



ANNUAL FOLLOW-UP QUESTIONNAIRE FORM

FORM CODE:

A	F	U
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VERSION: C 10/14/2008

ID NUMBER:

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CONTACT YEAR

--	--

LAST NAME:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

 INITIALS:

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Public reporting burden for this collection of information is estimated to average 6-15 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: **NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0281)**. Do not return the completed form to this address.

INSTRUCTIONS: This form should be completed during the interview portion of the participant's annual follow-up. 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 zeros 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.

ANNUAL FOLLOW-UP QUESTIONNAIRE (AFU)

A. VITAL STATUS

1. Date of status determination:

		/			/				
--	--	---	--	--	---	--	--	--	--

Month Day Year

2. Final Status:
{Circle one below}

3. Information obtained from:
{Circle one corresponding choice below}

Contacted and Alive	C	<table><tr><td>Phone</td><td>A</td><td>Go to Item 6</td></tr><tr><td>Personal Interview</td><td>B</td><td></td></tr><tr><td>Letter</td><td>C</td><td>Go to Item 23</td></tr></table>	Phone	A	Go to Item 6	Personal Interview	B		Letter	C	Go to Item 23
Phone	A	Go to Item 6									
Personal Interview	B										
Letter	C	Go to Item 23									
Contacted and Refused	F	Go to Item 52									
Reported Alive	R	<table><tr><td>Relative, spouse, acquaintance</td><td>D</td><td></td></tr><tr><td>Employer information</td><td>E</td><td>Go to Item 23</td></tr><tr><td>Other</td><td>F</td><td></td></tr></table>	Relative, spouse, acquaintance	D		Employer information	E	Go to Item 23	Other	F	
Relative, spouse, acquaintance	D										
Employer information	E	Go to Item 23									
Other	F										
Reported Deceased	D	<table><tr><td>Relative, spouse, acquaintance</td><td>G</td><td></td></tr><tr><td>Surveillance</td><td>H</td><td>Continue to Item 4</td></tr><tr><td>Other (National Death Index)</td><td>I</td><td></td></tr></table>	Relative, spouse, acquaintance	G		Surveillance	H	Continue to Item 4	Other (National Death Index)	I	
Relative, spouse, acquaintance	G										
Surveillance	H	Continue to Item 4									
Other (National Death Index)	I										
Unknown	U	Go to Item 52									

B. DEATH INFORMATION

4. Date of death:

		/			/				
Month		Day		Year					

5. Location of death:

a. City/ County

b. State:

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After Item 5, skip to Item 23, **Screen X.**

C. GENERAL HEALTH

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

- Excellent E
- Good..... G
- Fair F
- Poor P

7a. **[DO NOT ASK]** Has this participant previously completed version B of the AFU form?

If Yes, go to Q 9	Yes	Y
	No	N
	Unknown	U

7b. **[DO NOT ASK]** Has participant ever reported a heart failure diagnosis in AFU without a documented HF hospitalization in the Jackson Heart Study database? **(to be done for 1 year only).** Y N

If NO, skip to Q9

8. In a previous JHS phone call in [**< year >**], you indicated that you had been diagnosed with heart failure or congestive heart failure. Do you recall that you had such a diagnosis of heart failure?

Y N U

No or Unknown skip to Q9

What is the name and address of the doctor you last saw for heart failure?

8 a. Name: _____

8 b. Address: _____

8 c. What was the approximate date?

		/					
M	M		Y	Y	Y	Y	

8 d. **[DO NOT ASK]** Was this within 3 yrs. of today's date? Y N U

8 e. Were you hospitalized for heart failure at that time?

Y N U

If Yes, go to "obtain hospital information and date" Section F Q 28a and then return to Q 8g

8 f. Were you hospitalized for heart failure or congestive heart failure at another time?

Y N U

If Yes, go to "obtain hospital information and date" Section F Q 28a and return to Q 10.

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

Y N U

No or Unknown skip to Q 10.

What is the name and address of the doctor who said you had heart failure?

9. a. Name: _____

9. b Address: _____

9. c. What was the approximate date?

		/				
--	--	---	--	--	--	--

M M Y Y Y Y

9. d. **[DO NOT ASK]** Was this within 3 yrs. of today's date] Y N U

9. e. Were you hospitalized for heart failure at that time?

Y N U

If Yes, go to "obtain hospital information and date" Section F Q 28a and return to Q10

10. Has a doctor ever said that your heart is weak, or does not pump as strongly as it should, or that you had fluid on the lungs?

Y N U

No or Unknown skip to Q 11a.

What is the name and address of the doctor you saw?

