6. Since your last visit, have you received any care or treatment at another hospital?

1. NO 2. YES

6.1 What were you treated for?			6.2 Number of times seen	6.3 What was the most recent date? (Month, Year)	6.4 At which hospital were you seen most recently?
A. Stroke	1. NO	2. YES		____/____	
B. Splenic Sequestration	1. NO	2. YES		____/____	
C. Hepatic Sequestration	1. NO	2. YES		____/____	
D. Sepsis	1. NO	2. YES		____/____	
E. Pneumonia	1. NO	2. YES		____/____	
F. Meningitis	1. NO	2. YES		____/____	
G. Priapism	1. NO	2. YES		____/____	
H. Transfusion	1. NO	2. YES		____/____	
I. Surgery	1. NO	2. YES		____/____	
		SPECIFY:			
J. Other	1. NO	2. YES		____/____	
		SPECIFY:			

NOTE: HOSPITAL VISITS ONLY– IF MEDICAL RECORD REVIEW NECESSARY. COMPLETE A HOSPITAL VISIT MEDICAL RECORD RELEASE FORM FOR EACH

6. Since your last visit, have you received any care or treatment at another hospital?

1. NO 2. YES

6.1 What were you treated for?			6.2 Number of times seen	6.3 What was the most recent date? (Month, Year)	6.4 At which hospital were you seen most recently?
A. Stroke	1. NO	2. YES		____/____	
B. Splenic Sequestration	1. NO	2. YES		____/____	
C. Hepatic Sequestration	1. NO	2. YES		____/____	
D. Sepsis	1. NO	2. YES		____/____	
E. Pneumonia	1. NO	2. YES		____/____	
F. Meningitis	1. NO	2. YES		____/____	
G. Priapism	1. NO	2. YES		____/____	
H. Transfusion	1. NO	2. YES		____/____	
I. Surgery	1. NO	2. YES		____/____	
		SPECIFY:			
J. Other	1. NO	2. YES		____/____	
		SPECIFY:			

NOTE: HOSPITAL VISITS ONLY– IF MEDICAL RECORD REVIEW NECESSARY. COMPLETE A HOSPITAL VISIT MEDICAL RECORD RELEASE FORM FOR EACH

ASK OF FEMALE PATIENTS ONLY– FOR MALES SKIP TO QUESTION 9

7. Have you had a period in the last 12 months?

1. NO | 2. YES → GO TO QUESTION 8

7.1 Have your periods stopped because of any of the following:

1. Hysterectomy — In what year? ☐☐
2. Natural menopause — In what year? ☐☐
3. Other surgery/reason (SPECIFY): _____

9. DON'T KNOW WHY PERIODS STOPPED ☐☐☐.☐☐ OFFICE USE

8. Have you been pregnant since your last visit?

1. NO | 2. YES →

8.1 What was the outcome of that pregnancy?

1. Still pregnant
2. Full term delivery
3. Premature delivery
4. Voluntary abortion
5. Miscarriage/Stillbirth/Ectopic pregnancy

9. Are you currently employed for pay?

1. NO | 2. YES, ONE JOB | 3. YES, TWO OR MORE JOBS

9.1 Are you currently employed 35 hours or more each week (full-time) or less than 35 hours each week (part-time)?

1. FULL-TIME (≥ 35 HOURS) | 2. PART-TIME (< 35 HOURS)

9.2 Do you work outside your home? 1. NO (AT HOME) | 2. YES (OUTSIDE HOME)

9.3 What type of work do you do? (ASK FOR SPECIFIC JOB DUTIES) ☐☐☐ OFFICE USE

_____

9.4 What is your job title? ☐☐☐ OFFICE USE

_____

9.5 Does your employer know you have sickle cell disease? 1. NO | 2. YES | 9. DK

GO TO Q12, P.4

10. Which of the following best describes your present status? Are you:

- 01 Retired due to age or by choice?
- 02 Retired due to disability or illness?
- 03 On medical leave/medical disability?
- 04 Unemployed, not looking for work?
- 05 Unemployed and looking for work?
- 06 Unemployed temporarily but with a job to return to?
- 07 Working for family business?
- 08 A full-time student?
- 09 A full-time homemaker?
- 10 Volunteer for more than 20 hours per week?
- 11 Other (SPECIFY): _____

11. Have you ever been employed for pay? 1. NO 2. YES

GO TO QUESTION 13

11.1 How long ago were you last working?
- 1. Less than 1 year ago
- 2. Between 1 & 5 years ago
- 3. More than 5 years ago

12. Looking over your entire work history, please describe the type of work you consider to be your major occupation: OFFICE USE

