

S02r1 Demographic and Phenotypic Information

Patient's Identification Number _____

Visit Date: _____

Correction:

- Yes
 No

1. Is the patient fluent in English?

- Yes
 No

2. Is English the patient's first language?

- Yes
 No

2A. If No, what is the patient's first language? _____

3. What is the patient's ethnic group (choose one)?

- Hispanic or Latino
 Not Hispanic or Latino
 Unknown

4. What is the patient's race (choose one)?

- Black or African American
 American Indian or Alaskan Native
 Asian
 Native Hawaiian or Other Pacific Islander
 White
 Other
 Unknown

4A. If Other, specify: _____

5. What is the patient's national/geographic origin (choose one)?

- UK
 France
 Canada
 Africa
 Caribbean
 USA
 Other
 Unknown

5A. If Other, specify: _____

6. What is the patient's biological mother's ethnic group (choose one)?

- Hispanic or Latino
 Not Hispanic or Latino
 Unknown

7. What is the patient's biological mother's race (choose one)?

- Black or African American
 American Indian or Alaskan Native
 Asian
 Native Hawaiian or Other Pacific Islander
 White
 Other
 Unknown

7A. If Other, specify: _____

8. What is the patient's biological mother's national/geographical origin (choose one)?

- UK
 France
 Canada
 Africa
 Caribbean
 USA
 Other
 Unknown

8A. If Other, specify: _____

9. What is the patient's biological father's ethnic group (choose one)?

- Hispanic or Latino
- Not Hispanic or Latino
- Unknown

10. What is the patient's biological father's race (choose one)?

- Black or African American
- American Indian or Alaskan Native
- Asian
- Native Hawaiian or Other Pacific Islander
- White
- Other
- Unknown

10A. If Other, specify: _____

11. What is the patient's biological father's national/geographical origin (choose one)?

- UK
- France
- Canada
- Africa
- Caribbean
- USA
- Other
- Unknown

11A. If Other, specify: _____

12A. Patient's current grade (xx): _____

12B. Patient's most recently completed grade (xx): _____

12C. Has patient ever repeated a grade?

- Yes
- No

12C-1A. If Yes, grade repeated (xx) _____

12C-1B. Number of times grade repeated (xx): _____

12C-2A. If Yes, grade repeated (xx): _____

12C-2B. Number of times grade repeated (xx): _____

12C-3A. If Yes, grade repeated (xx): _____

12C-3B. Number of times grade repeated (xx): _____

12C-4A. If Yes, grade repeated (xx): _____

12C-4B. Number of times grade repeated (xx): _____

12D. Is the patient in a classroom setting requiring special attention?

- Yes
- No

12E. Does the patient have an Individual Educational Plan (IEP) in place?

- Yes
- No

12E-1. If Yes, what grade was it implemented? (xx) _____

12F. Does the patient have a 504 plan in place (USA sites only)?

- Yes
- No

12F-1. If Yes, what grade was it implemented? _____

13. Head of Household: What is the highest grade or level of school that you have completed or the highest degree that you have received?

- 1st
- 2nd
- 3rd
- 4th
- 5th
- 6th
- 7th
- 8th
- 9th
- 10th
- 11th
- 12th, no diploma
- High school graduate
- GED or equivalent
- Some college, no degree
- Associate degree, occupational, technical degree
- Associate degree (academic program)
- Bachelor's degree
- Master's degree
- Professional/doctoral degree (MD, JD, DDS, DVM, PhD)
- Refused to answer
- Unknown

14. Marital status of primary caregiver:

- Married
- Widowed
- Separated
- Divorced
- Never married
- Living with partner
- Refused to answer
- Unknown

15. Relationship of primary caregiver to patient:

- Mother
- Father
- Niece or nephew
- Aunt or uncle
- First cousin
- Second cousin
- Unknown cousin
- Grandparent
- Great grandparent
- Great great grandparent
- Great aunt or great uncle
- Great great aunt or great great uncle
- Foster parent
- Other

15A. If Other, specify:

16. Yearly family income (\$USD):

- < \$10,000
- \$10,000 to \$19,999
- \$20,000 to \$29,999
- \$30,000 to \$39,999
- \$40,000 to \$49,999
- \$50,000 to \$59,999
- \$60,000 to \$69,999
- \$70,000 to \$79,999
- \$80,000 to \$89,999
- \$90,000 to \$99,999
- \$100,000 to \$149,999
- >= \$150,000
- Refused to answer
- Unknown

