Improving Sickle Cell Care for Adolescents and Adults in Chicago
Improving Sickle Cell Care for Adolescents and Adults in Chicago (ISAAC)

**PROJECT BRIEF:** ISAAC is a 6-year NIH/NHLBI-funded study intended to improve clinical care and patient outcomes of people with sickle cell disease by designing, testing, and implementing an integrated model of longitudinal and emergency care. ISAAC takes a multidisciplinary approach by incorporating design as a partner in a traditionally clinical space. The design research team’s role on the project is to integrate the real-world experiences of ED providers, clinic-based providers, and primary care doctors who care for people with Sickle Cell into a systematic understanding of key stakeholders and to drive toward better interventions.

**TEAM:** I worked on ISAAC across two phases of the project (Spring 2017 and Summer 2017), each phase comprised of 4-person teams. I acted as the project lead over the summer phase.

**WHAT WE DID:** Primary and Secondary Research, Coding and Analysis, Service Blueprinting, Opportunity Discovery, Prototyping.

**PROCESS** (kind of)

- **PLAN**
  - stakeholder map
  - field kit development

- **BUILD CONTEXT**
  - literature review
  - tools analysis

- **DISCOVER**
  - stakeholder interviews
  - direct observation
  - coding & analysis

- **SYNTHESIZE**
  - insight & opportunity identification
  - design principles
  - model development
  - system mapping
  - service blueprinting
  - space build-out

- **DELIVER**
  - stakeholder presentations (x3)
  - poster presentation at SCDAA annual conference

Two phases of interviews & observations

**PHASE ONE**
- Community health workers
- Social workers
- Sickle cell doctors & nurses
- Patient support group

**PHASE TWO**
- ED doctors
- ED charge nurse

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**ISAAC // Field notes**
*Clinic and ED Observations*

**Targets for direct observation and documentation**
- Behavioral mapping
- Documentation of patient/staff experiences
- Processes + interactions
- Staff roles
- Site-level messages + cues

**ISAAC // Field notes**
*Nurse in-situ interview*

**Section A — Professional experience with treating sickle cell**

1. How long have you been practicing? How long have you worked at this facility?
2. How often do you interact with sickle cell patients?
3. What is your role in sickle cell patients care? Tell me about the medical care you provided for patients with SCD.

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**8.2 Emergency Department**

**ISAAC // Field notes**
*Clinic and ED Observations*

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**8.3 Sickle Cell Center**

**ISAAC // Field notes**
*Nurse in-situ interview*
Capturing the emotional experience of caring for patients with sickle cell disease

Picture pulls helped facilitate conversations about what it feels like to care for patients with sickle cell disease, giving participants a way to anchor emotions and open up to sharing stories.

“This one is because I do get a broken heart because I have seen so many of them die, and it’s just so painful when it happens...I see so much pain and death it hurts.” —social worker

“A lot of patients and family members feel a big burden, a big weight on them. Many of them don’t like to admit that when the patient comes to their demise, it’s a relief.” —social worker
Drawing out tacit knowledge through activities and prototypes

Interview participants tested and gave feedback on a pre-existing digital tool that a UI sickle cell provider had co-developed. Interviewees helped us understand how a tool such as this one may or may not fit into their workflow, how well they’d trust a similar tool, and the pieces of information they’d find useful.

The “care circle” activity, completed by sickle cell nurses and physicians, helped our team map secondary and tertiary stakeholders in the sickle cell care ecosystem, as well as communication gaps and opportunities.
Organizing the data through rigorous grounded theory coding

Our team of four undertook grounded theory coding of over 20 stakeholder interviews. We worked through our inter-coder reliability checks with hundreds of post-it notes and hours of discussion. These sessions were arduous but critical for developing a shared mental model of our data set.

We collaboratively built a list of over 300 codes encompassing everything from patient experience to providing care in the ED. This code list was adopted by the national ISAAC team for ongoing use over the course of the project.
Developing a new understanding barriers & facilitators analysis, design requirements

During coding and analysis, we began collecting **barriers and facilitators**, as well as noting behaviors and perceptions, across the ecosystem of care. Mapping the relationships between these entities began to showcase the complexity and interdependencies within this system and identify particularly fraught junctures.

During synthesis, our team transformed insights into an in-depth set of **design requirements** for use by the national team and future ISAAC designers. We used the **Multi-level Requirements Framework** in order to generate principles for how a solution needs to function across different contexts.
Care delivery experience in the ED
service blueprint organizes critical activities & interactions

We shared this service blueprint with sickle cell physicians and ED doctors during a final share-out. It served as a neutral centerpiece on which we could hang more sensitive conversations.

For example, in our interviews we learned that sickle cell patients are categorized as a low priority in the ED and this is a point of contention. We were able to surface this conversation by diving into the Triage portion of the blueprint and facilitating discussion.

We compared what the treatment process looks like “on paper” to real life discussing factors like: institutional approach to care; ED providers’ attitudes toward comfort with administering opioids; prior experiences with SCD patients; and job satisfaction.
Using space to organize & communicate findings

Our team created a space where our research could "live," visible to anyone who wanted to walk through and useful for our team as we collected and processed research. The project bay became a critical space for stakeholder engagement, connecting them back to the stories we were hearing, as well as getting quick feedback on new ideas (like sketched prototypes).