

WOMEN'S INTERAGENCY HIV STUDY
QUESTION BY QUESTION SPECIFICATIONS
FORM FIS: FOOD INSECURITY STUDY

The *Food Insecurity Study Form* is used to obtain information to describe the cohort in terms of their access to food ("food security"), as well as their diet, sources of governmental or non-governmental assistance, how subsistence needs compete with health care, and attitudes towards HIV. 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.

General Instructions:

1. For questions containing an open-ended specify box linked to the response "other," interviewers should neatly print responses exactly in the words of the participant.

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

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.

- B1 to B3. **HAND PARTICIPANT RESPONSE CARD FIS1 FOR USE WITH QUESTIONS B1 THROUGH B3.** 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 B1**, 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 B3**, 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.
- B4. 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 B6**.

- B5. **HAND PARTICIPANT RESPONSE CARD FIS2.** The purpose of this question is to probe for the frequency of food reduction among the participant or other adults reported in Question B4.
- 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?’”
- B6 to B8. 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 their own experiences for these questions.
- B9. This question returns to asking about the participant or other adults in her household. For **Question B9**, if the response to this question is NO, then skip to **Question B11**.
- B10. **HAND PARTICIPANT RESPONSE CARD FIS2.** The purpose of this question is to probe for the frequency of food reduction reported in Question B9.
- 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.
- B11. This is a screening question to assess whether there have been any children under 18 living in the household during the last 6 months.
- Ask about the participant’s own children and anyone else’s children *living in the same household* – i.e., children who the participant might be sharing food with and whose food intake the participant might be responsible for. If the participant is acting as a caretaker for children in the household by providing meals, even if the children do not live with her (e.g., a grandmother feeding the children during the day), clarify that she can answer for this household and these children.
 - If the response to this question is NO, then skip to **Section C** on Dietary Quality.

READ INTRODUCTION TO CHILD-REFERENCED QUESTIONS.

- B12 to B14. **HAND PARTICIPANT RESPONSE CARD FIS1 FOR USE WITH QUESTIONS B12 THROUGH B14.** These questions ask the participant to think about situations their *children* 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 B13**, 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.
- B15 to B16. Ask these questions about cutting or skipping meals of the *children* in the household (yes/no), emphasizing “any” of the children.

- If the meals of only one child in the household was cut or skipped, the response should be YES (even if other children were not affected).
- For **Question B16**, if the response is NO, then skip to **Question B18**.

B17. **HAND PARTICIPANT RESPONSE CARD FIS2.** The purpose of this question is to probe for the frequency of food reduction reported in Question B16.

- If the participant answers something other than the options on the response card (e.g., “sometimes,” “maybe once”), clarify by pointing to the response card and asking her which option most closely matches her answer.

B18 to B19. Ask these questions about child hunger and severe food insecurity in the household (yes/no).

- Be aware that these are sensitive questions that might make participants feel uncomfortable because child hunger is likely to indicate severe household food insecurity.

B20. Indicate whether this is the participant’s baseline visit. If response is “yes,” skip to Section C and proceed to administer the entire form.

B21. Indicate whether this is an odd-numbered visit. If response is “yes,” skip to end of form.

SECTION C: DIETARY QUALITY (REACH*)

READ THE INTRODUCTION TO THE PARTICIPANT.

This section assesses overall diet quality by capturing the relative intake of fruits and vegetables, proteins, fat and fiber over the past month, that is, the past 30 days. Answers are captured as *times per day, week, month, or year*. The participant may respond with another frequency that will need to be translated to the option given.

- If the participant answers “never,” enter “00” times per year
- If the participant answers “every day,” “every week,” or “every month,” do not assume this means *once* per day, week or month. Instead, probe for the number of times per day, week, month, or year.
- Although the question asks about the past month, we include a “times per year” option to allow for the possibility that the participant consumes the item less frequently.
- If the participant doesn’t know the answer to a particular question, enter “-8” times per year.
- If the participant answers “sometimes,” “every once in a while,” etc., probe for a frequency that can be described as times per day, week, month, or year.

C1. If necessary, clarify that other types of meat will be asked about in the next two questions (e.g., Hamburgers).

C3. If necessary, clarify that this question does not include chicken or turkey lunch meats. Any kind of lunch meats should be answered as part of Question C1. However, the participant should include other processed chicken entrees, such as Chicken Nuggets.

C5. If necessary, clarify that seafood includes shrimp, prawns, lobster, and other shellfish, such as clams, mussels and oysters.

