

ISAAC Patient Recruitment Scripts (Version 1, 5/9/17)

Includes:

ISAAC Project In-Clinic Recruitment Script

ISAAC Project Patient Interview Screener

ISAAC Project - Patient In-Clinic Recruitment Script

Study investigator will sit in the Sickle Cell Disease Center waiting room at UIC, and recruit individuals for participation within the study. Investigator approach to potential participants is as follows.

Hello, my name is <<name>>, and I'm a researcher on a project about Sickle Cell Disease called ISAAC. ISAAC stands for Improving Sickle cell care for Adults and Adolescents in Chicago. We are interested in learning more about what life is like for people living with and managing Sickle Cell Disease in everyday life, like home, work or school. We are looking for participants between the age of 15 and 44 who have diagnosed Sickle Cell Disease or caregivers of adult patients with cognitive impairments. We would like to interview patients or caregivers of patients. We will ask questions about living with Sickle Cell and personal experiences getting medical care for sickle cell. We're offering participants \$50 for an hour and a half of their time. Are you someone with Sickle Cell disease or a caregiver that would be interested in this project? If so, are you between the ages of 15 and 44 or are you a caregiver of an adult patient with cognitive impairments? An adult for this study is anyone over the age of 19.

If patient says "Yes," the investigator will explain the following. If patient says, "No," the investigator will thank them for their time and leave them with a patient flyer in case they change their minds.

Great, thank you so much.

Before we talk more, it's important to know a couple more things about the project.

First, your care (or the care of the patient you assist) will not change at UIC's clinic or other UIC departments if you decide not to participate. We will not tell your doctors (or the doctors who see the patient you assist) if you participated or not. You can also change your mind about participating at any time.

Second, if you decide to participate, we will keep all of your information confidential. I am part of the research team at the IIT Institute of Design. IIT is doing all the patient interviews. So only the 6 people at IIT will know that it was you who completed the interview. With your permission, we would like to audiotape the interview. This helps us stay true to what people say to us. However, we will not include any information in that recording that can identify you. Doctors at UIC and Sinai, as well as sickle cell researchers at sites around the country, may see the final results of the study, but they will not be able to tell which patients participated

The results of the interviews will not directly benefit you; however, they will be used to develop patient programs and tools that could improve care management for all Sickle Cell Disease patients.

Do you have any questions on the things I've explained? *Investigator will answer accordingly.*

We are trying to get a range of perspectives from sickle cell patients and caregivers. One way we are doing that is to make sure we talk to patients of different ages. I have some age ranges, would you be willing to tell me what age range you fall into? *If participant is a caregiver for a patient with cognitive impairments, ask "how old is the sickle cell patient you care for?"*

Age ranges with say the following:

15-19 years old

20-26 years old

27-44 years old

Researchers will use a spreadsheet to determine what age groups are still needed for research.

If the participant is in an age group has already been filled:

Unfortunately, we already have enough participants in that age range already. But thank you for your time and your willingness to talk with us. Please watch for ISAAC updates from UIC.”

If the participant is in an age group that needs to be filled:

If you’re still interested in participating, we can set up a time and location where the interview will take place. Does that sound good?

If patient says “Yes,” the investigator will explain the following. If patient says, “No,” the investigator will thank them for their time and leave them with a patient flyer in case they change their minds.

All interviews last about one and a half hours and we have a \$50 dollar gift certificate for your time. We can conduct them in your home or at a different place that is more comfortable. What day do you think you may have time for the interview?

At this time, investigator coordinates with patient to schedule a date, time, and location that works for both parties. The investigator gathers the patient’s name, preferred contact information (email or telephone), and interview address and records them in a scheduling spreadsheet stored on Box, a secure and password-protected website. At the end of the scheduling, the investigator thanks the patient again and reviews with them that the researcher will confirm the interview date a day in advance of the interview to make sure the time still works.

NOTE: at time of interview, all patients will go through informed consent procedures and sign the consent form prior to starting study activities.

ISAAC patient interview screener

"Hello, you've reached the Improving Sickle cell care in Chicago project. This is <<Name>>. How can I help you?"

"If patients are calling to enroll: Thank you so much for contacting us about the study. Is this a good time to talk? Great.

I'm a researcher on a project about Sickle Cell Disease called ISAAC. ISAAC stands for Improving Sickle cell care for Adults and Adolescents in Chicago. We are interested in learning more about what life is like for people living with and managing Sickle Cell Disease in everyday life, like home, work or school. We are looking for participants between the age of 15 and 44 who have diagnosed Sickle Cell Disease or caregivers of adult sickle cell patients with cognitive impairments. We would like to interview patients or caregivers of adult patients. We will ask questions about living with Sickle Cell and personal experiences getting medical care for sickle cell. We're offering participants \$50 for an hour and a half of their time. Are you someone with sickle cell disease or a caregiver of an adult sickle cell patient that would be interested in this project? If so, are you between the ages of 15 and 44 or are you a caregiver of an adult patient with cognitive impairments? An adult for this study is anyone over the age of 19.

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The results of the interviews will not directly benefit you; however, they will be used to develop patient programs and tools that could improve care management for all Sickle Cell Disease patients.

Do you have any questions on the things I've explained? *Investigator will answer accordingly.*

We are trying to get a range of perspectives from sickle cell patients and caregivers of adult sickle cell patients with cognitive impairments. One way we are doing that is to make sure we talk to patients of different ages. I have some age ranges, would you be willing to tell me what age range you fall into? *If*

participant is a caregiver for a patient with cognitive impairments, ask “how old is the sickle cell patient you care for?”

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If the participant is in an age group that needs to be filled:

Great. Thank you. We are interested in hearing patients experiences with sickle cell over their lifetime.

Can I ask, where did you get sickle cell care when you were a child? *If participant is a caregiver for a patient with cognitive impairments, ask “We have a question about the patient you care for, do you know where they received sickle cell care as a child?”*

Thank you.

All responses go to next question.

Can I also ask what age you were when you learned you had sickle cell? *If participant is a caregiver for a patient with cognitive impairments, ask “We have another question about the patient you care for, do you know how old they were when they found out they had sickle cell?”*

Thank you. We will ask you for more details about that during the interview.

All responses go to next question.

Do you know what type of sickle cell disease you have? *If participant is a caregiver for a patient with cognitive impairments, ask “Do you know what kind of sickle cell your family member / friend / client has?”*

Ok. Thank you for that.

All responses go to next question.

Are you currently seeing a doctor about your sickle cell? Is your doctor at UIC or Sinai? *If participant is a caregiver for a patient with cognitive impairments, ask “We have one last question about the patient you care for, are they currently seeing a doctor for sickle cell? Is their doctor at UIC or Sinai?”*

If patient says “Yes,” the investigator will explain the following. If patient says, “No,” the investigator will thank them for their time.

If you're still interested in participating, we can set up a time and location where the interview will take place. Does that sound good?

All interviews last about one and a half hours and we have a \$50 dollar gift certificate for your time. We can conduct them in your home or at a different place that is more comfortable. What day do you think you may have time for the interview?

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