



Improving Health Research for Small Populations

A Workshop

January 18 and 19, 2018

**The NAS Building
2101 Constitution Ave. NW
Washington, DC 20418**

NAS Lecture Room

AGENDA

Brief Statement of Task

A National Academies of Sciences, Engineering, and Medicine ad hoc planning committee will organize a public workshop to discuss the methodological challenges of conducting research on small, underrepresented population subgroups in health research. The workshop will consider ways of addressing the challenges of conducting epidemiological studies or intervention research with small population groups, including alternative study designs, innovative methodologies for data collection, and innovative statistical techniques for analysis. Specifically, the workshop will address approaches for identification, recruitment, and retention of study participants to maximize the sample sizes of small groups in research studies; epidemiological design and analytics approaches for small samples; and intervention study design and analytic approaches for subpopulations.

This workshop is co-sponsored by the National Cancer Institute (NCI), the National Institute on Minority Health and Disparities (NIMHD), and the Office of Behavioral and Social Sciences Research (OBSSR) of the National Institutes of Health. Support for this workshop was also provided, in part, by the Robert Wood Johnson Foundation. The views expressed here do not necessarily reflect the views of the Foundation.

DAY 1: Thursday, January 18, 8:30 AM - 5:00 PM (NAS Lecture Room)

8:00 - 8:30 AM Registration (East Court); Refreshments Available

WELCOME AND INTRODUCTIONS

8:30 MODERATOR: **Graham Colditz**, *Committee Chair, Washington University in St. Louis, Opens the Workshop*

- 8:35 Welcome to the National Academy of Sciences
Brian Harris-Kojetin, *Director, Committee on National Statistics, National Academy of Sciences, Engineering, and Medicine*
- 8:45 Motivation and Objectives for the Workshop
Robert T. Croyle, *Director, Division of Cancer Control and Population Sciences, National Cancer Institute*

9:00 **SESSION I:** What do we Mean by Small Populations? How to Decide when a Small Population is Important or Meaningfully Different Enough to Study? Why did we Structure the Workshop this Way?

MODERATOR: **Graham Colditz**, *Committee Chair, Washington University in St. Louis*

- 9:05 **Howard Koh**, Harvard T.H. Chan School of Public Health, *The Importance of Health Research on Small Populations*
- 9:35 **Scarlett Lin Gomez**, University of California, San Francisco, *Data Issues in Studying Small Populations: Challenges, Opportunities, and a Case Study*
- 9:50 **Lisa Signorello**, Division of Cancer Prevention, National Cancer Institute, *Fielding Studies in Underrepresented Populations: Challenges and Considerations*
- 10:05 **Floor Discussion**

10:20 **BREAK** (refreshments available in East Court)

10:40 **SESSION 2:** Challenges in Using Available Data for Small Population Health Research

MODERATOR: **Lance Waller**, *Committee Member, Emory University*

- 10:45 **Kelly Devers**, NORC, *The Feasibility of Using Electronic Health Records and Electronic Health Data for Research on Small Populations*
- 11:05 **Chris Fowler**, Pennsylvania State University, *Using Geospatial Methods with Demographic Data to Identify Populations*
- 11:25 **Ellen Cromley**, Consultant, *Using Geospatial Methods with Other Health and Environmental Data to Identify Populations*

11:45 **Floor Discussion**

12:00 PM **LUNCH** (available in East Court)

1:00 **SESSION 3:** Techniques Used in Survey Research to Identify and Find Small Populations for Health Research

MODERATOR: **Graham Kalton**, *Committee Member, Westat*

- 1:05 **Marc Elliot**, Rand, *Probability Sampling Methods for Small Populations*
- 1:25 **Sunghee Lee**, University of Michigan, *Two Applications of Respondent Driven Sampling: Ethnic Minorities and Illicit Substance Users*
- 1:45 **Patrick Sullivan**, Emory University, *Venue-Based and On-line Sampling*
- 2:05 **Krista Gile**, University of Massachusetts, Amherst, Invited Discussant
- 2:25 **Floor Discussion**

2:45 **BREAK** (refreshments available in East Court)

3:00 **SESSION 4:** New and Emerging Designs for Intervention Studies

MODERATOR: **James Allen**, *Committee Member, University of Minnesota Medical School*

- 3:05 **Amy M. Kilbourne**, University of Michigan, *Designs for Dissemination and Implementation Research for Small Populations*
- 3:35 **Christine Lu**, Harvard Medical School, *Quasi-experimental Designs with Application to Small Populations*
- 3:55 **Diane Korngiebel**, University of Washington, *Addressing the Challenges of Research with Small Populations*
- 4:15 **Patrick H. Tolan**, University of Virginia, Invited Discussant
- 4:35 **Floor Discussion**

5:00 PM **PLANNED ADJOURNMENT**

DAY 2: Friday, January 19, 8:30 AM - 2:00 PM (NAS Lecture Room)

(Refreshments available in East Court from 8:00 AM)

8:30 AM MODERATOR: **Graham Colditz**, *Committee Chair, Washington University in St. Louis*
Welcome and Introductions to Second Day

8:40 SESSION 5: Recruitment, Retention, and Collection of Data with a Focus on Small or Hard to Reach Populations

MODERATOR: **Jan Probst**, *Committee Member, University of South Carolina*

- 8:45 **Vetta Sanders-Thompson**, Washington University in St. Louis, *Issues and Challenges Associated with Recruitment and Retention for Health Research*
- 9:05 **F. Douglas Scutchfield**, University of Kentucky, *Improving Health Research in Rural Areas*
- 9:25 **Kathi Mooney**, University of Utah, *Using Technology for Recruitment, Retention, Data Collection, and Intervention Delivery*
- 9:45 **Tracy L. Onega**, Dartmouth University, Invited Discussant
- 10:05 **Floor Discussion**

10:20 **BREAK** (refreshments available in East Court)

10:40 SESSION 6: Analysis Techniques for Small Population Research

MODERATOR: **Lance Waller**, *Committee Member, Emory University*

- 10:45 **Rick H. Hoyle**, Duke University, *Design and Analysis Considerations in Research with Small Samples*
- 11:05 **Thomas A. Louis**, Johns Hopkins Bloomberg School of Public Health, *Bayesian Methods for Small Population Analysis*
- 11:25 **Katherine R. McLaughlin**, Oregon State University, *Estimating the Size of Hidden Populations*
- 11:45 **Floor Discussion**

12:00 PM **LUNCH** (available in East Court; seating available in Great Hall)

1:00 SESSION 7: Wrap-up and Concluding Remarks

MODERATOR: **Gordon Willis**, *National Cancer Institute*

- 1:00 **Steering Committee.** Panel Discussion – Next Steps in Improving Health Research for Small Populations
- 1:30 **Floor Discussion**

2:00 PM **ADJOURNMENT**