

# Reiniciar, reformular e repensar: avançando na equidade em saúde na ciência comportamental

Lori E. Crosby PsyD

July 25, 2024

# Declaração de posicionalidade

Reconheço a influência potencial que meu ponto de vista como uma mulher educada, negra, de língua inglesa, sem deficiência, americana e cisgênero tem em minha pesquisa e ensino.



# Agradecimentos

- Parceiros de pais e jovens adultos
- Parceiros da Comunidade/CABs
- Equipes SCD
- Estudantes de Colaboração e Design da LiveWell
- Kamilah Wood, MD
- Emily McTate, PhD
- Amy Beck, PhD
- Monica Mitchell, PhD
- Soumitri Sil, PhD
- Farrah Jacquez, PhD



# Objetivos de aprendizagem

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Discuta a importância de centrar as experiências vividas de pacientes e comunidades em esforços de pesquisa destinados a promover a equidade em saúde na ciência comportamental.

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Identificar estratégias para envolver ativamente indivíduos com experiências vividas e comunidades ao longo de todo o processo de pesquisa, para aumentar o rigor e o impacto científico.

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Compreender a importância de reformular estruturas conceituais e adotar metodologias voltadas para os determinantes sociais e estruturais da saúde para promover a equidade em saúde.

# Liderando com experiência vivida



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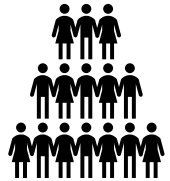
## REINICIALIZAR

# INOVAÇÃO E DESIGN THINKING EM CIÊNCIA COMPORTAMENTAL





# Doença falciforme (SCD)



**Doenças genéticas do sangue que afetam aproximadamente 100.000 pessoas nos EUA**



**Doença hereditária mais comum em todo o mundo**



**Maior prevalência entre indivíduos de ascendência africana**



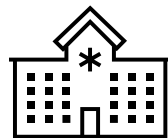
**1 em cada 500 negros americanos tem SCD**



# Preconceito Racial e Estigma na SCD



**O viés do provedor leva à subavaliação e subgestão da dor em negros americanos**



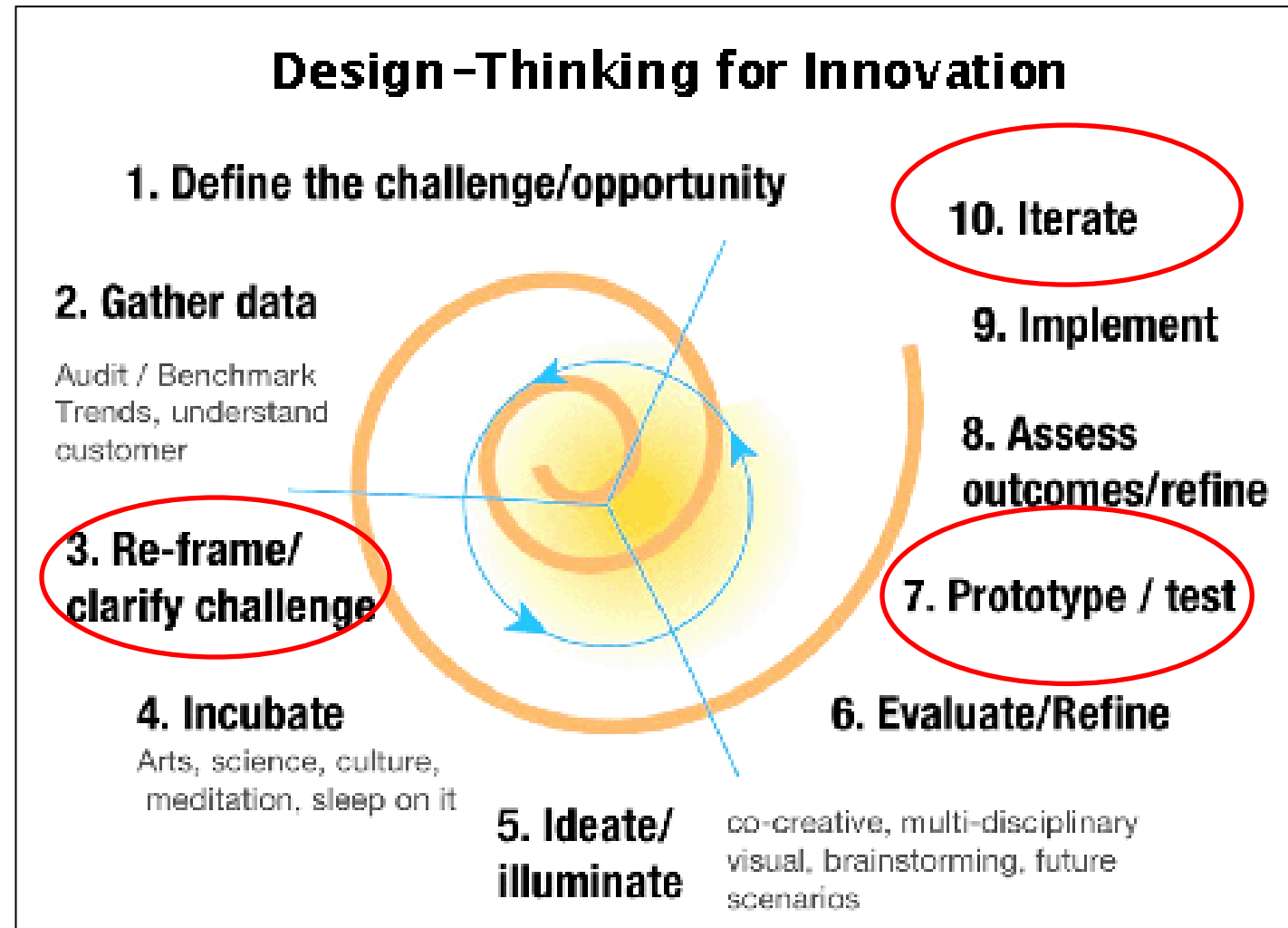
**Consequências diretas e indiretas do estigma na saúde social, psicológica e fisiológica na DF**

