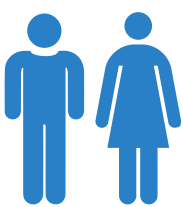


Formative communication touchpoints V4 10/3



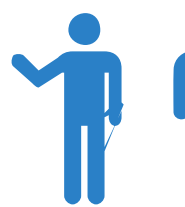
Diagnosis

Testing for sickle cell disease



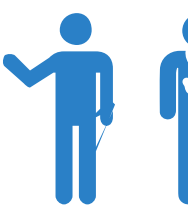
Routine pediatric care

Receiving childhood treatments



Transition to adult care

Owning + planning for the future



Routine adult care

Self-management



Crisis care

ED visits

1

2

3

4

5

Patient + family

includes household

What **information** is provided to caregivers about SCD?

What **expectations** are set about the future of the child and care needs?

What are family's **attitudes and responses** to this diagnosis?

What are family's **anxieties** about this diagnosis?

How does the family build **routines + habits** to meet the needs of the SCD child?

What does “**routine care**” look like to caregivers? What do they wish it looked like?

What does **comprehensive longitudinal care** for sickle cell disease look like for patients? For caregivers?

What **self-management practices** are encouraged?

How are **children** enrolled in their own care? At what age?

How does the child **integrate** this information to inform practices? What **tools** are they given?

What are the **barriers** to participating in routine care? Which are most problematic?

How do adolescents form **relationships** with PCPs?

What **questions** do transitioning adolescents have?

What **information/education** is provided to adolescents? What other kinds of supports are they offered?

How is self-management **encouraged**? Who is doing this?

What self-management **tools + practices** do adolescents use and adopt most easily?

How does a patient define a great/ **effective outcome** of SCD care?

What are the **routines and habits** patients build to integrate self-management practices + drug regimens into home life? Work life? School life?

What **resources** are adults guided to? Which ones are they **influenced** by?

Ideally, what **services** should patients and families be offered?

How do patients **decide** if/when to initiate hydroxyurea use?

Once a prescription is filled, what are the **barriers** to daily use?

How does **comprehensive longitudinal care** vary by age group?

How does **comprehensive longitudinal care** vary over a patient's lifetime?

What are the **barriers** to adult patients participating in routine care? Which are most problematic?

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 an SCD patient?

What **tools** support effective patients + clinicians conversations today?

What constitutes **acceptable crisis** treatment to a patient?

How do patients prepare for/response to pain crises? How does that affect daily life for patients and caregivers?

Community

schools, churches, employers

How does the community— church, school, employer— **acknowledge** SCD?

What are **attitudes and responses** of the community to the needs of an SCD child?

What **supports** are available in the community?

What are **attitudes and responses** of the school to the needs of an SCD child?

What **accommodations** does the school make for SCD children?

What are **attitudes and responses** of colleges + trade school to the needs of an SCD child?

What **accommodations** do colleges + employers make for SCD patients? How do patients learn about this?

How does a school or employer define a great/effective **outcome** of SCD care?

What is the **desired level** of information or involvement for schools and employers regarding the status of SCD patients?

What **accommodations** will colleges + employers make for SCD patients? How do patients learn about this?

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?

Medical staff

PCPs, specialists, nurses + admin

What **supports** are available to staff to orient caregivers to SCD?

What are **best practices** in preparing caregivers to manage longitudinal care of an SCD child?

What does **comprehensive longitudinal care** for sickle cell disease look like?

What **services** are caregivers offered? Ideally, what **services** should caregivers be offered?

What educational **materials** are caregivers offered?

What does a typical **outpatient visit** look like for a child with SCD? What kind of relationships are build?

What are all the **settings** in which “care” really takes place? Who is involved in this?

What **stakeholders** are needed to deliver the necessary comprehensive care for pediatric patients? Caregivers, clinicians, CHWs, others? Where does this care take place?

How do doctors decide if/when to **prescribe** hydroxyurea to children?

How do doctors **explain** hydroxyurea, its usage and side effects to caregivers?

What **supports** are staff provided for hydroxyurea conversations?

How is hydroxyurea use **monitored/ adapted** in children?

How do clinics **prepare** transitioning adults to manage their disease while in college? While employed?

What **expectations** are set about a patient's prospects for the future?

What **services** are caregivers offered? Ideally, what **services** should caregivers be offered?