C6. If necessary, clarify that this question includes if these items are eaten on their own, or as a condiment or ingredient in something else (e.g., on pizza).

- C7. The objective of this question is to understand how often participants eat high fat or high sugar snacks.
- If necessary, clarify that “chips” includes any kind of processed, crunchy snack chip, such as potato chips, tortilla chips, or Cheetos.
- C8. The objective of this question is to gather information on intake of sugar-sweetened beverages.
- Sunny Delight and Tang are given as examples, but it may be necessary to give additional examples (e.g., Kool Aid, Gatorade).
 - Diet soda and 100% fruit juices are excluded, but a later question will ask about full fruit juice.
- C11. We are looking for information on how often the participant eats egg dishes (e.g., breakfast eggs, egg salad), rather than foods that have some egg in them, like cakes, (these are captured in other questions).
- C12. Emphasize “whole” milk here, as the next question will ask about low-fat milk.
- C15. By “eat fruit,” we mean fresh fruit as well as canned or frozen fruit.
- C16. If necessary, clarify that fried potatoes means any kind of fried potato including hash browns, and potato pancakes.
- C17. If necessary, clarify that we are asking about any kind of non-fried potato, including baked, boiled, steamed or roasted potato, as well as potatoes used in soups or stews.
- C18. By “vegetables,” we mean fresh vegetables, as well as canned or frozen. If necessary, clarify that “green salad” means salad with lettuce or another kind of green leafy vegetable (e.g., spinach) and does not include potato salad, egg salad, or other kinds of starchy salads.

SECTION D: SOCIOECONOMIC DATA (D1 and D2 from NHANES 2010*)

READ THE INTRODUCTION TO THE PARTICIPANT.

- D1. The purpose of this question is to assess whether the participant’s *household* has more than \$5000 in savings, including in checking accounts.
- Make sure to stress this is not just the participant’s own savings, but other people who live with her.
 - If the participant is having a hard time answering, or isn’t sure what you mean by “savings,” clarify that you mean any money they have saved as cash, savings or checking accounts, stocks, bonds, mutual funds, retirement funds (such as pensions, IRAs, 401ks), and certificates of deposit.
 - If the answer to this question is YES, then skip to **Question D3**.
- D2. **HAND PARTICIPANT RESPONSE CARD FIS3.** For participants whose households have less than \$5000 in savings, ask them to say or point out on the response card how much their household has in total savings.
- Just like in Question D1, if necessary clarify that you mean any money they have saved as cash, savings or checking accounts, stocks, bonds, mutual funds, retirement funds (such as pensions, IRAs, 401ks), and certificates of deposit.

D3.

READ QUESTION INTRODUCTION. This question refers to the participant's *current or most recent household*. This means that if the participant currently lives on her own, but in the last year shared a household with another person, she should include government benefits received by members of that household even if she no longer lives there. Below are explanations of the categories of government benefits we are interested in. Most people should know whether they receive these benefits. If they say "don't know," mark NO for that option.

- a) Supplemental Security Income (SSI) and Social Security Disability Income (SSDI) are federal programs that provide monthly financial support to people with disabilities. Although also administered by the Social Security Administration, SSDI and SSI are different from Social Security retirement benefits. Disability is defined as a physical or mental condition expected to last at least one year that prevents the individual from working. Some people with HIV qualify for disability benefits, but having HIV does not guarantee receipt of SSI or SSDI.
- b) Social Security refers to retirement benefits paid to individuals (or spouses or dependents of individuals) who paid Social Security taxes while working. Even if the participant is not retirement age, they might still be receiving Social Security if they are the spouse or dependent of a beneficiary.
- c) State or private disability or workers' compensation are other programs that pay people who become seriously injured or disabled. These benefits may be in addition to or instead of federal disability benefits. Do not assume that the participant receives these benefits if they receive SSI or SSDI, or vice versa.
- d) Unemployment insurance, sometimes also called unemployment compensation or benefits, are payments made by the government to unemployed people. In order to receive these payments, people generally have to register as unemployed, and demonstrate that they are seeking work and do not currently have a job. If the participant is unemployed, do not assume they receive unemployment insurance.
- e) Veteran's benefits encompass a wide variety of types of assistance for people who have served in the U.S. military. These include disability benefits, pensions, assistance for homeless veterans, vocational rehabilitation benefits, and others. We are interested if anyone in the household received any of these types of benefits.
- f) Temporary Assistance to Needy Families (TANF) is sometimes called "family assistance," "welfare for women with children," or simply "welfare." It is a federal cash assistance program for low income American families with dependent children, administered by the states.
- g) General Assistance is a program run by either the State or County for individuals with no other form of income who do not qualify for any other benefits program (e.g. TANF, SSI/SSDI, unemployment insurance)
- h) The Other category captures any other source of government assistance women report receiving. This includes if the participant receives benefits from a program that she isn't sure is one of the listed programs, especially TANF, since programs may go by different names in her state. For example, TANF in California is called CalWorks. Therefore, if the participant uses the "Other" category, please probe for the name of the program, so that we can assess whether it is truly a new program, or simply one of the listed programs by a different name.