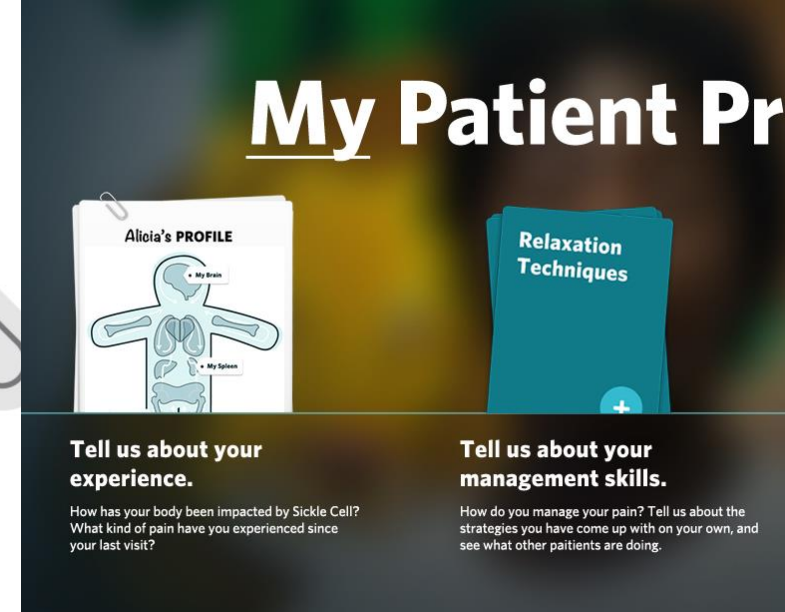
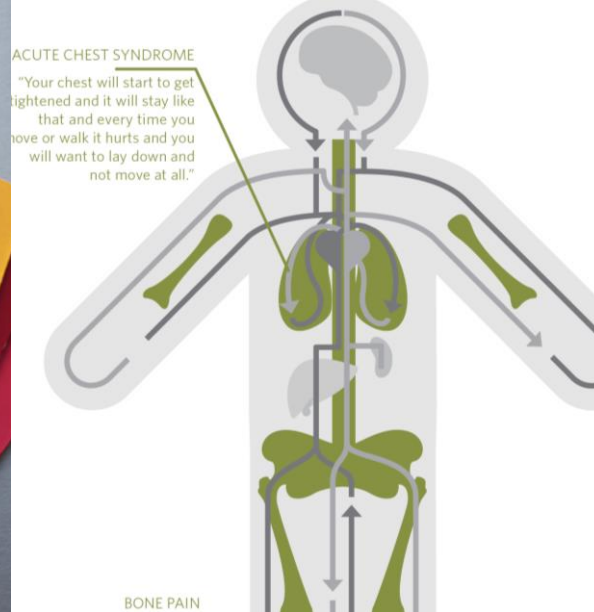


**Relacionam-se diretamente com a desigualdade de recursos para pacientes com DF.**



# Design Thinking





Desenvolvimento de ferramentas para pacientes e profissionais para melhorar a transição para a saúde de adultos para adolescentes com doença falciforme

