

**Attachment 14:**  
**Focus Group Screening Questionnaires**

## Table of Contents

Phone Script for Opt Out Letter – Patients Ages 9-13, Parents/Caregivers (CCHMC).....	14-3
Phone Script Self-Referral – Patients Ages 9-13, Parents/Caregivers, Providers (CCHMC).....	14-6
Phone Script Opt Out Letter – Patients Ages 14-17, Parents/Caregivers (Nemours).....	14-10
Phone Script Self-Referral – Patients Ages 14-17, Parents/Caregivers (Nemours).....	14-13
Phone Script for Opt Out Letter – Patients Ages 18+, Patients Mixed Ages, Parents/Caregivers (CNMC).....	14-17
Phone Script Self Referral – Patients Ages 18+, Patients Mixed Ages, Parents/Caregivers, Providers (CNMC).....	14-20
Phone Script Screener – Summer 2013 – Patients Ages 18+ (CNMC).....	14-25
Telephone Reminder Script – Summer 2013 – Patients Ages 18+ (CNMC).....	14-27
Telephone Reminder Script – Parents/Caregivers (CNMC).....	14-28

## Improving Sickle Cell Transitions of Care through Health Information Technology: Phase 1

### *Phone Script for Opt Out Letter (CCHMC)*

**IF LEAVING MESSAGE:** This message is for Mr. or Ms. [INSERT ADULT NAME FROM PATIENT'S MEDICAL RECORD] regarding the letter you received about discussion groups we are conducting at Nemours Children's Clinic. My name is \_\_\_\_\_. Please contact us at 904-\_\_\_\_\_ at your earliest convenience. Thank you.

**IF SOMEONE ANSWERS:** Hello, may I please speak with Mr. or Ms. [INSERT ADULT NAME FROM PATIENT'S MEDICAL RECORD].

**ONCE CONFIRMED ADULT IS ON LINE:** My name is \_\_\_\_\_ calling from Nemours Children's Clinic. A week ago we sent you a letter from Dr. Kalinyak about discussion groups that we will be having for patients and parents seen in our Sickle Cell Center. Do you remember seeing that?

**NO:** I'm sorry you didn't receive the letter. We sent it to (*street name*) – is that still correct for your family? If yes, continue. If no, record answer.

Is this a good time for me to tell you about this new study, it will only take a couple of minutes?

(If the person indicates they would like to see the letter first, confirm their full address and tell them we will resend and will call back in one week.)

**YES: CONTINUE** (*Age Appropriate*)

**NO: SCHEDULE DAY/TIME TO CALL BACK**

### **If Contacting for Both Parent and Child (child = 9-13 years old):**

We are having discussion groups to help us learn about the health care experiences parents/caregivers of kids with sickle cell and kids with sickle cell have. We would also like to learn about your experiences and/or needs with transitioning between health care systems (for example going from the emergency room to the inpatient unit or from a pediatric facility to adult facility). Also, we would like to learn more about your current use of technology (i.e. cell phones, computers, laptops, tablets, etc.) and how technology could be used to improve care. We hope that these discussion groups will help us learn more about this so in the future we can create patient-friendly tools to improve the health care experience for patients and families living with sickle cell.

Public reporting burden for this collection of information is estimated to average 5 minutes per response, the estimated time required to complete the survey. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: AHRQ Reports Clearance Officer Attention: PRA, Paperwork Reduction Project (0935-XXXX) AHRQ, 540 Gaither Road, Room # 5036, Rockville, MD 20850.

We will have two discussion groups: one for parents and one for kids that are about your child's same age. Parents and children will not be in the same room together. We will also ask both of you to fill out a brief questionnaire (5-10 questions) about yourselves. The discussion groups will be audiotaped and someone from the study will also take notes to make sure that we don't miss anything that you tell us. Your responses will be kept confidential to the extent permitted by law, including AHRQ's confidentiality statute, 42 USC 299c-3(c). We do not record your names and your child's sickle cell team will not see any of your specific information.

The discussion groups will last roughly **2 hours long**, and will be led by a professional interviewer.

The parent session is taking place **<Day>**, **<Date>** at **<Time>**.

The child session is taking place **<Day>**, **<Date>** at **<Time>**.

As a thank you, we are offering **\$50 cash** for sharing your opinions.

Would this be something that you and/or your child might be interested in attending?

<b>YES: CONTINUE (PAGE 3)</b>	<b>NO: THANK AND TERMINATE</b>
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**If Contacting for Parent Only:**

We are having a discussion group to help us learn about the health care experiences parents/caregivers of kids with sickle cell have. We would also like to learn about your experiences and/or needs with transitioning between health care systems (for example going from the emergency room to the inpatient unit or from a pediatric facility to adult facility). Also, we would like to learn more about your current use of technology (i.e. cell phones, computers, laptops, tablets, etc.) and how technology could be used to improve care. We hope that this discussion group will help us learn more about this so in the future we can create patient-friendly tools to improve the health care experience for patients and families living with sickle cell.

At the discussion group we will also ask you to fill out a brief questionnaire (5-10 questions) about yourself. The discussion groups will be audiotaped and someone from the study will also take notes to make sure that we don't miss anything that you tell us. Your responses will be kept confidential to the extent permitted by law, including AHRQ's confidentiality statute, 42 USC 299c-3(c). We do not record your name and your child's sickle cell team will not see any of your specific information.

The discussion groups will last roughly **2 hours long**, and will be led by a professional interviewer. It will be taking place **<Day>**, **<Date>** at **<Time>**.

As a thank you, we are offering **\$50 cash** for sharing your opinions.

Would this be something that you might be interested in attending?

To ensure that the group begins on time, we ask that you arrive **AT LEAST 15 minutes** before the group begins.

**The groups will be taking place at Cincinnati Children's Hospital (Main Campus) which is located at 3333 Burnet Avenue.**

Now, may I get your contact information so that we can provide you specific (i.e. building location and room number) directions to our facility? Also, we like to have it in case we need to contact you to let you know about any changes to the groups.

