WOMEN'S INTERAGENCY HIV STUDY QUESTION BY QUESTION SPECIFICATIONS FORM 26: PSYCHOSOCIAL MEASURES

Guidelines for completing Form 26, "Psychosocial Exam." Note that not every question is detailed in these QxQs, but only those requiring further explanation than that listed on Form 26.

General Instructions:

- 1. Use the form version dated 10/01/03.
- 2. Obtain the date of the participant's previous **even-numbered** visit (i.e., the last visit at which the entire F26 was administered to the participant) and record it in question A6. Some sections of this form refer to a different time frame than the participant is used to from other interview forms. Since the entire F26 is currently administered only at even-numbered visits, all questions asking about occurrences during the time period since the participant's (MONTH) study visit will refer to the time period since the participant's last study visit during which F26 was administered (i.e., her last even-numbered study visit). The date of her last even-numbered study visit should be read aloud in the questions where (MONTH) appears. Please ensure that the participant is aware of the frame of reference for questions on this form. The participant should be reminded of the date [MONTH/DAY/YEAR], as needed, during the interview.
- 3. For questions containing an open-ended specify box linked to the response "other," interviewers should <u>print</u> responses exactly in the words of the respondent.

Indicators for the beginning and end of all subforms have been added to the form. This has been done for data entry purposes only and will not affect how the form is completed.

SECTION A: GENERAL INFORMATION

This section at the beginning of the form should be completed before administering the psychosocial exam. Record the actual time you began F26 in the space provided for "Time Module Began" and the actual time you ended the exam in the space denoted "Time Module Ended" on the last page of the form. Remember to use leading zeros. For example: 08:00.

Beginning with visit 19, the CES-D Depression Scale (Section C only) will be administered at every visit, while the entire form will continue to be administered only at even-numbered visits. Therefore, if the form is being administered at an odd-numbered visit, the interviewer should follow the skip patterns indicated in questions A8 and C21 so that only the CES-D is completed.

For even-numbered visits, begin the form by reading the introduction to the participant. Insert the date of the participant's last **even-numbered** visit (from question A6) into the introduction.

SECTION B: QUALITY OF LIFE SCALE

B1–B10: These questions contain a standardized scale to measure quality of life. Read each question and response category exactly as it is worded and circle the appropriate response. If the participant is hesitant, **PROBE** for a response by saying, "We are interested in your opinion— so, whatever it means to you." If the participant has difficulty deciding between answers, **PROBE** for an appropriate response by saying, "Which choice is closest?" or, "I can only circle one answer—which choice best reflects your experience?"

Some of the questions refer to specific time frames (such as in the past four weeks or since the participant was last administered F26), while others do not refer to a particular period of time. Please be aware of this both as you read the question and as you probe for an answer from the participant.

Many of the questions use the phrasing "in general" or "generally." When reading the questions, these words should be emphasized.

Some questions include phrases such as "bodily pain" that the participant might ask the interviewer to clarify. **PROBE** for an answer by saying, "We are interested in your opinion—so, whatever you consider to be bodily pain." This should be applied to all situations in which the participant is confused about a certain phrasing.

- B7. **HAND PARTICIPANT RESPONSE CARD 13A.** This question has an introduction and four sections. First, read the introduction. Then ask the participant "How much does <u>your</u> health limit:" and insert each section.
- B8. This question has an introduction and eight sections (a–h). First, read the introduction and then ask the participant, "How much of the time during the past four weeks:" and insert each section.
- B10. If the participant has trouble deciding on an exact number, repeat the question stressing the phrase, "*Please tell me which number is closest.*" If the participant answers "5 and 1/2" or "between 4 and 5," **PROBE** for an appropriate response by saying, "I can only record one choice. Of the numbers listed on the scale, which one would you choose?"

SECTION C: CES-D DEPRESSION SCALE

These questions (C1–C20) utilize a standardized scale to measure depression. All questions should be asked exactly as they are worded. If necessary, reiterate to the participant that we are interested in *her opinion*, in whatever way she understands the question. **PROBE** further by reminding her that there are no right or wrong answers. NOTE: The time frame for these questions is one week. The interviewer should emphasize the phrase "during the past week" as she reads each question.

