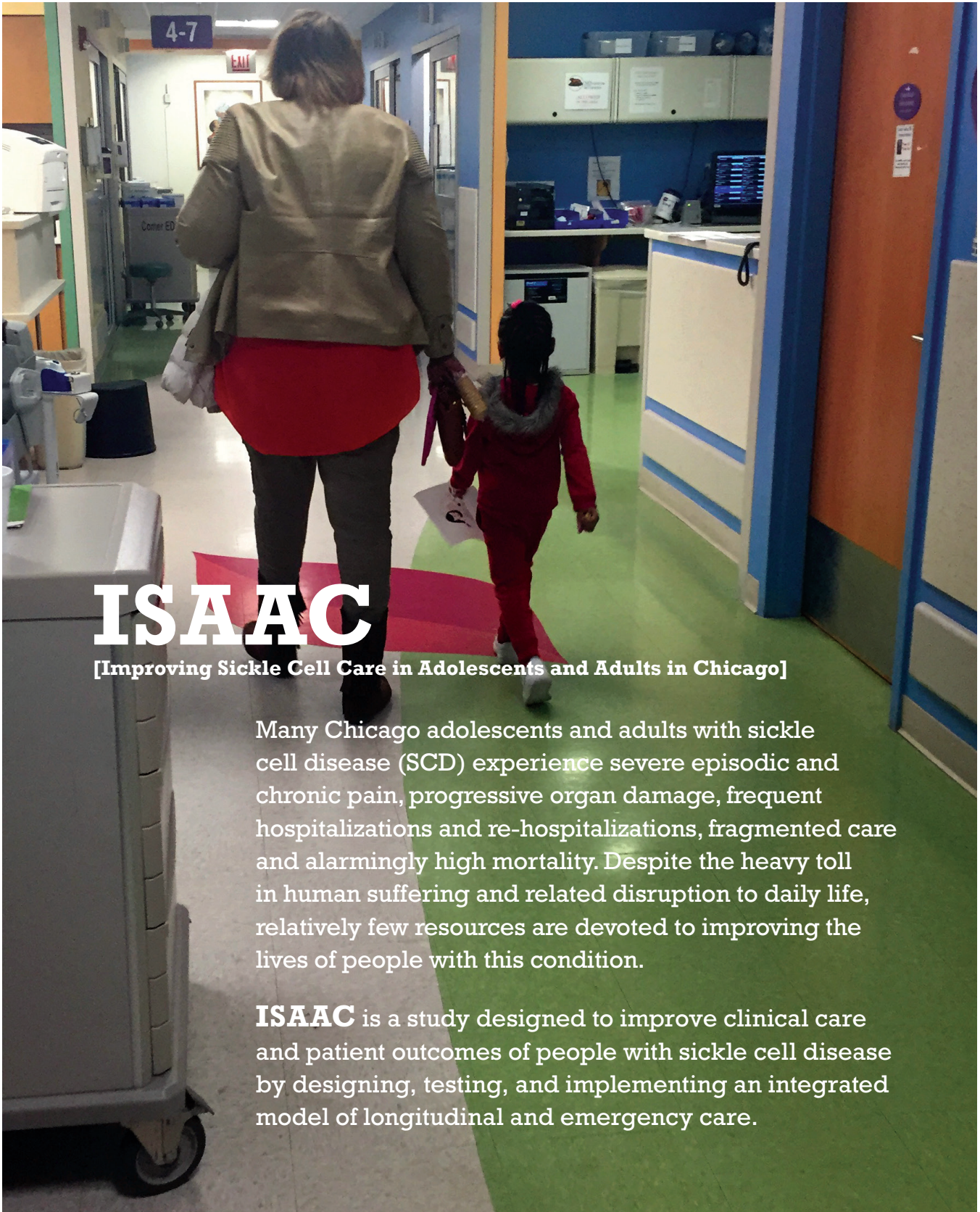




Bridging healthcare to patients to
Improve Sickle Cell care in Chicago



ISAAC

[Improving Sickle Cell Care in Adolescents and Adults in Chicago]

Many Chicago adolescents and adults with sickle cell disease (SCD) experience severe episodic and chronic pain, progressive organ damage, frequent hospitalizations and re-hospitalizations, fragmented care and alarmingly high mortality. Despite the heavy toll in human suffering and related disruption to daily life, relatively few resources are devoted to improving the lives of people with this condition.