Concessão NHLBI #: 1K07HL108720

**PESQUISA:  
ENTENDA**

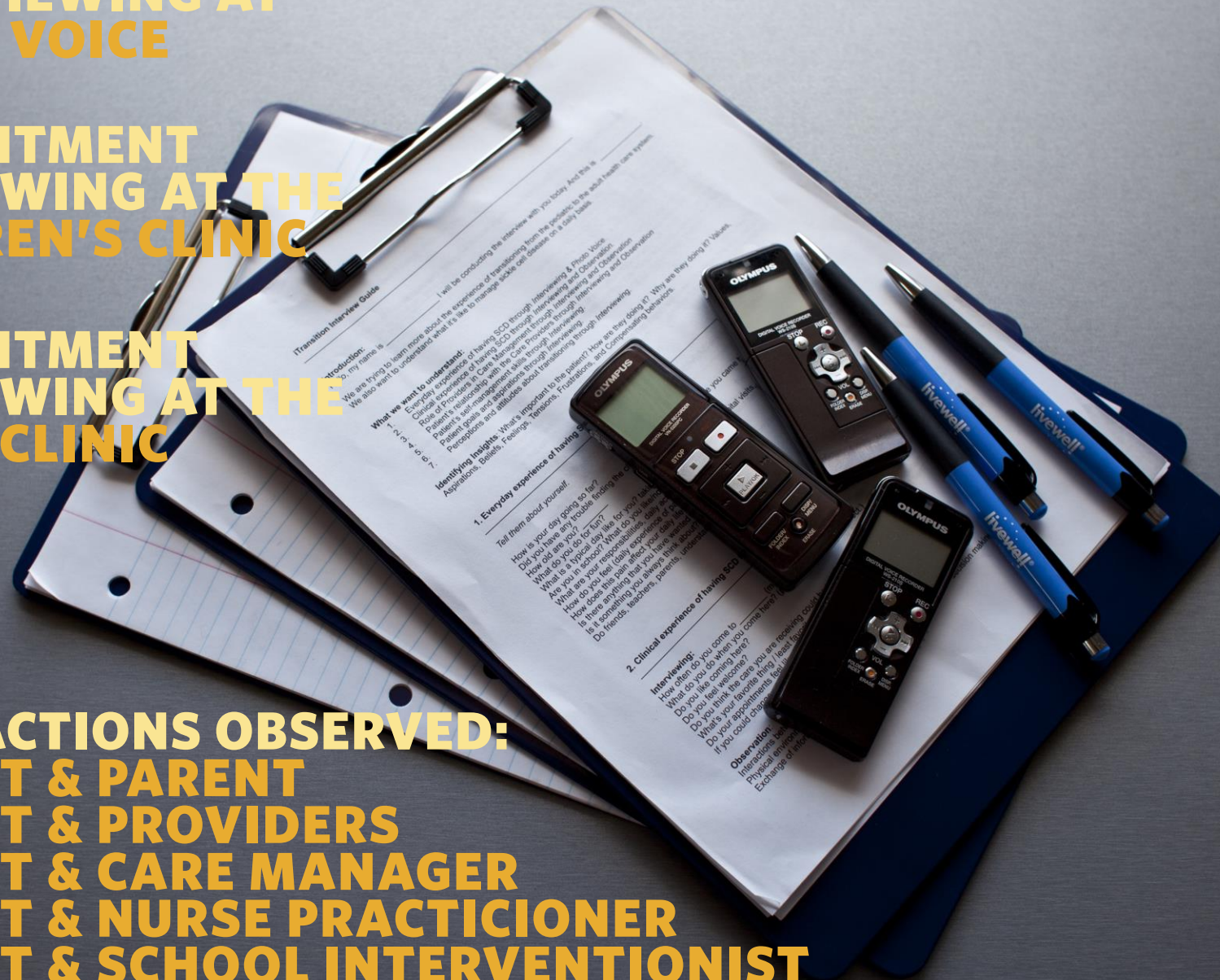
**INVESTIGAÇÃO:  
SÍNTESE**

**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**



# IDENTIFICAR OPORTUNIDADE ÁREAS & IDEATE



COMO PODEMOS...  
AJUDAR OS PACIENTES A CONECTAR  
AS HABILIDADES DE  
AUTOGERENCIAMENTO AO FUTURO  
QUE ELES IMAGINAM PARA SI  
MESMOS?



**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."



# Conclusões e próximos passos

Modelo de como as equipes de saúde e design podem trabalhar juntas para enfrentar os principais desafios da saúde

Objetivo alcançado de desenvolver ferramentas centradas no paciente\*

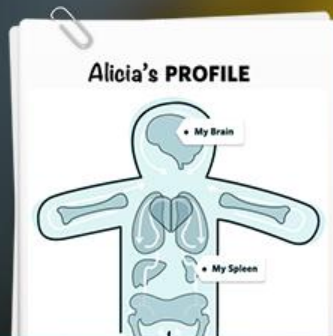
Protótipos da ferramenta foram testados e avaliados com pacientes e profissionais

