Examining the Knowledge, Attitudes, and Beliefs of Sickle Cell Disease Patients, Parents of Patients With Sickle Cell Disease, and Providers Towards the Integration of CRISPR in Clinical Care

National Human Genome Research Institute (NHGRI), Bethesda, Maryland, United States

Background:

Sickle cell disease (SCD) is caused by a genetic defect that affects how hemoglobin is made. Due to this, people with SCD have abnormally-shaped red blood cells, which can result in poor oxygen transport in the body and increase risk of blood clots. CRISPR Cas9 is a new tool which allows scientists to snip and edit genes in a way that is faster, cheaper, and more precise than other gene-editing tools. Recently, research has been done using CRISPR Cas9 to correct the sickle cell gene in animal models and human cells. Researchers want to understand the views of those with SCD, parents of people with SCD, and the providers of these patients regarding use of CRISPR Cas9 in clinical trials and treatment.

Objectives:

To study the attitudes, beliefs, and opinions of those with SCD, parents of those with SCD, and providers on the use of CRISPR Cas9 gene-editing. An additional purpose of this study is to assess the utility of an educational tool for improving understanding of CRISPR Cas9.

Eligibility:

People ages 18 and older who speak English and either have SCD, are a parent of someone with SCD, or are a physician for people with SCD.

Design:

Participants will be screened via phone. Those with SCD will be screened with data from their SCD genotype.

Participation lasts about 2 hours.

Participants will fill out three surveys.

Participants will watch a video about CRISPR Cas9.

Participants will engage in a focus group session. This will be audiotaped and analyzed.

The data from the survey questions and focus groups may be used for future research. However, all personally identifiable information will be removed before data is shared.

Participants data will be identified with a code number instead of their name.

Participants may be invited to join future studies of SCD.