NYU Langone Health
Office of Science and Research
Clinical and Translational Science Institute
Integrating Special Populations Core
Engaging Special Populations Best Practice Brief
LGBTQIA+ Population
7 December 2022

Overview

Demographic Profile

In 2020, 4.5% of the US population identified as lesbian, gay, bisexual, transgender, queer or other sexual orientation/gender identity (LGBTQ+),[1] which accounts for approximately 11,343,000 U.S. adults.[1] The state of New York reported a total LGBTQ+ population of 800,000, which accounts for 5.1% of the overall NYC adult population.[1] Subpopulation analyses shows that of the 5.1% LGBTQ+ population in NYC, 4.9% identify as LGBQ and 0.6% identify as transgender.[2] Bisexual women and gay men account for the largest demographic of the LGBTQ+ NYC population.[2] Large percentages of those who are younger (below the age of 34), without a high school education, earning less than $25,000, currently unemployed, experiencing homelessness, and living with a disability identify as LGBTQ+.[2,3] Thirty eight percent of the transgender NYC population has experienced homelessness, and over 15% have reported experiencing financial hardship, food insecurity or workplace discrimination.[4]

LGBTQ+ in NYC

- **58% of NYC LGBTQ+ adults are non-Hispanic White.**
- **The largest demographic of LGBTQ+ are lesbian & bisexual women.**
- **77% of LGBTQ+ NYC adults live below the poverty line.**
- **Most of the LGBTQ+ population lives in Manhattan.**

Figure 1. Demographic Data of LGBTQ+ adult population in NYC, provided by UCLA School of Law Williams Institute.[3]
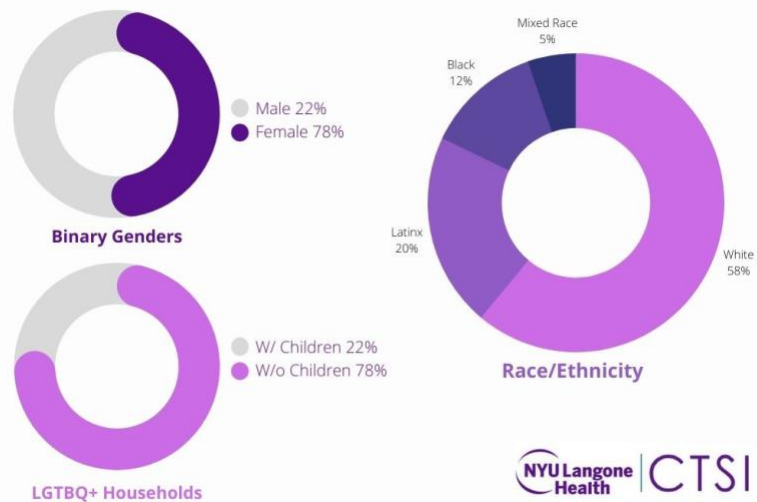

Figure 2. Gender, Race/Ethnicity and Age Data of LGBTQ+ adult population in NYC, adapted from the UCLA School of Law Williams Institute.[3] Data on nonbinary persons not provided in NYC.

Health Profile

LGBTQ+ individuals face inequities caused by structural factors, including homophobia and transphobia, and limited access to resources and support mechanisms both interpersonally and medically.[5] Nationally, LGBTQ+ populations are at higher risk for certain adverse health outcomes compared to heterosexual populations.[5] Across behavioral and physical health spectrums, LGBTQ+ populations suffer higher rates of disease/infection, worse disease outcomes, and have overall less access to care.[5] Health outcomes commonly reported among LGBTQ+ adults include smoking (19.3%), binge or heavy drinking (22.6%), poor diet (23.9%), depressive disorders (31.1%) and self-reported poor mental health, such as problems with stress, depression, or emotion regulation (17.9%).[3] For example, LGBTQ+ patients have higher risk for HIV infection, obesity, and breast, cervical, and anal cancers.[5] 47% of LGBTQ+ NYC adults have reported experiencing physical or verbal abuse, or been denied fair/equal treatment in their lifetime.[4]

