Health Status Assessment Form

SCDAA Michigan Health Status Assessment Form

Introduction:

1. This is a survey for Michigan residents with sickle cell disease.
2. Surveys like this are often done with other illnesses. "Stand up and be counted!"
3. The goal of this interview is to document unmet needs.
4. The information will be shared with the Michigan Department of Community Health.
5. We will share the results from this survey with you. Stay tuned!
6. This survey is voluntary. You can skip any questions if they make you uncomfortable or stop at any time.
7. All answers will be kept confidential, and all results will be de-identified before presenting in public.

☐ Patient advocate shared the above information with client
☐ Client agrees to participate ☐ Client does not wish to participate
(Fill out and submit first page only)

Patient Advocate Reminders:

1. We are just collecting information, and not all the tests and screenings are necessary for everyone.
2. Questions about appointments made and kept are designed to help identify different common reasons people are unable to follow up or seek care.
3. DO NOT LEAVE ANY BLANK SPACES, ANSWER EVERY QUESTION IN PENCIL
4. Questions refer to the date of the interview.

START TME_____ STOP TIME _____

Client Information

Patient advocate _____ Date of interview ☐☐-☐☐-☐☐☐☐

Name of client _____ Date of birth of client ☐☐-☐☐-☐☐☐☐

Sex of client ☐ Male ☐ Female

Person interviewed ☐ Client (>17) ☐ Parent or Guardian: _____

Phone Number _____

Address _____

City, ZIP code _____ ☐☐☐☐☐

Secondary Phone _____

Email Address _____

MCIR ID _____

Diagnosis _____

Which one or more of the following would you say is your race ?

- ☐ Black
  - ☐ African (client or client's parents were born in Africa)
- ☐ White
- ☐ American Indian
- ☐ Asian/Pacific Islander
- ☐ Multi-racial

Don't read out loud:
☐ Don't know
☐ Refused

Were you born in Michigan?

☐ Yes
☐ No _____

Don't read out loud:
☐ Don't know
☐ Refused

Are you of Hispanic, Latino/a, or Spanish origin?

☐ Yes
☐ No

Don't read out loud:
☐ Don't know
☐ Refused

Are you of Arab or Chaldean origin?

☐ Yes
  ☐ Arab
  ☐ Chaldean
☐ No

Don't read out loud:
☐ Don't know
☐ Refused

PROVIDER VISITS

1. Do you / your child have a primary care physician?

☐ Yes
Name of physician _____
Phone: _____

☐ No
☐ Don't Know
☐ Refused to respond

2. Do you / your child have a hematologist (blood specialist)?

☐ Yes
Name of hematologist _____
Phone: _____
How many times in the past 12 months have you visited your hematologist?
_____ Visits

☐ No
☐ Don't Know
☐ Refused to respond

Task:
Make a referral and follow up in 3 months

Note: "Sickle Cell Specialist" or "Hematologist" is a physician who specializes in treating conditions that involve the blood such as sickle cell disease

3. How old were you / your child when you found out you / your child had sickle cell disease?

☐ During Infancy
☐ 2-5 years
☐ 6-10 years
☐ 11-17 years
☐ 18 years or older
☐ Don't know
☐ Refused to respond

4. How did you find out you / your child had sickle cell disease?

☐ Newborn screening
☐ Presented with pain or other symptoms
☐ Other _____
☐ Don't know
☐ Refused to respond

5. In the past 12 months, how many times have you / your child visited a primary care doctor?

_____ Visits ☐ N/A (no primary care doctor)

If zero, have you visited a primary care doctor in the last:

☐ 2 years
☐ 3-5 years
☐ > 5 years
☐ Never
☐ Don't Know
☐ Refused to respond

6. Is your / your child's hematologist also your / their primary care physician?

☐ Yes
☐ No
☐ Don't Know
☐ N/A
☐ Refused to respond

7. In the past 12 months have you / your child visited another health care professional?

☐ Yes
Check all that apply:

- ☐ Cardiologist (heart)
- ☐ ENT (ear/nose/throat)
- ☐ Gastroenterologist (stomach/intestines)
- ☐ Mental Health Professional
- ☐ Nephrologist (kidney)
- ☐ Neurologist
- ☐ OB/Gynecologist
- ☐ Ophthalmologist (eye)
- ☐ Pulmonologist (lung)
- ☐ Physical Therapist
- ☐ Urologist (urinary tract specialist)
- ☐ Neurosurgeon (brain surgeon)
- ☐ Orthopedic (bone surgeon)
- ☐ Other: _____

☐ No
☐ Don't Know
☐ Refused to respond

8. If you / your child were having difficulty coping, would you consider seeking the services of a mental health professional like a psychologist or psychiatrist?

☐ Yes
☐ No
☐ Don't Know
☐ Refused to respond

9. If you / your child were having difficulty coping, would you consider seeking the services of a faith-based counselor?

☐ Yes
☐ No
☐ Don't Know
☐ Refused to respond

SICKLE CELL HISTORY

Note: "Pain episode" includes any significant pain (not headache) lasting at least 24 hours

10. In the past 12 months, have you / your child experienced sickle cell pain episodes?

☐ Yes
How many times?
- ☐ 1-3
- ☐ 4-6
- ☐ 7-10
- ☐ 11-20
- ☐ >20
- ☐ I have pain all the time

☐ No
☐ Don't Know
☐ Refused to respond

Examples of narcotics: *codeine, Tylenol #3,#4, morphine, oxycodone/Oxycontin, Lortab, Dilaudid, MS Contin, Vicodin, Darvocet*

11. Have you / your child used narcotics in the past 12 months (like morphine or Tylenol #3) to manage your pain?

☐ Yes
☐ No
☐ Don't Know
☐ N/A (no pain episodes)
☐ Refused to respond

12. How many of your / your child's pain episodes in the past 12 months required narcotics (like morphine or Tylenol #3)?

☐ 0
☐ 1-3
☐ 4-6
☐ 7-10
☐ 11-20
☐ >20
☐ I /my child takes narcotics every day
☐ Don't know
☐ N/A (no pain episodes)
☐ Refused to respond

13. How many of your/your child's pain episodes in the past 12 months required a hospital visit (ER or inpatient)?

- ☐ 0
- ☐ 1-3
- ☐ 4-6
- ☐ 7-10
- ☐ 11-20
- ☐ >20
- ☐ Don't know
- ☐ N/A (no pain episodes)
- ☐ Refused to respond

14. In the past 12 months, about how many times have you/your child gone to the emergency room without being admitted to the hospital? (Include SCD-related *and* non-SCD-related visits in the past 12 months. If you are not sure, give your best estimate.)

- ☐ Don't Know
- ☐ Refused to respond

15. In the past 12 months, about how many times have you/your child been admitted to the hospital? (Include SCD-related *and* non-SCD-related admissions in the past 12 months. If you are not sure, give your best estimate.)

- ☐ Don't Know
- ☐ Refused to respond

The next set of questions has to do with how you feel about the care you receive.

16. In the past 12 months, on a scale of 1 to 5, how satisfied have you been with the care you/your child have received in the emergency room?

- ☐ 1 (Not satisfied at all)
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5 (Very satisfied)
- ☐ N/A
- ☐ Don't Know
- ☐ Refused to respond

17. Have you/your child ever been refused care in an emergency room?

- ☐ Yes ---------- EXPLAIN:
- ☐ No
- ☐ Don't Know
- ☐ Refused to respond

18. In the past 12 months, on a scale of 1 to 5, how satisfied have you been with the care you have received from your/your child's hematologist?

- ☐ 1 (Not satisfied at all)
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5 (Very satisfied)
- ☐ N/A
- ☐ Don't Know
- ☐ Refused to respond

19. Please rate the following statement: In the past 12 months, I have felt knowledgeable about how to manage my / my child's sickle cell disease.

- ☐ 1 (Not satisfied at all)
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5 (Very satisfied)
- ☐ N/A
- ☐ Don't Know
- ☐ Refused to respond

Task:
Suggest another educational session to address any discomfort

20. Please rate the following statement: In the past 12 months, my / my child's doctors and nurses have been respectful about my values, beliefs and traditional remedies when recommending treatment for sickle cell disease.

- ☐ 1 (Not satisfied at all)
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5 (Very satisfied)
- ☐ N/A
- ☐ Don't Know
- ☐ Refused to respond

21. Have you / your child experienced or had:

	EVER			IN THE PAST 12 MONTHS		
Fever	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
Asthma	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
Acute Chest Syndrome/Pneumonia	☐ Yes	☐ No	☐ Don't know	☐ Yes	☐ No	☐ Don't Know
Heart Failure	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
Pulmonary Hypertension	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
Hepatitis	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
Sepsis (Infection in the blood)	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
Stroke	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
Silent Infarct	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
Urinary Tract Infection	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
Dialysis	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
Leg ulcers	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
Sickle eye damage	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
• Laser eye treatment	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
Gallstones	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
• Removal of Gall bladder*	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
Priapism (males only) ☐ Female	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
• Shunt ☐ Female	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
Hand-foot syndrome	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
Splenic Sequestration	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
• Removal of spleen*	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
Osteomyelitis	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
Avascular necrosis (AVN)						
• Hip	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
◦ Hip Replacement	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
◦ Hip Coring	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
• Shoulder	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
Aplastic crisis	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
Tonsillectomy	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
Adenoidectomy	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know
Depression	☐ Yes	☐ No	☐ Don't Know	☐ Yes	☐ No	☐ Don't Know

** Once-in-a-lifetime procedures*

22. Are you / your child currently on hydroxyurea? *(Hydrea or Droxy)*

- ☐ Yes
- ☐ No

  Has a health professional ever talked to you about hydroxyurea?

  - ☐ Yes
  - ☐ No
  - ☐ Don't Know

  Task: ***Discuss hydroxyurea therapy***
- ☐ Don't Know
- ☐ Refused to respond

23. Have you / your child ever had a blood transfusion?

- ☐ Yes
- ☐ No (skip to question 26)
- ☐ Don't Know
- ☐ Refused to respond

24. In the past 12 months, have you / your child had a blood transfusion?

- ☐ Yes

  What was the reason for the most recent blood transfusion? *(select one)*

  - ☐ Low hemoglobin
  - ☐ Pre-surgery
  - ☐ Acute chest syndrome
  - ☐ Splenic sequestration
  - ☐ Priapism
  - ☐ Pain
  - ☐ Stroke
  - ☐ Abnormal TCD
  - ☐ Silent infarct
  - ☐ Other
  - ☐ Don't Know
- ☐ No
- ☐ Don't Know
- ☐ Refused to respond

25. In the past 12 months, have you / your child been on a routine chronic transfusion program?

- ☐ **Yes**

  What is the main reason? *(select one)*

  - ☐ Stroke
  - ☐ Abnormal TCD
  - ☐ Silent Infarct
  - ☐ Splenic sequestration
  - ☐ Priapism
  - ☐ Leg ulcer
  - ☐ Recurrent Pain
  - ☐ Don't Know
  - ☐ Other
  - ☐ Refused to respond

  Are you currently on iron chelation therapy? (Desferal or exjade)

  - ☐ Yes
  - ☐ No

    Has a healthcare professional talked to you about iron chelation therapy in the past 12 months?

    - ☐ Yes
    - ☐ No
    - ☐ Don't Know
    - ☐ Refused to respond

    Task: ***Suggest discussing and follow up in 3 months***
  - ☐ Don't Know
  - ☐ Refused to respond
- ☐ **No**
- ☐ **Don't Know**
- ☐ **Refused to respond**

Iron chelation therapy: *When you have had many transfusions, iron can build up in your system and it needs to be removed.*

26. Have you/your child had a bone marrow transplant?

- ☐ Yes
- ☐ No

Did you know that bone marrow transplant was a possible cure for sickle cell disease?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ N/A

- ☐ Don't know
- ☐ Refused to respond

Bone Marrow Transplant: *Bone marrow transplant is a cure for SCD. It's not offered to all patients because of risks. It is usually done on younger patients. Outcomes are improving with ongoing research.*

SICKLE CELL SCREENING

Transcranial Doppler (TCD) Screening

For clients 2-16 years old with HbSS or HbS-beta thalassemia zero: (all others skip to next page)

- ☐ Not applicable

Age: _____ Sickle cell type: _____

27. In the past 12 months, has your child had a transcranial doppler screening?

- ☐ **Yes**

Was the test abnormal?

- ☐ Yes
- ☐ No
- ☐ Don't Know
- ☐ Refused to respond

- ☐ **No**

How many years ago was your child's last TCD?

- ☐ 2 years
- ☐ 3-5 years
- ☐ > 5 years
- ☐ Never
- ☐ Don't Know
- ☐ Refused to respond

In the past 12 months, has a health professional talked to you and your child about a TCD screening?

- ☐ Yes

Was screening recommended?

- ☐ *Yes, upcoming appointment*
- ☐ *Yes, but no appointment made*

Why not? (select all that apply)

- ☐ Have not gotten to it yet
- ☐ No insurance coverage
- ☐ Refused
- ☐ No transportation
- ☐ Unknown
- ☐ Other
- ☐ Refused to respond

Task: ***Follow up in 3 months***

- ☐ *No*
- ☐ *Don't Know*
- ☐ *Refused to respond*

- ☐ No
- ☐ Don't Know
- ☐ Refused to respond

Task: ***Suggest discussing and follow up in 3 months***

- ☐ **Don't Know**
- ☐ **Refused to respond**

Echocardiogram

(Usually recommended once per year for ages 15 and older, ASK EVERYONE)

28. In the past 12 months, have you / your child had an echocardiogram? *(Sound wave test of the heart)*

☐ **Yes**

Was the test abnormal?

☐ Yes

Have you ever received follow-up from a specialist?

☐ Yes
☐ No
☐ Don't Know
☐ Refused to respond

☐ No
☐ Don't Know
☐ Refused to respond

☐ **No**

How many years ago was your/your child's last echocardiogram?

☐ 2 years
☐ 3-5 years
☐ > 5 years
☐ Never
☐ Don't Know
☐ Refused to respond

In the past 12 months, has a health professional talked to you/your child about an echocardiogram?

☐ Yes

Was screening recommended?

☐ *Yes, upcoming appointment*
☐ *Yes, but no appointment made*

Why not? (select all that apply)

☐ Have not gotten to it yet
☐ No insurance coverage
☐ Refused
☐ No transportation
☐ Unknown
☐ Other
☐ Refused to respond

Task: ***Suggest discussing and follow up in 3 months***

☐ *No*
☐ *Don't Know*
☐ *Refused to respond*

☐ No
☐ Don't Know
☐ Refused to respond

Task: ***Suggest discussing if over age 15 and follow up in 3 months***

☐ **Don't Know**

☐ **Refused to respond**

Pulmonary Function Testing

NOTE: Every child over age 5 may not need testing

(Usually recommended for age 5 and older, ask EVERYONE ages 5 and older)

☐ Not applicable (age 0-4 years old)

29. In the past 12 months, have you/your child had a pulmonary function test (PFT)?

☐ **Yes**

Was the test abnormal?

☐ Yes

Have you ever received follow-up from a specialist?

☐ Yes
☐ No
☐ Don't Know
☐ Refused to respond

☐ No
☐ Don't Know
☐ Refused to respond

☐ **No**

How many years ago was your/your child's last pulmonary function test?

☐ 2 years
☐ 3-5 years
☐ > 5 years
☐ Never
☐ Don't Know
☐ Refused to respond

In the past 12 months, has a health professional talked to you/your child about a pulmonary function test?

☐ Yes

Was screening recommended?

☐ *Yes, upcoming appointment*
☐ *Yes, but no appointment made*

Why not? (select all that apply)

☐ Have not gotten to it yet
☐ No insurance coverage
☐ Refused
☐ No transportation
☐ Unknown
☐ Other
☐ Refused to respond

Task:
Follow up in 3 months

☐ *No*
☐ *Don't Know*
☐ *Refused to respond*

☐ No
☐ Don't Know
☐ Refused to respond

Task:
Suggest getting a baseline if client is over age 17 or has had ACS (acute chest syndrome)

☐ **Don't Know**

☐ **Refused to respond**

Pulmonary function tests *are a series of different breathing tests usually done by a lung specialist. The patient blows into a mouthpiece. This test is often done on kids with asthma or acute chest syndrome. Do not confuse with incentive spirometer where patients suck in air to keep lungs open.*

Retinopathy screening

(Usually recommended routinely for SC clients age 10 and older and SS clients age 15 and older, ASK EVERYONE.)

30. In the past 12 months, have you / your child been to an ophthalmologist to look for changes in the back of your eyes?

☐ **Yes**

Was the test abnormal?

☐ Yes

Have you ever received follow-up from a specialist?

☐ Yes
☐ No
☐ Don't Know
☐ Refused to respond

☐ No
☐ Don't Know
☐ Refused to respond

About retinal screening:
The ophthalmologist gives you eye drops which expand your pupils.

☐ **No**

How many years ago was your/your child's last retinal screening?

☐ 2 years
☐ 3-5 years
☐ > 5 years
☐ Never
☐ Don't Know
☐ Refused to respond

In the past 12 months, has a health professional talked to you/your child about retinal screening?

☐ Yes

Was screening recommended?

☐ *Yes, upcoming appointment*
☐ *Yes, but no appointment made*

Why not? (select all that apply)

☐ Have not gotten to it yet
☐ No insurance coverage
☐ Refused
☐ No transportation
☐ Unknown
☐ Other
☐ Refused to respond

Task:
Suggest discussing and follow up in 3 months

☐ *No*
☐ *Don't Know*
☐ *Refused to respond*

☐ No
☐ Don't Know
☐ Refused to respond

Task:
Suggest discussing and follow up in 3 months if client is at least 15 or has HbSC and is age 10 or older

☐ **Don't Know**

☐ **Refused to respond**

ROUTINE HEALTH SCREENING

Pap smear

Ask all women age 15 and older (All others skip to next page)

(Usually recommended that women have a pap smear at age 21 and then every two or three years after.)

☐ Not applicable (female under age 15 or male)

31. Have you/your child had a pap smear in the last 12 months?

☐ **Yes**

Was the test abnormal?

☐ Yes

Have you ever received follow-up from a specialist?

☐ Yes
☐ No
☐ Don't Know
☐ Refused to respond

☐ No
☐ Don't Know
☐ Refused to respond

☐ **No**

How many years ago was your/your child's last pap smear?

☐ 2 years
☐ 3-5 years
☐ > 5 years
☐ Never
☐ Don't Know
☐ Refused to respond

In the past 12 months, has a health professional talked to you/your child about a pap smear?

☐ Yes

Was a pap smear recommended?

☐ *Yes, upcoming appointment*
☐ *Yes, but no appointment made*

Why not? (select all that apply)

☐ Have not gotten to it yet
☐ No insurance coverage
☐ Refused
☐ No transportation
☐ Unknown
☐ Other
☐ Refused to respond

Task: ***Follow up in 3 months***

☐ *No*
☐ *Don't Know*
☐ *Refused to respond*

☐ No
☐ Don't Know
☐ Refused to respond

Task: Suggest discussing if appropriate

☐ **Don't Know**

☐ **Refused to respond**

Mammogram

Ask all women age 40 and older (All others skip to next page)

(Usually recommended that women age 40 or older have mammograms every 1 to 2 years)

☐ Not applicable (female under age 40 or male)

32. Have you had a mammogram in the last 12 months?

☐ **Yes**

Was the test abnormal?

☐ Yes

Have you ever received follow-up from a specialist?

☐ Yes
☐ No
☐ Don't Know
☐ Refused to respond

☐ No
☐ Don't Know
☐ Refused to respond

☐ **No**

How many years ago was your last mammogram?

☐ 2 years
☐ 3-5 years
☐ > 5 years
☐ Never
☐ Don't Know
☐ Refused to respond

In the past 12 months, has a health professional talked to you about a mammogram?

☐ Yes

Was screening recommended?

☐ *Yes, upcoming appointment*
☐ *Yes, but no appointment made*

Why not? (select all that apply)

☐ Have not gotten to it yet
☐ No insurance coverage
☐ Refused
☐ No transportation
☐ Unknown
☐ Other
☐ Refused to respond

Task: ***Follow up in 3 months***

☐ *No*
☐ *Don't Know*
☐ *Refused to respond*

☐ No
☐ Don't Know
☐ Refused to respond

Task: Suggest discussing and follow up in 3 months

☐ **Don't Know**

☐ **Refused to respond**

Colonoscopy

Ask everyone age 50 and older (All others skip to next page)

(Usually recommended that adults receive colonoscopy screenings every 10 years beginning at age 50 and up to age 75.

☐ Not applicable (Under age 50)

33. Have you had a colonoscopy in the last 12 months?

☐ **Yes**

Was the test abnormal?

☐ Yes

Have you ever received follow-up from a specialist?

☐ Yes
☐ No
☐ Don't Know
☐ Refused to respond

☐ No
☐ Don't Know
☐ Refused to respond

☐ **No**

How many years ago was your last colonoscopy?

☐ 2 years
☐ 3-5 years
☐ > 5 years
☐ Never
☐ Don't Know
☐ Refused to respond

In the past 12 months, has a health professional talked to you about a colonoscopy?

☐ Yes

Was screening recommended?

☐ *Yes, upcoming appointment*
☐ *Yes, but no appointment made*

Why not? (select all that apply)

☐ Have not gotten to it yet
☐ No insurance coverage
☐ Refused
☐ No transportation
☐ Unknown
☐ Other
☐ Refused to respond

Task: ***Follow up in 3 months***

☐ *No*
☐ *Don't Know*
☐ *Refused to respond*

☐ No
☐ Don't Know
☐ Refused to respond

Task: Suggest discussing and follow up in 3 months

☐ **Don't Know**

☐ **Refused to respond**

NUTRITION

34. Do you / your child currently take folic acid?

- ☐ Yes
- ☐ No
- ☐ Don't Know
- ☐ Refused to respond

35. Do you / your child currently take Vitamin D?

- ☐ Yes
- ☐ No
- ☐ Don't Know
- ☐ Refused to respond

36. Do you / your child currently take multivitamins?

- ☐ Yes
- ☐ No
- ☐ Don't Know
- ☐ Refused to respond

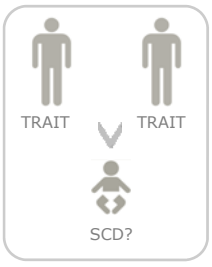
GENETIC COUNSELING

Next, we would like to ask you three questions about how sickle cell gets passed on to children from parents. Your answers will help Michigan programs learn more about how to teach people about sickle cell disease in the future.

Ask parent or guardian the following questions if SCD client is age 0-15. Ask the SCD client if age 16 or older.

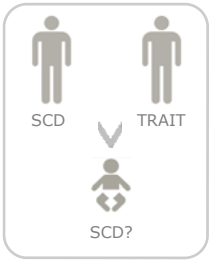
37. If both parents have sickle cell trait, what is the chance of their child having sickle cell DISEASE?

- ☐ A. 0% (no chance) → *Task: wrong answer* ***Explain and ask again in 3 months***
- ☐ B. 25% (1 in 4)
- ☐ C. 50% (1 in 2) → *Task: wrong answer* ***Explain and ask again in 3 months***
- ☐ D. 100% (always disease) → *Task: wrong answer* ***Explain and ask again in 3 months***
- ☐ Don't Know → *Task: wrong answer* ***Explain and ask again in 3 months***
- ☐ Refused to respond



38. If one parent has SCD and the other has sickle cell TRAIT, what is the chance of their child having sickle cell DISEASE?

- ☐ A. 0% (no chance of SCD) → *Task: wrong answer* ***Explain and ask again in 3 months***
- ☐ B. 25% (1 in 4) → *Task: wrong answer* ***Explain and ask again in 3 months***
- ☐ C. 50% (1 in 2)
- ☐ D. 100% (always disease) → *Task: wrong answer* ***Explain and ask again in 3 months***
- ☐ Don't Know → *Task: wrong answer* ***Explain and ask again in 3 months***
- ☐ Refused to respond



39. If you knew that your partner had sickle cell trait, do you think it would influence your decision about having children?

A. SCD Client	☐ Yes	☐ No	☐ Don't Know	☐ N/A	☐ Refused to respond
B. Parent of SCD Client	☐ Yes	☐ No	☐ Don't Know	☐ N/A	☐ Refused to respond

INSURANCE & ACCESS TO CARE

40. What kind of health insurance do you / your child have? **Name of insurance** _____
(select all that apply)

- ☐ None
- ☐ Medicaid
- ☐ Medicaid HMO/health plan
- ☐ MI Child
- ☐ Medicare
- ☐ Private Commercial
- ☐ Private HMO
- ☐ TriCare
- ☐ Other: _____
- ☐ Don't know
- ☐ Refused to respond

41. Are you / your child currently enrolled in any of the following?
(select all that apply)

- ☐ Food stamps
- ☐ FIA grant (DHS)
- ☐ MI Infant Health Program (MIHP)
- ☐ SSI
- ☐ SSD
- ☐ Social Security
- ☐ Early On
- ☐ WIC
- ☐ CSHCS
- ☐ Don't know
- ☐ Refused to respond
- ☐ None

Task:
If under age 21 and not on CSHCS, make a referral and follow up in 3 months

42. Do you have adequate transportation for medical appointments?

- ☐ Yes
- ☐ No
- ☐ Sometimes
- ☐ Don't know
- ☐ Refused to respond

43. How do you get to routine medical appointments? (Select all the apply)

- ☐ My own car
- ☐ Get rides from family and friends
- ☐ Transportation service
- ☐ Bus
- ☐ Taxi
- ☐ Walk
- ☐ Don't know
- ☐ Refused to respond

44. What source of transportation do you have for medical emergencies? (Select all the apply)

- ☐ My own car
- ☐ Get rides from family and friends
- ☐ Transportation service
- ☐ Bus
- ☐ Taxi
- ☐ Walk
- ☐ Ambulance
- ☐ Don't know
- ☐ Refused to respond

45. Was there a time in the past 12 months when you / your child needed to see a doctor but could not because of cost?

- ☐ Yes
- ☐ No
- ☐ Don't Know
- ☐ Refused to respond

DEMOGRAPHICS

46. How many people live in your / your child's household?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8 or more
- ☐ Don't know
- ☐ Refused to respond

47. Do you (the SCD client) have biological children?

- ☐ Yes

  If "*yes*": How many?

