

SAMPLING METHODOLOGY AND UNDERSTANDING TOBACCO- RELATED DISPARITIES IN SMALL POPULATIONS: LGBT OF COLOR POPULATIONS & MIGRANT FARM WORKERS

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IF YOU ARE NOT COUNTED,
YOU DO NOT EXIST.

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- Health research findings, specially from large-scale full-probability surveys, are one of the key corner stones that drive funding for public health programs, health care dollars, informs health policy, national and state health goals, funding for future research, influence study section reviewers, and so on

The lack of data on a population or communities experiencing health disparities will only exacerbate the disparities and any relief or remediation will be furthered away

- 
- The Journeys
 - Meeting Process
 - Recommendations

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The Journeys

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Why do this work?

□ NCTOH 2002

□ Healthy People 2010

- ...eliminate health disparities that occur by race and ethnicity, gender, education, income, geographic location, disability status, or sexual orientation.....progress toward the target for individual populations and progress toward the goal to eliminate disparities are independent of each other.

■ **Healthy People 2010 – not enough data to justify keeping “sexual orientation” in the 2010 goals to eliminate disparities**

■ **Healthy People set up data collection goals to**

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□ Why do this work?

- In 2003 we saw the first ever population based study on adult LGBT and tobacco use in the US (actually world wide)
 - Statewide random digit dial (RDD) survey of LGBT and tobacco use in California
- In 2004 findings from the CA statewide survey are presented at a meeting in Sacramento, CA
 - Smoking prevalence for the LGBT population (30.4%) is about double that of the general population (15.4%) as reported by the 2002 CTS
 - The LB women's rate is almost 200% higher than CTS woman's rate (32.5% vs. 11.9%)
 - The GB men's rate is about 50% higher than that for CTS men (27.4% versus (vs.) 19.1%)

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- Why do this work?
 - What about LGBT of color in CA?
 - Not enough N in cells to conduct analysis by race and ethnicity

WHAT the _ _ _ _ ?!?!?!?!?!?!?!?!?!?!?!?!?!?!?!?!?

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- Why do this work?
 - Community knowledge vs. scientific knowledge
 - What to do, what to do, what to do
 - Need to be counted to exist – at least in the research world
- TReND was the answer
 - 2005 funding from NCI, Legacy, TRDRP
 - LGBT of Color Sampling Methodology meeting in 2006

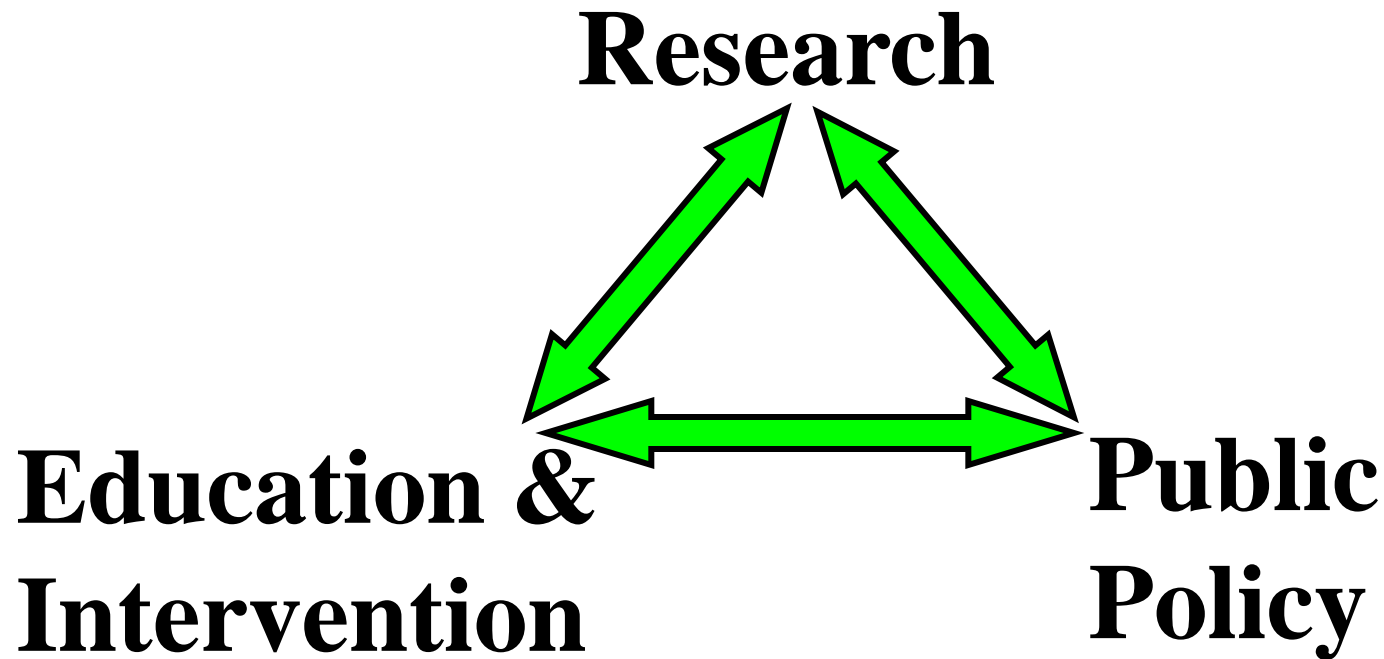
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- Why do this work?
 - A second journey, but different path:
 - Migrant Farmworker Sampling Methodology Report
 - Work in the US but die in Mexico and Guatemala
 - Report looking at the issue of sampling mobile populations, e.g., migrant farmworkers soon to be released by TReND
- Both of these journeys have not been traveled alone, but in partnership with TReND members and others outside of TReND – I thank them and the communities who benefit from our collective work thank them

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Ramifications

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- It is necessary that we begin to better understand health disparities in small, hidden, mobile, or hard-to-reach populations otherwise we will miss some of the most affected individuals who will continue to disproportionately suffer and die being invisible
- Understanding these disparities requires that we collect appropriate data in a manner that allows us to use those data to develop interventions to reduce the burden of health disparities, in this case tobacco

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- The answer lies not in any factor intrinsic to a particular group, but in what is a significant methodological challenge facing scientists today: the need to define what constitutes a “representative” sample of populations inadequately captured by large-scale, full probability surveys.

