

Reboot, Reframe and Re-envision: Advancing Health Equity within Behavioral Science

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July 25, 2024

Positionality Statement

I acknowledge the potential influence that my viewpoint as an educated, Black, English-speaking, able-bodied, American, and cis-gender female has on my research and teaching.



Acknowledgements

- Parent and Young Adult Partners
- Community Partners/CABs
- SCD Teams
- LiveWell Collaborative & Design Students
- Kamilah Wood, MD
- Emily McTate, PhD
- Amy Beck, PhD
- Monica Mitchell, PhD
- Soumitri Sil, PhD
- Farrah Jacquez, PhD



Learning Objectives

Discuss the importance of centering the lived experiences of patients and communities in research endeavors aimed at advancing health equity within behavioral science.

Identify strategies for actively involving individuals with lived experiences and communities throughout the entire research process, to enhance scientific rigor and impact.

Understand the importance of reframing conceptual frameworks and adopting methodologies targeting social and structural determinants of health to advance health equity.

Leading with Lived Experience

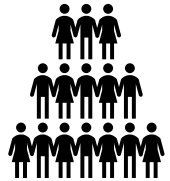


REBOOT

INNOVATION AND DESIGN THINKING IN BEHAVIORAL SCIENCE



Sickle Cell Disease (SCD)



Genetic blood disorders affecting approximately **100,000 people in U.S.**



Single **most common inheritable** disease **worldwide**



Highest prevalence among individuals of **African ancestry**



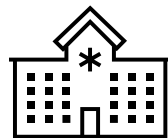
1 in 500 Black Americans have SCD



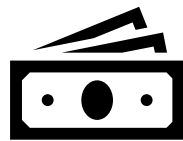
Racial Bias & Stigma in SCD



Provider bias leads to the underassessment and under-management of pain in Black Americans