**Complete Contact Information****Name:****Cell Phone:****Alt Phone:**

# Improving Sickle Cell Transitions of Care through Health Information Technology: Phase 1

## Phone Script Self-Referral (CCHMC)

Thank you for calling about the Improving Sickle Cell Transitions of Care study. With whom am I speaking? \_\_\_\_\_ (record name)

**Are you a patient with, parent/caregiver of, or a provider of someone with sickle cell?**

- Patient
- Parent/caregiver
- Provider

**IF PATIENT:** May I please speak with Mr. or Ms. [INSERT ADULT NAME FROM PATIENT'S MEDICAL RECORD].

**ONCE CONFIRMED ADULT IS ON LINE:** My name is \_\_\_\_\_ calling from Nemours Children's Clinic. <Insert Child's Name> called about discussion groups we are having for patients and parents/caregivers of patients with sickle cell disease.

**1. How did you hear about the study?**

- Flyer (Patient/Parent) – Go to Question 1a.
- Provider Referral (Patient/Parent) – Go to Question 1a
- E-mail (Provider) – Go to Page 3.

**1a. Are you calling about the focus group for parents, children or both?**

- Parent
- Child
- Both

**IF CALLING FOR CHILD OR BOTH:** How old is your child? \_\_\_\_\_

**If child is 9-13 years old:** Is this a good time for me to tell you about the study, it will only take a couple of minutes? *Read script below.*

Public reporting burden for this collection of information is estimated to average 5 minutes per response, the estimated time required to complete the survey. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: AHRQ Reports Clearance Officer Attention: PRA, Paperwork Reduction Project (0935-XXXX) AHRQ, 540 Gaither Road, Room # 5036, Rockville, MD 20850.

**If child is <9 or >13 years old:** Unfortunately, your child is not eligible to participate at this time. The focus group for children is for kids between the ages of 9 and 13. Would you be interested in learning more about the focus group for parents/caregivers?

**If yes:** *Read parent only script – Page 3*

**If no:** *Thank and terminate*

**Both Parent and Child (child = 9-13 years old):**

We are having three discussion groups to help us learn about the health care experiences parents/ caregivers of children with sickle cell and children, adolescent and young adults with sickle cell have. We would also like to learn about your experiences and/or needs with transitioning between health care systems (for example going from the emergency room to the inpatient unit or from a pediatric facility to adult facility). Also, we would like to learn more about your current use of technology (i.e. cell phones, computers, laptops, tablets, etc.) and how technology could be used to improve care. We hope that these discussion groups will help us learn more about this so in the future we can create patient-friendly tools to improve the health care experience for patients and families living with sickle cell.

We will have three discussion groups: one for parents, one for children and adolescents and one for young adults. Parents and children will not be in the same room together. We will also ask both of you to fill out a brief questionnaire (5-10 questions) about yourselves. The discussion groups will be audiotaped and someone from the study will also take notes to make sure that we don't miss anything that you tell us. Your responses will be kept confidential to the extent permitted by law. We do not record your names and your child's sickle cell team will not see any of your specific information.

The discussion groups will last roughly **2 hours**, and will be led by a professional interviewer.

The parent session is taking place **<Day>,<Date> at <Time>**.

The child and adolescent session is taking place **<Day>,<Date> at <Time>**.

The young adult session is taking place **<Day>,<Date> at <Time>**.

As a thank you, we are offering each of you a **\$50 gift card** for sharing your opinions.

Would this be something that you and/or your child might be interested in attending?

<b>YES: CONTINUE (PAGE 4)</b>	<b>NO: THANK AND TERMINATE</b>
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**Child Only:**

We are having discussion groups to help us learn about the health care experiences of kids with sickle cell disease. We would also like to learn more about what it is like when<insert kid's name> goes from the emergency room to the inpatient unit or from the hospital to home. Also, we would like to learn more about <insert kid's name> current use of technology, such as: cell phones, computers, laptops, tablets, etc.) and how technology could be used to improve care. We hope that these discussion groups will help us learn more about this so in the future we can create patient-friendly tools to improve the health care experience for patients and families living with sickle cell.

The discussion group will include other children about <insert kid's name> same age. We will also ask him/her to fill out a brief questionnaire (5-10 questions) about themselves (e.g. age,

gender, grade in school, etc.). The discussion groups will be audiotaped and someone from the study will also take notes to make sure that we don't miss anything that is said. Your responses will be kept confidential to the extent permitted by law. We do not record any names and your child's sickle cell team will not see any of his/her specific information.

The discussion groups will last roughly **2 hours**, and will be led by a professional interviewer.

The child session is taking place **<Day>,<Date> at <Time>**.

As a thank you, we are offering **\$50 cash** for <insert kid's name> sharing his/her opinions.

Would this be something that your child might be interested in attending?

<b>YES: CONTINUE (PAGE 4)</b>	<b>NO: THANK AND TERMINATE</b>
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**Parent:**

We are having a discussion group to help us learn about the health care experiences parents/caregivers of kids with sickle cell have. We would also like to learn about your experiences and/or needs with transitioning between health care systems (for example going from the emergency room to the inpatient unit or from a pediatric facility to adult facility). Also, we would like to learn more about your current use of technology (i.e. cell phones, computers, laptops, tablets, etc.) and how technology could be used to improve care. We hope that this discussion group will help us learn more about this so in the future we can create patient-friendly tools to improve the health care experience for patients and families living with sickle cell.

At the discussion group we will also ask you to fill out a brief questionnaire (5-10 questions) about yourself. The discussion groups will be audiotaped and someone from the study will also take notes to make sure that we don't miss anything that you tell us. Your responses will be kept confidential to the extent permitted by law, including AHRQ's confidentiality statute, 42 USC 299c-3(c). We do not record your name and your child's sickle cell team will not see any of your specific information.

The discussion group will last roughly **2 hours**, and will be led by a professional interviewer. It will be taking place **<Day>,<Date> at <Time>**.

As a thank you, we are offering **\$50 cash** for sharing your opinions.

Would this be something that you might be interested in attending?

<b>YES: CONTINUE (PAGE 4)</b>	<b>NO: THANK AND TERMINATE</b>
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**Provider:**

We are having a discussion group for pediatric and adult providers who care for patients with sickle cell disease. We would like to understand provider experiences and barriers with transitioning patients from pediatric to adult care. We will also discuss key barriers and information needs for providers of patients with SCD. Finally, we would like to receive your



feedback on the value and components of a possible tool that would support care transitions. The information you provide will be used to develop a technology based health data management tool.

