ANNUAL FOLLOW-UP FORM

ID NUMBER: ☐☐☐☐☐☐☐ FORM CODE: A F U DATE: 8/29/2011 Version D

ADMINISTRATIVE INFORMATION

0a. Completion Date: ☐☐/☐☐/☐☐☐☐ (Month / Day / Year) 0b. Staff ID: ☐☐☐ 0c. CY: ☐☐

Instructions: *This form should be completed during the interview portion of the participant's follow-up. The Date is the day the contact was made or is the date the status determination was made. Special missing values are allowed for cases where the response "Don't know", "Refused", "Unknown", or "N/A" is not listed as an option.*

INTRODUCTION SCRIPT: "Hello, this is [your name] from the Jackson Heart Study. May I please speak with [name of contact]?"

"Hello [name of respondent]. My name is [your name] and I am from the Jackson Heart Study. May I have a few minutes of your time to ask about your health in the past year"?

A. STATUS

1. Result of contact for the interview *(select one)*
   - a. Participant contacted, agreed to be interviewed... ☐ → **GO TO QUESTION 17**
   - b. Contacted, refused to be interviewed..... ☐ → **GO TO QUESTION 72**
   - c. Proxy/Informant contacted ..... ☐
   - d. Other person contacted ..... ☐
   - e. Contact pending; continue to attempt to contact .. ☐ → **SAVE AND CLOSE FORM**
   - f. Window closed; unable to contact ..... ☐ → **SAVE AND CLOSE FORM**

2. Is the participant deceased?
   - Yes..... ☐
   - No ..... ☐ → **GO TO QUESTION 29**

B. DEATH INFORMATION

3. Death reported by: (select one)
   - Relative/Spouse/Acquaintance..... ☐
   - Surveillance..... ☐
   - Other (e.g., Obituary, Social Security Administration)..... ☐

4. Date of death: ☐☐/☐☐/☐☐☐☐ (Month / Day / Year)

5. Location of death:

a. City: _____ c. State: ☐☐

b. County: _____

6. Are you able to answer some questions about any hospitalizations that occurred since our last contact with [name] on [mm/dd/yyyy]?

Yes..... ☐ → **GO TO QUESTION 7**
No ..... ☐

6a. Is there someone else who could answer these questions?

Yes - person located..... ☐
Yes - reschedule remainder of interview..... ☐ → **GO TO QUESTION 72**
No ..... ☐ → **GO TO QUESTION 72**

HOSPITALIZATIONS (for deceased participants)

7. Was [name] hospitalized for a heart attack, or heart condition, or stroke since our last contact on [mm/dd/yyyy]?

Yes..... ☐
No ..... ☐ → **GO TO QUESTION 10**

8a. Hospital Name, City, State: ☐▼

8a1. Specify hospital name, city, and state if not in drop down list: _____

8b. Approximate date of hospitalization: ☐☐/☐☐☐☐
Month Year

Second hospitalization, if applicable

9a. Hospital Name, City, State: ☐▼

9a1. Specify hospital name, city, and state if not in drop down list: _____

9b. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

10. Did [name] stay overnight as a patient in a hospital for any other reason since our last contact?

Yes..... ☐
No ..... ☐ → **GO TO QUESTION 14**

11a. Hospitalization Reason: _____

11b. Hospital Name, City, State: ☐▼

11b1. Specify hospital name, city, and state if not in drop down list: _____

11c. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

Second hospitalization, if applicable

12a. Hospitalization Reason: _____

12b. Hospital Name, City, State: ☐▼

12b1. Specify hospital name, city, and state if not in drop down list: _____

12c. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

Third hospitalization, if applicable

13a. Hospitalization Reason: _____

13b. Hospital Name, City, State: ☐▼

13b1. Specify hospital name, city, and state if not in drop down list: _____

13c. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

OUTPATIENT TREATMENT (for deceased participants)

14. Was [name] admitted to an emergency room or a medical facility for outpatient treatment since our last contact?

Yes..... ☐
No ..... ☐ → **GO TO QUESTION 72**

15. Was this related to a heart problem or difficulty breathing?

Yes..... ☐
No ..... ☐ → **GO TO QUESTION 72**

16a. Hospital/Medical Facility Name, City, State: ☐▼

16a1. Specify hospital/medical facility name, city, and state if not in drop down list: _____

16b. Approximate date of admission: ☐☐/☐☐☐☐ → **GO TO QUESTION 72**
Month Year

C. GENERAL HEALTH

17. Now I will ask you [name] some questions about your health. Over the past year, compared to other people your [name's] age, would you say that your [name's] health has been excellent, good, fair or poor?

