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

SICKLE CELL
TRAIT
AWARENESS

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Background

- 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**.

Project Goal

Develop an interactive web-based tool that to provide health information about sickle cell trait.

Methods

Primary Research

Secondary Research

Interviews

Recruitment & Surveys

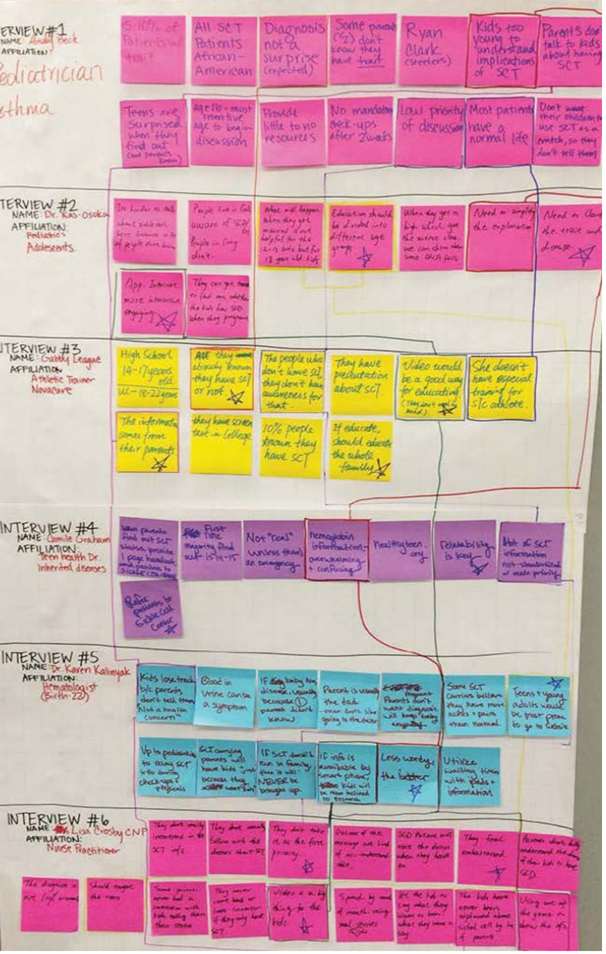
Literature Review

Benchmarking Websites

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

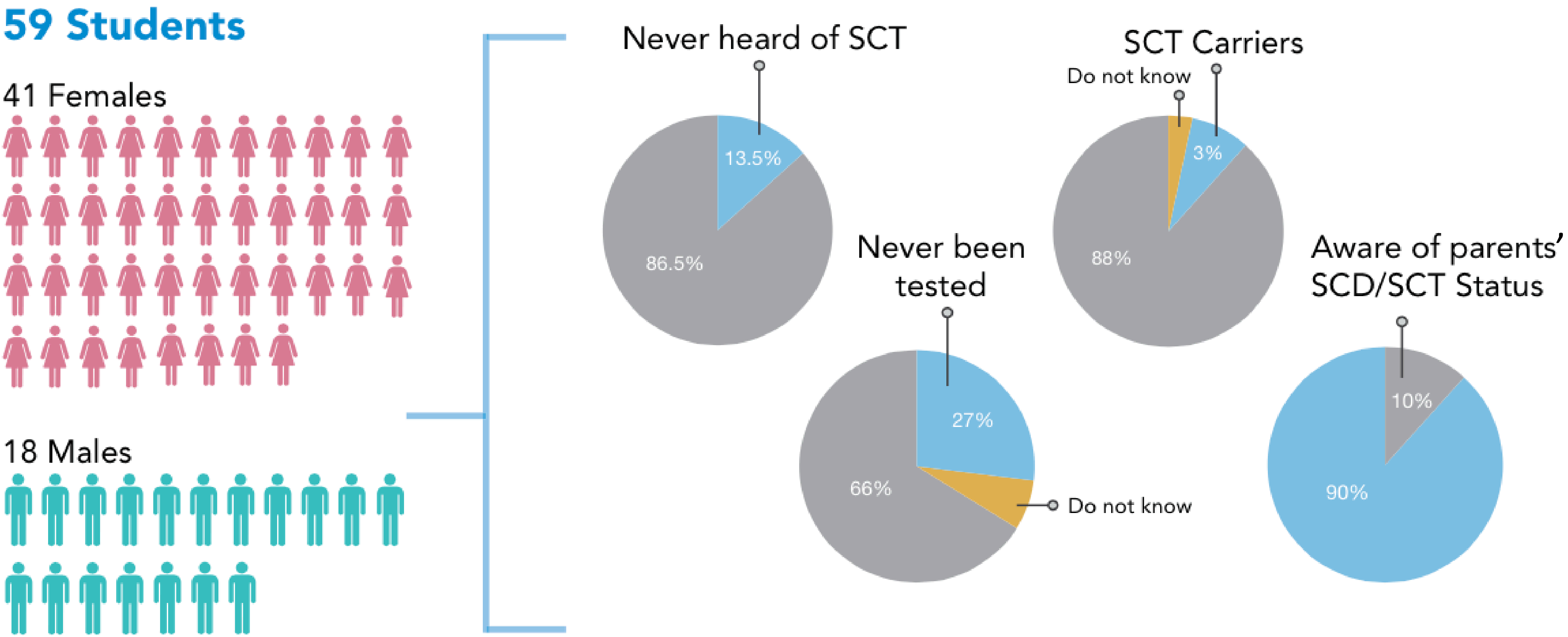
SCT Carrier Findings

- 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

Community Research

SCD Research Day

UC Health Fair Findings



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.”**

Laird L, Dezateux C, Anionwu EN. Neonatal screening for sickle cell disorders: what about the carrier infants? BMJ 1996;313:407– 411.

Use of Celebrity Spokesperson

Geno Atkins

"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.**"

Bell, K. (2013). Celebrity as cultural authority: Media, representation and the politics of fame. Dissertation Abstracts International Section A, 74.
Choi, C., & Berger, R. (2010). Ethics of celebrities and their increasing influence in 21st century society. Journal of Business Ethics, 91, 313-318.
Duvall, S. (2011). From walking the red carpet to saving the world: Global celebrity, media, and commodity activism. Dissertation Abstracts International Section A, 71.
Tufekci, Z. (2013). "Not this one": Social movements, the attention economy, and microcelebrity networked activism. American Behavioral Scientist, 57, 848-870.