_____

_____

12.1 What was the job title? _____ OFFICE USE

13. Have you ever had a job which involved any of the following (CHECK NO OR YES FOR EACH OF A–G)

A. Farmwork?	1. NO	2. YES
B. Millwork?	1. NO	2. YES
C. Construction?	1. NO	2. YES
D. Demolition?	1. NO	2. YES
E. Remodeling?	1. NO	2. YES
F. Mining?	1. NO	2. YES
G. Chemical processing?	1. NO	2. YES

IF NOT CURRENTLY WORKING, GO TO QUESTION 17; ELSE GO TO QUESTION 14

14. During the past 2 weeks, have you missed any whole days from work?

1. NO

2. YES

14.1 During the past 2 weeks, on how many whole days did you miss work? (Days) ☐☐

14.2 Of those whole days missed from work, how many were missed due to your own health-related problems? (WHOLE DAYS ONLY) (Days) ☐☐

15. During the past 2 weeks, on how many days have you left work early or gone to work late due to your own illness (this includes doctor's appointments)? (Days) ☐☐

16. During the past 2 weeks, were you unable to carry out your usual work-related activities?

1. NO

2. YES

16.1 Excluding those days in Questions 14 and 15, on how many different days during the past 2 weeks were you unable to carry out your usual work-related activities? (Days) ☐☐

16.2 What was the reason for this limitation? _____ ☐☐ OFFICE USE

_____

17. During the past 2 weeks were you unable to carry out your usual household activities?

1. NO

2. YES

8. NOT APPLICABLE – NO HOUSEHOLD ACTIVITIES

17.1 On how many different days during the past 2 weeks were you unable to carry out your usual household activities? (Days) ☐☐

17.2 What was the reason for this limitation? _____ ☐☐ OFFICE USE

_____

18. During the past 2 weeks were you unable to carry out your usual recreational activities?

1. NO

2. YES

8. NOT APPLICABLE – NO RECREATIONAL ACTIVITIES

18.1 On how many different days during the past 2 weeks were you unable to carry out your usual recreational activities? (Days) ☐☐

18.2 What was the reason for this limitation? _____ ☐☐ OFFICE USE

_____

19. Are you able to walk up 10 steps without help? By help, I mean either the help of another person, including people who live with you, or the help of special equipment other than the stair rail. [1. NO] [2. YES]

20. Do you use any of the following, at least sometimes, to get around? (CHECK NO OR YES FOR EACH OF A-G)

A. Wheelchair?	[1. NO]	[2. YES]
B. Walker?	[1. NO]	[2. YES]
C. 4-pronged cane?	[1. NO]	[2. YES]
D. Single cane?	[1. NO]	[2. YES]
E. Leg brace?	[1. NO]	[2. YES]
F. Crutches?	[1. NO]	[2. YES]
G. Other?	[1. NO]	[2. YES]

SPECIFY: _____

_____

21. Are you able to dress yourself, including shoes and socks, without help?

[1. NO] [2. YES] [8. NOT APPLICABLE (AMPUTEE)]

22. How much of the time are you healthy enough to be able to do the things you would like to be doing? Would you say . . .

[1. ALL OF THE TIME] [2. MOST OF THE TIME] [3. SOME OF THE TIME] [4. ALMOST NEVER] [5. NEVER]

23. How would you rate your health in general as compared to others your age? Would you say it is . . .

[1. MUCH BETTER] [2. SOMEWHAT BETTER] [3. SAME] [4. SOMEWHAT WORSE] [5. MUCH WORSE]

24. How would you rate your health in general as compared to others with sickle cell disease? Would you say it is . . .

[1. MUCH BETTER] [2. SOMEWHAT BETTER] [3. SAME] [4. SOMEWHAT WORSE] [5. MUCH WORSE]

QUESTION 25 REFERS TO THE FOLLOWING SCALE:

1 = No Symptoms
2 = Minor Symptoms: Minimal disruption of lifestyle (10 days or less in past 6 months)
3 = Mild Symptoms: Intermittent problems requiring confinement to home or hospital (More than 10 days in past 6 months)
4 = Moderate Symptoms: Often unable to carry on normal activities
5 = Severe Symptoms: Severely disabled, in need of care most of the time

25. How would you rate the extent to which sickle cell disease has affected your life in the past 6 months? Rating: [ ]

26. Have you ever smoked cigarettes, a pipe or cigars? 1. NO 2. YES

→ GO TO QUESTION 29

27. Do you now smoke (CHECK NO OR YES FOR EACH OF A-C):

A. Cigarettes? 1. NO 2. YES
B. A pipe? 1. NO 2. YES
C. Cigars? 1. NO 2. YES

IF NO TO ALL OF A-C → GO TO QUESTION 28

IF YES TO ONLY ONE OF A-C

IF YES TO MORE THAN ONE OF A-C

27.1 Which do you do most often? 1. Smoke cigarettes 2. Smoke a pipe 3. Smoke cigars

27.2 (REFER TO MOST FREQUENT IN QUESTION 27.1)
When you smoke _____, about how many do you smoke in a day (cigarettes, pipefuls, etc.)? (Units) ___

27.3 In what year did you first smoke? ___ → GO TO QUESTION 28.1 9. DK

28. Have you smoked in the past 12 months?

1. NO 2. YES →

28.1 Have you tried to quit in the past 12 months? 1. NO 2. YES

Now I would like to ask you a few questions about drinking alcoholic beverages.