Excellent ..... ☐
Good ..... ☐
Fair ..... ☐
Poor ..... ☐

18. Since we last contacted you [name], has a doctor said you [name] had high blood pressure?

Yes ..... ☐
No ..... ☐

19. Since we last contacted you [name], has a doctor said you [name has] have diabetes or sugar in the blood?

Yes ..... ☐
No ..... ☐

20. Since we last contacted you [name], has a doctor told you [name] that you [name] had chronic lung disease, such as bronchitis, or emphysema?

Yes ..... ☐ → **GO TO QUESTION 24**
No ..... ☐

21a. Are there times when you [name] wake up at night because of difficulty breathing?

Yes ..... ☐
No ..... ☐

21b. Do you (Does [name]) have trouble breathing or shortness of breath when hurrying on the level?

Yes ..... ☐
No ..... ☐ → **GO TO QUESTION 22**
Unable to Walk ..... ☐ → **GO TO QUESTION 23**

21c. Do you (Does [name]) have trouble breathing or shortness of breath when walking at ordinary pace on a level surface?

Yes ..... ☐
No ..... ☐ → **GO TO QUESTION 23**

21d. Do you (Does [name]) stop for breath when walking at your own pace?

Yes ..... ☐
No ..... ☐ → **GO TO QUESTION 23**

21e. Do you (Does [name]) stop for breath after walking 100 yards on the level?

Yes ..... ☐
No ..... ☐ → **GO TO QUESTION 23**

22. Do you (Does [name]) have difficulty breathing when you are not walking or active?

Yes.....☐
No .....☐

23. Do you (Does [name]) usually have some cough or wheezing?

Yes.....☐
No .....☐

24. Since we last contacted you [name] on [mm/dd/yyyy], has a doctor said (that [name]) had asthma?

Yes.....☐
No .....☐

25. Since we last contacted you [name] has a doctor said that you ([name] has) have peripheral vascular disease or intermittent claudication?

Yes.....☐
No .....☐

26. Do you (Does [name]) have pain in your [name's] legs caused by a blockage of the arteries?

Yes.....☐
No .....☐

27. Do you (Does [name])often have swelling in your [name's] feet or ankles at the end of the day?

Yes.....☐
No .....☐→ **GO TO QUESTION 28**

27a. Is the swelling in your [name's] feet or ankles gone in the morning?

Yes.....☐
No .....☐

28. Since we last contacted you [name], has a doctor said you [name] had cancer?

Yes.....☐
No .....☐→ **GO TO QUESTION 30**

28a. Can you tell me in what part of the body the most recently diagnosed cancer was located?

_____

28b. What is the approximate date the cancer was diagnosed?

☐☐/☐☐☐☐ → **GO TO QUESTION 30**
Month Year

D. CARDIOVASCULAR EVENTS

29. May I ask you some questions about [name's] health?

Yes ..... ☐ → **GO TO QUESTION 30**
No..... ☐

29a. Is there someone else we can ask?

Yes, person located..... ☐→ **GO TO QUESTION 30**
Yes, reschedule remainder of interview..... ☐→ **GO TO QUESTION 72**
No ..... ☐→ **GO TO QUESTION 72**

PREVIOUS HEART FAILURE DIAGNOSIS

30. Previously diagnosed with heart failure?

Yes……..☐→ **GO TO QUESTION 37**
No……..☐→ **GO TO QUESTION 31**

RECENT HEART FAILURE DIAGNOSIS

31. Since we last contacted you [name] on [mm/dd/yyyy], has a doctor said that you [name] had heart failure or congestive heart failure?

Yes.....☐→ **GO TO QUESTION 33a**
No .....☐

32. Since we last contacted you [name] has a doctor said that your [name's] heart is weak, or does not pump as strongly as it should, or that you had fluid on the lungs?

Yes.....☐
No .....☐→ **GO TO QUESTION 37**

DOCTOR INFORMATION FOR HEART FAILURE/WEAK HEART

33. Name and address of the doctor you [name] saw:

33a. Name _____

33b. Address _____

33c. City: _____ 33d. State: ☐☐

33e. Approximate date: ☐☐/☐☐☐☐
Month Year

HOSPITAL INFORMATION FOR HEART FAILURE/WEAK HEART

34. Were you (Was [name]) hospitalized at that time?

Yes.....☐
No .....☐→ **GO TO QUESTION 36**

35a. Hospital/Medical Facility Name, City, State: ☐▼

35a1. Specify hospital/medical facility name, city, and state if not in drop down list: _____

35b. Approximate date of admission: ☐☐/☐☐☐☐
Month Year

"The Jackson Heart study would like to ask your physician to tell us more about your health. If you agree to do this I will send you a form that tells your physician that you authorize the Jackson Heart study to get this information from your doctor. Once you sign that form and mail it back to me I will contact your physician's office."

