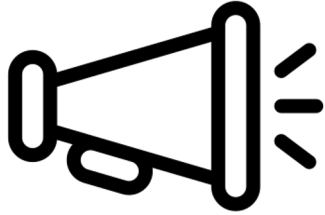


When Institutional Racism and UX Research Collide: A Case Study

March 12, 2021

Why are we sharing this case study?

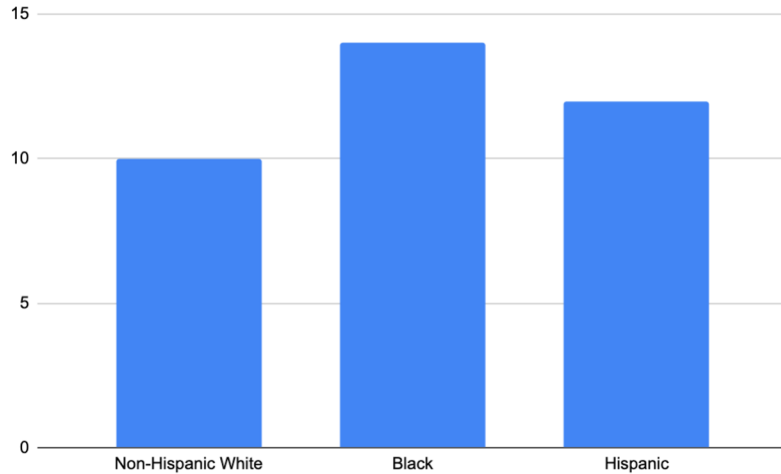


Speaking up even when a finding goes beyond scope.



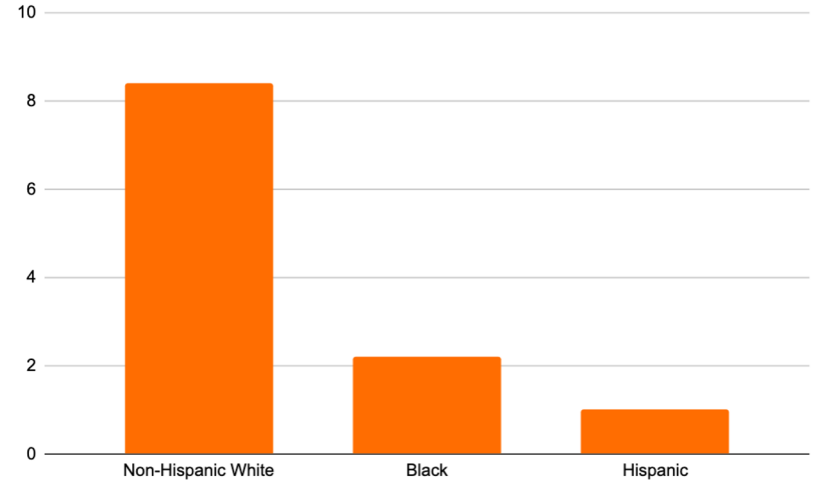
Articulating inequality through the framework of usability barriers.

Black and Latino/a individuals are more likely to develop Alzheimer's but less likely to participate in clinical trials than whites.



Percentage of **adults 65 and older with Alzheimer's Disease** by subgroup

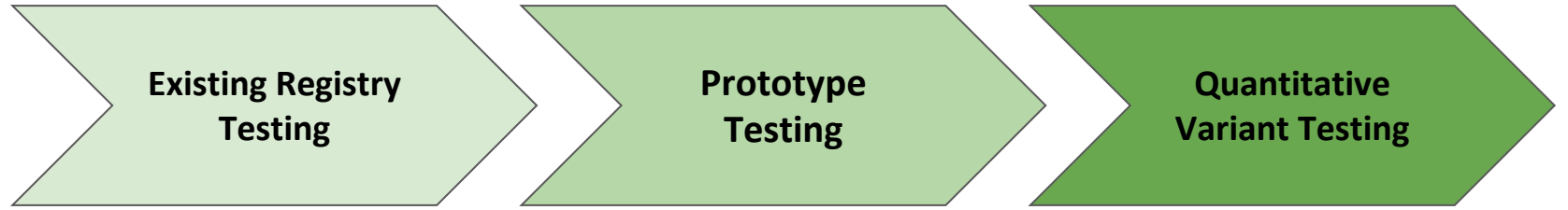
(Data from [cdc.gov](https://www.cdc.gov))




Enrollment ratios in clinicaltrials.gov trials

(Data aggregated by [Jaron Lockett, PhD, NIA, 2018](#))

Study Design



Project Goals

 ResearchMatch

En Español

Welcome / [Register Now](#)

Volunteer Agreement

Account Information


Contact Information

Demographic Data

Conditions

Medications

Account Preferences



 **Create a username and password**


To protect your ResearchMatch information, create a username and password that only you know.

