

CSCC
Collaborative Data Project
C-Data

Interview for Adult Subject

Version 5.2 06Sep2007

All items on pages 1-4 of the interview should be determined by the patient's responses only. The interview forms will serve as source documentation.

Item	Instructions
1. Race	<ul style="list-style-type: none"> The interviewer should either read all choices at once <u>or</u> read each choice separately and wait for a response. Check all racial groups the patient considers themselves to be a part of, <i>as reported by the patient</i>. If Other is marked, be sure to specify.
2. Ethnicity	Check the appropriate ethnicity, <i>as reported by the patient</i> .
3. Siblings (parts a-c)	<ul style="list-style-type: none"> Record the total number of siblings. This number should include siblings of all types, including half-siblings and step-siblings as well as biological siblings. If a number is recorded, be sure to fill in 3b) the number who have SCD and 3c) the number who do not have SCD. 3b and 3c should include only the siblings who share the same biological mother and father. Parts b and c may not be equal to the number recorded in part a (the total of all the subject's brothers and sisters).
4. Employment Status	<ul style="list-style-type: none"> Check the appropriate current employment status of the patient. If patient is NOT employed and NOT a student (Question 5), please skip Question 15.
5. Student Status	<ul style="list-style-type: none"> Check the appropriate current student status of the patient. If patient is NOT employed (Question 4) and NOT a student, please skip Question 15.
6. Highest Grade	<ul style="list-style-type: none"> Record the highest grade of school completed or the number of years of college completed. Enter 0 for pre-school or for children who have not yet begun school, K for Kindergarten, 1-12, 13= 1 year college, 14= 2 years college, etc.
7. Number of Individuals (≥19)	Record the number of individuals in the household who are 19 years of age and above . This number should include the patient, if applicable.
8. Number of Individuals (<19)	Record the number of individuals in the household who are 19 years of age and below . This number should include the patient, if applicable.

Note: This form must be reviewed and completed in its entirety and signed by the PI/Study Coordinator.

Item	Instructions
9. Insurance	<ul style="list-style-type: none"> • Check all that apply. • If Other is marked, be sure to specify.
10. Sickle cell related healthcare	<ul style="list-style-type: none"> • Check “Yes” or “No” to indicate if the patient has ever received sickle cell related health care from any other center or institution in the last 5 years. Check “Unknown” if patient is unsure or refuses to answer. • If Yes is marked, be sure to record where and how many times the patient was seen for each location to the best of the patient’s knowledge.
11. Transfusion	<ul style="list-style-type: none"> • Check “Yes” or “No” to indicate if the patient has ever received a transfusion. Check “Unknown” if patient is unsure or refuses to answer. • If Yes is marked, be sure to check the category that includes the approximate number of transfusions received, as estimated by the patient.
12. Headache	<ul style="list-style-type: none"> • Check “Yes” or “No” to indicate if the patient has ever had a headache in the past year. Check “Unknown” if patient is unsure or refuses to answer. • If Yes is marked, be sure to record how many headaches the patient had, how many occurred while having sickle cell pain, and how many headaches were not associated with sickle cell pain, fever/illness, or alcohol. • If no headaches occurred for question parts c and/or d, be sure to record a 0. • All numbers should be approximate. <p>Interviewers should feel free to help the patient determine the number of headaches for each part. For example, if the patient had 50 headaches in the past year, but is having trouble determining exactly how many of those headaches occurred while he/she had sickle cell pain, the interviewer may ask if the patient thinks that half, a third, etc. of those headaches occurred while he/she had sickle cell pain. If he/she agrees, record the number that corresponds with the fraction agreed upon by the patient.</p>
13. Unscheduled Visits	<ul style="list-style-type: none"> • Check “Yes” or “No” to indicate if the patient has ever had an unscheduled visit because of pain due to Sickle Cell Disease. Check “Unknown” if patient is unsure or refuses to answer. • If Yes is marked for pain due to Sickle Cell Disease, be sure to check the category that includes the number of unscheduled visits, as estimated by the patient.