17. Number of people in home age 17 or older (xx):

18. Number of people in home age 16 or younger (xx):

19. Type of health insurance (answer each item):

- 19A. Government Health Services (non-USA sites) Yes
 No
- 19B. Medicaid Yes
 No
- 19C. Private Yes
 No
- 19D. None Yes
 No
20. Did a doctor ever say that the patient had asthma? Yes
 No
- 20A. If Yes, does the patient still have asthma? Yes
 No
21. Has either or both of (patient's) biological parents ever been told by a doctor that he/she has asthma or hay fever at any age? Yes
 No
- 21A. If Yes, choose one: Mother
 Father
 Unknown
 Both parents
22. Does either the patient or the primary caretaker identify anyone living in the home who smokes or smoked tobacco products in the last 3 years, either inside or outside the home? Yes
 No
23. Handedness Right
 Left

Headaches

24. Does your child have recurring headaches (choose one)? If Yes, complete Items 25-32. If No, skip to Item 33. No
 Yes (< 1 per month)
 Yes (1-4 per month)
 Yes (>= 1 per week)
25. How long have headaches been present (choose one)? < 6 months
 6-12 months
 1-2 years
 > 2 years
26. Where is the headache typically located (choose one)? Bifrontal or bitemporal
 Right hemicranial
 Left hemicranial
 Vertex
 Occipital
 Non-localized, diffuse
27. Duration of typical headache (choose one)? < 10 minutes
 10-59 minutes
 1-6 hours
 > 6 hours

28. When does the headache most often occur (choose one)?

- During daytime at school
 During afternoon/evening after coming home from school
 Late evening, bed time
 No particular time

29. Severity of typical headache (choose one):

- No interruption of normal life activities
 Some disruption of normal life activities, but no need to go to bed
 Complete disruption of normal life activities, needs to go to bed
 Prevents sleep or requires patient to be examined by physician
 Awakens patient from sleep

30A. Other symptoms associated with some or most headaches: nausea or vomiting

- Yes
 No

30B. Other symptoms associated with some or most headaches: excessive sensitivity to light or sound

- Yes
 No

30C. Other symptoms associated with some or most headaches: fatigue, malaise

- Yes
 No

30D. Other symptoms associated with some or most headaches: sleep apnea

- Yes
 No

30E. Other symptoms associated with some or most headaches: excessive daytime sleep

- Yes
 No

30F. Other symptoms associated with some or most headaches: visual symptoms

- Yes
 No

30F-1. If Yes, specify:

30G. Other symptoms associated with some or most headaches: other

- Yes
 No

30G-1. If Other, specify:

31. Is medication taken for most headaches?

- No
 Yes, abortive or rescue medication
 Yes, daily preventative medication

31A. If Yes to abortive or rescue medication, specify:

31A. If Yes to preventative medication, specify:

31A-1. If Yes to rescue or abortive medication, how effective is it?

- Partial improvement most occasions
 Complete remission most occasions
 Little or no improvement most occasions

32. Are there other family members with a history of recurrent headaches?

- Yes
 No
 Don't know

32A. If Yes, have they been given the diagnosis of migraines?

- Yes
 No
 Don't know

33. Has the patient ever experienced a seizure?

- Yes
 No
 Don't know

33A. If Yes, was the seizure associated with fever?

- Yes
 No
 Don't know

33B. If Yes, was the seizure associated with pain crisis?

- Yes
 No
 Don't know

34. Have other family members had seizures?

- Yes
 No
 Don't know

34A. If Yes, relationship to patient:

35. Has the patient ever had a diagnosis of a silent stroke?

- Yes
 No
 Don't know

35A. If Yes, reason for MRI:

- Routine care or surveillance
 Suspected stroke
 Recurrent headaches
 Headache
 Seizure
 Abnormal TCD

35B. If Yes, year of diagnosis of silent stroke (yyyy):

36A. Do you know the patient's biological mother's date of birth?

- Yes
 No

36A-1. If Yes, enter patient's biological mother's date of birth (yyyy/mm/dd)?

36B. Does the patient's biological mother have sickle cell disease?

- Yes
 No
 Don't know

36B-1. If Yes, what type?

- Hgb SS
 HgB S(beta0) Thalassemia
 HgB SC
 Other
 Unknown

36C. Is the patient's biological mother alive?

- Yes
 No
 Don't know

36C-1. If No, year of death (yyyy):

36C-2. If No, cause of death:

37A. Do you know the patient's biological father's date of birth?

- Yes
 No

37A-1. If Yes, enter patient's biological father's date of birth? (yyyy/mm/dd)

37B. Does the patient's biological father have sickle cell disease?

- Yes
 No
 Don't know

37B-1. If Yes, what type?

