



***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 themselves**
 - 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 diseases¹⁻⁵**
 - 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 Z⁶
- **Reluctant to participate in research**
 - Similar to other stigmatized/marginalized groups⁷⁻⁹
- **Sexual orientation and gender Identity are hard to quantify**
 - Non-binary, fluid, and multidimensional¹⁰
 - 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)^{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^{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 methods¹⁵
 - 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 NSUM¹⁷
 - Same methodology, different equation
 - Less biased than NSUM
 - Requires some members of hidden population
 - Both methods are computationally complex

A Comparison of Sampling Methods

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

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

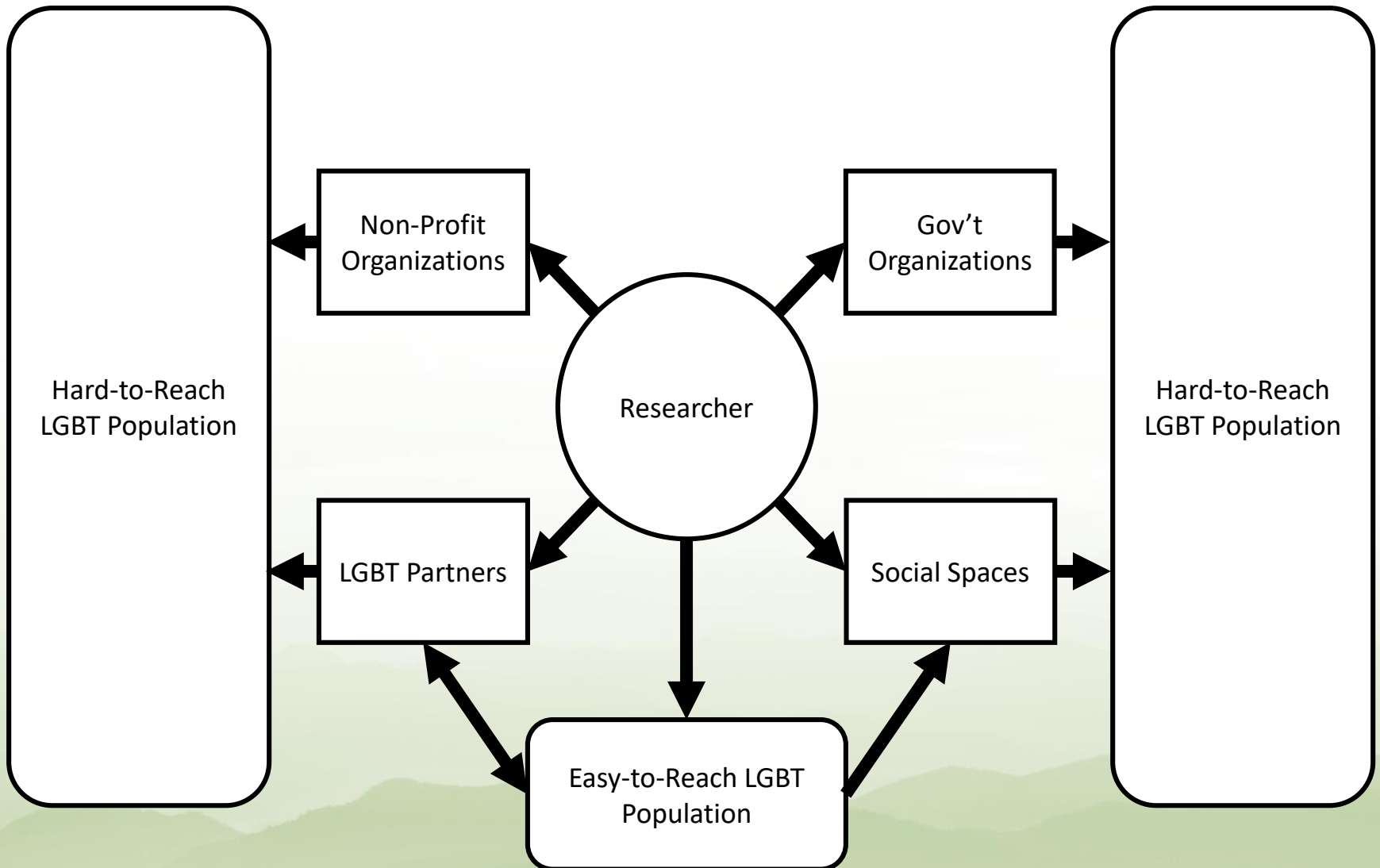
- **Community Partners can include:**
 - Non-profit organizations, advocacy groups, and other community organizations that serve the hidden population
- **Know the hidden population and how to find them**
 - These groups can provide an excellent launch pad for a survey
- **Know how to gain the population's 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



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^{12,18}**
 - 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

Topic	"Standard" Question*	Suggested Question
Sexual Orientation	Do you identify as:	Do you identify as:
	Straight/Heterosexual	Straight/Heterosexual
	Gay/Lesbian/Homosexual	Gay/Lesbian/Homosexual
	Bisexual	Bisexual
		Pansexual
		I'm not sure yet
		Other
		Who are you attracted to? Check all that apply:
		Men
		Women
		Non-Binary/Gender Queer/GNC/Other
		I'm not sure yet
		None

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^{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

Topic	"Standard" Question*	Suggested Question
Gender Identity	What is your sex?	What was your sex at birth?
	Male	Male
	Female	Female
	Do not know/ Not Sure	Intersex
		Do not know/ Not Sure
	Do you identify as transgender?	How do you describe yourself? Check all that apply:
	No	Male
	Yes, Male-to-Female	Female
	Yes, Female-to-Male	Non-Binary/Gender Queer/GNC
	Yes, GNC	Gender Fluid
	Do not know/ Not Sure	Other
		I'm not sure yet

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

Case Study:
The Southern LGBTQ Health Survey

Harless C, Nanney M, Johnson A, Polanski A, Beach-Ferrara J. *The Report of the 2019 Southern LGBTQ Health Survey*. Asheville, NC: Campaign for Southern Equality; 2019.

