Panel & Discussion on Health Disparities and Community Engagement for Inclusive Research and Recruitment

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https://wis.martinos.org/
Mental health inequities can be seen in:

- Prevalence
- Outcomes

Arundati Nagendra
Why?

• Racism impacts the development and treatment of mental illnesses
• Culture impacts the development and treatment of mental illness
  • Not enough culturally-focused research
  • Race/ethnicity being treated as a “nuisance variable”
  • Assessments – use and interpretation
• Not enough culturally-tailored treatment and systems of care
• Lack of representation
Why?

• Racism impacts the development and treatment of mental illnesses

• Culture impacts the development and treatment of mental illness

• Not enough culturally-focused research
  • Race/ethnicity being treated as a “nuisance variable”
  • Assessments – use and interpretation

• Not enough culturally-tailored treatment and systems of care

• Lack of representation
Overall Mission: to increase the diversity of those who participate in research

- How do we do this?
  - Consultations
  - Community Outreach and Events
  - Research

- Research coordinating = research + relationships
General Advice for Increasing Diversity and Inclusion in Research

• Build in multi-layered benefits
  • Direct Payment, study-wide newsletters, return of results to community, referrals to other research in/or around clinic, etc.

• Build relationships with...
  • The community, local Community Health Centers/local providers, research participants

• Build participant engagement and recruitment into your budget and study timeline
  • Ensure your study has the resources it needs to actualize these engagement and recruitment goals

• Address barriers to research
  • Barriers to research disproportionately affect marginalized communities. Reducing and eliminating these barriers whenever possible will help your research become more representative and thus, more generalizable
Of all forms of inequality, injustice in healthcare is the most shocking and inhuman.

—Martin Luther King, Jr.
Tuskegee – the origin of diverse recruitment
SHORT LIST OF MEDICAL ABUSES AGAINST BLACK COMMUNITY MEMBERS

Samuel Cartwright (1840s) - coined drapetomania and dysthaesthesia aethiopica to justify slavery

Marion Sims (1850s) - learned to repair prolapsed uteri on Black slaves without anesthesia

Joseph Goldberger (1912) - induced pellagra in prisoners

American South (1920s) - medical use of “idiot,” “imbecile,” & “moron” to force sterilization of Blacks

George Gey (1951) - took Henrietta Lacks’ cells without consent, created HeLa immortal cell line

Chester Southam (1952, 1963) - injected cancer cells in prisoners

Vertus Hardiman (1925) - skull dissolved after being irradiated as 5 year old, parents deceived

Ebb Cade (1941) - injected with plutonium, denied medical care after severe car accident

Eugene Saenger (1960-1971) - forged consent documents, irradiated patients

Johns Hopkins (1970) - misled participants, looking for genetic predisposition to crime

Centers for Disease Control (1990) - experimental measles vaccines for babies without consent

Columbia University (1997) - broke sealed juvenile records, specifically excluded Whites
MEDICAL ABUSES AGAINST OTHER GROUPS

Law 116 in 1937 – Forced sterilization in Puerto Rico

1960s – Mexican American women were sterilized in California

– Forced sterilization at ICE detection centers

Germany & Japan (World War II) – Vivisection

– Nazi human experimentation

John Charles Cutler (1940s) – The syphilis experiments in Guatemala

Perry Hudson (1950s) – Skid Row Cancer Study, prostate biopsy in homeless men
Respect for Persons

Must provide informed consent

Beneficence

Do no harm

All parties must understand and accept risks/benefits

Justice

Fair distribution of costs and benefits
HOW DO FEDERAL RESEARCH GUIDELINES ENCOURAGE INCLUSION?

