WISCONSIN
ALZHEIMER'S DISEASE
RESEARCH CENTER

Increasing Participation of Underrepresented Groups in Biomarker Research

Department of Veterans Affairs
United States of America

WAI
WISCONSIN
ALZHEIMER'S
INSTITUTE

Dorothy Farrrar Edwards PhD

University of Wisconsin Madison

What Are the Perspectives of Underrepresented Groups ?

- Do we have common understandings of clinical research and the research process?
- Will the potential benefits or advances developed through clinical research be equally available to all groups?
- Do all potential participants feel that they will be protected from unnecessary risks and potential harm?
- What are the "costs" of participation ?
- Who wins and who looses when these issues are not addressed ?

Background

- “Increasing Participation of Underrepresented Groups in Biomarker Studies”
- UW –NIMHD P-60 R-01
- Mixed Method Study
  - Four racial ethnic groups
    - African Americans
    - Latinos
    - Native Americans
    - Caucasians
- Interviews in English and Spanish

Study Goal

- Goal of the study is to develop and validate a culturally appropriate survey designed to assess community members’ attitudes toward clinical research and barriers and facilitators to participation in biomarker studies of:
    - Alzheimer’s disease
    - Cancer
    - Cardiovascular disease
    - Pulmonary disease
- Specific areas of inquiry included attitudes and beliefs regarding:
    - Blood draws for genetic testing
    - Collection of cerebrospinal fluid
    - Tissue biopsies
    - Neuroimaging
    - Brain donation and autopsy
- Develop culturally appropriate education and recruitment materials

Methods

- Key Informant Interviews
  - 96 (24 per group)
  - Stratified by age , gender and education
- Survey Item Data Bank
  - Item library of 550 items from published surveys
    - Trust/mistrust
    - Research participation
    - Attitudes toward specific types of investigators, types of research, health care institutions and providers
    - Types of biomarkers (saliva, blood, csf, brain donation)

Methods

- Cognitive Interviews
  - 2 Rounds
  - 144 participants
- Cognitive Interviews use a structured interview format with standard probes to better understand how study participants approach questions, response options and comprehension

- Conducted in English and Spanish

- Race/Ethnicity and Gender congruent interviewers

Methods

- 95 item telephone survey
  - Trust /mistrust
  - Participation (saliva, blood, tissue, csf, imaging, brain donation)
  - Participation(requestor, institutions, race/ethnicity,
  - Facilitators (study results , family has the disease, remuneration, transportation)
  - Barriers (pain, privacy, risk of infection, use of results)
  - Respondent characteristics

Telephone Survey

- 400 telephone interviews (100 per group)
- English
- Administered by the UW Survey Center
- Purchased names and telephone numbers –Wisconsin households
- Supplemented by community recruitment of Native American and Latino participants
- $20 remuneration
- Survey takes about 60 minutes

Key Informant Interviews

- Common and Community specific themes
- Lack of common understanding of what we mean by medical or clinical research
- Willingness to participate decreases by the perceived invasiveness of the biomarker: saliva, imaging, blood, biopsy, LP
- Brain donation attitudes are most variable across groups

Key Informant Interviews

- Caucasian Interviews
  - Most concerned about risk of infection
  - Time demands and inconvenience
  - Negative attitudes toward drug/device trials
- African American interviews
  - Mistrust of investigators/ research institutions
  - Concerns about pain and risk of long term paralysis with LP
  - Concerns that data will be used to promote negative stereotypes
  - Findings never shared with community

Key Informant Interviews

- Latino Interviews
  - Greater emphasis on ethnicity, gender and language skills of the investigator
  - Lack of familiarity with institutions
  - Concerns about privacy and immigration status
  - General positive attitudes about brain donation
  - General positive attitudes if research will benefit the community

Key Informant Interviews

- Native American
  - Historical abuses and lack of trust of institutions and investigators
  - Little engagement of investigators or health care providers with native communities
  - Significant variation across tribal communities
  - Gender of interviewer important for face to face interviews
  - Religious and spiritual beliefs affect willingness to provide biological specimens

Cognitive Interviews

We used these interviews to determine:

- Key biomarkers to include in the final survey
- Response dimensions about behavioral intentions to participate
- How to refer to research
- Ordering of questions on participation

Research Participation

Q: “In your own words what does the phrase medical research study mean to you ?”

- No common understanding of what we mean by “biomedical medical or clinical research”
- Lack of understanding was consistent across all racial and ethnic groups
- Responses ranged from positive to negative

What does the term “medical research” mean to you ?

- "To inoculate diseases, viruses and bacteria in animals like rats, rabbits or monkeys. When I go here (the US), I realized that it is also done with humans." (Latino male)
- “Like you go to a place and answer questions about your health history. Um, it can be psychological questions to, um, donating like blood or DNA, spit, going through a MRI machine” (Caucasian male)

What does the term “medical research” mean to you ?

- That they want to use me as a guinea pig, and I am not going to participate in a program like that**…**I don’t like to be prodded and poked.” (African American female)
- “I immediately thought of big, big corporate like pharmaceutical companies…this is the first thing that sort of popped into my head." (Caucasian female)

What does the term “medical research” mean to you ?

- “…like they are going to use my body and my life to investigate something, and there is a risk that it will go right or wrong.” (Latino female)

What does the term “medical research” mean to you ?

- “Looking for better ways of health, for health care, to improve on what's out there available to people.” (Caucasian female)

- “Finding out maybe, uh, your thoughts about, uh, medications and stuff like that.” (African American male)

Conclusions

- Study investigators and research teams need cultural competence training and guidance in developing recruitment materials and strategies
- Need for clear terminology and inclusive recruitment materials
- Community specific barriers
- Importance of relating the findings to the health of individuals and communities
- Biomarker research is possible but time consuming and labor intensive

Biomarkers Research Team

- Coinvestigators
  - Jennifier Dykema PhD –UW Survey Center
    - Ken Croes
    - Tara Piche
  - Tracy Schroepfer PhD
    - Wade Gunn
    - Jesus Renteria
    - Crystal Tortillote
    - Tim Annis
    - Rachel Byington
    - Christa Fields
    - Raquel Francisco
    - Sietta Parks
- Diane Turner PhD-Project Coordinator

Funding

- University of Wisconsin Health Disparities Research Center of Excellence
- Alexandra Adams MD & Christine Sorkness PhD PIs
- NIMHD P60 MD003428

- UW Institute for Clinical and Translational Research (CTSA)
- UW Collaborative Center for Health Equity