may dictate that one always cares for a family member, no matter what, making this question a poor measure of stigma, since then a majority of the respondents will answer *Yes* to this question. In the multicountry study, we found that some level of basic care is almost always given to family members with AIDS, but that it varied greatly and was often accompanied by stigma in the form of social and physical isolation and verbal abuse (taunting, scolding, chiding, blaming, shaming). In such cases, a general question on whether care would be given is not capturing stigma.

Another difficulty in using care as an indicator for stigma highlighted by the multicountry results is that in very poor households, families often have to make hard choices about how to spend scarce resources, whether monetary (e.g., choosing school fees over medicine for the family member with HIV) or labor (e.g., choosing going out to work the fields over staying home to care for a sick PLHA). The result of such choices may be experienced as stigma by a PLHA even though there may have been no intent to discriminate. A general question on care would not capture this type of nuance.

Gender too may affect the accuracy of measurement of stigma, so that one measure will capture stigma well for men but not for women. For example, gender may affect marital dissolution or abandonment. If women are asked whether they would leave a partner with HIV, they may answer *No*, because they are expected to care for their husbands no matter what and because their social and economic position does not allow them an alternative. Therefore, their *No* response might not mean that they do not display stigma toward the partner. At the same time, because of women's relative lack of power, a female partner might not be able to protect herself from infection if she were to stay and therefore might have to leave the relationship to protect herself, not as a sign of stigma toward her male partner.

For those reasons, a question about marriage dissolution would be a poor measure of stigma among women, but might be a good indicator of stigma on the part of men. Men have the power to blame a female partner for HIV, abandon her if they wish, and protect themselves by means of condom use or abstinence if they stay. If a man abandons a partner because of her HIV status, it may be a good indication of stigma. The way to address such nuances is to examine each question carefully to assess whether it has the potential to be capturing some phenomenon other than stigma.

A final challenge that needs to be kept in mind, particularly when analyzing stigma data across time, is that as programs intended to address HIV-stigma increase and awareness rise, there is a risk that survey data will show an increase in stigma that reflects not an increase in stigma itself, but an increase in reporting of stigma, because people will have become aware of it and able to identify it.

There is no readily apparent way to control for this potential problem. However, both process and monitoring data from programs can be examined to help determine whether an apparent increase in stigma is due to this problem. The multidimensional nature of stigma and the multiple measures collected to reflect it will also help control for the self-consciousness effect, since we would expect this kind of reporting increase (because of increasing awareness) to affect some dimensions of stigma more than others. In countries where a single word captures the concept of stigma, or as in the case of Tanzania, where the use of one word for stigma—*kunyanyapaa*—is gaining currency, a few questions about the word and its meaning could be added as controls for possible ambiguity of motivation on the part of respondents.

4.4 THIS Stigma Questions and Field Experience

Q. 514

Original English: If you knew that a shopkeeper or vendor had the AIDS virus, would you buy fresh vegetables from that person?

Original Swahili: Je, ikiwa ungefahamu kwamba muuza duka au mtembeza mboga ana virusi vya UKIMWI, ungeweza kununua mboga toka kwake?

Field experience: Interviewers experienced three problems with this question. First, since a *muuza duka* (shopkeeper) and an *mtembeza mboga* (food vendor/traveling food seller) are not the same, people wondered which one they were being asked about. Second, *mboga* is a general term that encompasses all kinds of food, from fresh vegetables to meat, so some people said they would buy vegetables, but not meat. Third, many people responded with "It depends," saying that they would buy from a person if the person was not sick or if the person had no sores. So there was a range of responses.

Field observations: The answer often given was "It depends on how sick the person is." Interviewers tried to push the respondents to give Yes/No/Don't Know answers. They ended up interpreting/coding an initial "It depends" answer in various ways.

Analysis note: The ambiguity in this question, both in terms of combining shopkeeper and food vendor and because whether the person with HIV is sick is an important factor in determining a response, makes it difficult to know what question the respondents actually answered. If the question were clearer, and if it specified "healthy" or "sick," the results could be substantially different (more valid). As noted in the general discussion above, in the pretest of the revised question there was a substantial difference between the percentage of respondents who answered *Yes* if the PLHA was healthy and the percentage of respondents who answered *Yes* if the PLHA was sick.

Changes: Muuza duka au mtembeza mboga (shopkeeper or food vendor) was replaced by muuza mboga, to avoid confusion. Nyama, samaki, mboga ya majani (meat, fish, vegetables) were added in brackets to specify what is meant by mboga. The phrase lakini haumwi (who is not sick) was added to reduce the number of people responding with "It depends."

Recommendation: Adopt the revised Swahili question, change the English question, and add another question, as shown below (new **Q. 514A**).

Revised Swahili Q. 514:

Ikiwa ungefahamu kwamba muuza mboga [nyama, samaki, mboga za majani] ana virusi vya UKIMWI, lakini haumwi; Je, ungeweza kununua mboga toka kwake?

Revised English Q.514:

If you learn that a fresh food vendor has the AIDS virus, but is not sick, would you buy fresh food from him/her?

New additional Q. 514A:

Je, kama anaumwa?

And if s/he is sick?

Q. 514A (Would become Q. 514B if the above change were adopted)

Original English: Would you shake hands with someone who is infected with the virus that causes AIDS?

Original Swahili: Je, unaweza kupeana mkono na mtu ambaye ameambukizwa virusi vinavyosababisha UKIMWI?

Field experience: Respondents had no problems understanding this question. However, many of them said "It depends," indicating that their final response would depend on whether the other person was sick or not.

Field observations: The answer given often depends on how sick the person is. Note that questions **514** and **514A** have different answer codes. **Q. 514A** allows for an answer of "It depends" or "Not sure" as part of the "I don't know" answer code.

Analysis note: As noted for the previous question, whether the PLHA in question is sick or not is likely to affect the response to this question. The fact that we do not know how respondents understood the question when they answered it makes the data from this question even more difficult to interpret.

Changes: The word vinavyasababisha was replaced by vya, and lakini haumwi (but is not sick) was added to reduce the number of people who responded with *Inategemea* (it depends).

Recommendation: Adopt the revised Swahili question, change the English question, and add an additional question, as shown below (Q. 514C).

Revised Swahili Q. 514A:

Je, unaweza kupeana mkono na mtu ambaye ameambukizwa virusi vya UKIMWI lakini haumwi?

Revised English Q. 514A:

Would you shake hands with a person infected with the AIDS virus, but who is not sick?

New additional question (would become 514C):

Je, kama anaumwa? And if s/he is sick?

Q. 515

Original English: If a member of your family got infected with the virus that causes AIDS, would you want it to remain a secret or not?

Original Swahili: Ikiwa mwanafamilia katika familia yako atakuwa ameambukizwa virusi vinavyosababisha UKIMWI; Je, ungependa ibakie kuwa siri au la?

Field experience: Many respondents were not sure what was meant by the *au la* at the end of the question. Some asked, "Being kept a secret from whom?" Others said that it depended on whether or not he was sick, for if he beame sick, then it would no longer be a secret in any case.

Field observations: The *au la* at the end of the question seemed to confuse respondents. Interviewers recommended stopping the question before the *au la*. Rephrasing observed included adding

iwe wazi ("that it be open") at the end instead of the *au la*. One woman (who in the end explained that she had a daughter with AIDS), gave a long explanation about how people in the community tease or look down on people who have AIDS. The interviewer finally coded the response as "remain secret."

