

# Human-Centered Design Report

Appendix (section 9 of 9)

& partners | June 2020

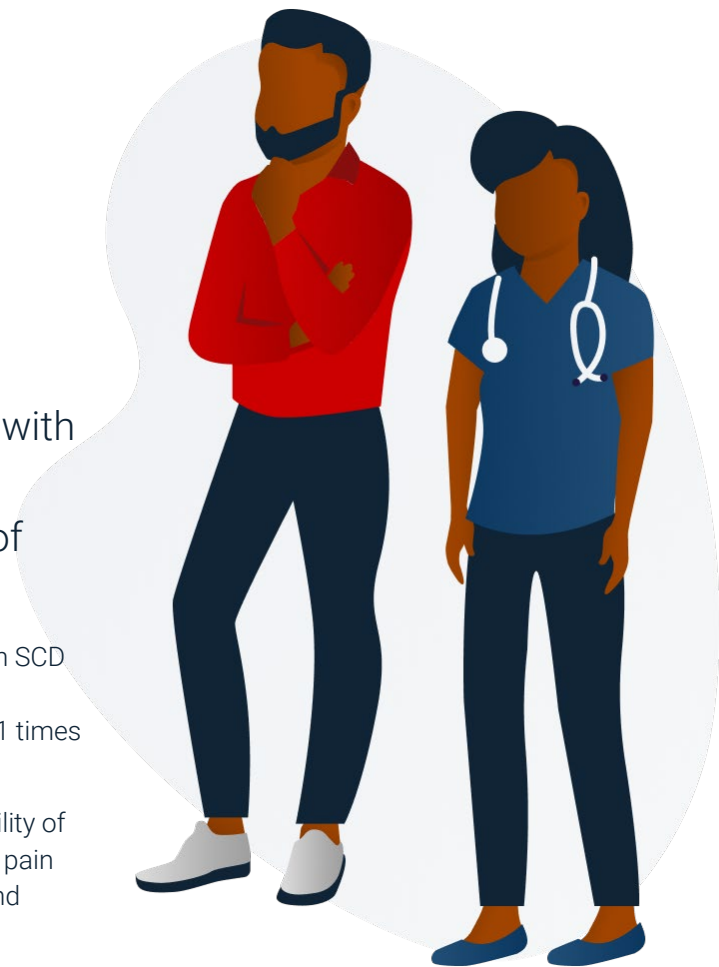


# About Health+ Sickle Cell Disease

Health+ Sickle Cell Disease is a project that aims at providing insights, stories, and journeys around the experience of people with Sickle Cell Disease (SCD) to accelerate the identification and implementation of innovative solutions to increase the quality of life for patients living with SCD.

SCD is the most common inherited blood disorder. About 100,000 Americans currently live with SCD and 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.



# Research Approach

## Recruitment

Medical experts and people with SCD and their families were recruited. HHS contacted many patient advocacy groups across the country on behalf of &Partners. Additionally, we reached out to people on Instagram, Twitter and Facebook.

## Methodology

Remote and in-person, semi-structured 60-minute interviews were conducted. A total of 24 interviews were conducted with people with SCD and their families, from a comprehensive variety of U.S. regions, genders, ages (all 18+), education, and care finance modes. 16 patients, 7 caregivers (2 of adults and 5 of children), and 1 sibling of a patient were interviewed.

A total of 4 interviews were conducted with subject matter experts: 2 with healthcare providers specializing in SCD, 1 with a nurse navigator, and 1 with a representative from the CDC.

## Interview Approach

Interviews centered around the quality of healthcare they received throughout their transition from childhood to adulthood, their experiences with emergency care, experiences with insurance, and navigating work and career.

## Synthesis

Interviews were analyzed in qualitative coding software Delve. Using Delve, we categorized interview segments according to their content. Examples of categories are "transition to adulthood", "emergency care", "care coordination", "insurance", "bureaucracy", "discrimination". Through this, we analyzed trends in how respondents described specific aspects of their experiences.

## Gaps and Limitations

Our patient and caregiver interviewee sample is majority female, and at least college-educated. In addition, most of them were recruited from patient advocacy groups, which may tend to be more educated on SCD and barriers to healthcare than patients who aren't connected with those groups. While we were able to find participants beyond those demographics, our sample may not be representative of the general population with SCD. Despite these gaps, we were able to gain some variety in interviewees and have honored this in our analysis.

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Sponsored by:



Thanks to Maia Laing, Alexander Wilson, David Wong, Marlene Peters-Lawrence, Dr. James Taylor, Dr. Gentry Wilkerson, Shamonica Wiggins, Jason Hairston (PISTIS), and the CODE team (Temilola Afolabi, Paul Kuhne, Matthew Rumsey, Kristann Orton, Nidhisha Philip, Joel Gurin) for invaluable contributions, feedback, collaboration and support.

Special thanks to all the people (patients, caregivers, advocates, community-based organizations, clinicians, policymakers) who contributed with their time, knowledge, experience, and connections for this project.

Created by **@partners**

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