Fantastic People and Where to Find Them: Effectively Surveying the LGBTQ Population

Phillip Hughes MS, Kimberly Leach MPH, & Chase Harless MSW
Introduction

Background Terminology

- **LGBT**: Lesbian, Gay, Bisexual, Transgender

- **Sexual Orientation**: Who a person is attracted to
  - Lesbian, Gay, Bisexual, Pansexual, Asexual, and others

- **Gender Identity**: How a person conceptualizes themself
  - Transgender, Gender Non-Conforming (GNC), Gender Non-Binary (GNB), Genderfluid, and others

Sexual orientation is who you go to bed with

Gender identity is who you go to bed as
Introduction

Why the LGBT population?

• Higher rate of: Adverse Childhood Experiences, Intimate Partner Violence, smoking, substance abuse, suicide, and several chronic diseases\textsuperscript{1-5}
  • Largely due to discrimination and social inequality

• Often disengaged from healthcare services due to discrimination and lack of culturally-competent providers
Introduction

Why is the LGBT population hard to reach?

• Small proportion of the population makes it hard to generate a probability sample
  • 4.5% as of 2018
  • 10% of Millennials/Gen Z

• Reluctant to participate in research
  • Similar to other stigmatized/marginalized groups

• Sexual orientation and gender identity are hard to quantify
  • Non-binary, fluid, and multidimensional
  • Ethically complex: potential for invalidation and “outing”
**Introduction**

**This Presentation**

- **We will discuss:**
  - Appropriate sampling methods
  - Benefits of integrating community partners
  - Assessing sexual orientation & gender identity effectively

- **We will present a case study on a recent LGBT survey:**
  - What worked well
  - Opportunities for Improvement
Finding the Sample
Finding the Sample

Respondent-Driven Sampling (RDS)

- Many studies utilize non-probability convenience samples
  - Snowball Sampling
  - Venue-Based Sampling

- Respondent Driven Sampling (RDS)\textsuperscript{11, 12}
  - Multiple waves of Snowball Sampling
  - Repeated waves until Markov equilibrium
    - Probability of being included in the final wave is independent of the probability of being recruited by the first wave
    - E.g., the probability of being recruited by the first wave gets “watered down” as more waves are added.
  - Functionally approximates a probability sample
  - Requires tracking recruiting IDs
Finding the Sample

Online Recruitment

- Relatively inexpensive
- Wide-reaching distribution

- **Most effective method for reaching hard to sample populations**\textsuperscript{13, 14}
  - 75% of studies on hidden populations found social media surveys to be most effective
  - Up to 2.5x faster than traditional methods

- **Drawbacks:**
  - 11% lower response rate than traditional methods\textsuperscript{15}
  - Non-probability sample unless combined with RDS
Finding the Sample

Sampling outside the LGBT Population

• For broad demographic-type questions about the LGBT population, it is possible to use probability samples
  • Network Scale-Up Method (NSUM)$^{16}$
    • Asks about how many people a participant knows:
      • From a known population
      • From the total population
      • From the hidden population
    • Good for population size estimates
  • Generalized NSUM$^{17}$
    • Same methodology, different equation
    • Less biased than NSUM
    • Requires some members of hidden population
• Both methods are computationally complex
# A Comparison of Sampling Methods

