Appendix 2.6a					О.М.В. 0925-02 exp. 7/92
ARI	<b>C</b> FA	MILY	HIST	FORY	FORM
ID NUMBER:		CONTACT YEAR:		FORM CODE:	HX VERSION: A 01-
LAST NAME:			INITIALS:		
Public reporting burder including time for rev needed, and completing or any other aspect of Reports Clearance Offi 20201, Attn. PRA; and Washington, D.C. 20503	iewing instructions, and reviewing the control this collection of cer, PHS, 721-H Huber to the Office of Mana	searching exis ollection of ir information inc rt H. Humphrey	ting data source formation. Send luding suggestic Bldg., 200 Indep	es, gathering a comments regar ons for reducir pendence Ave. S	and maintaining the dat ding the burden estimates this burden to SW, Washington, D.C.
last dig If a num correct question	entered above. When	ever numerical ghtmost box. I rectly, mark th the incorrect of corresponding	responses are re- inter leading zer- rough the incorr entry. For "mult to the most appr	equired, enter roes where nece rect entry with tiple choice" a ropriate respon	the number so that the essary to fill all box an "X". Code the and "yes/no" type
		rough it with a	n "X" and circle	e the correct 1	response.
	······		n "X" and circle		response.
This series of questions and your family's medica	FAMILY I		· · · · · · · · · · · · · · · · · · ·		response.
and your family's medica 1. Please tell me which following describes current marital stat	FAMILY I is about you I history. of the your		HXA screen 1 of 2. [INTERVIEWE] Was this p	11)	1 SHEET]
and your family's medica 1. Please tell me which following describes	FAMILY I is about you I history. of the your		HXA screen 1 of 2. [INTERVIEWE] Was this p	11) R: CHECK VISIT articipant's na	1 SHEET]
and your family's medica 1. Please tell me which following describes current marital stat	FAMILY I is about you il history. of the your us: Married Widowed	HISTORY FORM (I	HXA screen 1 of 2. [INTERVIEWE] Was this p	11) R: CHECK VISIT articipant's na	1 SHEET] atural l? Yes
and your family's medica 1. Please tell me which following describes current marital stat	FAMILY I is about you il history. of the your us: Married Widowed Divorced	HISTORY FORM (I M W D	HXA screen 1 of 2. [INTERVIEWE] Was this p	11) R: CHECK VISIT articipant's na ving at Visit 1	1 SHEET] atural 1? Yes
and your family's medica 1. Please tell me which following describes current marital stat	FAMILY I is about you il history. of the your us: Married Widowed	HISTORY FORM (I M W	HXA screen 1 of 2. [INTERVIEWE] Was this p	11) R: CHECK VISIT articipant's na ving at Visit 1	1 SHEET] atural l? Yes

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. (a) Is your natural mother living? 4. [INTERVIEWER: CHECK VISIT 1 SHEET] Was this participant's natural father living at Visit 1? Yes Y Yes Go to Item 4 No Ν -No Go to Item 6 Unknown U Unknown (b) Approximately how old was she when she died? ENTER "99" FOR AGES 99 OR OLDER. (c) What was the cause of your natural mother's death? Cancer С Heart Attack A Stroke S Other 0 (Specify) U Unknown . . FAMILY HISTORY FORM (FHXA screen 3 of 11) 5.(a) Is your natural father living? I would next like to ask a few questions about the health of your brothers and sisters. We are interested in your full Yes Y brothers and sisters, who have the same Go to Item 6 N mother and father that you do, including No those who have died or with whom you - Unknown U have lost touch. (b) Approximately how old was he when he died? ENTER "99" FOR 6. a. How many <u>full</u> brothers and sisters do you have? AGES 99 OR OLDER. (c) What was the cause of your If 00, go to Item 52. natural father's death? Cancer С b. How many brothers? Heart Attack A Stroke S c. How many sisters? 0 Other (Specify) Unknown U

FAMILY HISTORY FORM (FHXA screen 2 of 11)