At the discussion group we will also ask you to fill out a brief questionnaire (5-10 questions) about yourself. The discussion groups will be audiotaped and someone from the study will also take notes to make sure that we don't miss anything that you tell us. Your responses will be kept confidential to the extent permitted by law. We do not record your name and your child's sickle cell team will not see any of your specific information.

The discussion groups will last roughly **2 hours**, and will be led by a professional interviewer. It will be taking place **<Day>,<Date> at <Time>**.

As a thank you, we are offering **\$50 cash** for sharing your opinions.

Would this be something that you might be interested in attending?

<b>YES: CONTINUE</b>	<b>NO: THANK AND TERMINATE</b>
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To ensure that the group begins on time, we ask that you arrive **AT LEAST 15 minutes** before the group begins.

**The groups will be taking place at Cincinnati Children's Hospital (Main Campus) which is located at 3333 Burnet Avenue.**

Now, may I get your contact information so that we can provide you specific (i.e. building location and room number) directions to our facility? Also, we like to have it in case we need to contact you to let you know about any changes to the groups.

**Complete Contact Information**

**Name:**

**Cell Phone:**

**Alt Phone:**

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**Improving Sickle Cell Transitions of Care through Health Information Technology: Phase 1**

***Phone Script Opt Out Letter (Nemours)***

**IF LEAVING MESSAGE:** This message is for Mr. or Ms. **[INSERT ADULT NAME FROM PATIENT’S MEDICAL RECORD]** regarding the letter you received about discussion groups we are conducting at Nemours Children’s Clinic. My name is \_\_\_\_\_. Please contact us at 904-\_\_\_\_\_ at your earliest convenience. Thank you.

**IF SOMEONE ANSWERS:** Hello, may I please speak with Mr. or Ms. **[INSERT ADULT NAME FROM PATIENT’S MEDICAL RECORD]**.

**ONCE CONFIRMED ADULT IS ON LINE:** My name is \_\_\_\_\_ calling from Nemours Children’s Clinic. A week ago we sent you a letter from Dr. \_\_\_\_\_ about discussion groups that we will be having for patients and parents seen in our Sickle Cell Center. Do you remember seeing that?

**NO:** I’m sorry you didn’t receive the letter. We sent it to (*street name*) – is that still correct for your family? If yes, continue. If no, record answer.

Is this a good time for me to tell you about this new study, it will only take a couple of minutes?

(If the person indicates they would like to see the letter first, confirm their full address and tell them we will resend and will call back in one week.)

<b>YES: CONTINUE</b> ( <i>Age Appropriate</i> )	<b>NO: SCHEDULE DAY/TIME TO CALL BACK</b>
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**If Contacting for Both Parent and Child (child = 14-17 years old):**

We are having discussion groups to help us learn about the health care experiences parents/ caregivers of kids with sickle cell and kids with sickle cell have. We would also like to learn about your experiences and/or needs with transitioning between health care systems (for example going from the emergency room to the inpatient unit or from a pediatric facility to adult facility). Also, we would like to learn more about your current use of technology (i.e. cell phones, computers, laptops, tablets, etc.) and how technology could be used to improve care. We hope that these discussion groups will help us learn more about this so in the future we can create patient-friendly tools to improve the health care experience for patients and families living with sickle cell.

We are having discussion groups to help us learn about the health care experiences parents/ caregivers of kids with sickle cell and kids with sickle cell have. We would also like to learn about your experiences and/or needs with transitioning between health care systems (for example going from the emergency room to the inpatient unit or from a pediatric facility to adult facility). Also, we would like to learn more about your current use of technology (i.e. cell phones, computers, laptops, tablets, etc.) and how technology could be used to improve care. We hope that these discussion groups will help us learn more about this so in the future we can create patient-friendly tools to improve the health care experience for patients and families living with sickle cell.

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Parents and children will not be in the same room together. We will also ask you to fill out a brief questionnaire (5-10 questions) about yourselves. The discussion groups will be audiotaped and someone from the study will also take notes to make sure that we don’t miss anything that you tell us. Your responses will be kept confidential to the extent permitted by law, including AHRQ’s confidentiality statute, 42 USC 299c-3(c). We do not record your names and your child’s sickle cell team will not see any of your specific information.

The discussion groups will last roughly **2 hours long**, and will be led by a professional interviewer.

The parent session is taking place <Day>, <Date> at <Time>.

The child session is taking place <Day>, <Date> at <Time>.

As a thank you, we are offering **\$50 cash** for sharing your opinions.

Would this be something that you and/or your child might be interested in attending?

<b>YES: CONTINUE (PAGE 3)</b>	<b>NO: THANK AND TERMINATE</b>
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**If Contacting for Parent Only:**

We are having a discussion group to help us learn about the health care experiences parents/caregivers of kids with sickle cell have. We would also like to learn about your experiences and/or needs with transitioning between health care systems (for example going from the emergency room to the inpatient unit or from a pediatric facility to adult facility). Also, we would like to learn more about your current use of technology (i.e. cell phones, computers, laptops, tablets, etc.) and how technology could be used to improve care. We hope that this discussion group will help us learn more about this so in the future we can create patient-friendly tools to improve the health care experience for patients and families living with sickle cell.

At the discussion group we will also ask you to fill out a brief questionnaire (5-10 questions) about yourself. The discussion groups will be audiotaped and someone from the study will also take notes to make sure that we don't miss anything that you tell us. Your responses will be kept confidential to the extent permitted by law, including AHRQ's confidentiality statute, 42 USC 299c-3(c). We do not record your name and your child's sickle cell team will not see any of your specific information.

The discussion groups will last roughly **2 hours long**, and will be led by a professional interviewer. It will be taking place <Day>, <Date> at <Time>.

As a thank you, we are offering **\$50 cash** for sharing your opinions.

Would this be something that you might be interested in attending?

<b>YES: CONTINUE (PAGE 3)</b>	<b>NO: THANK AND TERMINATE</b>
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To ensure that the group begins on time, we ask that you arrive **AT LEAST 15 minutes** before the group begins.

