

Permission Form for Parents of Adolescents Aged 15-17

You are being asked to allow your child to take part in a discussion group. To participate in the discussion group is voluntary. You may refuse to give permission, or you may withdraw your permission for any reason. Even if you give your permission, your child can decide not to be in the discussion group or to leave early.

Please read the information below that tells about the discussion group. Be sure to ask if you have any questions. If you are willing to participate, 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 help from people with sickle cell disease to help figure out what kinds of information will be most useful and the best ways to present this information to teenagers.

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 creating materials that people and communities need to protect their health. 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 your child uncomfortable, they do not have to participate and still will receive an incentive for their participation.

Are there any benefits?

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

Will people find out what I say?

What your child says today will be treated in a secure manner and will not be disclosed. No one will be identified in any report or publication about this project. 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 is being said. We may show parts of it to others, to show them what we learned. We will erase any parts of the discussion that your child does not want others to see.

Will your child receive anything for being in this study?

As a token of appreciation for their interest, your child will receive \$75.00.

Who should you ask if you have any questions?

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

Do you want to help us?

I have read the above and give permission to allow my child to participate in this important project.

Printed name of child: _____

Your signature: _____

Please print your name: _____

Today's date: _____