# "What's Killing Us?"

## A Health Report from the National LGBTQ+ Women's Community Survey

By Jaime M. Grant, Jack Harrison-Quintana, Savy Elahian, and Genevieve Villamora

## EXECUTIVE SUMMARY

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 study, 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 on the longitudinal Harvard Nurses' Health Study II 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 in the study, identified "Toxic Social Exposure" as the driver of this theft of years of life. The Nurse's study underscored the critical importance of the survey's work to expose and address the complex labyrinth of discrimination impacting LGBTQ+ women's health across their lifespans.

## + A STAGGERING NUMBER OF TRAUMA SURVIVORS

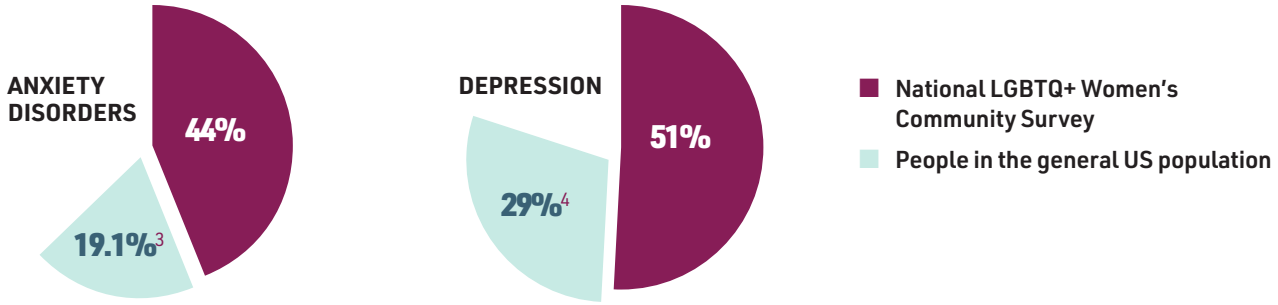
Sixty-six percent (66%) of study respondents report seeking treatment for trauma while the NAMI and the Veteran's National Center for PTSD report that 10-13% of women in the US experience trauma at some point in their lives.

## + 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%)




> "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%).

## + HIGH RATES OF ATTEMPTED SUICIDE

Twenty-two percent (22%) of respondents have attempted suicide, more than four 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.

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

## + HIGHER RATES OF ARTHRITIS, ASTHMA, CERVICAL CANCER, HIGH CHOLESTEROL, LUPUS, AND SKIN CANCER

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

| | 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] |

"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

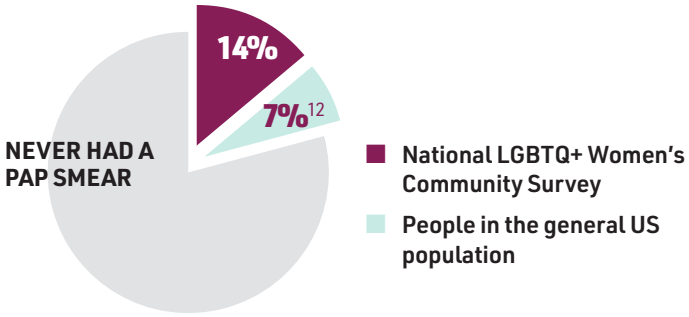
Only 55% report being under the care of a primary care physician compared to 77% of the US general population.[11] BIPOC respondents in the study were twice as likely to say they lacked access to quality healthcare as their white peers in the study.

Respondents reported a range of harassment and violence in healthcare settings. Three percent (3%) said they had experienced a sexually suggestive or predatory provider. 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. 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.

> "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."

## + BIASES ABOUT FLUIDITY AND RACISM CREATE 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. Racism and discrimination due to fluidity is a disparity-creating nexus for BIPOC women in the study.

## + 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 animate 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."

Recommendations that flow from these findings can be found at the close of the report.

# CHAPTER 1: INTRODUCTION

In 2019, a group of seasoned LGBTQ+ activists, scholars, and policy advocates came together to create the first National LGBTQ+ Women's Community Survey. The project was born of frustration at the lack of analysis about how racism, misogyny, anti-LGBTQ animus and other structures of violence combine to impact women who partner with women across the lifespan. In this report, we break down the study's key health findings and look at how they stack up to the experiences of people in the US general population.

**Our multiracial and multi-gender team agreed on several foundational values and aims which grew the study's methodology:**

1. We wanted to bring the unique needs of LGBTQ+ women into full view, to highlight both our vulnerabilities and our strengths, while challenging the underlying and often invisible sexist and racist values that drive LGBTQ+ movement priorities and dismiss our vulnerabilities.
2. We wanted the survey to tell the stories of anyone who had been perceived as, identified as, or lived their lives as women partnering with women, even if this was for a relatively short period. We believed that misogyny's punishment and reward systems impact all of us who move in the world as girls and women, regardless of when we find ourselves on that path.
3. We chose to study women partnering with women, specifically, because we wondered what the scaffolding of discrimination and violence that impacts all women would look like among women and nonbinary people who centered women in their sexual, familial and/or romantic lives. And we were very interested in seeing how these impacts played out across race, gender and sexual orientation.

Soon after we began to publish findings, in the spring of 2024, a team of researchers at the Harvard T.H. Chan School of Public Health published a paper based on the Nurses' Health Study II, a longitudinal cohort of over 100,000 female nurses that began collecting data in 1999.

The nurses study included a question on sexual orientation that had been hard won at the grassroots level in the early '90s by key lesbian health activists, including Marj Plumb, who was at the National Gay and Lesbian Task Force; Amber Hollibaugh, at Gay Men's Health Crisis in New York; Amelie Zurn, founder of Whitman Walker Clinic's Lesbian Health Services Program in DC (now defunct), and Kathleen DeBold, at the Mautner Project for Lesbians with Cancer (also no longer operating).

**The findings of the Nurse's Study were shocking.**

The analysis showed that women who identified as lesbians died 20% sooner than their heterosexual counterparts, and women who identified as bisexual died 37% sooner. If the average woman in the US lives to 76.33 years, that means lesbians live to about 61 and bi women to a shocking 48 years of age.[13]

The news of significantly shortened life expectancy hit our team very hard, and harder still as the deafening silence unfolded in the weeks that followed the announcement of these shattering findings. For our team, it increased an already intense call to action we felt around the health statistics we had been able to gather as part of the National LGBTQ+ Women's Community Survey.

When the first report of the study came out in 2023 under the title, *We Never Give Up The Fight*, some aspects of the context around this shortened lifespan became visible. That report covered gender and sexuality over the lifespan; education; disability; intimate partner violence (IPV); religious upbringing and life; sex, joy, and resilience; and the policy priorities that study's 5,002 respondents described.

**Some of the key findings there are worth noting, and carry over into the health report:**

- Forty-seven percent (47%) of respondents had survived at least one incident of intimate partner violence (IPV).
- Bisexual women who experienced IPV were exposed to male perpetrators more often than other women in the study, and these perpetrators employed more lethal forms of violence than LGBTQ women perpetrators.
- Fifty percent of respondents reported a disabling condition with 33% reporting a disabling mental health condition. BIPOC women experienced disability at a higher rate (54%) than their white peers in the study.
- People whose gender and sexuality were fluid or changing over the lifespan fared worse on almost every measure of discrimination, in every study domain, than their counterparts in the study whose gender and sexuality was less dynamic and did not change over the lifespan.
- Women of color reported more fluidity in their genders and sexuality than their white counterparts.

The discrimination and violence experienced across the domains covered in the *We Never Give Up the Fight* form part of the picture of what the Harvard scholars termed "toxic social exposure" – the social determinants of health that have led to the realities of early mortality for lesbians and bi women in the Nurse's Study.

In this report, for the first time, we deliver findings from the National LGBTQ+ Women's Community Survey that specifically illuminate the health and healthcare experiences of LGBTQ+ women and nonbinary participants in the study.

# I. Methodology

This report describes 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.

Study principals wondered: When LGBTQ+ women partner or make family with other LGBTQ+ women, how do the burdens of misogyny and other structures of violence impact their health? In what specific areas do we struggle? What strategies best support us in building health and the lives we want, regardless? How and under what circumstances are we thriving?

## II. Demographics

A full description of the demographics of the respondent community can be found in pages 34-45 of *We Never Give Up the Fight*, "A Portrait of Our Respondents." Therein, the study team notes the strengths and limitations of the sample. The size (N=5002) and nearly representational geographic spread of the respondent community allow us to make robust analyses of the data across many nuanced identity categories.

However, the length of the questionnaire ultimately hampered participation, with more than 35% of respondents failing to complete their surveys. So, while more than 8,000 women engaged with the study, only 5,002 completed all 170 questions (and thus qualified for full analysis here).

More than 40% of those who could not complete the survey were women of color and/or people living on low incomes. Accordingly, our sample over-represents the experiences of white women (73%) and women living on higher incomes. Also notable, is that 46% of the sample holds an advanced degree relative to 35% of women in the general population.

In terms of the findings in this specific report then, we are presenting the health experiences and outcomes of women with somewhat higher incomes and much higher levels of education than the general population of the US, including the BIPOC women in the study. So, while good news in the findings around health outcomes and access should be weighed against the relative privileges of the respondent community, bad news health outcomes are even more concerning given that whiteness and higher levels of education and income often confer protective health benefits.

Other demographic facets of interest for researchers and advocates include the high participation of lesbian or gay-identified women in the sample (56%), and those along the femme or feminine gender spectrum (52%). This may be the largest and most in-depth survey of femme lesbian experience gathered anywhere. Again, while this makes the data ungeneralizable to all LGBTQ+ women, it may point to specific vulnerabilities faced by femme-identified lesbian women in our communities, as well as particular strengths.

Three percent (3%) of respondents identify as asexual. Given the dearth of research on asexual women, these 150 respondents' answers to 170 questions constitute an extensive and noteworthy data resource.

Seven hundred and forty-four (744) respondents identified as transgender, with 56% along the trans masculine spectrum having identified as women in the past. Twenty-six percent (26%) identified as women currently but not in the past – along the trans feminine spectrum. Fifteen percent (15%) identified as a woman in the past and in the present, reporting their genders as nonbinary or genderqueer.

An important demographic detail in the study is that nearly one-third of respondents describe their sexuality as "fluid or changing." Capturing this detail turned out to be enormously significant as those with fluid and changing genders and sexualities had higher vulnerabilities and worse outcomes for many of our 170 questions, including the health series, as you can see in *We Never Give Up the Fight*, and you will see below.

# CHAPTER 2: DIAGNOSES

The survey asked respondents if they had ever received any of forty-four diagnoses. The question reads, "Have you ever been told by a doctor or health professional that you had any of the following conditions?"

In most of the results reported in this publication, we do not include answers that failed to reach a rounded 1%. In this section, despite limitations, we do include instances of very small respondent rates in order to make visible the experiences of those with conditions that are relatively rare but can nonetheless make major impacts on our community.

## DIAGNOSES

| | |
|---|---|
| Angina | 1% |
| Any type of alcohol or substance use problem | 6% |
| Any type of anxiety disorder | 44% |
| Any type of depression | 51% |
| Any type of psychosis or personality disorder | 4% |
| Arthritis | 24% |
| Asthma | 22% |
| Asthma Episode or Attack | 8% |
| Bacterial vaginosis | 10% |
| Cancer – Breast | 4% |
| Cancer – Cervical | 1% |
| Cancer – Colorectal | 0.4% |
| Cancer – Endometrial | 1% |
| Cancer – Uterine | 1% |
| Cancer – Lung | 0.3% |
| Cancer – Lymphoma | 0.4% |
| Cancer – Renal/Kidney | 0.2% |
| Cancer – Skin | 5% |
| Cancer – Thyroid | 1% |
| COPD | 2% |
| Coronary Heart Disease | 2% |
| Cysts in Ovaries | 13% |
| Diabetes | 7% |
| Differences of Sex Development (Intersex Variations) | 1% |
| Endometriosis | 7% |
| Gonorrhea | 2% |
| Heart Attack | 1% |
| Herpes | 7% |
| High Cholesterol | 23% |
| HPV | 7% |
| Hypertension (Blood Pressure) | 20% |
| Immunocompromised Condition | 8% |
| Irregular or Absent Menstrual Cycle | 16% |
| Lupus | 1% |
| Menopause | 26% |
| Multiple Sclerosis | 1% |
| Osteoporosis | 7% |
| Other STD | 3% |
| "Overweight" or "Obese" | 42% |
| PCOS | 7% |
| Prediabetes | 11% |
| Stroke | 1% |
| Syphilis | 0.4% |
| Trichomoniasis | 2% |

## INTERLUDE: LESBIAN HEALTH ACTIVISM TRAILBLAZER: CAITLIN RYAN

I worked in the early LGBTQ health movement in the 1970s – that's when I identified the need for a national lesbian health survey. I helped to start the National Lesbian and Gay Health (NLGHF) Foundation in 1979-80 and I was able to get the Ms. Foundation to provide initial funding to start planning the survey. I had to convince the men on the board of NLGHF that we could do the survey since nothing like this had ever been done and they didn't want to accept the grant from the Ms. Foundation to start the survey since they didn't think this was possible.

To frame the content – since this survey was also defining lesbian health – I did qualitative interviews with lesbians across the U.S. from diverse backgrounds while I was in social work school. This included Audre Lorde whom I knew in New York and who provided guidance on developing the questionnaire. I field tested three drafts of the survey with help from many organizations that helped to disseminate it, including the National Coalition of Black Lesbians and Gays and at the Third World Conference of Lesbians and Gays.

When I was the director of the 2nd NLGHF Conference and AIDS Forum in 1979, I did outreach across the U.S. to organize that conference. As part of this work. I recruited organizers in each state and the territories to do outreach for the conference. After the conference, I worked with them to help disseminate the lesbian health care survey.

I met Judy Bradford at the 1984 NLGHF conference that I coordinated, and I recruited her to help. I had been looking for someone who had access to a survey research lab to analyze the survey results for 4 years and no researcher would help since none of them were out and they were afraid that this would impact their job and career. Judy was a grad student and worked on the survey that was completed in 1985.

**– CAITLIN RYAN**

# I. Disparities in Diagnoses

**Arthritis**, **asthma**, **cervical cancer**, **high cholesterol**, **lupus**, and **skin cancer** were among the conditions reported at higher levels by the LGBTQ+ women and non-binary people who took the survey compared to women in the US population overall.

Disparities in mental health conditions, which are tremendously high, are discussed later in this report.