Changes: The word *vinavyosababisha* was replaced by *vya*, and *lakini haumwi* was added. The *la* at the end of the question was replaced by *isiwe siri*.

Recommendation: Adopt the revised Swahili and change the English question accordingly.

Revised Swahili Q. 515:

Ikiwa mwanafamilia katika familia yako atakuwa ameambukizwa virusi vya UKIMWI, lakini haumwi, ungependa ibakie kuwa: siri ya familia tu, au isiwe siri?

(Codes)

1. Siri ya familia

2. Isiwe siri

Revised English Q. 515:

If a member of your family has been infected with the AIDS virus, but is not sick, would you want it to remain a secret within the family, or not a secret?

(Codes)

1. Family secret

2. It should not be secret

Q. 515A

Original English: If a member of your family got infected with the virus that causes AIDS, would you be embarrassed or feel shame for your family?

Original Swahili: Ikiwa mwanafamilia katika familia yako atakuwa ameambukizwa virusi vinavyosababisha UKIMWI; Je, utajisikia vibaya au kuona kuwa ni aibu kwa familia?

Field experience: Many respondents were puzzled by the use of two expressions together: *kusikia vibaya* and *kuona kuwa ni aibu*. They said that they would be embarrassed (*kujisikia vibaya*) but not ashamed (*ni aibu*). So in fact they tried to answer *Yes* to one but *No* to the other. It is not clear how such answers were coded, but most likely they were coded as *Yes*.

Field observations: Two concepts are being queried in one question: feeling bad and feeling shame. Several respondents said "I would feel bad, but not ashamed," or simply "I would feel bad" without mentioning the "ashamed" part. All of those answers were coded as *Yes*.

Analysis note: Interpretation of the data from this question is very problematic. We cannot know whether respondents answered *Yes* to both feeling bad and feeling shame, or *Yes* to one and not the other. Additionally, we do not know how interviewers ended up coding the response.

Changes: The word *vinavyosababisha* was replaced by *vya*, and *unajisikia vibaya* was dropped.

Recommendation: Adopt the revised Swahili and change the English question.

Revised Swahili Q. 515A:

Ikiwa mwanafamilia katika familia yako atakuwa ameambukizwa virusi vya UKIMWI; Je, utaona kuwa ni aibu kwa familia?

Revised English Q. 515A:

If a member of your family has been infected with the AIDS virus, would you be ashamed about your family?

Q. 517 and Q. 517A

Original English: If a <u>female</u> teacher has the AIDS virus but is not sick, should she be allowed to keep teaching in the school?

And: If a <u>male</u> teacher has the AIDS virus but is not sick, should he be allowed to keep teaching in the school?

Original Swahili: Je, ikiwa mwalimu wa kike atakuwa na virusi vinavyosababisha UKIMWI, lakini haumwi, aruhusiwe kuendelea kufundisha?

And: Je, ikiwa mwalimu wa kiume atakuwa na virusi vinavyosababisha UKIMWI, lakini haumwi, aruhusiwe kuendelea kufundisha?

Field experience: This question was widely misunderstood. Many respondents, who thought they were being asked what is now happening in Tanzania, not what they thought themselves, answered *wanaruhusiwe* (they are allowed). In the pretest, there were still cases of confusion with the idea of being allowed to (by whom), so the group decided to drop the term *ahurusiwe* and just ask, "Should she continue teaching?"

Field observations: Q. 517 and **Q. 517A:** Most respondents answered *wanaruhusiwe*, meaning they are talking about what goes on in Tanzania rather than giving their own opinion of what should be allowed.

Analysis note: Interpretation of data from this question is very problematic. It appears that many respondents understood this question to be asking about what was happening in the country rather than their own opinion. Any use of this question in analysis needs to add this caveat.

Changes: The word *vinavyosababisha* was replaced by *vya*, and the question begins with *Kwa maoni yako* (in your opinion) to emphasize that the person's own opinion is being sought. The word *ahurusiwe* (be allowed) was also dropped.

Recommendation: Adopt the revised Swahili and change the English question.

Revised Swahili Qs. 517 and 517A:

Kwa maoni yako, ikiwa mwalimu wa kike atakuwa na virusi vya UKIMWI, lakini haumwi, aendelee kufundisha?

Kwa maoni yako, ikiwa mwalimu wa kiume atakuwa na virusi vya UKIMWI, lakini haumwi, aendelee kufundisha?

Revised English Qs. 517 and 517A:

In your opinion, if a female teacher has been infected with the AIDS virus but is not sick, should she continue teaching?

In your opinion, if a male teacher has been infected with the AIDS virus but is not sick, should he continue teaching?

General recommendation: All questions (Swahili and English) asking for a personal opinion (**Qs. 517B and C, 518 and 518A**) should begin with *Kwa maoni yako* (in your opinion), so as to ensure that respondents understand that it is their own opinion that is being sought. Appendix A displays the exact revised questions. No other changes were made to those questions.

Furthermore, we recommend that the order of several questions be changed so that the questions about children in school follow those about the teachers—specifically, what was **Q. 517B** now follows what was **Q. 518D**, and what was **Q. 518B** (chances of getting AIDS) follows what was **Q. 517B**.

4.5 New Stigma Questions Developed in the Workshop

The following questions were developed by the workshop participants as potential additional stigma-related questions. We recommend the first two, but not the third, for reasons given below each question.

1. Je, umeshawahi kusikia/kuona mjongwa wa UKIMWI akisimangwa? (Have you ever seen or heard someone with AIDS being mocked or insulted?)

This is a good question, since it captures one of the key dimensions of stigma within households and communities. In our multicountry research, mockery, insults, name-calling, and gossip were common—and particularly feared—forms of stigma.

2. Je, unaweza kula chakula kwenye sahani moja pamoja na mgonjwa wa UKIMWI? (Would you eat food from the same plate as someone sick with AIDS?)

This question works well to capture the fear of casual transmission that people have, which directly leads to an act that is visibly stigmatizing. This question will need to be adapted by cultural context to reflect the way people normally eat together from the same dishes.

3. Ikiwa ungefahamu kwamba mwenza/mpenzi wako ameambukizwa virusi vinavyosababisha UKIMWI wakati we hujaambakizwa; Je, utaendelea kuwa naye?

(If you were to learn that your partner or lover had been infected with the AIDS virus, and you were not infected, would you still live together?)

This is probably not a good measure of stigma among women because of current Tanzanian gender roles and inequalities that could influence the response.

- Often a woman will say *Yes*, not because she does not stigmatize her husband but because staying with husbands is expected, and because often the woman will have no other options (having nowhere else to go, or having no other financial resources to rely on except for the husband).
- Women may also say *Yes* because of their mistaken assumption that if a husband is infected, his wife will be too (showing little understanding of the possibility of discordancy in couples).
- On the other hand, because a wife has little power to negotiate safer sex (for example, to insist on the use of a condom)—particularly if her husband's HIV status has not been openly discussed—or if a woman has an abusive or alcoholic husband, her only way of protecting herself might be to leave; in such a case, her leaving would not be on account of stigma.

