

Target Populations Toolkit – Research with LGBTQ+ Populations

Table of Contents

A. Shifting Definitions	3
B. Troubled History between Research and the LGBT Community.....	3
C. Legacy of HIV/AIDS	4
D. Current Issues.....	4
II. Health and Research Practice	6
A. Best Practices and Interventions	6
B. Databases and Other Searchable Resources:	6
III. National and Local Data	6
A. General Information from National LGBT Health Education Center.....	6
B. Population Estimates.....	7
C. Other Data Resources	7
IV. Ethical and Regulatory Issues	8
A. Sensitivity among the Research Team	8
B. Special Concerns about Confidentiality	8
C. Confidentiality and Parental Consent with Children and Youth Under Age 18.....	9
V. Recruitment and Retention Best Practices	11
A. Need for Broader, More Diverse Recruitment.....	11
B. Recruitment Methods	11
C. Sampling Techniques.....	11
VI. Recruitment Templates	13
VII. Community Engagement Resources	13
A. Local Organizations	13
B. National Organizations	13
VIII. Researchers at UIC and C3 Working on the Issue	14
A. University of Illinois at Chicago.....	14
B. Northwestern University	15
C. University of Chicago	15
IX. Measuring Instruments.....	16
A. Scales Addressing LGBT Experience.....	16
B. Sexual History Tools	17
C. Attitudes toward LGBT from non-LGBT Community or Counselor Tools	17
X. Program Announcements for Grants	18
XI. Community Stakeholder Involvement.....	19
A. LGBT Specific Resources	19

B. General Resources for Individuals.....	19
C. General Resources for Organizations	19
XII. Team Readiness to Work with Special Populations.....	20
A. Cultural competency training	20
B. Team diversity representation	20
C. Implicit-association test (IAT) – Offers a way to probe unconscious biases.....	20
D. Scales to Evaluate Attitudes towards LGBT Population	20
Citing the CCTS’s Target Population Toolkit.....	21



Target Populations Toolkit – Research with LGBTQ+ Populations

I. Historical and Current Issues Regarding Research Population

A. *Shifting Definitions*

When describing this community, the most common term is LGBT, an acronym referring to sexual orientations (lesbian, gay, and bisexual) and a gender identity (transgender). Some have appended Q for queer, and others add further letters and symbols. As constructed, the term LGBT is not inclusive of all who identify as having a minority sexual orientation or gender identity. There is a movement within the research community to use the term sexual and gender minority (SGM) to describe the population. Sexual minorities include people who use that terminology to describe themselves, people who have partners of the same gender or minority gender, or people who are attracted to the same or a minority gender. Gender minorities include people whose self-identity does not match their assigned birth identity, whose gender expression does not match their assigned birth identity, or people whose social expression does not match cultural expectations of gender.¹ While SGM is more inclusive and avoids the problem of an expanding acronym, the widespread understanding of LGBT makes that term useful. This toolkit will mostly use LGBT with the understanding that it does not have universal acceptance. In conducting research, asking participants what their preferred terms are is a key part of showing respect and building rapport.

B. *Troubled History between Research and the LGBT Community*

Research involving the LGBT community has a troubled history, leading many in the LGBT community to be wary of participating in research. Understanding this history and current issues related to working with this community is essential for researchers, both in order to adjust the research design, and to improve engagement and retention efforts with the population.

The early to mid-20th Century saw many damaging theories and studies. In 1915, Ellis described the inversion theory, which posited that because lesbian and gay individuals' gender appeared to contradict their sex, they were sexual "inverts."² In Nazi Germany, researchers experimented with castration and hormone therapy to eliminate homosexuality. Such horrible acts were not limited to the Nazis, however. Documented research in Finland and the United States in the mid-20th Century used castration and shock therapy, with the latter continuing into the 1970s. In addition to physical means, researchers used psychoanalysis to "cure" homosexuality.³ Such techniques continue even today, with some politicians advocating the use of "conversion" therapy.

Even studies that were not directly harming individuals still used questionable practices or produced results that could be used as weapons. The *Tearoom Trade* study observed men exhibiting sexual behaviors in a public bathroom, then used their license plates to track them down for interviews. The study provided important findings in terms of countering the contemporary stereotype of men having sex with men as "degenerate;" and their confidentiality was not violated. Nevertheless, the consenting process was not transparent or fully voluntary.⁴ Research by Cameron has described lesbian and gay individuals as dangerous and predatory. Despite serious ethical concerns about his work, these studies have still been cited in arguments for anti-LGBT legislation.⁵

Recent history does not have quite the same level of exploitation, but problems do still arise. *Healthy People 2010*, a document guiding the practices of several government agencies, had sparse coverage of LGBT health. Consequently, a group of people active in the field of LGBT health wrote the *Healthy People 2010 Companion*

Target Populations Toolkit – Research with LGBTQ+ Populations

*Document for LGBT Health.*⁶ Although the initial oversight was corrected, it still represented a slight to the community.

C. Legacy of HIV/AIDS

HIV/AIDS continues to impact the LGBT community, both as a consequence of history and because disadvantaged groups continue to be disproportionately affected.