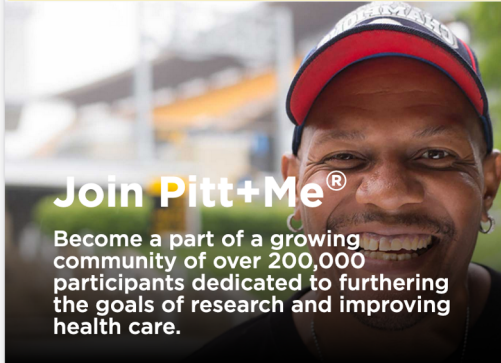
Your Username

Your Password

Repeat Password


 [View](#)





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Become a part of a growing community of over 200,000 participants dedicated to furthering the goals of research and improving health care.

Already a Pitt+Me member? [Log in](#)

 Please share some basic information.

NAME

FIRST NAME

LAST NAME

EMAIL

CONFIRM EMAIL

☐ I am over the age of 18

HOW DID YOU HEAR ABOUT US?

Please let us know!

[Become a Member](#)

We use cookies on our website to give you the most relevant experience by remembering your preferences and repeat visits. By clicking "Accept", you consent to the use of ALL the cookies.

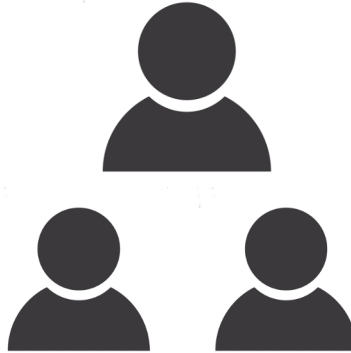
Project Stakeholders



Primary Agency Contact



Grand Funder Organization




Grant Team

Past and Present Challenges

“[M]y race has been treated like guinea pigs for most of our existence, so, it's something that is in the back of my head. And it is concerning, when I go see a doctor to the point that sometimes I get actually nervous. Shouldn't have to, but, sometimes, I do.”

—study participant (Black woman)





Please tell us about your gender and race.

GENDER

☐ Male ☐ Female ☐ Transgender ☐ Prefer not to Answer

RACE

<input type="checkbox"/> American Indian/Alaska Native	<input type="checkbox"/> White
<input type="checkbox"/> Asian	<input type="checkbox"/> Other/Unknown
<input type="checkbox"/> Black/African American	<input type="checkbox"/> Prefer not to Answer
<input type="checkbox"/> Native Hawaiian/Pacific Islander	

ETHNICITY

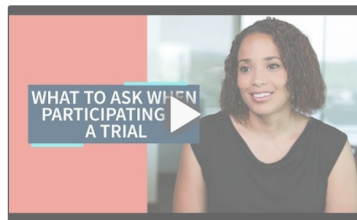
☐ Hispanic or Latino ☐ Not Hispanic or Latino ☐ Prefer not to Answer

“I don’t like how they ask for race. Like, why do they have to know what? What does it matter if I’m Black or white? I just don’t see why they have to know.”

—study participant (Black woman)

Building a Digital Relationship

Obvious targeting feels... obvious.



“Black people in general are oftentimes looked at as being disposable, you know?”

—study participant (Black woman)

Join Now

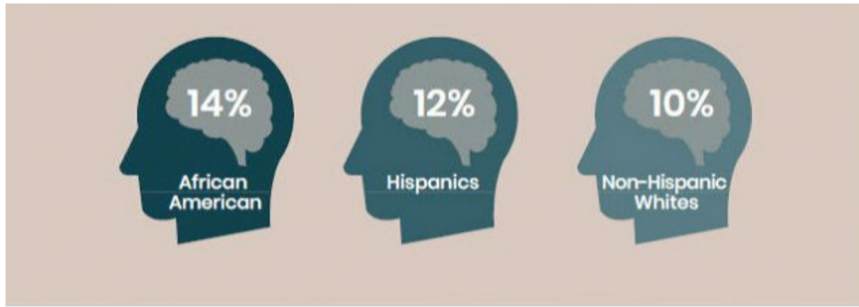
The Power of Testimonials

“I became more engaged once the experts stop talking, and you had the Black lady come on, and **she talked about her own experience and how important it was for the community.**”