36. May I send you this release form and an addressed envelope for you to mail it back?

Yes.....☐
No .....☐

If the participant agrees to receiving and signing the release form, remember to update the PHF form when the release form is sent to the participant, and then again when the release form is received back.

37. Since we last contacted you [name] on [mm/dd/yyyy] has a doctor said you [name] had a heart attack?

Yes.....☐
No .....☐ → **GO TO QUESTION 41**

38. Were you (Was [name]) hospitalized at that time?

Yes.....☐
No .....☐ → **GO TO QUESTION 41**

HOSPITAL INFORMATION FOR HEART ATTACK

39a. Hospital Name, City, State: ☐▼

39a1. Specify hospital name, city, and state if not in drop down list: _____

39b. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

Second hospitalization, if applicable

40a. Hospital Name, City, State: ☐▼

40a1. Specify hospital name, city, and state if not in drop down list: _____

40b. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

41. Since we last contacted you [name] has a doctor said you [name] had angina, angina pectoris or

chest pain due to heart disease?

Yes.....☐
No .....☐

42. Since we last contacted you [name] has a doctor said you [name] had an irregular heart beat called atrial fibrillation, or atrial fibrillation on a heart scan or electrocardiogram tracing?

Yes.....☐
No .....☐

43. Since we last contacted you [name] has a doctor said that you [name] had a blood clot in a leg or deep vein thrombosis?

Yes.....☐
No .....☐ → **GO TO QUESTION 46**

44. Were you [was 'name'] hospitalized for a blood clot in a leg or deep vein thrombosis at that time?

Yes.....☐
No .....☐ → **GO TO QUESTION 46**

HOSPITALIZATION FOR BLOOD CLOT IN LEG

45a. Hospital Name, City, State: ▼

45a1. Specify hospital name, city, and state if not in drop down list: _____

45b. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

46. Since we last contacted you [name], has a doctor said that you [name], had a blood clot in your lungs or a pulmonary embolus?

Yes.....☐
No .....☐ → **GO TO QUESTION 49**

47. Were you [was 'name'] hospitalized for a blood clot in your lungs or a pulmonary embolus at that time?

Yes.....☐
No .....☐ → **GO TO QUESTION 49**

HOSPITALIZATION FOR BLOOD CLOT IN LUNGS

48a. Hospital Name, City, State: ▼

48a1. Specify hospital name, city, and state if not in drop down list: _____

48b. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

49. Since we last contacted you [name], has a doctor said that you [name] had a stroke, slight stroke, transient ischemic attack, or TIA?

Yes.....☐
No .....☐→ **GO TO QUESTION 52**

50. Were you [was 'name'] hospitalized for this stroke, slight stroke, transient ischemic attack, or TIA?

Yes.....☐
No .....☐→ **GO TO QUESTION 52**

HOSPITALIZATION FOR STROKE OR TIA

51a. Hospital Name, City, State: ☐▼

51a1. Specify hospital name, city, and state if not in drop down list: _____

51b. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

E. ADMISSIONS

52. Have you stayed (Did [name] stay) overnight as a patient in a hospital for any other reason since our last contact?

Yes.....☐
No .....☐→ **GO TO QUESTION 58**

HOSPITALIZATION FOR OTHER REASON

53a. Hospitalization Reason: _____

53b. Hospital Name, City, State: ☐▼

53b1. Specify hospital name, city, and state if not in drop down list: _____

53c. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

HOSPITALIZATION FOR OTHER REASON

54a. Hospitalization Reason: _____

54b. Hospital Name, City, State: ☐▼

54b1. Specify hospital name, city, and state if not in drop down list: _____

54c. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

HOSPITALIZATION FOR OTHER REASON

55a. Hospitalization Reason: _____

55b. Hospital Name, City, State: ☐▼

55b1. Specify hospital name, city, and state if not in drop down list: _____

55c. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

HOSPITALIZATION FOR OTHER REASON

56a. Hospitalization Reason: _____

56b. Hospital Name, City, State: ☐▼

56b1. Specify hospital name, city, and state if not in drop down list: _____

56c. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

HOSPITALIZATION FOR OTHER REASON

57a. Hospitalization Reason: _____

57b. Hospital Name, City, State: ☐▼

57b1. Specify hospital name, city, and state if not in drop down list: _____

57c. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

58. Were you (Was [name]) admitted to an emergency room or a medical facility for outpatient treatment since our last contact on [mm/dd/yyyy]?