## A. ARTHRITIS

Twenty-four percent (24%) of respondents reported having received an arthritis diagnosis at some point in their lives, compared to 21% of US women overall.[14]

Our sample skews slightly older, with an average age 45.2, compared to the US general population (average age 38.6), and arthritis is more common among older women.

Still, this elevated risk of arthritis among LGBTQ+ women is also reflected in the CDC's Behavioral Risk Factor Surveillance System data from 2017 through 2019, as reported in "Health and Socioeconomic Well-Being of LBQ Women in the US."[15]

### Arthritis

LGBTQ+ Women's Community Survey Respondents: **24%**

Women in the US Population: **20.9%**

BRFSS (2017-2019), Straight Women: **29.2%**

BRFSS (2017-2019), All LBQ Women: **36.7%**

BRFSS (2017-2019), LBQ Cis Women: **36.6%**

BRFSS (2017-2019), LBQ Trans Women: **40.1%**

BRFSS (2017-2019), Straight Men: **23%**

BRFSS (2017-2019), GBQ Men: **24.8%**

## B. ASTHMA

Twenty-two percent (22%) of respondents reported having received an asthma diagnosis, which far exceeded women in the general US population (9.7%).[16]

Again, this resonates with the CDC's Behavioral Risk Factor Surveillance System data from 2017 through 2019, as reported in "Health and Socioeconomic Well-Being of LBQ Women in the US," where the rate for LBQ women was found to be 23.7%.[17] In both of these studies, asthma was shown to be an area in which LGBTQ+ women are more impacted than their straight counterparts.

### Asthma

LGBTQ+ Women's Community Survey Respondents: **22%**

Women in the US Population: **9.7%**

BRFSS (2017-2019), Straight Women: **16.3%**

BRFSS (2017-2019), All LBQ Women: **23.7%**

BRFSS (2017-2019), LBQ Cis Women: **21.9%**

BRFSS (2017-2019), LBQ Trans Women: **20.1%**

BRFSS (2017-2019), Straight Men: **11.7%**

BRFSS (2017-2019), GBQ Men: **17.5%**

## C. CANCER

As the National LGBT Cancer Network has noted, definitive research on cancer in LGBTQ+ women has yet to be conducted.[18] But, there is a body of evidence and community knowledge that LGBTQ+ women stand at the intersection of a cluster of risk factors that raise their risk of developing breast, cervical, and ovarian cancers – as Drs. Caitlin Ryan and Judy Bradford's groundbreaking lesbian health survey (1979-1985) first found. These risk factors are compounded by lower screening rates (explored later in this report) that lead to cancers being detected later when they are more difficult to treat.

"Health and Socioeconomic Well-Being of LBQ Women in the US," which used Behavioral Risk Factor Surveillance System data from the CDC between 2017 and 2019, found that LBQ women had higher rates than straight women for cancers overall, other than skin cancer.[29] In this study, the respondents had higher rates of skin and cervical cancers than women in the general US population; lower rates of breast, colorectal, lung, and renal cancers, as well as lymphoma; and similar levels of thyroid cancer.

### Cancer Disparities

| Type of Cancer | LGBTQ+ Women's Community Survey Respondents | Women in the US Population |
|---|---|---|
| Breast cancer | 4% | 13%[19] |
| Cervical cancer | 1% | .6%[20] |
| Colorectal cancer | 0.4% | 4%[21] |
| Endometrial cancer | 1% | N/A[22] |
| Uterine cancer | 1% | 3.1%[23] |
| Lung cancer | 0.3% | 5.88%[24] |
| Lymphoma | 0.4% | 1.92%[25] |
| Renal/Kidney cancer | 0.2% | 1.4%[26] |
| Skin cancer | 5% | 2%[27] |
| Thyroid cancer | 1% | 1.1%[28] |

In the next section, we explore cancer diagnoses in more depth, including for specific cohorts from within the respondent pool.

## D. COPD

Survey respondents reported diagnoses of chronic obstructive pulmonary disease (COPD) at a rate of 2%, which is lower than the 4.8% rate for women in the general US population.[30]

## E. CORONARY HEART DISEASE

The rate of coronary heart disease diagnoses for respondents to the National LGBTQ+ Women's Community survey was 2%. The risk of heart disease for women at age 40 in the general population is 24.9%.[31]

## F. OVARIAN CYSTS

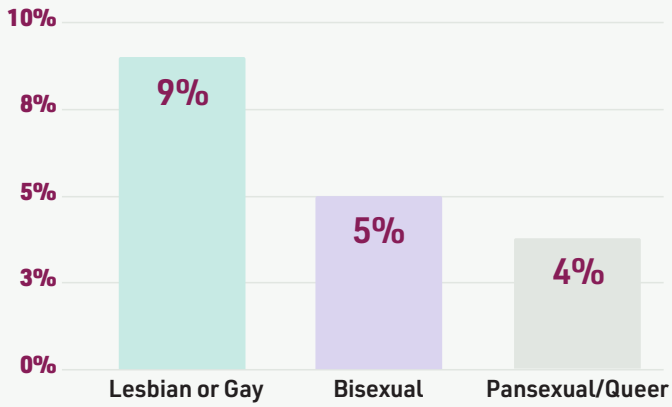
The respondents to the National LGBTQ+ Women's Community Survey reported ovarian cysts at 13%. This is lower than the 20% of women overall who are likely to develop at least one mass during their lifetime.[32]

## G. DIABETES

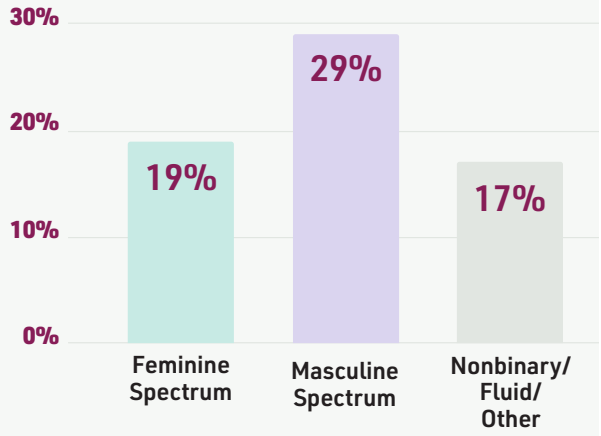
Seven percent (7%) of respondents reported having received a diabetes diagnosis. This is less than women in the general US population (9.7%).[33]

Lesbians had the highest rate among the sexual orientation cohorts. In terms of gender, masculine-spectrum respondents were the highest. In terms of race, BIPOC respondents' rate was one percent higher than their white peers.

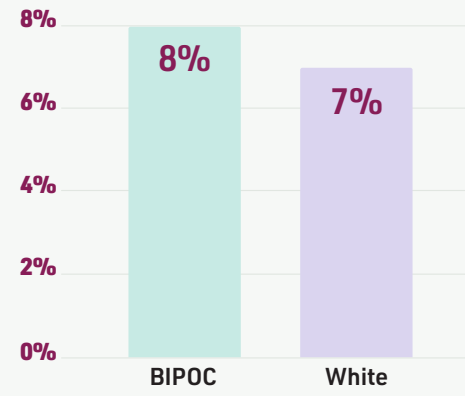
### Diabetes by Sexual Orientation




### Diabetes by Gender




### Diabetes by Race




### Diabetes

LGBTQ+ Women's Community Survey Respondents: **7%**

Women in the US Population: **10%**

BRFSS (2017-2019), Straight Women: **10.6%**

BRFSS (2017-2019), All LBQ Women: **12.5%**

BRFSS (2017-2019), LBQ Cis Women: **12.2%**

BRFSS (2017-2019), LBQ Trans Women: **21.5%**

BRFSS (2017-2019), Straight Men: **12.5%**

BRFSS (2017-2019), GBQ Men: **12.8%**

These results are lower than in the CDC's Behavioral Risk Factor Surveillance System data from 2017 through 2019 as reported in "Health and Socioeconomic Well-Being of LBQ Women in the US," where the incidence for LBQ women was found to be 12.5%.[34]

Other studies have shown an elevated risk for diabetes among LGBTQ+ women. Where we find this elevated risk in the survey is among masculine spectrum responses, at an alarming 29%. This points to the importance of asking nuanced questions around gender expression in health surveys of LGBTQ women, so that specific health precarities can be identified and addressed.

## H. INTERSEX CONDITIONS

interACT, an advocacy organization by and for intersex people in the United States offers the following definition: "Intersex is an umbrella term for differences in sex traits or reproductive anatomy. Intersex people are born with these differences or develop them in childhood. There are many possible differences in genitalia, hormones, internal anatomy, or chromosomes, compared to the usual two ways that human bodies develop."[35]

Respondents to the National LGBTQ+ Women's Community Survey were asked whether they had ever received any diagnoses that constitute an intersex variation. The term, "Differences of Sex Development," was also presented. Only 1% of respondents said yes.

In their work, Intersex Human Rights Australia uses a rate of 2% of all live births in the overall global population based on a preponderance of research.[36]

## I. ENDOMETRIOSIS

Between 2 and 10% of women ages 25 to 40 are impacted by endometriosis, a condition in which cells similar to the uterine lining, or endometrium, grow outside the uterus.[37] Postmenopausal endometriosis is reportedly between 2 and 5%.[38] Respondents to the National LGBTQ+ Women's Community Survey reported diagnoses of endometriosis at 7% across the lifespan.

## J. HEART ATTACK

Heart disease is the number one killer for people of all genders in the US, impacting more than 60 million women.[39] While only one percent (1%) or respondents to the National LGBTQ+ Women's Community Survey said they had experienced a heart attack, a very high percent reported living with high cholesterol, a major factor in the development of heart disease (see below).

## K. HIGH CHOLESTEROL

Twenty-three percent (23%) of respondents reported having received a diagnosis of high cholesterol. This is nearly double that of women in the general US population (12.1%).[40]

This is a much higher rate than that reported in "Health and Socioeconomic Well-Being of LBQ Women in the US," which used the CDC's Behavioral Risk Factor Surveillance System data from 2017 through 2019 wherein the rate for LBQ women was found to be 12.5%.[41]

Given the relative social and economic privilege in the respondent community, this number represents a serious health challenge and screening priority.

### High Cholesterol

Survey Respondents: **23%**

Women in the US Population: **12%**

BRFSS (2017-2019), Straight Women: **31.2%**

BRFSS (2017-2019), All LBQ Women: **33.6%**

BRFSS (2017-2019), LBQ Cis Women: **33.1%**

BRFSS (2017-2019), LBQ Trans Women: **52.4%**

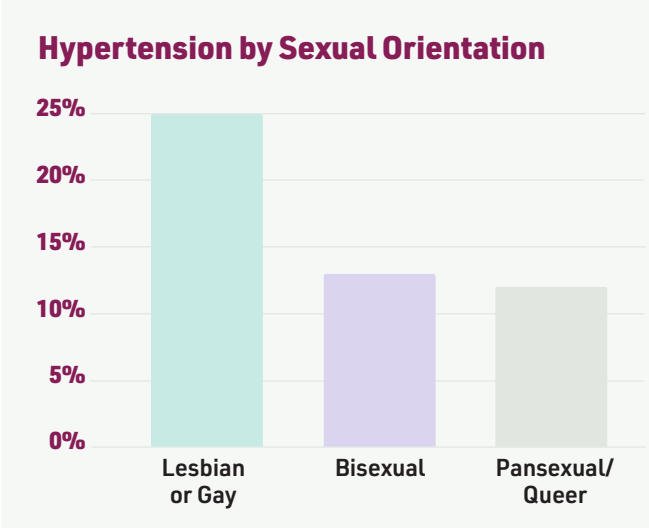
BRFSS (2017-2019), Straight Men: **34.6%**

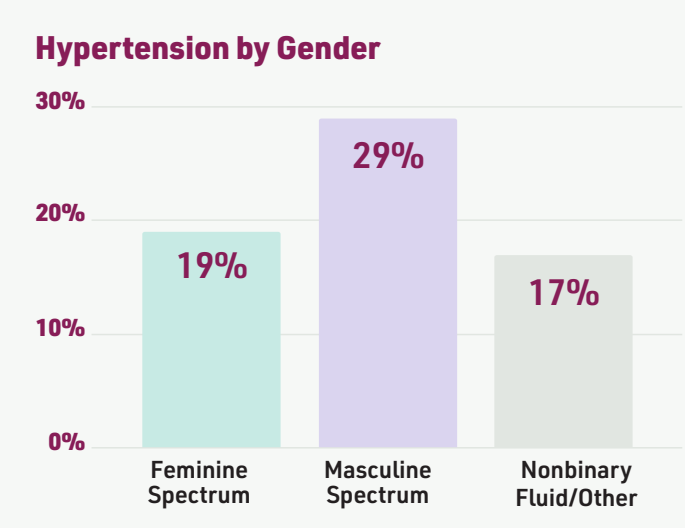
BRFSS (2017-2019), GBQ Men: **34.5%**

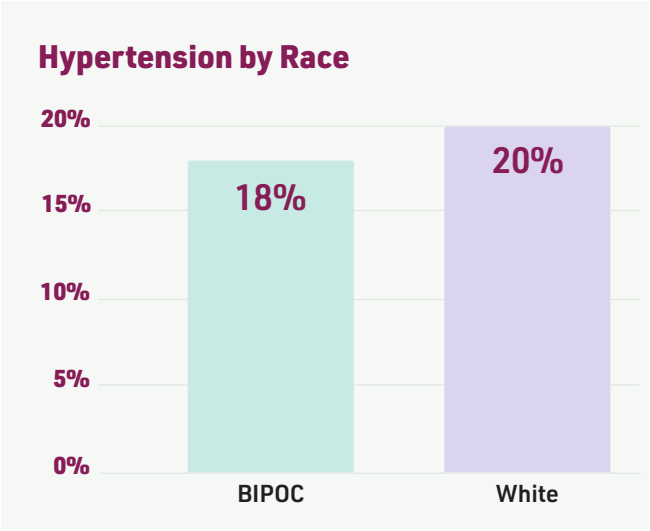
## L. HYPERTENSION

Twenty percent (20%) of respondents reported having received a diagnosis of hypertension or high blood pressure over the course of their lifetime. This is about half of the rate for women in the general US population (39.7%).[42]

Lesbians had the highest rate among the sexual orientation cohorts. In terms of gender, masculine-spectrum respondents were the highest. In terms of race, white respondents' rate was two percent higher than their BIPOC peers.




## M. IRREGULAR OR ABSENT MENSTRUAL CYCLE

Between 14 and 25% of women are impacted by menstrual irregularities.[43] Sixteen percent (16%) of respondents to the National LGBTQ+ Women's Community Survey reported having been diagnosed with an irregular or absent menstrual cycle.

