

ATTACHMENT H: WRITTEN INFORMED CONSENT DOCUMENTS

Sickle Cell Disease Treatment Demonstration Program

(DELETE THIS AND ALL OTHER INSTRUCTIONS IN ITALICS)

Name of Youth: _____

Name of Parent/Legal Guardian: _____

My name is _____ and I work for a company called *insert name of clinic or FQHC*. We are talking to youths about Sickle Cell Disease. The questions are about your health and the health care that you receive from doctors and others *(If applicable: Some of the questions may make you feel sad or uncomfortable)*.

_____ has given permission for you to talk with me about these things. If it is okay with you, I would like to ask you some questions.

You can decide not to participate. You can refuse to answer any question. *(If applicable: Your refusal would not affect any benefits that you may receive.)* You also have the right to stop the interview at any time

Anything you tell me is private. No one outside of the research team, including your parents, will know your answers. *(If applicable: There is one exception: If I learn during our talk that your life or health is in danger, I will tell someone whose job it is to see that you are safe and protected.)*

Our talk today will last no longer than 30 minutes. You will be given a copy of this consent form to keep.

(If applicable: We may have to ask you some more questions in the future).

May I ask you the questions?

- Child agrees
 - Child does not agree
 - Child did not appear to understand explanation
-

Signature/Mark of Child

Signature of Interviewer

Date

RTI Project Number _____

RTI IRB Approval Date _____

Assent Form Version Date _____