LGBTQ+ Engagement in Research

Community engaged research is the process of addressing issues affecting the target populations of a study by collaborating and involving those directly impacted by studies in the research process[6]. The extent to which a research study requires community involvement will vary depending on the needs of the study. Thus, community engaged research exists on a spectrum (as seen in Figure 3). For a community-engaged study that moves further to the right on the spectrum, there is greater community involvement with a stronger bidirectional relationship and shared leadership between researchers and the community[6]. Community-based participatory research (CBPR) studies are research studies formatted to incorporate community members into all stages of the research process.[6] The CBPR approach has shown much success in conducting research within disenfranchised communities since community engaged research facilitates trust and effective communication, which can later lead to community buy-in and future study sustainability.[6]

Community Engagement Spectrum

Increasing Level of Community Involvement, Impact, Trust, and Communication Flow

Outreach	Consult	Involve	Collaborate	Shared Leadership
Some Community Involvement	More Community Involvement	Better Community Involvement	Community Involvement	Strong Bidirectional Relationship
Communication flows from one to the other, to inform	Communication flows to the community and then back, answer seeking	Communication flows both ways, participatory form of communication	Communication flow is bidirectional	Final decision making is at community level.
Provides community with information.	Gets information or feedback from the community.	Involves more participation with community on issues.	Forms partnerships with community on each aspect of project from development to solution.	Entities have formed strong partnership structures.
Entities coexist.	Entities share information.	Entities cooperate with each other.	Entities form bidirectional communication channels.	Outcomes: Broader health outcomes affecting broader community. Strong bidirectional trust built.
Outcomes: Optimally, establishes communication channels and channels for outreach.	Outcomes: Develops connections.	Outcomes: Visibility of partnership established with increased cooperation.	Outcomes: Partnership building, trust building.	

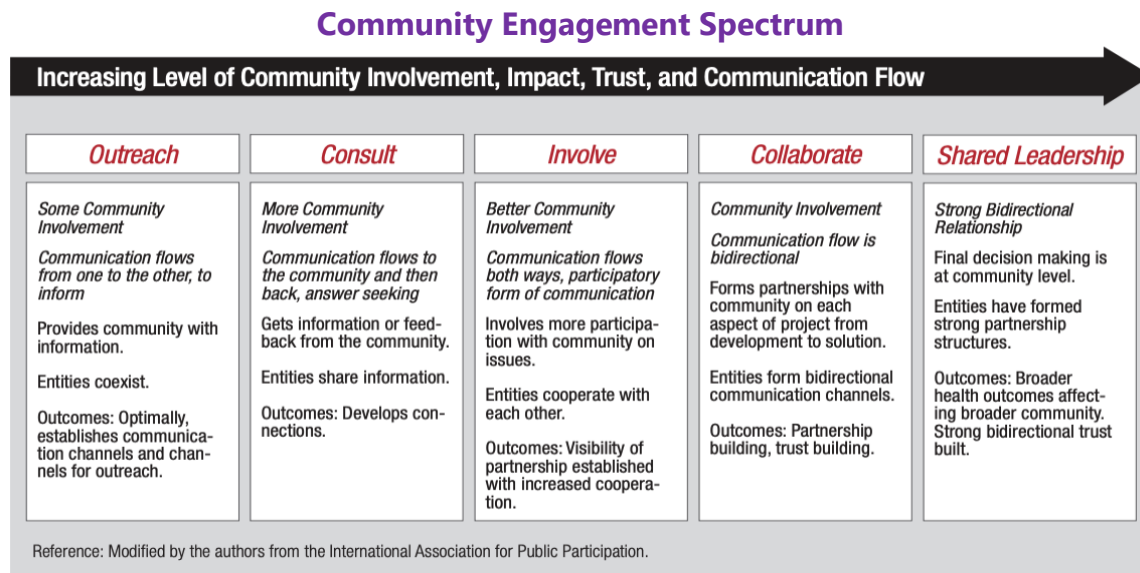Reference: Modified by the authors from the International Association for Public Participation.