## N. LUPUS

Lupus is an autoimmune disorder with unknown cause wherein the immune system attacks healthy tissue. Women are diagnosed with the disease nine times more often than men and may be impacted by inflammatory injuries to the skin, joint, heart, kidney, lung and brain.

Systematic Lupus impacts 128.7 out of every 100,000 women in the US (.0013%).[44] The rate of lupus reported in the LGBTQ+ Women's Community Survey, 41 out of 4962 responses to this question (.008%) is much higher by comparison.

## O. MULTIPLE SCLEROSIS

The rate of multiple sclerosis among US women is 450.1 per 100,000 (about .005%). The rate of MS reported in the LGBTQ+ Women's Community Survey is 30 out of 4962 (.006), which is slightly higher.[45]

## P. OSTEOPOROSIS

Osteoporosis is a chronic disease affecting one in three women over the age of fifty, compared to only one in five men, making it a critical women's health issue.[46] Seven percent (7%) of survey respondents reported receiving an osteoporosis diagnosis.

## Q. DIAGNOSES OF "OVERWEIGHT" AND "OBESITY"

Forty-two percent (42%) of survey respondents said a doctor had told them they were overweight or obese. This is less than US women overall at 69.4%.[47] Section 11, which presents a deeper dive into the diagnosis findings, contains a more in-depth look at these specific diagnoses and fat-phobia in the lives of survey respondents.

## R. PCOS

Polycystic ovary syndrome (PCOS) is a hormonal problem in which many small sacs of fluid develop along the outer edge of the ovary. It impacts about 10% of women overall and 7% of survey respondents.[48]

## S. PREDIABETES

Eleven percent (11%) of respondents reported having received a diagnosis of prediabetes. This is less than women in the general US population (19.4%).[49]

## T. SEXUALLY TRANSMITTED INFECTIONS

Across the board, LGBTQ+ women reported lower rates of sexually transmitted infections than women in the general population. The exception is gonorrhea, where a US national figure for women diagnosed with gonorrhea is unavailable but survey respondents reported a lower rate than a World Health Organization estimate for global women.

### Disparities in Sexually Transmitted Infections

| Sexually Transmitted Infection | LGBTQ+ Women's Community Survey Respondents | Women Overall |
|---|---|---|
| Bacterial vaginosis | 10% | 35% |
| Gonorrhea | 2% | .9%[50] |
| Herpes | 7% | 20%[51] |
| HPV | 7% | 80%[52] |
| Syphilis | 0.4% | N/A |
| Trichomoniasis | 2% | 8.1%[53] |

## U. STROKE

One percent (1%) of respondents reported having had a stroke. This is far less than women in the general US population (19%).[54]

# II. Disparities: Digging Deeper

## A. FAT-PHOBIA

When asked why they thought they were targeted for discrimination in the wide variety of domains covered in the survey, respondents ranked "my weight" fourth highest (18%), following sexism (38%), racism (34%) and anti-LGBTQ animus (26%).[55]

Conversely, they also reported loving their bodies, accessing pleasure with their partners, and enjoying the appreciation of the great variety of bodies affirmed in queer women's and non-binary spaces.[56]

The health statistics generated by the survey create a particularly salient lens through which to examine the gap between LGBTQ+ women embracing their bodies and the hostility they encountered about their bodies in a fatphobic world.

Survey respondents consistently reported diagnoses lower than the women's national rate for other health risks and conditions associated with being overweight. Eleven percent (11%) of the sample reported having received a pre-diabetes diagnosis compared to 19% of women in the general population.[57] Seven percent (7%) of respondents had a diabetes diagnosis compared to 10% of women in the general population.[58] The rate of hypertension diagnoses in the study sample (20%) is half that of women in the general population (40%).[59]

The only area in which respondents had a higher rate of diagnosis for a health condition possibly linked to weight is high cholesterol where the sample's 23% outstrips the general women's population rate of 12%.[60]

Since study respondents report "being targeted for my weight" as a significant driver of discrimination in their lives, this mix of findings – a high level of obesity diagnoses with a lower than average disease burden for conditions associated with "overweight" – suggest that medical personnel would do well to think critically about pathologizing weight when they serve LGBTQ+ women.

Doctors emphasizing weight loss as a primary health goal may alienate LGBTQ+ women, given the larger context of fatphobia in LGBTQ+ women's lives. Instead, medical personnel can be trained in the realities that queer women live in communities that affirm many different kinds of bodies and that their body type and size may be a source of pleasure and connection for them. Such pleasure and affirmation is in itself a health-generating phenomenon for LGBTQ+ women.

Doctors can then assess conditions that are typically considered related to weights, such as diabetes and hypertension, and proceed to address a patient's specific needs.

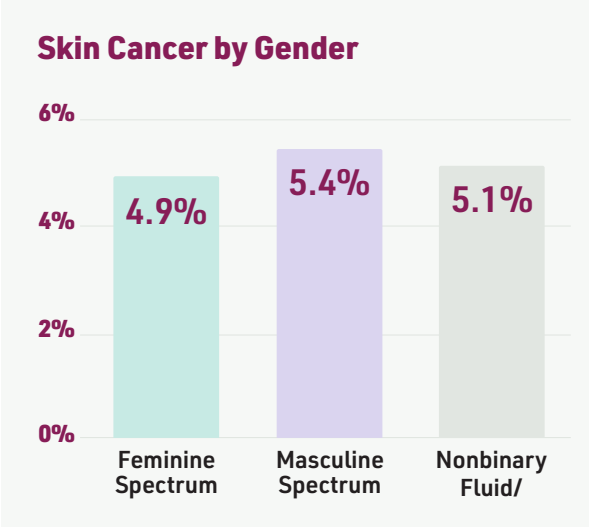
## B. CANCER

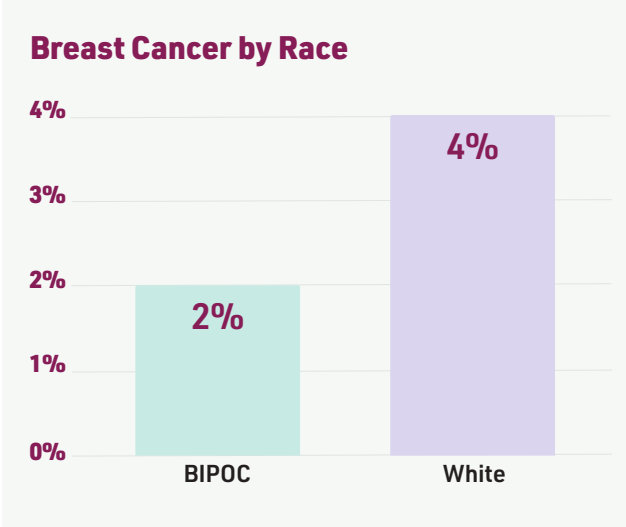
Crucial community-based research from the early 80s to the present has consistently recorded higher rates of gynecological and breast cancers among lesbian and bi women. Among respondents in the National LGBTQ+ Women's Community Survey, skin and cervical cancers register at a higher rate than the general population

Although the number of respondents from individual identity cohorts for several cancer diagnoses were not large enough for meaningful analysis, we can see a few things.

In terms of breast cancer, non-binary/fluid respondents were slightly more likely to report a diagnosis (4%) than their feminine-spectrum peers (3%). With skin cancer, masculine spectrum respondents had the highest rate.

BIPOC respondents were less likely than their white counterparts to report a breast cancer diagnoses.



# CHAPTER 3: ACCESS

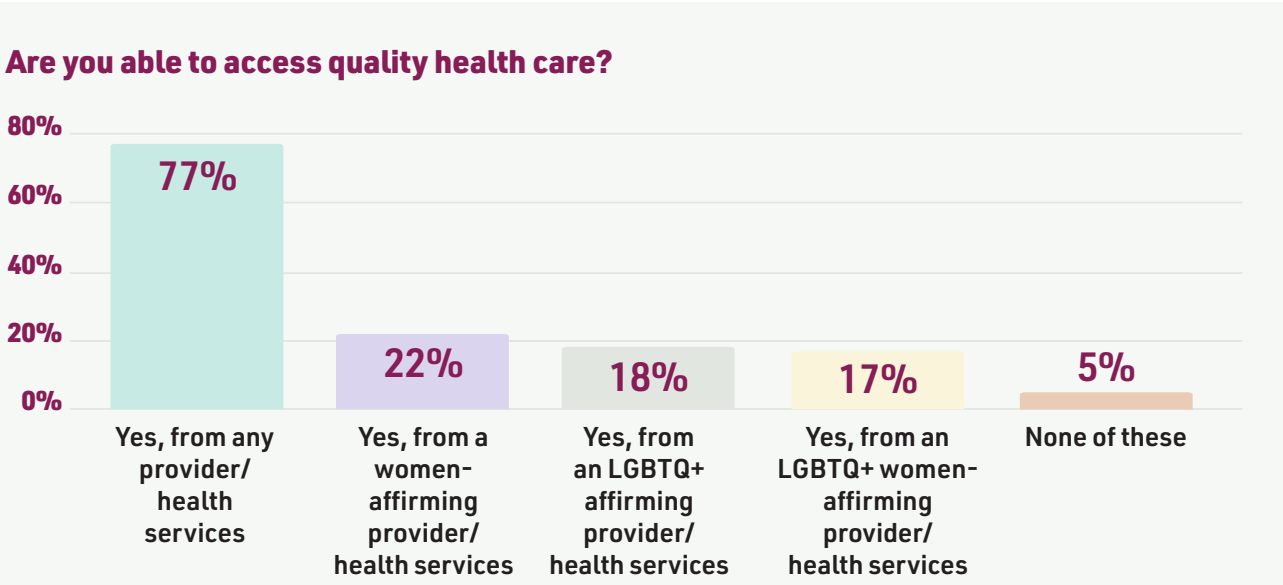
Respondents were asked to provide a general assessment of their healthcare access, and, overall, 77% of respondents said they were able to access quality care.

Respondents in the survey report that getting quality care meant engaging with specific kinds of healthcare settings, including explicitly women-affirming providers (22%), LGBTQ-affirming providers (18%), and specific LGBTQ women-affirming providers (17%).

Five percent (5%) of respondents said they do not have access to quality care.

As a proxy comparative, according to the US Census, in 2020, 91% of Americans had health insurance coverage.

## A. ARE YOU ABLE TO ACCESS QUALITY HEALTH CARE?



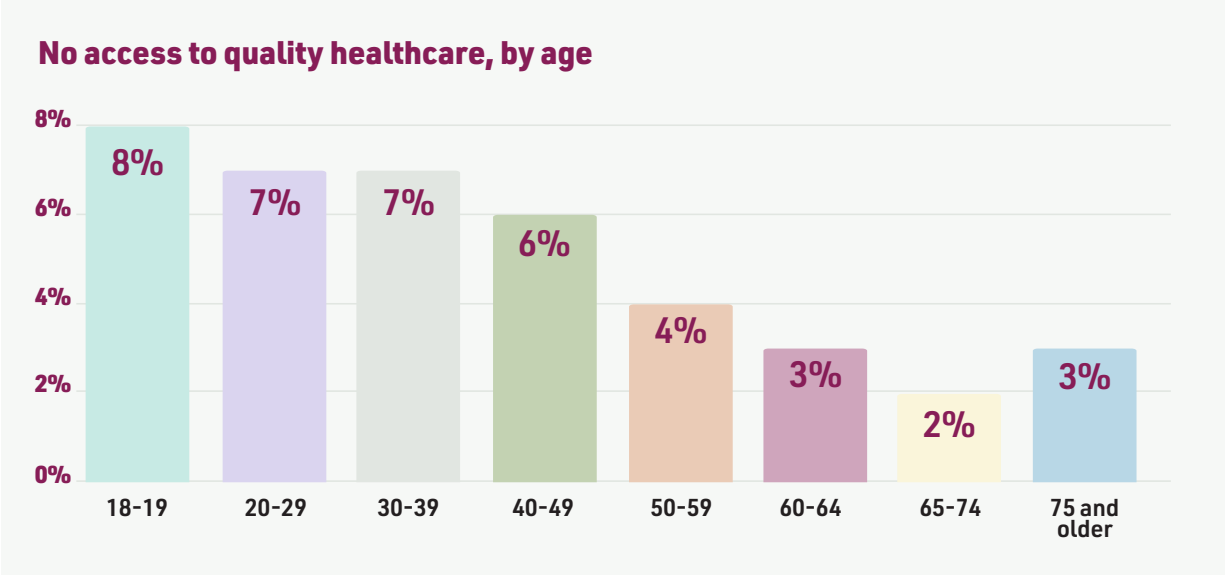

Since respondents could check any provider type that applies, we can see the level at which LGBTQ+ and women-specific and affirming care providers are serving many respondents.

In terms of sexual orientation, bisexual women (8%) and asexual women (8%) were among the most likely to have no access to quality healthcare. By comparison, only 3% of lesbians said the same.

**No access to quality healthcare, by sexual orientation**

Lesbian or Gay: **3%**
Bisexual: **8%**
Pansexual: **6%**
Queer: **7%**
Asexual: **8%**

Younger respondents were less likely to have access to quality care. Eight percent (8%) of eighteen and nineteen year olds said they had no access at all, making up the age group with the least access.



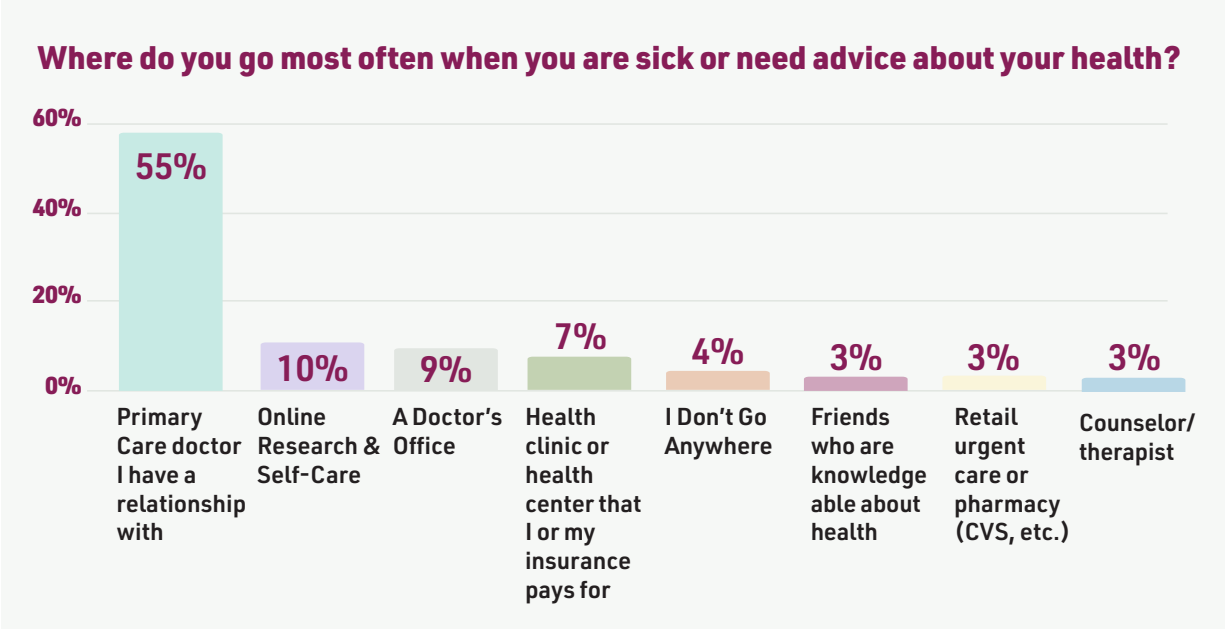

BIPOC respondents were twice as likely to say they lack access to quality healthcare (8%) than their white counterparts (4%).

