

## Is Research Right for Me?

SCENE 1: Melanie (patient), Medical Assistant and Researcher 1:

**Medical Assistant:** Melanie?

**Melanie (Melanie):** Hi!

**Medical Assistant:** Hi! I'm Heather, and this is Lisa (Research staff). Welcome to our clinic!

**Melanie:** Thank you! Nice to meet you.

**Researcher 1:** I see that you're looking at our research studies board. Do you mind if we take a few minutes to talk with you about some of the research studies we have going on here?

**Melanie:** Sure!

**Medical Assistant:** We actually have a lot of opportunities for our Melanies to get involved in our research- not only are we a center for medicine, but we're also a center for learning about teens. And the reason is that information that we learn from you we use to advance the field of adolescent and young adult health.

**Melanie:** Cool!

**Research Staff:** Have you participated in research before?

**Melanie** No, I haven't.

**Research Staff:** There are a lot of really great reasons why young people like you participate in research studies.

SCENE 2: WHY SHOULD WE GET INVOLVED?

**Youth 1:** I first got involved in research because I have sickle cell disease. I like the idea of helping people like me and learning more about my health. It's nice to know that something good for others can come from this experience.

**Researcher 2:** We really enjoy working with young adults and adolescents. We learn a lot from their experiences and the different changes that you're going through, and hearing from them, we really can help inform our research and our clinical practices.

**Youth 2:** I like sharing my experience with research staff to help them, and as being an expert as a teenager I'm able to give them useful information for when they conduct research involving adolescents and young adults.

**Researcher 3:** We are hoping you participate in research. There is so much we don't know, so when you do, you are helping contribute knowledge and understanding to the scientific community at large. And, depending on the study, you may be compensated for your time and efforts.

SCENE 3: (later) CONSENT

**Researcher 1:** (after explaining the research study to Melanie) So, we've talked about the purpose of the study, the risks, the benefits, and other information about what we are hoping to learn from this study... do you have any questions for me?

**Melanie:** Well, what happens next?

**Researcher 1:** If you choose to participate, we'll go over this consent form. It's a part of our informed consent process. We'll talk about the form, talk about the study in more detail, and then if you have any questions we can talk about those, too. If you decide to participate, I'll enroll you in the study then.

**Melanie:** (looking at the consent form.) Who will know that I'm participating in the study?

**Researcher 1:** The only people that will know that you're in THIS study are members of the research team. Other studies may require parent or guardian permission if you're under 18, but this one doesn't.

**Melanie:** If I choose not to participate, will my care at this clinic be affected?

**Researcher 1:** No, your health care will not be affected based on whether or not you choose to participate.

**Melanie:** One last question, who will have access to my information?

**Researcher 1:** The only people that have access to your information are the research team. Your information is kept confidential, which means that it's private, and that your personal information is not attached to the research study documents.

**Melanie:** Okay, thank you! I'm really excited to be involved in the study.

*Video created and approved by the Adolescent and Young Adult Medicine Youth Research Advisory Board (YRAB) of Children's Hospital of Pittsburgh of UPMC for the Center for Excellence in Child and Adolescent Health Research. January, 2017*