For those reasons, besides it being a hypothetical question, the third question is potentially problematic. It would be better to ask a direct question about whether the respondent *personally* knows anyone who was abandoned or divorced by his or her spouse/partner because of HIV/AIDS.

4.6 Recommendations for Stigma Indicators

We recommend a series of indicators to capture each of the key domains described above: 1) manifestations of stigma; 2) the two main underlying causes; and 3) disclosure. Below is a set of proposed indicators with attached questions intended to capture the information needed. To gain a full picture of stigma, we recommend including all of the questions. However, if space does not allow for inclusion of all, we have indicated some that could be made optional by marking them with an asterisk.

Please also note that we do not recommend three stigma questions that are now in the THIS—the two on teachers and the general one on care. It would be good to include them for comparative purposes if there is space to include them (in addition to those below). However, as noted in the previous discussion on problems, the care question is ambiguous, and the fact that it is a social norm to provide care to relatives means that this question may tell little about actual stigma. Both this question and the teacher questions yielded a high percentage of *Yes* responses (forthcoming analysis of DHS data by Lisanne Brown) and are likely to suffer from respondents giving the correct response, a tendency that will increase as awareness of stigma grows.

4.6.1 Manifestations of Stigma

Indicator: Percentage of respondents reporting personal knowledge of someone who has experienced HIV-related stigma.

Manifestations can be further broken down into social and institutional. The social ones are more visible within the community, therefore more likely to be reported on with this kind of indirect question. Our experience in the Indicators pilot was that only people who had been involved in caring for a PLHA knew about institutional-level discrimination. Because disclosure of status is not common, it makes sense that PLHA would rarely talk to others about their experiences of institutional HIV stigma.

Social

- Personally know someone who has been mocked, taunted, teased, or sworn at because they are known, or suspected, to have HIV
- Personally know someone who is no longer visited, or visited less, by family and friends because they are known, or suspected, to have HIV
- Personally know someone who has been abandoned or divorced by a partner because they are known, or suspected, to have HIV
- Personally know someone who has been physically isolated within their household; for example, given separate dishes and/or linens, made to sleep alone in own room, because they are known, or suspected, to have HIV
- Personally know someone who has had property (household goods, livestock, housing, land) taken away from them because they are known, or suspected, to have HIV
- Personally know someone who has lost respect and standing in the family and/or community because they are known, or suspected, to have HIV

Institutional

- Personally know someone who has been refused health care or received differential care in a facility—like having to wait longer, being denied certain treatment or procedures, being bounced from provider—because they are known, or suspected, to have HIV
- Personally know someone who has lost housing or been denied housing because they are known, or suspected, to have HIV
- Personally know someone who has been denied employment, lost a job, not been given further training opportunities or promotions because they are known, or suspected, to have HIV

4.6.2 Underlying Causes: Knowledge (Fear of Casual Transmission) and Values

Misconceptions about HIV transmission and stigmatizing actions that would imply fear of casual transmission

Indicator 1: Percentage of respondents expressing misconceptions about casual transmission of HIV.

• Can people be infected with the AIDS virus by eating from the same plate as someone who is sick with AIDS?

Other misconceptions are captured in the standard questions on knowledge of transmission.

In the ongoing indicators work, we ask about fear of transmission from saliva, sweat, and feces. In the qualitative work, we found that stigmatizing acts such as physical isolation of PLHA were related to fears of transmission via body fluids. It would be enlightening to measure people's knowledge of which body fluids can and cannot transmit HIV, as well as their level of knowledge about the length of time HIV can survive outside the body.

Indicator 2: Percentage of respondents expressing intention to engage in a stigmatizing action implying fear of casual transmission.

• If you learn that a fresh-food vendor has the AIDS virus, but is not sick, would you buy fresh food from him or her?

What if he or she were sick?

• Would you shake hands with a person who is infected with the AIDS virus but who is not sick?

What if he or she were sick?

Would you eat food cooked by a person who has the AIDS virus, but is not sick?*

What if he or she were sick?

Values: As reflected in shame and blame

Indicator 1: Percentage of respondents who judge or blame persons living with HIV for their illness.

• How much do you agree or disagree:

AIDS is a punishment for bad behavior

People with AIDS deserve their illness.

Indicator 2: Percentage of people would feel shame if they were associated with a PLHA.

• How much do you agree or disagree:

I would feel ashamed if someone in my family had AIDS

I would not be embarrassed to tell people that my family member died of AIDS

I would feel ashamed if I had HIV or AIDS

PLHA should be ashamed of themselves.

4.6.3 Disclosure of HIV Status

Indicator 1: Percentage of respondents who have had an HIV test and who have disclosed their HIV status to various key people (intimate partner, family members, health care providers, neighbors, employers).

Indicator 2: Percentage of respondents who would encourage a family member with HIV, who shows no physical signs of AIDS, to disclose their HIV status outside the family.

- If a member of your family has been infected with the AIDS virus, but is not sick, would you want it to remain a secret within the family, or not a secret?
- If a member of your family has been infected with the AIDS virus, but is not sick, would you advise them to be open about their status in the community?*

Indicator 3: Percentage of respondents who have not had an HIV test, who would disclose their HIV status to various key people (intimate partner, family members, health care providers, neighbors, employers) if they were tested.*

^{*} Optional question

CHAPTER 5 CONCLUSION

The principal objectives of this study were to evaluate respondents' understanding of questions related to sexuality and HIV/AIDS asked in the THIS and provide recommendations for the revision of questions if problems in comprehension were discovered. The study sought to determine how respondents understood questions, to assess to what extent respondents' understandings matched the intent of the questions, to understand the basis for misunderstanding where it occurred, and to recommend modifications based on the 4 months of field experience of the survey team. The revisions were made for consideration by NBS and the USAID Mission in finalizing the questions for the upcoming DHS survey in Tanzania.

The recommendations for revisions of questions in Swahili and also in English were made by consensus among all participants during the workshop. The suggested revisions were considered by NBS and USAID as the DHS questionnaire was finalized. Some recommendations were accepted and others were not. Similarly, the suggested revisions were also discussed in meetings held by DHS at ORC Macro headquarters, where some recommendations for changes in the questions were accepted and others were not.

In addition to providing specific recommendations for question modification, the study provided an opportunity to develop a model for rapid evaluation of questionnaires at the end of a survey. This model of question evaluation can be used to strengthen data collection and offer broadly applicable insights into issues of translation, construction, and comprehension of survey questions. Because the specific recommendations and process have already been discussed at length in the report, we focus this conclusion on a summary of issues that need to be considered more generally when conducting translations, as well as the types of problems found in questions that cause the most difficulty for comprehension.

5.1 Translation

DHS technical staff face a substantial linguistic challenge in nearly all countries where surveys are conducted: how to translate the original English (or French, or Spanish, or Portuguese) questions into several local languages in ways that are faithful to the intent of the questions as well as easily understood. In many countries, one individual or committee of people has translated each of the questions into a local language, and someone else has created a back translation into the language of origin. Back translations are then used to verify that the translation into a local language was correctly done. After verification, the questionnaires are printed in the local languages, and it is assumed that interviewers ask the questions as printed out.

In some countries, questions have been left in French, but a lexicon of key terms was produced to guide interviewers in asking questions. In such cases, finding evidence about how the questions were actually asked in the field, or identifying problem questions, would be difficult because each interviewer would need to recall how each question was translated most often.