10. a. Name: _____

10. b. Address: _____

10. c. What was the approximate date?

		/				
--	--	---	--	--	--	--

M M Y Y Y Y

10. d. **[DO NOT ASK]** Was this within 3 yrs. of today's date?

Y N U

10. e. Were you hospitalized for the weak heart muscle at that time?

Y N U

11. a. Has a doctor ever said that you had a heart attack?

Y N U

11. b. Has a doctor ever said that you had angina, angina pectoris or chest pain due to heart disease?

Y N U

If No or Unknown: Go to Q 12.

11. c. Were you first told that you had angina since we last contacted you on mm /dd/ yyyy?

Y N U

12. Has a doctor ever said that you had an irregular heart beat called atrial fibrillation, or atrial fibrillation on a heart scan or electrocardiogram tracing?

Y N U

13. a. Do you often have swelling in your feet or ankles at the end of the day?

Y N U

No or Unknown skip to Q 14.

13. b. Is the swelling in your feet or ankles gone in the morning?

Y N U

14. Has a doctor ever said that you had high blood pressure?

Y N U

15. Has a doctor ever said that you have diabetes or sugar in the blood?

Y N U

16. Has a doctor ever said that you had a blood clot in a leg or deep vein thrombosis?

Y N U

No or Unknown skip to Q 17a.

What is the name and address of the doctor you saw? (If same physician as above, no need to records address)

16. a. Name: _____

16. b. Address: _____

16. c. What was the approximate date?

		/				
M	M		Y	Y	Y	y

16. d. Were you hospitalized for a blood clot in a leg or deep vein thrombosis at that time?

Y N U

If Yes: go to obtain hospital information and date Section F Q 28a and return to Q.17a, below.

17. a. Has a doctor ever said that you had a blood clot in your lungs or a pulmonary embolus?

Y N U

No or Unknown skip to Q 18.

17. b. Were you hospitalized for a blood clot in your lungs or a pulmonary embolus at that time?

Y N U

If Yes: go to obtain hospital information and date Section F Q 28a and return to Q. 18.a.,below.

18. a. Has a doctor ever said that you had chronic lung disease, such as bronchitis, or emphysema?

Y N U

If No or U skip to Q 19a.

18. b. Were you told by the physician that you had chronic lung disease since we last contacted you on mm/dd /yyyy ?

Y N U

If Yes to either 18a or 18b: Go to Q 20.

19. a. Are there times when you wake up at night because of difficulty breathing?

Y N U

19. b. Do you have trouble breathing or shortness of breath when hurrying on the level?

Y N U Unable to walk → Go to Q 19 f

If No or U: Go to Q 19f.

19. c. Do you have trouble breathing or shortness of breath when walking at ordinary pace on a level surface?

Y N U

If No or U: Go to Q 19g.

19. d. Do you stop for breath when walking at your own pace?

Y N U

If No or U: Go to Q 19g.

19. e. Do you stop for breath after walking 100 yards on the level?

Y N U

If No or U: Go to Q 19g.

19. f. Do you have difficulty breathing when you are not walking or active?

Y N U

19.g. Do you usually have some coughing or wheezing?

Y N U

20. Has a doctor ever said that you had asthma?

Y N U

If No: Go to Q 20b.

20. a. Did the doctor say that you have asthma since we last contacted you on mm/dd/yyyy ?

Y N U

20. b. Do you have pain in your legs caused by a blockage of the arteries ?

Y N U

20. c. Has a doctor ever said that you have peripheral vascular disease or intermittent claudication ?

Y N U

21. a. Has a doctor ever said that you had cancer?

Y N U

Go to Item 22a

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

--	--	--	--	--	--	--	--	--	--

21. c. And the date it was diagnosed?

			/				
--	--	--	---	--	--	--	--

Month

Year

D. STROKE/TIA

22. a. Since our last contact on mm/dd/yyyy, have you been told by a physician that you had a stroke, slight stroke, transient ischemic attack, or TIA?

Yes Y

If "No", go to question 23

No N

22. b. Were you hospitalized for this stroke, slight stroke, transient ischemic attack or TIA? Yes Y

No N

If "Yes", ensure that this event is included in the "HOSPITALIZATIONS" section, Section F Q 28a, if appropriate.

E. ADMISSIONS

23. Were you (Was [name]) hospitalized for a heart attack since our last contact on (mm/dd /yyyy)?

Y N U

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

Y N U

If "Yes" to either 23 or 24, add to "HOSPITALIZATIONS" section F Q28a and return to Q. 25a.

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

Y N U

If No or Unknown: Go to Q 27a

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

Y N U

If No or Unknown: Go to Q 27a

What is the name and address of this medical facility?