AIDS was first identified as a unique disease in June 1981.⁷ This coincided with a rise in conservative forces in the United States and elsewhere; as a consequence, “...people infected with HIV were largely blamed for their infections, particularly if they were homosexual men or injecting drug users, the two groups in which most AIDS cases were first diagnosed in the United States.”⁸ Additionally, reductions to non-military government spending characterized the Reagan era. Just as the Centers for Disease Control and National Institutes for Health were facing one of their greatest challenges, funding was cut or stagnated.⁹ Funding would not be expanded for several years, giving the disease time to spread rapidly before effective treatments could be developed. As such, AIDS had a devastating impact on the health of the LGBT community: Dennis Medina notes that “perhaps one out of ten” of the people with whom he worked were still alive.¹⁰

History’s effects are still being felt for many. An oral histories book notes that, “Even now, it is hard for our contributors to recount those years without feeling sorrow for all the people who died; some potential contributors could not in fact write for us under such circumstances and withdrew from the project.”¹¹ Not all effects are negative: patient and community engagement with the LGBT community took off during this period, paving the way for later breakthroughs. However, much of the early engagement was with gay white men, leading to disparities in the burden of HIV/AIDS more recently. The HIV/AIDS prevalence per 100,000 people in 2007 was 76.7 for African-Americans, 34.6 for Pacific Islanders, 27.7 for Hispanics/Latinos, 12.8 for Native Americans, 9.2 for whites, and 7.7 for Asian-Americans.¹² Moreover, the prognosis for long-term survival is worst among Native Americans and African-Americans.¹³ Researchers working with the LGBT community should be aware of this history and the continued disparities related to HIV/AIDS.

D. Current Issues

Categories for gender, sex, and sexual orientation should be understood as simplifications of reality. Recent research suggests that gender is a social construct and operates more like a continuum or multitude rather than two neat categories. Likewise, meta-analysis has shown that at least 1.7% of infants are born with sexual characteristics that are ambiguous; in other words, they are intersex.¹⁴ When considering sexual orientation, one issue is the assumption that heterosexuality is the default, and all others orientations are deviances from that.¹⁵ Considering the spectrum of sexual orientations that people have expressed—lesbian, gay, bisexual, pansexual, asexual, and many more—the idea of a binary between heterosexual and not heterosexual seems overly simplistic. Adding to the complexity is that for many people, these traits are not fixed but fluid. As researchers, it is important to understand these complexities and respect people’s identities, and that these identities can change over time.

Intersectionality is another key issue. Being lesbian, gay, bisexual, and/or transgender is just one of the many facets of an individual’s identity. Many also face discrimination and/or hardship due to their race/ethnicity, age, socio-economic status, disability, or other part of their experience. In Brenick *et al.*, a study of black women having sex with women, 4-7% reported that they had experienced various types of sexual orientation

Target Populations Toolkit – Research with LGBTQ+ Populations

stigma, but 6-9% reported that they had experienced various types of race-based stigma.¹⁶ Mustanski's study with LGBT adolescents pointed out the tension that can be created if youth were to ask their parents about involvement in research studies.¹⁷ These two examples hint at the complexity many people who may participate in research deal with on an everyday basis. All researchers, but particularly those who come from a position of privilege (such as being white, male, adult, cisgendered, heterosexual, etc.), would do well to consider the experiences of those they are researching and listen to how those experiences impact their thoughts, feelings, and actions.¹⁸

¹ Park, A. (2016 June). A Development Agenda for Sexual and Gender Minorities. *The Williams Institute*. Retrieved 2017-09-12 from <https://williamsinstitute.law.ucla.edu/wp-content/uploads/Development-Agenda-for-Sexual-and-Gender-Minorities.pdf>.

² Silverschanz, P. (2007). Chapter 1: 1 What's "Queer" Got To Do With It?. In Meezan, W., & Martin, J.I. (Eds.), *Handbook of Research with Gay, Lesbian, Bisexual & Transgender Populations* (pp. 3-16). Abingdon, United Kingdom: Taylor & Francis Ltd.

³ Martin, J.I., & Meezan, W. (2007). Chapter 2: 2 Applying Ethical Standards to Research and Evaluations Involving Lesbian, Gay, Bisexual, and Transgender Populations. In Meezan, W., & Martin, J.I. (Eds.), *Handbook of Research with Gay, Lesbian, Bisexual & Transgender Populations* (pp. 19-39). Abingdon, United Kingdom: Taylor & Francis Ltd.

⁴ Martin, J.I., & Meezan, W. (2007).

⁵ Martin, J.I., & Meezan, W. (2007).

⁶ Corliss, H.L., Cochran, S.D., & Mays, V.M. (2007). Chapter 6: 6 Sampling Approaches to Studying Mental Health Concerns in the Lesbian, Gay, and Bisexual Community. In Meezan, W., & Martin, J.I. (Eds.), *Handbook of Research with Gay, Lesbian, Bisexual & Transgender Populations* (pp. 131-158). Abingdon, United Kingdom: Taylor & Francis Ltd.

⁷ Harden, V.A. (2012). *AIDS at 30: a History*. Dulles, Virginia, United States: Potomac Books. p. 1.

⁸ Harden, V.A. (2012). *AIDS at 30: a History*. Dulles, Virginia, United States: Potomac Books. p. 105.

⁹ Harden, V.A. (2012). *AIDS at 30: a History*. Dulles, Virginia, United States: Potomac Books. p. 99.

¹⁰ Medina, D. (2015). We are a part of the history of Texas that you must not exclude! In Quesada, U., Gomez, L., & Vidal-Ortiz, S. (Eds.), *Queer Brown Voices: Personal narratives of Latina/o LGBT activism* (pp. 47-63). Austin, Texas, United States: University of Texas Press.