29. How often do you usually drink beer?

0. Never
1. Less than once a month
2. Less than once a week
3. 1–2 days per week
4. 3–4 days per week
5. 5 or more days per week

29.1 Thinking of all the times you have had *beer* recently, when you drink *beer*, how much do *you usually drink* each time? (Beers) ___

29.2 When you drink *beer*, what is the *most you drink*? (Beers) ___

29.3 About *how often* do you drink this much *beer*?

1. Less than once a month
2. Less than once a week
3. 1–2 days per week
4. 3–4 days per week
5. 5 or more days per week

30. How often do you usually drink wine, or a punch containing wine?

0. Never
1. Less than once a month
2. Less than once a week
3. 1–2 days per week
4. 3–4 days per week
5. 5 or more days per week

30.1 Thinking of all the times you have had *wine* recently, when you drink *wine*, how much wine (or a punch containing wine) do *you usually drink* each time? (Glasses) ☐☐

30.2 When you drink *wine*, what is the *most you drink?* (Glasses) ☐☐

30.3 About *how often* do you drink this much *wine?*

1. Less than once a month
2. Less than once a week
3. 1–2 days per week
4. 3–4 days per week
5. 5 or more days per week

31. How often do you usually have drinks containing liquor (such as martinis, manhattans, highballs, or straight drinks)?

0. Never
1. Less than once a month
2. Less than once a week
3. 1–2 days per week
4. 3–4 days per week
5. 5 or more days per week

31.1 Thinking of all the times you have had *liquor* recently, when you have drinks containing *liquor*, how much do *you usually drink* each time? (Drinks) ☐☐

31.2 When you drink *liquor*, what is the *most you drink?* (Drinks) ☐☐

31.3 About *how often* do you drink this much *liquor?*

1. Less than once a month
2. Less than once a week
3. 1–2 days per week
4. 3–4 days per week
5. 5 or more days per week

32. Are you: 1. Never married 2. Married and living with your spouse 3. Divorced 4. Separated 5. Widowed

32.1 Does this represent a change since your last study visit? 1. NO 2. YES

33. How many people live in your household (unit) besides yourself? (Enter number) ☐☐

(IF ONE MENTIONED) Who is that?
(IF MORE THAN ONE) Who are they in relation to you?

RECORD NUMBER IN EACH BOX

33.1 (PROBE AT END): Anyone else?

	Number
A. SPOUSE/PARTNER	☐☐
B. MOTHER &/OR MOTHER-IN-LAW	☐☐
C. FATHER &/OR FATHER-IN-LAW	☐☐
D. DAUGHTERS	☐☐
E. SONS	☐☐
F. SISTERS	☐☐
G. BROTHERS	☐☐
H. OTHER FEMALE RELATIVES	☐☐
I. OTHER MALE RELATIVES	☐☐
J. OTHER UNRELATED FEMALES	☐☐
K. OTHER UNRELATED MALES	☐☐
L. TOTAL # (MUST EQUAL # ENTERED ABOVE IN Q33)	☐☐

34. Which of the following categories best describes your educational background? Have you:

☐ 01 Completed less than 6 grades?

☐ 02 Completed through grade 6?

☐ 03 Completed through grade 9?

☐ 04 Completed some high school?

☐ 05 Completed high school and graduated or received a GED?

☐ 06 Completed some technical training?

☐ 07 Completed some college, an associate's degree, technical training including apprenticeship?

☐ 08 Received a bachelors degree?

☐ 09 Received an advanced degree or studied beyond a bachelors degree?

35. What is your *primary* (largest) source of household income?

01 Social security?

02 S.S.I. or welfare?

03 Income from private pension?

04 Income from Worker's Compensation or other disability benefits?

05 Income from non-disability unemployment benefits?

06 Income from interest earning/dividends/rental income?

07 Income from government pension/veterans' pension?

08 Own income from job?

09 Spouse income from job?

10 Contributions from other household family member's income?

11 Contributions from other non-household family member's income?

12 Other source? (SPECIFY): _____

77 REFUSED TO ANSWER

99 DON'T KNOW

36. Counting *all* sources of income, such as Social Security, SSI, other pensions, interest, dividends, earnings, and contributions from family or other household members, which category includes the household's total *annual* income before taxes for 1988?