Numerous factors are involved in producing translations that are appropriate; that is, translations that are both faithful to the original intent and easily understood by respondents. Those factors include 1) the degree of dialectical variations within a country, 2) the clarity and simplicity of the questions in the original language (French, English, Spanish, Portuguese), 3) the degree of local facility for writing a specific language, and 4) the skill of the translators. Some translators are savvy and confident enough not to propose literal translations but instead seek to formulate questions reflecting the original intent of the questions. Some people assume that the intent of questions can be judged by most intelligent English

speakers, who will not differ in their judgment. Others maintain that it is necessary to consult the persons who originally formulated the questions to ascertain original intent.

Preparation of the translation for the THIS survey in Tanzania was simpler than for most countries in Africa because 1) only one local language was needed (Swahili), 2) dialectical variations are not large, and 3) the country has a long tradition of writing in Kiswahili. Although certain problems of translation into Kiswahili were identified, they were easy to correct and did not offer overall lessons for either translation or understanding.

5.2 Types of Problems

We found several questions that posed problems because of poor or inaccurate translations into Swahili. Since these problems were peculiar to this translation, and thus do not lend themselves to generalizations, they are not addressed below. Instead, we focus more closely on the issue of the overall comprehension of questions. We will describe the kinds of questions likely to pose problems, and we will give examples from the recent study of THIS questions.

In examining questions that proved problematic because of the original English, two types of problems can be described: problems derived from style, and problems derived from structure. Whereas the problems derived from style in English are likely to pose difficulties first for translators, and secondarily, perhaps, for respondents, the obstacles caused by the structure of a question pose more of a challenge for respondents.

Problems of style

By "style" we mean polite, elegant, or indirect language, the arrangement of clauses in longer sentences, and the way certain words or phrases are given emphasis. Question 611 is an example of a formula used for politeness that complicated a question quite unnecessarily. The question was one of the most difficult of all for respondents to understand.

Q. 611. Husbands and wives do not always agree on everything. Please tell me if you think a wife is justified in refusing to have sex with her husband when she knows he has a disease that can be transmitted through sexual contact?

The question is complicated by this phrase: *Please tell me if you think* The Swahili translator used a fairly literal translation that was simply not understood. Why not just say, *Is a wife justified* . . .? Since the linguistic conventions for how to be courteous and polite, and to whom, vary so greatly from one language or society to another, it is best to keep the English as simple as possible and encourage the translators to add appropriate phrases to achieve politeness in their own language.

Another style issue that can lead to problems is that of underlining words in English to denote emphasis. Question 309 serves as an example of the use of underlining to emphasize a particular point. In the THIS questionnaire, words were underlined for emphasis.

Q. 309. Now I need to ask you some questions about sexual activity in order to gain a better understanding of some family life issues. How old were you when you <u>first</u> had sexual intercourse (if ever)?

Although English readers and speakers are accustomed to seeing words and phrases underlined, and they know what it means, that understanding is not necessarily shared by speakers and writers in other languages. The meaning of an emphasis on a particular word in English does not necessarily translate into the same meaning when that word is emphasized in another ("target") language. That was the case in the THIS survey, in which many people thought they were being asked when they first started

having sex with their current partner. The sentence was modified by adding the word *kabisa* at the end of the question in the Swahili version and *the very first time* in the English version.

A third style challenge is in questions containing several clauses in English, especially ones that contain a question or a condition. It appears that in English it is conventional to begin with the phrase containing the question, and the conditional (limiting) clauses follow. Here are two examples:

- **Q. 502.** Can people reduce their chances of getting the AIDS virus by having just one sex partner who is not infected and who has no other partners?
- **Q. 504.** Can people reduce their chances of getting the AIDS virus by using a condom every time they have sex?

In other languages, the convention about the order of clauses might differ. A translator must carefully consider word-order conventions of the target language in choosing how to arrange the translated questions. In Swahili, people understood the questions better after we placed the conditions first and asked the question afterwards.

However, for some questions (e.g., Q. 502), rearranging the clauses was not sufficient to achieve comprehension. Because question 502 contains four separate clauses, many respondents were simply unable to follow.

The challenges presented to translators by linguistic style can best be resolved by a translation team that finds ways of conveying the original intent, using the proper target-language emphasis, and imposing the right conventions about clauses and terminology without seeking a literal translation. That kind of translation will not only result in a more efficient interviewing process, but will also yield data that are more accurate.

Problems of structure

By structure we mean the form of the sentence: questions that are long with several clauses, or that are abstract, that are hypothetical, or are ambiguous. Questions of that kind are often not understood as intended.

Questions that had more than two clauses nearly always presented problems of comprehension in the THIS questionnaire. In some of those questions, respondents tried to answer halfway through, in a mistaken belief that they had understood enough to respond. Examples of questions that were too long for easy comprehension are the following:

- **Q. 504.** Can people reduce their chances of getting the AIDS virus by using a condom every time they have sex?
- **Q. 611.** Husbands and wives do not always agree on everything. Please tell me if you think a wife is justified in refusing to have sex with her husband when she knows he has a disease that can be transmitted through sexual contact?
- **Q. 612.** When a wife knows her husband has a disease that can be transmitted through sexual contact, is she justified in asking that they use a condom when they have sex?

Although Q. 504 may not appear long, the question does contain four separate thoughts: 1) getting the AIDS virus; 2) reducing the risk of getting the virus; 3) using a condom during sex; and 4) being careful to use a condom for every sex act. The question is actually more complex than it first

appears, and many people found it difficult to understand. Questions 611 and 612 gave interviewers no end of problems in trying to rephrase or simplify in order to be understood.

In addition to the problem of the length of some questions, several other questions examined in the study were abstract in the original English, causing difficulties in comprehension. In the field, enumerators responded to the challenge by innovating ways of asking the questions more concretely, a modification that led to better comprehension. An example of such a question is the following:

Q. 317A:

Original English: In this relationship, do you feel you can say no to having sex when you do not feel like it?

Revised English: If this person wants to have sex with you again, can you refuse them if you don't feel like it?

Two changes were made here. The phrase *In this relationship* was changed to *this person. Do you feel you can say no* was changed to *Can you refuse them?* In both cases, the new phrasing was easier for the respondents to follow than the original version.

Another category of questions that is likely to be misunderstood or be met with an "It depends" answer are questions that present hypothetical situations and ask respondents to state what they would do in a situation. The THIS questionnaire contained many such questions in the HIV/AIDS section of the questionnaire. A few of the examples are as follows:

- **Q. 514.** If you knew that a shopkeeper or vendor had the AIDS virus, would you buy fresh vegetables from that person?
- **Q. 514A.** Would you shake hands with someone who is infected with the virus that causes AIDS?
- **Q. 515.** If a member of your family got infected with the virus that causes AIDS, would you want it to remain a secret or not?
- **Q. 515A.** If a member of your family got infected with the virus that causes AIDS, would you be embarrassed or feel shame for your family?

For each of those questions, modifications were made to facilitate comprehension and reduce the chances that people would answer with "It depends."

Ambiguity in the English questions because of their structure or wording poses challenges first for translators, then for respondents, and finally at the analysis stage. Several of the above examples combine the hypothetical challenge with the obstacle of ambiguity.