Yes..... ☐
No ..... ☐ → **GO TO QUESTION 61**

59. Was this related to a heart problem or difficulty breathing?

Yes..... ☐
No ..... ☐ → **GO TO QUESTION 61**

EMERGENCY ROOM/MEDICAL FACILITY INFORMATION

60a. ER/Facility Name, City, State: ☐▼

60a1. Specify ER/Facility name, city, and state if not in drop down list:_____

60b. Approximate date of hospitalization ☐☐/☐☐☐☐
Month Year

61. Since our last contact, (Did [name] stay) have you stayed overnight as a patient in a nursing home?

Yes.....☐
No .....☐

62. Are you (Is [name]) currently a resident of a nursing home or long-term care facility?

Yes.....☐
No .....☐

F. INVASIVE PROCEDURES

Next I am going to ask about various types of surgery and medical procedures. We are interested in those that occurred in the hospital, or in an emergency department, or as an outpatient.

63. Since we last contacted you [name], on [mm/dd/yyyy] have you [did name] had any surgery on your [name's] heart, or the arteries of your neck or legs, not counting surgery for varicose veins?

Yes.....☐
No .....☐ → **GO TO QUESTION 65**

64. Did you [name] have:

a. Coronary bypass?

Yes.....☐
No .....☐

b. Other heart procedure?

Yes.....☐ → Specify: _____
No .....☐

c. Carotid endarterectomy?

Yes.....☐
No .....☐ → **GO TO QUESTION 64e**

d. Site:

Right.....☐
Left.....☐
Both.....☐

e. Other arterial revascularization?

Yes.....☐ → Specify: _____
No .....☐

f. Any other type of surgery on your heart or the arteries of your [name's] neck or legs?

Yes.....☐
No .....☐

65. Since we last contacted you [name] on [mm/dd/yyyy] have you [did name have] had a balloon angioplasty or stent on the arteries of your [name's] heart, neck, or legs?

Yes.....☐
No .....☐ → **Go to Question 66**

Did you [name] have:

a. Angioplasty or stent of the coronary arteries of your [name's] heart:

Yes.....☐
No .....☐

b. Angioplasty or stent in the arteries of your [name's] neck:

Yes.....☐
No .....☐

c. Angioplasty or stent of the lower extremity arteries:

Yes.....☐
No .....☐

G. INTERVIEW

Now I would like to ask about medication use during the past two weeks.

66. Did you [name] take any medications during the past two weeks for:

a. High blood pressure?

Yes.....☐
No .....☐

b. High blood cholesterol?

Yes.....☐
No .....☐

c. Diabetes or high blood sugar?

Yes.....☐
No .....☐

d. Heart failure?

Yes.....☐
No .....☐

67. Are you [Is name] NOW taking aspirin, or a medicine containing aspirin, on a regular basis? This does not include Tylenol or Advil.

Yes.....☐
No .....☐

68. Does the participant have medications to report?

Yes.....☐
No .....☐ → **Go to Question 70**

69. Record names of medications.

Next, I have a few miscellaneous questions.

70. Do you (Does [name])now smoke cigarettes?

Yes.....☐
No .....☐

71. Please tell me which of the following describes your [name's] current marital status:

Married.....☐
Widowed .....☐
Divorced.....☐
Separated.....☐
Never Married.....☐

CLOSURE SCRIPT:

Talking to participant: "Thank you very much for answering these questions. You have previously provided us with information on how to contact you. To help us contact you next year, please tell me if the information I have is still correct."

If participant deceased: "We may need to contact a family member later. When would be a good time to call in that case?"

Otherwise: "Thank you very much for answering these questions. We will call _____ in about a year."

H. ADMINISTRATIVE INFORMATION

72. AFU Completion Status:

a. Complete.....☐
b. Partially complete; contact again within window (interruptions)...☐
c. Partially complete; unable to complete within window (done).....☐

Annual Follow-Up Other Form

ID NUMBER: | | | | | | | | CONTACT YEAR: | | | FORM CODE: AFO
VERSION D 10/15/2006

LAST NAME: | | | | | | | | | | | | INITIALS: | |

INSTRUCTIONS: This form should be completed each year during the annual follow-up call. ID Number, Contact Year, and Name must be entered above. Whenever numerical responses are required, enter the number so that the last digit appears in the rightmost box. Enter leading zeroes where necessary to fill all boxes. If a number is entered incorrectly, mark through the incorrect entry with an "X". Code the correct entry clearly above the incorrect entry. For "multiple choice" and "yes/no" type questions, circle the letter corresponding to the most appropriate response. If a letter is circled incorrectly, mark through it with an "X" and circle the correct response.

