The National LGBTQ+ Women's Community Survey:

Health Findings Brief

In 2019, a group of seasoned LGBTQ activists and researchers launched a first-ever National LGBTQ+ Women's Community Survey, driven by the passion and commitment of legendary lesbian organizer, Urvashi Vaid (1958-2022). The study was designed to investigate the complex web of discrimination and structural violence faced by women and nonbinary people who partner with women. This comprehensive survey involved 5,002 lesbian, gay, bi, pan, queer and asexual women across a broad spectrum of genders, reaching into every relevant domain of our respondents' lives, including formative family life; identity; education; disability; employment; religious life; sexuality and sexual practices; sociality and sports; economic security; housing; health; volunteerism and political life; parenting and children; aging; and intimate partner and state violence[1].

Study principals wondered: When LGBTQ+ women partner or make family with LGBTQ+ women, how do the burdens of misogyny, racism, ableism and other forms of discrimination add up in our lives? How do they impact our health specifically? What strategies best support us in building the lives we want, regardless? How and under what circumstances are we thriving?

We asked respondents to identify themselves on their own terms, leaving us with the ability to examine the data via multidimensional constructions of race, class, gender, age and sexuality. Accordingly, we are able to offer a nuanced view of the health disparities we uncovered, and the cumulative impacts of multi-layered discrimination and abuse in the lives of these respondents.

The survey's findings gained new urgency when a 2024 report based the longitudinal Harvard Nurses' Health Study II (N=100,000) revealed shockingly reduced life expectancies for lesbian and bisexual women.[2] This alarming discovery, which found lesbian and bi women living 20-37% shorter lives (respectively) than their heterosexual peers, identified "Toxic Social Exposure" as the driver of this theft of years of life. The Nurse's study underscored the critical importance of the National LGBTQ+ Women's Survey's work to expose and address the complex labyrinth of discrimination impacting LGBTQ+ women's health across their lifespans.

While a full report on our extensive findings is forthcoming, what follows is a brief on key findings and preliminary recommendations. We found:

A staggering number of trauma survivors

> Sixty-six percent (66%) of study respondents report seeking treatment for trauma while the NAMI and the Veteran's National Center for PTSD report that 10-13% of women in the US experience trauma at some point in their lives.

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[1] This report is based on the experiences of the 5,002 respondents as articulated by their answers to more than a dozen health-related questions. In this report, we present frequencies—the number of people who answered a question, or the number who chose a response from a list of multiple options. We did not weight the sample to correct for demographic shortcomings. We did not perform regression analyses to establish causal relationships or statistical significance.

[2] McKetta, Hoatson, Hughes, et al, "Disparities in Mortality by Sexual Orientation in a Large, Prospective Cohort of Female Nurses," *JAMA*. 2024; 331(19). https://jamanetwork.com/journals/jama/article-abstract/2818061

Extremely high rates of disability

Fifty percent (50%) are living with a disability, with 33% reporting a mental health disability. Moreover, 54% of BIPOC respondents reported living with a disability.

Among those impacted, 51% have never sought accommodations and only 15 percent report receiving any kind of workplace accommodation for their disability.

Nearly double the rate of depression (51%) and anxiety (44%) as people in the general population

	National LGBTQ+ Women's Community Survey	People in the general US population
Anxiety disorders	44%	19.1%[3]
Depression	51%	29%[4]

"I wish that I could receive mental health care, but I've never met a therapist who has any idea where I'm coming from as a queer person."

Devastating levels of exposure to intimate partner violence

Forty-seven percent (47%) have survived some form of intimate partner violence compared to 35.6% of women in the general population.

Among the more than 2,000 respondents experiencing IPV, fewer than 20% accessed any form of institutional support or care. They report the police as "not helpful at all" in 54% of the cases; and rate community-based LGBTQ+ services highly. Friends were reported as by far their most significant resource during an IPV crisis (57%).

Extremely high rates of attempted suicide

Twenty-two percent (22%) of respondents have attempted suicide, more than 4 times the rate of the general population, with even higher rates among trans (37%) and BIPOC (29%) respondents.

High rates of addiction and barriers to assessment

In terms of addiction, 6% of respondents reported having been told by a healthcare provider that they had a problem with drugs or alcohol. Thirty-eight percent (38%), however, said they thought they had a problem "some" or "most" of the time.