HAND PARTICIPANT RESPONSE CARD 16. First, read the instructions at the top of page 5. Then read each question and each of the response choices *printed on the card*. Please read the *complete* list of response choices to the participant. These are provided for you in the boxes at the top of pages 5 and 6. As you proceed down the list of questions, the participant may begin to understand the nature of the questions and the scale. Use your judgment to decide if it will be necessary to read each response choice once the pattern has been established. If you have any doubt about the participant's ability to answer the questions, read the response choices.

C21. If the form is being administered at an odd-numbered visit (i.e., only CES-D is administered), circle "YES" for question C21 and skip to question H4.

SECTION E: CHILDREN

This section deals with the participant's children, <u>including</u> biological, adopted, step, or foster children whom the participant considers to be her own, whether they live with her or not. It also deals with children who may have died. For this section, children are defined as children less than 18 years of age at the time of this interview. This definition should be stressed to the participant.

This section may be difficult for the participant because it is an extremely sensitive issue. The interviewer should allow the participant plenty of time to respond to particular questions. The interviewer may find that using a pause as a Probe in this section is helpful in facilitating the interview.

The interviewer should NOTE that the <u>skip patterns are tricky and complicated</u> throughout this section. Care should be taken to make sure that the interview correctly follows the prompt and skip pattern directions.

Please note as well that questions in this section which contain the qualifier "since your (MONTH) study visit" refer to the time period between now and the participant's last even-numbered study visit (i.e., her last interview at which the entire F26 was administered). Ensure that she understands the time frame for these questions differs from that on other forms.

- E1. This question includes all children (birth, step, foster, or adopted children) regardless of whether or not they are living with the participant. If the participant reminds you that she has already told you about biological children in F23, OB/GYN and Contraceptive History, remind her that this question also asks about adopted, step, and foster children. She should, however, be sure to include any biological children that you have already talked about.
- PROMPT: IF E2 = NO, DON'T KNOW OR DECLINED <u>AND</u> E1 = YES, THEN SKIP TO QUESTION E10.

IF E2 = NO, DON'T KNOW OR DECLINED <u>AND</u> E1 = NO, THEN DO NOT ADMINISTER ANY ADDITIONAL SECTION E QUESTIONS. READ PROMPT ON PAGE 10 AND PROCEED TO F1 OR H4 AS DIRECTED.

- E3a. Some responses to this question may be difficult to code such as joint or shared custody of the participant's children. Code such responses to reflect the participant's perception; if she feels that her children live with her, code it as such. If she is unsure how to respond, record her answers verbatim in the margin.
- E6. This question asks only about children who have died postnatally (after being born), and **does not include miscarriages or stillbirths.** If the participant does not indicate at this point that the child in question was miscarried or still born but does reveal this fact at subquestion **b** of questions **E7–E10** (which asks for the child's age at the time of his/her death), then the interviewer should return to question **E6** and correct the answer as needed, adjust the answer to question **E6a**, and make a note explaining the correction in the margin.
- PROMPT: IF E6 = NO, DON'T KNOW OR DECLINED <u>AND</u> E1 = YES, THEN SKIP TO QUESTION E10.

IF E6 = NO, DON'T KNOW OR DECLINED <u>AND</u> E1 = NO, THEN DO NOT ADMINISTER ANY ADDITIONAL SECTION E QUESTIONS. READ PROMPT ON PAGE 10 AND PROCEED TO F1 OR H4 AS DIRECTED.

E6a. Record the number of children who have died using leading zeros "0." For example: 01.

Before administering questions **E7–E9**, read the introduction. Because this is a sensitive and painful issue to be discussing, be attentive to the participant's needs in determining when to begin. The interviewer should encourage the participant to take all the time she needs before beginning these questions as well as throughout the duration of these questions.

- E7–E9: This series of questions is designed to collect information for up to three deceased children. If more than three children are reported deceased in question **E6a**, it may be necessary to Xerox these questions to capture the additional information. The interviewer may wish to obtain each child's initial or name for easy reference to that child throughout the sequence of questions; however, **do not record the child's name anywhere on the form**.
- Example for a response in months: If the child was six months old when he or she died, record "06" in the boxes and circle "1" for "MONTHS"; do not record "1/2" or "0.5" years. If the child was less than one month old when s/he died, record a "00" in the boxes, circle the "MONTHS" code, and write the number of weeks in the margin. For example, "2 weeks."

Example for a response in years: Record the number of years to the nearest integer rounding up or down as follows: If the participant says the child was five years and three months old when s/he died, record "05" and circle "2" for "YEARS." If the participant says the child was seven years and seven months old, code "08" in the boxes and circle "2." Remember to round down (to the next lower year) for responses less than six months; and to round up (to the next higher year) for responses of six months or more.

PROMPT: IF E1 = YES, SKIP TO QUESTION E10.

IF E1 = NO, DO NOT ADMINISTER ANY ADDITIONAL SECTION E QUESTIONS. READ PROMPT ON PAGE 10 AND THEN PROCEED TO F1 OR H4 AS DIRECTED.

- E11. Read the stem, "During the past 6 months, how worried or concerned have you been about" first and then insert each subquestion (a–f). If the participant answers, "somewhere between 2 and 3", PROBE for an appropriate response by asking, "Which is closer?"
- E13. In this question, "Hospitalization" includes overnight stays and admittance for special procedures. Visits to the Emergency Room alone should not be included unless they result in an admittance to the hospital. Record the number with leading zeros ("0") if the answer has only one digit. Example: "01."

PROMPT: FOR CALIFORNIA SITES AND ALL PARTICIPANTS UNDER 18 YEARS OF AGE, SKIP TO QUESTION H4 AND END THE INTERVIEW.

SECTION F: SEXUAL ABUSE

Dealing with disclosures of sexual abuse experiences can be an extremely painful and possibly traumatic experience. Participants who have had this experience may be at different stages of dealing with their own personal history of sexual abuse. Some may have buried memories of being victimized or are in the process of actively dealing with such a history that could result in deeply disturbing emotions while answering these questions. Others may feel more emotionally resolved about a history of such experiences. It is important in administering this section of the interview that the interviewer be sensitive to the emotional state of the participant.

Read the introduction and offer the woman an opportunity to collect herself as needed throughout this section of the interview. Reemphasize that questions in this section deal with the time period from the participant's last even-numbered visit until the present.

- F2. This question allows the participant to decline going into further detail about the sexual abuse that she experienced. If the participant indicates that she does not want to continue, circle "2" and skip to question **F4**. If the participant agrees to continue, circle "1" and go on to question **F3**.
- F3. Only record the offender's relationship to the participant, not the actual name of the person. For example, if she says, "It was Frank," ask her, "What is his relationship to you?" If she says Frank is her cousin, circle "1" at question F3f OTHER RELATIVE and write the word "cousin" on the line above SPECIFY.
- F4. The key words in this question are "now know."

SECTION G: DOMESTIC VIOLENCE

This section deals with the participant's experiences with physical abuse and coercive and controlling relationships. Like the questions dealing with sexual victimization, it is important to realize that a woman may have strong emotional feelings in answering these questions, yet she may also welcome an opportunity to talk about her experience. Another important issue is to be prepared to provide the appropriate resources for a woman who discloses a history of physical abuse and to assess the woman's current situation in terms of her immediate physical safety.

The questions in this section capture physical abuse in the time frame since the participant was last administered the entire F26 (i.e., at the participant's last even-numbered study visit), including threatening, intimidating and controlling behavior, the ability to negotiate for safer sex, and an assessment of her immediate physical safety. Reemphasize that questions in this section deal with the time period from the participant's last even-numbered visit until the present.

G1–G7: Read the seed question, "Since your (MONTH) study visit, has a current or previous partner" first, and insert the appropriate question for subquestions **G1–G7**.

SECTION H: PHYSICAL VIOLENCE

The same care and concerns applied to reading Section G (described above in the beginning of Section G) should also be applied when reading Section H, Physical Violence. Reemphasize that questions in this section deal with the time period from the participant's last even-numbered visit until the present.

- H2. This question allows the participant to decline going into further detail about the physical abuse that she experienced. If the participant indicates that she does <u>not</u> want to continue, circle "2" (NO) and skip to question **H4.** If the participant agrees to continue, circle "1" (YES) and continue with question **H3**.
- H3. For this question, only record the offender's relationship to the participant, not the actual name of the person (as described in the QxQs for question **F3**).

At the end of the interview, be sure to link the participant with appropriate intervention or referral indicated by her responses during the interview.