I would like to ask you about some health care experiences you may have had in the past year.

1. In the past year have you had any of the following tests or procedures?

	Yes	No	Don't Know	Refused	Missing	1a1-1c1. Reason? (see codes below)
1a. Echocardiogram	1	2	7	8	9		
1b. ECG	1	2	7	8	9		
1c. Exercise stress test	1	2	7	8	9		

IF YES TO ITEMS 1a-c, ASK: What was the reason for the test / procedure?
[IF USING PAPER FORM ENTER NUMBER IN TEXT BOX THAT CORRESPONDS TO ONE OF THE CODES DESIGNATED BELOW FOR EACH ITEM. IF USING DMS, SELECT FROM DROP DOWN MENU FOR EACH ITEM]

1a1 -1c1. Select from one of the following codes:

Routine physical 01	Heart failure / fluid on lungs 02
Follow up of heart problem (surgery/stent) 03	Heart murmur 04
Chest pain / discomfort 05	Heart rhythm disturbance 06
Other (Specify) 07	Don't know 77
Refused 88	Missing 99

1a2-1c2. Specify: | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | |

	Yes	No	Don't Know	Missing	Refused	
1d. CT/ MRI head	1	2	7	8	9	

IF YES TO ITEMS 1d, ASK: What was the reason for the test / procedure?
[IF USING PAPER FORM ENTER NUMBER IN TEXT BOX THAT CORRESPONDS TO ONE OF THE CODES DESIGNATED BELOW FOR EACH ITEM. IF USING DMS, SELECT FROM DROP DOWN MENU FOR EACH ITEM]

1d1. Select from one of the following codes: .....

Forgetfulness / trouble thinking 1
Stroke.....2
TIA or "little" strokes 3
Other (specify).....4
Don't know 7
Refused 8
Missing 9

1d2. Specify:

1e. Catheterization or angiogram 1 2 7 8 9

IF 1 e. is YES, ASK: Was that arteriogram to look at the blood vessels in your:

							2a1-2d1. Reason? (see codes below)
1e-1.	neck (Carotid arteriogram).....	1	2	7	8	9	
1e-2.	heart (Coronary arteriogram) .	1	2	7	8	9	
1e-3.	kidneys (Renal arteriogram) ..	1	2	7	8	9	
1e-4.	legs (peripheral vascular)	1	2	7	8	9	

IF YES TO ITEMS 1e1-1e4. ASK: What was the reason for the test / procedure?
[IF USING PAPER FORM ENTER NUMBER IN TEXT BOX THAT CORRESPONDS TO ONE OF THE CODES DESIGNATED BELOW FOR EACH ITEM. IF USING DMS, SELECT FROM DROP DOWN MENU FOR EACH ITEM]

2a-d. Select from one of the following codes:

Emergency for a heart attack 1
Emergency for a stroke..... 2
Follow up after heart attack or surgery / stent.....3
Doctors suspected disease/blockage .4
Chest pain / discomfort 5
Leg pain with walking..... 6

Other (Specify) ..... 7 Don't know..... 77

Refused..... 88 Missing.....99

2d. Specify:

3. In the past year (that is, since your last JHS contact), have you had any change in your family history? That is, have your natural parents, any of your full brothers or sisters, or your natural children died?

.... Yes 1

No 2

Don't Know 7

Refused 8

Missing 9

Go to Item 5

4. For each person who died, determine:

4-a1. Relationship?		4-a2. Cause of death?		4-a3. Age at death?
Mother	1	Cancer	1	
Father	2	Heart Attack	2	
Sibling	3	Stroke	3	
Child	4	Other (Specify)	4	
		Unknown	7	

4.a4 Specify:

4-b1. Relationship?		4-b2. Cause of death?		4-b3. Age at death?
Mother	1	Cancer	1	
Father	2	Heart Attack	2	
Sibling	3	Stroke	3	
Child	4	Other (Specify)	4	
		Unknown	7	

4-b4. Specify:

4-c1. Relationship?

Mother	1
Father	2
Sibling	3
Child	4

4-c2. Cause of death?

Cancer	1
Heart Attack	2
Stroke	3
Other (Specify)	4
Unknown	7

4-c3. Age at death? [ ][ ][ ]

4-c4. Specify: [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

[ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

4-d1. Relationship ?