Figure 3. As study moves further to the right on the spectrum, the greater bidirectional relationship and shared leadership between researchers and the community. Source: Principles of Community Engagement Report (2nd Ed.), Clinical and Translational Science Awards Consortium, Community Engagement Key Function Committee Task Force on the Principles of Community Engagement[5]

Best Practices in Engaging the LBGTQ+ Community

When addressing the LGBTQ+ community, there are several considerations to inform an effective community engaged approach:

- Consider the importance of disaggregating data for the LGBTQ+ community (e.g., collecting and reporting on all gender identity and sexual orientation sub-group data)[6]
- Establish relationships with community members or stakeholders (community advisory board, queer advocacy groups or partnership organizations) by attending and participating in local events, engaging with community members, and establishing a strong relationship with other allies[6]
- Emphasize warm, bidirectional, and interpersonal relationships to help address stigma, trauma, and distrust of medical institutions[6]
- Co-develop strategies for community outreach and engagement with community partners[6]
- Practice inclusivity by proactively identifying barriers and facilitators to study participation and reflect on assumptions of heterosexuality (i.e. avoid gender-specific pronouns, misgendering, and assuming child-bearing potential)[6]

Recruitment Best Practices

Outreach
- Establish a collaborative relationship with community-based LGBTQ+ organizations through community engagement efforts and create a community advisory board (CAB)[7]
- Partner with community leaders and trusted organizations to promote and advertise the research study in an appropriate and inclusive way[7]
- Train researchers in the history of the LGTBQ+ community so that they understand the fluidity and diversity of the LGBTQ+ community as well as the structural and historical factors that drive health inequities in this population[7]
- Utilize inclusive and empathetic research coordinators and/or other research staff members that can help ensure destigmatized engagement with community members[7]

Data collection, Scheduling and Costs
- Incorporate flexible data collection methods in your protocol (e.g., social media ads, interactive surveys, in-person intercept interviews)[8]
- Conduct data collection in flexible, high-traffic locations (e.g., 'safe spaces', queer nightclubs and bars, or establishments without a history of homophobia)[8]
- Follow-up intercept interviews with preferred contact method of participants to improve chances of further interaction[8]
- Develop relationship with LGBTQ+ community members and institution research team and IRB to help create payment method that meets community needs and builds trust within institution, while also working within budget means[9]
- Gather community input on cost for participation or contribution to determine adequate compensation and to prevent coercion or undue inducement[9]
- Consider lifestyles, behavioral practices, risk level, and payment preferences for study participants when determining compensation[9]

Education and Language
- Create marketing materials using plain language and larger fonts (see plain language guidelines [here](#))[10]
- Explain research objectives, protocols, PI contact information and follow up procedures with consideration for personal literacy and organizational health literacy (see health literacy guidelines [here](#))[11]
- Incorporate inclusive, community-preferred language in all consent documents and research instruments including open-ended demographic forms[7]

Cultural Sensitivity and Values
- Critically assess data collection questions and answer choices to determine whether certain options may be alienating (e.g., including gender identification, sex, gender expression, relationship types, and/or sexual identification answer options for survey questions)[7]
- Address participants by their preferred pronouns to indicate respect[7]
- Know the relationship between communities and your research institution prior to outreach and engagement as power dynamics are often longstanding between institutions and communities[7]
- Understand historical trauma as it relates to the LGBTQ+ community AND how this trauma interacts with other axes of oppression and individual trauma[7]

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Internal & External Resources