Which tested or promising research methods are most effective in sampling small, hidden, mobile, or hard-to-reach populations?

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Meeting Process

Meeting Process

- Each meeting was designed to identify barriers to sampling hard to find, hidden, and/or mobile populations and possible solutions.
 - Customized one day meeting
 - 20-25 participants – diverse group
 - Professionally
 - Area of expertise
 - Race/Ethnicity, gender, sexual orientation
 - Stakeholder representation

Meeting Process

□ Planning Structure

■ Pre-meeting preparation by participants

- Key articles to establish baseline knowledge

■ Morning Session

■ 4 presentations

- Demographic characteristics of target population
- A review of effective models/approaches to sample hard-to-reach, hidden and/or mobile populations
- Cultural/social/environmental factors in conducting research in target population
- The state of knowledge on tobacco use in target population

Meeting Process

□ Planning Structure (cont.)

■ Afternoon Session

- 3 working groups – group leader

- 4 questions to respond

- barriers to conducting research on target population

- best models/approaches to achieve adequate sampling target population

- issues in sampling specific subgroups within target population

- if/how sampling methods should be modified to conduct research on tobacco use

Meeting Process

- Editorial Group
 - Post meeting analysis and writing
 - Report drafts and review
 - Final report
- Dissemination plan and execution
 - Use knowledge brokerage model to disseminate and translate research findings

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Recommendations

Recommendations

- Strategies to achieve adequate sampling / addressing barriers
 - Definition/semantics
 - Cultural/social/environmental
 - Deeper understanding & Respect
 - Credibility & Commitment
- Socio-political & population historical experience with the scientific enterprise
- Formative research
 - Including ethnographic studies

Recommendations

- Sampling Methodology
 - Need to look at methodology fit with social, cultural, political, and environmental realities
 - Snowball sampling, Facility-based sampling, Targeted sampling, Time-location sampling, internet-based sampling, Household-based sampling
 - Respondent-driven sampling
 - Employment-based samples
 - Mixed-methods studies, whereby the combination of methods can balance the shortcomings of individual methods
 - Cognitive testing
 - Language and cultural tailoring of research instrument

Recommendations

- Tobacco specific recommendations
 - Role and use of tobacco
 - Standardize questions & definitions
 - Light and intermittent smokers
 - Situational or time specific use of tobacco
 - Study of subgroups

Recommendations



- Infrastructure needs
 - ▣ Building capacity
 - ▣ Study sections
 - ▣ Funding mechanism
 - ▣ Methodology studies

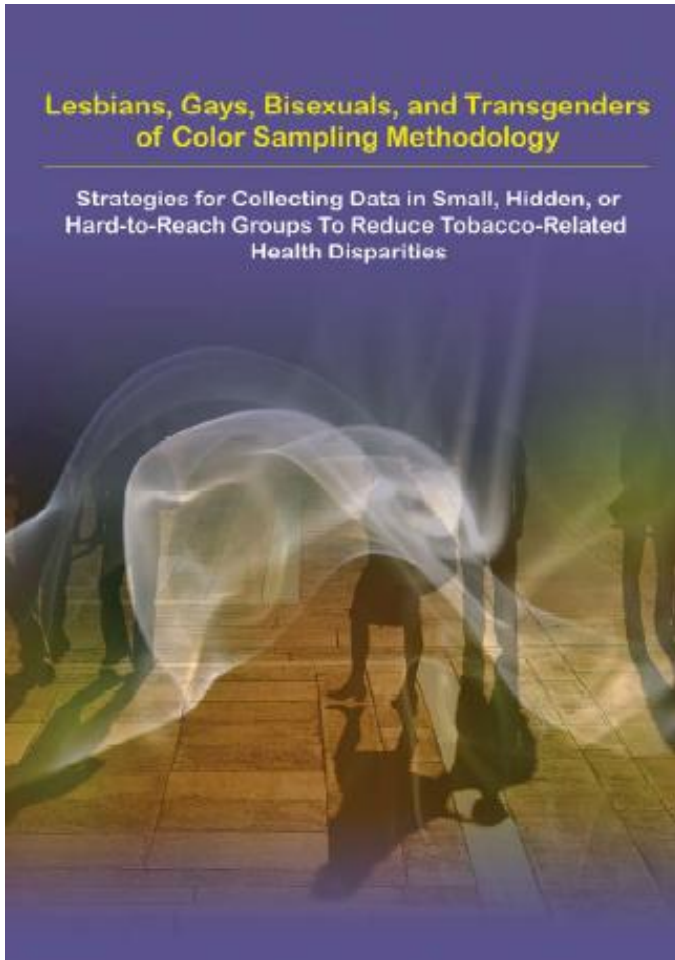
Recommendations



Indeed, the lack of data on these populations/communities creates a situation where a segment of the population remains invisible.

Thus initiatives and strategies to address health disparities may not have the much needed reach and impact on the health of these communities and individuals.

Reports



- **Migrant Farmworker Report will be released in a few weeks.**
- **tobaccodisparities.org**

**QUESTIONS ARE NEVER INDISCREET,
ANSWERS SOMETIMES ARE.**

OSCAR WILDE