

**** PATIENT INTERVIEW SECTION ****

8. Was patient interviewed? 1. NO 2. YES

↓
GO TO QUESTION 18

9. Date of interview (Month, Day, Year) _____/_____/_____

*** QUESTIONS 10 - 17 MAY BE ANSWERED BY PATIENT IN CLINIC OR IN A TELEPHONE INTERVIEW ***

10. 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

11. Do you use any of the following, at least sometimes, to get around?

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

↓
11.1 Specify: _____

12. Are you able to dress yourself, including shoes and socks, without help?
1. NO 2. YES 8. NOT APPLICABLE (AMPUTEE)

13. 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

14. How would you rate your health 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

15. 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 16 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

16. How would you rate the extent to which sickle cell disease has affected your life in the past 6 months?
Rating: |____|

17. Are you currently employed for pay? 1. NO 2. YES

18. Reason patient not interviewed (CHECK ONLY 1 RESPONSE)

1. Patient was unable to complete interview because of mental or physical disability
2. Patient refused to complete interview
3. Patient could not be contacted
4. Other reason

18.1 Specify reason _____

5. N/A - Interview completed

19. What resources did you use to try to establish contact with patient or to determine patient's vital status?
(CHECK NO OR YES FOR EACH OF A - T)

- | | | |
|---|-------|--------|
| A. Patient address/telephone information on file in office or in hospital chart | 1. NO | 2. YES |
| B. Relative of patient | 1. NO | 2. YES |
| C. Friend of patient | 1. NO | 2. YES |
| D. Other medical facility or clinic | 1. NO | 2. YES |
| E. Employer | 1. NO | 2. YES |
| F. School or Board of Education | 1. NO | 2. YES |
| G. Hospital Social Services Department | 1. NO | 2. YES |
| H. Standard Telephone Directory | 1. NO | 2. YES |
| I. Telephone directory organized by address | 1. NO | 2. YES |
| J. Neighbor/Landlord | 1. NO | 2. YES |
| K. Postal Service search | 1. NO | 2. YES |
| L. Vital Statistics records * | 1. NO | 2. YES |
| M. Voter Registration records * | 1. NO | 2. YES |
| N. Department of Motor Vehicles records | 1. NO | 2. YES |
| O. Social Security Administration | 1. NO | 2. YES |
| P. Public Aid Department | 1. NO | 2. YES |
| Q. Public utility company | 1. NO | 2. YES |
| R. Medical Examiner's Office | 1. NO | 2. YES |
| S. Equifax Support Services | 1. NO | 2. YES |
| T. Other | 1. NO | 2. YES |

19.1 Specify: _____

* public records

**** PHYSICIAN'S ASSESSMENT OF PATIENT'S HEALTH ****

**** QUESTIONS 20-21 ARE TO BE ANSWERED BY STUDY PERSONNEL MOST FAMILIAR WITH PATIENT'S MEDICAL HISTORY ****

20. Has the patient ever been diagnosed with:
(CHECK NO OR YES FOR EACH OF A-F)
- | | | |
|---|-------|--------|
| A. Stroke | 1. NO | 2. YES |
| B. Aseptic Necrosis | 1. NO | 2. YES |
| C. Asthma or other chronic lung disease | 1. NO | 2. YES |
| D. Chronic heart disease | 1. NO | 2. YES |
| E. Chronic liver disease | 1. NO | 2. YES |
| F. Chronic renal disease | 1. NO | 2. YES |

QUESTION 21 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 |
| 7 = Not Applicable: | Patient died more than 6 months ago |
| 9 = Unknown: | Patient not seen for more than 6 months |

21. Rate the overall degree of disability of the patient for the past 6 months: Rating |__|