SECTION E: RECEIPT OF FOOD ASSISTANCE (REACH*)

In this section we are interested in finding out all the places people are getting help in accessing food. It is separated out into *non-governmental* sources of assistance, such as community organizations, churches, etc., and *government programs*, such as the Supplemental Nutrition Assistance Program (i.e., food stamps).

READ THE INTRODUCTION TO THE PARTICIPANT. This introduction is for the first part of the section and instructs the participant to think first about *non-governmental* sources of assistance received by anyone in the household during the last year.

- E1. Ask the participant if she got any *non-governmental* food assistance at any time in the past year.
- Clarify that this *includes*, but is not limited to, church or clinic food programs, food banks, soup kitchens, and free food lines.
 - They should *exclude* food they got from government programs such as the Supplemental Nutrition Assistance Program (SNAP) (aka food stamps or food vouchers), the Women, Infants and Children's program (WIC), or any other source of food vouchers.
 - Include food assistance received by the participant or anyone in her household, even if she herself did not go to pick up the food.
 - If the answer to Question E1 is NO, then skip to **Question E4**.
- E2. Read each option and have the participant indicate YES/NO for each one. Options may not be mutually exclusive (for example, a soup kitchen in a church). In these cases, indicate YES for both options.
- e. "People outside your household" means any friends, family or other individuals who gave food to, or shared food with, the participant's household because they were perceived as not having enough food. Clarify that this does not include food received as part of a purely social gathering or other situation not related to their need for sufficient food.
- f. If the answer to "Other" is YES, then have the participant indicate the source of the food assistance. For example, an organization that delivers hot meals to people with HIV.
- E3. This question asks about the number of days the participant or her household members ate food they received from food assistance during the last 30 days.
- If the participant says "every day," enter ""30" days. If the participant answers "never," enter "00" days. Even if the participant's household received food assistance in the last year, they may not have eaten food from food assistance in the last 30 days.
 - If the participant doesn't know how many days, probe for more specificity by asking if the household ate the food most days, some days, or just a few days. From there, try to determine how many days the food was eaten – e.g., if it were about once per week, ask if she would say the food was eaten for about four days over the past 30 days.

- E4. READ THE INTRODUCTION FOR E4 TO THE PARTICIPANT. Ask the participant if her household received food vouchers, coupons or electronic debit cards – i.e., *governmental* food assistance – at any time in the past year.
- If necessary, explain that SNAP and WIC are governmental food assistance programs that provide cash assistance for food, and that SNAP is sometimes called “food stamps.”
 - Include food assistance received by the participant or anyone in her household, even if she herself is not the primary recipient.
 - Include food assistance received by the participant’s household through its own eligibility, as well as SNAP benefits given to them by someone else.
 - If the answer to Question E4 is NO, then skip to **Section F**.
- E5. Read each option and have the participant indicate YES/NO for each one, checking all that apply.
- c. If the answer to “Other” is YES, then have the participant indicate the source of the food vouchers, coupons, or electronic debit cards.
- E6. This question asks about the number of days the participant or her household members ate food they received from food vouchers, coupons or electronic debit cards during the last 30 days.
- If the participant says “every day,” enter “”30” days. If the participant answers “never,” enter “00” days. Even if the participant’s household received food assistance in the last year, they may not have eaten food from food assistance in the last 30 days.
 - If the participant doesn’t know how many days, probe for more specificity by asking if the household ate the food most days, some days, or just a few days. From there, try to determine how many days the food was eaten – e.g., if it were about once per week, ask if she would say the food was eaten for about four days over the past 30 days.

SECTION F: COMPETING DEMANDS (REACH*)

The purpose of these questions is to understand the trade-offs the participant and her household make between having adequate food and her health care. Answer options include “Always,” “Often,” “Sometimes,” and “Never”. We are interested both in what sacrifices she makes in her health care, and what sacrifices she makes in food for herself and her household.