**The groups will be taking place at Nemours Children's Clinic (Jacksonville Campus) which is located at 807 Children's Way.**

Now, may I get your contact information so that we can provide you specific (i.e. building location and room number) directions to our facility? Also, we like to have it in case we need to contact you to let you know about any changes to the groups.

**Complete Contact Information**

**Name:**

**Cell Phone:**

**Alt Phone:**

## Improving Sickle Cell Transitions of Care through Health Information Technology: Phase 1

### *Phone Script Self-Referral (Nemours)*

Thank you for calling about the Improving Sickle Cell Transitions of Care study. With whom am I speaking? \_\_\_\_\_ (record name)

**Are you a patient with, parent/caregiver of, or a provider of someone with sickle cell?**

- Patient
- Parent/caregiver
- Provider

**IF PATIENT:** May I please speak with Mr. or Ms. [INSERT ADULT NAME FROM PATIENT'S MEDICAL RECORD].

**ONCE CONFIRMED ADULT IS ON LINE:** My name is \_\_\_\_\_ calling from Nemours Children's Clinic. <Insert Child's Name> called about discussion groups we are having for patients and parents/caregivers of patients with sickle cell disease.

**1. How did you hear about the study?**

- Flyer (Patient/Parent) – Go to Question 1a.
- Provider Referral (Patient/Parent) – Go to Question 1a
- E-mail (Provider) – Go to Page 3.

**1a. Are you calling about the focus group for parents, children or both?**

- Parent
- Child
- Both

**IF CALLING FOR CHILD OR BOTH:** How old is your child? \_\_\_\_\_

**If child is 14-17 years old:** Is this a good time for me to tell you about the study, it will only take a couple of minutes? *Read script below.*

Public reporting burden for this collection of information is estimated to average 5 minutes per response, the estimated time required to complete the survey. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: AHRQ Reports Clearance Officer Attention: PRA, Paperwork Reduction Project (0935-XXXX) AHRQ, 540 Gaither Road, Room # 5036, Rockville, MD 20850.

**If child is <14 or >17 years old:** Unfortunately, your child is not eligible to participate at this time. The focus group for children is for kids between the ages of 14 and 17. Would you be interested in learning more about the focus group for parents/caregivers?

**If yes:** *Read parent only script – Page 3*

**If no:**            *Thank and terminate*

**Both Parent and Child (child = 14-17 years old):**

We are having discussion groups to help us learn about the health care experiences parents/ caregivers of kids with sickle cell and kids with sickle cell have. We would also like to learn about your experiences and/or needs with transitioning between health care systems (for example going from the emergency room to the inpatient unit or from a pediatric facility to adult facility). Also, we would like to learn more about your current use of technology (i.e. cell phones, computers, laptops, tablets, etc.) and how technology could be used to improve care. We hope that these discussion groups will help us learn more about this so in the future we can create patient-friendly tools to improve the health care experience for patients and families living with sickle cell.

We will have two discussion groups: one for parents and one for kids that are about your child’s same age. Parents and children will not be in the same room together. We will also ask both of you to fill out a brief questionnaire (5-10 questions) about yourselves. The discussion groups will be audiotaped and someone from the study will also take notes to make sure that we don’t miss anything that you tell us. Your responses will be kept confidential to the extent permitted by law, including AHRQ’s confidentiality statute, 42 USC 299c-3(c). We do not record your names and your child’s sickle cell team will not see any of your specific information.

The discussion groups will last roughly **2 hours**, and will be led by a professional interviewer.

The parent session is taking place **<Day>**, **<Date>** at **<Time>**.

The child session is taking place **<Day>**, **<Date>** at **<Time>**.

As a thank you, we are offering each of you **\$50 cash** for sharing your opinions.

Would this be something that you and/or your child might be interested in attending?

<b>YES: CONTINUE (PAGE 4)</b>	<b>NO: THANK AND TERMINATE</b>
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**Child Only:**

We are having discussion groups to help us learn about the health care experiences of kids with sickle cell disease. We would also like to learn more about what it is like when *<insert kid’s name>* goes from the emergency room to the inpatient unit or from the hospital to home. Also, we would like to learn more about *<insert kid’s name>* current use of technology, such as: cell phones, computers, laptops, tablets, etc.) and how technology could be used to improve care. We hope that these discussion groups will help us learn more about this so in the future we can create patient-friendly tools to improve the health care experience for patients and families living with sickle cell.

The discussion group will include other children about *<insert kid’s name>* same age. We will also ask him/her to fill out a brief questionnaire (5-10 questions) about themselves (e.g. age, gender, grade in school, etc.). The discussion groups will be audiotaped and someone from the study will also take notes to make sure that we don’t miss anything that is said. Your responses

will be kept confidential to the extent permitted by law, including AHRQ’s confidentiality statute, 42 USC 299c-3(c). We do not record any names and your child’s sickle cell team will not see any of his/her specific information.

The discussion groups will last roughly **2 hours**, and will be led by a professional interviewer.

The child session is taking place **<Day>**, **<Date>** at **<Time>**.

As a thank you, we are offering **\$50 cash** for <insert kid’s name> sharing his/her opinions.

Would this be something that your child might be interested in attending?

<b>YES: CONTINUE (PAGE 4)</b>	<b>NO: THANK AND TERMINATE</b>
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**Parent Only:**

We are having a discussion group to help us learn about the health care experiences parents/caregivers of kids with sickle cell have. We would also like to learn about your experiences and/or needs with transitioning between health care systems (for example going from the emergency room to the inpatient unit or from a pediatric facility to adult facility). Also, we would like to learn more about your current use of technology (i.e. cell phones, computers, laptops, tablets, etc.) and how technology could be used to improve care. We hope that this discussion group will help us learn more about this so in the future we can create patient-friendly tools to improve the health care experience for patients and families living with sickle cell.

At the discussion group we will also ask you to fill out a brief questionnaire (5-10 questions) about yourself. The discussion groups will be audiotaped and someone from the study will also take notes to make sure that we don’t miss anything that you tell us. Your responses will be kept confidential to the extent permitted by law, including AHRQ’s confidentiality statute, 42 USC 299c-3(c). We do not record your name and your child’s sickle cell team will not see any of your specific information.