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Comprehensive Sickle Cell Centers	Medical History Form IIA Patient Interview	Page: 2 of 4
Protocol # 2 Collaborative Data Project	Date of Interview: <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <div style="display: flex; justify-content: space-around; font-size: small;"> Day Month Year </div> Form Completed by: <input type="text"/> <input type="text"/> <input type="text"/>	CSCC ID: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Center code: <input type="text"/> <input type="text"/> <input type="text"/> Hospital code: <input type="text"/> <input type="text"/> <input type="text"/>

9. **What type of health insurance do you have?** *(check all that apply)*

Private
 Medicare
 Medicaid
 None
 Other _____

10a. **In the last 5 years, have you received sickle cell-related healthcare from any other center or institution?**

Yes
 No
 Unknown

10b. *[If yes]* **Where?** **How many times?**

11a. **Have you ever received a transfusion?** Yes No Unknown

11b. *[If yes]* **How many transfusions?** 1-5 6-20 21-99 100+

12a. **In the past year, have you ever had a headache?** Yes No Unknown

12b. *[If yes]* **How many headaches have you had?** _____

12c. **How many of these headaches occurred while you had sickle pain?** _____ *Put 0 for none*

12d. **How many of these headaches were not associated with sickle pain, fever/illness, or alcohol?** _____ *Put 0 for none*

13a. **Have you ever gone to a doctor's office, a day hospital, an emergency department, acute day clinic, or other clinic for unscheduled visits because of pain due to Sickle Cell Disease?**

Yes
 No
 Unknown

13b. *[If yes]* **How many times?** 1-5 6-20 21-99 100+

Item	Instructions
14. Unscheduled Visits (past year)	<ul style="list-style-type: none"> • Record the approximate number of unscheduled visits <i>in the past 12 months</i> because of pain due to Sickle Cell Disease. • If no unscheduled visits occurred because of pain due to Sickle Cell Disease, be sure to record a 0.
15. Missed work/school	<ul style="list-style-type: none"> • Record the approximate number of days the patient had to miss work or school due to his/her Sickle Cell Disease <i>in the past 12 months</i>. • If no days were missed due to Sickle Cell Disease, be sure to record a 0. • <i>If patient is not employed and is not a student</i>, please skip Question 15 and leave this question blank.
16. Painful Episodes treated at home	<ul style="list-style-type: none"> • Record the approximate number of painful episodes that were treated <i>solely</i> at home <i>during the past year</i> due to Sickle Cell Disease. • If no episodes were treated <i>solely</i> at home, be sure to record a 0.
Female Patients	<ul style="list-style-type: none"> • Check "NA" if the patient is male or is a female not of child-bearing potential. • If checked, leave the pregnancy section blank.
17. Currently pregnant	Check "Yes" or "No" to indicate if the patient is currently pregnant, as reported by the patient. Check "Unknown" if patient is unsure or refuses to answer.
18. Pregnancy History (parts a-h)	<ul style="list-style-type: none"> • Check "Yes" or "No" to indicate if the patient has <i>ever</i> been pregnant, as reported by the patient. Exclude current pregnancy, if applicable. Check "Unknown" if patient is unsure or refuses to answer. • If Yes is marked, be sure to record the number of previous pregnancies for each category. If no pregnancies for that category, record a 0 in the space provided. <p><i>Full term births</i> = # of full-term infants born 36 or more weeks of completed gestation, alive or dead <i>Miscarriages</i> = # of spontaneous abortions under 22 weeks <i>Live births</i> = # of infants, full term or preterm, born alive <i>Premature births</i> = # of preterm infants born 22 weeks to under 36 weeks, alive or dead <i>Abortions</i> = # of elective (induced) abortions under 22 weeks <i>Multiple births</i> = # of times multiple infants from the same pregnancy were born. *If multiple births did occur, record the type of multiple birth for each occurrence (i.e., "twins"). <i>Live children at present</i> = # of children currently living</p>

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Comprehensive Sickle Cell Centers	<h2 style="text-align: center;">Medical History Form IIA</h2> <p style="text-align: center;">Patient Interview</p>	<p style="text-align: right;">Page: 3 of 4</p>
<p style="text-align: center;">Protocol # 2</p> <p style="text-align: center;">Collaborative Data Project</p>	<p>Date of Interview: <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/></p> <p style="text-align: center;">Day Month Year</p> <p>Form Completed by: <input type="text"/> <input type="text"/> <input type="text"/></p>	<p>CSCC ID: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/></p> <p>Center code: <input type="text"/> <input type="text"/> <input type="text"/></p> <p>Hospital code: <input type="text"/> <input type="text"/> <input type="text"/></p>

14. In the past year, how many times have you come to the doctor's office, the day hospital, Emergency Department, acute day clinic, or other clinic for unscheduled visits because of pain due to Sickle Cell Disease? _____ *Put 0 for none*