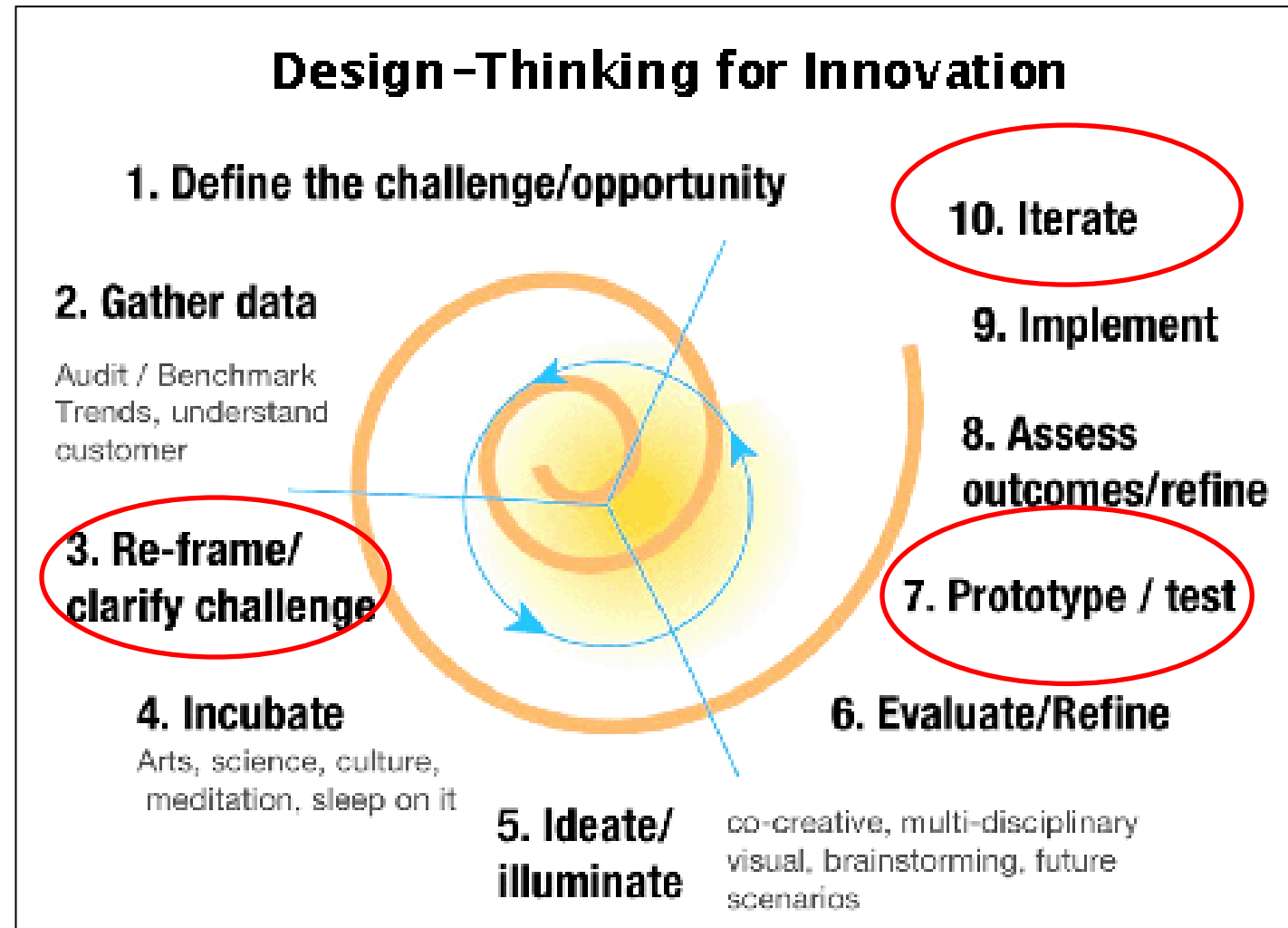


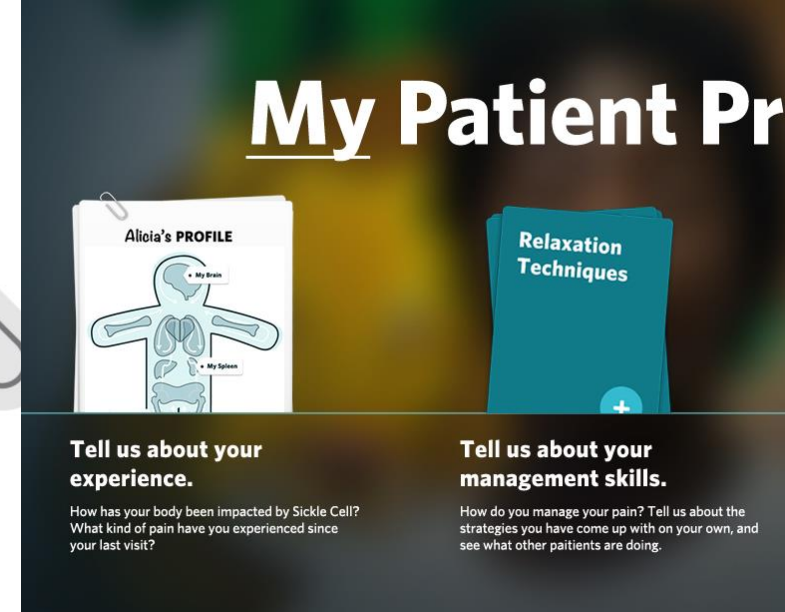
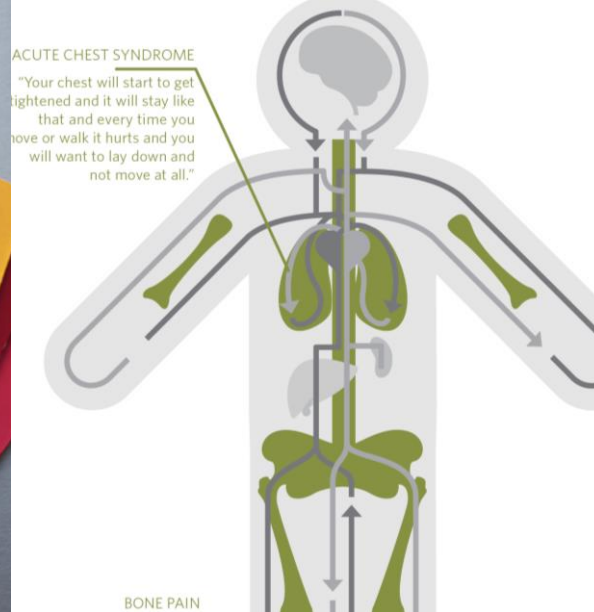
Direct and indirect consequences of stigma on **social, psychological, and physiological** health in SCD



Directly relate to **inequity of resources** for patients with SCD.

Design Thinking





Developing Patient and Provider Tools to Improve the Transition to Adult Healthcare for Adolescents with Sickle Cell Disease

NHLBI Grant#: 1K07HL108720

RESEARCH: UNDERSTAND

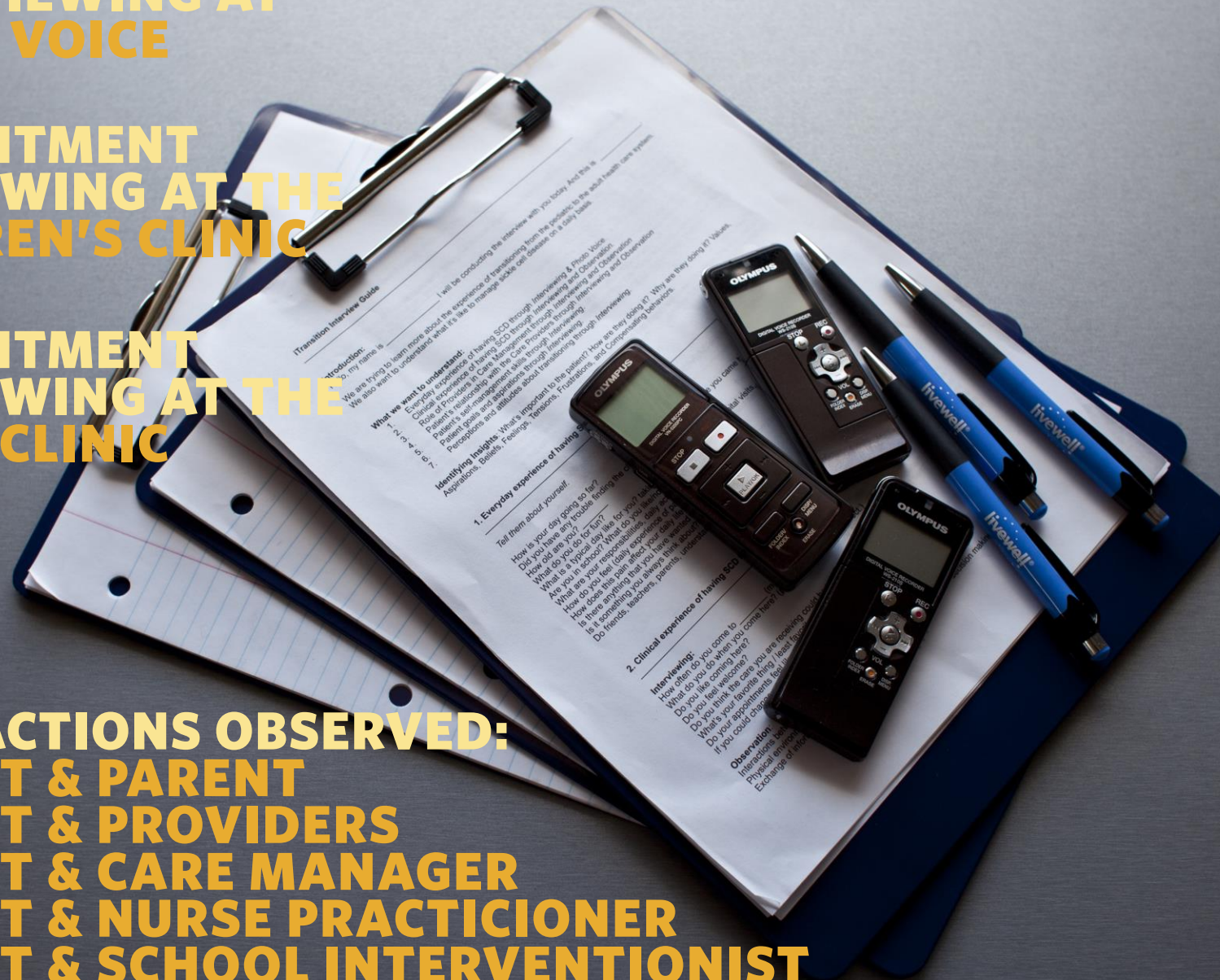
RESEARCH: SYNTHESIS

**INTERVIEWING AT
PHOTO VOICE**

**APPOINTMENT
SHADOWING AT THE
CHILDREN'S CLINIC**

**APPOINTMENT
SHADOWING AT THE
ADULT CLINIC**

**INTERACTIONS OBSERVED:
PATIENT & PARENT
PATIENT & PROVIDERS
PATIENT & CARE MANAGER
PATIENT & NURSE PRACTICIONER
PATIENT & SCHOOL INTERVENTIONIST**



**PATIENT MAPPING:
THEMES**

DAILY LIFE

FAMILY

CARE PROVIDER INTERACTION

ENVISIONING THE FUTURE

SELF MANAGEMENT

SOCIAL ASPECTS OF SCD

**ATTITUDES TOWARDS
TRANSITIONING**

IDENTIFYING OPPORTUNITY AREAS & IDEATE

HOW CAN WE...
HELP PATIENTS CONNECT SELF-
MANAGEMENT SKILLS TO THE
FUTURE THEY ENVISION FOR
THEMSELVES?



