

CSCC
Collaborative Data Project
C-Data

Interview for Pediatric Subject

Version 5.2 06Sep2007

Comprehensive Sickle Cell Centers	Medical History Form IIB Parent (or Accompanying Adult) Interview	Page: 1 of 3
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All items on pages 1-3 of the interview should be determined by the patient's (or accompanying adult's) responses only. The interview forms will serve as source documentation.

Item	Instructions
Who is accompanying this child today?	Check the one choice that best describes the relationship between the child (patient) and the adult who is accompanying them today.
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 (or accompanying adult)</i>. • If Other is marked, be sure to specify.
2. Ethnicity	Check the appropriate ethnicity of this child, <i>as reported by the patient (or accompanying adult)</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. Highest Grade	<ul style="list-style-type: none"> • Record the highest grade of school completed or the number of years of college this child has 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.
5. Number of Individuals (≥ 19)	Record the number of individuals in this child's household who are 19 years of age and above.
6. Number of Individuals (<19)	Record the number of individuals in this child's household who are 19 years of age and below. This number should include the patient.
7. Insurance	<ul style="list-style-type: none"> • Check all that apply. • If Other is marked, be sure to specify.

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

Comprehensive Sickle Cell Centers	Medical History Form IIB Parent (or Accompanying Adult) Interview	Page: 2 of 3
Item	Instructions	
8. Sickle cell related healthcare	<ul style="list-style-type: none"> • Check “Yes” or “No” to indicate if this child has ever received sickle cell related health care from any other center or institution in the last 5 years. Check “Unknown” if patient/accompanying adult 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 (or accompanying adult’s) knowledge. 	
9. 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 (or accompanying adult). 	
10. 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 (or accompanying adult). 	
11. 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 (or accompanying adult) 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>	
12. Unscheduled Visits (past year)	<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 (or accompanying adult) 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 (or accompanying adult). 	
13. Missed school (child)	<ul style="list-style-type: none"> • Record the appropriate number of school days this child has missed due to Sickle Cell Disease in the past year. • If no days were missed, be sure to record a 0. 	

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Item	Instructions
14. Missed work/school (parent)	<ul style="list-style-type: none"> • Record the approximate number of days the primary caregiver(s) of this child had to miss work or school due to this child's 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.
15. 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.
16. Income	<p>Please use the income card provided. After reading the question to the patient (or accompanying adult), 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 (or accompanying adult) seems to be uncomfortable answering the question, mark "H. Prefer not to answer".
17. For the Interviewer	Please check the appropriate response.

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