01 Less than $5,000

02 Between $5,000 and $9,999

03 Between $10,000 and $14,999

04 Between $15,000 and $19,999

05 Between $20,000 and $29,999

06 Between $30,000 and $49,999

07 Between $50,000 and $69,999

08 Between $70,000 and $99,999

09 $100,000 or more

77 REFUSED TO ANSWER

99 DON'T KNOW

QUESTIONS 37-44 ARE TO BE ANSWERED ONLY BY STUDY PERSONNEL

1 = No Symptoms
2 = Minor Symptoms: Minimal disruption of lifestyle (10 days or less in past 6 months)
3 = Mild Symptoms: Intermittent problems requiring confinement to home or hospital (More than 10 days in past 6 months)
4 = Moderate Symptoms: Often unable to carry on normal activities
5 = Severe Symptoms: Severely disabled, in need of care most of the time

37. Rate the overall degree of disability of the patient for the past 6 months: Rating: ☐

38. Is the patient currently on a *chronic* transfusion program?

☐ 1. NO ☐ 2. YES → 38.1 Is this new since the patient's last study visit? ☐ 1. NO ☐ 2. YES

39. Has the patient ever been diagnosed with:
(CHECK NO OR YES FOR EACH OF A–M)

	39.0 Diagnosed		39.1 What was the year of diagnosis (YEAR, OR DK IF UNKNOWN)
A. Gallstones?	1. NO	2. YES	☐☐
B. Renal Failure?	1. NO	2. YES	☐☐
C. Asthma?	1. NO	2. YES	☐☐
D. Chronic Heart Failure?	1. NO	2. YES	☐☐
E. Chronic Liver Failure?	1. NO	2. YES	☐☐
F. Iron Overload?	1. NO	2. YES	☐☐
G. Diabetes?	1. NO	2. YES	☐☐
H. Rheumatic Fever?	1. NO	2. YES	☐☐
I. Tuberculosis?	1. NO	2. YES	☐☐
J. Seizures?	1. NO	2. YES	☐☐
K. Viral Hepatitis?	1. NO	2. YES	☐☐

39.2 What type? (CHECK ONE)
☐ 1. Type A
☐ 2. Type B
☐ 3. Non-A, Non-B
☐ 6. Other
☐ 9. DK

L. Cancer?	1. NO	2. YES	☐☐

TYPE: _____

M. Other chronic disease?	1. NO	2. YES	☐☐

SPECIFY: _____

☐☐ OFFICE USE

40. Has the patient ever had the following procedure?
(CHECK NO OR YES FOR EACH OF A-D)

	40.0 Surgery or procedure		40.1 What year? (YEAR, OR DK IF UNKNOWN)
A. Cholecystectomy?	1. NO	2. YES	
B. Liver Biopsy?	1. NO	2. YES	
C. Renal Biopsy?	1. NO	2. YES	
D. Renal Dialysis?	1. NO	2. YES	

40.2 What year did dialysis start?

40.3 Is the patient still on dialysis? 1. NO 2. YES

41. Has the patient ever had the following vaccinations:
(CHECK NO, YES, DK FOR EACH OF A-D)

	41.1 Vaccination?			41.2 What is the month and year of the most recent? (MONTH AND YEAR, OR DK IF UNKNOWN)	
A. H. Influenza (HIB)?	1. NO	2. YES	9. DK		
B. Pneumococcus?	1. NO	2. YES	9. DK		
C. Hepatitis B?	1. NO	2. YES	9. DK		
D. Meningococcus?	1. NO	2. YES	9. DK		

42. Has the patient been referred for any additional tests, consultations, diagnostic work-ups, or procedures as the result of the physical exam or any specialized test(s) from his/her last study visit?

1. NO 2. YES

42.1 Consultation/Test	42.2 Outcome
A. _____ OFFICE USE	1. NORMAL 2. ABNORMAL 42.3 Was treatment or intervention recommended as a result of this referral? 1. NO 2. YES SPECIFY INTERVENTION: _____
B. _____ OFFICE USE	1. NORMAL 2. ABNORMAL 42.4 Was treatment or intervention recommended as a result of this referral? 1. NO 2. YES SPECIFY INTERVENTION: _____
C. _____ OFFICE USE	1. NORMAL 2. ABNORMAL 42.5 Was treatment or intervention recommended as a result of this referral? 1. NO 2. YES SPECIFY INTERVENTION: _____

43. Is the patient on Special B Status to be seen only at annual visits and not seen for special events because of distance from clinic? 1. NO 2. YES

44. Was a translator needed to complete this interview? 1. NO 2. YES

Name of Data Coordinator: _____

Signature: _____

Date (Month, Day, Year): ____/____/____