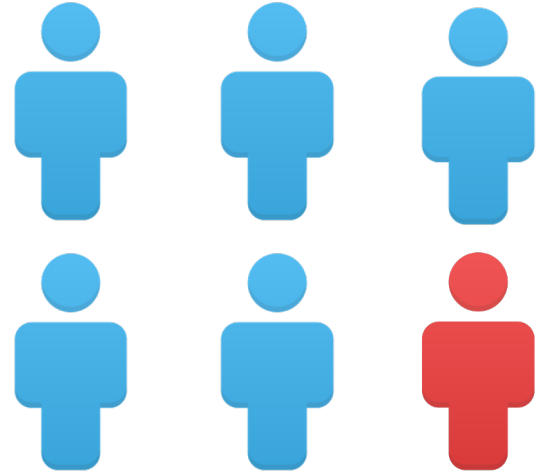
—study participant (Black woman)



Project Impact: Usability and the Health Belief Model



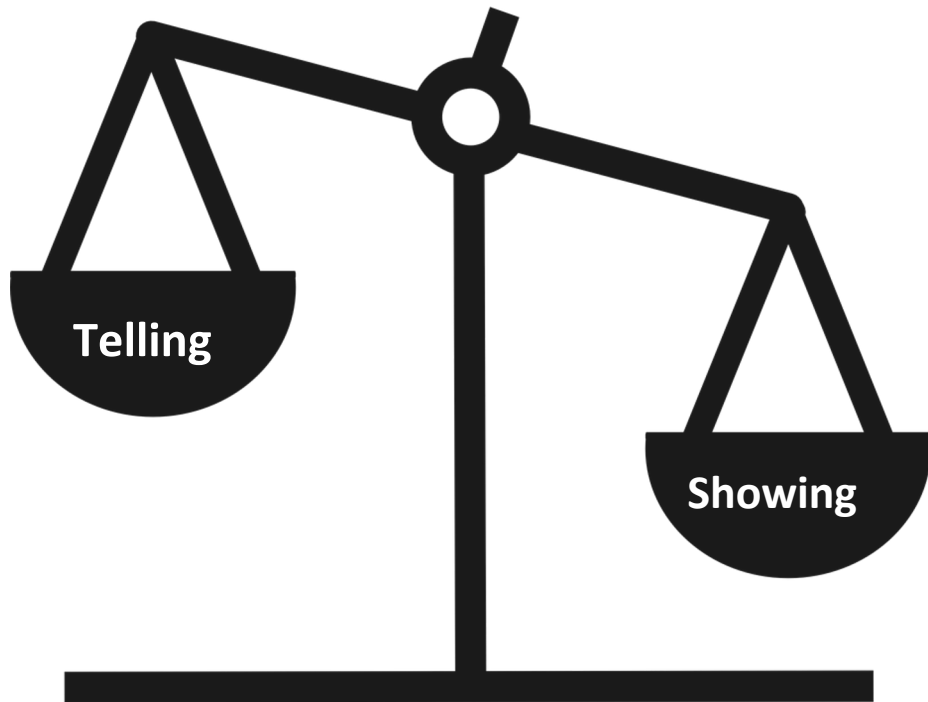
Percentage of adults 65 and older with Alzheimer's Disease (source: cdc.gov)



A statistic about Alzheimer's rates among different ethnic and racial groups **resonated strongly with 5 of 6 participants** in round 4.

Power and Decision Making

Finding: Showing > Declaring Commitment to Equity



“I want to see pictures of your leadership and board. **Do you have women? People of color?**”

—study participant (Black man)