Additionally, we asked if respondents' partners had a substance abuse problem. Twenty-eight percent (28%) said they had dated one person with a problem, and another 20% said they had dated *more than one person* who they believed had a problem.

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[3] National Alliance on Mental Illness, "Anxiety Disorders." 2017. https://www.nami.org/about-mental-illness/mental-health-conditions/anxiety-disorders

[4] Dan Witters, "U.S. Depression Rates Reach New Highs." Gallup. 2023. https://news.gallup.com/poll/505745/depression-rates-reach-new-highs.aspx

We find the low rate of respondent diagnoses combined with the high rate of respondent concern around their own drug alcohol use and the high rate of reported partners with alcohol or drug problems (48%) to be a serious "tell" around the lack of competent care our respondents are receiving around addiction assessment and treatment.

Higher rates of arthritis, asthma, cervical cancer, high cholesterol, lupus, and skin cancer

	National LGBTQ+ Women's Community Survey	Women in the general US population
Arthritis	24%	21%[5]
Asthma	22%	9.7%[6]
Cervical cancer	1%	0.6%[7]
High cholesterol	23%	12.1%[8]
Lupus	.008%	.0013%[9]
Skin cancer	5%	2%[10]

Respondents showed higher rates of these six physical conditions despite the sample having higher income levels and educational attainment than women in these general population -- assets typically associated with better health outcomes.

Particularly disturbing are nearly double the rates of high cholesterol, a driver of heart disease, and cervical cancer.

"Having breast cancer as a nonbinary person has been very complicated. When I wanted to have my breasts removed, they assumed I was overreacting to my diagnosis. Plus, they didn't know how to do a reconstruction for someone like me."

Barriers to primary care

Only 55% report being under the care of a primary care physician compared to 77% of the US general population.[11] BIPOC respondents in the study were twice as likely to say they lacked access to quality healthcare as their white peers in the study.

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[5] Fallon, Boring, Foster, Stowe, Lites, Odom, "Prevalence of Diagnosed Arthritis - United States, 2019-2021," *Morbidity and Mortality Weekly Report*. 2023; 72(41). https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10578950/

[6]U.S. Centers for Disease Control and Prevention, "National Current Asthma Prevalence by Select Sociodemographic Characteristics." 2021. https://www.cdc.gov/asthma/most_recent_national_asthma_data.htm

[7]National Institutes of Health, "Cancer Stat Facts: Cervical Cancer, National Cancer Institute, Surveillance, Epidemiology, and End Result Program." https://seer.cancer.gov/statfacts/html/cervix.html

[88]U.S. Centers for Disease Control and Prevention, "QuickStats: Prevalence of High Total Cholesterol Among Adults Aged ≥20 Years, by Age Group and Sex — National Health and Nutrition Examination Survey, 2015–2018." 2020. https://www.cdc.gov/mmwr/volumes/69/wr/mm6922a5.htm

[9] Izmirly, Parton, Wang, McCune, Lim, Drenkard, Ferucci, Dall'Era, Gordon, Helmick, Somers, "Prevalence of Systemic Lupus Erythematosus in the United States: Estimates From a Meta-Analysis of the Centers for Disease Control and Prevention National Lupus Registries." *Arthritis Rheumatol*. 2021;73(6). https://pubmed.ncbi.nlm.nih.gov/33474834/

[10]American Academy of Dermatology Association, "Skin Cancer." 2024. https://www.aad.org/media/stats-skin-cancer

[11] Levine, Linder, Landon, "Characteristics of Americans With Primary Care and Changes Over Time, 2002-2015." *JAMA Internal Medicine*. 2020; 180(3). https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/2757495

Respondents reported a range of harassment and violence in healthcare settings. One out of every fifty respondents (2%) said they had been refused treatment when a provider found out about their sexual orientation and/or gender identity. Three percent (3%) said they had experienced a sexually suggestive or predatory provider, and one out of every hundred (1%) reported being physically assaulted in a healthcare setting.

"I've struggled to access LGBTQ-informed care. Telehealth has made it possible for me to see certain providers like my therapist virtually, but I otherwise have to drive more than two hours for healthcare where I'm treated with basic dignity & respect."

Barriers to care when sick or in need

Postponement of care due to worries about discrimination and refusal of care by doctors was high, especially given that our respondent sample lives on slightly higher incomes than women in the general population.

Thirty percent (30%) of respondents said they had postponed or not tried to get needed care due to cost while 22% said that they had postponed or not tried to get needed care due to disrespect and discrimination.