Please note that:

- The first two questions are asked to ALL participants.
 - Note the clarification specifically for *HIV-positive* women not to include their ARV medications in their responses, since we ask about these in subsequent questions.
- The last two questions of this section are asked ONLY to participants with HIV.

READ THE INTRODUCTION TO THE PARTICIPANT.

HAND PARTICIPANT RESPONSE CARD FIS4 FOR USE WITH QUESTIONS F1, F2, F4, & F5.

F1 to F2. Ask the first two questions to all participants. Note that questions refer to food for the participant *or her household*. However, “healthcare” refers *only* to the participant.

- Then STOP and determine whether the participant is HIV-infected. If so, continue and read the clarification instructing the participant not to include her antiretroviral medications as part of her answer.

F3. DO NOT ASK THE PARTICIPANT HER HIV STATUS. Determine this from the participant record and indicate the answer on the form. If she is HIV-NEGATIVE, then skip to **Section G, Question G4**.

F4 to F5. These questions ask specifically about tradeoffs between taking antiretroviral (ARV) medications for HIV and food.

- If the participant states that she has not been prescribed ARVs, or has not yet started antiretroviral treatment, select “Not applicable” as the response option.
- For **Question F4**, stress the words “time *or* money getting *adequate* food...” We are interested in constraints on household food access because of limited resources.
- For **Question F5**, stress that money for ARV prescriptions includes “transport costs or paying for prescriptions.” If necessary, clarify that “paying for prescriptions” could mean co-pays or direct costs of medications.

SECTION G: HIV STIGMA (G1 adapted from Bunn 2007*; G4 adapted from UARTO*)

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

- Questions G1 to G3 are asked *only* to HIV-POSITIVE participants.
- Question G4 is asked *only* to HIV-NEGATIVE participants. The skip pattern in Section F (Question F3) will lead the interviewer directly to Question G4.

READ THE INTRODUCTION TO THE PARTICIPANT (SEPARATE INTRODUCTIONS FOR HIV-POSITIVE AND HIV-NEGATIVE).

- Introduction for HIV-positive participants precedes G1
- Introduction for HIV-negative participants precedes G4

G1. **HAND PARTICIPANT RESPONSE CARD FIS5.** 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, can 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 focuses 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 negative statement reflecting internalized stigma.
 - b. This question is phrased as a negative 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 negative statement reflecting internalized stigma.
- f. This question is phrased as a negative statement reflecting internalized stigma.
- g. This question is phrased as a positive 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 G1.
- h. This question is phrased as a negative statement reflecting perceived external stigma by health professionals.

G2. We are interested in whether the participant has ever 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 **Question G5**: End of the Module. Record the actual time you ended the module.
- In future versions of the questionnaire, we will modify this question to capture disclosure in the time period since that last WIHS interview, rather than continue to ask if she “ever” disclosed.

G3. 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.

G4. **HAND PARTICIPANT RESPONSE CARD FIS5.** 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.

Ask HIV-negative participants how strongly they agree or disagree with a set of statements. Possible answers are “strongly agree,” “agree,” “disagree,” or “strongly disagree.”

- a. This question is phrased as a negative statement reflecting stigmatizing attitudes.
- b. This question is phrased as a positive statement reflecting affirming attitudes.
- c. This question is phrased as a negative statement reflecting stigmatizing attitudes.
- d. This question is phrased as a negative statement reflecting stigmatizing attitudes. If the participant asks what “immoral behavior” is, do not give examples (to avoid stigmatizing behaviors). Instead, respond that the participant can interpret this in her own way.

- e. This question is phrased as a positive statement reflecting affirming attitudes.
- f. This question is phrased as a negative statement reflecting stigmatizing attitudes.
- g. This question is phrased as a negative statement reflecting stigmatizing attitudes.

G5. READ CONCLUSION TO END OF MODULE. Then record the actual time you ended the module.

**USDA HFSS* = U.S. Department of Agriculture Household Food Security Scale; *REACH* = Research on Access to Care in the Homeless cohort study of HIV-infected homeless and marginally housed adults in San Francisco; *NHANES 2010* = National Health and Nutrition Examination Survey; *Bunn 2007* = Measurement of stigma in people with HIV: A reexamination of the HIV Stigma Scale; *UARTO* = Uganda AIDS Rural Treatment Outcomes cohort.