Pedido de subsídio R21 para testar a ferramenta com uma população maior

# REFINAMENTO DE CONCEITO E PROTÓTIPO



# My Patient Profile



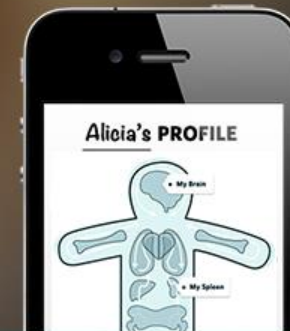
## **Tell us about your experience.**

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

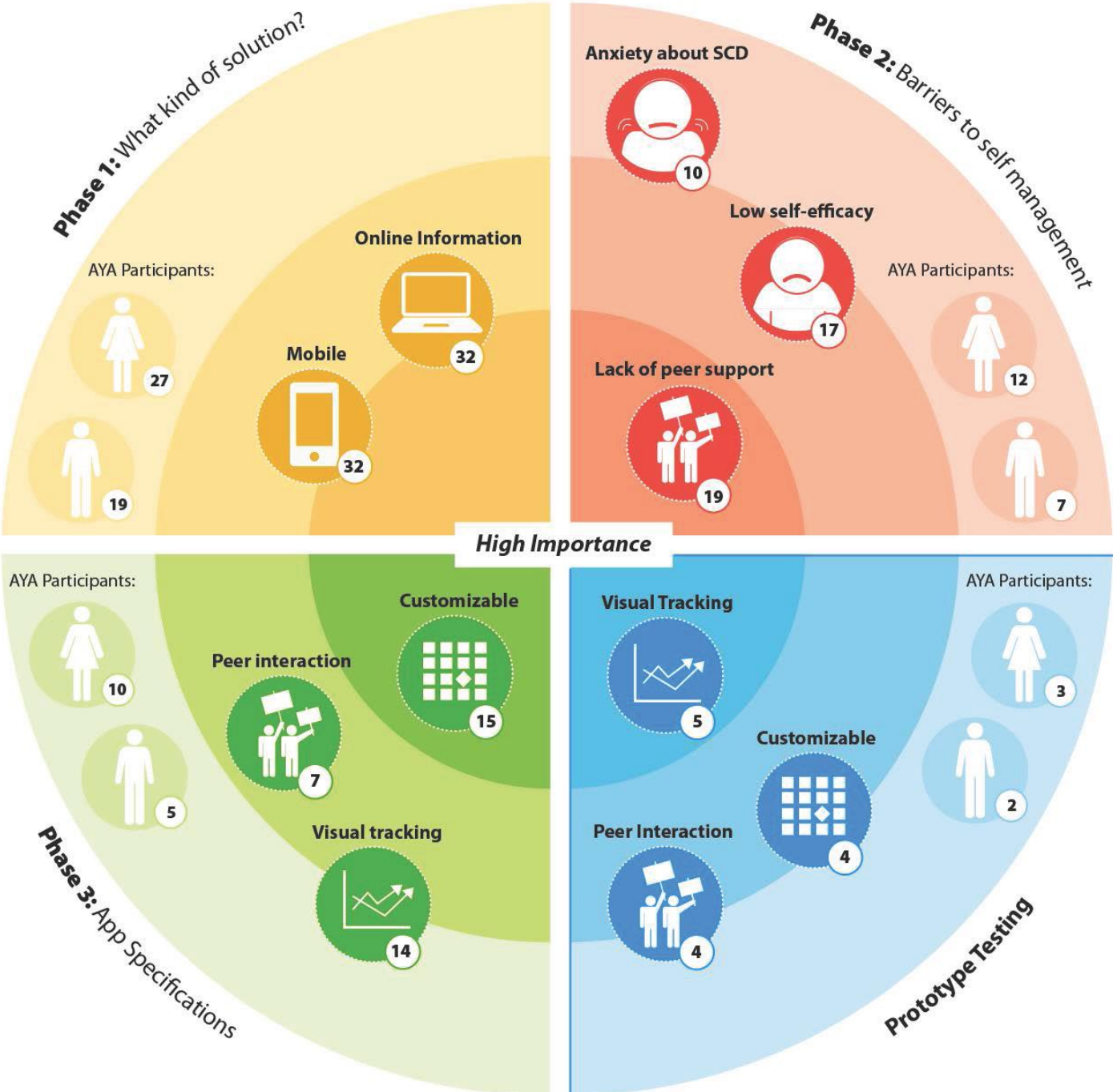
0 of 5 goals



# imanagescd



# Estudos para entender as necessidades e desenvolver a intervenção



Essa abordagem aumenta a relevância, o rigor (viabilidade) e o alcance. Em suas próprias palavras. . .



# Paradigma



## RE-ENVISION

01



Determinantes Sociais e  
Estruturais

02



Contexto

03



Dinâmica

04



Multilevel



# Envolvendo a comunidade

Indivíduos com experiência vivida, organizações colaborativas e outros que possam influenciar o trabalho

**NOTHING**

**ABOUT US**

**WITHOUT US**



# Anti- Racismo




- A prática de identificar e se opor ativamente ao racismo.
- O objetivo do antirracismo é mudar ativamente políticas, comportamentos e crenças que perpetuam ideias e ações racistas.

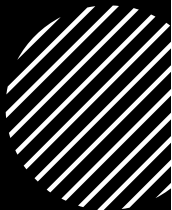

# Envolvimento da comunidade



- um processo estratégico com o objetivo específico de trabalhar com grupos identificados de pessoas para identificar e abordar questões que afetam seu bem-estar.
- O foco não está no indivíduo, mas no coletivo, levando em consideração a diversidade que existe em qualquer comunidade.



# Estratégias Anti-Racismo e Envolvimento Comunitário

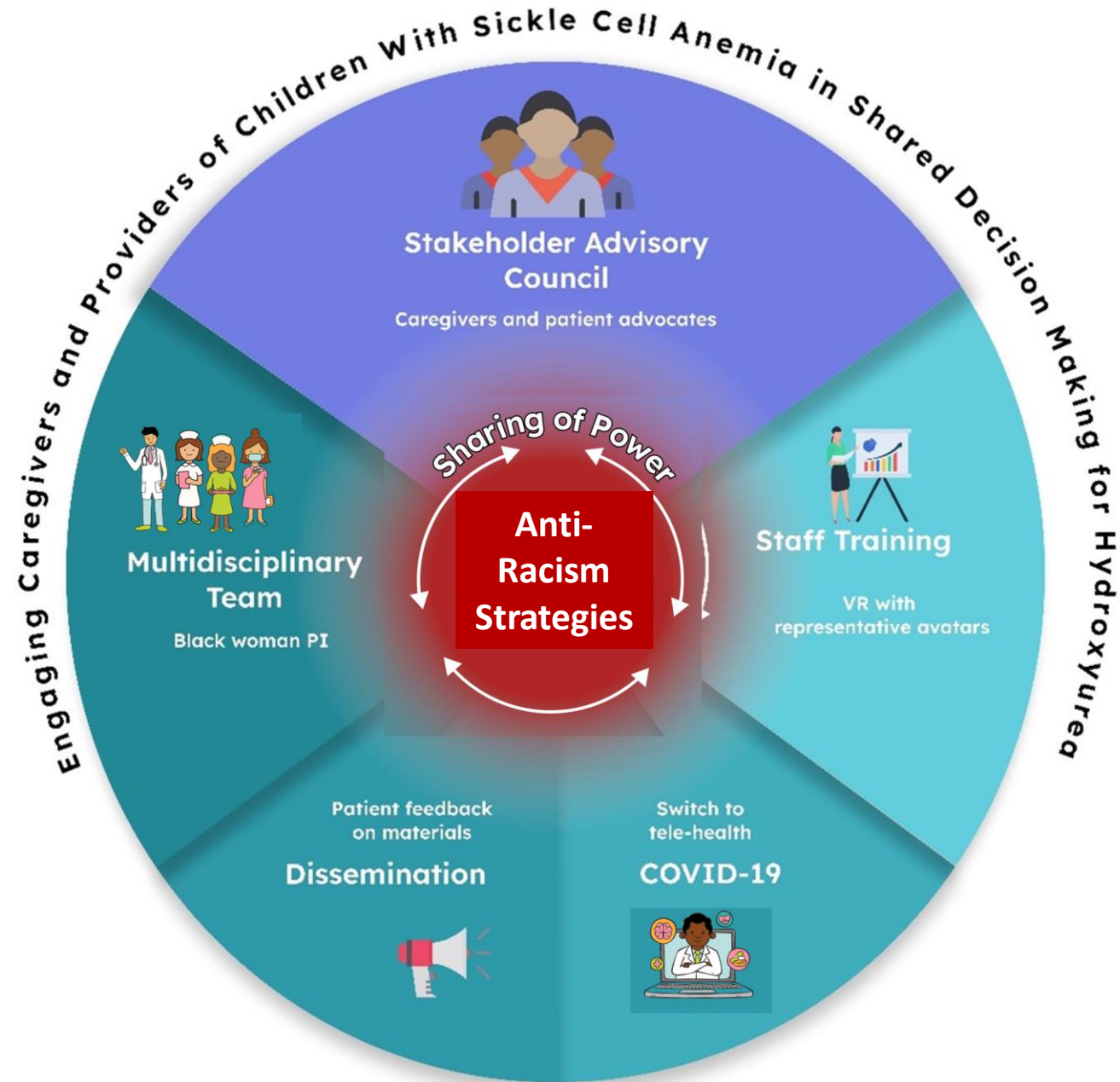


**Parceria com a comunidade  
em todas as fases da  
pesquisa**



Usando os resultados da  
pesquisa para informar  
práticas/políticas de saúde

# 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*.



# Equipe de investigação



Pessoas de cor



Estagiários para professores seniores  
(alunos de cor)



Múltiplas disciplinas



Parceiros/Colaboradores da Comunidade

# Desenho do estudo: Conselho Consultivo das Partes Interessadas

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- Desenho do estudo
- As partes interessadas sentiram que era importante coletar dados de prescrição de famílias que iniciam a hidroxiureia (por exemplo, foto do frasco de prescrição) porque esse era um resultado importante da tomada de decisão compartilhada



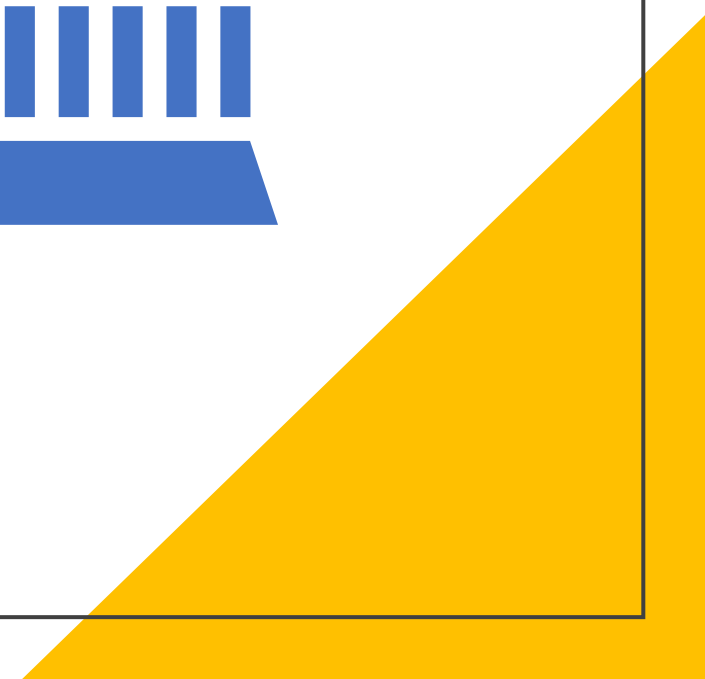
# Treinamento de Pessoal e Cultura de Estudo

- Cultura de Estudo

- Inclusivo e respeitoso – todos têm algo a contribuir
- Todos são bem-sucedidos – Expectativa da equipe
- Humildade Cultural
- Comunicação Inclusiva
- Laboratório Anti-Racista



# Telessaúde: Acesso e Qualidade do Atendimento





## Parceiro da Comunidade

- Expectativas
- Interesses e Especialidades
- Disponibilidade



Co-Disseminação

**Confiar  
Valor**

## Parceiro Acadêmico

- Científico
- Colocar
- Linha do tempo



Relacionamento e  
Comunicação

# Co-Disseminação

- Presentations

ASH PUBLICATIONS

blood

ISSUES FIRST EDITION ABSTRACTS COLLECTIONS

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>

AMERICAN SOCIETY OF HEMATOLOGY

blood

Volume 134, Supplement 1, 13 November 2019, Page 3402

901.Health Services Research-Non-Malignant Conditions

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

Lori E. Crosby PhD<sup>1</sup>, Francis J Real MD MD<sup>\*2</sup>, Bradley Cruse MFA<sup>\*1</sup>, David Davis MFA<sup>\*1</sup>, Melissa Klein MD MD<sup>\*2</sup>, Emily McTate PhD<sup>\*2</sup>, Anna M Hood PhD<sup>\*3</sup>, William Brinkman MD MD<sup>\*2</sup>, Rogelle Hackworth BS<sup>\*4</sup>, Charles T. Quinn MD<sup>5</sup>

- 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<sup>\*†</sup>, Anna M. Hood, PhD<sup>‡</sup>, David Davis, MFA<sup>§</sup>, Bradley Cruse, MFA<sup>§</sup>, Melissa Klein, MD, MEd<sup>\*†</sup>, Yolanda Johnson<sup>||</sup>, Emily McTate, PhD<sup>\*||</sup>, William B. Brinkman, MD, MEd, MSc<sup>\*†</sup>, Rogelle Hackworth, BS, Kenyon Hackworth, DC, Charles T. Quinn, MD, MS<sup>\*¶</sup>, and Lori E. Crosby, PsyD<sup>\*||</sup>