Perhaps the clearest example of the difficulties presented by ambiguity is Q. 505:

Can people get the AIDS virus by sharing food with a person who has AIDS?

Here is a case where the translator makes the first important decision. The concept of *sharing food* is inherently ambiguous in English, so a translator will have several ways of translating the verb to *share* food. What might be meant by sharing food? It might mean giving food to someone with AIDS; it could mean eating at the same table with someone with AIDS, or even eating from the same dishes. The concept was translated into Swahili as *kula pamoja na*, or *to eat with*. That is more direct, but it does not quite correspond to the original English, and it *still leaves room for interpretation on the part of the*

respondent. The question was modified to say *to eat from the same plate*, a phrasing that removes most of the ambiguity of the original question.

In summary, it is important to give attention to the construction of the original English questions to achieve accurate translation, facilitate comprehension of questions by respondents, improve the efficiency of fieldwork and, ultimately, ensure accurate data. The process used for this study provides a rapid, workable model for examining and modifying survey questions.

Appendix A: List of Original THIS Questions and Recommended Changes

Section 3

Q. 309

Original English: Now I need to ask you some questions about sexual activity in order to gain a better understanding of some family life issues. How old were you when you first had sexual intercourse (if ever)?

Revised English: Now I need to ask you some questions about sexual activity in order to get a better understanding of some family life issues. How old were you when you had sex for the very first time?

Original Swahili: Sasa nahitaji kukuuliza maswali fulani fulani juu ya tendo la kujamiiana ili kuweza kufahamu vema masuala ya maisha ya kifamilia. Je, ulikuwa na umri gani ulipokutana kimwili kwa mara ya kwanza (kama ulishawahi)?

Revised Swahili: Sasa nahitaji kukuuliza maswali fulani fulani juu ya tendo la kukutana kimwili ili kuweza kufahamu vema masuala ya maisha ya kifamilia. Je, ulikuwa na umri gani ulipokutana kimwili kwa mara ya kwanza kabisa?

Q. 311

Original English: The first time you had sexual intercourse, was a condom used?

Revised English: The first time you had sex, did either of you use a condom?

Original Swahili: Je, kwa <u>mara ya kwanza</u> ulipokutana kimwili, ulitumia mpira wa baba au mama (kondomu)?

Revised Swahili: Je, kwa mara ya kwanza ulipokutana kimwili, mmoja wenu alitumia kondomu [mpira wa baba au mama]?

Q. 313

Original English: Did you use a condom the last time you had sex?

Revised English: The last time you had sex, did either of you use a condom?

Original Swahili: Je, kwa mara ya mwisho ulipokutana kimwili, mpira wa baba au mama (kondomu) ulitumika?

Revised Swahili: Kwa mara ya mwisho ulipokutana kimwili; Je, mmoja wenu alitumia kondomu [mpira wa baba au mama]?

Q. 314

Original English: What was your relationship to the person with whom you last had sex?

No changes recommended to the English.

Original Swahili: Je, ni nini uhusiano wako na mtu uliyekutana naye kimwili kwa mara ya mwisho?

Revised Swahili: Je, ni nani kwako mtu uliyekutana naye kimwili kwa mara ya mwisho?

Q. 317

Original English: Do you think he is at least ten years older than you?

No changes recommended to the English.

Original Swahili: Je, unafikiri anakuzidi kwa angalau miaka 10?

Revised Swahili: Je, unafikiri anakuzidi kwa miaka 10 au zaidi?

O. 317A

Original English: In this relationship, do you feel you can say 'No' to having sex when you do not feel like it?

Revised English: If this person wants to have sex with you again, can you refuse them if you don't feel like it?

Original Swahili: Katika uhusiano huu, unahisi unaweza kusema hapana kufanya tendo la ngono ikiwa utakuwa hujisikii kufanaya?

Revised Swahili: Kama mtu huyu anataka kukutana kimwili na wewe kwa mara nyingine; Je, unaweza kumkatalia ikiwa hujisikii?

(Codes) 1. Anaweza kukataa 2. Hawezi kukataa 3. Hajui

Q. 320

Original English: The last time you had sexual intercourse with another person, was a condom used?

Revised English: The last time you had sex with another person, did either of you use a condom?

Original Swahili: Je, kwa mara ya mwisho ulipokutana kimwili na mtu mwingine, mpira wa baba au mama (kondomu) ulitumika?

Revised Swahili: Kwa mara ya mwisho ulipokutana kimwili na mtu mwingine; Je, mmoja wenu alitumia kondomu (mpira wa baba au mama)?

Q. 321

Original English: What is your relationship with this person?

No changes recommended to the English.

Original Swahili: Je, ni nini uhusiano wako na mtu huyu?

Revised Swahili: Je, mtu huyu ni nani kwako?

Q. 324

Original English: Do you think s/he is at least ten years older than you?

No changes recommended to the English.

Original Swahili: Je, unafikiri anakuzidi kwa angalau miaka 10?

Revised Swahili: Je, unafikiri anakuzidi kwa miaka 10 au zaidi?

Q. 326

Original English: Other than these two people, have you had sex with anyone else in the last 12 months?

Revised English: In addition to these two people you mentioned, have you had sex with anyone else during the last 12 months?

Original Swahili: Mbali na hawa watu wawili, je, umeshakutana kimwili na mtu mwingine yeyote katika kipindi cha miezi 12 iliyopita?

Revised Swahili: Zaidi ya hawa watu wawili ulionitajia; Je, katika kipindi cha miezi 12 iliyopita, umeshakutana kimwili na mtu mwingine yeyote?

O. 327

Original English: The last time you had sex with this third person, was a condom used?

Revised English: The last time you had sex with this third person, did either of you use a condom?

Original Swahili: Je, kwa mara ya mwisho ulipokutana kimwili na mtu huyu wa tatu, mpira wa baba au mama (kondomu) ulitumika?

Revised Swahili: Kwa mara ya mwisho ulipokutana kimwili na mtu huyu wa tatu; Je, mmoja wenu, alitumia kondomu [mpira wa baba au mama]?

O. 328

Original English: What is your relationship with this person?

No changes recommended to the English.

Original Swahili: Je, ni nini uhusiano wako na mtu huyu?

Revised Swahili: Je, mtu huyu ni nani kwako?

Q. 331

Original English: Do you think s/he is at least ten years older than you?

No changes recommended to the English.

Original Swahili: Je, unafikiri anakuzidi kwa angalau miaka 10?

Revised Swahili: Je, unafikiri anakuzidi kwa miaka 10 au zaidi?

Q. 333

Original English: In total, how many different people have you had sex with in the last 12 months?

Revised English: In the past 12 months, with how many people did you have sex?

Original Swahili: Kwa jumla, ni watu tofauti wangapi umekutana nao kimwili katika miezi 12 iliyopita?

Revised Swahili: Katika kipindi cha miezi 12 iliyopita; Je, ni watu wangapi umekutana nao kimwili?

Q. 334

Original English: In the last 12 months, did you have sex with a prostitute?

Revised English:

MALE: Did you ever pay anyone for sex during the last 12 months?

FEMALE: Were you ever paid by a man for sex during the past 12 months?

Original Swahili: Katika kipindi cha miezi 12 iliyopita, umewahi kukutana kimwili na malaya?