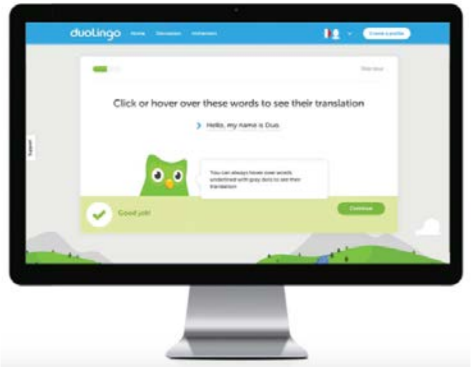
Benchmarking Findings

- 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

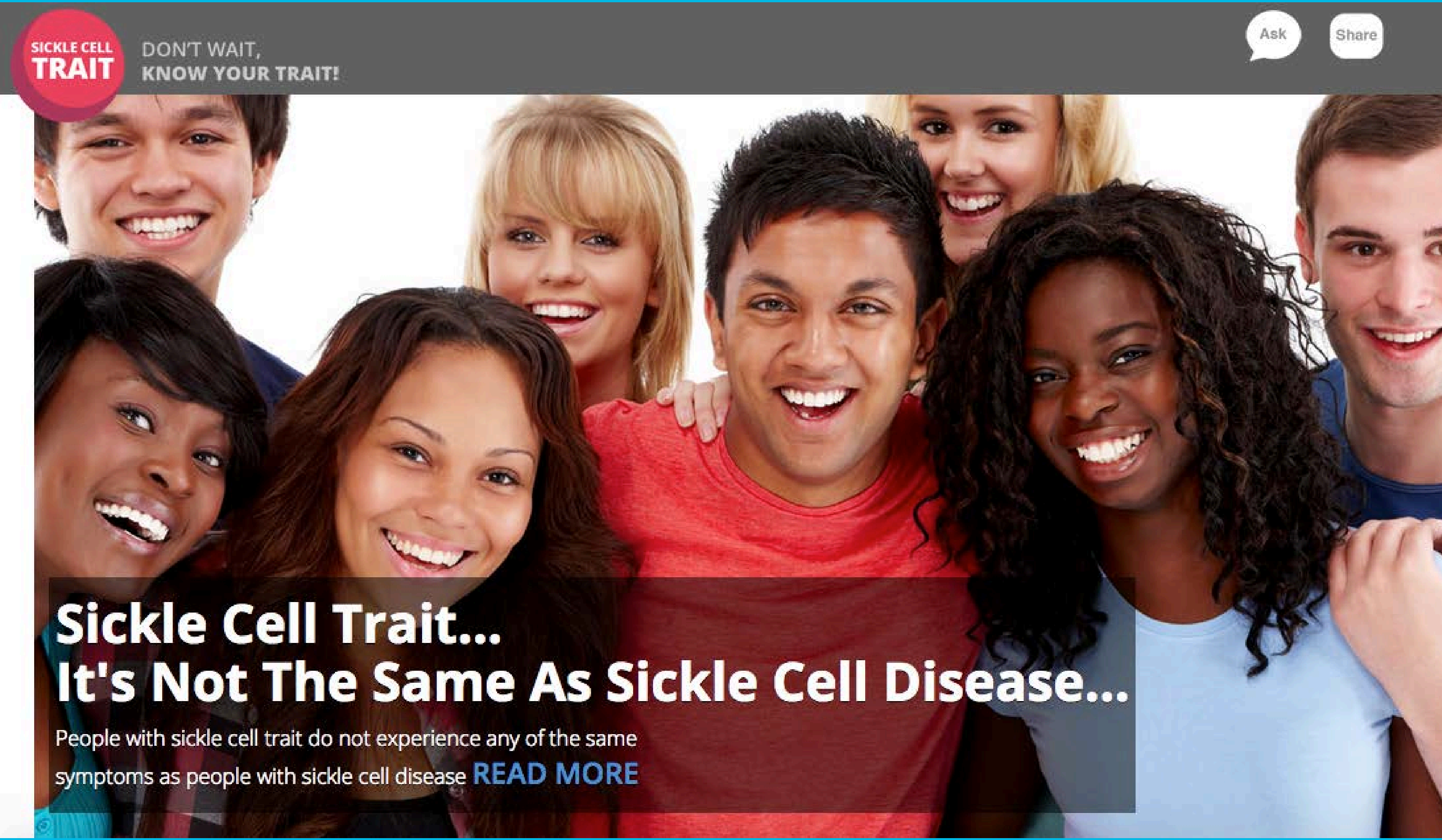
Asbestos Disease Awareness Organization



Click or hover over these words to see their translation

Duo Lingo

sicklecelltrait.org



DON'T WAIT,
KNOW YOUR TRAIT!