¹¹ Quesada, U. (2015). Conclusion. In Quesada, U., Gomez, L., & Vidal-Ortiz, S. (Eds.), *Queer Brown Voices: Personal narratives of Latina/o LGBT activism* (pp. 47-63). Austin, Texas, United States: University of Texas Press.

¹² Oramasionwu, C.U., Brown, C.M., Ryan, L., Lawson, K.A., Hunter, J.M., & Frei, C.R. (2009). HIV/AIDS Disparities: The Mounting Epidemic Plaguing US Blacks. *Journal of the National Medical Association*, 101(12) 1196-1204. [http://www.journalnma.org/article/S0027-9684\(15\)31130-5/pdf](http://www.journalnma.org/article/S0027-9684(15)31130-5/pdf)

¹³ Oramasionwu, C.U., Brown, C.M., Ryan, L., Lawson, K.A., Hunter, J.M., & Frei, C.R. (2009). HIV/AIDS Disparities: The Mounting Epidemic Plaguing US Blacks. *Journal of the National Medical Association*, 101(12) 1196-1204. [http://www.journalnma.org/article/S0027-9684\(15\)31130-5/pdf](http://www.journalnma.org/article/S0027-9684(15)31130-5/pdf)

¹⁴ Silverschanz, P. (2007). Chapter 1: 1 What's "Queer" Got To Do With It?. In Meezan, W., & Martin, J.I. (Eds.), *Handbook of Research with Gay, Lesbian, Bisexual & Transgender Populations* (pp. 3-16). Abingdon, United Kingdom: Taylor & Francis Ltd.

¹⁵ Silverschanz, P. (2007). Chapter 1: 1 What's "Queer" Got To Do With It?. In Meezan, W., & Martin, J.I. (Eds.), *Handbook of Research with Gay, Lesbian, Bisexual & Transgender Populations* (pp. 3-16). Abingdon, United Kingdom: Taylor & Francis Ltd.

¹⁶ Brenick, A., Romano, K., Kegler, C., & Eaton, L.A. (2017). Understanding the Influence of Stigma and Medical Mistrust on Engagement in Routine Healthcare Among Black Women Who Have Sex with Women. *LGBT Health*, 4(1), 4-10. DOI: 10.1089/lgbt.2016.0083

¹⁷ Mustanski, B. (2011 April 29). Ethical and Regulatory Issues with Conducting Sexuality Research with LGBT Adolescents: A Call to Action for a Scientifically Informed Approach. *Archives of Sexual Behavior*, 40, 673-686. DOI: 10.1007/s10508-011-9745-1

¹⁸ Silverschanz, P. (2007). Chapter 1: 1 What's "Queer" Got To Do With It?. In Meezan, W., & Martin, J.I. (Eds.), *Handbook of Research with Gay, Lesbian, Bisexual & Transgender Populations* (pp. 3-16). Abingdon, United Kingdom: Taylor & Francis Ltd.

Target Populations Toolkit – Research with LGBTQ+ Populations

II. Health and Research Practice

A. *Best Practices and Interventions*

[Addressing Health Care Disparities in the Lesbian, Gay, Bisexual, and Transgender Population: A Review of Best Practices](#)

[Advancing Methods for US Transgender Health Research](#)

[Challenges in Intervention Research for Lesbian and Bisexual Women](#)

[Global Health Burden and Needs of Transgender Populations: A Review](#)

[High-Impact HIV Prevention: CDC’s Approach to Reducing HIV Infections in the United States](#)

[The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding \[Institute of Medicine \(US\) Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities\]](#)

[Improving LGBT Cultural Competence in Nursing Students: An Integrative Review](#)

[A Model of Organizational Context and Shared Decision Making: Application to LGBT Racial and Ethnic Minority Patients](#)

[Serving Transgender People: Clinical Care Considerations and Service Delivery Models in Transgender Health](#)

[A Systematic Review of Mental Disorder, Suicide, and Deliberate Self-Harm in Lesbian, Gay and Bisexual People](#)

[Transgender People: Health at the Margins of Society](#)

B. *Databases and Other Searchable Resources:*

[Healthy People 2030 Best Practice Research Search](#)

III. National and Local Data

A. *General Information from National LGBT Health Education Center*

- LGBT youth are more likely to be homeless.
- Lesbian women are less likely to receive preventive cancer screenings.
- Gay men are at higher risk of HIV and other STDs, especially Black and Latino gay men.
- Lesbian and bisexual women are more likely to be overweight or obese.
- Transgender people have a high prevalence of HIV/STDs, violence victimization, and mental health issues, and are less likely to have health insurance than non-transgender people.

Target Populations Toolkit – Research with LGBTQ+ Populations

- Older LGBT people face additional barriers to health because of isolation and a lack of social services and culturally competent providers.
- LGBT populations have disproportionately high prevalence of tobacco, alcohol, and other substance use.

