

Fielding studies in underrepresented populations: challenges and considerations

Lisa B. Signorello, ScD

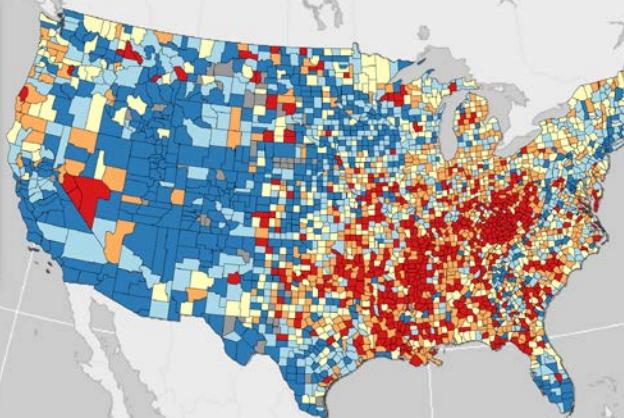
Senior Biomedical Scientist

Acting Director, Cancer Prevention Fellowship Program

Division of Cancer Prevention, NCI/NIH

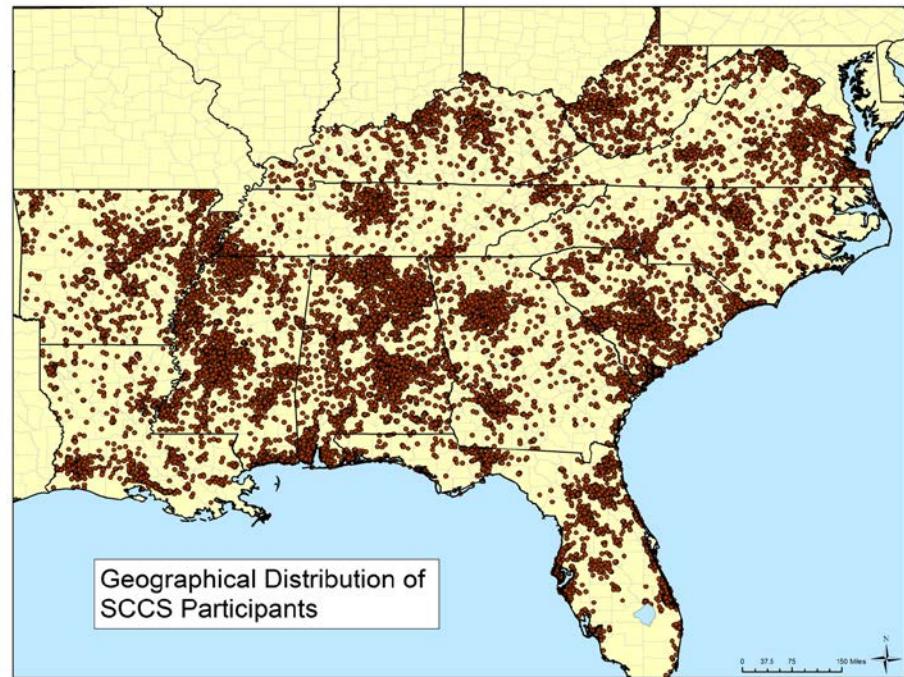
The views expressed in this presentation reflect those of the author and do not necessarily reflect the official views of the National Cancer Institute, the National Institutes of Health, the U.S. Department of Health and Human Services, or the federal government.

Age-Adjusted Death Rates by County (2010 to 2014)
All Races, All Malignant Cancers (Both Sexes)



Source: National Vital Statistics System. Rates are age-adjusted to the 2000 US standard population using SEER*Stat. More information: <https://gis.cancer.gov/geoviewer/data>