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

sicklecelltrait.org

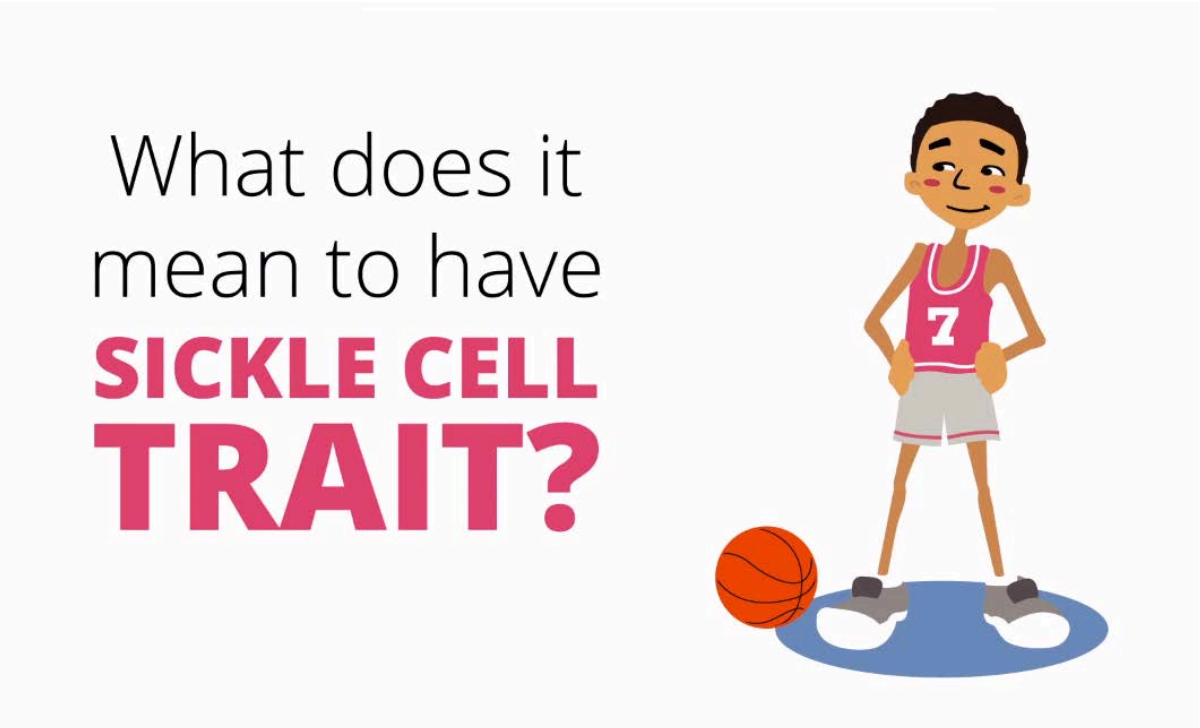
Teens
&
Young Adults

Parents
&
Families

Pregnancy
&
Family Planning

Athletes

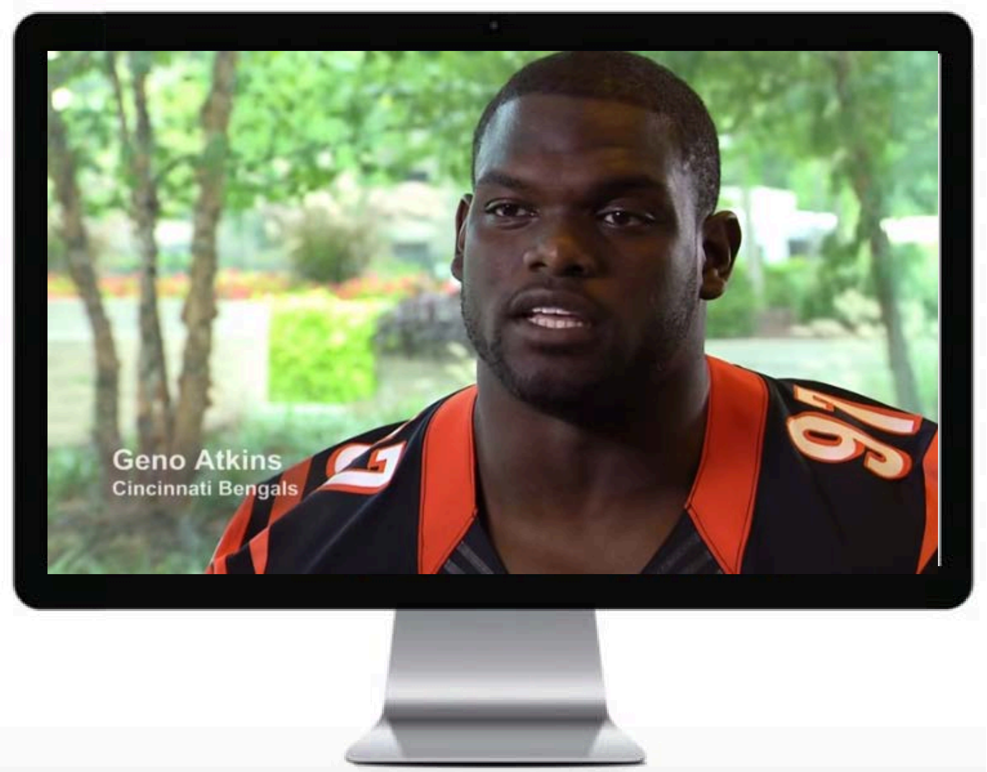
sicklecelltrait.org



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
Jan. 1, 2015 – May 10, 2015

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.