ISAAC Needs assessment framework V9

SOURCES OF INFORMATION

	ID + SUHI	ID + SUHI	SUHI + Robin		
	STAKEHOLDERS			**CONTEXT**	**POPULATION VIEW**
	1. Patients + family	**2. Medical staff**	**3. Community**	**4. Sites** *Where care takes place*	**5. Secondary data analysis**
Data collection methods	**Patient/family in-home interviews** Semi-structured interviews of 2- 3 hours each— with backpack + carekit inventory (what do they carry/use to manage SCD), experience mapping (SCD life impact) + care circle/supports drawing (who do they rely on), role definition, picture pull to identify metaphors for sickle cell experiences	**Clinical in-situ interviews** Semi-structured interview with decision-path mapping, EMR fit & feasibility, role assessment, bedside role play (if we can't do direct observation of patient care), picture pull to identify metaphors for sickle cell experiences	**Community expert interviews** Semi-structured interviews with policy review, communication tool review, picture pull to identify metaphors for sickle cell experiences	**Direct observation of sites** Behavioral mapping, documentation of patient/staff experiences, processes + interactions, staff roles, site-level messages + cues	**Databases** Analysis of existing Medicaid claims and health care utilization data (hospitalizations, readmissions, outpatient visits, ED visits)
Participants and size	5 15 - 19 (SS + SC) 5 20 - 30 (SS + SC) 5 31- 50 (SS + SC) 5 caregivers of cognitively impaired	4 SCD doctor 4 clinical nurses + research nurses 4 PCP 4 ED attending 4 ED triage 4 ED intern	2 social worker (1 per site) 2 community health organizer (1 per site) 3 CHWs with clients with SCD 6 school administrator and nurse (3 sites) 2 HR/employers 1 legal aide (housing) 1 Dept of Rehab (IL)	2 EDs 2 Clinics 15 Homes 1 support group 1 health fairs or events work	
	20 TOTAL	*24 TOTAL*	*17 TOTAL*	*6 TOTAL*	
	ID + Jana + Kristin	ID + Jana + Kristin	Kristin + Jana + Robin	ID	Jana + epi person
	GOALS + OBJECTIVES				
GOAL 1 Facilitate longitudinal sickle cell care	What does comprehensive longitudinal care for sickle cell disease look like for patients? For caregivers? What does "routine care" look like to caregivers? What do they wish it looked like? What does a typical outpatient visit look like for a patient with SCD? How does vary by age? Who are all the people involved in the longitudinal care process? What are their current roles in care facilitation and what are their desired roles? What resources and support does each group need to facilitate this process? What outcomes would justify buy-in for a new facilitation model? How do patients form relationships with the medical staff? What are the barriers to participating in routine care? Which are most problematic? What self-management tools + practices do patients use and adopt most easily? How does vary by age?	What does comprehensive longitudinal care for sickle cell disease look like for medical staff? What does "routine care" look like to medical staff? What do they wish it looked like? What does a typical outpatient visit look like for a patient with SCD? How does vary by age group (child, adolescent, adult)? What are all the settings in which "care" really takes place? Who is involved in this? Who are all the people involved in the longitudinal care process? What are their current roles in care facilitation and what are their desired roles? What resources and support does each group need to facilitate this process? What services are caregivers offered? Ideally, what services should caregivers be offered? What services address mental health and other psychosocial needs for patients? For caregivers? What educational materials are caregivers offered? Ideally, what materials should caregivers be offered? What expectations are set about a patient's prospects for the future?	For CHWs: What does comprehensive longitudinal care for sickle cell disease look like for patients and/or caregivers? What does "routine care" look like to patients and/or cargivers? What do they wish it looked like? for CHW: What services are caregivers offered? Ideally, what services should caregivers be offered? for CHW: What self-management practices are encouraged?	What are the settings where this intervention will need to be implemented? What are the resources needed to facilitate longitudinal care in each setting? What are the barriers to facilitating this process? What electronic tools are currently available that can help facilitate this process?	What is the hospitalization rate for sickle cell disease in Chicago? How does this rate vary geographically? By patient characteristic (gender, race/ethnicity, age)? How often are patients with sickle cell disease readmitted to the hospital within a short time frame after discharge? How many patients with sickle cell disease at UIC and Sinai hospital have had at least one outpatient visit within the past year? How does this vary by provider type (primary care, hematologist, sickle cell specialist, other)?