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 Hood<sup>1</sup>; Heather Strong<sup>2</sup>; Cara Nwankwo<sup>3</sup>; Yolanda Johnson<sup>2</sup>; James Peugh<sup>2</sup>; Constance A Mara<sup>2</sup>; Lisa M Shook<sup>4,5</sup>; William B Brinkman<sup>4,6</sup>; Francis J Real<sup>4,6</sup>; Melissa D Klein<sup>4,6</sup>; Rogelle Hackworth<sup>7</sup>; Sherif M Badawy<sup>8,9</sup>; Alexis A Thompson<sup>8,9</sup>; Jean L Raphael<sup>10</sup>; Amber M Yates<sup>11</sup>; Kim Smith-Whitley<sup>12,13</sup>; Allison A King<sup>14,15</sup>; Cecelia Calhoun<sup>15</sup>; Susan E Creary<sup>16</sup>; Connie M Piccone<sup>17</sup>; Aimee K Hildenbrand<sup>18,19</sup>; Steven K Reader<sup>18,19</sup>; Lynne Neumayr<sup>20,21,22</sup>; Emily R Meier<sup>23</sup>; Amy E Sobota<sup>24</sup>; Sohail Rana<sup>25</sup>; Maria Britto<sup>4,26,27</sup>; Kay L Saving<sup>28</sup>; Marsha Treadwell<sup>29</sup>; Charles T Quinn<sup>4,30</sup>; Russell E Ware<sup>4,5</sup>; Lori E Crosby<sup>2,4,27</sup>

Clinical Trials

SCT SOCIETY FOR 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

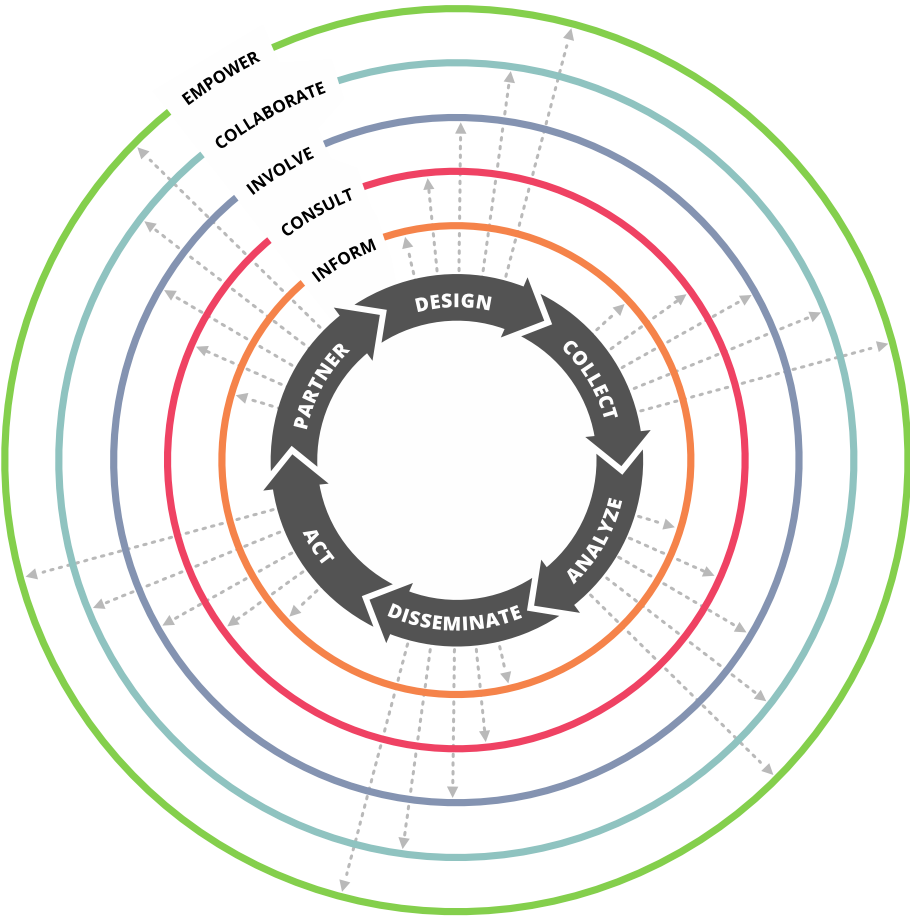
Heather Strong<sup>✉</sup>, Anna M Hood<sup>✉</sup>, L., and Lori E Crosby<sup>✉</sup> [View all authors and affiliations](#)

OnlineFirst | <https://doi.org/10.1177/17407745231154199>

Get access | Cite article | Share options | Information, rights and permissions | Metrics and citations

# 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.



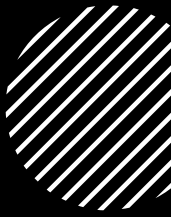
INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
Information is provided to community	Input is obtained from community	Researchers work directly with community	Community is partner in research process	Community leads research decisionmaking

Levels of participation based on:  
Spectrum of Public Participation, © International Association for Public Participation [www.iap2.org](http://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.



# Estratégias Anti-Racismo e Envolviment o Comunitário



Parceria com organizações comunitárias e partes interessadas para abordar mitos e promover a saúde



**Usando os resultados da pesquisa para informar práticas/políticas de saúde**



ATTACH Study

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



## Attitudes About COVID-19 And Health (ATTACH)

[Learn More](#)

### Equipe de estudo

Lori E. Crosby  
Mônica J. Mitchell  
Melina Butsch-Kovacic  
Stacey Gomes  
Sharon Watkins\*\*  
Amy Noser  
Catharine Whitacre  
Jennifer Allen  
Ana Hood  
Nádia Corral



# Objetivos do estudo

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- **Objetivo 1.** Examine as atitudes e crenças relacionadas ao COVID-19 e como elas se relacionam com a adesão às estratégias de mitigação (lavagem das mãos, uso de máscaras, distanciamento social) e ansiedade por características demográficas (raça/etnia, idade, status de trabalhador essencial).

**\*Dados em tempo real que podem ser usados para abordar intervenções para reduzir disparidades e desigualdades**

# População-alvo

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- Adultos >18 anos em Hamilton County
- Superamostra da comunidade negra e afro-americana



# Conselho Consultivo da Comunidade



This Photo by Unknown Author is licensed under [CC BY-SA-NC](#)

- Agência de Ação Comunitária do Condado de Hamilton
- Associação de Enfermeiras Negras da Grande Cincinnati
- Centro para fechar a lacuna de saúde
- Paternidade Colaborativa
- Su Casa
- Os construtores da comunidade
- Liga Urbana
- Conselho Consultivo da Comunidade de West End

Site do  
estudo

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.