ANTOINE
AGE: 21 / TRANSITIONING

i refuse.

"I know I'm ready. I just **don't want to go**. I can accept that fact."



LELEITA
AGE: 22 / TRANSITIONED

i trans sition.

PAIN

PAIN RATIN
Leleita suffers
Rates her pain

MANAGEMENT

UNDERSTAN
Leleita has a
causes her le

MEDICATION
Post-it notes
of medical int

"I didn't feel prepared...but I wouldn't say
I felt ambushed."

Conclusions & Next Steps

Model for how healthcare and design teams can work together to address major health care challenges

Achieved goal of developing patient-centered tools*

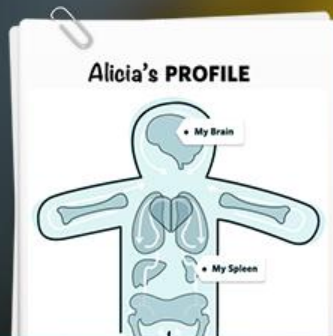
Prototypes of tool were tested and evaluated with patients and providers

R21 Grant application to test the tool with a larger population

CONCEPT & PROTOTYPE REFINEMENT



My Patient Profile



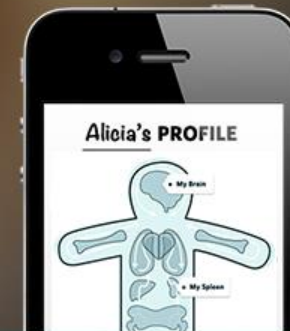
Tell us about your experience.

How has your body been impacted by Sickle Cell?
What kind of pain have you experienced since your last visit?



Tell us about your management skills.

How do you manage your pain? Tell us about the strategies you have come up with on your own, and see what other patients are doing.



Talk to your doctor.

Print out your profile or save it on your phone, and use it at your next visit to tell your practitioners how you have been doing.



SC | MANAGE

Let's get going! Choose what you want to learn about first:

- Know Your Pain Triggers and Treatments
- It's a total pain. You should talk about it.
 - No reservations



Pain Triggers

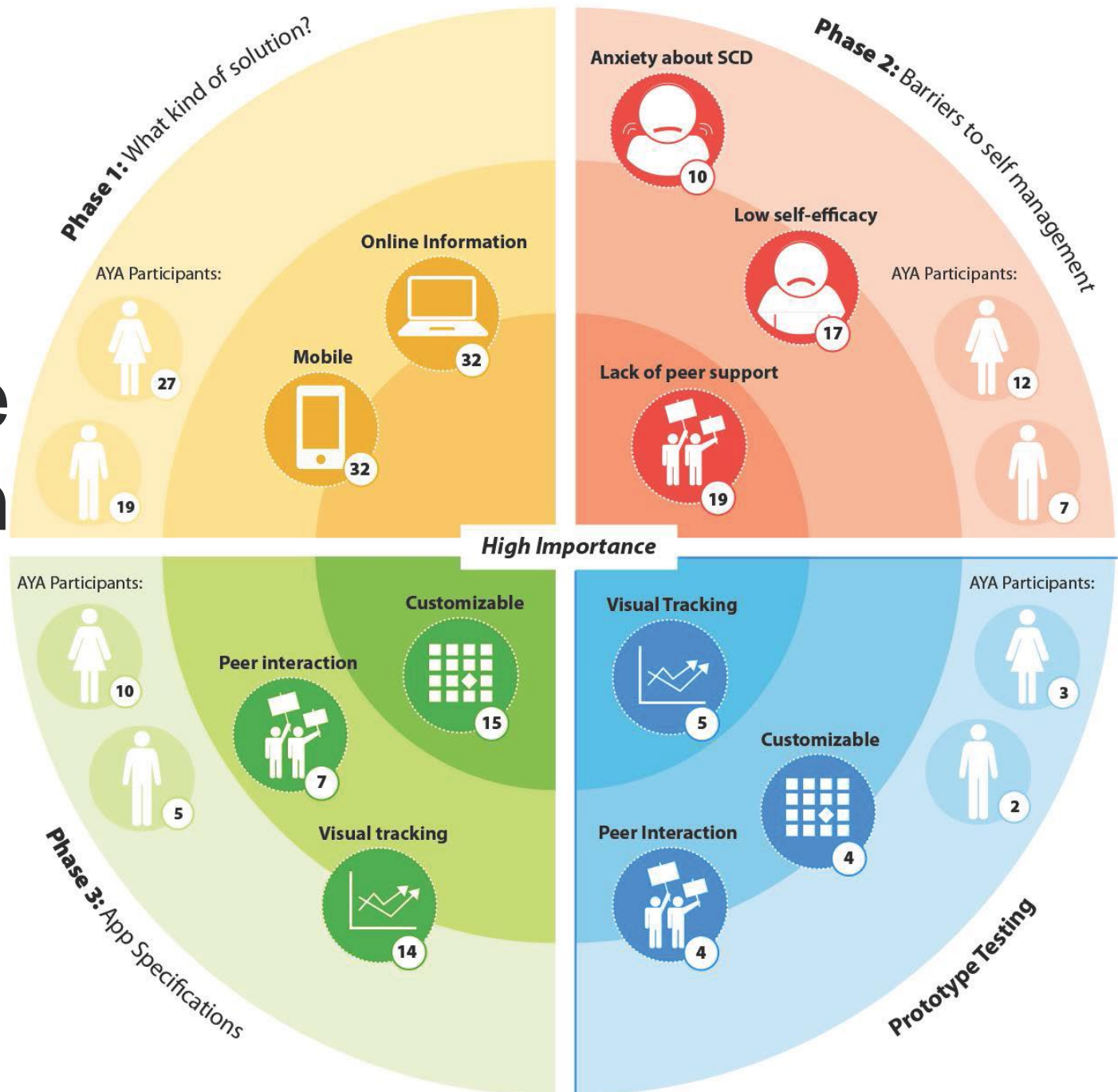
Know Your Pain Triggers and Treatments

0 of 5 goals



imanagescd

Studies to understand needs and develop the intervention



This approach increases the **relevance**, **rigor** (feasibility), and **reach**. In their own words . . .



Paradigm Shift



RE-ENVISION

01

Social and Structural
Determinants



02

Context



03

Dynamics



04

Multilevel





Engaging the Community

Individuals with lived experience, collaborative organizations, and others who may influence the work

NOTHING

ABOUT US

WITHOUT US

Anti-Racism



- The practice of actively identifying and opposing racism.
- The goal of anti-racism is to ***actively change*** policies, behaviors, and beliefs that perpetuate racist ideas and actions.