Numerous aspirational policies; all fell short
NIH Revitalization Act of 1993
NIH Policy - Inclusion of Women and Minorities 2001
Establishment of Special Populations offices within ICs at NIH
NIH Inclusion Across the Lifespan 2019
Many, many, many FDA strategies, guidelines, declarations
  ● Including new draft guidance from late June 2019

But why is diversity important for research?
Is it a social justice thing?
<table>
<thead>
<tr>
<th></th>
<th>WOMEN</th>
<th>WHITE</th>
<th>BLACK or AFRICAN AMERICAN</th>
<th>ASIAN</th>
<th>HISPANIC</th>
<th>AGE 65 AND OLDER</th>
<th>UNITED STATES</th>
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<tbody>
<tr>
<td><strong>AVERAGE</strong></td>
<td>56%</td>
<td>75%</td>
<td>8%</td>
<td>6%</td>
<td>11%</td>
<td>30%</td>
<td>54%</td>
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<tr>
<td><strong>Est US pop</strong></td>
<td>50.8%</td>
<td>76.5%</td>
<td>13.4%</td>
<td>5.9%</td>
<td>18.3%</td>
<td>16.0%</td>
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<tr>
<td><strong>Median CTS</strong></td>
<td>55%</td>
<td>78%</td>
<td>3%</td>
<td>5%</td>
<td>8%</td>
<td>11.5%</td>
<td>36%</td>
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<td><strong>CoV CTS (SD / mean)</strong></td>
<td>0.47</td>
<td>0.35</td>
<td>1.64</td>
<td>1.44</td>
<td>0.85</td>
<td>1.10</td>
<td>0.80</td>
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WHY YOU SHOULD CARE ABOUT RECRUITMENT (PLANS)

2018 - Research Participation

MGH

Boston
WHO IS CONSIDERED TO PROVIDE DIVERSITY IN CLINICAL TRIALS?

- Ethnic and Racial minorities
- Rural population
- Low socioeconomic status
  - Low income, low education
- Women
- LGTBQ+
WHY CAN’T WE RECRUIT DIVERSELY?

1. Lack of awareness of research opportunities
2. Deep mistrust of healthcare system and research studies
3. Confusion and concern over what research is
4. Limited transportation options / times
5. Inclusion / exclusion criteria (e.g., lumbar puncture, study partner)
6. Lack of plain language use in documents
7. Fear of placebo / fear of intervention
8. Health insurance coverage
9. Limited diversity on study staff
10. Insufficient return of value

Selected references:
Bonevski 2014 | BMC Med Res Method
Ejiogu 2011 | The Gerontologist
George 2004 | Am J Public Health
Gul & Ali 2009 | J Clin Nursing
Jackson Moy Evans 2016 | The Oncologist
Oh 2015 | PLoS Medicine
Otado 2015 | Clin Trans Sci
Probstfield & Frye 2011 | JAMA
Robinson & Trochim 2007 | Ethn Health
DIVERSITY AS A WORKFLOW PROBLEM

Sampling frame
- Lack of awareness of research opportunities
- Deep mistrust of healthcare system and research
- Confusion and concern over what research is

Awareness
- Limited transportation options / times
- Inclusion / exclusion criteria
- Lack of plain language use in documents

Engagement/Trust
- Fear of placebo / fear of intervention
- Health insurance coverage
- Limited diversity on study staff

Interest/Education
- Insufficient return of value

Return of Value
- Insufficient return of value

Screening

Randomization

CARE
at Massachusetts General Hospital
Jackson | under review
Epidemiology
Social media
Market research
Library sciences
Bioethics
Biostatistics
Clinical research

Sampling Frame
Awareness
Engagement / Trust
Interest / Education
Return of Value

Study Design
Randomization

Systemic
Individual

Jackson | under review
Here’s a little concrete advice

• Use plain language for everything, including your ICF
• Language equity shouldn’t be the problem it is, but let’s at least get English right
• Aim for 5th grade reading level, but no higher than 8th
• Use clinician champions and research ambassadors
• This becomes easier if you have a solid clinic / community presence
• Think about what you can offer clinicians to support research (hint: your expertise)
• Design for a strong return of value
• Beyond return of results - make it easy / free / fun to participate
• If you can’t return any results or decent compensation, do participant celebrations
• Sustained community entrenchment works but takes time
• Can’t float in and out, magic number seems to be around 7 years
• Talk to communities and families, not just prospective participants
To mark your attendance, please text code: LACTOR to 857-214-2277

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  - James Morill, MD, PhD
  - Angie Sanchez, MD
  - Juliana Ison
  - Mary C. Catanese, PhD & Lyssa Manning, MSc PMP (Moderators)

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