26. .a. Name: _____

26. .b. Address: _____

26. c. What was the approximate date?

		/				
M	M		Y	Y	Y	Y

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

Go to Item 40.

No N

For DECEASED, REPORTED ALIVE, or CONTACTED BY LETTER statuses, go to Q.52

27. b. Are you currently staying in a nursing home? Yes Y

No N

On the paper form, skip Section F and continue to Item 40. To skip in the DMS scroll down to item 40.

F. HOSPITALIZATIONS

For each time you were (he/she was) a patient in a hospital, I would like to obtain the reason you were (he/she was) admitted, the name of the hospital, and the date. When was the first time you were (he/she was) hospitalized since our last contact with you (him/her) on (mm/dd/ yyyy of last contact)? [Fill in, probing as necessary. Probe for additional hospitalizations. For linkage, H indicates that the hospitalization was reported; N indicates that the hospitalization was fully sought by Surveillance, and not found.]

28. a. Hospitalization Reason:

28. b. Hospital Name, City, and State:

28. c. Month and Year:

		/				
--	--	---	--	--	--	--

M M Y Y Y Y

28. d. Linkage Status: ☐
(H) or (N)

29. a. Hospitalization Reason:

29. b. Hospital Name, City, and State:

29. c. Month and Year:

		/				
--	--	---	--	--	--	--

M M Y Y Y Y

29. d. Linkage Status: ☐
(H) or (N)

30. a. Hospitalization Reason:

30. b. Hospital Name, City, and State:

30. c. Month and Year:

		/				
--	--	---	--	--	--	--

M M Y Y Y Y

30. d. Linkage Status: ☐
(H) or (N)

31. a. Hospitalization Reason:

31. b. Hospital Name, City, and State:

31. c. Month and Year:

		/				
--	--	---	--	--	--	--

M M Y Y Y Y

31. d. Linkage Status: ☐
(H) or (N)

32. a. Hospitalization Reason:

32. b. Hospital Name, City, and State:

32. c. Month and Year:

		/				
M	M		Y	Y	Y	Y

32. d. Linkage Status:

☐

(H) or (N)

33. a. Hospitalization Reason:

33. b. Hospital Name, City, and State:

33. c. Month and Year:

		/				
--	--	---	--	--	--	--

33. d. Linkage Status:

☐

(H) or (N)

34. a. Hospitalization Reason:

34. b. Hospital Name, City, and State:

34. c. Month and Year:

		/				
M	M		Y	Y	Y	Y

34. d. Linkage Status:

☐

(H) or (N)

35. a. Hospitalization Reason:

35. b. Hospital Name, City, and State:

35.c. Month and Year:

		/				
M	M		Y	Y	Y	Y

35. d. Linkage Status:

☐

(H) or (N)

36. a. Hospitalization Reason:

36. b. Hospital Name, City, and State:

36. c. Month and Year:

		/				
M	M		Y	Y	Y	Y

36. d. Linkage Status:

☐

(H) or (N)

37. a. Hospitalization Reason:

37. b. Hospital Name, City, and State:

37. c. Month and Year:

		/				
M	M		Y	Y	Y	Y

37. d. Linkage Status:

☐

(H) or (N)

38. a. Hospitalization Reason:

38. b. Hospital Name, City, and State:

38. c. Month and Year:

		/				
M	M		Y	Y	Y	Y

38. d. Linkage Status:

☐

(H) or (N)

39. a. Hospitalization Reason:

39. b. Hospital Name, City, and State:

39. c. Month and Year:

		/				

39. d. Linkage Status:

☐

(H) or (N)

G. INVASIVE PROCEDURES

"The following questions ask about various types of surgery and procedures.

We are interested in both those that occurred in the hospital or as an out-patient."

40. [DO NOT ASK]

Has participant completed a previous version 'A' or later of Annual Follow-up?

Go to Item 41b.	Yes	1
	No	2

41. a. Since we last contacted you on (mm/dd/yyyy) have you had surgery on your heart, or the arteries of your neck or legs, excluding surgery for varicose veins?

Go to Item 42.	Yes	1
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Go to Item 44a	No	2
----------------	----	---

41. b. Since your last Jackson Heart Study visit on (mm/dd/yyyy) have you had surgery on your heart, or the arteries of your neck or legs, excluding surgery for varicose veins?

Go to Item 44b.	Yes	1
	No	2

42. Did you have

a. Coronary bypass: Yes 1

No 2

b. Other heart procedure: Yes 1

No 2

42.b1. Specify: _____

c. Carotid endarterectomy: Yes Y

Go to Item 42e.

