

ADDRESSING THE CHALLENGES OF RESEARCH WITH SMALL POPULATIONS

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Focus for presentation (Srinivasan, et al., 2015)

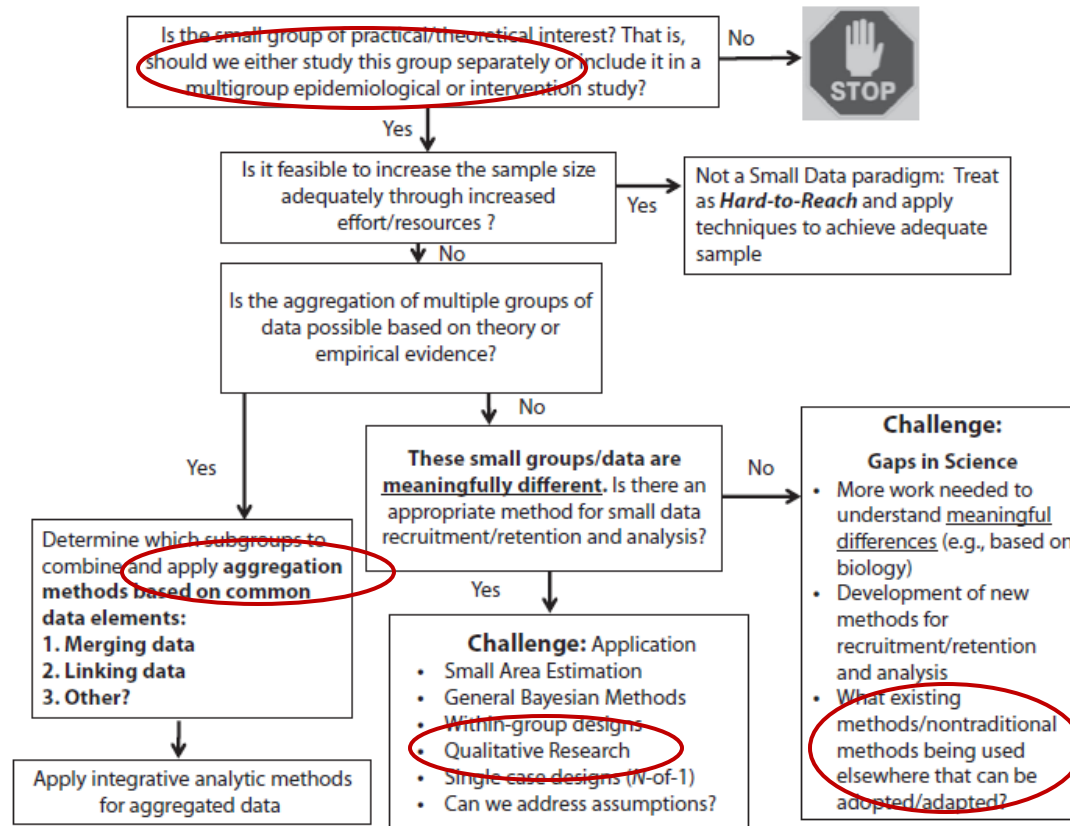


FIGURE 1—Research with small data: identifying challenges.

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.