B. Population Estimates

[US Census Bureau Same-Sex Couples: Provides broad population and housing data on same-sex couples.](#)

[Gallup Estimate of LGBT Population: Provides an estimate of how many people identify as LGBT, as of early 2017, as identified through polling.](#)

[Williams Institute Estimate of LGBT Population: Provides an estimate of the LGBT population, as identified through research meta-analysis.](#)

C. Other Data Resources

[CDC LGBT Health: Provides an array of health-related documents and data on the LGBT population.](#)

[The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding: This is a wide-ranging review of health and research of the LGBT community.](#)

[LGBTQ \(Lesbian, Gay, Bisexual, & Transgender Questioning\) Studies *: Databases: Links to further databases that may provide useful information about LGBT populations.](#)

[LGBTData.com: This site links to many population studies that include questions and/or data on the LGBT population.](#)

[Pew Research Center Survey of LGBT Americans \(Population and Characteristics\): This report describes the demographics, experiences, and opinions of a nationally-representative sample of LGBT Americans.](#)

[Sexual Orientation and Health Among U.S. Adults: National Health Interview Survey, 2013: In addition to a population estimate, it provides data on health indicators and behaviors for gay or lesbian, bisexual, and heterosexual respondents.](#)

[Williams Institute Searchable Database: Provides national and state-level statistics in easy-to-read visualizations.](#)

Target Populations Toolkit – Research with LGBTQ+ Populations

IV. Ethical and Regulatory Issues

Working with the LGBT community brings up additional considerations when thinking about ethics and submitting proposals to the IRB. UIC IRB policies can be found at <https://research.uic.edu/compliance/human-subjects-irbs/policies/>.

A. Sensitivity among the Research Team

Sensitivity is key for principal investigators, staff members, data collectors, and anyone else working on a study with sexual and gender minorities. Research team members should be knowledgeable about the group(s) with which they are working and the issues they face. This toolkit can help, but further reading and conversations will be necessary. Prejudice against the population being studied has no place in research. Many studies with LGBT populations can bring up very personal topics. Team members should have resources available to share with people who need support beyond what the study can provide. Additionally, the study purpose, methods, and materials should be respectful and inclusive.¹⁹ Making sensitivity a central aspect of the study, and continually checking in about it, will go a long way toward making the research more respectful and more likely to succeed.

For training materials and assessments to gauge research team members' sensitivity, see subsection XII Team Readiness to Work with Special Populations.

B. Special Concerns about Confidentiality

Privacy and confidentiality are serious concerns for people in the LGBT community. A survey of 8,126 Canadian men having sex with men indicated that 30% would be unwilling to disclose their sexual orientation in a large government survey (such as a census).²⁰ Thus, researchers should be cautious when using official estimates of the size of the LGBT community, for these estimates are likely to be lower than the actual proportion. Additionally, it demonstrates the reluctance that many in the LGBT community have for disclosing the orientation. Researchers should therefore be careful to preserve participants' confidentiality. At the same time, in clinic settings, research suggests that most heterosexual and LGBT patients appreciate being asked questions about their sexual orientation and gender identity.²¹ Context is key in how to approach discussions of orientation and identity.

Though social attitudes have been shifting, sexual orientation stigma still manifests as both an external and internal pressure for many people. Moreover, sexual orientation is an identity that can be concealed.²² There are different ways people can be out, including publicly acknowledging their orientation and identity to all, being out with some people but not others, or not being out at all. As such, an individual's right to maintain privacy about their identity must be respected. In addition to the normal safeguards of participants' data, researchers should also consider privacy when developing participant communication materials, conducting outreach, and discussing the study with others. For instance, studies may use a codename when calling participants. This way, if someone other than the participant answers, the participant's sexual or gender identity is not revealed through the name of the study. Additionally, focus group facilitators should take extra care to remind participants not to disclose others' participation in the group.²³ These are just some examples; privacy and confidentiality should be themes running throughout the study's design and implementation.

Target Populations Toolkit – Research with LGBTQ+ Populations

C. Confidentiality and Parental Consent with Children and Youth Under Age 18

Confidentiality is especially relevant when conducting research with LGBT youth who are under the age of 18. Research on 16 and 17 year old LGBT youth in Chicago indicated that, among those in contact with a parent, only 36% had a positive attitude towards asking their mother to be involved in the research process, and just 29% had a positive attitude towards asking their father. Moreover, there were significant differences between the youth who had favorable and unfavorable attitudes towards researchers contacting their parents, suggesting that requiring parental permission may bias research results.²⁴ Another study indicated that parental permission would be a significant barrier to youths' participation in a PrEP trial, particularly if they were not out to their family. At the same time, youth understood the risks, benefits, and randomization they would experience.²⁵ Additionally, a series of interviews with parents of LGBT youth found that most believed parental permission should not be required for minimal risk studies.²⁶

The UIC IRB offers the following guidance on waivers of parent/guardian permission for participation in research. See <https://research.uic.edu/compliance/human-subjects-irbs/policies/guidance-for-investigators-informed-consent/> for more information.

- VII. Waiver of Parent or Guardian Permission. The IRB may waive the requirement for obtaining permission from parents or guardians when:
- A. the research does not fall under FDA regulations, and
 - B. the research either:
 - 1. meets the provisions for waiver in 45 CFR 46.116(d)(1-4), [see below], or
 - 2. the IRB determines that the research is designed for conditions or a subject population for which parental or guardian permission is not a reasonable requirement to protect the subjects (for example, neglected or abused children).
 - 3. When the requirement for parental or guardian permission is waived according to above, an appropriate mechanism for protecting the children who will participate as subjects in the research is substituted. Also, the waiver must not be inconsistent with federal, state or local law. Selection of an appropriate mechanism is guided by the nature and purpose of the research activities, the risk and anticipated benefit to the subjects, and their age, maturity, status, and condition.
- ...the conditions for which consent may be waived at 45 CFR 46.116(d)(1-4):
- a. the research involves no more than minimal risk to the subject;
 - b. the waiver or alteration will not adversely affect the rights and welfare of the subjects;
 - c. the research could not practicably be carried out without the waiver or alteration; and
 - d. whenever appropriate, subjects will be provided with additional pertinent information after participation.