No N

d. Site:..... Right R

Left L

Both B

e. Other arterial
revascularization: Yes Y

No N

42. e1. Specify: _____

f. Any other type of surgery on your heart or the arteries of your neck or legs?

Yes Y

No N

43. [DO NOT ASK]

Has participant completed a previous version 'A' or later of Annual Follow-up?

Yes Y

Go to Item 44b.

No N

44. a. Since we last contacted you on (mm/dd/yyyy) have you had a balloon angioplasty or stent on the arteries of your heart, neck, or legs?

Go to Item 45a.

Yes Y

Go to Item 46.

No N

44. b. Since your last visit to the Jackson Heart Study on (mm/dd/yyyy) have you had a balloon angioplasty or stent on the arteries of your heart, neck, or legs?

Yes Y

Go to Item 46.

No N

45. Did you have:

a. Angioplasty or stent of the coronary arteries:	Yes	Y
	No	N
b. Angioplasty or stent in the arteries of your neck:	Yes	Y
	No	N
c. Angioplasty or stent of the lower extremity arteries:	Yes	Y
	No	N

H. INTERVIEW

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

46. Did you take any medications during the past two weeks for:

	<u>Yes</u>	<u>No</u>	<u>Unknown</u>
a. High Blood Pressure	Y	N	U
b. High Blood Cholesterol	Y	N	U
c. Diabetes or High Blood Sugar	Y	N	U
d. Heart Failure	Y	N	U

"Now I would like to ask about the prescription medications you currently use [optional: as mentioned in the scheduling reminder we sent recently]. Can I ask you to bring all the prescription medications you are taking to the telephone?"

47. [DO NOT ASK] Does the participant have medications to report?

Yes..... Y

No.....N

Participant refused to provide medication
information R

Unknown.....U

If the answer is NO, REFUSED, or UNKNOWN, skip to question 49

[Once participant has all medications or prescriptions] Please read the names of all the medications prescribed by a doctor. This includes pills, liquid medications, skin patches, inhalers, and injections. Please do not include over the counter medications.

[If asked: currently taking applies to medications taken in the past two weeks.

Medication Name

48.a. _____

48.b. _____

48.c. _____

48.d. _____

48.e. _____

48.f. _____

48.g. _____

48.h. _____

48.i. _____

48.j. _____

48.k. _____

48.l. _____

48.m. _____

48.n. _____

48.o. _____

48.p. _____

48.q. _____

48.r. _____

48.s. _____

48.t. _____

"Next I would like to ask you about your regular use of aspirin. This includes aspirin alone, or in a combination with another drug, such as aspirin in a cold medicine. By regular use, I mean taking aspirin at least once a week for several months."

49. Are you NOW taking aspirin, or a medicine containing aspirin, on a regular basis? This does not include Tylenol or Advil.

Yes Y

No N

Unknown U

I. OTHER ITEMS

"Next, I have a few miscellaneous questions."

50. Do you now smoke cigarettes? .. Yes Y

 No N

51. Please tell me which of the following describes your current marital status:

[READ EACH CATEGORY]

Married M

Widowed W

Divorced	D
Separated	S
Never Married	N

J. ADMINISTRATIVE INFORMATION

52. Code number of person completing this form:

--	--	--

53. Does participant (still) live within official the Jackson Heart Study boundaries? Yes Y

No N

Unknown U

54. Will the JHS be able to get his/her records via community surveillance? Yes Y

No N

55. Result code:

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Result Codes

- 01 – No Action Taken
- 02 – Tracing (Not yet contacted any source)
- 03 – Contacted, Interview Complete
- 031 – By proxy / informant
- 04 – Contacted, Interview Partially Complete or Rescheduled
- 05 – Contacted, Interview Refused
- 06 – Reported Alive, Will Continue to Attempt Contact This Year
- 07 – Reported Alive, Contact Not Possible This Year
- 08 – Reported Deceased
- 09 – Unknown / Lost to AFU
- 98– Does Not Want Any Further AFU Contact



FORM CODE: AFO
VERSION D 10/15/2006

INITIALS:

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

1 of 18

	<u>Yes</u>	<u>No</u>	<u>Don't Know</u>	<u>Missing</u>	<u>Refused</u>		
1d. CT/ MRI head	1	2	7	8	9	<input type="text"/>	<input type="text"/>

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 angiogram1 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	<input type="text"/>	<input type="text"/>
1e-2. heart (Coronary arteriogram) .	1	2	7	8	9	<input type="text"/>	<input type="text"/>
1e-3. kidneys (Renal arteriogram) ..	1	2	7	8	9	<input type="text"/>	<input type="text"/>
1e-4. legs (peripheral vascular)	1	2	7	8	9	<input type="text"/>	<input type="text"/>