Community-Engagement



- a **strategic process** with the specific purpose of **working with identified groups of people to identify and address issues affecting their well-being.**
- the focus is not on the individual but the **collective**, with consideration for the **diversity that exists within any community.**



Anti-Racism & Community Engagement Strategies

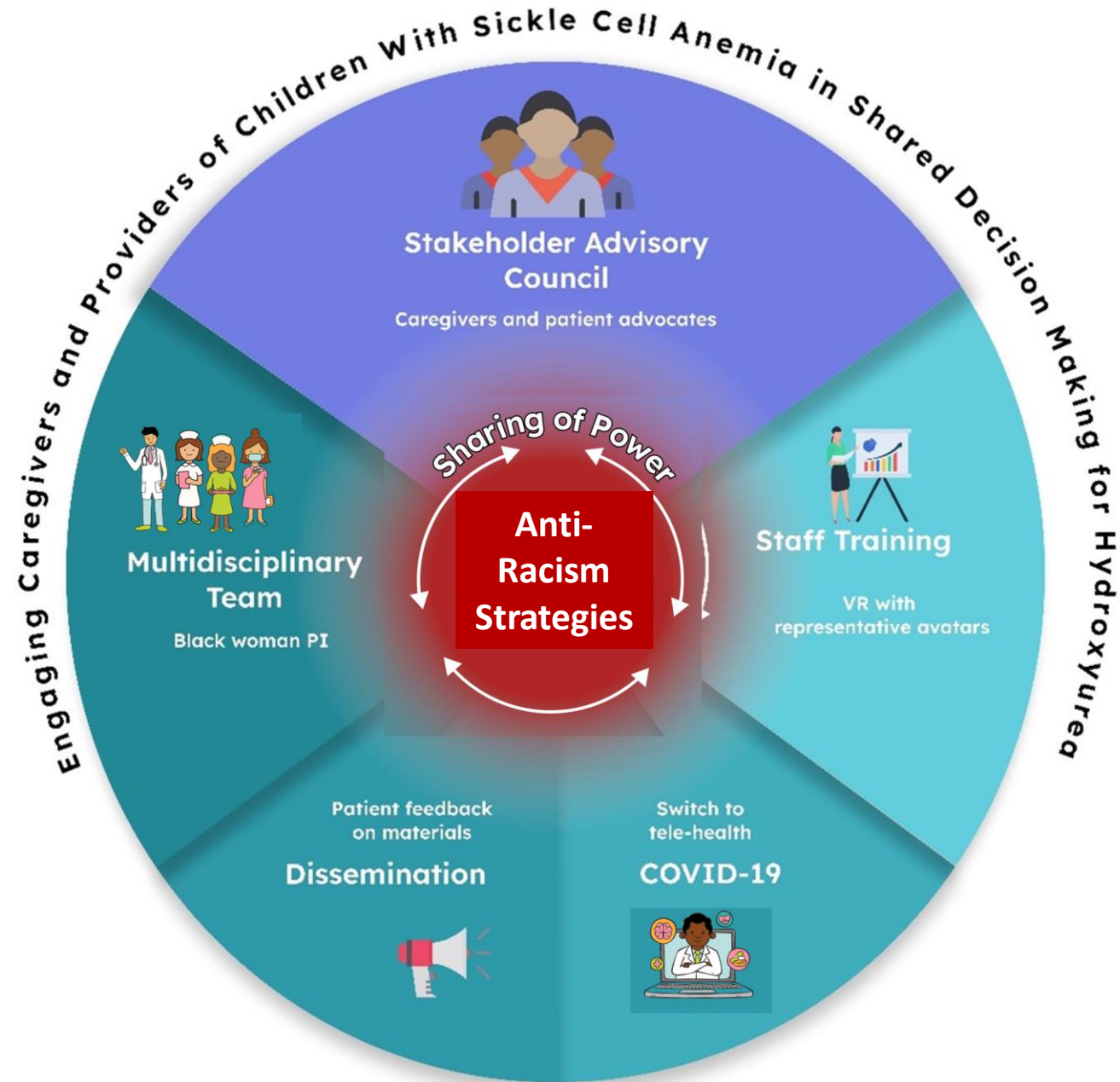


**Partnering with community
in all phases of the research**



Using research findings to
inform health
practices/policies

Engage HU



Williford, D. N., McTate, E. A., Hood, A. M., Reader, S. K., Hildenbrand, A. K., Smith-Whitley, K., ... & Crosby, L. E. (2022). Psychologists as Leaders in Equitable Science: Applications of Anti-Racism and Community Participatory Strategies in a Pediatric Behavioral Medicine Clinical Trial. *American Psychologist*.

Investigative Team



People of Color



Trainees to Senior Faculty (Students of Color)



Multiple Disciplines



Community Partners/Collaborators

Study Design: Stakeholder Advisory Council

- Study Design
 - Stakeholders felt it was important to collect prescription data from families who initiate hydroxyurea (e.g., picture of prescription bottle) because this was an important outcome of shared decision-making

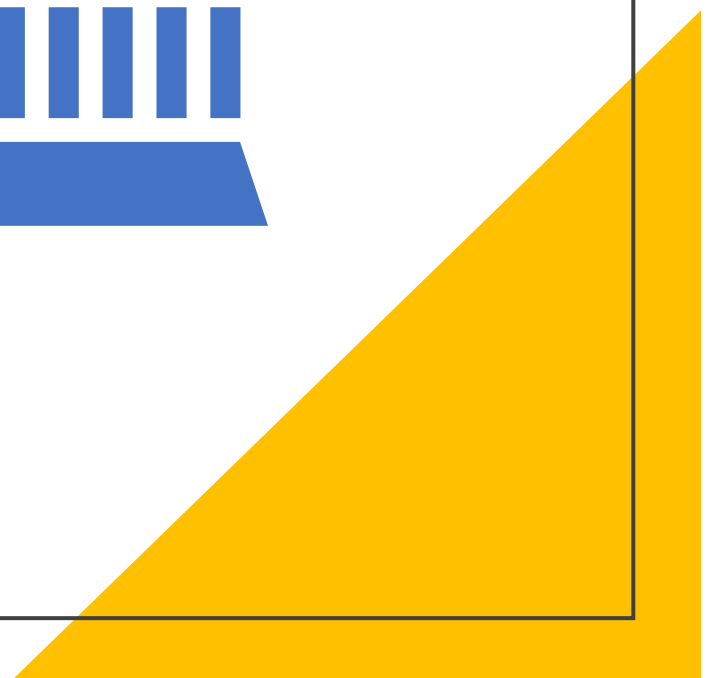


Staff Training & Study Culture

- Study Culture
 - Inclusive and respectful – everyone has something to contribute
 - Everyone succeeds – Team expectation
 - Cultural Humility
 - Inclusive Communication
 - Anti-Racist Lab