Mother	1
Father	2
Sibling	3
Child	4

4-d2. Cause of death ?

Cancer	1
Heart Attack	2
Stroke	3
Other (Specify)	4
Unknown	7

4-d3. Age at death? [ ][ ][ ]

4-d4. Specify: [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

[ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

5. In the past year (that is, since you last JHS contact), have any members of your family (natural parents, full siblings, natural children) been newly diagnosed (that is, have they been told by a health care provider that they have) with high blood pressure, heart disease, stroke, diabetes (sugar in the blood) or cancer?

.... Yes	1	
No	2	Go to Item 7
Don't Know	7	Go to Item 7
Refused	8	Go to Item 7
Missing	9	Go to Item 7

6. For each person who has a new diagnosis (been told by health care professional), determine:

6-a1. Relationship ?		6-a2. Told has ?		6-a3. Age at diagnosis
Mother	1	High blood pressure	1	
Father	2	Stroke	2	
Sibling	3	Heart Disease	3	
Child	4	Diabetes	4	
		Cancer	5	
		Other (Specify)	7	

6-a4. Specify:

6-b1. Relationship ?		6-b2. Told has ?		6-b3. Age at diagnosis
Mother	1	High blood pressure	1	
Father	2	Stroke	2	
Sibling	3	Heart Disease	3	
Child	4	Diabetes	4	
		Cancer	5	
		Other (Specify)	7	

6-b4. Specify:

6-c1. Relationship ?		6-c2. Told has ?		6-c3. Age at diagnosis
Mother	1	High blood pressure	1	
Father	2	Stroke	2	
Sibling	3	Heart Disease	3	
Child	4	Diabetes	4	
		Cancer	5	
		Other (Specify)	7	

6-c4. Specify:

6-d1. Relationship ?		6-d2. Told has ?		6-d3. Age at diagnosis ?
Mother	1	High blood pressure	1	
Father	2	Stroke	2	
Sibling	3	Heart Disease	3	
Child	4	Diabetes	4	
		Cancer	5	
		Other (Specify)	7	

6-d4. Specify:

People often go through difficult or stressful times (e.g., illness, problems at work, death of a close relative).

7. How much stress have you experienced over the past year? Have you experienced none, very little, mild stress, moderate stress, a lot of stress, or extreme stress?

None	1
Very little	2
Mild stress	3
Moderate stress	4
A lot of stress	5
Extreme stress	6
Don't Know	7
Refused	8
Missing	9

8. How often have you felt sad or depressed over the past year: almost never, seldom, sometimes, often, very often, or constantly? ..... Almost never 1

Seldom	2
Sometimes	3
Often	4
Very often	5
Constantly	6
Don't Know	7
Refused	8
Missing	9

9. How often have you felt nervous or tense over the past year? ..... Almost never 1

Seldom	2
Sometimes	3
Often	4
Very often	5
Constantly	6
Don't Know	7
Refused	8
Missing	9

10. How often have you felt you were treated unfairly or discriminated against over the past year?..... Almost never 1

Seldom	2
Sometimes	3
Often	4
Very often	5
Constantly	6
Don't Know	7
Refused	8
Missing	9

11. How well have you handled or coped with stressors you experienced over the past year? Would you say very poorly, poorly, fair, pretty well, well, or very well?

Very poorly	1
Poorly	2
Fair	3
Pretty well	4
Well	5
Very well	6
Don't Know	7
Refused	8
Missing	9

12. How satisfied are you with the help or support that you've received from others over the past year? Are you very dissatisfied, somewhat dissatisfied, a little dissatisfied, a little satisfied, somewhat satisfied, or very satisfied?

Very dissatisfied	1
Somewhat dissatisfied	2
A little dissatisfied	3
A little satisfied	4
Somewhat satisfied	5
Very satisfied	6
Don't Know	7
Refused	8
Missing	9

13. In the past year, have you seen:

	Yes	No	Don't Know	Refused	Missing
a. a dentist	1	2	7	8	9
b. a doctor or health professional for routine physical exam or general check-up, that is when you are not sick	1	2	7	8	9
c. a chiropractor	1	2	7	8	9
d. a person who uses acupuncture	1	2	7	8	9

		Yes	No	Don't Know	Refused	Missing
e.	a faith healer	1	2	7	8	9
f.	a person who heals with roots or herbs	1	2	7	8	9
g.	a person who practices astrology or reads zodiac signs	1	2	7	8	9
h.	a person who reads tea leaves, roots or palms	1	2	7	8	9

14. Are you currently covered by one or more health insurance programs that pays most or all of your health care expenses? .....