FAMILY HISTORY FORM	(FHXA screen 4 of 11)
<ul> <li>What is the first name of your first full brother or sister?</li> <li></li></ul>	<ul> <li>10. Is (name) living? <ul> <li>Yes</li> <li>Yes</li> <li>Yes</li> <li>Yes</li> <li>No</li> <li>N</li> <li>Unknown</li> <li>U</li> </ul> </li> <li>11. How old was (name) when he/she died? <ul> <li>12. Did (name) ever have a heart attack?</li> <li>Yes</li> <li>Yes</li> <li>Yes</li> <li>Yes</li> <li>Yes</li> <li>Yes</li> <li>Unknown</li> <li>U</li> </ul></li></ul>
FAMILY HISTORY FORM	(FHXA screen 5 of 11)
13. How old was (name) when he/she had his/her FIRST heart attack?	16. What is the first name of your second full brother or sister?
VERIFY IT WAS THE FIRST HEART ATTACK]	
14. Did (name) ever have a stroke? Yes Y Go to Item 16 Unknown U 15. How old was (name) when he/she had his/her FIRST stroke?	17. Is (name) a brother or a sister? Brother Sister 18. What was (name's) year of birth?
[VERIFY IT WAS THE FIRST STROKE]	·

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IF NO MORE SIBLINGS, GO TO ITEM 52

	(FRAR Screen b of 11)		
19. Is (name) living?	22. How old was (name) when he/she had his/her FIRST heart attack?		
Go to Item 21 NO N			
Unknown U	[VERIFY IT WAS THE FIRST HEART ATTACK]		
20. How old was (name) when he/she			
died?	23. Did (name) ever have a stroke?		
	Yes Y		
21. Did (name) ever have a heart attack?	Go to Item 25 No N Unknown U		
Yes Y	24. How old was name) when he/she had his/her FIRST stroke?		
Go to Item 23 Unknown U			
	[VERIFY IT WAS THE FIRST STROKE]		
	IF NO MORE SIBLINGS, GO TO ITEM 52		
1			
FAMILY HISTORY FORM	(FHXA screen 7 of 11)		
25. What is the first name of your third full brother or sister?	28. Is (name) living?		
	Go to Item 30 No N		
	Unknown U		
	29. How old was (name) when he/she died?		
26. Is (name) a brother or a sister? Brother B			
Sister S			
27. What was (name's) year of birth?	30. Did (name) ever have a heart attack?		
	Yes Y		
	Go to Item 32 No N		
•	Unknown U		

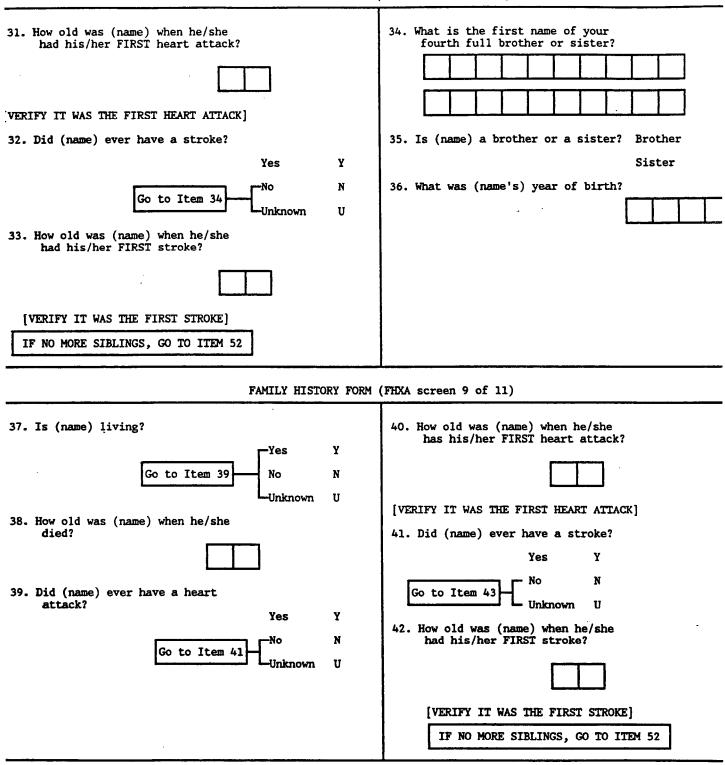
FAMILY HISTORY FORM (FHXA screen 6 of 11)

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• FAMILY HISTORY FORM (FHXA screen 8 of 11)



FAMILY HISTORY FORM	(FHXA screen 10 of 11)
43. What is the first name of your fifth full brother or sister?	46. Is (name) living?
	Yes Y
	Go to Item 48 No N
	Unknown U
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44. Is (name) a brother or a sister? Brother B	died?
Sister S	
45. What was (name's) year of birth?	18 Did (name) away have a heavy
	48. Did (name) ever have a heart attack?
	Yes Y
	Go to Item 50 No N
	Unknown U
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FAMILY HISTORY FORM	(FHXA screen 11 of 11)
49. How old was (name) when he/she	ADMINISTRATIVE INFORMATION
had his/her FIRST heart attack?	52. Date of data collection:
<b></b> 1	52. Dale of data collection:
[VERIFY IT WAS THE FIRST HEART ATTACK]	month day year
•	
50. Did (name) ever have a stroke?	53. Method of data collection:
50. Did (name) ever have a stroke? Yes Y	53. Method of data collection: Computer C
50. Did (name) ever have a stroke? Yes Y Go to Item 52	53. Method of data collection: Computer C Paper P
50. Did (name) ever have a stroke? Yes Y	53. Method of data collection: Computer C
50. Did (name) ever have a stroke? Yes Y Go to Item 52	53. Method of data collection: Computer C Paper P 54. Code number of person completing
50. Did (name) ever have a stroke? Yes Y Go to Item 52 Unknown U 51. How old was (name) when he/she	53. Method of data collection: Computer C Paper P 54. Code number of person completing

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## INSTRUCTIONS FOR THE FAMILY HISTORY FORM FHX, VERSION A, 1/16/90 PREPARED 04/03/90

The Family History (FHX) Form is administered to all cohort participants in Visit 2 during the clinic visit. The interview is completed during the interview portion of the clinic visit. The interviewer must be certified in general clinic interviewing and familiar with the ARIC date entry system (DES) and the "General Instructions for Completing Paper Forms" (in case the computer is down) prior to administering this form. Fields to remain blank should be blank on the paper form and "field forward" should be used to bypass them in the DES. Items in BRACKETS and/or CAPITAL LETTERS are instructions to the interviewer and are not read to the participant.

COMPLETE THE HEADER (paper form) by applying a long participant ID label and entering the participant's Name. READ THE QUESTIONS CLEARLY USING THE EXACT WORDING ON THE FORM.

At the outset, inform the participant that the following questions ask for information on both personal and his/her family's medical history. To complete the family history questions on the participant's full brothers and sisters, you may need scratch paper and a pen(cil) to record the name(s) and date of birth of each sibling if the participant did not bring in a list of names and birthdates for reference.

1. Read the question to the participant, emphasizing the word "current." Then read the responses. The responses are mutually exclusive, so record only one.

Items 2-5 refer to the health of the participant's natural mother and father. They do not apply to adoptive or step-parents. Items 6-51 refer to one or more full brothers or sisters.

The respondent may not know much about one or the other of his/her natural parents or full siblings. When this is the case, follow the skip patterns or accept estimated ages for death or onset of heart attack or stroke. It may be helpful to use lead-ins such as "I know you told me you don't know much about your father/mother/brother/sister, but could you tell me ...?"

2. DO NOT ASK THE PARTICIPANT THIS QUESTION. Review the ARIC PARTICIPANT INFORMATION SHEET (PIN) to determine the participant's mother's vital status at Visit 1. If mother was not living at Visit 1, enter the appropriate response (N) and go to item 4. If the mother was alive or status was unknown at Visit 1, enter Y or U and go to item 3.

3.(a)If the mother is living or her vital status is unknown, enter the appropriate response (Y or U) and go to item 4. Do <u>not</u> probe an "unknown" response as this may be a sensitive issue.

- (b) If the mother is deceased, enter N in (a) and ask the mother's approximate age at death. Enter "99" for ages 99 or older. Enter "==" if the age is unknown.
- (c) Read the question and code the response. If the respondent mentions a cause other than "Cancer", "Heart Attack", "Stroke" or "Unknown" or provides multiple causes of death, enter "O" for Other. Specify the

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other cause(s) of death in the automatic note log. Examples: diabetes and heart attack; stroke and congestive heart failure; cancer, pneumonia, and depression; automobile accident. Note that heart attack can include coronary thrombosis. Cancer can include leukemia and Hodgkins Disease. Cerebral hemorrhage and "blood clot in the brain" may be accepted as stroke. DO NOT PRINT OUT THE NOTE LOG.