ISAAC is a study designed 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.

Despite advances in treatment and curative strategies, this disease still causes much suffering and economic costs.

People with SCD suffer from a range of clinical complications, including severe pain episodes and acute chest syndrome. While best practices for managing SCD are available, often they are not put into practice. The ISAAC project will improve the health and lives of patients with SCD by assisting them in accessing consistent longitudinal care and taking their medicine, while supporting physicians in properly treating patient pain in the ED.

190,000

Emergency department (ED) visits each year

110,000

Hospital admissions each year

ISAAC targets 3 known barriers to care

1 Inadequate Treatment of Acute Pain Episodes

Patients with SCD often use emergency departments (EDs) for treatment of acute pain crisis. ED providers may not have knowledge of individual patient treatment plans. Unrelieved SCD pain is a leading cause of hospitalization, accounting for up 40% of Medicaid SCD patient readmissions within 30 days nationwide.

ISAAC is working with designers and researchers to develop a tool that helps patients with sickle cell disease communicate more effectively with ED providers to get the pain relief and care they need.

2 Inadequate Longitudinal Regular Ambulatory Care

Patients with SCD in Cook County, especially those from under-served and low income communities, face persistent barriers to appropriate disease management. Health inequity and fragmented medical care lead to increased acute pain episodes, reliance on EDs for care, and cycles of ED visits and hospital admissions.

ISAAC targets development of a patient-facing longitudinal care tool to promote health behaviors for improved self-management of SCD. Some patients will receive additional support through home visits with community health workers.

3 Inadequate Use of Hydroxyurea on a Regular Basis

Patients taking hydroxyurea have reduced episodes of pain and life threatening complications, and require fewer blood transfusions and hospitalizations. They also experience improved quality and length of life. Despite its benefits, hydroxyurea remains under-prescribed by healthcare providers and poorly adhered to by patients.

ISAAC proposes development of a new tool to address lack of adherence to hydroxyurea guidelines and usage at the provider, patient and system levels.

The ISAAC research team

ISAAC is comprised of a multi-institutional and transdisciplinary group of investigators.



IIT Institute of Design



UNIVERSITY OF SOUTH CAROLINA

Principle Investigators

Victor Gordeuk, MD
Contact Principal Investigator, UIC
Lewis Hsu, MD, UI Health
Abraham Wandersman, PhD
University of South Carolina
Jana Hirschtick, PhD
Sinai Health System, SUHI
Jerry Krishnan, MD, PhD
UI Health, Population Health

Co-investigators

Michael Berbaum, PhD, UI Health
Kishore Bobba, MD, Sinai Health System
Joseph Colla, MD, UI Health ED
Kim Erwin, MDes, IIT Institute of Design
Molly Martin, MD, MAPP, UI Health
Kay Saving, MD, UI Health
Robin Shannon, DNP, RN,
UIC College of Nursing
Rob Winn, MD, UI Health
Leslie Zun, MD, Sinai Health System

ISAAC engages stakeholders to build better interventions

Community experts

ISAAC is engaging social workers, community health organizers, school administrators, school nurses, the Illinois Department of Health, and legal aid workers to discuss policies, barriers to engagement, and other system-level issues.

Community advisory board

The ISAAC Community Advisory Council is comprised of a passionate group of stakeholders and advocates committed to improving the lives of patients, families and all those impacted by sickle cell disease. The Advisory Council is essential to informing the trajectory and supporting the success of ISAAC.

