

A Design Thinking Approach to Developing Educational Materials for Families about Sickle Cell Trait

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Introduction

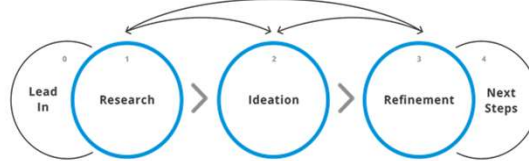
Sickle cell disease (SCD) is an inherited blood disorder affecting over 100,000 people in the United States. Most individuals with SCD and sickle cell trait (SCT) are diagnosed at birth with universal newborn screening (NBS). However, there is considerable variability with how families receive this information from state departments of health follow-up programs, primary care providers, and even community-based organizations. Moreover, there are not certifications for NBS coordinators, studies have shown that there is often a gap in knowledge and self-confidence in providing this information, as well as there are no evidence-based best practices or standards for what information should be delivered to families. 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.

The Cincinnati Comprehensive Sickle Cell Center (CCSCC) has hosted a Hemoglobinopathy Counselor Training Course for over 20 years, and it is one of the only such programs in the country. Pre-test and post-test data from the course has identified several gaps in knowledge and comfort levels among those doing frontline NBS counseling and demonstrated a clear need for an interactive training platform and companion materials to educate families.

Methods

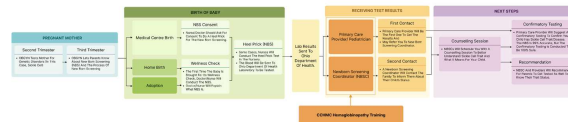
The CCSCC partnered with the Live Well Collaborative (LWC) to co-develop interactive toolkit to 1) develop culturally-sensitive, interactive training for NBS educators and 2) design educational aids for NBS educators to use when educating families.

During a 15-week semester, LWC used a validated design thinking process to translate user centered research into products and services that meet the needs of the end user.



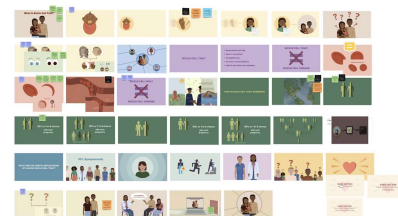
Phase 1 - Primary & Secondary Research + Benchmarking

- Benchmark existing educational tools
- Conduct Interviews with stakeholders
- Identify themes from interviews



Phase 2 - Ideation + Co-Creation Sessions

- Develop tools for co-creation sessions
- Translate insights from research phase into potential solutions
- Test prototypes with original stakeholder groups



Phase 3 - Refinement of Concept Development

- Concept refinement with stakeholder groups
- Build out strategies

Results

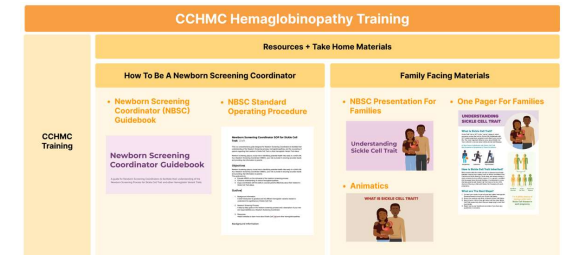
The multi-step co-design process culminated in several educational materials, that are easy to understand, culturally appropriate, scalable, and sustainable.

NBS Coordinator Education –

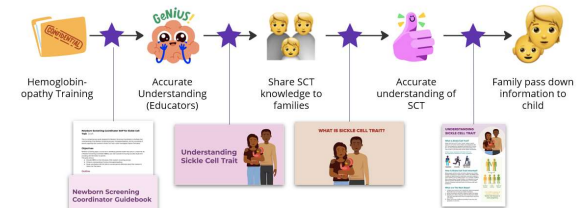
- SOP for documentation
- NBS Coordinator Guide Book

NBS Coordinator Guide for Families –

- Animatics
- NBS Coordinator Presentation for Families
- One Pager for Families



The materials provide educational interventions at several different time points in the education process.



Conclusion

There is the opportunity for this resource to be rapidly spread to NBS coordinators throughout the Ohio Department of Health Regional Sickle Cell Program across Ohio (PI: Shook) and an eight-state (Ohio, Indiana, Illinois, Michigan, Minnesota, North Dakota, South Dakota and Wisconsin) regional learning network (PI: Shook). This toolkit will also become a fundamental component of the Hemoglobinopathy Counselor Training program beginning in April 2024. Evaluation components (demographics, user satisfaction, and change in practice) will be integrated into the implementation process as well to ensure sustainability of the program.

Acknowledgements

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