Telehealth: Access & Quality of Care



Co-Dissemination

Community Partner

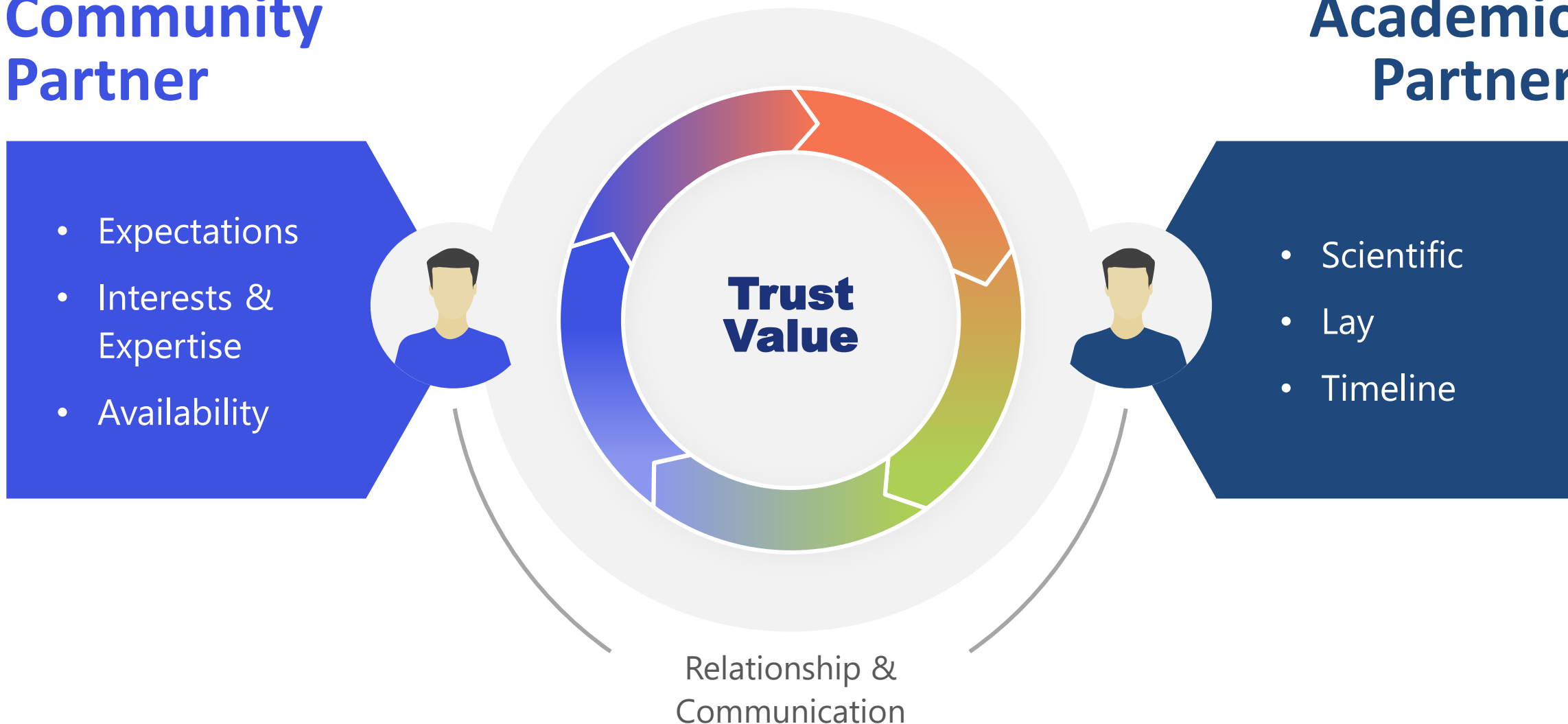
- Expectations
- Interests & Expertise
- Availability

Academic Partner

- Scientific
- Lay
- Timeline

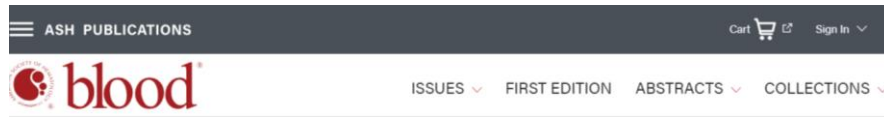
**Trust
Value**

Relationship &
Communication



Co-Dissemination

- Presentations



904.OUTCOMES RESEARCH-NON-MALIGNANT CONDITIONS | NOVEMBER 15, 2022

Optimizing Shared Decision Making about Hydroxyurea in Young Children with Sickle Cell Anemia

Aimee K. Hildenbrand, Allison A. King, Constance A Mara, Yolanda Johnson, Lisa M Shook, Catharine Whitacre, Maria T Britto, Charles T. Quinn, William Brinkman, Rogelle Hackworth, Jean L. Raphael, Vene N. Tubman, Alexis A. Thompson, Kim Smith-Whitley, Sherif M. Badawy, Susan E. Creary, Neha Bhasin, Marsha Treadwell, Steven K Reader, Angeli Rampersad, Amy Sobota, Lori E. Crosby

[Check for updates](#)

Blood (2022) 140 (Supplement 1): 10857-10859.

<https://doi.org/10.1182/blood-2022-167914>



901.Health Services Research-Non-Malignant Conditions

An Immersive Virtual Reality Curriculum for Pediatric Providers on Shared Decision Making for Hydroxyurea

Lori E. Crosby PhD¹, Francis J Real MD MD^{*2}, Bradley Cruse MFA^{*1}, David Davis MFA^{*1}, Melissa Klein MD MD^{*2}, Emily McTate PhD^{*2}, Anna M Hood PhD^{*3}, William Brinkman MD MD^{*2}, Rogelle Hackworth BS^{*4}, Charles T. Quinn MD⁵

- Publications

CLINICAL AND LABORATORY OBSERVATIONS

An Immersive Virtual Reality Curriculum for Pediatric Hematology Clinicians on Shared Decision-making for Hydroxyurea in Sickle Cell Anemia

Francis J. Real, MD, MEd^{*†}, Anna M. Hood, PhD[‡], David Davis, MFA[§], Bradley Cruse, MFA[§], Melissa Klein, MD, MEd^{*†}, Yolanda Johnson^{||}, Emily McTate, PhD^{*||}, William B. Brinkman, MD, MEd, MSc^{*†}, Rogelle Hackworth, BS, Kenyon Hackworth, DC, Charles T. Quinn, MD, MS^{*¶}, and Lori E. Crosby, PsyD^{*||}

Published on 21.5.2021 in Vol 10 , No 5 (2021) :May

Preprints (earlier versions) of this paper are available at <https://preprints.jmir.org/preprint/27650>, first published February 04, 2021.



