Developing Inclusive & Representative Research Populations

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The presentation today will focus on overall information and best practices for inclusive research.

I cannot speak on behalf of the populations we mention or discuss today. Nor can I claim to understand their lived experiences.
Outline

• Importance of inclusive research

• Underrepresented populations in research

• Barriers to inclusion

• Addressing the barriers

• Case Study: Including older adults

• Q&A
Learning Objectives

1. Understand the importance of inclusive research

2. Identify some of the known barriers to recruitment of underrepresented populations and think of effective ways to address the barriers

3. Understand and apply these solutions to including older adults in research
The Why: Importance of inclusive research

• To ensure participant demographics are reflective of disease demographics

• Because you cannot fully understand a disease and its treatments if you do not include in the research everyone who has the disease

• To be able to produce more representative, comprehensive research results applicable to the broadest population possible

• It’s just good science

• To be aligned with Federal regulations. The NIH\(^1\) requires grant applicants and awardees to have study populations that are representative of the disease being studied

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1. NIH Grants & Funding: [Inclusion Policies for Research Involving Human Subjects](http://www.nih.gov)
Underrepresented populations in research

In research, individuals and groups have been underrepresented based on their*:

- Race
- Ethnicity
- Age
- Sexuality
- Gender identity
- Faith and/or culture
- Socio-economic status
- Ability and/or mobility level
- Cognitive and/or developmental status
- Geographic location (e.g. rural areas)

*Not an exhaustive list
Barriers to inclusion in research

Barriers that exist include:

• History and lived experience
• Personal safety concerns
• Access to care
• Spoken or written language
• Immigration status
• Study site
• Protocol rigidity
• Timing
• Cost
Addressing the barriers

Measures/practices to ensure inclusion:

• Use of trauma informed language and care
• Community partnerships
• Adaptable study(ies)
• Flexible study times
• Accessible study locations
• Guardian/caregiver identification
• Translated materials and interpreter services
• Appropriate participant compensation
Addressing the barriers – Recruitment methods

• Operate in a way that is sensitive, respectful, transparent, and builds trust

• Build community relationships that are ongoing, fostered, and mutually-beneficial

• Use multiple recruitment methods and tailor them to your population

• Put retention methods in place

• Ensure recruitment materials are inclusive and representative
Recruitment Materials: Images

Do potential participants see themselves reflected in the images of your materials?
Recruitment Materials: Words

In your recruitment materials and communication, it’s important to consider:

- Writing is at a 6th grade reading level
- Words are in plain/simple language
- Use people first language
- Sensitive wording
- Large enough font size
- Culturally competent content
- Gender neutral communication style
- Documents are in the right language
- Words are respectfully inclusive
Case Study:
Including older adults in research
The current situation...

- There are more Americans today age 65 and older than any other time in history (~49 million)\(^1\)

- These numbers are expected to grow, with ‘older adult’ being one of the fastest growing age groups\(^2\)

- Many diseases are common in older people, yet little research has been done in older ages\(^3\)

- Many diseases are distinctly different in older adults, yet haven’t been studied in these age groups\(^4\)

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1. National Institute on Aging: Strategic Directions for Research
2. U.S. Census Bureau: Older Population and Aging
3. Lockett et al. “Adequacy of Inclusion...”
4. Cherubini et al. “Fighting against Age Discrimination...”
Known barriers to older adult inclusion

• Rigid protocol eligibility criteria
  • Limited age range, no comorbidities, certain mobility level required

• Time
  • Length of study, consent process, timing and frequency of study visits

• Ability or mobility level of participant

• Cognitive status of participant (due to age or disease/condition)

• Accessibility of study site
  • Location and accommodations

• Transportation concerns

• Schedule and availability of caregiver (if applicable)
Solutions to inclusion / Addressing the barriers

1. Evaluate and redesign the study protocol if needed or able to
   • Ensure exclusion criteria is based on scientific necessity only
   • Adapt study procedures and measurement tools to participants
   • Lengthen study timelines to account for the extra time needed

2. Build flexibility and adaptability into your study
   • Accommodate study visits to participant’s and/or their caregiver’s schedules
   • Ensure the site is accessible
   • Consent family member/caregiver into study
3. Plan for appropriate resources
   • Budget for the extra time, staff, resources and finances needed

4. Overcome transportation issues
   • Use car services, rideshares or taxis
   • Home visits or telehealth appointments

5. Recruitment and retention
   • Use multiple recruitment methods
   • Put retention methods in place
   • Adapt recruitment materials to older adult participants
Example—Mr. Scott

Mr. Scott
• New diagnosis Parkinson disease
• Lives with wife in senior housing community
• Neither drive; daughter takes them to church
• Served in the military
Ideas for Mr. Scott’s Recruitment

• **New diagnosis Parkinson disease**
  - Use EHR-based tools to identify newly diagnosed patients
  - Post study flyers in clinic space
  - Advertise through support groups and disease associations

• **Lives with wife in senior housing community**
  - Flyers posted in key areas (e.g. community centers, fitness centers)
  - Attend and ‘table’ at community and outreach events
  - Provide free health talks at senior centers or housing communities
Ideas for Mr. Scott’s Recruitment

- **Neither drive; daughter takes them to church**
  - Arrange for transportation to visit and/or have home visits
  - Consent daughter into study as proxy
  - Post study flyer on community bulletin board of church or use space to provide free health talks

- **Served in the military**
  - Post study flyers in VFW halls
  - Advertise through veteran activity and support groups
  - Paid social media ads on veteran focused sites (e.g. Rally Point)
Questions?
Thank You

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