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



Geographical Distribution of
SCCS Participants

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

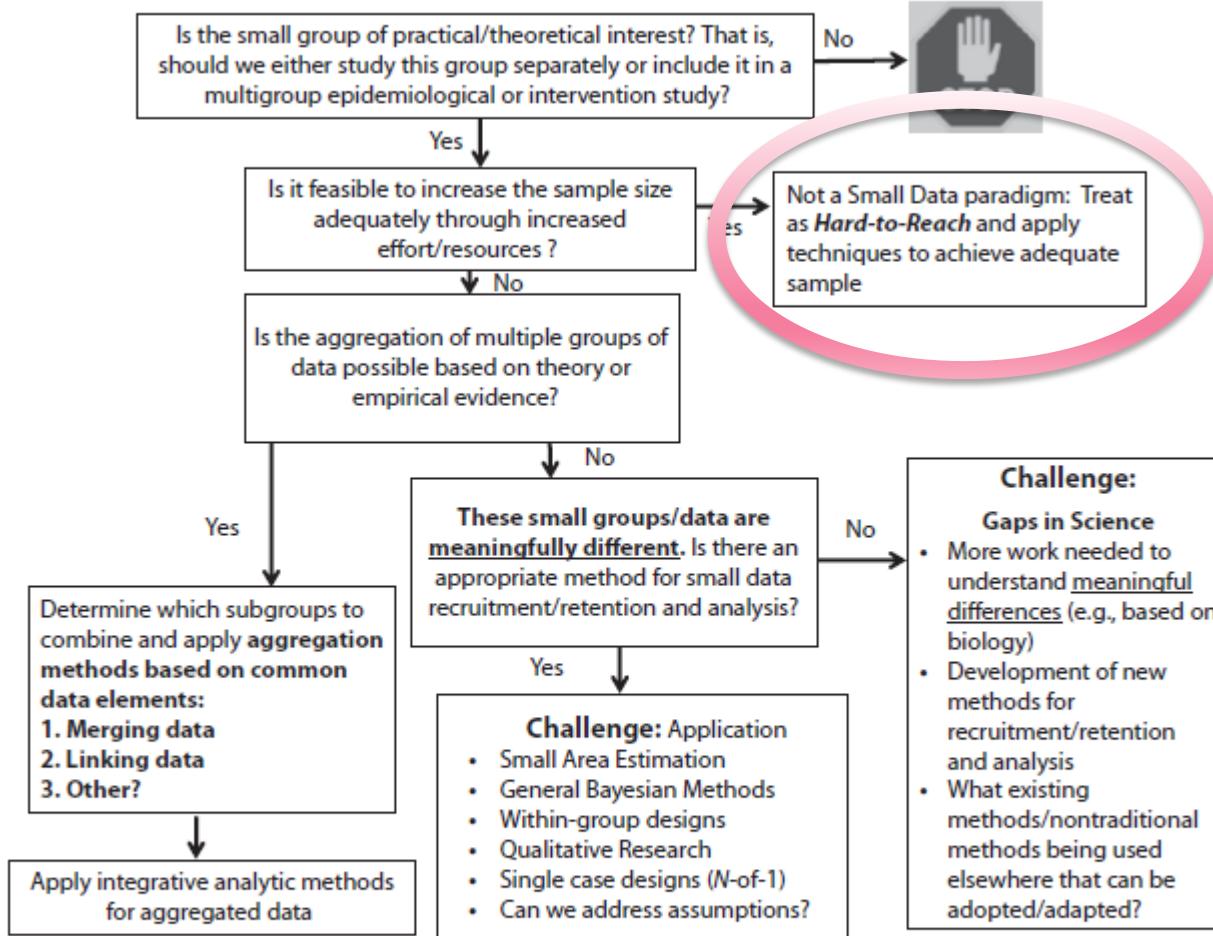


FIGURE 1—Research with small data: identifying challenges.

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



Community-based, in-person recruitment



Community-based, in-person recruitment

Community engagement and trust building



Community-led boards

Understanding decision-making structure and priorities

Meetings and visits

Continuous dialogue

Earning trust and confidence

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

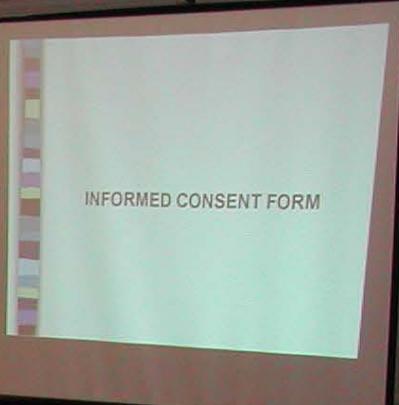
Medical Director

CEO

Community hire

Director of Nursing





INFORMED CONSENT FORM



SCCS
Neal Guthrie
White River Rural Health Center, Inc., Chillicothe, AR



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?



**NATIONAL
CANCER
INSTITUTE**

www.cancer.gov

www.cancer.gov/espanol