What educational **materials** are caregivers offered?

How does a clinician define a great/ effective outcome of SCD care?

How is **self-management** encouraged? **Whose job** is this in the clinic? How does this fit the clinic workflow?

What **tools** are used to explain self-management? Where are they located and who has access to them?

What **services** are adults offered? Who does this?

How do doctors decide if/when to **prescribe** hydroxyurea for adults?

How do doctors **explain** hydroxyurea, its usage and side effects to patients?

What **supports** are staff provided for hydroxyurea conversations?

How is hydroxyurea use **monitored/ adapted**? How could this be made more acceptable?

What are the **FAQs** patients have about their health? About their drug regimen?

What are commonly reported **barriers** to best practice self-management + drug adherence?

What **stakeholders** are needed to deliver the necessary comprehensive care for pediatric patients? Caregivers, clinicians, CHWs, others? Where does this care take place?

Is communication and record sharing across medical sites a **barrier** to care?

What kinds of conversations need to be had in the ER?

What **tools** support effective patients + clinicians conversations today?

What constitutes acceptable crisis treatment?

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?

Are there **consequences** to providing appropriate treatment? Are there consequences to *not* providing appropriate treatment?

How often are sickle cell patients subsequently **hospitalized** after visiting an ED?

How do ED/acute care physicians determine the appropriate dosage of pain medication to treat a pain crisis?

Community Health Workers

What **services** address mental health and other psychosocial needs for caregivers after a child's diagnosis?

What **services** are caregivers offered? Ideally, what **services** should caregivers be offered?

What does “**routine care**” look like to caregivers? What do they wish it looked like?

What does **comprehensive longitudinal care** for sickle cell disease look like? For patients? For caregivers?

What **self-management practices** are encouraged?

How are **children** enrolled in their own care? At what age?

What **services** address mental health and other psychosocial needs for patients? For caregivers?

What **stakeholders** are needed to deliver the necessary comprehensive care for pediatric patients? Caregivers, clinicians, CHWs, others? Where does this care take place?

How do CHWs **prepare** transitioning adults to manage their disease while in college? While employed?

What does **comprehensive longitudinal care** for sickle cell disease look like? For patients?

What **resources** are adults guided to? Which ones are they **influenced** by?

Ideally, what **services** should patients and families be offered?

What **stakeholders** are needed to deliver the necessary comprehensive care for pediatric patients? Caregivers, clinicians, CHWs, others? Where does this care take place?

What **services** address mental health and other psychosocial needs for patients?

What are commonly reported **barriers** to best practice self-management + drug adherence?

What should a typical ED visit look like for a patient with sickle cell?

Care harmonization tool

Coordinate longitudinal care between PCPs, specialists within and across different clinical settings

Pain passport

Clarify optimal pain management; foster effective communication between ED staff and patient

Empowerment tool (hydroxyurea)

Improve adherence, clarify benefits + regimen, provide patient support

Tool development

Multi-level design requirements

1. Content

readability and usability

2. User roles + needs

supporting stakeholders

3. Context of use

in-situ use: clinic, ED, home

Care harmonization tool

promotes regular longitudinal care and education of HCPs

What are the evidence based guidelines that need to be included?

What other components does the tool need to function well?

What is the appropriate level of readability and length for each stakeholder?

What are the informatics requirements to make this tool succeed?

Who are all the users of this tool?

What are the communication objectives for each user group of this tool?

What components does each user group need?

What constitutes an acceptable tool for each user group?

What are the best formats for this tool for each user in each setting?

What outcomes would justify use of this tool among patients and clinicians?

How can this tool facilitate the corresponding outcomes?

What are all the contexts of use for the tool?

What resources are needed to implement the tool with each user group?

What are the barriers / fit requirements to successful implementation of each tool?

What electronic tools are available in the clinic/acute care setting today that could help advance the goals of each tool?

Pain passport

an individualized pain management tool for use in the ED and hospital

What are the evidence based guidelines that need to be included?

What other components does the tool need to function well?

What is the appropriate level of readability and length for each stakeholder?

What are the informatics requirements to make this tool succeed?

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Empowerment tool

tracking hydroxyurea usage and providing feedback to patient and provider

What are the evidence based guidelines that need to be included?

What other components does the tool need to function well?

What is the appropriate level of readability and length for each stakeholder?

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