- Hgb SS
 HgB S(beta0) Thalassemia
 HgB SC
 Other
 Unknown

37C. Is the patient's biological father alive?

- Yes
 No
 Don't know

37C-1. If No, year of death (yyyy): _____

37C-2. If No, cause of death: _____

38. Does the patient have siblings? If No or Unknown, skip to Item 45.

Yes
 No
 Unknown

38A. If Yes, how many siblings (xx)? _____

Enter information for up to 6 siblings on this form (Form 2, Items 39-44). If you need to enter additional siblings, use Form 38.

39A. Do you know the sibling's date of birth?

Yes
 No

39A-1. If Yes, enter sibling's date of birth (yyyy/mm/dd): _____

39B. Gender:

Male
 Female

39C. Hemoglobin genotype:

SS
 SC
 S beta thalassemia zero
 Sickle cell trait
 AA normal
 Unknown

39D. Asthma:

Yes
 No
 Unknown

39E. Same biological mother:

Yes
 No
 Unknown

39F. Same biological father:

Yes
 No
 Unknown

40A. Do you know the sibling's date of birth?

Yes
 No

40A-1. If Yes, enter sibling's date of birth (yyyy/mm/dd): _____

40B. Gender:

Male
 Female

40C. Hemoglobin genotype:

SS
 SC
 S beta thalassemia zero
 Sickle cell trait
 AA normal
 Unknown

40D. Asthma:

Yes
 No
 Unknown

40E. Same biological mother:

Yes
 No
 Unknown

40F. Same biological father:

- Yes
 No
 Unknown

41A. Do you know the sibling's date of birth?

- Yes
 No

41A-1. If Yes, enter sibling's date of birth
(yyyy/mm/dd):

41B. Gender:

- Male
 Female

41C. Hemoglobin genotype:

- SS
 SC
 S beta thalassemia zero
 Sickle cell trait
 AA normal
 Unknown

41D. Asthma:

- Yes
 No
 Unknown

41E. Same biological mother:

- Yes
 No
 Unknown

41F. Same biological father:

- Yes
 No
 Unknown

42A. Do you know the sibling's date of birth?

- Yes
 No

42A-1. If Yes, enter sibling's date of birth
(yyyy/mm/dd):

42B. Gender:

- Male
 Female

42C. Hemoglobin genotype:

- SS
 SC
 S beta thalassemia zero
 Sickle cell trait
 AA normal
 Unknown

42D. Asthma:

- Yes
 No
 Unknown

42E. Same biological mother:

- Yes
 No
 Unknown

42F. Same biological father:

- Yes
 No
 Unknown

43A. Do you know the sibling's date of birth?

- Yes
 No

43A-1. If Yes, enter sibling's date of birth
(yyyy/dd/mm):

43B. Gender:

- Male
 Female

43C. Hemoglobin genotype:

- SS
 SC
 S beta thalassemia zero
 Sickle cell trait
 AA normal
 Unknown

43D. Asthma:

- Yes
 No
 Unknown

43E. Same biological mother:

- Yes
 No
 Unknown

43F. Same biological father:

- Yes
 No
 Unknown

44A. Do you know the sibling's date of birth?

- Yes
 No

44A-1. If Yes, enter sibling's date of birth (yyyy/mm/dd):

44B. Gender:

- Male
 Female

44C. Hemoglobin genotype:

- SS
 SC
 S beta thalassemia zero
 Sickle cell trait
 AA normal
 Unknown

44D. Asthma:

- Yes
 No
 Unknown

44F. Same biological mother:

- Yes
 No
 Unknown

44F. Same biological father:

- Yes
 No
 Unknown

45. Please mark the patient's sickle hemoglobinopathy diagnosis:

- Hgb SS
 Hgb S beta thalassemia zero

46A. Most recent quantitative hemoglobin - date (yyyy/mm/dd):

46B. Most recent quantitative hemoglobin - unit:

- Conventional: g/dl
 SI: mmol/L

46B-1. Most recent quantitative hemoglobin - value (xx.x g/dl):

46B-1. Most recent quantitative hemoglobin - value (x.xx mol/L):

47A. Percent of Type S hemoglobin (xx %):

47B. Percent of Type F hemoglobin (xx %):

47C. Percent of Type A&#8322; hemoglobin (xx %):

48. What is the patient's date of birth (yyyy/mm/dd)? _____

48A. Patient's birth weight (xx.x lbs.): _____

48B-1. Patient's gestational age - weeks (xx): _____

48B-2. Patient's gestational age - days (x): _____

49. What is the patient's gender? Male
 Female

50. What is the patient's baseline oximetry reading (xxx %)? (sitting at rest in outpatient hematology clinic for at least 3 minutes and with no current illness) _____