Engaging Caregivers and Providers of Children With Sickle Cell Anemia in Shared Decision Making for Hydroxyurea: Protocol for a Multicenter Randomized Controlled Trial

Anna M Hood¹, Heather Strong², Cara Nwankwo³, Yolanda Johnson², James Peugh², Constance A Mara², Lisa M Shook^{4,5}, William B Brinkman^{4,6}, Francis J Real^{4,6}, Melissa D Klein^{4,6}, Rogelle Hackworth⁷, Sherif M Badawy^{8,9}, Alexis A Thompson^{8,9}, Jean L Raphael¹⁰, Amber M Yates¹¹, Kim Smith-Whitley^{12,13}, Allison A King^{14,15}, Cecelia Calhoun¹⁵, Susan E Creary¹⁶, Connie M Piccone¹⁷, Aimee K Hildenbrand^{18,19}, Steven K Reader^{18,19}, Lynne Neumayr^{20,21,22}, Emily R Meier²³, Amy E Sobota²⁴, Sohail Rana²⁵, Maria Britto^{4,26,27}, Kay L Saving²⁸, Marsha Treadwell²⁹, Charles T Quinn^{4,30}, Russell E Ware^{4,5}, Lori E Crosby^{2,4,27}

Clinical Trials



Impact Factor: 2.599 / 5-Year Impact Factor: 2.989

[JOURNAL HOMEPAGE](#)

Restricted access | Research article | First published online February 16, 2023

Using the consolidated framework for implementation research to identify recruitment barriers and targeted strategies for a shared decision-making randomized clinical trial in pediatric sickle cell disease

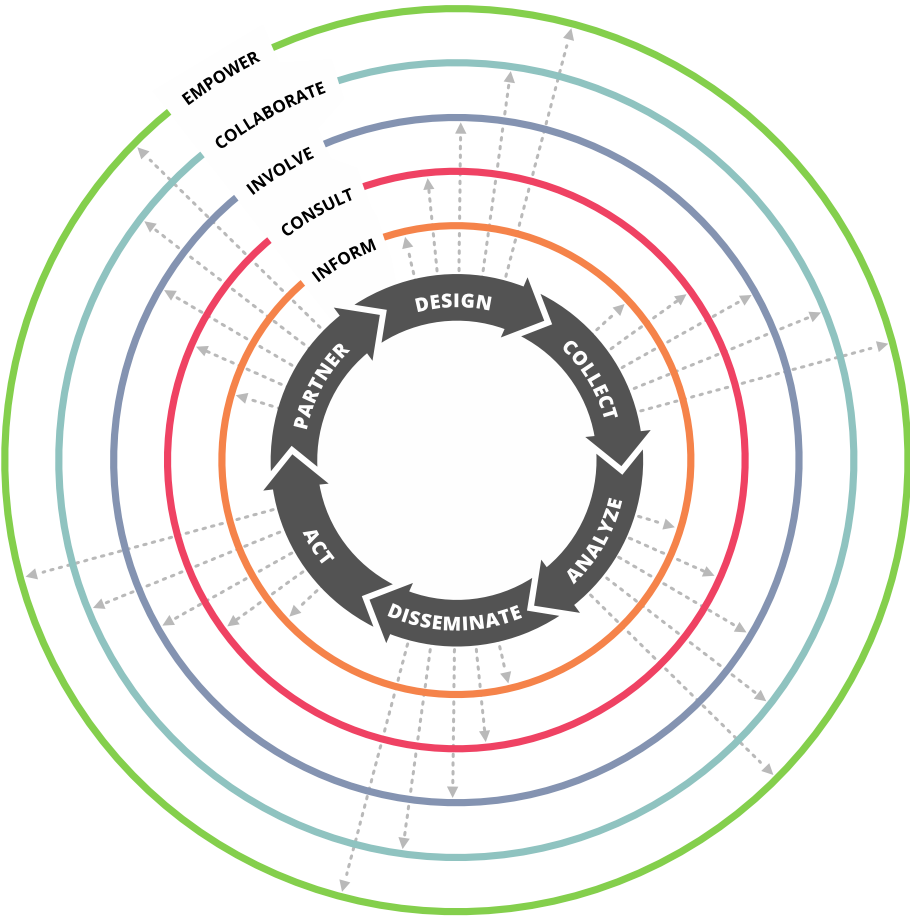
Heather Strong[✉], Anna M Hood[✉], L., and Lori E Crosby[✉] [View all authors and affiliations](#)

[OnlineFirst](#) | <https://doi.org/10.1177/17407745231154199>

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Participation Choice Points in the Research Process

At each step in the research process, there is a choice about the degree of participation. The choice guides the selection of research methods and tools.



INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
Information is provided to community	Input is obtained from community	Researchers work directly with community	Community is partner in research process	Community leads research decisionmaking

Levels of participation based on:
Spectrum of Public Participation, © International Association for Public Participation www.iap2.org

Figure from:
Vaughn, L. M., & Jacquez, F. (2020). Participatory research methods—Choice points in the research process. *Journal of Participatory Research Methods*, 1(1), 13244.



Anti-Racism & Community Engagement Strategies



Partnering with community organizations and stakeholders to address myths and promote health



Using research findings to inform health practices/policies

ATTACH Study

[Join the Study](#) [Resources](#) [ATTACH Study Polls](#)



Attitudes About COVID-19 And Health (ATTACH)

[Learn More](#)

Study Team

Lori E. Crosby

Monica J. Mitchell

Melina Butsch-Kovacic

Stacey Gomes

Sharon Watkins**

Amy Noser

Catharine Whitacre

Jennifer Allen

Anna Hood

Nadia Corral

ATTACH



Study Aims

- **Aim 1.** Examine COVID-19-related attitudes and beliefs and how they relate to adherence to mitigation strategies (handwashing, wearing masks, social distancing) and anxiety by demographic characteristics (race/ethnicity, age, essential worker status).

***Real-time data that can be used to address interventions to reduce disparities and inequities**

Target Population

- Adults >18 years old in Hamilton County
- Oversample the Black and African-American Community



Community Advisory Board



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- Hamilton County Community Action Agency
- Black Nurses Association of Greater Cincinnati
- Center for Closing the Health Gap
- Fatherhood Collaborative
- Su Casa
- The Community Builders
- Urban League
- West End Community Advisory Board

Study
Website

ATTACH Study

[Join the Study](#)

[Resources](#)

[ATTACH Study Polls](#)



ATTACH Study Resources

COVID-19 is one of the greatest public health challenges of our time and has changed all aspects of our daily lives.

We understand that people want scientifically driven information but navigating multiple websites can be challenging.

This page will be updated regularly with resources and guidance from the CDC.

Infodemic

COVID-19 VACCINES

CCTST | Center for Clinical
& Translational
Science & Training

VACCINE MYTHS

VACCINE FACTS

Vaccines were rushed and are not safe.



No safety shortcuts were taken. Thousands of people participated in the studies.

There were not enough people of color or people in my age group in the vaccine studies.



The vaccine has been shown effective in all ages and races including African-Americans, Hispanic/Latinos and Native Americans.

It has severe side effects, including death.



For most people, side effects are mild and go away in 1-2 days. There were no reported deaths in the vaccine studies. Side effects are continuing to be monitored.