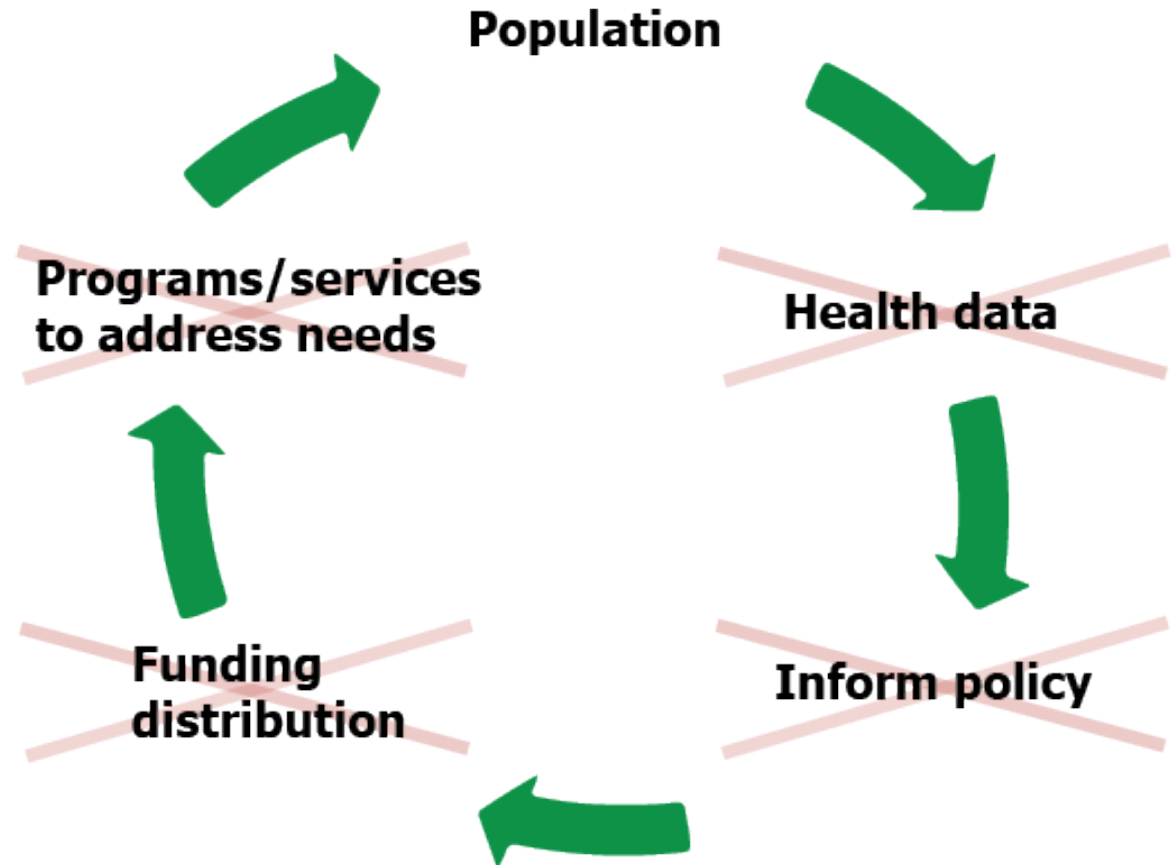
- Has the small population experienced disadvantage as a population or group?
 - ▣ For example, consider the social determinants of health (SDOH)
- Could health disparities research inform resource distribution to address SDOH?
 - ▣ Not necessarily more healthcare (Woolf, et al., 2007)

Small populations & data aggregation

Justice and equity and the role of qualitative methods

The (lack of) data cycle (Tauvalii 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 INFLICT 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

Goal

ADDED RELEVANCE

Health-related

Communities can already identify priority health concerns.

- Types of health concerns
- Severity of health concerns
- Access to health care

Goal

ADDED RELEVANCE

How do we leverage the community wisdom of small populations?

By focusing on co-production and co-creation in our approaches, frameworks, and methodologies.

The future is co-production (Turakhia and Combs, 2017)

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.

Goal

INVESTMENT → OUTCOMES

Co-production (table adapted from Israilov and Cho, 2017)

Challenges	Benefits
Addressing data “hierarchy”	Qualitative context improves local relevance
Engagement takes time	Stakeholder investment in activity/intervention/policy
Recognizing diverse expertise	Stakeholders learn from each other; no “one” expert
Achieving consensus	Development of transparent and inclusive process

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

...and industry...