The discussion group will last roughly **2 hours**, and will be led by a professional interviewer. It will be taking place **<Day>**, **<Date>** at **<Time>**.

As a thank you, we are offering **\$50 cash** for sharing your opinions.

Would this be something that you might be interested in attending?

<b>YES: CONTINUE (PAGE 4)</b>	<b>NO: THANK AND TERMINATE</b>
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**Provider:**

We are having a discussion group for pediatric and adult providers who care for patients with sickle cell disease. We would like to understand provider experiences and barriers with transitioning patients from pediatric to adult care. We will also discuss key barriers and information needs for providers of patients with SCD. Finally, we would like to receive your feedback on the value and components of a possible tool that would support care transitions. The information you provide will be used to develop a technology based health data management tool.

At the discussion group we will also ask you to fill out a brief questionnaire (5-10 questions) about yourself. The discussion groups will be audiotaped and someone from the study will also take notes to make sure that we don't miss anything that you tell us. Your responses will be kept confidential to the extent permitted by law, including AHRQ's confidentiality statute, 42 USC 299c-3(c). We do not record your name and your child's sickle cell team will not see any of your specific information.

The discussion groups will last roughly **2 hours**, and will be led by a professional interviewer. It will be taking place **<Day>**, **<Date>** at **<Time>**.

As a thank you, we are offering **\$50 cash** for sharing your opinions.

Would this be something that you might be interested in attending?

<b>YES: CONTINUE</b>	<b>NO: THANK AND TERMINATE</b>
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**To ensure that the group begins on time, we ask that you arrive AT LEAST 15 minutes before the group begins.**

**The groups will be taking place at Nemours Children's Clinic (Jacksonville Campus) which is located at 807 Children's Way.**

Now, may I get your contact information so that we can provide you specific (i.e. building location and room number) directions to our facility? Also, we like to have it in case we need to contact you to let you know about any changes to the groups.

**Complete Contact Information**

**Name:**

**Cell Phone:**

**Alt Phone:**

Form Approved OMB No. 0935-XXXX Exp. Date XX/XX/20XX
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**Improving Sickle Cell Transitions of Care through Health Information Technology: Phase 1**

***Phone Script for Opt Out Letter (CNMC)***

**IF LEAVING MESSAGE:** This message is for Mr. or Ms. **[INSERT ADULT NAME FROM PATIENT'S MEDICAL RECORD]** regarding the letter you received about discussion groups



we are conducting at Nemours Children’s Clinic. My name is \_\_\_\_\_. Please contact us at 904-\_\_\_\_\_ at your earliest convenience. Thank you.

**IF SOMEONE ANSWERS:** Hello, may I please speak with Mr. or Ms. **[INSERT ADULT NAME FROM PATIENT’S MEDICAL RECORD]**.

**ONCE CONFIRMED ADULT IS ON LINE:** My name is \_\_\_\_\_ calling from Nemours Children’s Clinic. A week ago we sent you a letter from Dr. \_\_\_\_\_ about discussion groups that we will be having for patients and parents seen in our Sickle Cell Center. Do you remember seeing that?

**NO:** I’m sorry you didn’t receive the letter. We sent it to (*street name*) – is that still correct for your family? If yes, continue. If no, record answer.

Is this a good time for me to tell you about this new study, it will only take a couple of minutes?

(If the person indicates they would like to see the letter first, confirm their full address and tell them we will resend and will call back in one week.)

<b>YES: CONTINUE</b> ( <i>Age Appropriate</i> )	<b>NO: SCHEDULE DAY/TIME TO CALL BACK</b>
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**If Contacting for Both Parent and Child (child = 9-22 years old):**

We are having discussion groups to help us learn about the health care experiences parents/ caregivers of kids with sickle cell and kids with sickle cell have. We would also like to learn about your experiences and/or needs with transitioning between health care systems (for example going from the emergency room to the inpatient unit or from a pediatric facility to adult facility). Also, we would like to learn more about your current use of technology (i.e. cell phones, computers, laptops, tablets, etc.) and how technology could be used to improve care. We hope that these discussion groups will help us learn more about this so in the future we can create patient-friendly tools to improve the health care experience for patients and families living with sickle cell.

We sam you to fill out a brief questionnaire (5-10 questions) about yourselves. The discussion groups will be audiotaped and someone from the study will also take notes to make sure that we don’t miss anything that you tell us. Your responses will be kept confidential to the extent permitted by law, including AHRQ’s confidentiality statute, 42 USC 299c-3(c). We do not record your names and your child’s sickle cell team will not see any of your specific information.

Public reporting burden for this collection of information is estimated to average 5 minutes per response, the estimated time required to complete the survey. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: AHRQ Reports Clearance Officer Attention: PRA, Paperwork Reduction Project (0935-XXXX) AHRQ, 540 Gaither Road, Room # 5036, Rockville, MD 20850.

The discussion groups will last roughly **2 hours long**, and will be led by a professional interviewer.

The parent session is taking place <Day>, <Date> at <Time>.

The child session is taking place <Day>, <Date> at <Time>.

As a thank you, we are offering **\$50 cash** for sharing your opinions.

Would this be something that you and/or your child might be interested in attending?

**YES: CONTINUE (PAGE 3)**

**NO: THANK AND TERMINATE**

### **If Contacting for Parent Only:**

We are having a discussion group to help us learn about the health care experiences parents/caregivers of kids with sickle cell have. We would also like to learn about your experiences and/or needs with transitioning between health care systems (for example going from the emergency room to the inpatient unit or from a pediatric facility to adult facility). Also, we would like to learn more about your current use of technology (i.e. cell phones, computers, laptops, tablets, etc.) and how technology could be used to improve care. We hope that this discussion group will help us learn more about this so in the future we can create patient-friendly tools to improve the health care experience for patients and families living with sickle cell.

At the discussion group we will also ask you to fill out a brief questionnaire (5-10 questions) about yourself. The discussion groups will be audiotaped and someone from the study will also take notes to make sure that we don't miss anything that you tell us. Your responses will be kept confidential to the extent permitted by law, including AHRQ's confidentiality statute, 42 USC 299c-3(c). We do not record your name and your child's sickle cell team will not see any of your specific information.