¹⁹ LGBT Foundation. (2017). *Ethical Research: Good Practice Guide to Researching LGBT Communities and Issues*. Manchester, United Kingdom.

²⁰ Ferlatte, O., Hottes, T.S., Trussler, T., & Marchand, R. (2017). Disclosure of Sexual Orientation by Gay and Bisexual Men in Government-Administered Probability Surveys. *LGBT Health*, 4(1), 68-71. DOI: 10.1089/lgbt.2016.0037

Target Populations Toolkit – Research with LGBTQ+ Populations

- ²¹ Cahill, S., Singal, R., Grasso, C., King, D., Mayer, K., Baker, K., & Makadon, H. (2014 September 8). Do Ask, Do Tell: High Levels of Acceptability by Patients of Routine Collection of Sexual Orientation and Gender Identity Data in Four Diverse American Community Health Centers. *PLOS One*, 9(9). DOI: 0.1371/journal.pone.0107104
- ²² Brenick, A., Romano, K., Kegler, C., & Eaton, L.A. (2017). Understanding the Influence of Stigma and Medical Mistrust on Engagement in Routine Healthcare Among Black Women Who Have Sex with Women. *LGBT Health*, 4(1), 4-10. DOI: 10.1089/lgbt.2016.0083
- ²³ LGBT Foundation. (2017). *Ethical Research: Good Practice Guide to Researching LGBT Communities and Issues*. Manchester, United Kingdom.
- ²⁴ Mustanski, B. (2011 April 29). Ethical and Regulatory Issues with Conducting Sexuality Research with LGBT Adolescents: A Call to Action for a Scientifically Informed Approach. *Archives of Sexual Behavior*, 40, 673–686. DOI: 10.1007/s10508-011-9745-1
- ²⁵ Fisher, C.B., Arbeit, M.R., Dumont, M.S., Macapagal, K., & Mustanski, B. (2017). Self-Consent for HIV Prevention Research Involving Sexual and Gender Minority Youth: Reducing Barriers Through Evidence-Based Ethics. *Journal of Empirical Research on Human Research Ethics*, 11(1), 3-14. DOI: 10.1177/1556264616633963
- ²⁶ Newcomb, M.E., Clifford, A., Greene, G.J., & Mustanski, B. (2016). Parent Perspectives about Sexual Minority Adolescent Participation in Research and Requirements of Parental Permission. *Journal of Adolescent Health*, 59, 443-449. DOI: 10.1016/j.jadohealth.2016.05.014

Target Populations Toolkit – Research with LGBTQ+ Populations

V. Recruitment and Retention Best Practices

A. *Need for Broader, More Diverse Recruitment*

People recruited into past studies with the LGBT community have not, as a whole, been representative of the entire community. Many studies have recruited samples that are heavily drawn from male adults in cities or college campuses.²⁷ Using these samples may have introduced bias into the research, making the results not applicable to others, such as females, youth under age 18, and people living in rural areas. Future research should either attempt to get a truly representative sample or over-sample these sub-populations to correct this disparity.

B. *Recruitment Methods*

Recruiting LGBT participants can require a variety of techniques. Online recruitment holds significant potential because of the ability to reach a variety of participants relatively cheaply. When using online recruitment, a variety of sources should be considered: a study of men’s willingness to take the PrEP medication to prevent HIV infection showed significant differences in age, race, proportion insured, and other variables when using multiple online venues.²⁸ Local organizations, whether affiliation groups, service providers, or advocacy groups, can be an effective way to access participants. When doing so, transparency and respect are crucial to secure buy-in and support. A listing of such organizations is available at [<link to section VII>](#). Monetary incentives can be helpful. However, care must be taken to ensure they are set at the right level: too low, and they will not truly incentivize participation; too high, and they can undermine voluntary participation. See IRB section for further information [<link to section IV>](#).

C. *Sampling Techniques*

A variety of sampling techniques are available to researchers, and the strengths and weaknesses of each should be assessed before choosing the study methods. A review of techniques follows, drawn from a book chapter by Corliss, Cochran, and Mays.²⁹

- **Convenience Sampling:** Research using convenience sampling relies on asking people at a certain place (physical or online) to participate in the study. Many research studies have used this technique and produced important results. Plus, it is efficient both in terms of time and financial resources. But, it is nonrandom (does not follow an equal probability of selection method), so significant bias can occur.
- **General Population-Based Surveys:** These surveys are constructed to secure a representative sample of the general population. Moreover, the data are often made accessible for secondary research, often at no or little cost. However, they do not provide the depth that surveys focused on the LGBT community can offer, their definitions may not fit those of interest to the researcher, and people may not be willing to disclose sexual orientation when they perceive stigma attached to it.
- **High-Gay Density Neighborhood Samples:** Areas that have been identified in population-based surveys to have high proportions of gay men can become the population from which a sample is derived. This can allow for efficient access to larger numbers of LGBT participants, more in-depth analysis, and heterosexual comparison groups. Nevertheless, the results may not be generalizable to the LGBT community as a whole. This is particularly true when studying LGBT women, who tend not to be as geographically concentrated as LGBT men.