Additionally, respondents were not seeking key preventive screenings at the rates of women in the general population.

	National LGBTQ+ Women's Community Survey	**Women in the general US population**
Never had a Pap smear	14%	7%[12]

LGBTQ+ women are both twice as likely to never have had a pap smear as women in the general population, and twice as likely to suffer from cervical cancer.

"My doctors have always been well-intentioned but not well-informed. For example, my PCP told me I didn't need a pap smear because I wasn't sexually active with men. I went home and learned that that wasn't correct, so I had to ask for a pap again at my next visit."

Fluidity creates health precarities

Respondents whose gender and sexuality were fluid or changing over the lifespan fared worse on almost every health measure than their counterparts in the study whose gender and sexuality did not change over the lifespan.

BIPOC respondents reported fluid and changing genders and sexuality more often than their white counterparts in the study. Racism and discrimination due to fluidity is a disparity-creating nexus for BIPOC women in the study.

[12] Sirovich, Welch, "The frequency of Pap smear screening in the United States." *Journal of General Internal Medicine*. 2004; 19(3). https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1492158/

Drivers of discrimination – an endangering mix

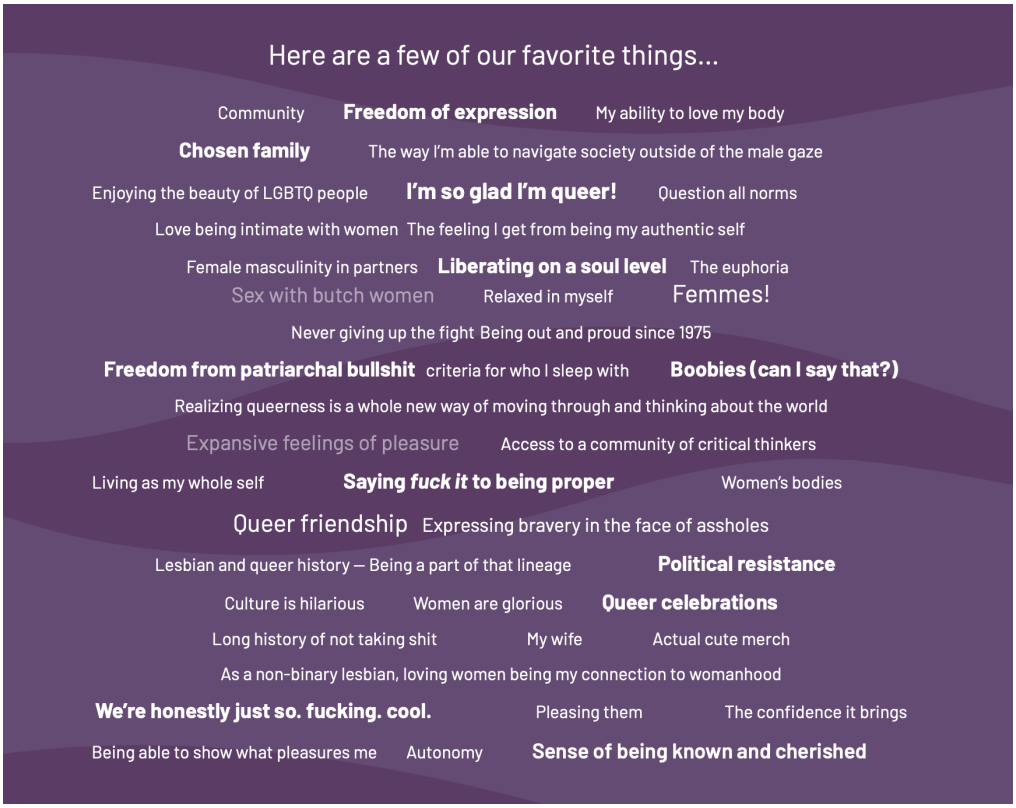
When asked why they thought they were being targeted for discrimination or abuse, respondents listed these top four drivers: 1. Sexism -- because I am a woman (38%). 2. Racism (34%). 3. Anti-LGBTQ+ prejudice (26%). 4. Targeted due to my weight (18%).

Respondent insights into the drivers of the discrimination against them are a unique contribution of the study and should drive much of the thinking and organizing for LGBTQ+ women's health and social and economic security going forward.