Non-Verbal Cues and Reactions



 BrainHealth
REGISTRY 



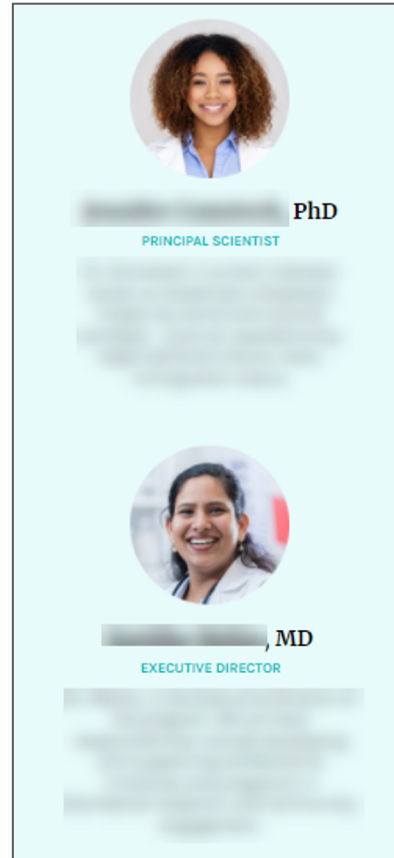
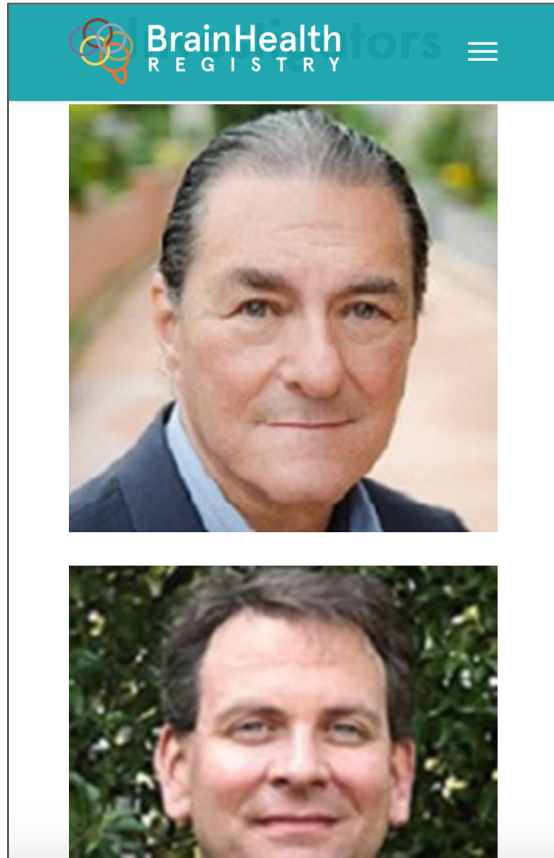
Who Is Involved
Leading the
Discovery of
Treatments for
Alzheimer's
Parkinson's and
Other Brain
Disorders

Lead Scientific

 BrainHealth
REGISTRY 

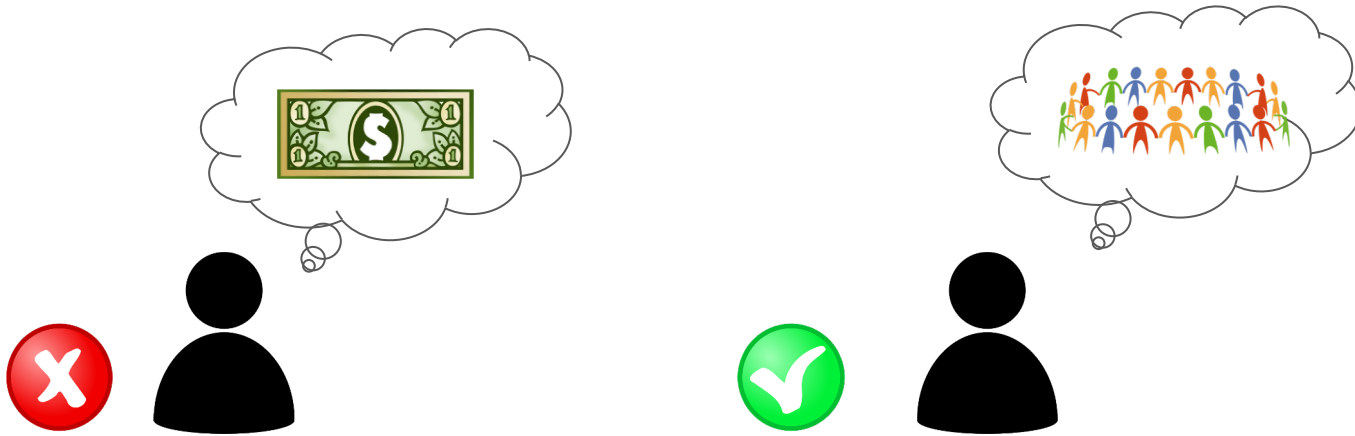


Project Impact: Inequality is a usability problem.