Items 4 and 5 refer to the respondent's natural father and are the same as those for the natural mother. Follow the instructions for items 2 and 3.

Items 6-51 record demographic and health information on the participant's full brothers and sisters. Define "full" as those siblings who have the <u>same</u> mother <u>and</u> father as the respondent. Information is collected on up to five full siblings, starting with the eldest and working back toward the youngest (the participant need not be among the five oldest siblings), including those who have died or with whom the participant has lost contact.

6. Read the introductory statement. Ask item 6 and enter the response. If there are any full siblings, determine how many are brothers and how many are sisters. If there are no siblings (00), go to the administrative section (items 52-54) at the end of the form. If the participant does not know a siblings' exact date of birth, an approximate date will suffice. If the participant gives a range of dates, take the midpoint and record the appropriate date. <u>Do not</u> record date ranges in a notelog.

If more than one full sibling is reported, ask the participant if you can review with him/her the list of siblings he/she brought to the field center, or ask the participant to tell you their names and the year of their birth and record them on the piece of scratch paper. Inform the participant that no member of his/her family will be contacted by the ARIC study without the participant's prior knowledge. Then ask for the names of the five full brothers and sisters who would be the oldest if they were all living today and put a check beside their names.

Before asking item 7, and introductory statement such as "We will start with the oldest brother or sister" should be used.

- 7. (7, 16, 25, 34, 43). Only the first name is collected, but it may be a double or composite name, e.g., "Mary Jo". "First full brother or sister" refers to the first of up to five names that you are collecting. Once you have established which siblings meet these criteria, it is not necessary to record them on the form in any particular order. If the participant changes a sibling's date of birth, it will be necessary to either (1) correct the date you have recorded for that person or (2) delete that person's name and birth year and replace it with the name and birth year of a sibling who now meets the criteria.
- 8. (8, 17, 26, 35, 44) Ask the question of the participant in a confirmatory mode; for example,

"And (name of sibling) is your brother (sister)?"

- 9. (9, 18, 27, 36, 45) Record both the century and the decade. If unknown, probe to determine if the respondent can provide an estimate of the year of birth and record the approximate year. If no estimate can be provided, enter "====".
- 10. (10, 19, 28, 37, 46) If the sibling is living or vital status is unknown, enter Y or U and skip the following item.
- 11. (11, 20, 29, 38, 47) If the sibling is deceased, record the age at death. If the age at death is unknown, probe to determine if the respondent can provide an estimate of the age at death and record the approximate age. If the sibling was less than one year old, record 0. If no estimate can be provided, enter "==".
- 12. (12, 21, 30, 39, 48) If no heart attack is reported (a definite "no" or "don't know"), skip the following item.
- 13. (13, 22, 31, 40, 49) Emphasize that it is the age at the <u>first</u> heart attack that interests you. If the age is unknown, probe to determine if the respondent can provide an estimate of the age of the first heart attack and record the approximate age. If no estimate can be provided; enter "==".
- 14. (14, 23, 32, 41, 50) If no stroke is reported (a definite "no" or "don't know"), skip the following item.
- 15. (15, 24, 33, 42, 51) Emphasize that it is the age at the <u>first</u> stroke that interests you. If the age is unknown, probe to determine if the respondent can provide an estimate of the age of the first stroke and record the approximate age. If no estimate can be provided, enter "==".

Collect the same demographic and health data on each of the participant's eligible siblings or until you have recorded data on the five eldest checked off on your list, whichever comes first. The second set of questions asks for information on the "second" full brother or sister checked off on the list (items 16-24), the third set on the "third" full brother or sister (items 25-33), and so on. Since the birth year of each sibling is recorded, it is not necessary to list the siblings in order from eldest to youngest.

When the participant has no other full (eligible) siblings, tear up the scratch paper with the list of names and birth dates in front of the participant and then complete the administrative questions at the end of the form.

- 52. Record the date of the interview using the standard date format.
- 53. Record "C" if the form was completed on the computerized data entry screen, or "P" if the paper form was used.
- 54. The person at the clinic who has performed the interview and completed the form must enter his/her code number in the boxes provided.