**No access to quality healthcare, by race**

White: **4%** / BIPOC: **8%**

## B. WHERE DO YOU GO MOST OFTEN WHEN YOU ARE SICK OR NEED ADVICE ABOUT YOUR HEALTH?

Having a primary care physician with whom a patient has an established, trusting relationship often provides the best standard of care. Unfortunately, one out of three Americans does not have access to primary care doctors,[61] leaving them in a more precarious position when something happens with their health.



Fifty-five percent (55%) reported they go to a primary care physician with whom they have a relationship when they are sick or need health advice, which is much lower than the general population's access to and relationship with a primary care doctor, at 77%.

Going to a primary care physician you know and trust represents the gold standard of care, particularly for patients who may face discrimination in healthcare settings like those in this sample. Other common responses included a doctor's office (9%), clinics that take the respondents' insurance (7%), friends who are knowledgeable about health (3%), counselors and therapists (3%), and retail urgent care clinics or pharmacies (3%).

Care settings that less than 2% of respondents selected include Planned Parenthood and LGBTQ+ health center, acupuncturists, chiropractors, community healers, emergency rooms, free clinics, and homeopaths.

Only 4% of respondents said they don't go anywhere when they're sick, with an additional 10% who said they do their own research and care.

Looking at the experience of respondents through the lens of sexual orientation, those who identified as lesbians or gay were the most likely to have a primary care doctor (62%), the least likely to rely on online research (7%), and the least likely to say they go nowhere when they are sick or need advice about health. Bi, pan, queer, and asexual respondents all experienced reduced levels of access to the highest quality care settings.

**Respondents who have a primary care physician, who rely on their own research, and who have nowhere to go when they are sick or need health advice, by sexual orientation**

**Primary Care doctor I have a relationship with**

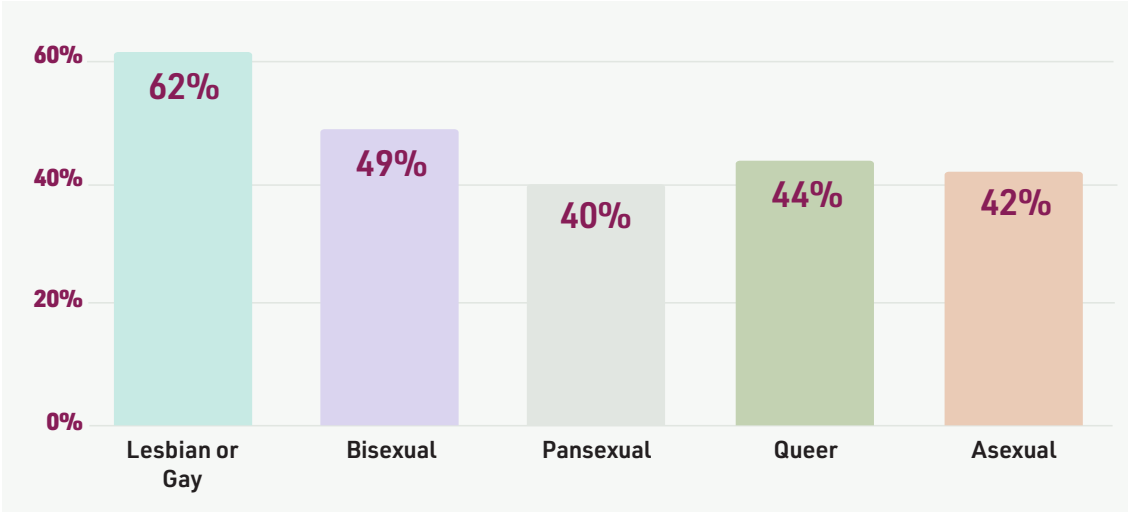
Lesbian or Gay: 62%
Bisexual: 49%
Pansexual: 40%
Queer: 44%
Asexual: 42%

**Online research and self-care**

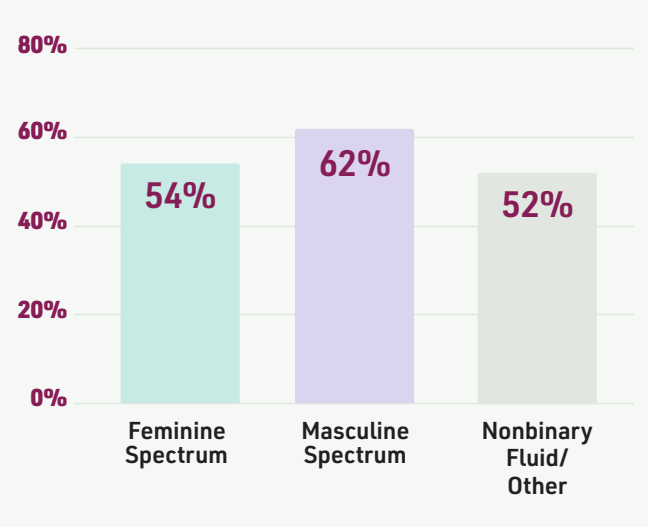
Lesbian or Gay: 7%
Bisexual: 11%
Pansexual: 15%
Queer: 13%
Asexual: 15%

**I don't go anywhere**

Lesbian or Gay: 3%
Bisexual: 6%
Pansexual: 5%
Queer: 4%
Asexual: 4%



In terms of gender, non-binary respondents were less likely to have a primary care physician (52%), compared to their femme spectrum (54%) and masculine spectrum (62%) peers. Non-binary respondents were also far more likely to rely on their own internet research (11%), perhaps as a way to avoid discrimination.




**Respondents who have a primary care physician, who rely on their own research, and who have nowhere to go when they are sick or need health advice, by gender**

**Primary Care doctor I have a relationship with**

Femme Spectrum: 54%
Masc Spectrum: 62%
Non-binary/Fluid/Other: 52%

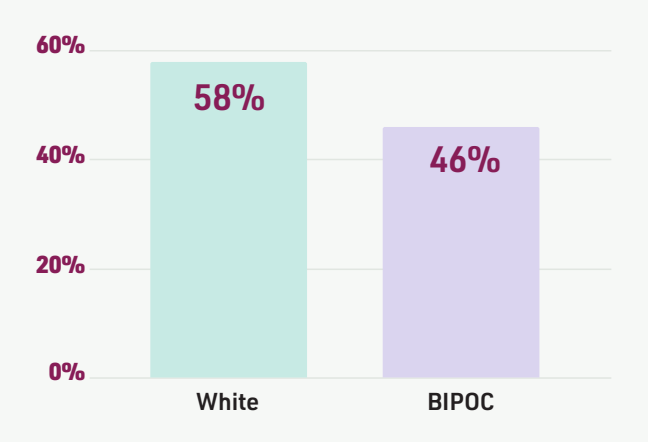
**Online research and self-care**

Femme Spectrum: 9%
Masc Spectrum: 7%
Non-binary/Fluid/Other: 11%

**I don't go anywhere**

Femme Spectrum: 3%
Masc Spectrum: 4%
Non-binary/Fluid/Other: 4%

Even with a relatively privileged sample of BIPOC respondents, the differences in access based on race are clear. BIPOC respondents were less likely to have access to a primary care physician (46%) compared to their white counterparts (58%). They were also more likely to rely on their own research (11%). Finally, respondents of color were more likely to do nothing when they're sick or need health advice at 5% compared to 3% for white respondents.




**Respondents who have a primary care physician, who rely on their own research, and who have nowhere to go when they are sick or need health advice, by race**

**Primary Care doctor I have a relationship with**

White: 58%
BIPOC: 46%

**Online research and self-care**

White: 9%
BIPOC: 11%

**I don't go anywhere**

White: 3%
BIPOC: 5%

## C. PREVENTATIVE SCREENINGS

Community knowledge has long held that LGBTQ+ women avoid doctors due to difficulty finding competent care providers, and that we especially avoid doctors around screenings that pertain to our sexuality, intimate spaces, and queer embodiments. Accordingly, grassroots health education of the past 30+ years has focused on supporting LGBTQ+ women and nonbinary people in seeking preventive screenings due to community-reported health disparities and risks.

An interesting area of inquiry within the study was to observe how our community education efforts might be impacting the pursuit of Pap smears and mammograms, especially. Would we find respondents seeking preventive pap smears and mammograms at similar rates to their heterosexual peers? Additionally, we assessed diabetes screenings, which are much less invasive and personal, but also addresses the crucial issue of prevention. We wondered if it would be easier for these same respondents to access preventive diabetes screenings?

### Pap Smears

A Pap smear, also called a Pap test or Papanicolaou test, is a screening for cervical cancer and other conditions. They are a crucial aspect of healthcare for everyone who has a cervix and should be routine. The American College of Obstetricians and Gynecologists recommends that, under most circumstances, women over the age of 21 should have a Pap smear at least every three years.[62]

**Pap Smears**

In the last five years: 73%
Five or more years ago: 13%
Never: 14%

The majority of survey respondents (nearly 87%) had had a Pap smear at some point in their lives. In general population surveys, 93% of women in the US report having had at least one pap smear. This differential (6%) seems significant given the higher incidence of cervical cancer found here.

Seventy-three (73%) of respondents had had a Pap smear in the past five years. An additional 13% had had one but it had been five years or more. Unfortunately, 14% had never had a Pap smear, making it less likely that cervical cancer could be detected early and treated.

This aligns with data made visible in the CDC's Behavioral Risk Factor Surveillance System, which shows LBQ women were less likely (69.4%) than their straight counterparts (79.7%) to have had a Pap test in the past five years.[63]

### Pap Smears by Sexual Orientation

| In the last five years | Five or more years ago | Never |
|---|---|---|
| Lesbian: 72% | Lesbian: 18% | Lesbian: 11% |
| Bisexual: 75% | Bisexual: 8% | Bisexual: 16% |
| Pansexual: 72% | Pansexual: 7% | Pansexual: 21% |
| Queer: 80% | Queer: 8% | Queer: 13% |

It's clear that here, as in many places in the study, people who trouble the binary – bisexual and pansexual respondents – are accessing this crucial preventive care less often than their lesbian or gay-identified peers, with fully 21% of pansexual respondents reporting never having had a Pap smear.

In general, the higher a respondent's asset base, the more likely they were to have accessed Pap smears.

### Pap Smears by Class

| In the last five years | Five or more years ago | Never |
|---|---|---|
| Living in Poverty: 44% | Living in Poverty: 25% | Living in Poverty: 17% |
| Working Class: 51% | Working Class: 23% | Working Class: 12% |
| Middle Class: 50% | Middle Class: 23% | Middle Class: 15% |
| Upper Class/Top 1%: 57% | Upper Class/Top 1%: 21% | Upper Class/Top 1%: 13% |

Among women in the US general population who have never had an abnormal Pap smear, 55% report obtaining an annual Pap test. We don't know the status of our respondents in terms of a history of ab/normal Pap smears, but if we assumed that all respondents had a clear history, only upper class women in the study are possibly reaching this level of health surveillance.

## Mammograms

A mammogram is a chest X-ray that can help detect breast cancer and other diseases. Recommendations on frequency vary, but around age forty-five, most women should start having routine mammograms. This recommendation pertains to transgender men as well as transgender women if they've accessed hormone therapy as part of transition-related care.[64]

**Mammograms**

In the last five years: 9%
Five or more years ago: 9%
Never: 42%

Again, the CDC's Behavioral Risk Factor Surveillance System provides another view of this same phenomenon. There, LBQ women aged forty and over were less likely (42.8%) to have ever had a mammogram than their heterosexual counterparts (70.8%).[65]

In terms of sexual orientation, lesbians were much more likely than their counterparts of other sexual orientations to have accessed mammograms.

### Mammograms by Sexual Orientation

| In the last five years | Five or more years ago | Never |
|---|---|---|
| Lesbian: 57% | Lesbian: 10% | Lesbian: 27% |
| Bisexual: 28% | Bisexual: 7% | Bisexual: 61% |
| Queer: 27% | Queer: 9% | Queer: 59% |
| Pansexual: 25% | Pansexual: 8% | Pansexual: 62% |

White respondents were more likely than their BIPOC counterparts to have accessed mammograms.

### Mammograms by Race

| In the last five years | Five or more years ago | Never |
|---|---|---|
| BIPOC: 38% | BIPOC: 8% | BIPOC: 48% |
| White: 46% | White: 9% | White: 39% |

## Diabetes Screening

**Diabetes Screening**

In the last five years: 48%
Five or more years ago: 7%
Never: 41%

Diabetes screenings refer to blood tests that measure a person's blood sugar levels to determine if they have diabetes, prediabetes, or gestational diabetes. In November of 2023, the CDC reported that 136 million people in the US suffer from diabetes or are living with prediabetes, increasing their risk for serious adjacent health problems and curtailed life expectancy. BIPOC people in general are at higher risk for diabetes than their white peers and people living in poverty are also at much higher risk for the disease than those living at 500% or more above the federal poverty line.

### Diabetes Screening by Sexual Orientation

| In the Past five years | Five or more years ago | Never |
|---|---|---|
| Lesbian: 58% | Lesbian: 7% | Lesbian: 32% |
| Bisexual: 36% | Bisexual: 7% | Bisexual: 53% |
| Pansexual/Queer: 36% | Pansexual/Queer: 7% | Pansexual/Queer: 53% |

An estimated 52% of the general population has accessed diabetes screening in the past three years.[66] Forty eight percent (48%) of respondents in the National LGBTQ+ Women's Community survey report securing diabetes screening in the past five years. We might assume then that the disparity between the screening rate for the general pop and our respondents is greater than the four years we can see with this difference in framing of the question.

