ADDRESSING THE CHALLENGES OF RESEARCH WITH SMALL POPULATIONS

Improving Health Research for Small Populations Workshop
Washington, DC, Jan. 18-19, 2018
Focus for presentation (Srinivasan, et al., 2015)

FIGURE 1—Research with small data: identifying challenges.
Talk agenda

- Bioethics and small populations research
- Small populations and data aggregation
  - The “data cycle”
  - Data challenges when population numbers are small
  - Qualitative methods and data aggregation
  - Summary of case study findings
- Role of co-production and some approaches
Should we study this group separately?

Visiting three “pillars” of bioethics in a small populations context
Beneficence and non-maleficence

- Does the population benefit from separate study?
  - Relevant data
  - Tailored interventions
  - Resources to address local needs

- Could there be harm from separate study?
  - Inadequate numbers for meaningful results
  - Potential use of data to stigmatize group

- Could there be harm if not studied separately?
  - Invisibility to research agendas, resource allocators
  - Inappropriate interventions with low uptake
  - Perpetuation of disparity
Respect for autonomy

The idea of autonomy and respect should be expanded beyond the traditional application to individuals.

- Does the population have an ethno-cultural community identity?
- Other community identity (i.e., beyond hard to reach)?
- Health disparities research must:
  - Respect individual autonomy
  - And community autonomy and identity
Justice and equity

Opportunities to address injustice and inequity should guide health disparities research.

- Has the small population experienced disadvantage as a population or group?
  - For example, consider the social determinants of health (SDOH)

- Could health disparities research inform resource distribution to address SDOH?
  - Not necessarily more healthcare (Woolf, et al., 2007)
Small populations & data aggregation

Justice and equity and the role of qualitative methods
The (lack of) data cycle (Tualii et al., 2014)

- Lack of data → inequitable distribution of resources → increased health disparities

Goal: BREAK THE CYCLE
Data collection challenges (Korngiebel, et al., 2015)

Current methods do not support the collection of accurate data for small populations.

- Low survey response rates (state, regional, national)
- Ethnic and racial misclassification
  - Including ad hoc assigning of “category” by outsiders

Challenge: REVISE CURRENT METHODS
Data aggregation challenges

Current methods do not support relevant aggregation of data for small populations.

- Groups of unequal size are collapsed
  - E.g., Asians (96%)/Pacific Islanders (4%)
  - Issues of smaller group subsumed by larger

- Or imposed categories neglect context
  - E.g., Native Hawaiians and other Pacific Islanders
  - Some SDOH may be shared but some may not

Challenge DISPARITIES ARE MASKED
What is valid data?

Some data are considered more “valid” than others.

- Defining valid data
  - Privileging types of data ➔ gatekeeping
  - Aggregation ➔ gatekeeping

- Ways of knowing (See for example, Walker and Bigelow, 2011)

- Role of qualitative data
  - Context
  - Perspective

Challenge

EXPAND IDEA OF “DATA”
“THE TAKE HOME POINT IS THAT DATA SHOULD BE ETHICAL—AND DO NO HARM. SMALL, LARGE, WHATEVER FORM IT TAKES, IT SHOULD NEVER INFLECT HARM ON A PEOPLE.

THAT ETHICAL STANCE SOMETIMES REQUIRES US TO WORK WITH DATA IN WAYS WE MIGHT NOT HAVE LEARNED IN BIOSTATS COURSES THAT VALUED THE NORMAL DISTRIBUTION.

WE SOMETIMES HAVE TO DIG DEEPER, AND ALWAYS WITH HUMILITY, RESPECT, AND KINDNESS.”

~DR. MAILE TAUALII
Case study: aggregation insights

What tribal partners recommended
Mixing it up: a case study  
(Van Dyke, et al. 2016)

**Study timeline**

- **2009** conference with Indigenous and Tribal health leaders to identify the issue
- **2011** bioethics administrative supplement to U54
- **2012-2013**: Data collection and analysis
- **2014-2016**: Tribal review and publications
Mixing it up: a case study

Communities share their criteria for improved data aggregation.

- Five tribes
  - Varying sizes
  - Engagement approach: Tribal Participatory Research (Fisher and Ball, 2003)

- What characteristics should be considered when data are aggregated?

Goal MORE RELEVANT DATA
The qualitative approach

Qualitative methodologies ➔ direct engagement.

- Data collection
  - Key informant interviews and focus groups
- Analysis
  - Single coding with study team review
  - Consensus resolution
  - Member checking

Goal: MORE RELEVANT DATA
What we learned

Many factors might inform data aggregation.

- Tribal partners identified significant variables
  - Geographic proximity
  - Community type (urban/rural; coastal/inland)
  - Culture
  - Presence/absence of contaminated environment
  - Type/severity of health concerns
  - Access to health care
  - Generational cohort

Result  
ADDED RELEVANCE
Geographic proximity was important…

…but was not the whole story.

- Community type (urban/rural; coastal/inland)
- Presence/absence of contaminated environment
Health-related

Communities can already identify priority health concerns.

- Types of health concerns
- Severity of health concerns
- Access to health care
How do we leverage the community wisdom of small populations?

By focusing on co-production and co-creation in our approaches, frameworks, and methodologies.
Collaborative co-creation is the future of health research and health care interventions and delivery—and may have particular relevance for small populations.

- Generating value together
  - The data aggregation method above is an example of co-production
- Users and communities co-shape and co-make interventions/products/services
- Such approaches prioritize and invest in collaborations with those most affected by data, research, interventions.
## Co-production

*(table adapted from Israilov and Cho, 2017)*

<table>
<thead>
<tr>
<th>Challenges</th>
<th>Benefits</th>
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<tbody>
<tr>
<td>Addressing data “hierarchy”</td>
<td>Qualitative context improves local relevance</td>
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<tr>
<td>Engagement takes time</td>
<td>Stakeholder investment in activity/intervention/policy</td>
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<td>Recognizing diverse expertise</td>
<td>Stakeholders learn from each other; no “one” expert</td>
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<tr>
<td>Achieving consensus</td>
<td>Development of transparent and inclusive process</td>
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</tbody>
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**FOCUS**  
**PARTNERSHIPS ADD VALUE**
Approaches from the social sciences...

An example: Community-based participatory research (CBPR) (Israel, et al., 1998)

- A values-based approach
- All partners contribute expertise to defining the issue and determining the action to take
- Communities are constantly consulted
  - Before: what is the priority?
  - During: Set-up, data, collection, analysis
  - After: Review and dissemination of results; what next?

Goal IMPROVE HEALTH
Some industry approaches may be particularly helpful in partnerships with small populations.

- Example: User-Centered Design (contextual design; user-centered system design; user experience) (Nielsen Norman Group)
  - Researches the “lived” context of an intervention
  - Focus on end users & key stakeholders working together to create and refine
  - Use of diverse data collection techniques (IDEO)

Goal

IMPROVE HEALTH
Community-Based Participatory Research

Relationship building

- Determine or confirm priority

Engagement and admin work

- Intervention deployment and data collection

Data analysis

- Results review and dissemination

What next?

User-Centered Design for intervention creation

- Generative and Formative research
- Iterative creation
- Usability and user XP testing
- Revisions
- Piloting

Deployment version

Dissemination and Implementation Research:
How might D&I be incorporated with these frameworks to enhance success?
References


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