Research & Recruitment Resources	NYULH Trainings & Resources*	Health Profiles	National Organizations
Reaching Adolescent Gay, Bisexual, and Queer Men Online study	CDC Plain Language	Unveiling of HIV dynamics among transgender women in Brazil study	GLAAD LGBTQ Resource List
The Pride Study: A longitudinal cohort study on community engagement, recruitment, and retention of sexual and gender minority adults	CDC Health Literacy	Health care provider perceptions of fertility with transgender patients and families study	Equality Federation
Sexual and Gender Minority Adolescents' Perspectives on the Risks and Benefits of Sex Research study	CDC Select Terms for Populations	Cigna Healthcare LGBTQ+ Health Disparities Report	Human Rights Campaign (HRC)
Advancing methods for US transgender health research study	FOCUS Inclusive Mindset Training	The Health of Lesbian, Gay, Bisexual, and Transgender People	National LGBTQ Task Force
Strategies in the Recruitment of HIV-Positive Men Who Have Sex With Men study	FOCUS Design Thinking, Social Innovation, and Complex Systems Training	Parents, Families and Friends of Lesbians and Gays (PFLAG) LGBTQ Health Resources	Parents, Families and Friends of Lesbians and Gays (PFLAG)
Maximizing respondent-driven sampling field procedures in health research recruitment of sexual minorities study	FOCUS Using Gender Pronouns Training	CDC Lesbian, Gay, Bisexual, and Transgender Health Resources	American Civil Liberties Union (ACLU)
Comparative Analysis of Recruitment Strategies in a Study of Men Who Have Sex with Men (MSM)	FOCUS Building Inclusive Work Communities Training	HHS Health & Well-being for Lesbian, Gay, Bisexual and Transgender Americans	Anti-Violence Project
Recruitment and Participation of Older Lesbian and Bisexual Women in Intervention Research study	FOCUS Understanding and Supporting LGBTQ+ Employees Training	HealthyPeople 2020 Lesbian, Gay, Bisexual, and Transgender Health	CenterLink
Multiple strategies to identify HIV-positive black men who have sex with men and transgender women in New York City study	FOCUS Intro to LGBTQ+ Terminology and Key Concepts	Callen-Lorde LGBTQ health care	National Center for Lesbian Rights (NCLR)
Developing Online Recruitment and Retention Methods for HIV Prevention Research Among Adolescent Males Who Are Interested in Sex with Males study	FOCUS Creating Patient Centered Care Environments for LGBTQ+ Patients and Families Training	NYC Health + Hospitals LGBTQ Healthcare	COLAGE
Recruitment of Underrepresented Minority Researchers into HIV Prevention Research study	FOCUS Gender Transition Guidelines for Faculty, Students and Staff Training	NYC Health - LGBTQ Health Resources	GMHC
Mental health, social adversity, and health-related outcomes in sexual minority adolescents study	FOCUS Being an Ally Resource	The New York State LGBT Health & Human Services Network	Matthew Shepard Foundation

Research and Recruitment Resources	NYULH Trainings & Resources*	Health Profiles	National Organizations
At-risk youth participation of surveillance studies involving HIV testing study	FOCUS Strategic Resources and Support Services for Investigators & Study Teams	New York State Lesbian, Gay, Bisexual and Transgender Health Resources	Out & Equal
Conducting Anonymous, Incentivized, Online Surveys with Sexual and Gender Minority Adolescents Study	FOCUS Talking About Race at Work Training	Weill Cornell Medicine Wellness Qlinic LGBTQ Health Resources	
	FOCUS Marketing to Diverse Audiences Training		
	FOCUS Creating a Culture of Collaboration Training		
	FOCUS Communicating Across Cultures Training		
	FOCUS Best Practices for Managing Projects Across Cultures Training		
	FOCUS Cultural Competency at NYULH Training		
	FOCUS Interpersonal Communication Training		
	FOCUS Strategies to Foster Inclusive Language Training		
	FOCUS Inclusivity in Committed Allies Training		
	FOCUS Leading Inclusive Teams Training		
	FOCUS Confronting Bias: Thriving Across Our Differences Training		
	FOCUS Addressing Unconscious Bias in Medicine Training		
	FOCUS Managing a Diverse Team Training		
	FOCUS Diversity, Inclusion and Belonging Training		

* FOCUS only accessible with Kerberos ID