HOW CAN WE INCREASE KNOWLEDGE RETENTION BY IMPROVING THE QUALITY OF EDUCATIONAL MATERIALS TO ENSURE ACCURATE RECEPTION OF SICKLE CELL TRAIT EDUCATION?

SICKLE CELL TRAIT NBS EDUCATIONAL KIT

Create materials for NBSCs and parents that are easy to understand, culturally appropriate, scalable, and sustainable.

WHEN:

Fall 2023

SKILLS INVOLVED:

Primary Research
Interviews
Benchmarking
Secondary Research
Service Mapping
Animation

SPONSOR TEAM

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> “There are misconceptions and false information spread around the community about SCT. We need to standardize materials to disseminate accurate information to NBSCs and families.”
> - Physician

> “I learned (in the consultation) that sickle cell trait was there to protect against malaria and it is inherited. It is not my fault that my child has sickle cell trait.”
> - Parent

Most individuals with sickle cell disease and sickle cell trait are diagnosed at birth with universal newborn screening (NBS). However, there is considerable variability in how families receive this information from state departments of health follow-up programs, primary care providers, and even community-based organizations. There is often a gap in knowledge and self-confidence in sharing information, as there are no certifications or evidence-based best practices for NBS coordinators. There are also cultural and social determinants of health factors that should be considered when providing this information to families and should be integrated into NBS training.

Research

The team conducted 10 interviews with partners, Newborn Screening Coordinators, and parents to understand the current landscape of sickle cell trait (SCT) education. To complement the primary research, the team benchmarked current sites, videos, websites, handouts, and physical kits that explain SCT. In addition, after gaining functional literacy the team began visualizing maps to help partners and LWC staff gain a contextual understanding of sickle cell trait education.

Ideation

From the research, the team synthesized educational content necessary for NBSCs and families. NBSCs will require a guidebook, standard operating procedures, and a counseling presentation for families. Meanwhile, families need a one-pager and video animations that highlight key information about sickle cell trait. To achieve this, the team brainstormed ideas for font, color, and character style that could be uniformly applied across the educational materials. Throughout the process, the LWC team collaborated with the partner team on educational content, storyboard order, and the selection of the appropriate style to proceed with.

Tools Used:

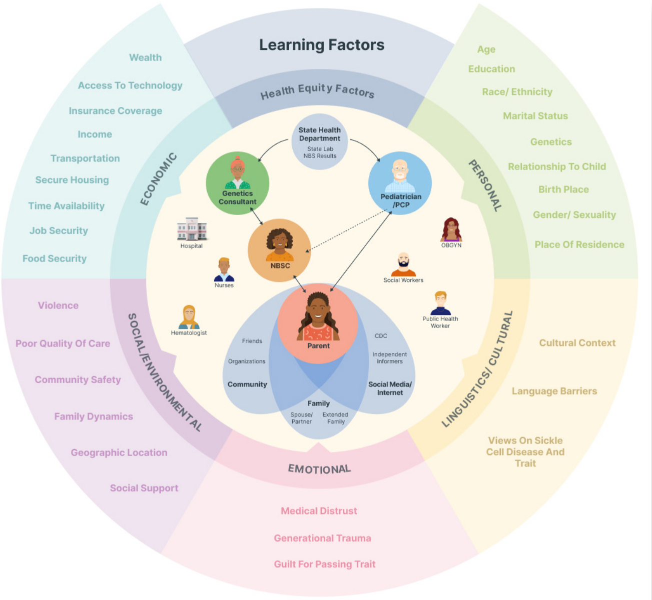
1. **User Validation Interview**
   This approach validated the essential messages in storytelling and video creation.
2. **Stakeholder Map**
   An overview that visualized the situations and stakeholders surrounding families of children with SCT.
3. **System Mapping**
   Used to provide a simplified conceptual understanding of a complex system that was used to understand the SCT follow up process.

Refinement

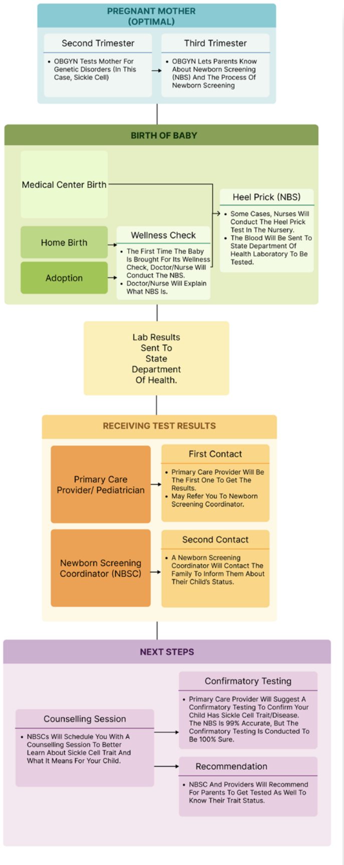
During the refinement phase, the team organized 8 validation sessions involving NBSCs, families, and LWC team members. Participants were prompted to highlight their main takeaways from the slideshow, confirming the team's success in conveying key messages about sickle cell trait: Clarifying that it is not sickle cell disease, it is inherited, and cannot transform into the disease. Additionally, the team consulted with CCHMC hemoglobinopathy trainers to validate the content for the NBSC SOP and guidebook.

Key Benefits of Deliverables:

01. Animation: Universal education for NBSCs.
02. Takehome one pager: For families to reference later.
03. Guide and Counseling Presentation: Helps to counsel families effectively and sensitively.
04. SOP and Counseling Presentation : Provides educational resources for NBSCs to reference.



Stakeholder map that includes the people involved, as well as external factors that may impact how information is recieved and shared.


PREGNANT MOTHER (OPTIMAL)

Second Trimester
- OBGYN Tests Mother For Genetic Disorders (In This Case, Sickle Cell)

Third Trimester
- OBGYN Lets Parents Know About Newborn Screening (NBS) And The Process Of Newborn Screening

BIRTH OF BABY

Medical Center Birth

Home Birth

Adoption

Wellness Check
- The First Time The Baby Is Brought For Its Wellness Check, Doctor/Nurse Will Conduct The NBS.
- Doctor/Nurse Will Explain What NBS Is.

Heel Prick (NBS)
- Some Cases, Nurses Will Conduct The Heel Prick Test In The Nursery.
- The Blood Will Be Sent To State Department Of Health Laboratory To Be Tested.

Lab Results Sent To State Department Of Health.

RECEIVING TEST RESULTS

Primary Care Provider/ Pediatrician

First Contact
- Primary Care Provider Will Be The First One To Get The Results.
- May Refer You To Newborn Screening Coordinator.

Newborn Screening Coordinator (NBSC)

Second Contact
- A Newborn Screening Coordinator Will Contact The Family To Inform Them About Their Child's Status.

NEXT STEPS

Counselling Session
- NBSCs Will Schedule You With A Counselling Session To Better Learn About Sickle Cell Trait And What It Means For Your Child.

Confirmatory Testing
- Primary Care Provider Will Suggest A Confirmatory Testing To Confirm Your Child Has Sickle Cell Trait/Disease. The NBS Is 99% Accurate, But The Confirmatory Testing Is Conducted To Be 100% Sure.

Recommendation
- NBSC And Providers Will Recommend For Parents To Get Tested As Well To Know Their Trait Status.

System map of the Newborn Screening process from before birth to after follow up.

Where is it now?

The Sickle Cell Center will begin to share the resources at the annual hemoglobinopathy training.