Behavioral Economics to Transform Trial Enrollment Representativeness

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Introduction

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The BETTER Center Mission

To develop and test behavioral economic interventions that surmount the barriers to randomized controlled trial (RCT) participation faced by disenfranchised racial and ethnic groups, women, persons of low socioeconomic status (SES), and others with or at risk for cardiovascular disease.
Advances in cardiovascular care and outcomes are stymied by difficulty in enrolling and retaining patients in randomized clinical trials (RCTs).

Enrollment and retention challenges disproportionately affect Black and Hispanic/Latinx people, women, and people living in rural areas, resulting in skewed RCT samples.

Diagnosing and addressing challenges to RCT enrollment and retention for underrepresented groups is of critical importance for cardiovascular research programs.

Schwartz, et al. NEJM 2023; 388: 1252-1254
In simple terms...

Participation-to-Prevalence Ratio (PPR)
### Trial representativeness: How do we get there?

<table>
<thead>
<tr>
<th>Incentive</th>
<th>Black Patients</th>
<th>White Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>$0</td>
<td>17%</td>
<td>30%</td>
</tr>
<tr>
<td>$200</td>
<td>36%</td>
<td>36%</td>
</tr>
<tr>
<td>$500</td>
<td>46%</td>
<td>49%</td>
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</table>

- Build trust in medical research and institutions
- Promoting fairness for potential participants and communities
- Generating biomedical knowledge

Schwartz, et al. NEJM 2023; 388: 1252-1254
Project One: Barriers and Facilitators to Trial Representativeness

GOAL

Understand how and when targeted behavioral economic-informed strategies may increase RCT enrollment and retention of people who are Black, Hispanic/Latinx, women, or live in rural settings.

P.S. What is Behavioral Economics?

Behavioral economics studies the effects of psychological, cognitive, emotional, cultural and social factors in the decisions of individuals or institutions.
Project One

**Approach**
- **Potential barriers: (current state)**
  - Lack of information
  - Research team composition
- **BE facilitation strategies:**
  - Default enrollment
  - Use of mobile technologies

**Recruitment**
- **Potential barriers: (current state)**
  - Mistrust, discomfort
  - Travel-related barriers
- **BE facilitation strategies:**
  - Opt-out consent
  - Enhanced active choice
  - Financial incentives

**Retention**
- **Potential barriers: (current state)**
  - Mistrust, discomfort
  - Travel-related barriers
caregiver responsibilities
  - Research team composition
- **BE facilitation strategies:**
  - Financial incentives
  - Enhanced active choice
  - Transportation support

- **Enrolled RCT sample with decreased representation**
- **Final RCT sample with further decreased representation**
Project 1: Barriers & Facilitators of Trial Representativeness

**AIM 1**
- Systematic review of 2,304 articles

**AIM 2**
- Review of 92 W2H articles

**AIM 3**
- Freelisting (80 surveys)
- Discrete choice experiments (150-200 surveys)
- Focus groups (TBD)

PI's: Meghan Lane Fall and Rachel Kohn
Where do we come in?  Aim 1

Reach out to RCT investigators to follow-up and confirm their recruitment, consent, and financial strategies

Using REDCap, we went through 68 RCT studies and characterized each study’s recruitment, consent, and financial strategies.
Data Collection: REDCap & Email

**Recruitment Strategies**
- Phone call
- Text Message
- Email
- Mailed Letter
- In-person
- Electronic patient portal
- Not specified
- Other

**Consent Strategies**
- Opt-In consent
- Opt-Out consent
- Waiver of Consent
- Not specified
- Other

**Financial Strategies**
- Direct Payments
- Transportation Payments
- Lottery Payments
- Not specified
- Other
- Did not provide financial incentives
Where do we come in?  Aim 3

- Review codes and cross-check them with the ETR framework
- Look at free-listing survey data and glean salient themes to code for in qualitative analysis
Survey Questions

What should researchers do?

What should researchers not do?

Should researchers pay participants—how much?
## Qualitative Analysis

<table>
<thead>
<tr>
<th>Themes</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>“Ease fears, discuss why the study is being conducted, explain it’s voluntary”</td>
</tr>
<tr>
<td>Participant centeredness</td>
<td>“Listen to everyone’s opinions”</td>
</tr>
<tr>
<td>Education</td>
<td>“Explain to them why research is important and educate them on the types of studies you’re doing”</td>
</tr>
<tr>
<td>Recruitment</td>
<td>“Recruit ideal candidates who can give quality feedback and people who will not drop out prematurely”</td>
</tr>
<tr>
<td>Compensation</td>
<td>“Compensate people to participate”</td>
</tr>
<tr>
<td>Benefit / value of research</td>
<td>“Socialize the study from the achievements that could be made and how they benefit the community”</td>
</tr>
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Relationships & Networks
- Institution type (e.g., academic vs. community)
- Presence of community partnerships, advisory committees
- Perceived responsibility for contributing to research

“Physiological” Pathways
- Ability to understand consent forms
- Fears about participating in research
- Importance of access to research opportunities

Systems of power
- Consent procedures
- Recruitment strategies
- Financial Incentives
- Participation supports (e.g., childcare, transportation)
- Supports participants with limited English proficiency

Individual Factors
- Socioeconomic status
- Social determinants of health
- Age
- Primary language
- Comorbidities
- Prior research participation
- Experience with racism or discrimination in health care
- Home and work responsibilities

ETR Framework
The Joint Research Project (JRP) is chartered by Center for Health Incentives and Behavioral Economics (CHIBE) and the Palliative and Advanced Illness Research (PAIR) Center.

Mission: To promote research conduct based on shared principles of racial justice, equity, and inclusion.

Objective: To develop and disseminate evidence-based, best practices and guidelines for the conduct of inclusive and anti-racist research that advances the science and practice of health equity.
Our Roles

- **Literature Review**: Addressing barriers to conducting anti-racist/DEIA research
- **Manuscript**: Helping to write and review a JRP manuscript
- **Payment Method**: Worked to create payment method to help with future studies
- **Roybal Retreat**: Helping to form and review the JRP Presentation at the retreat
Takeaways

- Importance of working in a team and a research center
- How implicit bias can affect quality of healthcare
- Gained experience in qualitative research
- Intersection of Medicine & Research
THANK YOU

- Erich Dress
- Emma Britez Ferrante
- Jasmine Silvestri
- Maayra Butt
- Shira Blady
- Tamar Klaiman
- Dorothy Sheu
- Dr. Scott Halpern
- Joanne Levy
- ChiChi Nwadiogbu
THANK YOU

Adina Lieberman

Managing Director of the BETTER Center; Director for Diversity, Equity, and Inclusion Program Development at the PAIR Center and amazing mentor