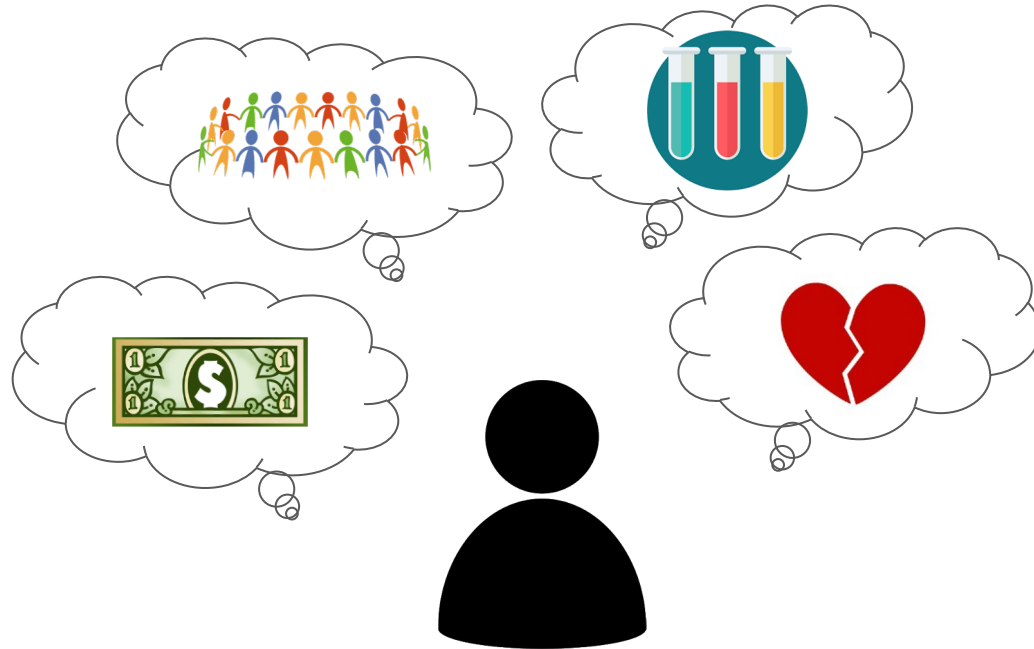


Incentives and Respect

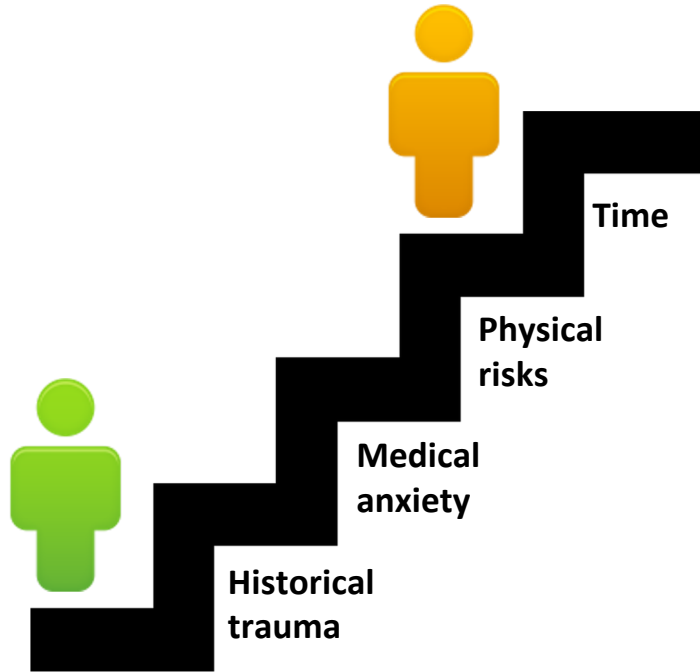
Client Assumption: “Mercenary” participants are not a good fit for this registry.



Finding: Altruism and the desire to be paid are not mutually exclusive.



Payment can build trust and respect.