51. Most recent vital signs during well child visit:

51A. Visit date (yyyy/mm/dd): _____

51B. Pulse rate (xxx beats/minute): _____

51C-1. Blood pressure - systolic (xxx mmHg): _____

51C-2. Blood pressure - diastolic (xxx mmHg): _____

51D. Respirations (xx breaths/minute): _____

51E. Temperature - unit: Conventional: Degrees, Fahrenheit
 SI: Degrees, Celsius

51E-1. Temperature (xxx.x degrees, Fahrenheit): _____

51E-1. Temperature (xx.x degrees, Celsius): _____

51F. Height - unit: Conventional: Inches (in.)
 SI: Centimeters (cm.)

51F-1. Height (xx in.): _____

51F-1. Height (xxx cm.): _____

51G. Weight - unit: Conventional: Pounds (lbs.)
 SI: Kilograms (Kg.)

51G-1. Weight (xxx lbs.): _____

51G-1. Weight (xxx Kg.): _____

52. Current status:

52A-1. HIV antibody test: Positive
 Negative
 Not tested

52A-2. Year (yyyy): _____

52B-1. Hepatitis A antibody (IgG): Positive
 Negative
 Not tested

52B-2. Year (yyyy): _____

52C-1. Hepatitis B surface antigen

- Positive
 Negative
 Not tested

52C-2. Year (yyyy):

52D-1. Hepatitis B core antigen (IgG):

- Positive
 Negative
 Not tested

52D-2. Year (yyyy):

52E-1. Hepatitis C antibody:

- Positive
 Negative
 Not tested

52E-2. Year (yyyy):

53. Current Medications and Treatment (answer each item):

53A. Penicillin:

- Yes
 No

53B. Folic Acid:

- Yes
 No

53C. Other:

- Yes
 No

53C-1. If Other, specify:

53D. Other:

- Yes
 No

53D-1. If Other, specify:

53E. Other:

- Yes
 No

53E-1. If Other, specify:

53F. Other:

- Yes
 No

53F-1. If Other, specify:

53G. Other:

- Yes
 No

53G-1. If Other, specify:

53H. Overnight oxygen:

- Yes
 No

54. Record steady state hematology values. Please be sure to record lab values in the units posted on this form.

54A. Date of specimen (yyyy/mm/dd): _____

54B. Hemoglobin - unit: Conventional: g/dl
 SI: mmol/L

54B-1. Hemoglobin (xx.x g/dl): _____

54B-1. Hemoglobin (x.xx mmol/L): _____

54C. Hematocrit (xx %): _____

54D. RBC (xx.x m/mm¹⁷⁹): _____

54E. WBC (xxxxx cu): _____

54F. Neutrophils (xx %): _____

54G. Bands (xx %): _____

54H. MCV (xxx.x fl): _____

54I. MCH (xx.x pg): _____

54J. MCHC - unit: Conventional: g/dl
 SI: g/L

54J-1. MCHC (xx g/dl): _____

54J-1. MCHC (xxx g/L): _____

54K. Platelets - unit: Conventional: X 10¹⁷⁹/mm¹⁷⁹;
 SI: X 10⁸³¹³/L

54K-1. Platelets (xxxxxxx X 10¹⁷⁹/mm¹⁷⁹): _____

54K-1. Platelets (xxxxxx X 10⁸³¹³/L): _____

54L. MPV (xx.x fl): _____

54M. Reticulocytes - unit: Conventional: %
 SI: Proportion of 1.0

54M-1. Reticulocytes (xx.x %): _____

54M-1. Reticulocytes (x.xxx proportion of 1.0): _____

55. Immunizations (answer each item):

55A. Haemophilus influenzae Type B: Yes
 No
 Unknown

55A-1. If Yes, enter year (yyyy): _____

55B. Pneumovax Yes
 No
 Unknown

55B-1. If Yes, enter year (yyyy): _____

55C. Meningococcus C

- Yes
 No
 Unknown

55C-1. If Yes, enter year (yyyy):

55D. Meningococcus A:

- Yes
 No
 Unknown

55D-1. If Yes, enter Year (yyyy):

55E. Hepatitis B:

- Yes
 No
 Unknown

55E-1. If Yes, enter year (yyyy):

55F. Hepatitis A:

- Yes
 No
 Unknown

55F-1. If Yes, enter year (yyyy):

55G. Influenza vaccine:

- Yes
 No
 Unknown

55G-1. If Yes, enter year (yyyy):