The discussion groups will last roughly **2 hours long**, and will be led by a professional interviewer. It will be taking place <Day>, <Date> at <Time>.

As a thank you, we are offering **\$50 cash** for sharing your opinions.

Would this be something that you might be interested in attending?

**YES: CONTINUE (PAGE 3)**

**NO: THANK AND TERMINATE**

### **If Contacting Young Adult (ages 18 or older):**

We are having a discussion group to help us learn about the health care experiences of young adults with sickle cell disease. We would also like to learn about your experiences and/or needs with transitioning between health care systems (for example going from the emergency room to the inpatient unit or from a pediatric facility to adult facility). Also, we would like to learn more about your current use of technology (i.e. cell phones, computers, laptops, tablets, etc.) and how technology could be used to improve care. We hope that this discussion group will help us learn more about this so in the future we can create patient-friendly tools to improve the health care experience for patients and families living with sickle cell.

At the discussion group we will also ask you to fill out a brief questionnaire (5-10 questions) about yourself. The discussion groups will be audiotaped and someone from the study will also take notes to make sure that we don't miss anything that you tell us. Your responses will be kept confidential to the extent permitted by law. We do not record your name and your child's sickle cell team will not see any of your specific information.

The discussion groups will last roughly **2 hours long**, and will be led by a professional interviewer. It will be taking place **<Day>,<Date> at <Time>**.

As a thank you, we are offering **\$50 gift card** for sharing your opinions.

Would this be something that you might be interested in attending?

<b>YES: CONTINUE (PAGE 3)</b>	<b>NO: THANK AND TERMINATE</b>
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To ensure that the group begins on time, we ask that you arrive **AT LEAST 15 minutes** before the group begins.

**The groups will be taking place at the Sickle Cell Clinic on the 4<sup>th</sup> floor of the East Tower of Children's National Medical Center which is located at 111 Michigan Ave, NW, Washington, DC.**

Now, may I get your contact information so that we can provide you specific (i.e. building location and room number) directions to our facility? Also, we like to have it in case we need to contact you to let you know about any changes to the groups.

**Complete Contact Information**

**Name:**

**Cell Phone:**

**Alt Phone:**

# Improving Sickle Cell Transitions of Care through Health Information Technology: Phase 1

## Phone Script Self Referral (CMNC)

Thank you for calling about the Improving Sickle Cell Transitions of Care study. With whom am I speaking? \_\_\_\_\_ (record name)

**Are you a patient with, parent/caregiver of, or a provider of someone with sickle cell?**

- Patient
- Parent/caregiver
- Provider

**IF PATIENT:** May I please speak with Mr. or Ms. [INSERT ADULT NAME FROM PATIENT’S MEDICAL RECORD].

**ONCE CONFIRMED ADULT IS ON LINE:** My name is \_\_\_\_\_ calling from Nemours Children’s Clinic. <Insert Child’s Name> called about discussion groups we are having for patients and parents/caregivers of patients with sickle cell disease.

**1. How did you hear about the study?**

- Flyer (Patient/Parent) – Go to Question 1a.
- Provider Referral (Patient/Parent) – Go to Question 1a
- E-mail (Provider) – Go to Page 3.

**1a. Are you calling about the focus group for parents, children or both?**

- Parent
- Child
- Both

**IF CALLING FOR CHILD OR BOTH:** How old is your child? \_\_\_\_\_

**If child is 9-13 years old:** Is this a good time for me to tell you about the study, it will only take a couple of minutes? *Read script below.*

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this time. The focus group for children is for kids between the ages of 9 and 13. Would you be interested in learning more about the focus group for parents/caregivers?

**If yes:** *Read parent only script – Page 3*

**If no:** *Thank and terminate*

**Both Parent and Child (child = 9-22 years old):**

We are having three discussion groups to help us learn about the health care experiences parents/ caregivers of children with sickle cell and children, adolescent and young adults with sickle cell have. We would also like to learn about your experiences and/or needs with transitioning between health care systems (for example going from the emergency room to the inpatient unit or from a pediatric facility to adult facility). Also, we would like to learn more about your current use of technology (i.e. cell phones, computers, laptops, tablets, etc.) and how technology could be used to improve care. We hope that these discussion groups will help us learn more about this so in the future we can create patient-friendly tools to improve the health care experience for patients and families living with sickle cell.

We will have three discussion groups: one for parents, one for children and adolescents and one for young adults. Parents and children will not be in the same room together. We will also ask both of you to fill out a brief questionnaire (5-10 questions) about yourselves. The discussion groups will be audiotaped and someone from the study will also take notes to make sure that we don't miss anything that you tell us. Your responses will be kept confidential to the extent permitted by law. We do not record your names and your child's sickle cell team will not see any of your specific information.

The discussion groups will last roughly **2 hours**, and will be led by a professional interviewer.

The parent session is taking place **<Day>,<Date> at <Time>**.

The child and adolescent session is taking place **<Day>,<Date> at <Time>**.

The young adult session is taking place **<Day>,<Date> at <Time>**.

As a thank you, we are offering each of you a **\$50 gift card** for sharing your opinions.

Would this be something that you and/or your child might be interested in attending?

<b>YES: CONTINUE (PAGE 4)</b>	<b>NO: THANK AND TERMINATE</b>
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**Child/Adolescent Only:**

We are having discussion groups to help us learn about the health care experiences of kids with sickle cell disease. We would also like to learn more about what it is like when<insert kid's name> goes from the emergency room to the inpatient unit or from the hospital to home. Also, we would like to learn more about <insert kid's name> current use of technology, such as: cell phones, computers, laptops, tablets, etc.) and how technology could be used to improve care. We hope that these discussion groups will help us learn more about this so in the future we can create patient-friendly tools to improve the health care experience for patients and families living with sickle cell.

The discussion group will include other children about <insert kid's name> same age. We will also ask him/her to fill out a brief questionnaire (5-10 questions) about themselves (e.g. age,

gender, grade in school, etc.). The discussion groups will be audiotaped and someone from the study will also take notes to make sure that we don't miss anything that is said. Your responses will be kept confidential to the extent permitted by law. We do not record any names and your child's sickle cell team will not see any of his/her specific information.