It can give you COVID.



The vaccine does not contain a live virus.

It can make you infertile.



There is no evidence that it causes infertility.

It can change your DNA.



It is impossible for the vaccine to change your DNA.

It does not protect against the new COVID-19 variants.



Initial data suggest that the vaccines approved for emergency use are protective, but this will continue to be monitored.

Kids cannot be vaccinated.



The emergency authorization for the Pfizer vaccine is for ages 16 and older. Studies are being conducted for children ages 12 and up and more studies will be starting soon.

There are 2 vaccines - one for the white community and one for other communities.



ALL vaccines have been good (>85%) at preventing moderate-severe disease from COVID-19.

The vaccine will cost a lot of money.



The vaccine is free.

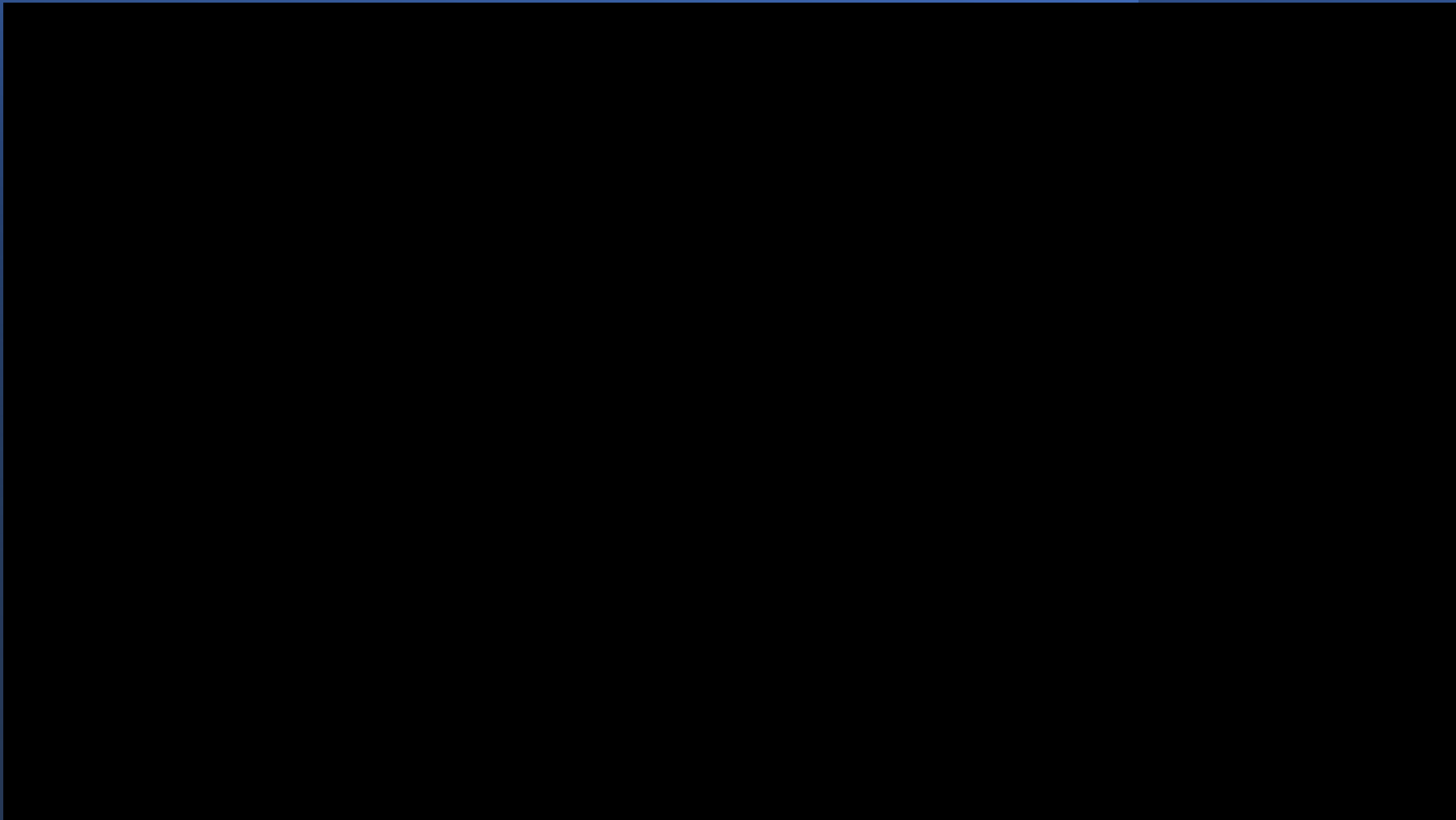
The vaccine will not be available close to my home.