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?

References

1. Baams L. Disparities for LGBTQ and Gender Nonconforming Adolescents. *Pediatrics*. 2018;141(5):e20173004. doi:10.1542/peds.2017-3004
2. Quinn GP, Sanchez JA, Sutton SK, et al. Cancer and lesbian, gay, bisexual, transgender/transsexual, and queer/questioning (LGBTQ) populations: Cancer and Sexual Minorities. *CA: A Cancer Journal for Clinicians*. 2015;65(5):384-400. doi:10.3322/caac.21288
3. Reuter TR, Newcomb ME, Whitton SW, Mustanski B. Intimate partner violence victimization in LGBT young adults: Demographic differences and associations with health behaviors. *Psychology of Violence*. 2017;7(1):101-109. doi:10.1037/vio0000031
4. Matthews AK, Breen E, Kittiteerasack P. Social Determinants of LGBT Cancer Health Inequities. *Seminars in Oncology Nursing*. 2018;34(1):12-20. doi:10.1016/j.soncn.2017.11.001
5. Greenwood G. Correlates of heavy substance use among young gay and bisexual men: The San Francisco Young Men's Health Study. *Drug and Alcohol Dependence*. 2001;61(2):105-112. doi:10.1016/S0376-8716(00)00129-0
6. Newport F. In U.S., Estimate of LGBT Population Rises to 4.5%. Washington, DC: Gallup; 2018.
7. Gray A, Macapagal K, Mustanski B, Fisher CB. Surveillance studies involving HIV testing are needed: Will at-risk youth participate? *Health Psychology*. 2020;39(1):21-28. doi:10.1037/hea0000804

References

8. Newcomb ME, Clifford A, Greene GJ, Mustanski B. Parent Perspectives About Sexual Minority Adolescent Participation in Research and Requirements of Parental Permission. *Journal of Adolescent Health*. 2016;59(4):443-449. doi:10.1016/j.jadohealth.2016.05.014
9. Corbie-Smith G, Thomas SB, St. George DMM. Distrust, Race, and Research. *Arch Intern Med*. 2002;162(21):2458. doi:10.1001/archinte.162.21.2458
10. Heckathorn DD. Respondent-Driven Sampling: A New Approach to the Study of Hidden Populations. *Social Problems*. 1997;44(2):174-199. doi:10.2307/3096941
11. Heckathorn DD. Comment: Snowball versus Respondent-Driven Sampling. *Sociological Methodology*. 2011;41(1):355-366. doi:10.1111/j.1467-9531.2011.01244.x
12. Hyde JS, Bigler RS, Joel D, Tate CC, van Anders SM. The future of sex and gender in psychology: Five challenges to the gender binary. *American Psychologist*. 2019;74(2):171-193. doi:10.1037/amp0000307
13. Topolovec-Vranic J, Natarajan K. The Use of Social Media in Recruitment for Medical Research Studies: A Scoping Review. *J Med Internet Res*. 2016;18(11):e286. doi:10.2196/jmir.5698

References

14. Manfreda KL, Bosnjak M, Berzelak J, Haas I, Vehovar V. **Web Surveys versus other Survey Modes: A Meta-Analysis Comparing Response Rates.** *International Journal of Market Research.* 2008;50(1):79-104. doi:10.1177/147078530805000107
15. Kayrouz R, Dear BF, Karin E, Titov N. **Facebook as an effective recruitment strategy for mental health research of hard to reach populations.** *Internet Interventions.* 2016;4:1-10. doi:10.1016/j.invent.2016.01.001
16. Maltiel R, Raftery AE, McCormick TH, Baraff AJ. **Estimating population size using the network scale up method.** *Ann Appl Stat.* 2015;9(3):1247-1277. doi:10.1214/15-AOAS827
17. Feehan DM, Salganik MJ. **Generalizing the Network Scale-up Method: A New Estimator for the Size of Hidden Populations.** *Sociological Methodology.* 2016;46(1):153-186. doi:10.1177/0081175016665425
18. Park A. **Reachable: Data Collection Methods for Sexual Orientation and Gender Identity.** The Williams Institute; 2016.
19. Harless C, Nanney M, Johnson A, Polanski A, Beach-Ferrara J. *The Report of the 2019 Southern LGBTQ Health Survey.* Asheville, NC: Campaign for Southern Equality; 2019.



UNC Health Sciences at MAHEC Department of Research
121 Hendersonville Rd
Asheville, NC 28806

Contact Us

Phillip.Hughes@mahec.net

Kimberly.Leach@mahec.net

Chase.Harless@mahec.net