Yes	1	
No	2	
Don't Know	7	Skip 16
Refused	8	Skip 16
Missing	9	Skip 16

15. How long has it been since you had health insurance coverage? .....

Less than 1 year	1	
1 to 2 years	2	
More than 3 years	3	Skip 20
Don't Know	7	Skip 20
Refused	8	Skip 20
Missing	9	Skip 20

16. Are you currently covered by any of the following program (**Answer each item**)

		Yes	No	Don't Know	Refused	Missing
a.	Private health insurance such as Blue Cross/Blue Shield?	1	2	7	8	9
b.	Medicaid or public aid?	1	2	7	8	8

	Yes	No	Don't Know	Refused	Missing
c. Medicare, a government plan that pays health care bills for people aged 65 and over?	1	2	7	8	9
d. Veterans Administration, CHAMPUS, or TRICARE?	1	2	7	8	9
e. Other	1	2	7	8	9

17. (**Answer all items**) Have you experienced any of the following changes in health insurance benefits in the past year, or since your last JHS annual follow up telephone call?

	Yes	No	Don't Know	Refused	Missing
a. An increase in the price of the premiums	1	2	7	8	9
b. A cut in benefits	1	2	7	8	9
c. An increase in your share of the medical costs	1	2	7	8	9

18. Has there been a time in the past year when you did not have health insurance coverage?

Yes	1
No	2
Don't Know	7
Refused	8
Missing	9

19. On average, how much do you pay each month for your medication?

Less then $20	1
$20 – $40	2
$41 – $75	3
$76 – 100	4
$101 – $250	5
More than $250	6
Don't know	7
Refused	8
Missing	9

20. Do you have health insurance that helps you pay for your medications? ..... Yes 1

No 2 — Go to Item 23

Don't Know 7

Refused 8

Missing 9

21. Do you pay a co-payment when you fill your medication?

Yes 1

No 2

Don't Know 7

Refused 8

Missing 9

22. Some medication insurance plans have various "limits" on what they will cover when paying for medications. I am going to read a list of possible limitations that your insurance plan may have. For each item, please tell me if your plan this limit.

	Yes	No	Don't Know	Refused	Missing
a. My plan has no limits on my medication coverage	1	2	7	8	9
b. My plan has a dollar limit per month.....	1	2	7	8	9
c. IF YES to 22b, ask: How much is the dollar limit?	☐☐☐				
d. My plan limits the number of medications it will pay for per month (or quarter if using 3 month prescriptions).	1	2	7	8	9
e. IF YES to 22d, ask: How many medications can you obtain?	☐☐				
f. My plan limits how often I can fill my prescriptions.....	1	2	7	8	9
g. IF YES to item 22f, ask: What is the time limit for filling your prescriptions?	☐☐				
h. Any other limits?.....	1	2	7	8	9

i. List……

Next I will ask you some questions regarding the care that you have received in your doctor's or nurse practitioner's office or in some health care clinic.

23. How many times in the past year did you go to a doctor's or nurse practitioner's office to get care for yourself?

None	01 → Go to Item 29
1	02
2	03
3	04
4	05
5 to 9	06
10 or more	07
Don't Know	77
Refused	88
Missing	99

24. How often did your doctor or other health care providers listen carefully to you?

Never	1
Sometimes	2
Usually	3
Always	4
Don't know	7
Refused	8
Missing	9

25. How often did your doctor or other health providers explain things in a way you could understand?

Never	1
Sometimes	2
Usually	3
Always	4
Don't Know	7
Refused	8
Missing	9

26. How often did your doctor or other health care providers show respect for what you had to say? .....

Never	1
Sometimes	2
Usually	3
Always	4
Don't Know	7
Refused	8
Missing	9

27. How often did your doctor or other health care providers spend enough time with you? .....

Never	1
Sometimes	2
Usually	3
Always	4
Don't Know	7
Refused	8
Missing	9

28. Overall, how satisfied have you been with the quality of health care you have received in the past year? .....

Very satisfied	1
Somewhat satisfied	2
Somewhat dissatisfied	3
Very dissatisfied	4
Not sure	5
Don't Know	7
Refused	8
Missing	9

Now I will ask you questions regarding any problems that you have had when you have tried to get health care.

