

Outreach to Diverse Communities

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Disclosure of Relevant Financial Relationships

I, Jonathan Jackson, PhD, have been asked to disclose any significant relationships with commercial entities that are either providing financial support for this program or whose products or services are mentioned during my presentations.

I have no relationships to disclose.

I may discuss the use of vaccines in a manner not approved by the U.S. Food and Drug Administration.

But in accordance with ACIP recommendations.

Our site's experiences in diverse recruitment

- Massachusetts Alzheimer's Disease Research Center, located within MGH
 - Founded 1984, funded by P50 center grant
 - Currently focused on early detection and prevention of Alzheimer's disease
- Organized under six Cores
 - Core E - Outreach, Recruitment, & Education

Our site's experiences in diverse recruitment

- Outreach, Recruitment, & Education Core
 - Diverse recruitment a key priority
 - Diverse mix of researchers and staff
 - Engagement of both medical and lay communities
 - Community Advisory Board

Our site's experiences in diverse recruitment

- Difficulties
 - No existing clinical registry
 - Very strong resistance to minority screen mandate across sites
 - Non-diverse study staff
 - Low-accessibility site
 - Sporadic relationship with Community Advisory Board
 - Poor reputation among minority communities
 - “Competition” from nearby AD research center, historically closer to minority community

Present situation	Inputs	Outputs		Outcomes		
		Activities	Actors	Short	Medium	Long

Mistrust of health establishment	Staff time	Serve within community orgs	Community leaders	Shift in onus to take charge of health to diverse communities	Improve diverse recruitment & retention	Sustained, mutually beneficial partnership with diverse communities
Barriers to clinical care	Money	Engage with advisory board				
Low diverse participation for clinical care	Materials & equipment	Train staff to avoid microaggressions	Current participants	Ongoing dialogue between med team & community leaders	Improve diverse health literacy & access	
No guarantee of long-term retention		Adjustment of research group values	Create focus groups	Future study participants		
Poor research generalizability due to lack of diversity		Modify health protocol	Participant families	Researchers understand diversity as valuable source of stat variance	Create robust datasets that reflect US population	
		Translate study materials				
		Free health screenings				
		Educational talks	Research collaborators			
		Normalize diverse health concerns				

**What's Happening
Now**

Agents of Change

Goals

Actions

Actors

Short

Medium

Long

What are some barriers to clinical care?

Confusion
& concern
over
medical
care

Patient may
be blamed
for health
issues

Limited
diversity
on care
staff

Medical
materials
use the
wrong
language

Tuskegee
and other
harmful
experiment
s

Inconvenien
t times &
locations

**What's Happening
Now**

Agents of Change

Goals

Actions

Actors

Short

Medium

Long

Who should be involved in this process?

**Community
leaders**

**Current
patients**

**Future
patients**

**Patient
families**

**Healthcare
providers**

**What's Happening
Now**

Agents of Change

Goals

Actions

Actors

Short

Medium

Long

**What short-term goals can we agree on?
(6-9 months)**

Shift onus to
take charge
of health to
diverse
communities

Ongoing
dialogue
between med
team &
community

Heightened
awareness &
positive
views toward
research

**What's Happening
Now**

Agents of Change

Goals

Actions

Actors

Short

Medium

Long

**What medium-term goals can we agree on?
(1-2 years)**

Improve
minority
recruitment &
retention

Improve
minority health
literacy &
access

**What's Happening
Now**

Agents of Change

Goals

Actions

Actors

Short

Medium

Long

**What long-term goals can we agree on?
(2-5 years)**

Sustainable,
mutually
beneficial
partnership with
minority
communities

Development of
treatment plan
that works for
everyone

**What's Happening
Now**

Agents of Change

Goals

Actions

Actors

Short

Medium

Long

How can we accomplish these goals?

Immediately

Regularly
engage with
CAB

Serve within
community
organizations

Free health
screenings

Educational
talk series

This year

Train staff to
avoid
microaggression
s

Modify protocols
to make it easier
to receive care

Translate study
materials into
other languages

Within 18 months

Create focus
groups in
each
neighborhood
to help us
improve

Begin to
normalize
diverse
participation
in med care

Outreach & Entrenchment

- High rates of poverty
- “Retirement” not a reality
- Lack of time/trust
- Linguistic isolation
- Physically proximal social networks as locus of support
- Community is primary source of information
- Strong focus on family
- Multi-pronged approach:
 - Personalize the disease
 - Lower cost of participation
 - Increase ease of participation
 - Build trust within communities
 - Provide current information about health matters
 - Provide additional services