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	Go to Item 5
Don't Know	7	
Refused	8	
Missing	9	

4. For each person who died, determine:

4-a1. Relationship?	4-a2. Cause of death?	4-a3. Age at death?			
Mother 1	Cancer 1	<table border="1" style="display: inline-table; width: 40px; height: 25px; border-collapse: collapse;"> <tr><td style="width: 15px; height: 25px;"></td><td style="width: 15px; height: 25px;"></td><td style="width: 10px; height: 25px;"></td></tr> </table>			
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	<table border="1" style="display: inline-table; width: 40px; height: 25px; border-collapse: collapse;"> <tr><td style="width: 15px; height: 25px;"></td><td style="width: 15px; height: 25px;"></td><td style="width: 10px; height: 25px;"></td></tr> </table>			
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

No

Don't Know

Refused

Missing

1

2

7

8

9

Go to Item 7

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

6-a1. Relationship ?

Mother	1
Father	2
Sibling	3
Child	4

6-a2. Told has ?

High blood pressure	1
Stroke	2
Heart Disease	3
Diabetes	4
Cancer	5
Other (Specify)	7

6-a3. Age at diagnosis

6-a4. Specify:

6-b1. Relationship ?

Mother	1
Father	2
Sibling	3
Child	4

6-b2. Told has ?

High blood pressure	1
Stroke	2
Heart Disease	3
Diabetes	4
Cancer	5
Other (Specify)	7

6-b3. Age at diagnosis

6-b4. Specify:

6-c1. Relationship ?

Mother	1
Father	2
Sibling	3
Child	4

6-c2. Told has ?

High blood pressure	1
Stroke	2
Heart Disease	3
Diabetes	4
Cancer	5
Other (Specify)	7

6-c3. Age at diagnosis

6-c4. Specify:

6-d1. Relationship ?

Mother	1
Father	2
Sibling	3
Child	4

6-d2. Told has ?

High blood pressure	1
Stroke	2
Heart Disease	3
Diabetes	4
Cancer	5
Other (Specify)	7

6-d3. Age at diagnosis ?

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

<u>extreme stress</u> ? 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:

	<u>Yes</u>	<u>No</u>	<u>Don't Know</u>	<u>Refused</u>	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

	<u>Yes</u>	<u>No</u>	<u>Don't Know</u>	<u>Refused</u>	<u>Missing</u>
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
Refused	8
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
Don't Know	7
Refused	8
Missing	9

Skip 20

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

	<u>Yes</u>	<u>No</u>	<u>Don't Know</u>	<u>Refused</u>	<u>Missing</u>
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

	<u>Yes</u>	<u>No</u>	<u>Don't Know</u>	<u>Refused</u>	<u>Missing</u>
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?

	<u>Yes</u>	<u>No</u>	<u>Don't Know</u>	<u>Refused</u>	<u>Missing</u>
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 than \$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	Go to Item 23
No	2	
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.

	<u>Yes</u>	<u>No</u>	<u>Don't Know</u>	<u>Refused</u>	<u>Missing</u>
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?	<div> <div></div> <div></div> <div></div> </div>				
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?	<div> <div></div> <div></div> </div>				
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?	<div> <div></div> <div></div> </div>				
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
- | | |
|------------|----|
| 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)
- | | <u>Yes</u> | <u>No</u> | <u>Don't Know</u> | <u>Refused</u> | <u>Missing</u> |
|---|------------|-----------|-------------------|----------------|----------------|
| a. Did not fill a prescription.....1 | 1 | 2 | 7 | 8 | 9 |
| b. Did not see a specialist when needed1 | 1 | 2 | 7 | 8 | 9 |
| c. Skipped a medical test, treatment of follow-up1 | 1 | 2 | 7 | 8 | 9 |
| d. Had medical problems, but did not see a doctor or nurse practitioner.....1 | 1 | 2 | 7 | 8 | 9 |
| Other | | | | | |
32. How confident are you that you can get high quality health care 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

No 2

Go to Item 35b

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

No 2

Go to Item 35c

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

No 2

Go to Item 39

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

No 2

Go to Item 39

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
No	2
Not Applicable	9

Go to Item 43a

Go to Item 44a

42b. Is a heart problem the main cause of your not being able to work?

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

Go to Item 44a

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]-----[]-----[STOP
Employed, but temporarily away from regular work	2		

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

Unemployed, looking for work	1]-----[]-----[STOP
Unemployed, not looking for work	2		

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:

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