# Infodemia

## 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.

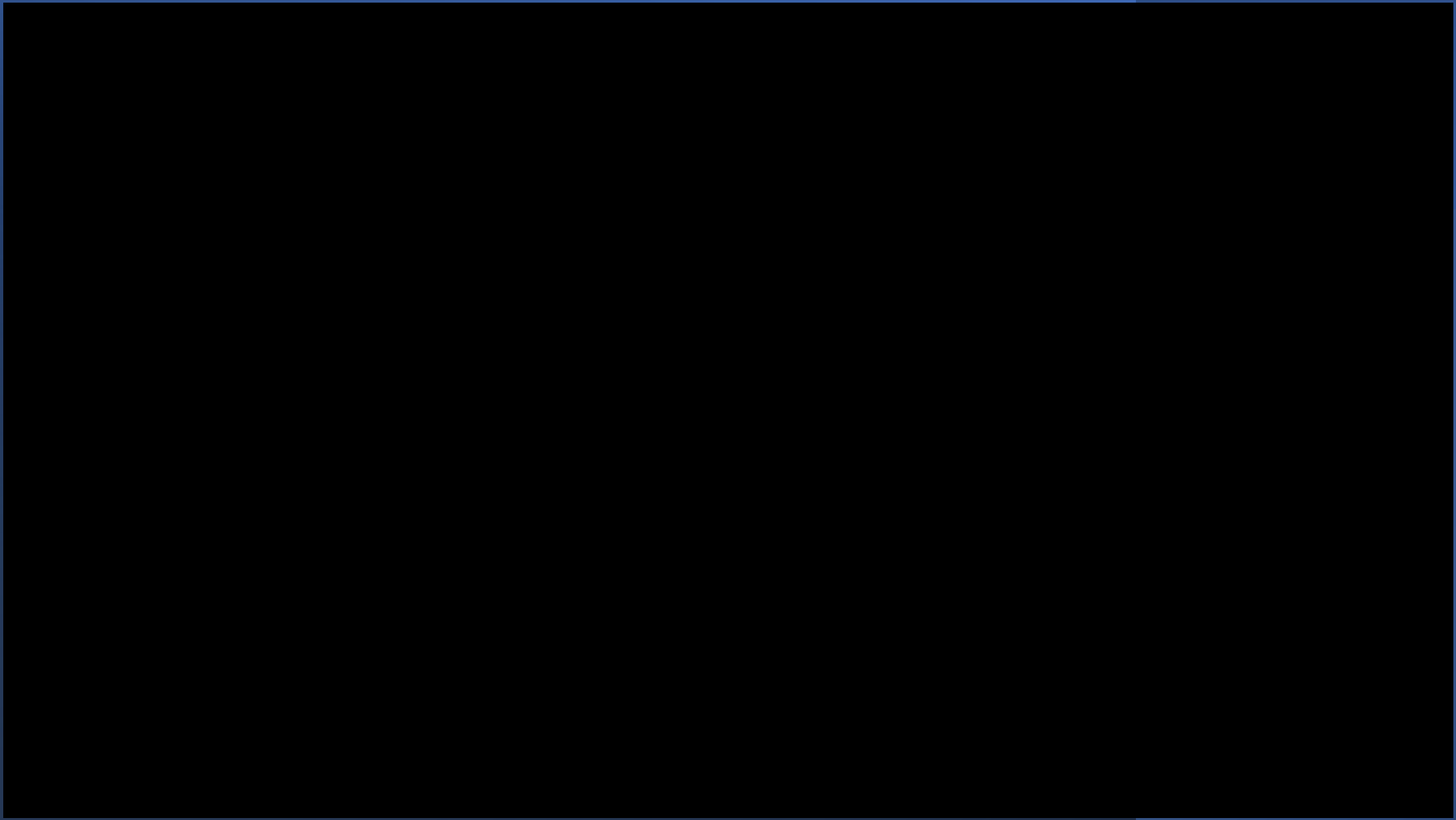
The vaccine will not be available close to my home.