Revised Swahili:

MALE: Katika kipindi cha miezi 12 iliyopita; Je, umewahi kumlipa yeyote kwa ajili ya kukutana naye kimwili?

FEMALE: Katika kipindi cha miezi 12 iliyopita; Je, umewahi kulipwa na mwanaume yeyote kwa ajili ya kukutana naye kimwili?

Revised Q. 334A

Original English: The last time you had sex with a prostitute, did you use a condom?

Revised English: The last time you had sex with that person, did either of you use a condom?

Original Swahili: Mara ya mwisho ulipojamiana na malaya, ulitumia mpira (kondomu)?

Revised Swahili: Kwa mara ya mwisho ulipokutana kimwili na mtu huyo; Je, mmoja wenu alitumia kondomu (mpira wa baba au mama)?

Q. 335

Original English: In the past 12 months has anyone forced you to have sex when you did not want to?

Revised English: In the past 12 months, have you ever been forced to have sex when you did not want to? (question applies to spouses)

Original Swahili: Katika miezi 12 iliyopita, umewahi kulazimishwa na yeyote kujamiiana naye wakati ambapo wewe hukutaka kujamiiana?

Revised Swahili: Katika kipindi cha miezi 12 iliyopita, umewahi kulazimishwa kukutana kimwili ambapo wakati wewe hukutaka (swali linawahusu hata waliooana)?

Q. 336

Original English: In total, how many different people have you had sex with in your lifetime?

Revised English: In your entire lifetime, how many people have you had sex with?

Original Swahili: Kwa jumla, ni watu wangapi tofauti tofauti umejamiiana nao katika maisha yako hadi sasa?

Revised Swahili: Katika maisha yako hadi sasa; Je, ni watu wangapi umeshakutana nao kimwili?

Q. 337

Original English: Do you know of a place where a person can get condoms?

Revised English: If someone needs a condom, where will they get it?

Probe: Any other place?

Original Swahili: Je, unafahamu mahali ambapo mtu anaweza kupata mpira wa baba au mama (kondomu)?

Revised Swahili: Kama mtu anahitaji kondomu; Je, atapata wapi?

Probe: Kuna sehemu nyingine yoyote?

Section 5

Q. 502

Original English: Can people reduce their chances of getting the AIDS virus by having just one sex partner who is not infected and who has no other partners?

No changes recommended to the English.

Original Swahili: Je, watu wanaweza kupunguza uwezekano wao wa kuambukizwa virusi vya UKIMWI kwa kuwa na mpenzi mmoja ambaye hajaambukizwa na ambaye hana wapenzi wengine?

Revised Swahili: Kwa kuwa na mpenzi mmoja tu, ambae hajaambukizwa, na hana wapenzi wengine, je, watu wanaweza kupunguza uwezekano wao wa kuambukizwa virusi vya UKIMWI? (By having only one partner, who is not infected, and who has no other partner, can people reduce their risk of being infected with HIV?)

Q. 503

Original English: Can people get the AIDS virus from mosquito bites?

No changes recommended to the English.

Original Swahili: Je, watu wanaweza kuambukizwa UKIMWI kwa kuumwa na mbu?

Revised Swahili: Je, watu wanaweza kuambukizwa virusi vya UKIMWI kwa kuumwa wa mbu? (Can people be infected with the AIDS virus through mosquito bites?)

Q. 504

Original English: Can people reduce their chances of getting the AIDS virus by using a condom every time they have sex?

Revised English: By using condoms each time they have sex, can people reduce their chances of being infected with the AIDS virus?

Original Swahili: Je, watu wanaweza kupunguza uwezekano wa kuambukizwa virusi vya UKIMWI kwa kutumia mpira wa baba au mama kila mara wafanyapo tendo la ngono?

Revised Swahili: Kwa kutumia kondomu (mpira wa baba au mama) kwa kila tendo la kukutana kimwili, je, watu wanaweza kupunguza uwezekano wao wa kuambukizwa virusi vya UKIMWI?

Q. 505

Original English: Can people get the AIDS virus by sharing food with a person who has AIDS?

Revised English: Can people be infected with the AIDS virus by eating from the same plate as someone who is sick with AIDS?

Original Swahili: Je, watu wanaweza kuambukizwa virusi vya UKIMWI kwa kula pamoja na mgonjwa wa UKIMWI?

Revised Swahili: Je, watu wanaweza kuambukizwa virusi vya UKIMWI kwa kula kwenye sahani moja na mgonjwa wa UKIMWI?

Q. 506

Original English: Can people reduce their chance of getting the AIDS virus by not having sex at all?

Revised English: Can people reduce their chances of being infected with the AIDS virus if they stop having sex altogether?

Original Swahili: Je, watu wanaweza kupunguza uwezekano wa kuambukizwa virusi vya UKIMWI kwa kutofanya tendo la ngono kabisa?

Revised Swahili: Kwa kuacha kabisa kukutana kimwili; Je, watu wanaweza kupunguza uwezekano wa kuambukizwa virusi vya UKIMWI?

Q. 508 (See page 23 for explanation of why we recommend combining Q. 508 and Q. 509.)

Original English: Is there anything (else) a person can do to avoid or reduce the chances of getting AIDS or the virus that causes AIDS?

Revised English Q. 508 and 509 combined: What can a person do in order to avoid or reduce their chances of being infected by the AIDS virus?

Original Swahili: Je, kuna kitu chochote kile ambacho mtu anaweza kufanya ili kuepuka au kupunguza uwezekano wa kupata UKIMWI au virusi vinavyosababisha UKIMWI?

Revised Swahili Q. 508 and 509 combined: Mtu anaweza kufanya nini ili kuepuka au kupunguza kupata maambukizi ya virusi vya UKIMWI?

Q. 512 (See page 23 for a possible alternative formulation to the series of PMTCT questions.)

Original English: Can the virus that causes AIDS be transmitted from mother to a child:

During pregnancy? During delivery? By breastfeeding?

Revised English: Is it possible for a child to be infected by the AIDS virus:

During pregnancy? During delivery? By breastfeeding?

Original Swahili: Je, inawezekana mtoto akaambukizwa virusi vinavyosababisha UKIMWI kutoka kwa mama yake:

Wakati wa ujauzito? Wakati wa kujifungua? Kwa kumnyoyesha?

Revised Swahili: Inawezekana mtoto akaambukizwa na virusi vya UKIMWI:

Wakati wa ujauzito? Wakati wa kujifungua? Kwa kumnyoyesha?

Q. 514 (Note that an additional question is recommended—see below.)

Original English: If you knew that a shopkeeper or vendor had the AIDS virus, would you buy fresh vegetables from that person?

Revised English: If you learned that a fresh-food vendor had the AIDS virus but was not sick, would you buy fresh food from him/her?

Original Swahili: Je, ikiwa ungefahamu kwamba muuza duka au mtembeza mboga ana virusi vya UKIMWI, ungeweza kununua mboga toka kwake?

Revised Swahili: Ikiwa ungefahamu kwamba muuza mboga [nyama, samaki, mboga ya majani] ana virusi vya UKIMWI, lakini haumwi; Je, ungeweza kununua mboga toka kwake?

New additional Q. 514A Je, kama anaumwa? (And if s/he is sick?)

