WOMEN'S INTERAGENCY HIV STUDY QUESTION-BY-QUESTION SPECIFICATIONS

FORM WAVE: WOMEN'S ADHERENCE AND VISIT ENGAGEMENT (WAVE) STUDY

SECTION B: HIV STIGMA (B1 adapted from Bunn 2007*)

The purpose of these questions is to understand the attitudes that HIV-positive people have towards HIV and people with HIV.

- Questions B1 to B3 are asked only to HIV-POSITIVE participants. READ THE INTRODUCTION TO THE PARTICIPANT.
- Introduction for HIV-positive participants precedes Question B1.
- **B1. HAND PARTICIPANT RESPONSE CARD WAVE1.** Ask HIV-positive participants how strongly they agree or disagree with a set of statements. Possible answers are "strongly agree," "agree," "disagree," or "strongly disagree."
 - If the participant has trouble answering the question or is not sure of her answer, ask her if she generally agrees or disagrees with the statement. Then, ask whether she agrees/disagrees strongly. Alternatively, ask if she agrees/disagrees "a little" or "a lot." If she says "a lot," indicate "strongly" agree or disagree as her response.

Parts a-g of this question focus on *internalized stigma*, or negative self-perceptions or attitudes people have about themselves because of their HIV status. The last question focuses on discrimination in health care settings.

- Statements are phrased either in a negative or positive way. Read each statement neutrally without indicating through tone of voice or expression that the statement is good or bad.
- a. This question is phrased as a <u>negative</u> statement reflecting internalized stigma.
- b. This question is phrased as a <u>negative</u> statement reflecting internalized stigma.
- c. This question is phrased as a negative statement reflecting internalized stigma.
- d. This question is phrased as a negative statement reflecting internalized stigma.
- e. This question is phrased as a <u>negative</u> statement reflecting internalized stigma.
- f. This question is phrased as a negative statement reflecting internalized stigma.
- g. This question is phrased as a <u>positive</u> statement reflecting the *lack of* internalized stigma. Stress the "never" in "I *never* feel ashamed..." since this is the one positively phrased statement in Question B1.
- h. This question is phrased as a <u>negative</u> statement reflecting perceived external stigma by health professionals.
- **B2.** We are interested in whether the participant has <u>ever</u> disclosed her HIV status to anyone *other than a health care provider*, at any time in her life.

- If the answer is NO, then skip to **Section C**.
- For participants who have ever disclosed their HIV status, read each option indicating to whom she disclosed, and indicate YES or NO. Note that categories may not be mutually exclusive. In this case, for any overlapping options where "sexual partner" is included (for example, "past sexual partner" and "neighbor") select only "sexual partner." However, if two other options overlap (for example, "friend" and "neighbor"), ask her to choose the label that best fits that person's relationship to her.
 - h. If needed, clarify that "public disclosure" means talking about her HIV status in public, for example in front of people in a public place or social gathering, at a rally, in a meeting, or in a newspaper article.
 - i. If the answer to "Other" is YES, then have the participant indicate to whom she disclosed her HIV status.

SECTION C: FOOD SECURITY AND HUNGER (from USDA HFSS**)

General Instructions:

- 1. For questions containing an open-ended specify box linked to the response "other," interviewers should type in responses exactly in the words of the participant.
- 2. Researchers have found that people may feel defensive and uncomfortable about these types of questions. Stress to the participant that her responses are strictly confidential.

This section encompasses a scale developed by the USDA to determine the extent and severity of food insecurity and hunger in the United States. Food insecurity, as measured by this scale, refers to the limited or uncertain availability of nutritionally adequate and safe foods because of financial constraints, and is measured at the household level; some questions ask about the participant, adults, or children in the household. Hunger is a severe manifestation of food insecurity. We are interested in measuring food insecurity because it has been linked to increased HIV risk and poor HIV health outcomes, including poor adherence to antiretroviral therapy and disease progression.

READ THE INTRODUCTION TO THE PARTICIPANT.

- C1-C3. HAND PARTICIPANT RESPONSE CARD WAVE2 FOR USE WITH QUESTIONS C1
 THROUGH C3. These questions ask the participant to think about situations their household experienced during the last 6 months that might indicate food insecurity. These situations are posed as statements for which possible answers are "Often true," "Sometimes true," and "Never true."
 - If the participant requests it, repeat the statement again.
 - If the participant gives an answer other than the indicated options (e.g., "True," or "Once or twice," probe again to determine whether it was "Sometimes" or "Often" true.
 - For **Question C1**, emphasize the word *worry* in this statement: "We *worried* whether our food would run out..." If necessary, clarify that this question is

- about worry about food running out, regardless of whether food actually ran out.
- For Question C3, if necessary clarify that "a balanced meal" generally means a
 variety of foods that together provide good nutrition for health. However, the
 foods in a balanced meal may look different depending on dietary needs and
 restrictions, or cultural food preferences.
- C4. Ask whether the participant or other adults in the household reduced their food intake because there wasn't enough money for food (YES/NO).
 - Stress the "other adults" since this question does not use the word "household" or "we," to make it clear this is not just about the participant alone.
 - If the response to this question is NO, then skip to **Question** C6.
- **C5. HAND PARTICIPANT RESPONSE CARD WAVE3.** The purpose of this question is to probe for the frequency of food reduction among the participant or other adults reported in Question C4.
 - If the participant answers something other than the options on the Response Card (e.g., "sometimes," "maybe once," etc.), clarify by pointing to the Response Card and asking her which option most closely matches her answer. For example, "You said maybe once? So [pointing to Response Card], would that be 'Only one or two months?'"
- **C6-C8.** For these three questions, we are only interested in what happened to the participant and not to other household members. Therefore, emphasize the "you" in these questions, and if necessary clarify that the participant should only think about her own experiences for these questions.
- **C9.** This question returns to asking about the participant or other adults in her household.
 - For **Question C9**, if the response to this question is NO, then skip to **Question C11**.
- **C10. HAND PARTICIPANT RESPONSE CARD WAVE3.** The purpose of this question is to probe for the frequency of food reduction reported in Question C9.
 - If the participant answers something other than the options on the response card (e.g., "sometimes," "maybe once," etc.), clarify by pointing to the response card and asking her which option most closely matches her answer.
- **C11. READ CONCLUSION TO END OF MODULE.** Then record the actual time you ended the module.

References:

*Bunn 2007 = Measurement of stigma in people with HIV: A reexamination of the HIV Stigma Scale.

**USDA HFSS = U.S. Department of Agriculture Household Food Security Scale.