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

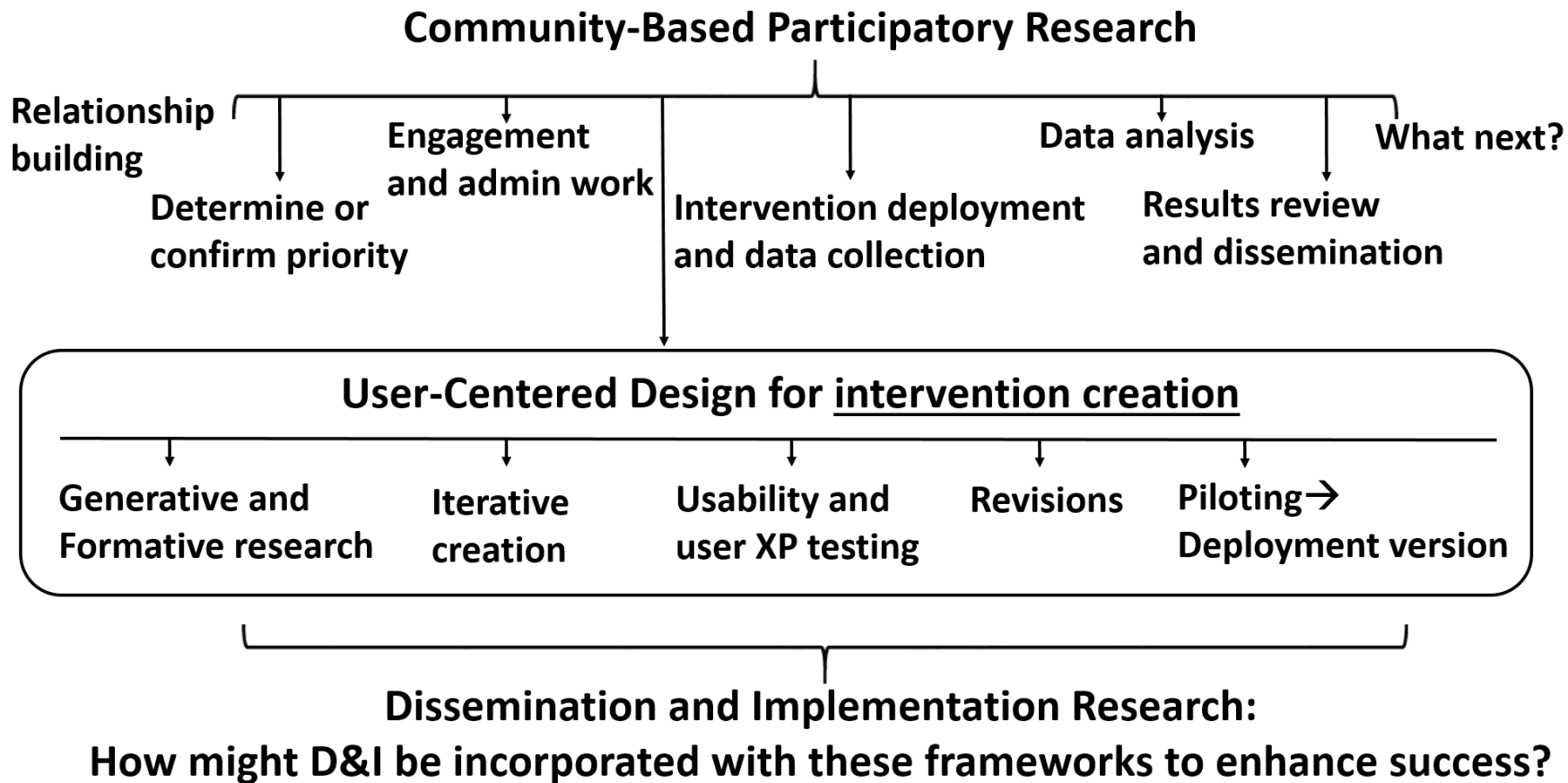
- Example: User-Centered Design (contextual design; user-centered system design; user experience) (Nielsen Norman Group)
 - ▣ Researches the “lived” context of an intervention
 - ▣ Focus on end users & key stakeholders working together to create and refine
 - ▣ Use of diverse data collection techniques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

Goal

IMPROVE HEALTH

...interwoven.

COPRODUCTION



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SPECIAL THANKS TO
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Thanks for your time! Questions? dianemk@uw.edu