Clinic and ED staff

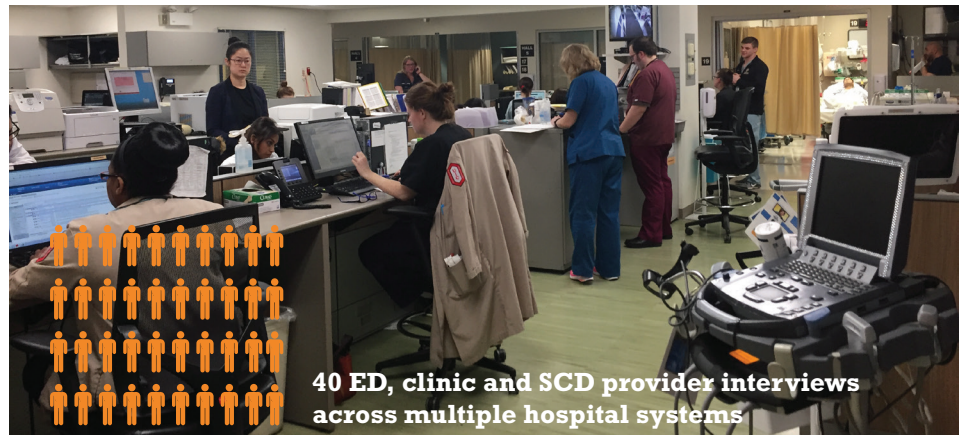
ISAAC is integrating the real-world experiences of ED providers, clinic-based providers, and primary care doctors who care for people with Sickle Cell into a systematic understanding of key stakeholders.

Patients + families

ISAAC is exploring the patient experience of living with SCD through their interactions with healthcare providers, the healthcare system, and their practices at-home.



24 expert + community interviews



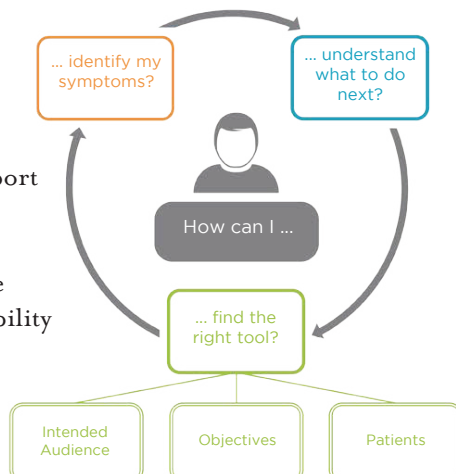
40 ED, clinic and SCD provider interviews across multiple hospital systems



20 patient + family interviews

Assessing patient tools

ISAAC is analyzing a broad spectrum of educational and support tools encountered by patients and their families to determine their usability, readability and accessibility.



90+ SCD education tools



ISAAC brings a community together to help build a comprehensive picture of SCD in Chicago

The application of a comprehensive multi-sector accountability approach is novel and absolutely crucial to the advancement of the field of SCD treatment. I am excited to be a part of this proposed program. — *Dr. Joe Colla, Emergency Medicine, UI Health*

At LCHC, we strive to continuously improve our programs and services. We understand sickle cell disease is a problem and we are interested in working with ISAAC to create a plan to better address the needs of sickle cell patients in the medical environment and our in the community. — *Dr. Bruce Rowell, Chief Clinical Officer of Quality, Lawndale Christian Health Center*

HAVE A HEART is a Chicago-based Foundation with 25 years of experience in advocating for patients with sickle cell disease from the local to state and national level. The ISAAC proposal holds great potential for making major progress in improving care for the sickle cell patients of Cook County and Chicago. — *Bonnye Johnson, Board President, Have a Heart for Sickle Cell Anemia*

The IDPH School Health Program fully supports the ISAAC plan to engage school-based health centers as vital community partners toward achieving the specific aims throughout the study. — *Victoria Jackson, School Health Program Administrator, Il. Dept of Public Health*



SCDAI will be pleased serve on the Advisory Board for ISAAC, participating in both in-person meetings and telephone conference calls. We are excited about the ISAAC focus of improving regular longitudinal care, regular use of hydroxyurea, and effective treatment of acute pain episodes. — *TaLana Hughes, Executive Director, Sickle Cell Disease Association of Illinois*

I am pleased that we share a sense of urgency to push translation of innovative research findings in sickle cell to real world application, and this proposal builds upon our practical experience as leaders of sickle cell programs here and in other cities. — *Dr. Lewis Hsu, hematologist, UI Health*

We are confident this project could greatly facilitate the good work done by the Disability Access Centers to reduce learning barriers and enable persons with sickle cell disease to be in college, in class and successful. — *David Saunders, Interim President, Malcolm X City College*