55H. Prevnar:

- Yes
 No
 Unknown

55H-1. If Yes, enter year (yyyy):

56. Patient's past medical history:

56A. Dactylitis:

- Yes
 No

56A-1. If Yes, number of events (xx):

56A-2. Age at first dactylitis event (xx):

56B. Splenic sequestration (acute) (xx):

- Yes
 No

56B-1. If Yes, number of events (xx):

56B-2. Age at first splenic sequestration (xx):

56C. Documented UTI:

- Yes
 No

56C-1. If Yes, number of events (xx):

56D. Aplastic crisis/Parvovirus:

- Yes
 No

56D-1. If Yes, enter year (yyyy):

56E. Salmonella infection:

- Yes
 No

56E-1. If Yes, enter year (yyyy): _____

57F. Pneumococcal meningitis: Yes
 No

56F-1. If Yes, enter year (yyyy): _____

56G. Meningococcal meningitis: Yes
 No

56G-1. If yes, enter year (yyyy): _____

56H. Other bacterial meningitis: Yes
 No

56H-1. If Yes, enter year (yyyy): _____

56I. Non-bacterial meningitis (i.e., viral): Yes
 No

56I-1. If Yes, enter year (yyyy): _____

56J. Priapism: Yes
 No
 NA

56J-1. If Yes (yyyy): Stuttering < 24 hours
 Stuttering >= 24 hours
 Continuous < 24 hours
 Continuous >= 24 hours

56K. Avascular necrosis: Yes
 No

56K-1. If Yes, check all that apply: Right hip
 Left hip
 Right shoulder
 Left shoulder

56L. Common bile duct obstruction: Yes
 No

56M. Central venous line: Yes
 No

56N. Highest total bilirubin in the last three years, when patient is well - unit: Conventional: mg/dL
 SI: $\mu\text{mol/L}$

56N-1. Highest total bilirubin in the last three years, when patient is well - value (xxx.x mg/dL): _____

56N-1. Highest total bilirubin in the last three years, when patient is well - value (xxx.x $\mu\text{mol/L}$): _____

56O. Baseline creatinine - unit: Conventional: mg/dL
 SI: $\mu\text{mol/L}$

56O-1. Baseline creatinine - value (xxx.x mg/dL): _____

56O-1. Baseline creatinine - value (xxx $\mu\text{mol/L}$): _____

56P. Baseline BUN - unit: Conventional: mg/dL
 SI: mmol/L

56P-1. Baseline BUN - value (xxx.x mg/dL): _____

56P-1. Baseline BUN - value (xx.xx mmol/L): _____

56Q-1. Highest blood pressure in the last year - systolic (xxx mmHg): _____

56Q-2. Highest blood pressure in the last year - diastolic (xxx mmHg): _____

57. Past Surgeries: To the best of your knowledge, has the patient ever had any of the following surgeries? If the patient has had the same surgery in two different years, please record each surgery on a separate line.

57A. Tonsillectomy/Adenoidectomy: Yes
 No
 Don't know

57A-1. If yes, enter year (yyyy): _____

57B. Splenectomy: Yes
 No
 Don't Know

57B-1. If Yes, enter year (yyyy): _____

57C. Cholecystectomy: Yes
 No
 Don't Know

57C-1. If Yes, enter year (yyyy): _____

57D. Other, specify: _____

57D-1. Enter year (yyyy): _____

57E. Other, specify: _____

57E-1. Enter year (yyyy): _____

57F. Other, specify: _____

57F-1. Enter year (yyyy): _____

57G. Other, specify: _____

57G-1. Enter year (yyyy): _____

57H. Other, specify: _____

57H-1. Enter year (yyyy): _____

57I. Other, specify: _____

57I-1. Enter year (yyyy): _____

58. Has the patient experienced any of the following problems during the past three years?

58A. Transient ischemic attack: Yes
 No

58B. Hospitalization for pain: Yes
 No

58B-1. If Yes, how many admissions? (xx) _____

58C. Hospitalization for acute chest syndrome (ACS):

- Yes
- No

58C-1. If Yes, how many admissions? (xx)

58D. Hospitalization for asthma/respiratory symptoms:

- Yes
- No

58D-1. If Yes, how many admissions? (xx)

58E. Emergency department visits for pain:

- Yes
- No

58E-1. If Yes, how many visits? (xx)

58F. Emergency department visits for ACS:

- Yes
- No

58F-1. If Yes, how many visits? (xx)

58G. Emergency department visits for asthma/respiratory symptoms:

- Yes
- No

58G-1. If Yes, how many visits? (xx)

Staff I.D. #:
