

## Study Protocol

### 1. Convening the Group

- ✓ As people arrive have Patient Advocate direct them to refreshments.
- ✓ Approximately 5 minutes before the start of the discussion, the Facilitator will introduce herself and other MDCH and SCDA-MI staff in the room.
- ✓ The Facilitator will ask if there are any questions regarding the information or any concerns regarding the tape recording. If there are concerns and a participant does not want their voice heard on the tape, there are two options.
  - They may decline to participate in the group
  - Hand them a blank paper to give their written comments to the Facilitator at the end of the session. They may also write down questions for the Facilitator to pose to the group during discussion.

### 2. Opening Remarks and General Instructions

- ✓ Give general 'housekeeping instructions (restrooms, break, etc.)
- ✓ Explain the general purpose and process of the discussion group.
- ✓ Discussion Groups with people directly impacted give more insight and understanding to the issues.
- ✓ To garner more information in regards to the strategic plan – their concerns, questions, pros and cons about services, what should be taken into consideration when developing issues to address, etc.
- ✓ Outline general ground rules and discussion guidelines – the importance of everyone speaking up, speaking one at a time, asking for clarification if a question is not understood, and being prepared for the facilitator to interrupt to assure all topics are being covered and for clarification of statement if needed.
- ✓ Address the issue of confidentiality – No personal information will be collected by MDCH.

### 3. Group Discussion

Following is a list of suggested questions for the focus group dialogue, along with “probes” that can be used as a guide to stimulate discussion if needed. Please try to make sure participants discuss all six questions during the time allotted for the focus group, covering as many of the themes suggested by the probes as possible.

1. What community resources have you found most helpful in managing your/your child’s diagnosis of sickle cell?
  - What community resources would you like to see created for individuals with sickle cell disease?
2. What gets in the way of you/your child being able to attend scheduled appointments for sickle cell care?
  - If needed, specific issues might be brought up like cost, transportation, child care, time off from work/school, other obligations, etc.
3. Have you talked with anyone about using a medication called hydroxyurea as treatment for your/your child’s sickle cell disease? Was it recommended that you/your child take hydroxyurea? What factors influenced your decision to take/not take this medication?
4. When you/your child need immediate care because of pain episodes due to sickle cell disease, where do you usually go for care?
  - Have you/your child ever used a day treatment center or emergency room for pain management?
  - What was this experience like, and how was it different from the emergency room?
  - If you do not use a day clinic regularly for care, what barriers prevent you from doing so?

5. What has been done to help prepare you/your child for transitioning from pediatric to adult care for sickle cell disease?
  - What should health providers (doctors, nurses, social workers, child life specialists, etc.) be doing to help prepare individuals to transition to adult care?

6. Is there anything else you would like to tell us about sickle cell disease that we haven't discussed?

**4. Closing Discussion**

- ✓ Inform participants that the time allotted for discussion has ended and turn off tape recorder.
- ✓ Thank them for their participation.
- ✓ Distribute one gift card to each participant.

**Agenda**

<b>20 minutes</b>	<b>Convening the Discussion Group</b> Focus group participants arrive; they are asked to review participant brochure again. Light refreshments are available.	<b>Group</b>
<b>10 minutes</b>	<b>Opening remarks and general instructions</b>	<b>Facilitator</b>
<b>60 minutes</b>	<b>Group discussion</b> (facilitator activates tape recorder)	<b>Group</b>
<b>10 minutes</b>	<b>Closing the Discussion Group</b> Participants are thanked for their participation. Facilitator explains the next step for strategic planning. Gift cards are distributed.	<b>Facilitator</b>

**Focus Group Locations**

<b>Detroit</b>	<b>Patient Advocate: Tracie Conic</b> 18516 James Couzens Detroit, MI 48235
<b>Saginaw/Flint</b>	<b>Patient Advocate: Ben Frazier</b> 100 S. Jefferson, Suite 402 Saginaw, MI 48607
<b>Lansing</b>	<b>Patient Advocate: Linda Carter</b> 913 W. Holmes Rd., Suite 123 Lansing, MI 48910
<b>Kalamazoo/Benton Harbor</b>	<b>Patient Advocate: Tiffany Chatman</b> 769 Pipestone Street Benton Harbor, MI 49023
<b>Grand Rapids</b>	<b>Patient Advocate: Ruth Shovan</b> 745 Eastern Avenue S.E. Grand Rapids, MI 49503