GOAL 2 Effectively manage acute pain in emergency setting	How do patients choose an ED when having a pain crisis? What does a typical ED visit look like for a patient with sickle cell? Do experiences vary by patient type (frequent flyers v occasional users)? What are the attitudes and responses of the staff to a SCD patient? Who are the integral stakeholders in the effective acute pain management process? What are their current roles in acute pain management and what are their desired roles? What resources and support does each group need to facilitate this process? What related outcomes would justify buy-in for the new facilitation model? What constitutes acceptable crisis treatment to a patient? How do patients prepare for/response to pain crises? How do pain crises affect daily life for patients and caregivers?	What does a typical ED visit look like for a patient with sickle cell? Do experiences vary by patient type (frequent flyers v occasional users)? What should a typical ED visit look like for a patient with sickle cell? What are the attitudes and responses of the staff to a SCD patient? Who are the integral stakeholders in the effective acute pain management process? What are their current roles in acute pain management and what are their desired roles? What resources and support does each group need to facilitate this process? What related outcomes would justify buy-in for the new facilitation model? What kinds of conversations need to be had in the ED? What tools support effective patients + clinicians conversations about acute pain management today? What constitutes acceptable crisis treatment to medical staff? What are barriers to getting the proper dose of pain medication? At the clinician level? At the clinic/hospital level? At a systems level? What are the accelerators to getting the proper dose of pain medication? How do ED/acute care physicians determine the appropriate dosage of pain medication to treat a pain crisis? Are there consequences to providing/not providing appropriate treatment? How often are sickle cell patients subsequently hospitalized after visiting an ED?	What are attitudes and responses of schools or employers to a pain crisis? What are practices of schools or employers to an extended absence due to a pain crisis? For CHWs: What should a typical ED visit look like for a patient with sickle cell?	What are the settings where this intervention will need to be implemented? What are the resources needed to facilitate effective acute pain management in each setting? What are the barriers to facilitating this process? What electronic tools are currently available that can help facilitate this process?	What is the ED visit rate for primary diagnosis of sickle cell disease in Chicago? How does this rate vary geographically? By patient characteristic (gender, race/ethnicity, age)? What percentage of patients who visit an ED for sickle cell-related complications are subsequently hospitalized?
Goal 3 Enable effective hydroxyurea use	How do patients decide if/when to initiate hydroxyurea use? Once a prescription is filled, what are the barriers to daily use? Who are the integral stakeholders in the hydroxyurea use process? What are their current roles in hydroxyurea use and what are their desired roles? What resources and support does each group need to facilitate this process? What related outcomes would justify buy-in for the new facilitation model?	How do doctors decide if/when to prescribe hydroxyurea? How is hydroxyurea use monitored/adapted? What are commonly reported barriers to best practice self-management + drug adherence? Who are the integral stakeholders in the hydroxyurea use process? What are their current roles in hydroxyurea use and what are their desired roles? What resources and support does each group need to facilitate this process? What related outcomes would justify buy-in for the new facilitation model? How do doctors explain hydroxyurea, its usage, and side effects, to caregivers and/or patients? What support is staff provided for hydroxyurea conversations? How could hydroxyurea use be made more acceptable?	For CHWs: What are commonly reported barriers to best practice self-management + drug adherence?	What are the settings where this intervention will need to be implemented? What are the resources needed to facilitate effective hydroxyurea use in each setting? What are the barriers to facilitating this process? What electronic tools are currently available that can help facilitate this process?	What is the medication possession ratio for hydroxyurea among eligible patients with sickle cell disease?