When we look at screening in terms of sexual orientation, we can see that lesbians are likely accessing screening at a higher rate than the general population, but bi, pan and queer women are accessing screening at much lower levels, leaving them at risk.

### Diabetes Screening by Race

| In the last five years | Five or more years ago | Never |
|---|---|---|
| BIPOC: 43% | BIPOC: 7% | BIPOC: 46% |
| White: 50% | White: 7% | White: 40% |

As per the general population, white respondents in the study were more likely than their BIPOC counterparts to have accessed diabetes screening.

# CHAPTER 4: EXPERIENCES OF HEALTHCARE

Access to culturally competent healthcare is a fundamental human right that women of all sexual orientations and LGBTQ+ people of all genders are routinely denied.

Women who center other women in their sexual and romantic lives experience discrimination in a range of forms when accessing healthcare – from the simply unnecessary, such as imposed pregnancy testing, to outright denial of services, and even physical violence.

Because of this, many LGBTQ+ women report postponing and avoiding care, even when they need it, because they fear the reality with which they may be met at a doctor's office.

However, LGBTQ+ women have also been at the forefront of organizing around their own community health, establishing specialized services and networks of care when mainstream options prove inadequate.

The National LGBTQ+ Women's Community Survey asked a variety of questions about respondents' experiences accessing healthcare, including instances of respect and affirmation alongside extreme oppression.

### Have you ever experienced the following in a healthcare setting?

- My doctor or other health care provider knew I was LGBTQ+ and treated me with respect: **43%**
- My doctor or other health care provider properly gendered me: **31%**
- I postponed or did not try to access preventative, medical, and/or mental health care because I could not afford it: **30%**
- My doctor or other health care provider was well-trained in LGBTQ+ women's health issues, asked good questions and provided great care: **26%**
- I postponed or did not try to get the medical care I needed because of disrespect or discrimination from doctors or health care providers: **22%**
- I postponed or did not try to get the mental health care I needed because of disrespect or discrimination from doctors or health care providers: **17%**
- I was given unnecessary pregnancy tests: 16%
- I was given unnecessary and inappropriate birth control education and advice: **15%**
- My doctor or other health care provider asked me unnecessary or inappropriate questions about my LGBTQ+ identity that were not related to the reason for my visit: **9%**
- My doctor or other health care provider used sexist or anti-women language during my visit: **7%**
- My doctor or other health care provider gave me anti-LGBTQ+ "advice" during my visit: **5%**
- I was verbally harassed in a health care setting: **4%**
- I experienced unwanted sexual contact (such as, fondling, sexual assault or rape) in a health care setting: **4%**
- I experienced unnecessary or "rough" genital, breast or chest-related procedure in a health care setting that I believe was related to my LGBTQ+ identity or presentation: **4%**
- My doctor or other health care provider used harsh or abusive language with me: **3%**
- My doctor or other health care provider was sexually suggestive or predatory: **3%**
- Upon finding out I was an LGBTQ+, a doctor or other provider refused to treat me: **2%**
- Upon finding out I was an LGBTQ+, a doctor refused to answer my questions: **1%**
- I was not allowed to use the appropriate bathrooms or other facilities: **1%**
- I was physically attacked in a health care setting: **1%**
- Other: **7%**
- None of the above: **24%**

> "Within the past few years, my doctors' office updated their forms to include a field about sexuality. They also updated their website to say that they are LGBTQ welcoming/inclusive. I was happy about that."

Because LGBTQ women have unique health needs, the best care comes when we are free to be open and honest with our doctors and can get the most nuanced and appropriate advice. Unfortunately, only 43% of respondents said that their doctor or healthcare provider knew they were LGBTQ+ and treated them with respect. Thirty-one percent (31%) of respondents said that a doctor or other healthcare provider properly gendered them, and only 26% said their doctor or other health care provider was well-trained in LGBTQ+ women's health issues, asked good questions, and provided great care.

### Affirming treatment in healthcare settings, by sexual orientation

**My doctor or other health care provider knew I was LGBTQ+ and treated me with respect**

Lesbian: 44%
Bisexual: 34%
Pansexual: 37%
Queer: 51%
Asexual: 28%

**My doctor or other health care provider properly gendered me**

Lesbian: 28%
Bisexual: 30%
Pansexual: 38%
Queer: 39%
Asexual: 31%

**My doctor or other health care provider was well-trained in LGBTQ+ women's health issues, asked good questions and provided great care**

Lesbian: 25%
Bisexual: 21%
Pansexual: 29%
Queer: 32%
Asexual: 17%

### Affirming treatment in healthcare settings, by class

**My doctor or other health care provider knew I was LGBTQ+ and treated me with respect**

Poverty Class: 36%
Working Class: 42%
Middle Class: 44%
Upper Class/Top 1%: 29%

**My doctor or other health care provider properly gendered me**

Poverty Class: 26%
Working Class: 28%
Middle Class: 32%
Upper Class/Top 1%: 36%

**My doctor or other health care provider was well-trained in LGBTQ+ women's health issues, asked good questions and provided great care**

Poverty Class: 22%
Working Class: 25%
Middle Class: 26%
Upper Class/Top 1%: 36%

In terms of sexual orientation, bisexual (34%) and asexual (28%) respondents were much less likely to have come out to their doctor and been met with respect. In terms of socioeconomic status, wealthier respondents were more likely to have a healthcare professional they could come out to and be met with respect. Correspondingly, BIPOC respondents were less likely (37%) than their white counterparts (45%) to have said yes to this question.

Looking at these same questions by gender reveals that masculine spectrum (29%) and non-binary (28%) respondents were much less likely to have been appropriately gendered by healthcare providers, compared to those on the femme spectrum (34%).

### Affirming treatment in healthcare settings, by gender

**My doctor or other health care provider knew I was LGBTQ+ and treated me with respect**

Femme Spectrum: 43%
Masc Spectrum: 45%
Non-binary/Fluid/Other: 42%

**My doctor or other health care provider properly gendered me**

Femme Spectrum: 34%
Masc Spectrum: 29%
Non-binary/Fluid/Other: 28%

**My doctor or other health care provider was well-trained in LGBTQ+ women's health issues, asked good questions and provided great care**

Femme Spectrum: 26%
Masc Spectrum: 26%
Non-binary/Fluid/Other: 26%

### Affirming treatment in healthcare settings, by race

**My doctor or other health care provider knew I was LGBTQ+ and treated me with respect**

White: 45%
BIPOC: 37%

**My doctor or other health care provider properly gendered me**

White: 32%
BIPOC: 27%

**My doctor or other health care provider was well-trained in LGBTQ+ women's health issues, asked good questions and provided great care**

White: 27%
BIPOC: 23%

Finally, when it comes to race, BIPOC respondents experienced less affirming treatment by healthcare professionals across the board, compared to their white counterparts. As one respondent said: "With health, as with all of the questions, when you are a queer black woman, it's not always clear whether you're receiving bad treatment specifically because you're queer. In fact, often I feel I'm receiving bad treatment specifically because I'm black or specifically because I'm a black woman."

## UNNECESSARY TREATMENT

One of the indicators that a healthcare professional is not meeting their queer women patients where they are is the use of unnecessary or inappropriate care. Sixteen percent (16%) of respondents said they were given an unnecessary pregnancy test when at the doctor, and 15% said they were given unnecessary and inappropriate birth control education and advice. An additional 9% reported being asked unnecessary or inappropriate questions about their LGBTQ+ identity that were unrelated to the reason for their visit.

### Unnecessary Treatment by Medical Providers

Unnecessary Pregnancy Test: 16%

Unnecessary birth control advice: 15%

Unnecessary questions: 9%

### Unnecessary treatment, by sexual orientation

**Unnecessary Pregnancy Test**

Lesbian: 14%

Bisexual: 15%

Asexual: 14%

**Unnecessary birth control advice**

Lesbian: 13%

Bisexual: 15%

Asexual: 12%

**Unnecessary questions**

Lesbian: 7%

Bisexual: 7%

Asexual: 8%

## MEDICAL AVOIDANCE

A large number of respondents reported postponing or otherwise avoiding healthcare, including care that would have been preventative and also care that was an immediate need. The reasons included lack of financial access and past experiences of discrimination.

### Medical avoidance

I postponed or did not try to get preventative, medical, and/or mental health care because I could not afford it: 30%

I postponed or did not try to get the medical care I needed because of disrespect or discrimination from doctors or health care providers: 22%

I postponed or did not try to get the mental health care I needed because of disrespect or discrimination from doctors or health care providers: 17%

Bisexual, pansexual, and asexual respondents were consistently more likely to have avoided care than their lesbian counterparts. In terms of gender, non-binary respondents had highly elevated levels of medical avoidance.

### Medical avoidance, by sexual orientation

**I postponed or did not try to access preventative, medical, and/or mental health care because I could not afford it**

Lesbian: 23%
Bisexual: 35%
Pansexual: 42%
Queer: 43%
Asexual: 29%

**I postponed or did not try to get the medical care I needed because of disrespect or discrimination from doctors or health care providers**

Lesbian: 17%
Bisexual: 24%
Pansexual: 27%
Queer: 32%
Asexual: 26%

**I postponed or did not try to get the mental health care I needed because of disrespect or discrimination from doctors or health care providers**

Lesbian: 12%
Bisexual: 19%
Pansexual: 23%
Queer: 27%
Asexual: 20%

### Medical avoidance, by gender

**I postponed or did not try to get preventative, medical, and/or mental health care because I could not afford it**

Feminine Spectrum: 28%
Masculine Spectrum: 25%
Non-binary/Fluid: 34%

**I postponed or did not try to get the medical care I needed because of disrespect or discrimination from doctors or health care providers**

Feminine Spectrum: 21%
Masculine Spectrum: 20%
Non-binary/Fluid: 24%

**I postponed or did not try to get the mental health care I needed because of disrespect or discrimination from doctors or health care providers**

Feminine Spectrum: 16%
Masculine Spectrum: 13%
Non-binary/Fluid: 20%

The impacts of these postponements are obvious when we look at the health outcomes and community disparities of LGBTQ+ women's health.

## MEDICAL REFUSAL

### Medical refusal

Upon finding out I was LGBTQ+, a doctor or other provider refused to treat me: 2%

Upon finding out I was LGBTQ+, a doctor refused to answer my questions: 1%

### Medical refusal, by sexual orientation

**Upon finding out I was LGBTQ+, a doctor or other provider refused to treat me**

Lesbian: 2%
Bisexual: 1%
Asexual: 2%

**Upon finding out I was LGBTQ+, a doctor refused to answer my questions**

Lesbian: 1%
Bisexual: 1%
Asexual: 1%

### Medical refusal, by gender

| Upon finding out I was LGBTQ+, a doctor or other provider refused to treat me | Upon finding out I was LGBTQ+, a doctor refused to answer my questions |
|---|---|
| Feminine Spectrum: 2% | Feminine Spectrum: 1% |
| Masculine Spectrum: 3% | Masculine Spectrum: 2% |
| Non-binary/Fluid: 2% | Non-binary/Fluid: 1% |

> "Was sexually assaulted by my childhood doctor due to my gender and sexual expression."

### Medical refusal, by class

| Upon finding out I was LGBTQ+, a doctor or other provider refused to treat me | Upon finding out I was LGBTQ+, a doctor refused to answer my questions |
|---|---|
| Poverty Class: 3% | Poverty Class: 1% |
| Working Class: 2% | Working Class: 2% |
| Middle Class: 2% | Middle Class: 1% |
| Upper Class/Top 1%: 1% | Upper Class/Top 1%: 1% |

In terms of class, unsurprisingly, wealthier people were less likely to have been refused service or treatment.

### Medical refusal, by race

| Upon finding out I was LGBTQ+, a doctor or other provider refused to treat me | Upon finding out I was LGBTQ+, a doctor refused to answer my questions |
|---|---|
| White: 2% | White: 1% |
| BIPOC: 2% | BIPOC: 2% |

## HARASSMENT & VIOLENCE

Doctors' offices, hospitals, and other sources of care were often unsafe spaces for study participants. Four percent (4%) of respondents experienced unnecessary or "rough" genital, breast or chest-related procedures they believed were related to being LGBTQ+ identity. Three percent (3%) reported enduring sexual harassment by a medical professional, and fully one out of every one hundred respondents (1%) reported that they were physically assaulted in a healthcare setting.

This is contextualized by the epidemic of sexual harassment perpetrated against women of all sexual orientations and gender identities in medical settings. A 2021 study done by the National Institute of Health revealed almost 5% of women and 2% of men have experienced sexual misconduct by health care professionals.[67]

### Harassment & Violence in Healthcare Settings

My doctor or other health care provider was sexually suggestive or predatory: **3%**

I experienced unnecessary or "rough" genital, breast or chest-related procedure in a health care setting that I believe was related to my LGBTQ+ identity or presentation: **4%**

I was physically attacked in a health care setting: **1%**

### The Experiences of Trans Respondents

#### Have you ever experienced the following in a healthcare setting?

My doctor or other health care provider knew I was LGBTQ+ and treated me with respect: 52%

My doctor or other health care provider properly gendered me: 47%

I postponed or did not try to get preventative, medical, and/or mental health care because I could not afford it: 44%

My doctor or other health care provider was well-trained in LGBTQ+ women's health issues, asked good questions and provided great care: 37%

I postponed or did not try to get the medical care I needed because of disrespect or discrimination from doctors or health care providers: 39%

I postponed or did not try to get the mental health care I needed because of disrespect or discrimination from doctors or health care providers: 36%

I was given unnecessary pregnancy tests: 20%

I was given unnecessary and inappropriate birth control education and advice: 17%

My doctor or other health care provider asked me unnecessary or inappropriate questions about my LGBTQ+ identity that were not related to the reason for my visit: 22%

My doctor or other health care provider used sexist or anti-women language during my visit: 9%

My doctor or other health care provider gave me anti- LGBTQ+ "advice" during my visit:

I was verbally harassed in a health care setting: 12%

I experienced unwanted sexual contact (such as, fondling, sexual assault or rape) in a health care setting: 5%

I experienced unnecessary or "rough" genital, breast or chest-related procedure in a health care setting that I believe was related to my LGBTQ+ identity or presentation: 7%

My doctor or other health care provider used harsh or abusive language with me: 6%

My doctor or other health care provider was sexually suggestive or predatory: 3%

Upon finding out I was LGBTQ+, a doctor or other provider refused to treat me: 6%

Upon finding out I was LGBTQ+, a doctor refused to answer my questions: 3%

I was not allowed to use the appropriate bathrooms or other facilities: 5%

I was physically attacked in a health care setting: 2%

Other: 11%

None of the above: 14%

# CHAPTER 5: MENTAL HEALTH

> "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."

LGBTQ+ women in the study report significant mental health conditions. The survey asked questions pertaining to mental health diagnoses, needing and seeking care for PTSD and addictions, and suicide attempts.

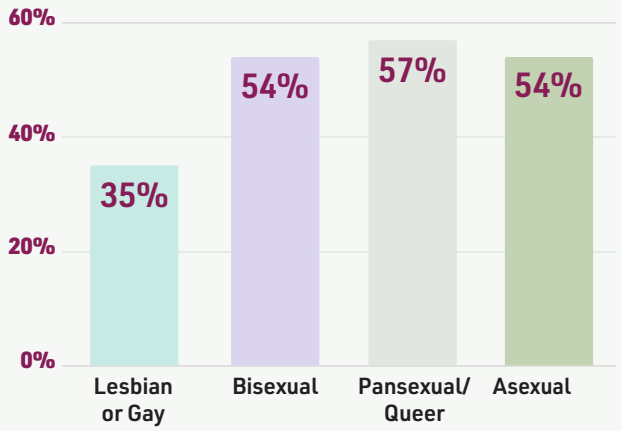
In the design of the survey instrument, content warnings appeared before questions about suicide and self-harm, encouraging respondents to access support if the material brought up traumatic memories. The same is true of this report. **The Trevor Project**[68] specializes in suicide prevention for some LGBTQ+ people, but, as the results of this survey show, there are all kinds of ways our community seeks out support, including from queer friends. Please take care while reading this section and reach out for support if you need it.

## A. ANXIETY

Forty-four (44%) percent of respondents reported having received a diagnosis for an anxiety disorder. That's nearly double the rate of women in the general population (23.4%).[69]

Pansexual/queer respondents had the highest rate among the sexual orientation cohorts. In terms of gender, feminine-spectrum respondents were the highest. In terms of race, white respondents' rate was four percent higher than their BIPOC peers.

### Any Type of Anxiety Disorder




### Anxiety by Sexual Orientation

Lesbian or Gay: 35%

Bisexual: 54%

Pansexual/Queer: 57%

Asexual: 54%

### Anxiety by Gender

Feminine Spectrum: 46%

Masculine Spectrum: 34%

Nonbinary/Fluid/Other: 45%

### Anxiety by Race

BIPOC: 41%

White: 45%

## B. DEPRESSION

Fifty-one (51%) percent of respondents reported having received a diagnosis of depression. That's more than double the rate of women in the general population (24%).[70]

In terms of gender, nonbinary/fluid respondents were the highest. In terms of race, white respondents' rate was six percent higher than their BIPOC peers.

**Depression by Gender**
Feminine Spectrum: 49%
Masculine Spectrum: 45%
Nonbinary/Fluid/Other: 55%

**Depression by Race**
BIPOC: 46%
White: 52%

## C. PERSONALITY DISORDERS & PSYCHOSIS

Four percent (4%) of respondents reported having been diagnosed with a personality disorder or any kind of psychosis.

## D. TRAUMA

The World Health Organization estimates that 3.9% of the world population has experienced Post-Traumatic Stress Disorder. The Department of Veteran Affairs' Center for PTSD reports that 8% of women in the US will experience PTSD at some point in their lives.

Appallingly, more than half of respondents in the National LGBTQ+ Women's Community Survey who answered the question on trauma treatment identified as people who had needed and sought this kind of care at some point in their lives (61%). Identity cohorts within the study more likely to have needed trauma treatment included non-binary respondents (65%) and those living on lower incomes (77%).

**Needed and Sought Trauma Care, by Class**
Living in Poverty: 77%
Working Class: 68%
Middle Class: 57%
Upper Class: 53%

**Needed and Sought Trauma Care, by Gender**
Feminine Spectrum: 60%
Masculine Spectrum: 56%
Non-binary: 65%

When we consider the shortened lifespan findings reported in the Harvard Nurses Study, surviving trauma needs to move to the highest level of consideration in terms of the "toxic social exposure" that is killing LGBTQ+ women who partner with women. So too, must normalizing treatment for trauma and making it accessible move to the top of the list of health priorities.

> "The mental health system needs so much more funding and skilled facilities. I have actually been fortunate in some ways, but have also been put in dangerous situations."

In terms of age, the cohort least likely to have needed and accessed trauma treatment were those in their 40s. Younger respondents were less likely and older respondents were even less likely to have responded in the affirmative, though differences in access to such treatment over the course of elders' lives may play a role in this result.

### Needed and Sought Trauma Care, by Age

**18-19**: 59%
**20-29**: 67%
**30-39**: 68%
**40-49**: 69%
**50-59**: 57%
**60-64**: 55%
**65-74**: 49%
**Over 75**: 44%

## E. ADDICTION

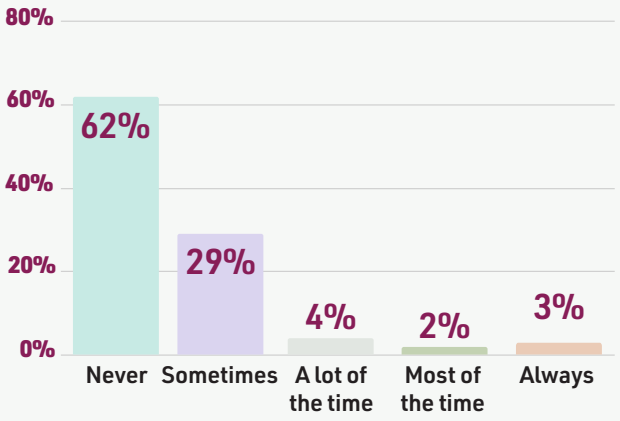
When we asked how often respondents have thought they had a problem with drugs or alcohol, the majority (62%) said never. But nearly a third (29%) said they had sometimes thought that, with another 4% saying "a lot of the time," 2% "most of the time," and 3% "always."

Asexual and lesbian respondents were much less likely than bisexual and pan/queer respondents to report having a problem with drugs and alcohol.

### Never thought they had a problem with drugs or alcohol

Lesbian: 64%
Bisexual: 59%
Pansexual/Queer: 54%
Asexual: 86%

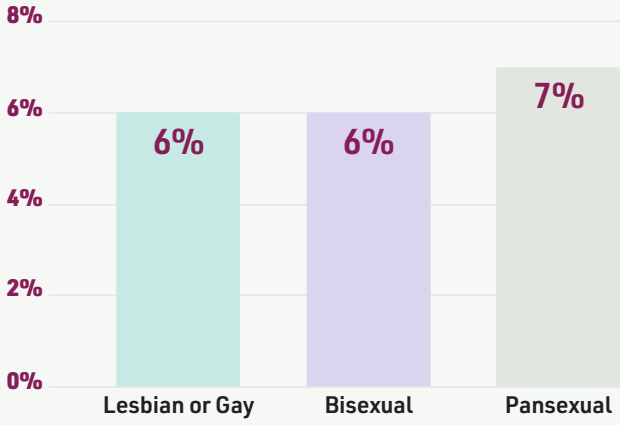
### How often have you thought you had a problem with drugs or alcohol




Another way we asked about addication was to inquire whether respondents had ever been told by a medical provider that they had a problem with alcohol or substance abuse. Six percent (6%) said they had, compared to 6.4% of women in the general US population.

Pansexual/queer women were the most likely of the sexual orientation cohorts to have been diagnosed with a substance problem. In terms of gender, masculine spectrum respondents had the highest rate. In terms of race, BIPOC respondents' rate was one percent higher than their white peers.

### Substance Abuse Diagnosis by Sexual Orientation



**Substance Abuse Diagnosis by Gender**

Feminine Spectrum: 5%

Masculine Spectrum: 9%

Nonbinary/Fluid/Other: 7%

**Substance Abuse Diagnosis by Race**

BIPOC: 7%

White: 6%

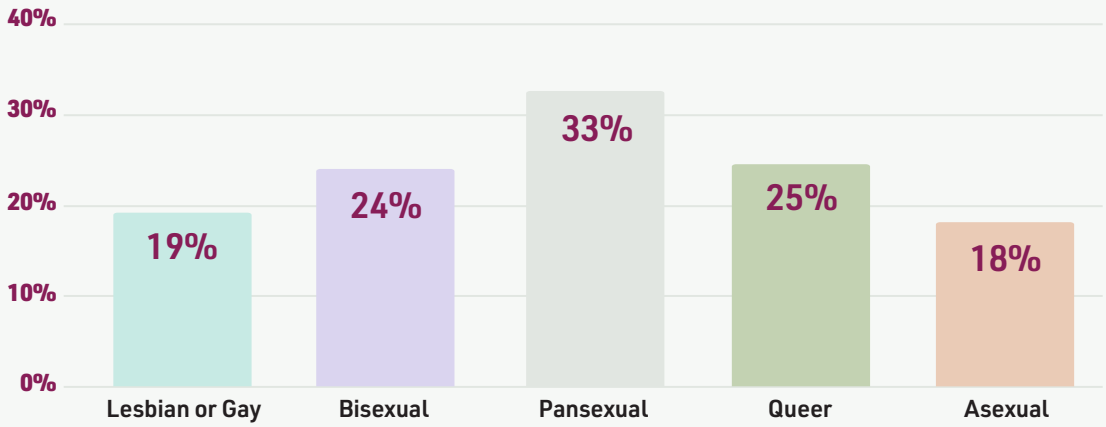
Additionally, we asked if respondents had partnered with anyone they believed had a substance abuse problem. Twenty-eight percent (28%) said they had dated one person with a problem, and another 20% said they had dated more than one person who they believed had a problem. Fifty-two percent (52%) said no.

## F. SUICIDE

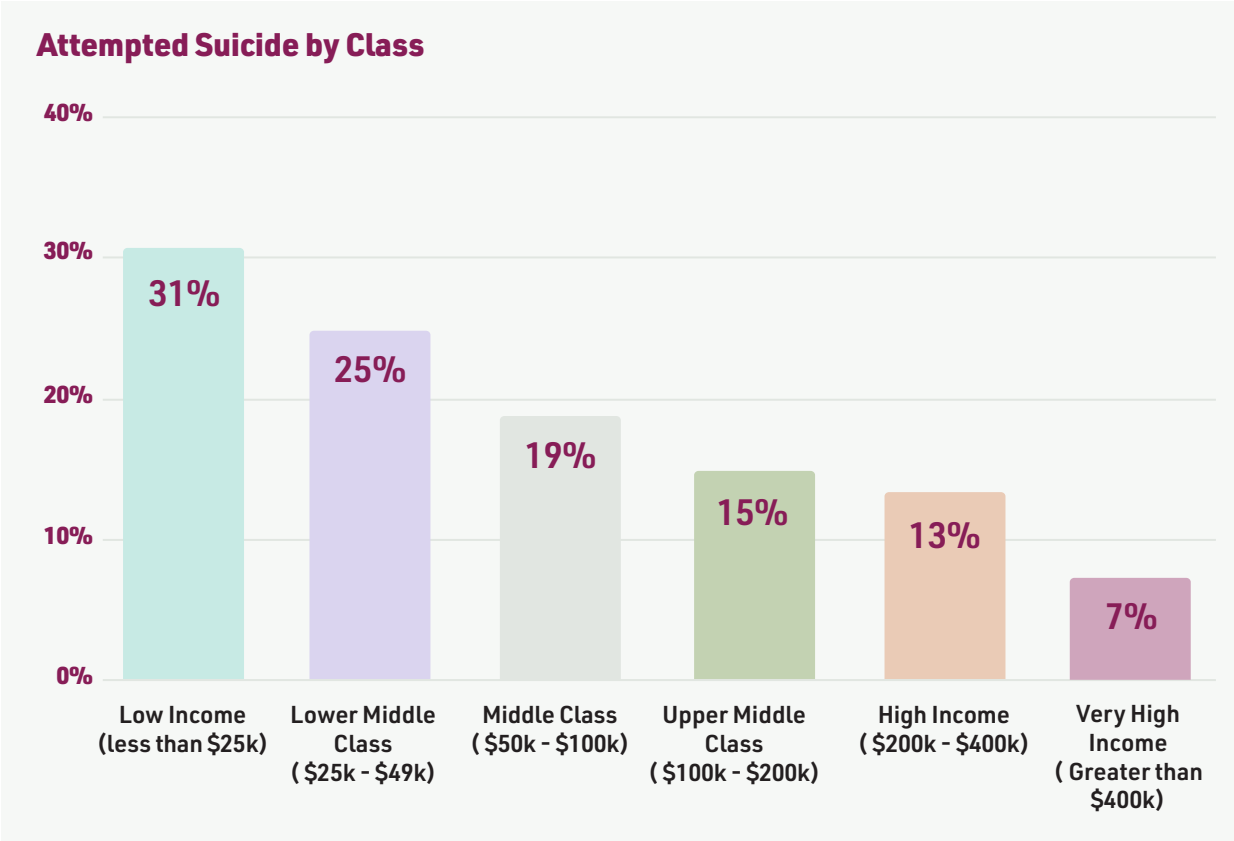
Twenty-two percent (22%) of respondents said they have attempted suicide at some point in their lifetime.

Bisexual (24%), pansexual (33%), and queer (25%) respondents were more likely than their lesbian (19%) counterparts to have attempted suicide.

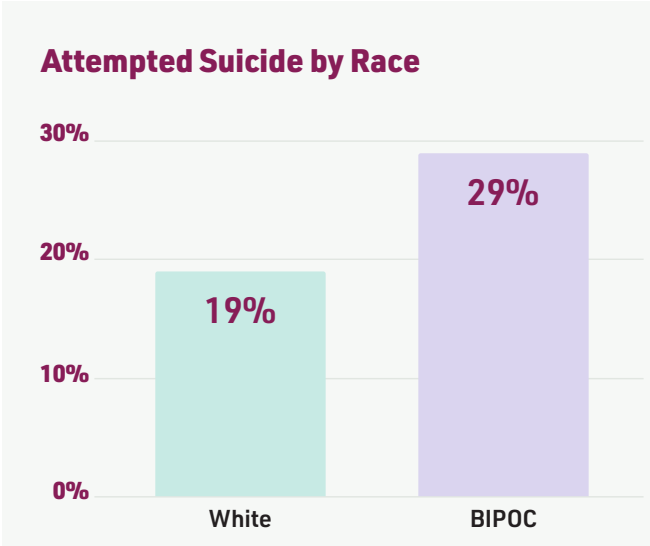
**Attempted Suicide by Sexual Orientation**



Responses about suicide attempts were also very different depending on resource base, with higher income respondents being much less likely to have made an attempt (7.3%) than lower income respondents (30.7%).

