A Design-Thinking Approach To Developing An Educational Sickle Cell Trait Website

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• Sickle cell trait (SCT) affects at least 3 million people in the US, primarily African-Americans.
• Studies have shown that few individuals know they have SCT.
• Babies in all 50 states are now tested at birth.
Background

- Primary care providers often do not have the newborn screening test results.
- Children may change primary care providers as they get older and records may not follow.
- Parents often do not understand or remember to share information about SCT with their child during adolescence.
**Background**

- Important to **share SCT status with teens** during the key period when decisions about future reproduction may be made.

- Two people with SCT may have a child with **sickle cell disease**.
Develop an interactive web-based tool that provides health information about sickle cell trait.
Methods

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Findings and Insights

Visual Inspiration
Interviews

5 healthcare providers
1 athletic trainer
3 individuals with SCT
Interview Findings

Doctor Findings
- Identification of SCT at birth is not surprising for most parents
- Most people with SCT are unaffected in every day life
- Minimal discussion of Sickle Cell Trait amongst family members and doctors
- Lack of reliable information

Athletic Trainer Findings
- Has had experience with SCT-carrying athletes and have never had an issue with the trait affecting performance
- Has never had to refer an athlete to a doctor

SCT Carrier Findings
- Reliable website/digital tool would be helpful and easier than visiting the sickle cell clinic
- Lack of clarity in the difference between sickle cell trait and sickle cell disease
- Discussion isn’t made a priority unless someone in the family has sickle cell disease

Cincinnati Children’s
Community Research

SCD Research Day
UC Health Fair Findings

59 Students

41 Females

18 Males

Never heard of SCT

86.5%

13.5%

Never been tested

SCT Carriers

88%

3%

Do not know

Aware of parents’ SCD/SCT Status

90%

10%

Do not know
Literature Findings

“For more than 3 decades, individuals with SCT have been identified. Despite widespread screening neonatally, prenatally, and in the community, we found significant misinformation about what it means to be a carrier and its health and reproductive implications. The misinformation is usually transmitted by well-meaning family members. … Additionally, to break the cycle of misinformation that is transmitted by and within families, the development and evaluation of alternative educational modalities that promote genetic literacy are needed.”

Kruti Acharya, MD; Colleen Walsh Lang, BA, BS; Lainie Friedman Ross, MD, PhD, A Pilot Study to Explore Knowledge, Attitudes, and Beliefs about Sickle Cell Trait and Disease, Journal of the National Medical Association, vol. 101, Nov 2009, pg. 1163.

“Open communication regarding hemoglobinopathy trait status not only leads to increased awareness of the general information but also promotes an attitude of personal responsibility and ownership of the information.”

“Research on celebrity activism indicates we tend to listen to what to celebrities have to say and view their public involvement as beneficial to society; we view celebrities as a cultural authority.”


Benchmarking Findings

- Write well
- Avoid boring content and entertainment overload
- Keep it uncluttered
- Make it snappy
- Don’t talk down to teens

- Let teens control the social aspect
- Design for smaller screens
- 3 Target audiences (kids, teens, young adults in family planning) stage
- Feature real stories
- Digital Campaign

Teen Health
Asbestos Disease Awareness Organization
Duo Lingo
Sickle Cell Trait...
It's Not The Same As Sickle Cell Disease...

People with sickle cell trait do not experience any of the same symptoms as people with sickle cell disease. READ MORE
What does it mean to have SICKLE CELL TRAIT?

http://sicklecelltrait.org/img/WhatIsSCT.mp4
The Geno Atkins Story

https://youtu.be/cMjBS7f13Os
Website Analytics

Launched - January 1, 2015

In first month, 150 unique users with 459 unique page views.

Users from US, Brazil, and Africa spent an average of 2 minutes and 30 seconds per page.
Website Analytics

991 unique users have accessed website
125 returning visitors

Average viewing time per page is 2.06 minutes

Most viewed pages after “Home Page”:
• Teens (60%)
• Parents (17%)
• Family Planning (14%)
• Athletes (9%)
Value of using a Design Thinking Approach

- Collaborative process
- Multi-disciplinary team approach
- User-centered research methods allow for collection of unique insights/needs
- Designers translate these insights into visualizations/prototypes of possible solutions
- Iterative process allows for user testing and refinement
Conclusions

• National literature review and local data collection suggest knowledge gaps about SCT among teens/young adults.

• User-centered website sicklecelltrait.org is anticipated to facilitate education.

• Next step is to develop a plan to inform healthcare providers, coaches, schools and community based-organizations about the website.