The discussion groups will last roughly **2 hours**, and will be led by a professional interviewer.

The child session is taking place **<Day>,<Date> at <Time>**.

As a thank you, we are offering **\$50 cash** for <insert kid's name> sharing his/her opinions.

Would this be something that your child might be interested in attending?

<b>YES: CONTINUE (PAGE 4)</b>	<b>NO: THANK AND TERMINATE</b>
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**Parent:**

We are having a discussion group to help us learn about the health care experiences parents/caregivers of kids with sickle cell have. We would also like to learn about your experiences and/or needs with transitioning between health care systems (for example going from the emergency room to the inpatient unit or from a pediatric facility to adult facility). Also, we would like to learn more about your current use of technology (i.e. cell phones, computers, laptops, tablets, etc.) and how technology could be used to improve care. We hope that this discussion group will help us learn more about this so in the future we can create patient-friendly tools to improve the health care experience for patients and families living with sickle cell.

At the discussion group we will also ask you to fill out a brief questionnaire (5-10 questions) about yourself. The discussion groups will be audiotaped and someone from the study will also take notes to make sure that we don't miss anything that you tell us. Your responses will be kept confidential to the extent permitted by law, including AHRQ's confidentiality statute, 42 USC 299c-3(c). We do not record your name and your child's sickle cell team will not see any of your specific information.

The discussion group will last roughly **2 hours**, and will be led by a professional interviewer. It will be taking place **<Day>,<Date> at <Time>**.

As a thank you, we are offering **\$50 cash** for sharing your opinions.

Would this be something that you might be interested in attending?

<b>YES: CONTINUE (PAGE 4)</b>	<b>NO: THANK AND TERMINATE</b>
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**Young Adult Patient (aged 18 and over) Only:**

We are having a discussion group to help us learn about the health care experiences of young adults with sickle cell disease. We would also like to learn about your experiences and/or needs with transitioning between health care systems (for example going from the emergency room to the inpatient unit or from a pediatric facility to adult facility). Also, we would like to learn more about your current use of technology (i.e. cell phones, computers, laptops, tablets, etc.) and how

technology could be used to improve care. We hope that this discussion group will help us learn more about this so in the future we can create patient-friendly tools to improve the health care experience for patients and families living with sickle cell.

At the discussion group we will also ask you to fill out a brief questionnaire (5-10 questions) about yourself. The discussion groups will be audiotaped and someone from the study will also take notes to make sure that we don't miss anything that you tell us. Your responses will be kept confidential to the extent permitted by law. We do not record your name and your sickle cell team will not see any of your specific information.

The discussion group will last roughly **2 hours**, and will be led by a professional interviewer. It will be taking place **<Day>,<Date> at <Time>**.

As a thank you, we are offering **\$50 cash** for sharing your opinions.

Would this be something that you might be interested in attending?

<b>YES: CONTINUE</b>	<b>NO: THANK AND TERMINATE</b>
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**Provider:**

We are having a discussion group for pediatric and adult providers who care for patients with sickle cell disease. We would like to understand provider experiences and barriers with transitioning patients from pediatric to adult care. We will also discuss key barriers and information needs for providers of patients with SCD. Finally, we would like to receive your feedback on the value and components of a possible tool that would support care transitions. The information you provide will be used to develop a technology based health data management tool.

At the discussion group we will also ask you to fill out a brief questionnaire (5-10 questions) about yourself. The discussion groups will be audiotaped and someone from the study will also take notes to make sure that we don't miss anything that you tell us. Your responses will be kept confidential to the extent permitted by law. We do not record your name and your child's sickle cell team will not see any of your specific information.

The discussion groups will last roughly **2 hours**, and will be led by a professional interviewer. It will be taking place **<Day>,<Date> at <Time>**.

As a thank you, we are offering **\$50 cash** for sharing your opinions.

Would this be something that you might be interested in attending?

<b>YES: CONTINUE</b>	<b>NO: THANK AND TERMINATE</b>
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**To ensure that the group begins on time, we ask that you arrive AT LEAST 15 minutes before the group begins.**

**The groups will be taking place at the Sickle Cell Clinic on the 4<sup>th</sup> floor of the East Tower of Children's National Medical Center which is located at 111 Michigan Ave, NW, Washington, DC.**

Now, may I get your contact information so that we can provide you specific (i.e. building location and room number) directions to our facility? Also, we like to have it in case we need to contact you to let you know about any changes to the groups.

**Complete Contact Information**

**Name:**

**Cell Phone:**

**Alt Phone:**



**Sickle Cell Adolescent Transition – Patients 18 and Older**  
***Phone Script Screener – Summer 2013 (CNMC)***

**IF LEAVING MESSAGE:** This message is for Mr. or Ms. [INSERT PATIENT NAME FROM SAMPLE] to discuss issues affecting young adults with sickle cell disease. My name is \_\_\_\_\_. Please contact us at (202)476-1333 at your earliest convenience. Thank you.

**IF SOMEONE ANSWERS:** Hello, may I please speak with Mr. or Ms. [INSERT PATIENT NAME FROM SAMPLE].

**ONCE CONFIRMED PATIENT IS ON LINE:** My name is \_\_\_\_\_. We are calling on behalf of **Children's National Medical Center** because you have received sickle cell care at Children's National.

We are conducting discussion groups with adolescents and young adults with sickle cell disease and would like to invite you to come to our offices to participate. We are thinking of developing an app, or something you can use on your phone, on your iPad, or some other device that hasn't even been invented yet – that will help you live better with sickle cell disease.

We are most interested in hearing about your experiences with health care and your ideas about what would make a good app for people with sickle cell disease during care transitions.

All information that is discussed will be held strictly confidential and you will never be mentioned by name.

Would this be something that you might be interested in attending or hearing more about?

<b>YES: CONTINUE</b>	<b>NO: THANK AND TERMINATE</b>
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The session is taking place \_\_\_\_\_ [INSERT DATE AND TIME OF FOCUS GROUP MEETING]. There will be other adolescents and young adults there and everyone will be part of the group discussion. It will last approximately 2 hours and will be led by a professional interviewer.