  - ☐ 1
  - ☐ 2
  - ☐ 3
  - ☐ 4
  - ☐ 5
  - ☐ 6+

- ☐ No
- ☐ Don't know
- ☐ Refused to respond

48. Are you (the SCD client) currently employed? (Select all the apply)

☐ N/A, Client is age 0-17

- ☐ Full time
- ☐ Part time
- ☐ Unemployed
- ☐ Student
- ☐ Retired
- ☐ Don't know
- ☐ Refused to respond

49. Has your employment status been impacted by SCD?

☐ N/A, Client is age 0-17

- ☐ Yes

  Have you been referred to vocational rehab?

  - ☐ Yes
  - ☐ No
  - ☐ Don't know
  - ☐ Refused to respond

  Task: Make a referral and follow up in 3 months

- ☐ No
- ☐ N/A
- ☐ Don't know
- ☐ Refused to respond

50. What is the approximate annual household income from all sources (including food stamps)?

- ☐ Less than $5,000
- ☐ $5,000 to less than $20,000
- ☐ $20,000 to less than $35,000
- ☐ $35,000 to less than $50,000
- ☐ $50,000 to less than $75,000
- ☐ $75,000 or more
- ☐ Don't Know
- ☐ Refused to respond

DEMOGRAPHICS

51. What is the approximate annual income of the SCD individual (including food stamps)?

- ☐ SCD Individual is under age 18
- ☐ Less than $5,000
- ☐ $5,000 to less than $20,000
- ☐ $20,000 to less than $35,000
- ☐ $35,000 to less than $50,000
- ☐ $50,000 to less than $75,000
- ☐ $75,000 or more
- ☐ Don't Know
- ☐ Refused to respond

52. Education level of the SCD individual, and of the primary caregiver if SCD individual is under age 18

SCD Individual

Grade completed as of today:

- ☐ Not yet in school
- ☐ Currently in school, highest grade COMPLETED: ____
- ☐ Not in school, highest grade COMPLETED: ____
- ☐ High School Diploma
- ☐ GED
- ☐ Post-High School Training other than College (Vocational, Technical, etc)
- ☐ Some College
- ☐ College Degree
- ☐ Post-Graduate Education
- ☐ Refused to respond

Primary Caregiver

☐ N/A, Client is age 18+

Grade completed as of today:

- ☐ Currently in school, highest grade COMPLETED: ____
- ☐ Not in school, highest grade COMPLETED: ____
- ☐ High School Diploma
- ☐ GED
- ☐ Post-High School Training other than College (Vocational, Technical, etc)
- ☐ Some College
- ☐ College Degree
- ☐ Post-Graduate Education
- ☐ Refused to respond

53. Has the SCD individual ever been enrolled in special education?

- ☐ Yes
- ☐ No
- ☐ Don't Know
- ☐ N/A (not in school yet)
- ☐ Refused to respond

54. Has the SCD individual ever had an individualized education program (IEP) and/or 504 Plan?

- ☐ Yes
  - ☐ Individualized education program (IEP)
  - ☐ 504 Plan
  - ☐ Both IEP and 504 Plan
- ☐ No
- ☐ Don't Know
- ☐ N/A (not in school yet)

55. Do you use any of the following? (select all that apply)

SCD Client	Parent/Guardian
☐ Email	☐ Email
☐ Facebook	☐ Facebook
☐ Text messaging	☐ Text messaging
☐ Internet	☐ Internet
☐ Twitter	☐ Twitter

---------- **Make a copy of this page and place in client file** ----------

SCDAA-Michigan Health Status Assessment Form

Name of client _____

Date completed _____

How do you prefer to be contacted? ***For SCDAA purposes only***

- ☐ Email (_____)
- ☐ Facebook/Myspace (name _____)
- ☐ Text messaging (cell phone number _____)
- ☐ Phone (_____)

SCDAA Notes and follow-up:

Alternate phone numbers: **Contact** _____ **Number** _____

Contact _____ **Number** _____