Target Populations Toolkit – Research with LGBTQ+ Populations

- **Longitudinal Cohort Studies:** Following the same cohort over several years offers the advantage of being better able to understand causation between variables. Aside from this, the advantages and disadvantages of how the participants were recruited remain the same. Moreover, it is obviously time-consuming, expensive, and can suffer from attrition.
- **Time-Space Probability Samples:** This technique specifies a time and place where people of interest to the researcher are expected to gather. The research team selects a systematic sample of all attendees. It can be efficient and facilitate access to otherwise hard-to-reach groups, and is more robust than simple convenience sampling. At the same time, bias can be introduced by the selection of venues, so careful consideration is needed before selection.
- **Adaptive Sampling:** This is a technique that changes over time based on evolving observations and samples. Information gathered from initial samples is analyzed to figure out where and how additional samples should be gathered. Careful planning and statistical techniques allow for representative samples to be derived. Adaptive sampling is especially effective at obtaining samples for rare populations.
- **Yoked Design:** After using another technique for the primary sampling, LGBT respondents are asked to recruit a friend or relative who can serve as a comparison based on the variables of interest. Doing so can help create a comparison group that reflects similar racial, geographic, and socioeconomic characteristics. A source of bias can be that those who can recruit a companion are likely to be healthier and higher-functioning than those who are not, but methods exist to reduce this bias.
- **Twin Studies:** Using twins, one in the group of interest and the other not, can be effective at providing a comparison group. However, the universe of twins is significantly lower than the population as a whole, posing a challenge to recruitment.
- **Followback Designs:** Conducting further studies with an already identified group can allow for more detailed information to be gathered about them. It has the potential to be more efficient and cost-effective than starting from scratch. Bias can still be introduced, however, in that those who respond to the follow-up are more likely to be healthy and geographically stable than non-respondents.

Choosing a technique will require considering the goals of the study, the financial and human resources available, and the timeframe for completion.

²⁷ Elze, D.E. Chapter 3: 3 Strategies for Recruiting and Protecting Gay, Lesbian, Bisexual, and Transgender Youth in the Research Process. In Meezan, W., & Martin, J.I. (Eds.), *Handbook of Research with Gay, Lesbian, Bisexual & Transgender Populations* (pp. 40-68). Abingdon, United Kingdom: Taylor & Francis Ltd.

²⁸ Grov, C., Rendina, H.J., Jimenez, R., & Parsons, J.T. (2016). Using Online Settings to Identify Gay and Bisexual Men Willing to Take or with Experience Taking PrEP: Implications for Researchers and Providers. *AIDS Education and Prevention*, 28(5), 378-392.

²⁹ Corliss, H.L., Cochran, S.D., & Mays, V.M. (2007). Chapter 6: 6 Sampling Approaches to Studying Mental Health Concerns in the Lesbian, Gay, and Bisexual Community. In Meezan, W., & Martin, J.I. (Eds.), *Handbook of Research with Gay, Lesbian, Bisexual & Transgender Populations* (pp. 131-158). Abingdon, United Kingdom: Taylor & Francis Ltd.

Target Populations Toolkit – Research with LGBTQ+ Populations

VI. Recruitment Templates

[CCTS CEC Recruitment Templates Toolbox](#)

VII. Community Engagement Resources

A. Local Organizations

[AIDS Foundation of Chicago](#)

[Center on Halstead](#)

[Chicago Foundation for Women](#)

[Equality Illinois](#)

[Howard Brown Health Center](#)

[Illinois Safe Schools Alliance](#)

[Midwest AIDS Training & Education Center](#)

[PRIDE Institute](#)

B. National Organizations

[Accord Alliance](#)

[Fenway Health](#)

[GLAAD - The Gay and Lesbian Alliance Against Defamation](#)

[GLSEN - Gay, Lesbian and Straight Education Network](#)

[Human Rights Campaign](#)

[Lambda Legal](#)

[National Center for Lesbian Rights](#)

[National Center for Transgender Equality](#)

[The National Gay and Lesbian Taskforce](#)

[OutRight Action International](#)

Target Populations Toolkit – Research with LGBTQ+ Populations

VIII. Researchers at UIC and C3 Working on the Issue

A. *University of Illinois at Chicago*

[Wendy Bostwick, PhD, MPH](#)

Wendy Bostwick, PhD, MPH is a faculty member at the University of Illinois at Chicago (UIC) College of Nursing. Her profile provides information about her research interests, publications, and expertise in LGBTQ+ health, mental health, and substance use.

[Antonio Jimenez, PhD](#)

Antonio Jimenez is Director at the University of Illinois at Chicago's School of Public Health and Community Outreach Intervention Projects. His skills and expertise encompass various aspects of public health, with a particular focus on HIV prevention, drugs, surveillance, harm reduction, public health education, community engagement, and addressing health disparities.

[Jennifer Brier](#)

Jennifer Brier is a faculty member in the Gender and Women's Studies department at UIC. Her profile highlights her research on the history of sexuality, HIV/AIDS, and social movements, as well as her involvement in various academic and community initiatives.

[James A. Swartz, PhD](#)

James A. Swartz, PhD is a professor at the UIC Jane Addams College of Social Work. His profile offers an overview of his research, teaching, and community engagement activities, with a focus on mental health, substance abuse, and HIV prevention among vulnerable populations.

[David McKirnan, PhD](#)

David McKirnan, PhD is a faculty member in the Department of Psychology at UIC. His profile showcases his research in the areas of sexual health, substance abuse, and HIV prevention, with an emphasis on developing interventions for at-risk populations.

[Robert Bailey, PhD](#)

Robert Bailey, PhD is a professor at the UIC School of Public Health. His profile provides information on his research interests, projects, and publications related to HIV/AIDS, sexually transmitted infections, and global health, particularly in sub-Saharan Africa.