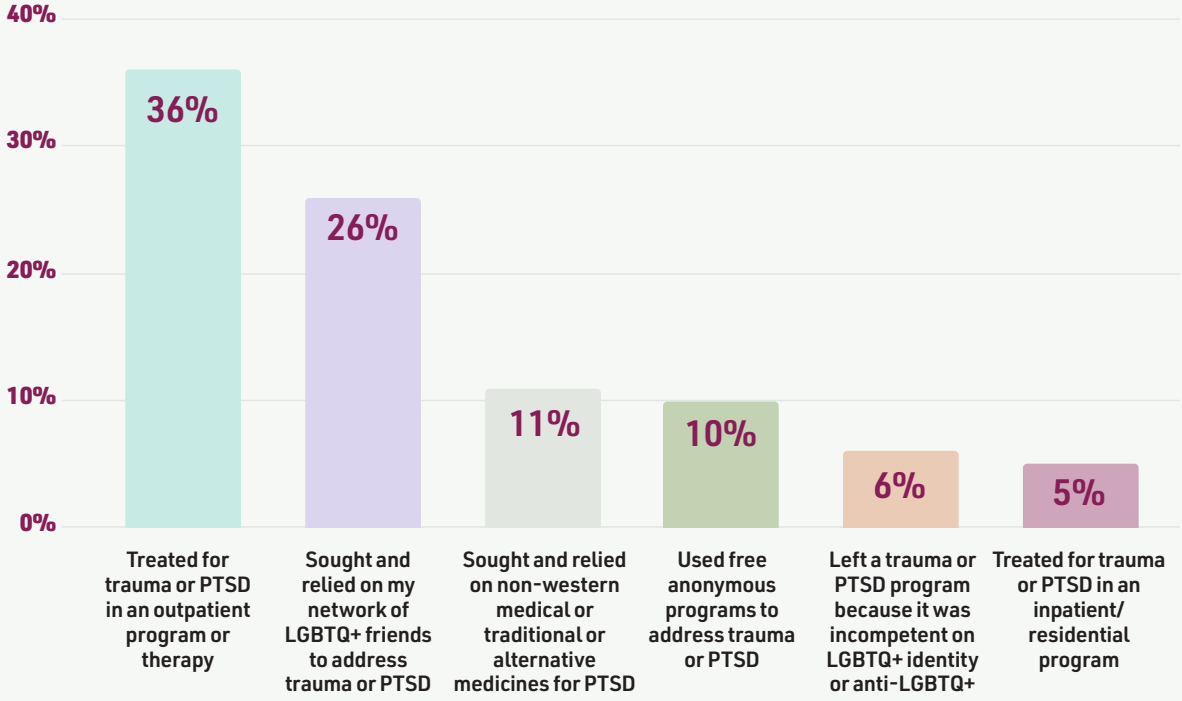


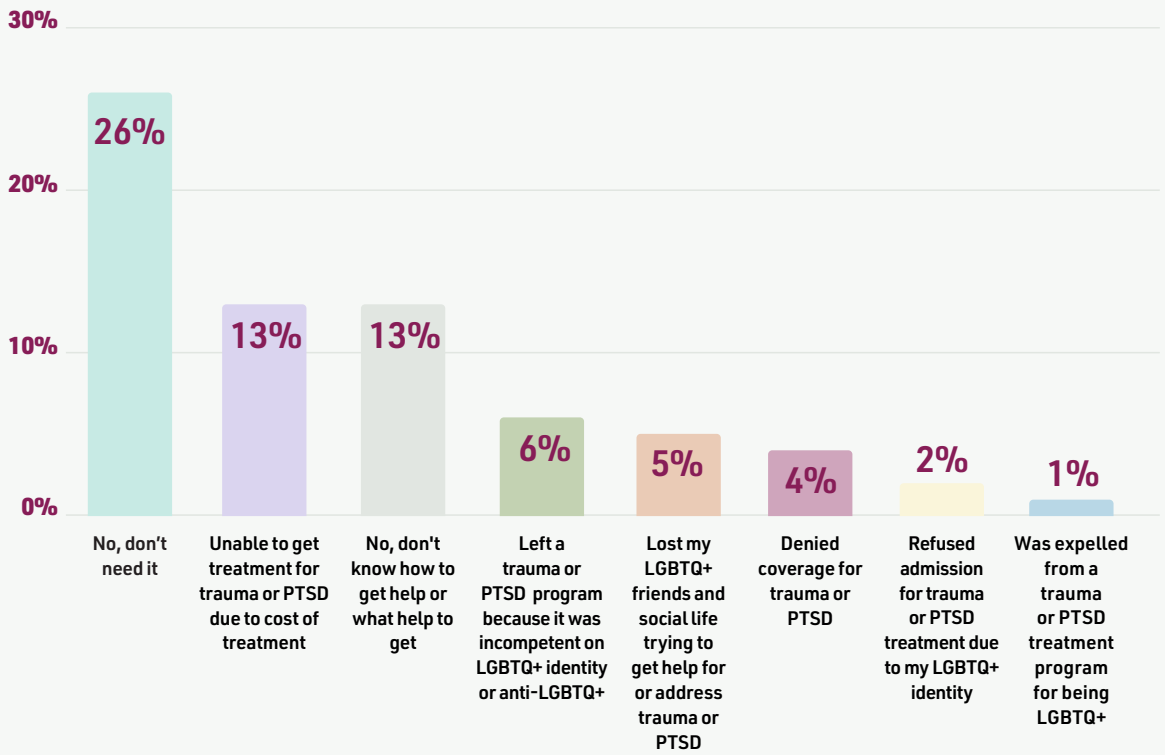

BIPOC respondents were also much more likely to have attempted suicide (29%) compared to white respondents (19%).



## G. THE MENTAL HEALTH OF TRANS RESPONDENTS

### Needed or Sought Treatment for Trauma or Post-Tramumatic Stress Disorder (PTSD)



In terms of addiction, many trans respondents reported thinking they had a problem with drugs and alcohol. Twelve percent (12%) said they think they have a problem a lot of the time, most of the time, or always. This is slightly higher than the 9% of respondents overall.

### How often have you thought you had a problem with drugs or alcohol for Trans Respondents

| Never | Sometimes | A lot of the time | Most of the time | Always |
|---|---|---|---|---|
| Trans Respondents: 55% | Trans Respondents: 32% | Trans Respondents: 7% | Trans Respondents: 3% | Trans Respondents: 2% |
| All Respondents: 62% | All Respondents: 29% | All Respondents: 4% | All Respondents: 2% | All Respondents: 3% |

Thirty-seven percent (37%) of trans respondents reported having attempted suicide at some point in their lives. This was much higher than the reported 22% among respondents overall. This 37% figure is roughly eight times the suicide rate for the general US population (4.6). It aligns with the rate trans Americans reported in the *2015 US Transgender Survey* (40%).[71]

### Suicide Attempts over the Lifespan

Trans Respondents to the National LGBTQ+ Women's Community Survey: 37%

All Respondents to the National LGBTQ+ Women's Community Survey: 22%

Overall US population: 4.6%

All Respondents to the 2015 US Transgender Study: 40%

## H. HOUSING.

Housing is health care. When analyzing the biggest threats to LGBTQ+ women's health and vitality in the survey, a few standouts include intimate partner violence (IPV) and disability, specifically around mental health disabilities including depression, anxiety and trauma.

If you line up these significant health threats with the core housing findings in the study, which showed nearly 50% of the respondents owning their housing while only 19.5% were solo homeowners and 30.5% jointly owning. By contrast, home ownership in the US general population is 65.7%. Despite the respondent community having race, class and educational privilege relative to the general population, study participants' homeownership is nearly 16% lower than their peers.

Moreover, when asked about challenges to their housing security, 16% of respondents noted that "a breakup led to a difficult housing change or instability."

Housing affordability, access to mortgages and the option for solo ownership are all key health issues for LGBTQ+ women facing high rates of IPV and disability.

# CHAPTER 6: CONCLUSION & RECOMMENDATIONS

The respondent community in the National LGBTQ+ Women's Community Survey is predominantly white, femme, lesbian, and possessed of higher educational attainment and incomes than the general population in the US. Despite these identities and privileges, many of which historically align with better health care access and health outcomes, findings in the survey show that study participants are nonetheless bearing up under tremendous health challenges and appalling disparities.

Additionally, BIPOC, bi and pansexual, and genderfluid respondents in the study, as well as those living on lower incomes – report poorer health access, outcomes and treatment in medical settings than their white, more affluent, and lesbian or gay-identified counterparts. Trans respondents also consistently fared worse on nearly every health measure than study participants who were not trans-identified.

**Core health concerns revealed in the data include**

- The overwhelming trauma burden in this respondent community (66%)
- Extremely high rates of disability (50%)
- Double the rate of depression (51%) and anxiety (44%) relative to the general population
- Devastating level of exposure to intimate partner violence (47%)
- Low access to Primary Care Providers (55%) compared to the general population (77%)
- Extremely high rates of attempted suicide (22%), four times that of the general population
- High rates of addiction and barriers to treatment
- Higher rates of arthritis, asthma, cervical cancer, high cholesterol, lupus, and skin cancer than women in the general population
- Barriers to primary care
- Barriers to care when sick or in need

For one of the final questions of the survey, we asked respondents to write in their top four policy priorities. Overwhelmingly, "Universal Access to Healthcare" topped the list. Some termed this "Medicare for All," others wrote "Free, Universal Healthcare," and still others said "Single Payer." Survey architects decided on a write in for this category so as not to prompt or bias respondents with a pre-arranged list.

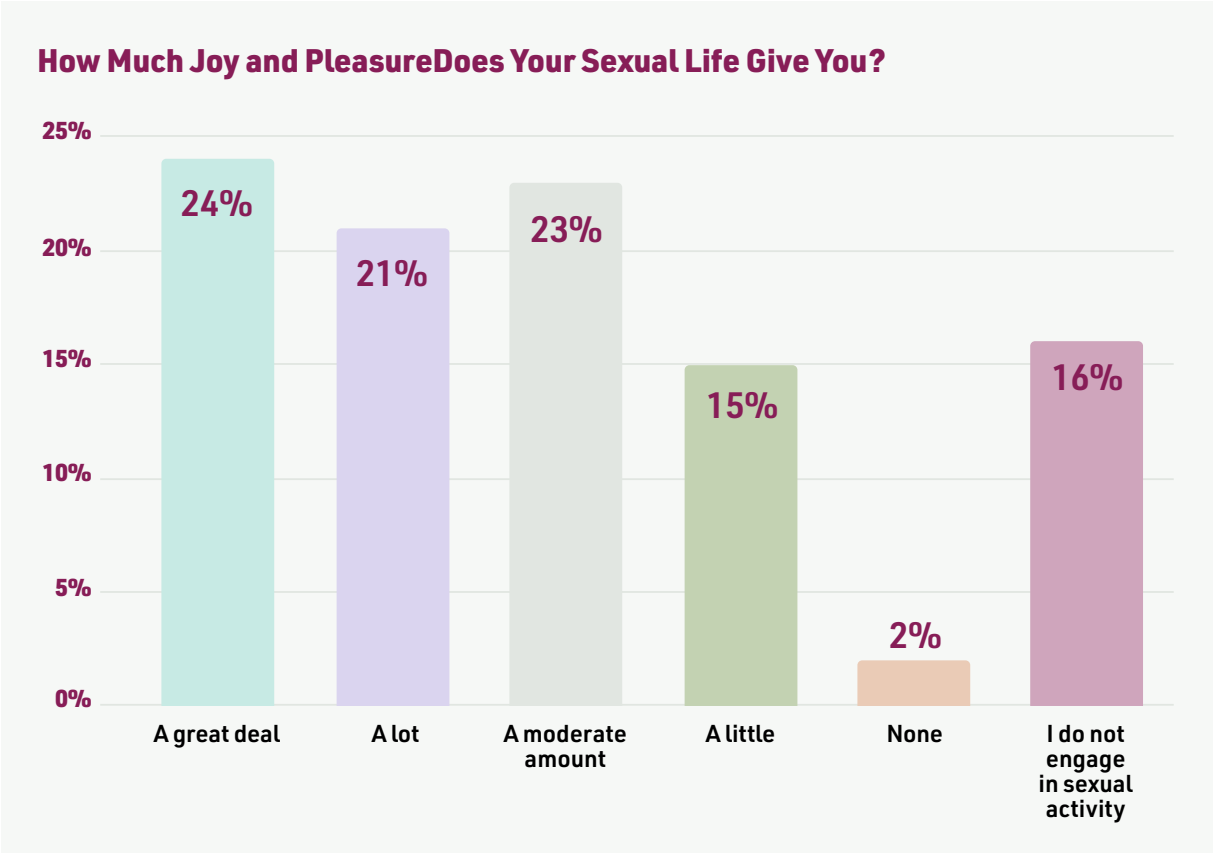
When looking at the health conditions LGBTQ+ face, it's easy to see why free, universal healthcare tops their list of priorities. It's notable that even with a white-majority sample living on relatively high incomes, concern about access to health care for their families, their LGBTQ+ communities, and broader society is paramount.

For, while respondents reported a broad range of exposures to discrimination and violence across all of the major domains of the study (education, housing, employment, family and religious life, policing and incarceration, etc.), they also reported on their sources of joy and pleasure with resounding force.

