

WOMEN'S INTERAGENCY HIV STUDY
QUESTION BY QUESTION SPECIFICATIONS
FORM 25c: ENGAGEMENT IN CARE MEASURES

SECTION A: GENERAL INFORMATION

This section at the beginning of the form should be completed before administering the engagement in care questions. Record the actual time you began *F25c* 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.

Some sections of this form (Section C and Section E) will be asked only at even-numbered WIHS visits so please pay careful attention to the skip patterns.

If the participant is HIV-positive, continue to Section B. If the participant is HIV-negative, follow the skip pattern in Question A8 and skip to Section D.

SECTION B: CONTINUITY OF CARE

Begin Section B by reading the *Introduction to Participant*. The questions in this section all refer to the participant's "regular HIV care." If the participant is unclear about the meaning of the term "regular HIV care," read the definition in the introduction again. 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.

- B1: If the participant reports she has never received regular HIV care, skip to Section D. If the participant reports ever receiving regular care, enter a date that is six months prior to the current WIHS visit date. For example, if the current WIHS visit date is 7/15/13, then six months prior to that date would be 1/15/13.
- B2-4: These questions all reference a six-month recall period. Use a calendar to show the participant the start date and, if the participant has an appointment book, use that to help her recall visits.
- B2: If the participant responds "Yes" to Question B2, fill in the number of times she went for regular HIV care in Question B3. If the participant responds "No," skip to Question B4.
- B3: If the participant is unsure of the exact number of times she has gone for regular HIV care, ask for her best guess.
- B4: If the participant responds "Yes" to Question B4, fill in the number of times that she missed regularly scheduled visits in Question B4a. If the participant is unsure of the exact number of times, ask for her best guess.
- B6: If this is an odd-numbered visit, skip to Section D. If it is an even-numbered visit, proceed to Section C.

SECTION C: TRUST IN HIV CARE PROVIDERS, HEALTH CARE EMPOWERMENT, BARRIERS TO CARE

These questions contain standardized scales to measure trust in care providers (Safran), health care empowerment (Johnson, et al.) and barriers to care (Kalichman).

C1-C8: Read the introductory paragraph for this set of questions. **HAND PARTICIPANT RESPONSE CARD 12A.** Read each question 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 best reflects your opinion.”* 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 opinion?”* Reinforce WIHS confidentiality if the participant seems concerned about possible disclosure of responses to questions about their care providers.

C9-C16: Read the introduction to this set of questions. **USE RESPONSE CARD 12A.** Read each question exactly as it is worded and circle the appropriate response.

C17a-h: This set of questions again references a six month time period. Read the stem question and each response statement and record the appropriate response (Yes or No). If a participant is unsure how to answer a particular question, repeat the stem question and relevant response statement again. If the participant is still unsure, say *“I can only record Yes or No. Of these, which one would you choose?”*

SECTION D: SOCIAL SUPPORT, SOCIAL ISOLATION, ANXIETY

This section contains standardized scales assessing social support (MOS SSS), social isolation (Hughes, R-UCLA) and anxiety (GAD-7).

D1-D3: Read the introduction statement. Read each question and all of the response options. Record the appropriate response. If the participant is unsure, repeat the questions and response options. If she is still unsure, say *“I can only record one of these answers. Of these, which one would you choose?”*

D4-D18: Read the introductory paragraph for this set of questions. **HAND PARTICIPANT RESPONSE CARD 12B.** Read each statement and record the response. Note that only Question D16 has a Not Applicable response option. 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 opinion?”*

D19-D25: Read the introductory paragraph for this set of questions. **HAND PARTICIPANT RESPONSE CARD 12C.** Read each statement and record the response. If the participant has difficulty deciding between answers, *“I can only record one of these answers. Of these, which one would you choose?”*

D26: If this is an odd-numbered visit, skip to Section F. If it is an even-numbered visit, proceed to Section E.

SECTION E: SPIRITUALITY

This section includes questions from a standardized scale that assesses spirituality (FACIT-SP).

E1-E12: Read the introduction statement. **HAND PARTICIPANT RESPONSE CARD 12D.** Read each statement and record the response. If the participant has difficulty deciding between answers, say ***“I can only record one answer. Of these, which one would you choose?”*** For Questions E10 and E11, if the participant is HIV-negative, answer “NA” (code = 5).

SECTION F: LIFETIME DISCRIMINATION

This set of questions is from standardized scales (Williams, MMIS) that ask about different kinds of discrimination that participants may have experienced in their lives. Participants will be asked these questions only once, the first time they are administered the *F25c*.

F0. Skip to Question F9 if participant has answered the questions in Section F at a previous visit. This information will be included on the Visit Control Sheet (VCS).

Read the introduction to this section. **HAND PARTICIPANT RESPONSE CARD 12E** for subquestions c-e in Questions F1-F6.

F1-F6: Ask the main question. If the participant answers “No,” skip to the next main question. If the participant answers “Yes,” ask subquestions a-e. Read each subquestion and record the response. If the participant is unsure the of number of times to report for subquestion a, say ***“Please give me your best guess for the number of times.”*** If the participant has difficulty deciding between answers to subquestions b-e, ***“I can only record one answer. Of these, which one would you choose?”***

If the participant is HIV-negative, answer “NA” (6) for subquestion e in Questions F1 through F6.

At the completion of this form, record the end time in Question F9 and proceed to *Form 26*.