<table>
<thead>
<tr>
<th>Method</th>
<th>Advantages</th>
<th>Disadvantages</th>
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</thead>
<tbody>
<tr>
<td>Snowball</td>
<td>Cost-effective</td>
<td>Biased Results*</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Non-probability Sample</td>
</tr>
<tr>
<td>Respondent-Driven (RDS)</td>
<td>Cost-effective</td>
<td>Computationally Challenging</td>
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<tr>
<td></td>
<td>Approximates a Probability Sample</td>
<td>Requires Added Survey Length</td>
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<tr>
<td>Online Recruitment</td>
<td>Cost-effective</td>
<td>Lower Response Rate</td>
</tr>
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<td></td>
<td>Broad Access to Potential Respondents</td>
<td>Non-probability Sample</td>
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<tr>
<td></td>
<td>Most Effective for Hard-to-Reach Sample</td>
<td></td>
</tr>
<tr>
<td>Network Scale-Up (NSUM)</td>
<td>Sample Can be Outside Target Population</td>
<td>Potentially Biased Results*</td>
</tr>
<tr>
<td></td>
<td>Allows for Probability Sampling</td>
<td>Computationally Challenging</td>
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<td>Requires Added Survey Length</td>
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<td></td>
<td></td>
<td>Questions Limited in Scope</td>
</tr>
<tr>
<td>Generalized NSUM</td>
<td>Allows for Probability Sampling</td>
<td>Requires Sampling Target Population</td>
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<tr>
<td></td>
<td>More Accurate Estimate than NSUM</td>
<td>Computationally Challenging</td>
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<td></td>
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<td>Requires Added Survey Length</td>
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</table>

Table 1. A Comparison of Methods for Surveying the LGBTQ Population. * While all sampling methods can suffer from bias, those mentioned above are more likely to be biased than other methods.
Leveraging Community Partners
Leveraging Community Partners

Community partners as facilitators

- **Community Partners can include:**
  - Non-profit organizations, advocacy groups, and other community organizations that serve the hidden population

- **Know the hidden population and how to find them**
  - These groups can provide an excellent launch pad for a survey

- **Know how to gain the population’s trust**
  - Hidden populations are reluctant to be surveyed due to fear of stigma
  - Strong collaboration with community partners can help bridge that gap
Leveraging Community Partners

Community partners as researchers

- Community partners can help identify research blind spots
  - Propose future research topics
  - Identify cultural training gaps for research staff

- Community partners can also be invaluable during study design & analysis
  - Help craft culturally-appropriate questions
  - Offer interpretation of findings

- While not necessarily researchers, these organizations have strong cultural and topical knowledge. Use it!
Leveraging Community Partners

Hard-to-Reach LGBT Population

Non-Profit Organizations

Gov’t Organizations

LGBT Partners

Social Spaces

Easy-to-Reach LGBT Population
Asking the Right Questions
Asking the Right Questions

Sexual Orientation

- Most available guidance on sexual orientation questions comes from the Williams Institute, but evidence is thin

- **Most common question:**
  - “How do you Identify – Heterosexual (straight), Homosexual (gay/lesbian), Bisexual, or other”
  - Reduces a complex identity to four categories

- **Possible improvements**
  - More options: including “I’m not sure yet.”
    - Can always combine categories later if needed
  - 2-part question
    - “How do you identify” – Sexual Identity
    - “Who are you attracted to” – Sexual Attraction
### Asking the Right Questions

<table>
<thead>
<tr>
<th>Topic</th>
<th>&quot;Standard&quot; Question*</th>
<th>Suggested Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexual Orientation</td>
<td>Do you identify as:</td>
<td>Do you identify as:</td>
</tr>
<tr>
<td></td>
<td>Straight/Heterosexual</td>
<td>Straight/Heterosexual</td>
</tr>
<tr>
<td></td>
<td>Gay/Lesbian/Homosexual</td>
<td>Gay/Lesbian/Homosexual</td>
</tr>
<tr>
<td></td>
<td>Bisexual</td>
<td>Bisexual</td>
</tr>
<tr>
<td></td>
<td>Pansexual</td>
<td>Pansexual</td>
</tr>
<tr>
<td></td>
<td>I'm not sure yet</td>
<td>I'm not sure yet</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>Other</td>
</tr>
<tr>
<td></td>
<td>Who are you attracted to? Check all that apply:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Men</td>
<td>Men</td>
</tr>
<tr>
<td></td>
<td>Women</td>
<td>Women</td>
</tr>
<tr>
<td></td>
<td>Non-Binary/Gender</td>
<td>Non-Binary/Gender</td>
</tr>
<tr>
<td></td>
<td>Queer/GNC/Other</td>
<td>Queer/GNC/Other</td>
</tr>
<tr>
<td></td>
<td>I'm not sure yet</td>
<td>I'm not sure yet</td>
</tr>
<tr>
<td></td>
<td>None</td>
<td>None</td>
</tr>
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Table 2. Common Sexual Orientation and Gender Identity Questions and Suggested Alternatives. GNC = Gender non-conforming. *Standard Questions are from 2018 Behavioral Risk Factor Surveillance Survey conducted by the CDC. 54
Asking the Right Questions

