Fielding studies in underrepresented populations: challenges and considerations

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January 2018
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Southern Community Cohort Study (SCCS)  
R01 CA092447 PI: Blot, Zheng  
~85,000 participants in a longitudinal study

Signorello et al., J Nat Med Assoc, 2005
US subgroup populations

African American  Rural  Poor

Proportion of US population  13%  19%  13%

Health differences
Not well represented in population-based cancer research
Access challenges
FIGURE 1—Research with small data: identifying challenges.
Some commonalities: Hard-to-Reach and Small Groups

Gaps in knowledge
Untapped or overtapped populations

**Study design / methodology:**
1. Identify and access population
2. Recruitment
3. Data collection
4. Retention

- Intensified efforts
  - Planning
  - Developmental groundwork
  - Time and resources
- New strategies?
Access to subgroup population of interest

Why?

Serve communities with high levels of poverty in rural and urban areas, who are medically underserved.

Communities access the CHCs for services other than just health care.

What failed?

- Telephone contact – within selected zipcodes
- Mail – within selected zipcodes
- Community Health Center (CHC) – telephone contact with patients
- Community Health Center (CHC) – mailed contact with patients
65% African American
61% household income < $15,000
33% less than a high school education
Community-based, in-person recruitment

Community Engagement

Trust Building

Making it win:win
Community-based, in-person recruitment

Community engagement and trust building

- Understanding decision-making structure and priorities
- Meetings and visits
- Continuous dialogue
- Earning trust and confidence

Community-led boards
Community-based, in-person recruitment

Making it win:win

- Addressing the health concerns of the population through research (altruistic benefits)
- Capacity building
- Funding
- Access to aggregate data
- Enhanced CHC activities useful in their own grant applications
CHC Engagement

Medical Director

CEO

Community hire

Director of Nursing
Montgomery Primary Health Care Center, Montgomery, AL
St. Matthews Family Health Center, St. Matthews, SC
Data Collection

Primary data collection, and the potential need for tailoring.

Exposures → Unique
- Understanding the context
- Focus groups, other foundational work
- Develop and validate questions or instruments
- Develop new biomarkers
- Develop new geospatial indices

Exposures → Not unique
- Language
- Cultural slang / colloquialisms
- Literacy
- Need validation in the specific population
- Questions or instruments need adaptation
Retention

Hard to reach can mean hard to reach again

- Collect more contact information at baseline
- Offer avenues “in” to update information or collect follow-up data
- Expand the options of where and how you look for participants

- New technologies?
Conclusions

Including underrepresented groups in research is important.

• Large and small scale studies of underrepresented populations / population subgroups share some (but not all) challenges.

• Efficacy and efficiency: can we maximize both?