[Stacey Horn, PhD](#)

Stacey Horn, PhD is a faculty member at the UIC College of Education. Her profile highlights her expertise in qualitative research methods, educational policy, and social justice issues, showcasing her contributions to the field of education.

[Rohan Jeremiah, PhD](#)

Rohan Jeremiah, PhD is a faculty member at the UIC College of Nursing. His profile presents his research interests and expertise in HIV prevention, substance use, and mental health among marginalized populations, highlighting his commitment to reducing health disparities.

Target Populations Toolkit – Research with LGBTQ+ Populations

B. Northwestern University

[Brian S Mustanski, PhD](#)

Brian S Mustanski, PhD is a faculty member at Northwestern University's Feinberg School of Medicine. His profile highlights his research in the field of LGBTQ+ health, with a focus on HIV prevention and mental health among sexual and gender minority populations.

[Robert Garofalo, MD, MPH](#)

Robert Garofalo, MD, MPH is a physician and researcher at Northwestern University's Feinberg School of Medicine. His profile showcases his expertise in adolescent medicine, HIV prevention, and transgender health, emphasizing his commitment to providing comprehensive healthcare to LGBTQ+ youth.

[Amy Johnson, PhD](#)

Amy Johnson, PhD is a faculty member at Northwestern University's Feinberg School of Medicine. Her profile highlights her research interests in the areas of health disparities, HIV prevention, and sexual health among marginalized populations, particularly Black and Latino communities.

[Kathryn Macapagal, PhD](#)

Kathryn Macapagal, PhD is a researcher at Northwestern University's Feinberg School of Medicine. Her profile presents her work in the field of sexual and gender minority health, with a focus on understanding the impact of digital technology on the well-being and sexual behavior of LGBTQ+ youth.

[Lisa Kuhns, PhD](#)

Lisa Kuhns, PhD is a faculty member at Northwestern University's Feinberg School of Medicine. Her profile showcases her expertise in adolescent medicine, LGBTQ+ health, and HIV prevention, with a specific emphasis on the healthcare needs and interventions for transgender and gender nonconforming youth.

C. University of Chicago

[John Schneider, MD](#)

John Schneider, MD is a faculty member at the University of Chicago's Pritzker School of Medicine. His profile highlights his research and clinical work in the field of infectious diseases, including HIV prevention and epidemiology, with a focus on community-based interventions and healthcare disparities.

[Marshall H. Chin, MD, MPH](#)

Marshall H. Chin, MD, MPH is a physician and researcher at the University of Chicago Medicine. His profile showcases his expertise in health disparities, healthcare quality improvement, and community-based interventions, with a focus on addressing racial and ethnic disparities in healthcare access and outcomes.

Target Populations Toolkit – Research with LGBTQ+ Populations

IX. Measuring Instruments

A. Scales Addressing LGBT Experience

[Assessing Identity and Level of Outness](#)

[Assessment of LGBT Youths' Needs in Health Care Settings](#)

[Attitudes Toward Bisexuality Scale](#)

[Behavioral Self-Disclosure Scale \(BDQ\): Measures outness with various groups and situations](#)

[Community Connectedness among Diverse Sexual Minority Populations](#)

[Components of Attitudes toward Homosexuality](#)

[The Daily Heterosexist Experiences Questionnaire: Measuring Minority Stress Among Lesbian, Gay, Bisexual, and Transgender Adults](#)

[Emotional Distress Among LGBT Youth: The Influence of Perceived Discrimination Based on Sexual Orientation \(includes a section on sexual orientation\)](#)

[Gay Affect and Life Events Scale, Modified: Measures the occurrence and impact of stressful events including LGBT-specific questions](#)

[Godfrey-Richman ISM Scale \(M-GRISMS\) \(designed to measure stereotypes, prejudice, and discrimination towards various ethnic and religious groups, as well as sexist and heterosexist attitudes\)](#)

[Hardiness in LGBT Adults](#)

[Involvement and Overtness Measure for Lesbians](#)

[Lesbian Feminist Subscale of the Feminist Perspectives Scale](#)

[Lesbian Partner Abuse Scale](#)

[Lesbian, Gay, and Bisexual Identity Scale](#)

[Multicomponent AIDS Phobia Scale](#)

[Multiple Minority Stress: The LGBT People of Color Microaggressions Scale](#)

[Psychological Sense of LGBT Community Scale](#)

[Recalled Gender Identity Scale](#)

Target Populations Toolkit – Research with LGBTQ+ Populations

[Sexual Orientation Beliefs](#)

[Sexual Stigma among Lesbian, Bisexual and Queer Women](#)

[Stressor and Resilience Factors for Lesbians, Gay Men, and Bisexuals](#)

B. Sexual History Tools

[CDC Ask, Screen, Intervene 3-part Curriculum](#)

[Module 1 handouts including questionnaires](#)

[CDC’s Guide to Taking a Sexual History](#)

[The Proactive Sexual Health History \(article contains series of questions to assess for sexual history\)](#)

C. Attitudes toward LGBT from non-LGBT Community or Counselor Tools

[Biphobia Scale](#)

[Evaluating the Phobias, Attitudes, and Cultural Competence of Master of Social Work Students toward the LGBT Populations](#)

[Heterosexual Attitudes Toward Homosexuals \(HATH\)](#)

[Homophobia Scale](#)

[The Lesbian, Gay, and Bisexual Affirmative Counseling Self-Efficacy Inventory \(LGB-CSI\)](#)

