

WOMEN'S INTERAGENCY HIV STUDY

QUESTION-BY-QUESTION SPECIFICATIONS

FORM HX: FAMILY AND PERSONAL MEDICAL HISTORY

Guidelines for completing Form HX, “*Family and Personal Medical History.*”

The *Family and Personal Medical History* form is designed to obtain the participant's personal and family medical history, including all immediate family members. For this module, immediate family members are considered birth mothers, birth fathers, and full brother(s)/full sister(s). The participant's family history will be obtained first followed then by their own medical history. For new recruits, this form will be administered at their baseline visit.

General Instructions:

1. All dates should be recorded in the MM/DD/YY format unless otherwise noted. For dates that must be completed on the form, if the participant cannot remember the exact month (and day), probe for the season. Use “15” for the day if the specific day cannot be recorded. Probe for the season and assign the month as follows:

| | | | | |
|--------|---|---------|---|----|
| Summer | = | July | = | 07 |
| Fall | = | October | = | 10 |
| Winter | = | January | = | 01 |
| Spring | = | April | = | 04 |

Interviewers should have available an appropriate calendar to aid the participant in determining dates.

2. For questions containing an open-ended specify box linked to the response “other,” interviewers should print responses exactly in the words of the respondent.
3. Follow the skip patterns as they appear on the form.

SECTION A: FAMILY MEDICAL HISTORY

READ THE INTRODUCTION TO THE PARTICIPANT

- A1. Ask the participant if she has any knowledge of the health history of her birth, or biologic, family. This would include her birth mother, birth father, full brother(s), and full sister(s) including both living and deceased members of her birth family. “Full” brother/sister means that the participant and her sibling (brother or sister) have the same mother **and** father. This does not include extended family such as aunts, uncles, cousins, nieces, nephews, or grandparents. If she has any knowledge of just one family member’s health, she should answer “YES” to this question. If the participant is adopted, or lost her family at a young age, and as a result has no knowledge of her birth family’s health history, she should answer “NO” to this question. If she has answered “NO,” skip to **Section B, Personal Medical History**. If she answered “YES,” ask the participant **Questions A4 through A12**.
- A4. Ask the participant if anyone in her birth family, including mother, father, full sisters, or full brothers have ever been told by a health care provider that they had cancer of any kind. When considering this question, the participant should include both living and deceased members of her birth family. If she answers “YES” to **Question A4**, proceed to **Question A4a**. If she answers “NO,” skip to **Question A6**.
 - a. Ask the participant which member(s) of her birth family were told by a health care provider that they had cancer. Circle all answers that are appropriate. If she has had more than one brother or sister in her family that have been told by a health care provider that they have had cancer, circle the appropriate answer for brother or sister. **Question A5** will allow her to provide data for each sibling.

- A5a–c. Ask the participant to give more detailed information on the types of cancers that her family members were diagnosed with and the age at which they were diagnosed. **Questions A5a through c** should be answered for each family member that was reported in **Question A4a**. If she has reported more than three family members with cancer, Xerox the questions and insert them behind page 3. Remember to answer these questions for all brothers or sisters, if indicated (remember that in **Question A4a**, there is not an individual listing of same sex siblings and you must therefore probe for this information when asking the participant **Question A5a**). Before completing **Question A5**, make sure the answers in **Question A5** are consistent with the family members listed in **Question A4**.
- b. Ask the participant what type of cancer her family member was diagnosed with. It is very important to explain to the participant that we want to know where the cancer was first found. It is not uncommon for cancer to spread to other areas of the body; however, we only want to know where the cancer was when her family member was initially diagnosed with cancer.
- c. Ask the participant the age of the family member when he/she was initially diagnosed with cancer. If the participant is able to tell you the exact age of her family member, circle the corresponding age range listed on the form. If the participant is unsure of the family member’s age at the time of diagnosis, read the age range categories to the participant and ask her to estimate as best she can. If the participant is still unable to determine her family member’s age, ask the participant if her family member was older or younger than 50 and then read her the pertinent age categories again. Try to narrow the participant down to one of the age ranges listed on the form, asking her to estimate as best she can.
- A6a–f. Ask the participant if any of their family members were ever told by a health care provider that they had high blood pressure, stroke, congestive heart failure, high cholesterol, diabetes, or a blood clot (in any area of the body) that required treatment. Again, as in **Question A4a**, if the participant has had more than one sister or brother that has had a particular illness, just circle the corresponding answer. You do not need to indicate that there are multiple same sex siblings with a specific illness.
- A7. Ask the participant if her biological mother was ever told by a health care provider that she had osteoporosis. This condition may be referred to as “thin” or “brittle” bones.
- A8. Ask the participant if her biological mother or biological father has ever fractured, or broken, her/his hip.
- A9a–b. Ask the participant if her mother or any female sibling has ever been told by a healthcare provider that she had a heart attack at age 65 or younger. It is very important to emphasize “age 65 or younger” when asking this question. If the participant is unsure of her family member’s age, prompt her for more information to narrow her answer down to an age range below or above 65. If the participant answers “YES” to **Question A9a**, ask her **Question A9b**. Circle the corresponding answer for the female relative(s) that had this condition. As in **Question A4a**, there is no need to indicate if there was more than one sister that has had a heart attack before the age of 65.
- A10a–b. Ask the participant if her father or any male sibling has ever been told by a health care provider that he had a heart attack at age 55 or younger. It is very important to emphasize “age 55 or younger” when asking this question. If the participant is unsure of her family member’s age, prompt her for more information to narrow her answer down to an age range below or above 55. If the participant answers “YES” to **Question A10a**, ask her **Question A10b**. Circle the corresponding answer for the male relative(s) that had this condition. As in **Question A4a**, there is no need to indicate if there was more than one brother that has had a heart attack before the age of 55.
- A11a–b. Ask the participant if any of her birth relatives has ever been told by a health care provider that he/she had kidney disease. If the participant answers “YES” to **Question A11a**, ask her **Question A11b**. Circle the corresponding answer for the family member(s) that had this condition.
- c. Ask the participant to tell you the total number of birth relatives that have had kidney disease. If, for example, her father and two sisters were told they had kidney disease, that would equal “3” relatives.