29. In the past year, how much of a problem has it been to get the health care, medical tests, or treatment you or your doctor or nurse practitioner believed necessary? ..A big problem 1

A small problem 2

Not a problem 3

Don't Know 7

Refused 8

Missing 9

30. Has there been a time in the past year when you went without needed health care because of costs?.....Yes 1

No 2 — Skip to 32

Don't Know 7

Refused 8

Missing 9

31. What type of health care did you do without because of costs? (**Answer each item**)

	Yes	No	Don't Know	Refused	Missing
a. Did not fill a prescription	1	2	7	8	9
b. Did not see a specialist when needed	1	2	7	8	9
c. Skipped a medical test, treatment of follow-up	1	2	7	8	9
d. Had medical problems, but did not see a doctor or nurse practitioner	1	2	7	8	9

Other _____

32. How confident are you that you can get high quality health are when you need it?..... Very confident 1

Somewhat confident 2

Not too confident 3

Not at all confident 4

Don't Know 7

Refused 8

Missing 9

33. [DO NOT ASK] Is the participant male or female? ..... Male 1 — Go to Item 39

Female 2

34. [DO NOT ASK] Has the participant completed a previous version "A" or "B" of Annual Follow-up? ..... Yes 1

Go to Item 35b — No 2

35 a. Since we last contacted you on (mm/dd/yyyy), have you taken or used any female hormone pills, skin patches, shots or implants? ..... Yes 1 — Go to Item 35c

No 2 — Go to Item 39

35 b. Since your JHS visit on (mm/dd/yyyy), have you taken or used any female hormone pills, skin patches, shots or implants? ..... Yes 1

Go to Item 39 — No 2

Please give me the names of the female hormones you have used since our last contact (since that exam), starting with any you may be taking currently or with the most recent one. Please exclude hormone creams.

35 c. Name 1:

36. Code 1: .....

37. Have you also used a second female hormone since we last contacted you? ..... Yes 1

Go to Item 39 — No 2

37a. Name 2:

38. Code 2: .....

I. FUNCTIONAL STATUS:

"Now I would like to find out whether you can do some physical activity without help. By 'without help' I mean without the assistance of another person. These questions refer to the last 4 weeks."

39. Are you able to do heavy work around the house, like shoveling snow or washing windows, walls or floors without help? ..... Yes 1
No 2
Don't Know 7
Refused 8
Missing 9

40. Are you able to walk up and down stairs without help? ..... Yes 1
No 2
Don't Know 7
Refused 8
Missing 9

41. Are you able to walk half a mile without help? That's about 8 ordinary blocks. ..... Yes 1
No 2
Don't Know 7
Refused 8
Missing 9

42a. Are you ABLE to go to work? ..... Yes 1 → Go to Item 43a
No 2
Not Applicable 9 → Go to Item 44a

42b. Is a heart problem the main cause of your not being able to work? ..... Yes 1
No 2 → Go to Item 44a
Don't Know 7
Refused 8
Missing 9

43a. During the past 4 weeks, have you missed work for at least half a day because of your health? ..... Yes 1
No 2 → Go to Item 44a

43b. On how many days has this happened? (maximum 28) ..... ☐☐ days

44a. Are you able to do your usual activities, such as work around the house or recreation? ..... Yes 1 → Go to Item 45a
No 2

44b. Is a heart problem the main cause of your being unable to do this (these) activity(ies)? ..... Yes 1
No 2
Don't Know 7 → Go to item 46a
Refused 8
Missing 9

When you add the refused and missing codes to this one, make sure to extend the go to box to include all responses

45a. During the past 4 weeks, have you had to cut down on your usual activities, (such as work around the house or recreation), for half a day or more because of your health? ..... Yes 1
No 2

45b. On how many days has this happened? (maximum 28) ..... ☐☐ days

L. EMPLOYMENT STATUS

46a. Please tell me which of the following best describes your employment status: ..... Homemaking 1 → STOP
Employed 2
Unemployed 3 → Go to Item 46c
Retired 4 → Go to Item 46d

46b. Which of these two categories best describes your "employed" status:.....

Employed at a job for pay, either full or part-time 1

Employed, but temporarily away from regular work 2

→ STOP

46c. Which of these two categories best describes your "unemployed" status:.....

Unemployed, looking for work 1

Unemployed, not looking for work 2

→ STOP

46d. Which of these two categories best describes your "retired" status: .....

Retired from my usual occupation and not working 1

Retired from my usual occupation, but working for pay 2

Administrative Information

47. Date of data collection: ..... | | | / | | | / | | | | |

m m / d d / y y y y

48. Method of data collection:..... Computer 1

Paper Form 2

49. Data Collection..... In Clinic 1

Off Site 2

50. Code number of person completing this form: ..... | | | |