[Lesbian, Gay, and Bisexual Knowledge and Attitudes Scale for Heterosexuals \(LGB-KASH\)](#)

[LGBT Ally Identity Measure](#)

[Modern Homophobia Scale](#)

[Sexual Orientation Counselor Scale](#)

Target Populations Toolkit – Research with LGBTQ+ Populations

X. Program Announcements for Grants

[American Psychological Foundation Roy Scrivner Memorial Research Grants](#)

[American Psychological Foundation Wayne F. Placek Grants](#)

[CCTS Pilot Grant Program](#)

[Funders for LGBT Issues 2015 Report on Lesbian, Gay, Bisexual, Transgender and Queer Grantmaking by U.S. Foundations](#)

[GLMA Lesbian Health Fund](#)

National Institutes of Health

- [Research on the Health of Transgender and Gender Nonconforming Populations \(R01\)](#)
- [Research on the Health of Transgender and Gender Nonconforming Populations \(R21\)](#)
- [Sexual and Gender Minority \(SGM\) Research Coordinating Committee \(RCC\) Grants](#)

[Point Foundation LGBT Scholarships](#)

[The Society for the Psychological Study of Social Issues - The Clara Mayo Grants](#)

[UAB - Center for Clinical and Translational Science - Pilot Funding](#)

[The Williams Institute Small Research Grants](#)

Target Populations Toolkit – Research with LGBTQ+ Populations

XI. Community Stakeholder Involvement

A. *LGBT Specific Resources*

[UIC Chancellor’s Committee on the Status of Lesbian, Gay, Bisexual, Transgender, Queer People and Allies](#)

[UIC Gender and Sexuality Center](#)

B. *General Resources for Individuals*

[National Institutes of Health – Clinical Research Trials & You](#)

[Research Fundamentals for Activists](#)

[Research Match \(search for clinical trials to join\)](#)

C. *General Resources for Organizations*

Alliance for Research in Chicagoland Communities, Northwestern University

- [Assessing your Organization’s Research Environment and Capacity](#)
- [Community-Based Participatory Research 101](#)
- [Community-Engaged Research Funding & Grantwriting Tips and Strategies](#)
- [Community Partner Resources](#)
- [Considering and Developing Your Organization’s Research Purpose](#)
- [Introduction to Qualitative Research Methods](#)
- [Introduction to Research Design](#)
- [NIH Biosketch for Community Partner](#)
- [Patient and Stakeholder Engagement \(PCORI\)](#)
- [University 101](#)

[Center for Clinical and Translational Sciences](#)

- [Recruitment, Retention, and Community Engagement Program](#)

[Clinical Trials Database](#)

[A Quick Start Guide to Conducting Community-Engaged Research Southern California Clinical and Translational Science Institute, Office of Community Engagement](#)

[UIC Office of Community Engaged Research and Implementation Science](#)

[UIC Office of Community Engagement and Neighborhood Health Partnerships](#)

Target Populations Toolkit – Research with LGBTQ+ Populations

XII. Team Readiness to Work with Special Populations

A. Cultural competency training

[Cultural Competence Assessment Instrument \(CCAI\)](#)

[Cultural Competence in HIV Care](#)

[National Research and Training Center \(NRTC\) Training and Education: Toolkit and Training on Assessing Cultural Competency in Peer-Run Mental Health Programs](#)

B. Team diversity representation

Making sure that the research team has some representation of the target special population group helps establish trust, understanding, and credibility. For example, having a person who identifies as LGBT when needing to recruit participants among the LBGT community, or having an African-American person on the research team when surveying other African-American individuals, can make for a more effective study.

C. Implicit-association test (IAT) – Offers a way to probe unconscious biases

[Implicit Association Test \(IAT\)](#)

[Look Different's Implicit Association Tests](#)

[Project Implicit](#)

D. Scales to Evaluate Attitudes towards LGBT Population

[Biphobia Scale](#)

[Evaluating the Phobias, Attitudes, and Cultural Competence of Master of Social Work Students toward the LGBT Populations](#)

[Heterosexual Attitudes Toward Homosexuals \(HATH\)](#)

[Homophobia Scale](#)

[The Lesbian, Gay, and Bisexual Affirmative Counseling Self-Efficacy Inventory \(LGB-CSI\)](#)

[Lesbian, Gay, and Bisexual Knowledge and Attitudes Scale for Heterosexuals \(LGB-KASH\)](#)

[LGBT Ally Identity Measure](#)

[Modern Homophobia Scale](#)

[Sexual Orientation Counselor Scale](#)

Target Populations Toolkit – Research with LGBTQ+ Populations

Citing the CCTS’s Target Population Toolkit

The LGBTQ+ Target Population Toolkit was developed by the UIC Center for Clinical and Translational Science’s Recruitment, Retention and Community Engagement Program.

The National Institutes of Health requires that investigators cite the CTSA grant if they used any CCTS services or resources to support their research. The CCTS relies on these citations as a critical performance measure when reporting annual productivity to NIH.

To cite the CCTS, the following text is recommended:

“The University of Illinois at Chicago Center for Clinical and Translational Science is supported by the National Center for Advancing Translational Sciences, National Institutes of Health, through Grant UL1TR002003. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.”

Recommended APA Toolkit Citation: Target Population Toolkit. (2023). Center for Clinical and Translational Science, University of Illinois at Chicago. Retrieved from <https://ccts.uic.edu/tools/community-engagement-toolbox/priority-population-toolkit/downloads/>.