Personal And Family Health History Form Instructions PFH Version A, 10/06/2000 QxQ Date 02/21/2001

I. GENERAL INSTRUCTIONS

The Personal and Family Health History (PFH) is the first section of the Home Induction Interview and collects information on the participant's health status, personal health history and family health history. The exact wording and order of the questions should be followed to ensure standardization. Questions should not be skipped unless indicated by the skip pattern instructions. Because there are several skip patterns in this section, the interviewer should be very familiar with the flow of the questions to insure smooth administration with a conversational tone. The interviewer must be certified and have working knowledge of the document "General Instructions for Completing Paper Forms" prior to completing this form. ID Number, Contact Year and Name should be completed as described in that form. Initiate the form by reading the script at the beginning of the form as printed.

II. SPECIFIC INSTRUCTIONS

Health Status

1. This standardized question is intended to assess the participant's assessment of their overall health status in comparison with other persons in their same age range. Circle the response provided by the respondent.

Personal Health Problems

2-11. This is a series of questions regarding particular health conditions diagnosed by a health care provider. Enter YES, NO or UNSURE/UNKNOWN for each item that identifies a specific condition (Items 2-11a). A response is positive (YES) only if the condition was diagnosed by a health care provider. A diagnosis of "borderline" is coded as YES if the participant's condition was diagnosed by a health care provider as borderline. For example, a participant may tell you that "My doctor told me I have borderline diabetes" or "My doctor said I had a touch of sugar." NOTE: For item 7a, "kidney problem" does not refer to bladder infections.

NO is recorded is (1) the respondent was told by a health care provider that s/he did <u>not</u> have the condition specified, (2) was never told by a health care provider that s/he had the condition, or (3) was never tested for the condition.

UNSURE/UNKOWN is recorded if the respondent is not sure that the health care provider said s/he had this condition. The code of UNSURE/UNKNOWN

is most frequently used when the respondent cannot remember accurately what the health care provider said. Do not define the condition yourself based on the respondent's answer. Record ambiguous responses in a note log.

For each YES response to Items 2-11a, in items 2-11b enter the age at which the respondent was first told of this condition by a health care provider. If the respondent does not remember the exact age or year which a health care provider first told her or him of the condition, ask for and record a best estimate of the age. You may assist the respondent in pinpointing an age by asking if they can recall any particular events or other timing that may help them specify the age at which this occurred.

12. Enter YES or NO. If YES, record reason for hospitalization in the boxes for Item 12b. If additional space is needed to capture complete response, use note log.

Family Health History

This next series of questions is intended to obtain information on parental, sibling and children's health history. The same series of questions is asked for each relative group. Careful attention to the skip patterns is needed to assure a conversational tone in asking these questions.

- 13. Do not ask this question. Record YES, NO or UNKNOWN from information obtained on the ELG form, item 12a. If mother is still living (YES), SKIP to item 16. If mother is no longer living (NO), continue with the next item in the series. If UNKNOWN, SKIP to Item 17.
- 14. Record age at which mother died in years.
- 15. Record cause of mother's death using the pre-coded responses. Do not read the list to the respondent, simply mark the best answer from what they say. If the cause of death is not in the list, specify cause in the response boxes in 15.b.
- 16. Record current age of mother in years.
- 17-21 This series of items is intended to capture current health history information if the respondent's mother is still living. Read each condition and record YES, NO or UNSURE/UNKNOWN. As before for the respondent health history, for each YES response, ask the age at which the mother was first told of this condition and record the age in years in items 17-21b, as appropriate.
- 22. Do not ask question. Record YES, NO or UNKNOWN from information obtained on the ELG form, item 11a. If father is still living (YES), SKIP to item 25. If father is no longer living (NO), continue with the next item in the series. If UNKNOWN, SKIP to Item 26.

- 23. Record age at which father died in years.
- 24. Record cause of father's death using the pre-coded responses. Do not read the list to the respondent, simply mark the best answer from what they say. If the cause of death is not in the list, specify cause in the response boxes in 15.b.
- 25. Record current age of father in years.
- 26-30. This series of items is intended to capture health history information on the respondent's father. Read each condition and record YES, NO or UNSURE/UNKNOWN. As before, for the respondent health history, for a YES response to items 28, 29 or 30, ask the age at which the father was first told of this condition and record the age in years in items 28-30b, as appropriate.
- 31. This series of items is intended to clarify numeric information on respondent siblings. Read the transition script as written. Obtain information on number of living brothers and sisters from Item 14, ELG form, already completed earlier in the interview and clarify the number as per the script:
 - "Now I have a few questions about your full brothers and sisters. Count only those who have the same natural mother and natural father as you, even if they are no longer living or you are no longer in touch with them. Do not include adopted or step brothers or sisters. Earlier you indicated that you have ____ brothers and ____sisters still living."
- 31a. Do not use this question. Using information already obtained from the ELG form, Item 14, Record the number of full brothers still living. If the respondent changes the number based on your summary in the script above, clarify the accurate number and correct as needed on the ELG form as well as in this item.
- 31b. Using information already obtained from the ELIGIBILITY FORM, Item 14, Record the number of full sisters still living. If the respondent changes the number based on your summary in the script above, clarify the accurate number and correct as needed on the ELG form as well as in this item.
- 31c. Record YES if there are other siblings who are no longer living and continue with the next item. If there are no other siblings who are no longer living, record NO and SKIP to Item 31.f.
- 31d. Record number of full brothers who are no longer living.
- 31e. Record number of full sisters who are no longer living.
- 31f. Total the number of full brothers and sisters adding together the number from

- Items 31a, 31b, 31d, and 31c. If there are no siblings, enter 00 in the appropriate space.
- 32-36. This next series of item is to obtain health history information on the respondent's siblings. For each item, the respondent is asked if any of their siblings have ever had each of the specific diseases listed. If YES, in 32-36b, record the number of siblings affected with the condition. For items 34-36, if YES record the number of siblings who were younger than age 60 when they were first told of the condition.
- 37. This item is intended to verify the number of living adult children. Read the transition script as written. Obtain information on number of children from Item 13 on the ELG Form, already completed earlier in the interview:

"I have a few questions about your natural children. Earlier you indicated that you have ____ biological children still living.

Verify that the number is the same as recorded in Item 6, ELG. If different, clarify the difference and make the correction on the ELG form.

- 37a. Using information already obtained from the ELG from, item 16, record the number of natural children still living.
- 37b. Record the number of children currently over the age of 18.
- 37c. Determine if there are biological children no longer living.
- 37d. If there are biological children no longer living, record number.

If there are no living children over the age of 18 <u>AND</u> no children who are no longer living, go to Item 43.

38-42. This next series of item is to obtain health history information on the respondent's adult children. For each item, the respondent is asked if any of their children over the age of 18, living or no longer living, have ever had each of the specific diseases listed. If YES, in 38-42b, record the number of children affected with the condition. For items 40-42, if YES record the number of children who were younger than age 60 when they were first told of the condition.

Administrative

- 43. Enter date of data collection.
- 44. Enter code of person completing the form.