- A12a–b. Ask the participant if any of her birth relatives has ever been on dialysis. If the participant answers “YES” to **Question A12a**, ask her **Question A12b**. Circle the corresponding answer for the family member(s) that were on dialysis.
- c. Ask the participant to tell you the total number of birth relatives that have been on dialysis. If, for example, her father and two sisters were on dialysis, that would equal “3” relatives.

SECTION B: PERSONAL MEDICAL HISTORY

READ THE INTRODUCTION TO THE PARTICIPANT.

- B1. Ask the participant how old she was the first time she had her menstrual period. If she cannot remember her exact age, ask her to estimate as best she can.
- B2a–f. Ask the participant is she has ever been told by a health care provider that she had a heart attack (MI, or myocardial infarction), congestive heart failure, stroke (CVA), high cholesterol, angina or chest pain related to heart disease, or a transient ischemic attack. If she answers “YES” to any of these conditions, ask the participant in what year she was diagnosed with the illness or condition. If she cannot remember, ask her how old she was when she was diagnosed with the illness or condition. If still unable to provide an age, ask her to estimate as best she can.
- B3. Ask the participant if she has ever had a blood clot in her legs that required treatment. If she has had a blood clot elsewhere in her body, she should not answer “YES” to this question.
- B4. Ask the participant if she has ever had a blood clot in her lungs that required treatment. If she has had a blood clot elsewhere in her body, she should not answer “YES” to this question.
- B5. Ask the participant if she has ever been told by a health care provider that she has had a liver problem other than hepatitis. She should not answer “YES” to this question if the only liver problem she has ever had was hepatitis. If she answers “NO” to this question, skip to **Section C**. If she answers “YES” to this question, proceed to ask her **Questions B5a through B5i**.
- a–i. Ask the participant if she has ever had cirrhosis, liver failure, ascites (abnormal fluid in the belly), yellow jaundice, bleeding from enlarged veins in the esophagus (“food tube”) or stomach, fatty liver (a build-up of fat in liver cells), alcoholic liver damage, hepatic encephalopathy (confusion or decreased awareness caused by liver disease), or any other liver disease other than hepatitis.

SECTION C: MEDICATIONS

HAND PARTICIPANT RESPONSE CARD D4h.

- C1. Ask the participant if she has ever taken any of the hormone replacement therapies (HRT) listed on **Response Card D4a** for longer than one month. Be sure to emphasize that she should only answer “YES” if she has taken the medication for more than one month. Inform her that these medications could have been taken in the form of a pill, cream, or patch worn on the skin. Once the participant determines if she has or has not taken a hormone replacement therapy, circle the corresponding answer on the form. If she answers “YES” to this question, complete Question C1a and then proceed to ask the participant **Questions C1b through c**. If the participant reports “Other HRT,” specify the exact HRT in **Question C1a**. If she answers “NO” to this question, skip to **Question C2**.
- a. This question is not to be read to the participant. The interviewer is to code the type of hormone replacement therapy taken by the participant based upon the response given in **Question C1**. There are four categories of hormone replacement therapies: (1) estrogen, (2) progesterone, (3) combination, and (4) other. If the participant reports she has taken both an estrogen and a progesterone HRT, code **Question C1a** as “Combination.” If the participant responds that she has taken a hormone replacement therapy listed in the “other” category, specify the type she has taken where indicated on the form.

- b. Ask the participant the reason(s) she was taking a hormone replacement therapy. Circle “YES” for each reason she reports taking hormone replacement therapy. If she answers “Other,” specify the reason on the form.
- c. Ask the participant how old she was when she began taking hormone replacement therapy. If she does not know her exact age, ask her to estimate as best she can.