"Most of my problems with healthcare has been due to being a woman and for being obese. While pregnant I received my best care. Immediately after giving birth, I received my worst care. The healthcare was for the fetus, not me."

Identity, community, friendship, and sex – queer joy and connection are our safety nets

The study's 5002 respondents wrote in 15,006 responses to this final question: ***What are your three favorite things about being a LGBTQ+ woman?*** A tiny subset follows:



Along with these responses, answers to study questions on sexuality and sexual practices indicate that respondents are having more sex than people in the general population, and that their sex lives bring them significant joy and pleasure (see p. 147-166, *"We Never Give Up the Fight"*.) This finding is especially significant in the face of the barriers outlined above. Combined with the write ins on their favorite things, and respondent reports on relying on friends in time of crisis (see p. 20, *"We Never Give Up the Fight"*.) study participants make clear the centrality of queer identity, community, friendship, and sex to their health and well-being.

Preliminary Recommendations:

1. If, as the Harvard Nurses study points out – *toxic social exposure* is truncating LGBTQ+ women's life expectancy, then ***culturally congruent care*** in the form of highly trained and well-resourced LGBTQ+-identified medical staff and doctors is paramount.

   Toxic social exposure in the doctor's office is -- in a word -- deadly.

   Addressing health disparities means creating the possibility for strong relationships with LGBTQ+-identified primary care providers and community-informed, accessible screening.

   Doctors who understand, for example, the wide range of embodiments that LGBTQ+ women possess and express, and who observe these bodies live, love, and thrive in the daily context of their lives – are irreplaceable health care resources for LGBTQ+ women. And, as study after study of the general population confirms the persistence of health disparities among BIPOC people, BIPOC queer and trans doctors and nurses are a literal lifeline to BIPOC LGBTQ+ women.

   Many aspects of LGBTQ+ women's lives that are routinely problematized and pathologized in health care settings – from our weight to our sexualities to our mental health conditions – are more legible in the eyes of LGBTQ+ docs who better understand the toxic social exposures we are surviving, as well as the creative and varied ways that LGBTQ+ women partner, make family, and make joy.

2. Create community-developed treatment and respite centers for trauma. Over the past 20 years, the queer and BIPOC-led transformative justice movement has created the theory and practices essential for addressing the widespread trauma burden in our communities. Almost none of these treatment modalities and priorities are widely funded – generative somatics, peer story-telling and support, trauma-informed bodywork, queer identity affirmation and sexual pleasure, and friendship-as-medicine among them. An LGBTQ+ movement that serves the needs of LGBTQ+ women would have this research & development work as well as a corresponding re-orientation of funding near the very top of its list of priorities.

3. Pursuant to #2, we need much more significant organizing around funding for LGBTQ+-driven mental health treatment models. Mental health models that don't center the resiliencies found in the study – friendships, sex, and queer embodiments, entirely miss key factors that preserve and promote LGBTQ+ women and non-binary people's health (See *We Never Give Up the Fight*, Chapter 6, Sexual Practices, Resilience and Joy.)

4. IPV services funding must prioritize training our friends in effective IPV response (57% report friends as their best resource during an IPV crisis). In terms of institutional funding (only 20% of survivors turned to institutions for support) -- investing in community-based care versus policing and carceral responses is critical to survivor well-being.

5. Housing is health care. Improving housing access and access to homeownership is an IPV intervention, a disability intervention, a mental health intervention, etc. Solutions that are de-carceral and also address housing stabilization and recovery resources for LGBTQ+ abusers are paramount.

6. Build community education campaigns around securing workplace accommodations and disability benefits; improve access to social and advocacy events in LGBTQ+ community-based settings; fight for the leadership of disabled activists in LGBTQ+ spaces. Fund and prioritize disability benefits navigation and legal advocacy at our community centers.

7. Create LGBTQ+-specific, accessible, community-informed health navigation and treatment advocacy around IPV, sexual trauma, depression, anxiety and substance abuse.

8. Build funding and support for free PTSD support groups in our community centers – specifically around IPV, sexual trauma, sexist, racist, fat-phobic and anti-LGBTQ+ discrimination, and poverty.

9. Grow funding and support for free depression and anxiety support groups in community- based settings.

10. Grow funding for free, non-carceral, LGBTQ+ friendly, trauma-informed drug and alcohol peer support.

11. Support queer friends as first responders to crisis in LGBTQ+ women's lives. Respect and foreground queer friendship as medicine.

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