

## **Assent for Adolescents Aged 15-17**

Please read the information below that tells about this discussion group. Your parent needs to give permission for you to be part of this group. You do not have to be part of this discussion group if you don't want to, even if your parent has already given permission.

### **What are we trying to do?**

We are trying to develop materials for people with sickle cell disease to help prevent some of the problems of sickle cell. We want to talk to a group of people with sickle cell disease to help to figure out what kinds of information will be most helpful and how to share 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 better manage their health problems. AIR is a not-for-profit research organization.

### **How long will it take?**

The discussion group will last 2 hours.

### **What are the good things that might happen?**

You will help us figure out what important information people with sickle cell disease need. We hope this will help people get better care for their sickle cell and avoid the complications of this disease.

### **What are the bad things that might happen?**

Sometimes things happen to people in research projects that may make them feel bad. These are called "risks." There are no risks that we know of associated with being in this discussion group. You may leave the group at any time. If you decide to leave, you still will still receive an incentive for your participation.

### **Will people find out what I say?**

What you say today will be treated in a secure manner and will not be disclosed. That means that whatever you say in the group, stays in the group. 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.

### **Will you get any monies or gifts?**

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

### **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](mailto:rlevine@air.org).

- For questions about your rights as someone who is part of this discussion group, contact AIR's Institutional Review Board at IRB@air.org, toll free at 1-800-634-0797 or c/o 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: \_\_\_\_\_