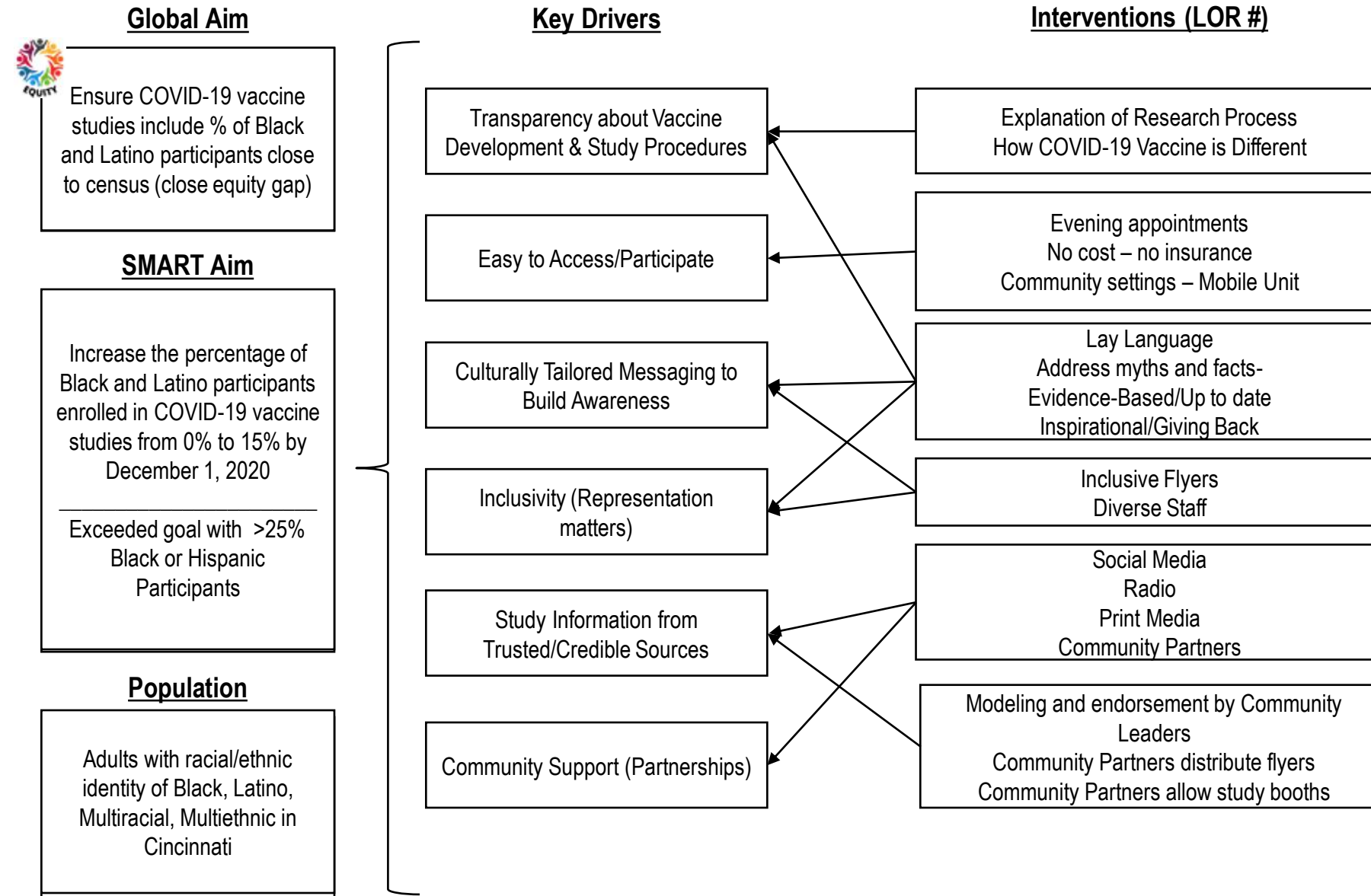


The vaccine will be available in neighborhood soon.

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

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# Mudanças na prática

- Fontes confiáveis devem ajudar a lançar a vacina e educar o público
- Fornecer informações sobre transporte e suporte
- Consultas à noite e nos fins de semana
- Site central para informações e inscrições



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## Jovens se envolvem!

148 Participantes

98 Inquéritos a Adolescentes

Dados positivos sobre a conscientização sobre o COVID

Dados positivos sobre vacinações/intenções COVID

45 Envios de Vídeo no Concurso de Vídeo

## Vamos nos envolver!

125+ Famílias

Outros dados pendentes

28 Fotos no Concurso de Fotografia



## 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](https://bit.ly/3FAo1FV)

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



JOIN THE ZOOM HERE

## 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](https://redcap.link/Youth-COVID_Challenge)  
Registration and release form required



SUBMIT YOUR ENTRY HERE





Citação dos pais do bate-papo:

"Sinto-me à vontade agora vacinando meus filhos e também recebendo outra dose da Pfizer [para mim]."

# Estruturas conceituais



**REFORMULAR**

# SOCIAL DETERMINANTS AND SOCIAL NEEDS: MOVING BEYOND MIDSTREAM



# Equality



# Equity



# Justice



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# Mudando a dinâmica de poder

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



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"> <li>•Staff study retraining and ongoing training/review of recruitment/enrollment specific topics (e.g., in-person vs phone recruitment)</li> <li>•In-person site visits (if necessary)</li> <li>•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</li> </ul>
	<ul style="list-style-type: none"> <li>•Reflecting &amp; Evaluating</li> <li>•Planning Champions</li> </ul>	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"> <li>•Increase monthly individual site calls (now weekly) and monthly PI calls (now bi-monthly)</li> <li>•Add monthly all-coordinators calls</li> <li>•Extend study timeline by 6 months</li> <li>•Reduce overall study recruitment goal that still allows for retention of statistical power</li> <li>•Redefine site-specific monthly recruitment goals</li> <li>•Add additional clinic sites</li> </ul>
	<ul style="list-style-type: none"> <li>•Leadership Engagement</li> <li>•Relative Priority</li> <li>•Implementation Climate</li> <li>•Goals &amp; Feedback</li> </ul>	<ul style="list-style-type: none"> <li>Inconsistent communication among site staff and site PIs</li> <li>Sites’ actual recruitment capacity differed from what was indicated during study development (e.g., fewer active patients, staff turnover)</li> </ul>	
Outer Setting	<ul style="list-style-type: none"> <li>•Patient Needs &amp; Resources</li> <li>•Cosmopolitanism</li> </ul>	Inconsistent patient clinic attendance and engagement	<ul style="list-style-type: none"> <li>•Staff make calls to reschedule no-show/canceled clinic appointments</li> <li>•Staff call potential participants to remind of clinic appointment (7-30 days away) and introduce the study</li> <li>•Partner with community organizations to distribute study marketing materials to extend study reach</li> </ul>
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.



# Temos as habilidades e o treinamento

\* Oportunidade de parceria entre  
disciplinas



"Todas as grandes coisas vêm de pequenos começos. A semente de todo hábito é uma única e minúscula decisão. Mas à medida que essa decisão é repetida, um hábito brota e se fortalece. As raízes se entrincheiram e os galhos crescem. "

James Claro