Q. 514A (Would become Q. 514B if above change adopted—Note recommended additional question below.)

Original English: Would you shake hands with someone who is infected with the virus that causes AIDS?

Revised English: Would you shake hands with a person who had been infected with the AIDS virus but was not sick?

Original Swahili: Je, unaweza kupeana mkono na mtu ambaye ameambukizwa virusi vinavyosababisha UKIMWI?

Revised Swahili: Je, unaweza kupeana mkono na mtu ambaye ameambukizwa virusi vya UKIMWI lakini haumwi?

New additional question (would become **514C**): Je, kama anaumwa? (And if s/he is sick?)

Q. 515

Original English: If a member of your family got infected with the virus that causes AIDS, would you want it to remain a secret or not?

Revised English: If a member of your family were infected with the AIDS virus but was not sick, would you want it to remain a secret within the family or not?

(*Codes*) 1. Family secret 2. It should not be secret

Original Swahili: Ikiwa mwanafamilia katika familia yako atakuwa ameambukizwa virusi vinavyosababisha UKIMWI; Je, ungependa ibakie kuwa siri au la

Revised Swahili: Ikiwa mwanafamilia katika familia yako atakuwa ameambukizwa virusi vya UKIMWI, lakini haumwi, ungependa ibakie kuwa: siri ya familia tu, au isiwe siri?

(*Codes*) 1. Siri ya familia 2. Isiwe siri

Q. 515A

Original English: If a member of your family got infected with the virus that causes AIDS, would you be embarrassed or feel shame for your family?

Revised English: If a member of your family has been infected with the AIDS virus, would you be ashamed about your family?

Original Swahili: Ikiwa mwanafamilia katika familia yako atakuwa ameambukizwa virusi vinavyosababisha UKIMWI; Je, utajisikia vibaya au kuona kuwa ni aibu kwa familia?

Revised Swahili: Ikiwa mwanafamilia katika familia yako atakuwa ameambukizwa virusi vya UKIMWI, je, utaona kuwa ni aibu kwa familia?

Q. 517 and Q. 517A

Original English: If a <u>female</u> teacher has the AIDS virus but is not sick, should she be allowed to keep teaching in the school?

And: If a <u>male</u> teacher has the AIDS virus but is not sick, should he be allowed to keep teaching in the school?

Revised English Qs. 517 and 517A: In your opinion, if a female teacher has been infected with the AIDS virus, but is not sick, should she continue teaching?

And: In your opinion, if a male teacher has been infected with the AIDS virus, should he continue teaching?

Original Swahili: Je, ikiwa mwalimu wa kike atakuwa na virusi vinavyosababisha UKIMWI, lakini haumwi, aruhusiwe kuendelea kufundisha?

And: Je, ikiwa mwalimu wa kiume atakuwa na virusi vinavyosababisha UKIMWI, lakini haumwi, aruhusiwe kuendelea kufundisha?

Revised Swahili Qs. 517 and 517A: Kwa maoni yako, ikiwa mwalimu wa kike atakuwa na virusi vya UKIMWI, lakini haumwi, aendelee kufundisha?

And: Kwa maoni yako, ikiwa mwalimu wa kiume atakuwa na virusi vya UKIMWI, lakini haumwi, aendelee kufundisha?

Q. 518B (Note the recommendation of an additional question below. See page 25 for suggested revision in the order of questions. In the new order, the new question would be Q. 518D.)

Original English: Do you think your chances of getting AIDS are small, moderate, great, or no risk at all?

Revised English: Do you think your own chances of getting AIDS are low, average, high, or no risk at all?

Additional Recommended Question: Reflecting on your relationship with your partner, do you think your own chances of getting AIDS are low, average, high, or no risk at all?

Original Swahili: Je, unadhani nafasi yako kupata UKIMWI, ni ndogo, ya wastani, ni kubwa au haiwezekani kabisa?

Revised Swahili: Je, unadhani nafasi yako wewe mwenyewe ya kupata UKIMWI ni ndogo, ya wastani, ni kubwa au haiwezekani kabisa?

Additional Recommended Question: Ukitilia maanani, mahusiano yako na mwenzi wako; Je, unadhani nafasi yako ya kupata UKIMWI ni ndogo, ya wastani, ni kubwa au haiwezekani kabisa?

O. 521

Original English: Now I would like to ask some questions about your last birth. Did you see anyone for antenatal care during that pregnancy?

No changes recommended to the English.

Original Swahili: Sasa ningependa nikuulize baadhi ya maswali kuhusiana na uzazi wako wa mara ya mwisho. Je, ulimuona yeyote kwa ajili ya huduma kwa wajawazito wakati wa ujauzito huo?

Revised Swahili: Sasa ningependa nikuulize baadhi ya maswali kuhusiana na uzazi wako wa mara ya mwisho; Je, ulipata huduma ya wajawazito wakati wa ujauzito huo?

O. 526

Original English: Where was the test done?

[If source is hospital, health center, or clinic, write the name of the place. Probe to identify the type of source and circle the appropriate code.]

No changes recommended to the English.

Original Swahili: Vipimo hivyo vilifanyika wapi?

Probe: [Ikiwa ni hospitali, kituo cha afya, au kliniki, andika jina la mahali. Dadisi kutambua aina ya umiliki wa mahali hapo kisha zungushia sehemu inayohusika.]

Revised Swahili: Vipimo hivyo vilifanyika wapi?

Probe: [Ikiwa ni hospitali, kituo cha afya, au kliniki, au sehemu nyingine yoyote. Andika jina la mahali. Dadisi kutambua aina ya umiliki wa mahali hapo kisha zungushia sehemu inayohusika.]

Additional Probe: Kuna sehemu nyingine yoyote? (Any other place?)

Q. 533

Original English: There are many reasons why people do not get tested for HIV. Can you tell me why you have not been tested?

No changes recommended to the English except add codes—see below.

Original Swahili: Kuna sababu nyingi zinazowafanya watu kutopima virusi. Je, unaweza kuniambia ni kwa nini hujapima?

Revised Swahili: Kuna sababu nyingi zinazowafanya watu kutopima virusi. Je, wewe una sababu gani? There are many reasons why people do not get tested for the AIDS virus. And what is your reason?)

Add codes:

- a) Mbali sana (It is very far away)
- b) Hajui mahali pa kupimia (I don't know where to go)
- c) Atahitaji kuomba ruhusa (s/he has to ask permission)

Section 6

Q. 602

Original English: Apart from AIDS, have you heard about other infections that can be transmitted through sexual contact?

No changes recommended to the English.

Original Swahili: Mbali na UKIMWI, Je, umeshawahi kusikia juu ya maambukizo ya aina nyingine yanayoweza kuenezwa kwa kujamiiana?

Revised Swahili: Mbali na UKIMWI, je, umeshawahi kusikia juu ya majongwa ya aina nyingine yanayoweza kuenezwa kwa kukutana kimwili. (Besides AIDS, have you heard about any other diseases that are transmitted through sexual intercourse?)

Q. 611

Original English: Husbands and wives do not always agree on everything. Please tell me if you think a wife is justified in refusing to have sex with her husband when she knows he has a disease that can be transmitted through sexual contact?

No changes recommended to the English.