Gender Identity

- The Williams Institute is again one of the best resources, but there are some available articles in the literature, as well\textsuperscript{12,18}
  - Gender is a difficult construct to assess in one question
  - Requires a tradeoff:
    - Open Ended: Inclusive and accurate, but hard to analyze
    - Categorical: Easy to analyze, but masks heterogeneity

- **Solution: Use multiple questions!**
  - “What was your sex at birth – Male, Female, Intersex, Unsure”
  - “How do you describe yourself? Check all that apply: Male, Female, Non-binary/gender queer/gender non-conforming, genderfluid, other, I’m not sure yet
## Asking the Right Questions

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<td>What is your sex?</td>
<td>What was your sex at birth?</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>Male</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>Female</td>
</tr>
<tr>
<td></td>
<td>Do not know/ Not Sure</td>
<td>Intersex</td>
</tr>
<tr>
<td></td>
<td>Do not know/ Not Sure</td>
<td></td>
</tr>
<tr>
<td>Do you identify as transgender?</td>
<td>How do you describe yourself? Check all that apply:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>Male</td>
</tr>
<tr>
<td></td>
<td>Yes, Male-to-Female</td>
<td>Female</td>
</tr>
<tr>
<td></td>
<td>Yes, Female-to-Male</td>
<td>Non-Binary/Gender Queer/GNC</td>
</tr>
<tr>
<td></td>
<td>Yes, GNC</td>
<td>Gender Fluid</td>
</tr>
<tr>
<td></td>
<td>Do not know/ Not Sure</td>
<td>Other</td>
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Case Study: 
The Southern LGBTQ Health Survey

The Southern LGBTQ Health Survey

About the study

- 14.8 million LGBTQ people in the United States
  - 5.1 million in the Southeastern US
  - 500,000 of those are Transgender – the most of any region in the US.

- The Campaign for Southern Equality (CSE) conducted a study seeking to assess the health and healthcare of southern LGBTQ individuals.
  - When published in 2019, it was the largest study of its kind with over 5600 respondents.
The Southern LGBTQ Health Survey

The Methods

• **Snowball sampling**
  • Used a mix of online distribution and paper surveys, both available in English and Spanish.

• **Worked with over 25 community organizations to aid in distributing the survey**
  • Recruited Survey Ambassadors – LGBTQ individuals paid to directly assist in distributing the survey to ethnically diverse regions.
  • The organization with the most referrals received a $500 grant from CSE’s Southern Equality Fund. All participants were enrolled in a raffle for a $25 gift card.

• **LGBT individuals were incorporated into the research team to develop survey questions.**
The Southern LGBTQ Health Survey

Lessons Learned

• What worked:
  • Snowball sampling & distribution through community partners resulted in a large sample
    • Community partners helped alleviate reluctance to participate
  • Online distribution further increased distribution footprint
  • Sexual Orientation question – “check all that apply” with MANY response options
The Southern LGBTQ Health Survey

Lessons Learned

- **Opportunities for Improvement**
  - Snowball sampling limits generalizability – RDS would have offered an improvement
  - Ethnic, Racial, & Geographic underrepresentation – RDS or NSUM could have aided in using the available data to make unbiased estimates
  - Gender Identity question – Open ended response
    - Took the entire team several hours to sort and categorize
Questions?