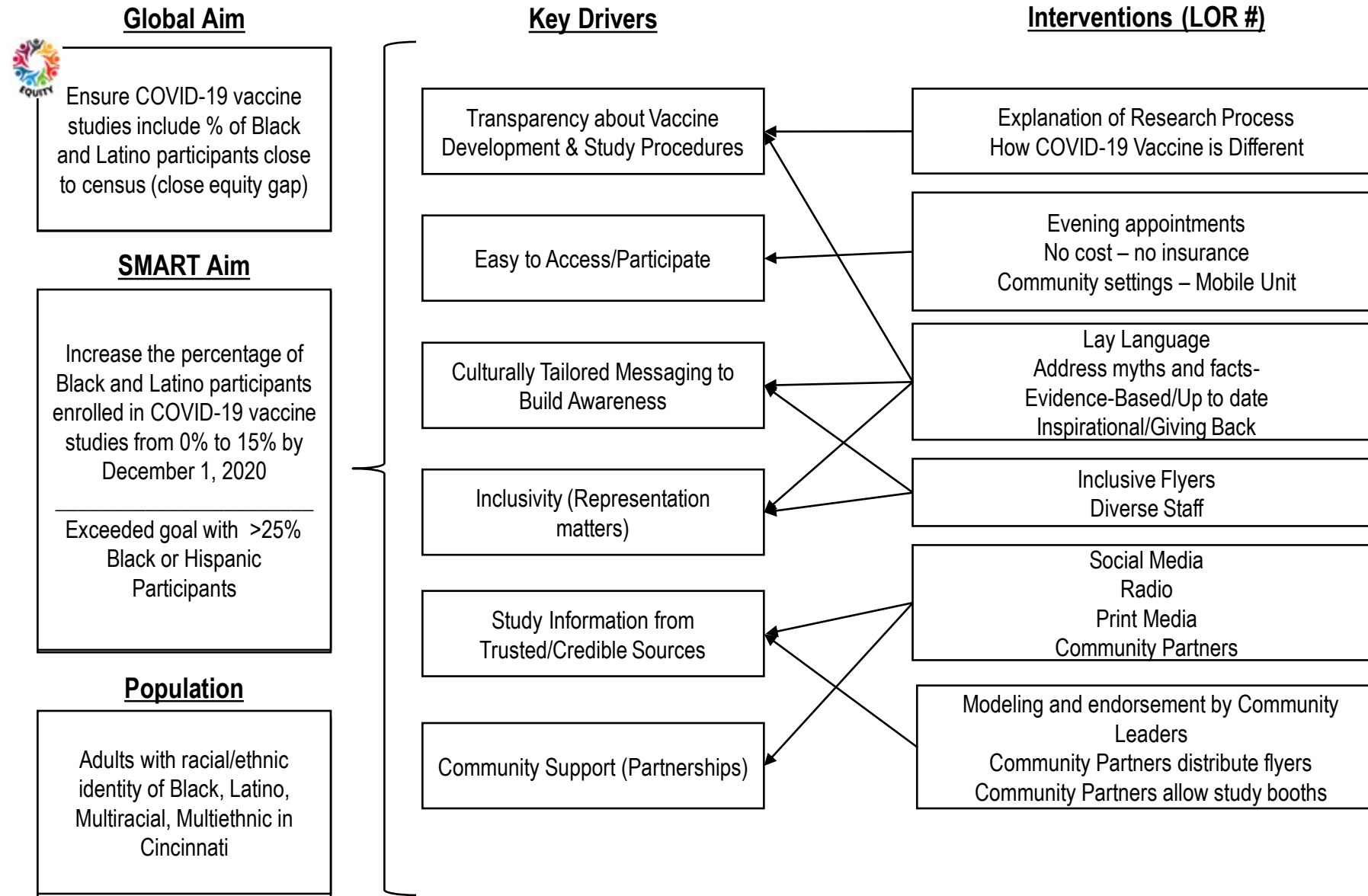


The vaccine will be available in neighborhood soon.

Adapted from Sanford Health - COVID-19 Vaccines Debunking the Myths

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Practice Changes

- Trusted sources should help roll out the vaccine and educate the public
- Provide information on transportation and supports
- Appointments in evenings and on weekends
- Central website for information and sign-ups



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Youth Engage!

148 Participants

98 Surveys on Adolescents

Positive Data on COVID Awareness

Positive Data on COVID Vaccinations/Intentions

45 Video Submissions in Video Contest

Let's Engage!

125+ Families

Other Data Pending

28 Photos in Photo Contest



Let's Engage!

COVID-19 Vaccines for Kids

Featuring The Cincinnati Zoo Professionals and Animals, special guest from the Cincinnati Reds, and Cincinnati Children's Health Professionals

Parents, students and others are invited to join virtually

Wednesday, December 8 | 6 – 7 pm
Join the Zoom event: bit.ly/3FAo1FV

All participants will receive two tickets to the Cincinnati Zoo's Festival of Lights for attending and completing the survey.

COVID-19 PHOTO CHALLENGE

Submit your photo showing how you stay safe during COVID-19.

All submissions and winners will receive prizes (Top Prizes \$50).
Winner will be featured during the Let's Engage! Program on December 8.

- Focus on COVID-19 or COVID-19 Vaccinations
- Feature ways that youth can take care of themselves during COVID (e.g. vaccinations, masking, mental health, etc.)
- Can include an individual or your whole family

Submit your entry here: redcap.link/Youth-COVID_Challenge
Registration and release form required



Parent Quote from the Chat:

"I feel at ease now getting my kids vaccinated and also getting another Pfizer dose [for myself]."

Conceptual Frameworks



REFRAME

SOCIAL DETERMINANTS AND SOCIAL NEEDS: MOVING BEYOND MIDSTREAM



Equality



Equity



Justice



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Changing Power Dynamics

	Savior-Designed System	Ally-Designed System	Equity-Empowered System
Description	<ul style="list-style-type: none">•Rescue/save vulnerable groups without considering root causes•Policy and practice does more harm than good•Difficult to navigate	<ul style="list-style-type: none">•Intends to challenge systemic oppression•Unites with disparity group to create a system centered on dignity, respect, and equality	<ul style="list-style-type: none">•Centers on experience of disparity group•Emphasis on addressing root causes•Share power, establish equitable decision making
Residual Impact	<ul style="list-style-type: none">•Top-down experts•Victim blaming•Gate keeping•Labeling	<ul style="list-style-type: none">•Paternalism•One-sided approach•Tokenism	<ul style="list-style-type: none">•Provide trauma- and bias-reducing care•Amplify lived experience•Unapologetically name root causes•Promote economic equity

CFIR Domain	Relevant CFIR Constructs	Recruitment Barriers	Strategies Implemented
Process	•Engaging	Gaps in research staff knowledge and understanding of trial	<ul style="list-style-type: none"> •Staff study retraining and ongoing training/review of recruitment/enrollment specific topics (e.g., in-person vs phone recruitment) •In-person site visits (if necessary) •Identify a site “champion” to promote the study and take ownership checking site recruitment needs for the day and work with staff to make a plan for scheduling needs
	<ul style="list-style-type: none"> •Reflecting & Evaluating •Planning Champions 	Limited recruitment planning/staff unavailable to recruit	
Inner Setting	•Networks & Communication	Study prioritized at sites less than other studies/initiatives	<ul style="list-style-type: none"> •Increase monthly individual site calls (now weekly) and monthly PI calls (now bi-monthly) •Add monthly all-coordinators calls •Extend study timeline by 6 months •Reduce overall study recruitment goal that still allows for retention of statistical power •Redefine site-specific monthly recruitment goals •Add additional clinic sites
	<ul style="list-style-type: none"> •Leadership Engagement •Relative Priority •Implementation Climate •Goals & Feedback 	<ul style="list-style-type: none"> Inconsistent communication among site staff and site PIs Sites’ actual recruitment capacity differed from what was indicated during study development (e.g., fewer active patients, staff turnover) 	
Outer Setting	<ul style="list-style-type: none"> •Patient Needs & Resources •Cosmopolitanism 	Inconsistent patient clinic attendance and engagement	<ul style="list-style-type: none"> •Staff make calls to reschedule no-show/canceled clinic appointments •Staff call potential participants to remind of clinic appointment (7-30 days away) and introduce the study •Partner with community organizations to distribute study marketing materials to extend study reach
CFIR: Consolidated Framework for Implementation			

Strong, H., Hood, A. M., Johnson, Y., Hackworth, R., Reed-Shackelford, M., Ramaswamy, R., ... & Crosby, L. E. (2022). Using the consolidated framework for implementation research to identify recruitment barriers and targeted strategies for a shared decision-making randomized clinical trial in pediatric sickle cell disease. *Clinical Trials*, 17407745231154199.



We have the
skills and
training

* Opportunity to partner across
disciplines

“All big things come from small beginnings. The seed of every habit is a single, tiny decision. But as that decision is repeated, a habit sprouts and grows stronger. Roots entrench themselves and branches grow. ”

James Clear