Original Swahili: Si wakati wote mke na mume hukubaliana katika kila kitu. Tafadhali nieleze ikiwa unafikiri ni halali mke kukataa kufanya ngono na mume wake wakati akijuwa mumewe ana ugonjwa unaoambukiza kwa kukutana kimwili?

Revised Swahili: Si wakati wote mke na mume hukubaliana katika kila kitu. Je, ni halali mke kukataa kukutana kimwili na mumewe wakati akijuwa mumewe ana ugonjwa unaoambukiza kwa kukutana kimwili (kujamiiana)? (Husbands and wives do not always agree on everything. Is it right for a wife to refuse sex with her husband if she knows he is suffering from an illness transmitted through sexual intercourse?)

Q. 612

Original English: When a wife knows her husband has a disease that can be transmitted through sexual contact, is she justified in asking that they use a condom when they have sex?

No changes recommended to the English.

Original Swahili: Wakati mke anajuwa kwamba mume wake ana ugonjwa unaoambukiza kuenea kwa kujamiliana, ni halali kumuomba watumie mpira (kondomu) wakati wa kujamiiana?

Revised Swahili: Wakati mke anajuwa kwamba mumewe ana ugonjwa unaoambukiza kwa kukutana kimwili; Je, ni halali kumuomba watumie kondomu [mpira wa baba au mama] wakati wa kukutana kimwili (kujamiiana)? (When a wife knows that her husband is suffering from a disease transmitted through sexual intercourse, is it right to ask him to use a condom for sex?)

Appendix B: Questions Raised by Field Observations But Not Dealt With in the Workshop

Section 3:

Q. 303 For Women

Original English: Besides yourself, does your husband have other wives or does he live with other women as if married?

Original Swahili: Mbali na wewe, je, mume wako ana wake wengine au kuishi na wanawake wengine kama watu waliooana?

Field observations: This question elicited from many women a response of *Yes, my husband was having sex with another woman.* A few wives knew that their husbands had had children by other women. If a wife indicated that, the interviewer would then probe: *Is he married to this woman or living with her like married?* The answer was usually *No.* The response was then coded as *no other wives*, even though the woman knew or suspected that her husband had other partners.

If the intent of the question is to measure official polygyny, this question works well. However, if we are interested in knowing about risk for HIV and other STIs, then it seems we are losing some important information about what women know about their partners' behavior and their risk as a result. If it is important here to find out about HIV and other STI risk, then it would help to add either another question or coding that allows for other nonmarital partners.

Q. 312

Original English: When was the <u>last</u> time you had sexual intercourse?

Original Swahili: Je, ni lini ulipokutana kimwili kwa <u>mara ya mwisho</u>?

Field observations: Asking this question brought forth shyness and giggles from respondents. Often the question had to be repeated or rephrased. Rephrasing included changing *mara ya mwisho* (the last time) to *siku ya mwisho* (the last day) or *ni muda gani imepita tangu....* (how much time has passed since...?).

Interviewers also thought that married respondents would assume the question was asking only about the marital partner or that they might choose to report on the spouse even if their most recent sexual encounter had been with someone else. One respondent was observed requesting clarification on this point by asking *Here in the house, or outside?* Without knowing just how important this aspect is, there might be a simple way to emphasize in this question (being careful not to offend) that what we are asking about is the respondent's most recent sexual encounter, whether or not it was with his/her spouse.

O. 319

Original English: Have you had sex with any other people in the past 12 months?

Original Swahili: Je, umewahi kukutana kimwili na watu wengine wowote katika kipindi cha miezi 12 iliyopita?

Field observations: This question needs clarification at times and interviewers say they find that some respondents do not understand that we are asking about someone different from the person they just reported on in the previous section. So interviewers get to the end of the sequence, only to find it is the same person as reported on in 312-318: the person with whom they last had sex. Some interviewers were adding *mbali na huuyu*—of which a literal translation would be "beyond this person"—to make sure the respondent understands that it is now someone different who is being asked about.

The same observation applies to Q. 326.

Q. 339

Original English: Have you ever seen or heard the slogan Ishi?

Original Swahili: Je, umeshawahi kuona au kusikia msemo usemao "Ishi"?

Field observations: This question had to almost always be repeated, sometimes multiple times, with an additional explanation to say that the question was not asking about the word *ishi* ("to live") as used in everyday language, but about the program "ISHI."

Q. 341

Original English: What do you think of when you hear the word "Ishi"?

Original Swahili: Je, unafikiri nini mara usikiapo neno "Ishi"?

Field observations: This question also needed repeating and explanation. Several respondents replied with a question, *Wanaongelea mambo gani?* (They talk about what stuff?) Interviewers recommended a modification along the lines of *Ujumbe gani unapata kutokana na neno ishi?* (What kind of information do you get...?)

Q. 342

Original English: During the past 12 months, did you ever watch a talk show on television called "Femina?"

Original Swahili: Katika miezi 12 iliyopita, umewahi kuangalia onesho la mazungumzo kwa njia ya televisheni liitwalo "Femina?"

Field observations: More people seemed to know the magazine *Femina* than the TV show. So they would often say, "I have not seen it on TV, but have read the magazine."

Section 4

Q. 402

Original English: How old was your husband/partner on his last birthday?

Original Swahili: Je, mume au mwenza wako ana umri gani?

Field observations: This question was very problematic, because many wives do not know their husband's age. Many insisted they didn't know, and the back-and-forth with the interviewer trying to get them to give an age slowed the interview considerably. It also makes one wonder about the level of

accuracy of the information collected. It would be instructive to see how much data are missing for this question. Perhaps it would be helpful to add a "Don't know" category.

Q. 406

Original English: What was your (last) husband's/partner's occupation? That is, what kind of work did he mainly do?

Original Swahili: Je, ni nini ilikuwa kazi ya mume/mwenzi wako wa mwisho? Yaani, ni shughuli gani kuu ambayo alikuwa akifanya?

Field observations: This question has the same problem as Q. 402. Many women simply do not know.

Section 5

Q. 513

Original English: Are there any special drugs that a pregnant woman infected with the AIDS virus can take to reduce the risk of transmission to the baby?

Original Swahili: Je, kuna dawa zozote maalum ambazo mwanamke mjamzito ambaye ameambukizwa virusi vinavyosababisha UKIMWI anaweza kuzitumia ili kupunguza hatari ya kuambukizwa mtoto?

Field observations: This question often needed repeating. Because it is so long, by the end it appeared that the respondent had forgotten the beginning of the question.

Q. 516

Original English: If a relative of yours became sick with the virus that causes AIDS, would you be willing to care for him or her in your own household?

Original Swahili: Je, ikiwa ndugu yako atakuwa mgonjwa kutokana na virusi vinavyosababisha UKIMWI, utakuwa tayari kumhudumia katika kaya yako mwenyewe?

Field observations: This question appeared to get a very quick, almost automatic answer, rather as though the respondents knew that the correct/appropriate answer was *Yes*, or that there was absolutely no question whether they would care for a relative who had AIDS. It would be instructive to look at the frequencies on this question.

The interviewers also noted that "care" can mean many things, and that in some cases, this question led to lengthy answers, or a request for clarifications (such as "What do you mean by 'care'?"). Perhaps the question could be made more specific. In the multicountry study on stigma, we found that although care was almost always given at some minimal level, the level of quality of the care and the stigma that came with it did vary, often directly in relation to the closeness of the kinship ties.