15. In the past year, how many days of work or school have you missed due to your Sickle Cell Disease? (If patient is not employed and is not a student, please skip this question.) _____ *Put 0 for none*

16. In the past year, what was the total number of painful episodes due to Sickle Cell Disease for which you were treated solely at home? _____ *Put 0 for none*

For Female Patients: NA (for males and females not of child-bearing potential)

17. Are you currently pregnant? Yes No Unknown

18a. Have you ever been pregnant (exclude current pregnancy if applicable)? Yes No Unknown

[If yes] How many previous pregnancies have resulted in: (number)

18b. ____ Full term births 18c. ____ Miscarriages (spontaneous abortions) 18d. ____ Live Births

18e. ____ Premature births 18f. ____ Abortions (elective) 18g. ____ Multiple Births

18h. ____ Live children at present

[If 18g is a number other than '0'] Record the type of multiple birth for each (i.e., "twins"):

Multiple birth 1: _____

Multiple birth 2: _____

Multiple birth 3: _____

Multiple birth 4: _____

Multiple birth 5: _____

Item	Instructions
19. Tobacco (past year)	Check "Yes" or "No" to indicate if the patient used any type of tobacco <i>in the past 12 months</i> . Check "Unknown" if patient unsure or refuses to answer.
20. Tobacco (current use)	<ul style="list-style-type: none"> • Check "Yes" or "No" to indicate if the patient is using any type of tobacco <i>currently</i>. Check "Unknown" if patient is unsure or refuses to answer. • If Yes is marked, be sure to have the patient provide a number for each of the tobacco categories listed. <i>If no products from a category were used, record a 0.</i> • In addition to the approximate number of each product, select the appropriate time period over which use occurred, day or week. <p>For the occasional tobacco user (less than 1 of any product per week), mark No to the question "Do you currently use tobacco?" and leave 20b – 20e blank.</p>
21. Alcohol (past year)	Check "Yes" or "No" to indicate if the patient used any type of alcohol <i>in the past 12 months</i> . Check "Unknown" if patient unsure or refuses to answer.
22. Alcohol (current use)	<ul style="list-style-type: none"> • Check "Yes" or "No" to indicate if the patient is using any type of alcohol <i>currently</i>. Check "Unknown" if patient is unsure or refuses to answer. • If Yes is marked, be sure to have the patient provide a number for each of the alcohol categories listed. <i>If no products from a category were used, record a 0.</i> • In addition to the approximate number of each product, select the appropriate time period over which use occurred, week or month. <p>For the occasional drinker (less than 1 of any product per month), mark No to the question "Do you currently drink alcohol?" and leave 22b – 22d blank.</p>
23. Income	<p>Please use the income card provided. After reading the question to the patient, have them respond with the letter that best describes their yearly income.</p> <ul style="list-style-type: none"> • Total income includes the total income of each member of the patient's household from all sources including jobs, disability payments, or money from the government. • If the patient seems to be uncomfortable answering the question, mark "H. Prefer not to answer".

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Comprehensive Sickle Cell Centers	Medical History Form IIA Patient Interview	Page: 4 of 4
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Tobacco Use in the past year

19. Did you use any type of tobacco in the past year? Yes No Unknown

20a. Do you currently use tobacco? Yes No Unknown

[If yes] 20b. What is your usual number of **cigarettes**? _____ per

day
week

20c. What is your usual number of **cigars**? _____ per

day
week

20d. How often do you use **snuff/chew**? _____ per

day
week

20e. How often do you smoke a **pipe**? _____ per

day
week

Alcohol Use in the past year

21. Did you drink any type of alcohol during the past year? Yes No Unknown

22a. Do you currently drink alcohol? Yes No Unknown

[If yes] 22b. What is your usual number of **beers**? _____ per

week
month

22c. What is your usual number of **glasses of wine**? _____ per

week
month

22d. What is your usual number of **other alcoholic drinks**? _____ per

week
month

23. Which of these letters best describes your household's yearly income? This includes the total amount of money for all members of your household combined, from all sources including jobs, disability payments or money from the government?

A. Under \$4,999 D. \$15,000-24,999 G. \$45,000 and over

B. \$5,000-9,999 E. \$25,000-34,999 H. Prefer not to answer

C. \$10,000-14,999 F. \$35,000-44,999 I. Don't know

PI/SC Signature: _____ Date: _____