

## Summary

### Health Focus

Sickle Cell Disease (SCD)

### Goal

Accelerate the identification and implementation of innovative solutions to increase the quality of life for patients living with SCD.

### Background

SCD is the most common inherited blood disorder. About 100,000 Americans currently live with SCD, but the disease disproportionately affects African Americans.

SCD is costly, expenditures for patients with SCD are estimated to be 6 times higher than non-SCD patients in Medicaid and 11 times higher than non – SCD patients with private insurance. African Americans disproportionately experience challenges with access, quality, and affordability of care, patients with SCD may encounter racial discrimination when seeking treatment for acute pain crises, including accusations of “drug seeking”, extended emergency department wait times, and difficulty filling prescriptions (Lazio et al., 2013; Ringwalt et al., 2015)

# Advancing Health Equity through Data and IT:

## Sickle Cell Disease

*Using design and technology to uncover many opportunities to explore new solutions around critical health and wellness issues affecting large segments of the population*



Health+ (“health plus”) is an ongoing series of research and code-a-thon cycles sponsored by the Department of Health and Human Services Office of the CTO. It is focused on specific, high-impact health issues, with the goal of fostering technology solutions and creative problem solving. Leveraging innovation is the key to accelerating affordable and effective methods of improving quality of life for patients living with SCD.

### Personas and User Stories

We will conduct landscape research focused on developing deep understanding of the challenge, the audience, and the vision set forth. Utilizing Human Centered Design (HCD) methods, conducting problem validation with stakeholders, identification of salient user stories, formation of personas, and journey maps to inform the round table vision.

### Roundtable Discussion

Together, we will work hand-in-hand to execute a roundtable with identified stakeholders, match emerging themes to data sets, and prepare artifacts necessary so that a product team is able to execute different strategies during the code-a-thon.

### Themes, Data, and Code – A- Thon

Engage with patients, subject matter experts and policy makers to develop a gathering of technologists, where they’ll be provided with the necessary information, as well as guidance, to create technological solutions that address the challenge identified and fulfill the vision at the outset.

### Timeline