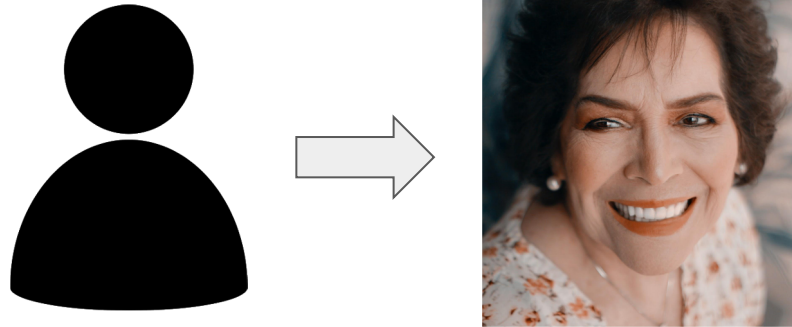


“I want to know that I’m going to get paid, I see it as a sign of respect. I give you my time, **I should be compensated accordingly.**”

—study participant (Black man)

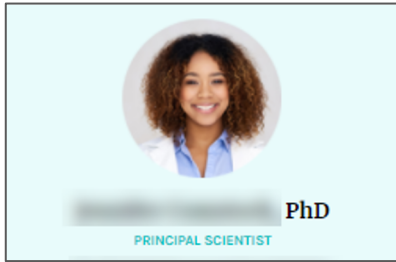
Project Impact: Breaking Down Prejudice Around Payment

- The “perfect user” does not exist.
- Abstract persona vs. real narrative.

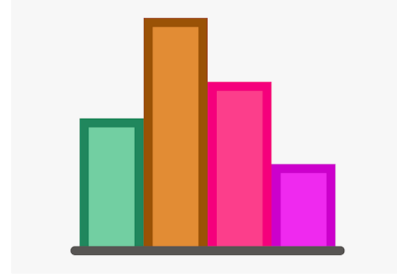


Takeaways

Changes Based on Our Research



About Us with pictures



Infographics and more icons

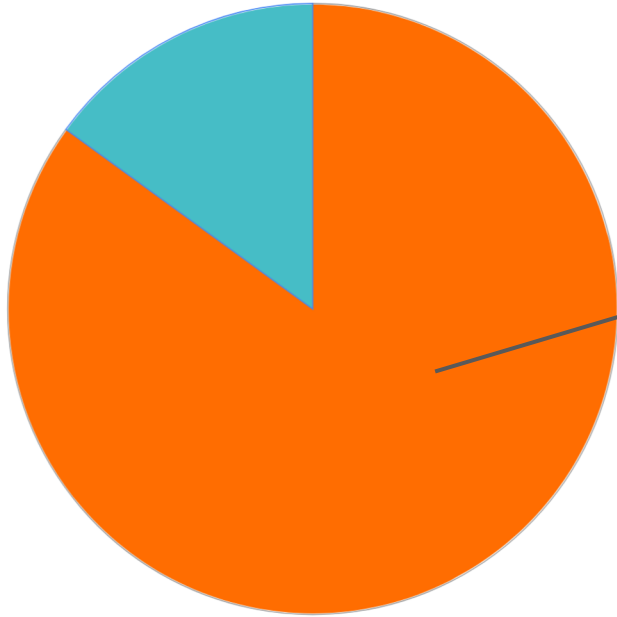


Testimonials



Incentive information

Organizational Impact: Understanding → Trust → Enrollment

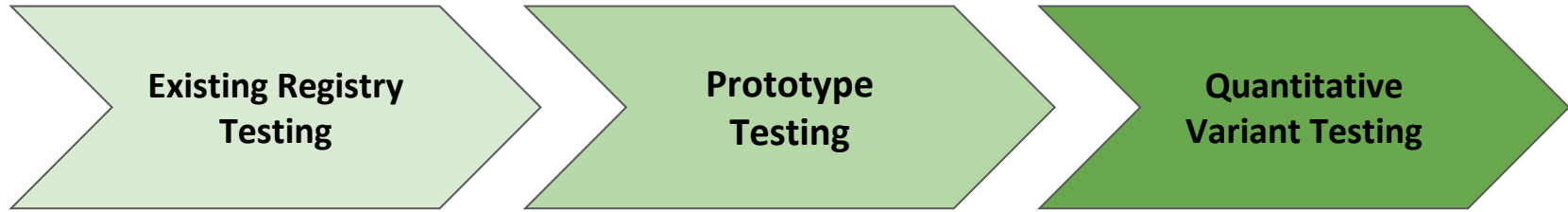


At least **85% of participants** from different health literacy and race/ethnicity sub-groups said it was somewhat or very **important to see diversity among program staff** on the website.

Reflection and discussion

Appendix: Additional Study Details

Study Overview



- 40 participants
- Moderated interviews
- **Goal:** Learn from the registries that are out there now.

- 6 participants per round (4 rounds)
- Moderated interviews
- **Goal:** Rapidly improve registry prototype with user feedback.

- 600 participants
- Unmoderated testing
- **Goal:** Evaluate effectiveness of final prototype.