

Informed Consent for Adults

Please read the information below that tells about our discussion group. Be sure to ask if you have any questions. If you are willing to participate in the discussion group, please sign your name at the bottom and give the form back to us. We will give you a copy of the form to keep.

What are we trying to do?

We are trying to develop informational materials for people to help prevent some of the complications of sickle cell disease. We need your help to figure out what kinds of information will be most useful and the best ways to present this information.

Who is doing this research?

The Centers for Disease Control and Prevention (CDC) has hired the American Institutes for Research (AIR) to carry out this project. The CDC is a U.S. government agency whose mission includes developing materials to help people protect their health and avoid disease complications. AIR is a not-for-profit research organization.

How long will it take?

The discussion group will last 2 hours.

Are there any risks?

There are no known risks in participating in the discussion group. If the discussion makes you uncomfortable, then you don't have to participate and you still will receive an incentive for your participation.

Are there any benefits?

You will help us figure out what important information should be shared with people with sickle cell disease. We hope this will help people take better care of their sickle cell and avoid the complications of this disease.

Will people find out what I say?

What you say today will be treated in a secure manner and will not be disclosed. With your okay, we will be taping the discussion. This helps make sure our notes are correct, and lets us pay full attention to what you are saying. We may show parts of it to others, to show them what we learned and how we learned from you. We will erase any parts of the discussion that you do not want others to see.

What else should I know?

As a token of appreciation for your interest, you will receive a total of \$75.

- For more information about this project, you can contact Dr. Roger Levine, at 650-843-8160 or rlevine@air.org.
- For questions about your rights as a participant in this interview or focus group, contact AIR's Institutional Review Board at IRB@air.org or call toll free at 1-800-634-0797 or write them at IRB, 1000 Thomas Jefferson Street, NW, Washington, DC 20007.

Do you want to help us?

Before we begin your discussion group, we will ask you to confirm that you have read and understood the above information, and that you agree to participate. If you decide you do not want to talk with us, just let us know.

I have read the above and agree to participate in this important project.

Your signature: _____

Please print your name: _____

Today's date: _____