And as a thank you, we are offering a **\$50 gift card** for sharing your opinions. We will also be able to help with reimbursement for transportation if needed.

Would this date and time work for you?

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**YES: CONTINUE**

**NO: THANK AND TERMINATE**

With your permission, we'd like to schedule you as participating on **[INSERT DATE AND TIME OF FOCUS GROUP MEETING]**.. We would like to send you written information with directions, verifying the time and date of the meeting, and numbers to call if you need to reschedule or can't make it. Would that be ok?

What is the best address to send that information to? **[RECORD ADDRESS]**

Also, is there a phone number where we can reach you in case we need to contact you to let you know about any changes to the groups?

Do you use email? Would you like this information sent by email to you as well?

### **Complete Contact Information**

**Name:**

**Address:**

**Cell Phone:**

**Alt Phone:**

**Email:**

**One last thing, Do you think one of your parents may be interested in participating in a parent discussion group on the same topic?**

**[If yes, are they available now to speak with me? If yes, Utilize the parent telephone recruitment script.**

**If no, collect their contact information.]**

**Before we say goodbye, are there any questions I can answer for you? [record questions, if you cannot answer say, that is a good questions, I don't have the answer for you right now. With your permission, I will look into it and give you a call back in the next 1-2 days. Would that be ok?]**

**Thank you so much for taking the time to speak with me. We look forward to seeing you on [date, time, place]. We ask that you arrive AT LEAST 15 minutes before the group begins so we can get everyone settled in and started on time.**

**REMINDER:** If you wear glasses or contacts please make sure to wear or bring them to the groups as you may be looking at materials during the session.

**Please also bring picture ID for checking into the groups. We will be sending all of this information to you as well.**

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The groups will be taking place at the Sickie Cell Clinic on the 4<sup>th</sup> floor of the East Tower of Children's National Medical Center which is located at 111 Michigan Ave, NW, Washington, DC.

Form Approved OMB No. 0935-XXXX Exp. Date XX/XX/20XX
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**Sickle Cell Adolescent Transition – Patients 18 and Older**  
***Telephone Reminder Script – Summer 2013 (CNMC)***

**IF LEAVING MESSAGE:** This message is for Mr. or Mrs. [INSERT ADULT NAME FROM SAMPLE] to remind you about the focus group meeting to discuss about issues affecting young adults with sickle cell disease that we previously talked about. The session is taking place \_\_\_\_\_ [INSERT DATE AND TIME OF FOCUS GROUP MEETING]. It will last approximately 2 hours. As a thank you, we are offering \$50 cash for sharing your opinions. My name is \_\_\_\_\_. Please contact us at (202)476-1333 if you have questions or concerns. Otherwise, we will see on in the sickle cell clinic on \_\_\_\_\_ [INSERT DATE AND TIME OF FOCUS GROUP MEETING]. Thank you.

**IF SOMEONE ANSWERS:** Hello, may I please speak with Mr. or Ms. [INSERT ADULT NAME FROM SAMPLE].

**ONCE CONFIRMED ADULT IS ON LINE:** My name is \_\_\_\_\_. I'm calling to remind you about the focus group meeting to discuss about issues affecting young adults with sickle cell disease that we previously talked about. The session is taking place \_\_\_\_\_ [INSERT DATE AND TIME OF FOCUS GROUP MEETING]. It will last approximately 2 hours. As a thank you, we are offering \$50 cash for sharing your opinions. Please contact us at (202)476-1333 if you have questions or concerns. Otherwise, we will see on in the sickle cell clinic on \_\_\_\_\_ [INSERT DATE AND TIME OF FOCUS GROUP MEETING]. Thank you.

All information that is discussed will be held strictly confidential and you will never be mentioned by name.

Public reporting burden for this collection of information is estimated to average 5 minutes per response, the estimated time required to complete the survey. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: AHRQ Reports Clearance Officer Attention: PRA, Paperwork Reduction Project (0935-XXXX) AHRQ, 540 Gaither Road, Room # 5036, Rockville, MD 20850.
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## Sickle Cell Adolescent Transition – Summer 2013 Telephone Reminder Script – Parent (CNMC)

**DO NOT LIST CHILD NAME until confirmed adult is on the line.  
DO NOT LIST CHILD NAME in any form of message, whether on a voicemail or with another person  
in household.**

**IF LEAVING MESSAGE:** This message is for Mr. or Mrs. [INSERT ADULT NAME FROM SAMPLE] to remind you about the focus group meeting to discuss about issues affecting children and adolescents with sickle cell disease that we previously talked about. My name is \_\_\_\_\_. The session is taking place \_\_\_\_\_ [INSERT DATE AND TIME OF FOCUS GROUP MEETING]. It will last approximately 2 hours. As a thank you, we are offering **\$50 cash** for sharing your opinions. Please contact us at (202)476-1333 if you have questions or concerns. Otherwise, we will see on in the sickle cell clinic on \_\_\_\_\_ [INSERT DATE AND TIME OF FOCUS GROUP MEETING]. Thank you.

**IF SOMEONE ANSWERS:** Hello, may I please speak with Mr. or Ms. [INSERT ADULT NAME FROM SAMPLE].

**ONCE CONFIRMED ADULT IS ON LINE:** My name is \_\_\_\_\_. I'm calling to remind you about the focus group meeting to discuss about issues affecting children and adolescents with sickle cell disease that we previously talked about. The session is taking place \_\_\_\_\_ [INSERT DATE AND TIME OF FOCUS GROUP MEETING]. It will last approximately 2 hours. As a thank you, we are offering **\$50 cash** for sharing your opinions. Please contact us at (202)476-1333 if you have questions or concerns. Otherwise, we will see on in the sickle cell clinic on \_\_\_\_\_ [INSERT DATE AND TIME OF FOCUS GROUP MEETING]. Thank you.

All information that is discussed will be held strictly confidential and you will never be mentioned by name.

Public reporting burden for this collection of information is estimated to average 5 minutes per response, the estimated time required to complete the survey. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: AHRQ Reports Clearance Officer Attention: PRA, Paperwork Reduction Project (0935-XXXX) AHRQ, 540 Gaither Road, Room # 5036, Rockville, MD 20850.