The study's final question asked respondents to write in their three favorite things about being an LGBTQ+ woman. The graphic below lifts just a smattering of viewpoints from this unique reporting, the direct speech of our respondents:

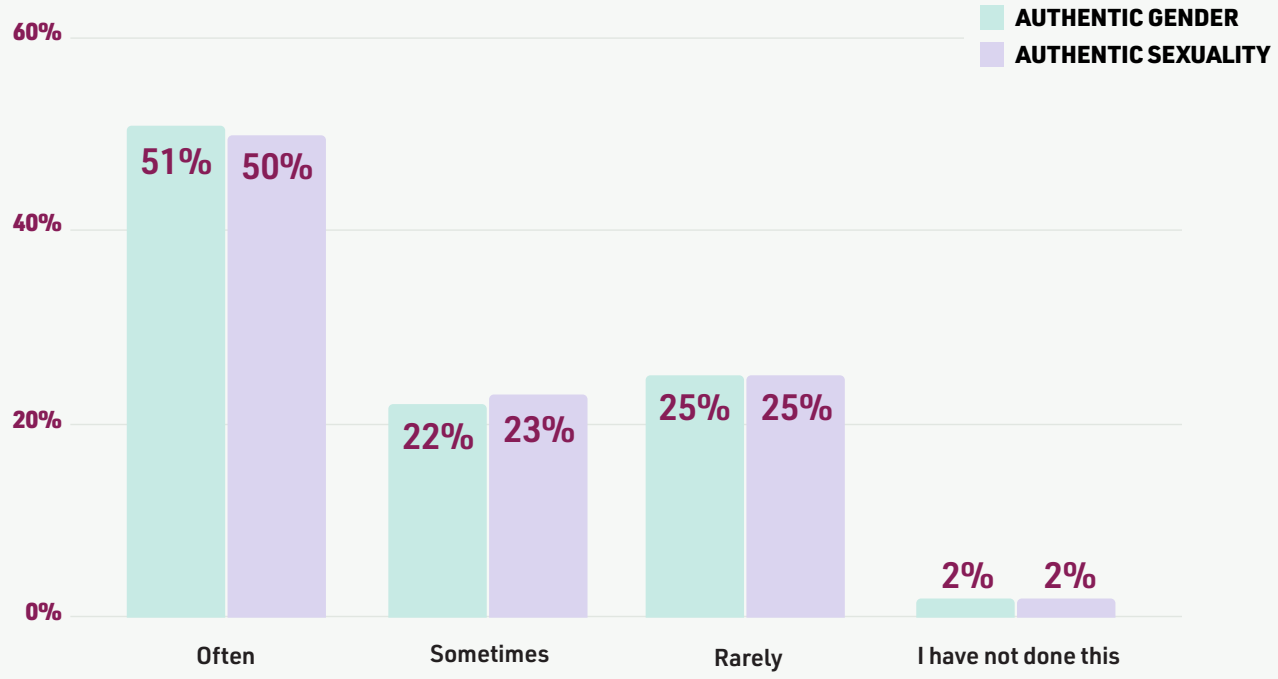

In effect, this language offers critical resistance to the four drivers of discrimination and abuse captured in so many of the different study domains, from employment to housing to health care. Resistance to sexism, racism, anti-queer biases, and fat-phobias ring through this language, which alternately illuminates connection, embodied joy, lust, and a kind of ungovernable, anarchic insistence on being themselves.

Moreover, additional data on sex, pleasure and intimacy provide another point of strength and connection for our respondents. For example, data on frequency of sex in respondents' lives indicate that they are having more sex than women in the general population per the annual social survey. And a large majority of study participants (68%) report that their sex lives bring them moderate to a great deal of joy and pleasure.




Given hardships recorded in so many areas of LGBTQ+ women's lives in the study, this data points to an important avenue for joy and resilience. Respondents also overwhelmingly report (73%) their intimate lives as a crucial place of authenticity around their gender and sexuality.

## 73% of Respondents "Often" or "Sometimes" have Consensual Sex in Their Authentic Gender or Sexuality




Taken together, what does data on friendship, sex and intimacy, and their favorite things tell us about key frameworks for health and care for LGBTQ+ women? The recommendations below flow from these points of resilience.

# Recommendations

1. If, as the Harvard Nurses study points out – toxic social exposure is truncating LGBTQ+ women's lives, then culturally congruent care in the form of community-devised health spaces and highly trained and well-resourced LGBTQ+-identified medical staff and doctors offers a crucial intervention.

   ## 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 perceived differently in the eyes of LGBTQ+ doctors 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 – that put survivors in the driver's seat of treatment protocols, emphasize community care and free support, critique big Pharma driven interventions, and draw on survivor wisdom vs. licensed social workers and other "professional" leaders – are widely funded. 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. 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[72]

4. Intimate Partner Violence (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.

(continued)

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. Create spaces 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. Create spaces for free depression and anxiety support groups in community-based settings.

10. Create spaces for free, non-carceral, LGBTQ+ friendly, trauma-informed drug and alcohol treatment and peer support.

# THANK YOU

**Thanks to the National Center for Lesbian Rights for creating a permanent home for the Urvash Vaid National LGBTQ+ Women's Community Survey.**

### Thanks to our funders of this report:

The Laughing Gull Foundation, The New York Women's Foundation, The National Center for Lesbian Rights, The Boston Mayor's Office for LGBTQIA2S+ Advancement, The Freeman Foundation, and an anonymous activist donor.

For the project as a whole: The Arcus Foundation, The Laughing Gull Foundation, The New York Women's Foundation, The Billie Jean King Leadership Initiative, Wellspring Philanthropic Fund, Ford Foundation, The Collaborative for Gender and Reproductive Equity, The Boston Mayor's Office for LGBTQIA2S+ Advancement, Grindr for Equality, Palette Fund, Rising Fund, Field Hamilton Fund, Linda Kettner, Dee Mosbacher, The Masto Foundation, The Ms. Foundation, The Astraea Lesbian Foundation for Justice, donors of the Horizons Foundation, The Freeman Foundation, and The Johnson Family Foundation.

Thank you to our 120 **community partner organizations** that supported the development of our survey questionnaire and distributed links to the survey to their community members.

Thank you to our intrepid **advisory board** of activist researchers, whose expertise and commitment drove this project.

Data repository provided by the Critical Racism Lab at Emory University under the direction of Dr. Ali Alyasah Sewell

Citation detail: Grant, Jaime M., Harrison-Quintana, Jack, Elahian, Savy, and Villamora, Genevieve, *What's Killing Us?*

# ENDNOTES


[1] This report is based on 5,002 respondents' experiences 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

[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

[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

[8] 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

[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/

[13] While this is not a random sample, and participants in the Nurses Study were born between 1945 and 1964, the magnitude and longitudinal strength of the study give us a credible and shocking look at life expectancy for lesbian and bi baby boomers that can and should drive our concerns for life expectancy among all LGBTQ+ women, of all ages.

[14] 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/

[15] Wilson, Gordon, Mallory, Choi, Badgett, "Health and Socioeconomic Well-being of LBQ Women in the US." Williams Institute, 2021. https://williamsinstitute.law.ucla.edu/wp-content/uploads/LBQ-Women-Mar-2021.pdf

[16] 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

[17] https://williamsinstitute.law.ucla.edu/wp-content/uploads/LBQ-Women-Mar-2021.pdf "Health and Socioeconomic Well-Being of LBQ Women in the US" UCLA School of Law Williams Institute, March 2021, pg. 50, Table 26.

[18] National LGBT Cancer Network , "Lesbians and Cancer." https://cancer-network.org/cancer-information/lesbians-and-cancer/

[19] American Cancer Society, "Key Statistics for Breast Cancer." 2024. https://www.cancer.org/cancer/types/breast-cancer/about/how-common-is-breast-cancer.html

[20] 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

[21] National Institutes of Health, "Cancer Stat Facts: Colorectal Cancer." https://seer.cancer.gov/statfacts/html/colorect.html

[22] Statistics are routinely gathered about uterine cancers overall.

[23] National Institutes of Health, "Cancer Stat Facts: Uterine Cancer." https://seer.cancer.gov/statfacts/html/corp.html

[24] American Cancer Society, "Key Statistics for Lung Cancer." 2024. https://www.cancer.org/cancer/types/lung-cancer/about/key-statistics.html#:~:text=Overall%2C%20the%20chance%20that%20a,t%2C%20the%20risk%20is%20lower

[25] American Cancer Society, "Key Statistics for Non-Hodgkin Lymphoma." 2024. https://www.cancer.org/cancer/types/non-hodgkin-lymphoma/about/key-statistics.html#:~:text=Non%2DHodgkin%20lymphoma%20(NHL),will%20be%20diagnosed%20with%20NHL

[26] American Cancer Society, "Key Statistics About Kidney Cancer." 2024. https://www.cancer.org/cancer/types/kidney-cancer/about/key-statistics.html

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

[28] National Institutes of Health, "Cancer Stat Facts: Thyroid Cancer." https://seer.cancer.gov/statfacts/html/thyro.html

[29] Wilson, Gordon, Mallory, Choi, Badgett, "Health and Socioeconomic Well-being of LBQ Women in the US." Williams Institute, 2021. https://williamsinstitute.law.ucla.edu/wp-content/uploads/LBQ-Women-Mar-2021.pdf

[30] American Lung Association, "COPD Trends Brief: Prevalence." https://www.lung.org/research/trends-in-lung-disease/copd-trends-brief/copd-prevalence

[31] Lloyd-Jones, Larson, Beiser, Levy, "Lifetime risk of developing coronary heart disease", The Lancet, 1999. https://www.thelancet.com/pdfs/journals/lancet/PIIS0140673698102799.pdf

[32] Mobeen, Apostol, "Ovarian Cyst." National Library of Medicine National Center for Biotechnology Information. 2023. https://www.ncbi.nlm.nih.gov/books/NBK560541/

[33] U.S. Centers for Disease Control and Prevention, "Prevalence of both diagnosed and undiagnosed diabetes." 2024. https://www.cdc.gov/diabetes/php/data-research/index.html#:~:text=Among%20the%20U.S.%20population%20overall,Table%201a%3B%20Table%201b

[34] Wilson, Gordon, Mallory, Choi, Badgett, "Health and Socioeconomic Well-being of LBQ Women in the US." Williams Institute, 2021. https://williamsinstitute.law.ucla.edu/wp-content/uploads/LBQ-Women-Mar-2021.pdf

[35] interACT Advocates for Intersex Youth, "FAQ." https://interactadvocates.org/faq/

[36] Intersex Human Rights Australia, "Intersex population figures." 2019. https://ihra.org.au/16601/intersex-numbers/

[37] The Johns Hopkins University School of Medicine, "Endometriosis." https://www.hopkinsmedicine.org/health/conditions-and-diseases/endometriosis

[38] Secosan, Balulescu, Brasoveanu, Balint, Pirtea, Dorin, Pirtea, "Endometriosis in Menopause–Renewed Attention on a Controversial Disease." Diagnostics, 2020; 10(3). https://pmc.ncbi.nlm.nih.gov/articles/PMC7151055/

[39] U.S. Centers for Disease Control and Prevention, "About Women and Heart Disease." 2024. https://www.cdc.gov/heart-disease/about/women-and-heart-disease.html

[40] "QuickStats: Prevalence of High Total Cholesterol Among Adults Aged ≥20 Years, by Age Group and Sex – National Health and Nutrition Examination Survey, 2015–2018," Morbidity and Mortality Weekly Report, 2020; 69(22). https://www.cdc.gov/mmwr/volumes/69/wr/mm6922a5.htm#:~:text=During%202015%E2%80%932018%2C%20the%20prevalence,%E2%80%9339%20years%20(7.5%25)

[41] Wilson, Gordon, Mallory, Choi, Badgett, "Health and Socioeconomic Well-being of LBQ Women in the US." Williams Institute, 2021. https://williamsinstitute.law.ucla.edu/wp-content/uploads/LBQ-Women-Mar-2021.pdf

[42] Ostchega, Fryar, Nwankwo, Nguyen, "Hypertension Prevalence Among Adults Aged 18 and Over: United States, 2017–2018", National Center for Health Statistics Data Brief, 2020; 364. https://www.cdc.gov/nchs/products/databriefs/db364.htm

[43] Eunice Kennedy Shriver National Institute of Child Health and Human Development, "How many women are affected by menstrual irregularities?" National Institute of Health. 2017. https://www.nichd.nih.gov/health/topics/menstruation/conditioninfo/affected#

[44] 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 and Rheumetology, 2021. https://pubmed.ncbi.nlm.nih.gov/33474834/

[45] Wallin, Culpepper, Campbell, Nelson, Langer-Gould, Marrie, Cutter, Kaye, Wagner, Tremlett, Buka, Dilokthornsakul, Topol, Chen, LaRocca, US Multiple Sclerosis Prevalence Workgroup, "The prevalence of MS in the United States: A population-based estimate using health claims data." Neurology. 2019; 92(10). https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6442006/

[46] Keen, Reddivari, "Osteoporosis in Females." National Institute of Health. 2023. https://www.ncbi.nlm.nih.gov/books/NBK559156/

[47] National Institute of Diabetes and Digestive and Kidney Diseases, "Overweight and Obesity Statistics." National Institute of Health. https://www.niddk.nih.gov/health-information/health-statistics/overweight-obesity#

[48] Deswal, Narwal, Dang, Pundir, "The Prevalence of Polycystic Ovary Syndrome: A Brief Systematic Review." Journal of Human Reproductive Sciences. 2020; 13(4). https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7879843/

[49] U.S. Centers for Disease Control and Prevention, "National Diabetes Statistics Report." 2024. https://www.cdc.gov/diabetes/php/data-research/index.html

[50] Kirkcaldy, Weston, Segurado, Hughes, "Epidemiology of Gonorrhoea: A Global Perspective," Sex Health. 2019;16(5). https://www.publish.csiro.au/sh/Fulltext/SH19061

[51] Office on Women's Health: OASH, "Genital Herpes." U.S. Department of Health and Human Services. https://www.womenshealth.gov/a-z-topics/genital-herpes#

[52] Minnesota Cancer Reporting System, "Quick Facts: HPV-Associated Cancer." Minnesota Department of Health. 2024. https://www.health.state.mn.us/data/mcrs/data/qfhpv.html

[53] Muthusamy, Elangovan, "A Study on the Prevalence of Genital Trichomoniasis among Female Outpatients Attending Sexually Transmitted Infection Clinic in a Tertiary Care Hospital." Journal of Laboratory Physicians. 2017; 9(1). https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5015492/

[54] U.S. Centers for Disease Control and Prevention, "National Diabetes Statistics Report." 2024. https://www.cdc.gov/diabetes/php/data-research/index.html

[55] Grant, Sewell, "We Never Give Up the Fight: A Report of the National LGBTQ+ Women's Community Survey." 2023. Page 84. https://lalgbtcenter.org/wp-content/uploads/2023/10/LGBT-Womens-Survey-Full-2023.pdf

[56] Grant, Sewell, "We Never Give Up the Fight: A Report of the National LGBTQ+ Women's Community Survey." 2023. Pages 147-166. https://lalgbtcenter.org/wp-content/uploads/2023/10/LGBT-Womens-Survey-Full-2023.pdf

[57] U.S. Centers for Disease Control and Prevention, "National Diabetes Statistics Report." 2024. https://www.cdc.gov/diabetes/php/data-research/index.html

[58] U.S. Centers for Disease Control and Prevention, "Fast Facts on Diabetes." 2024. https://www.cdc.gov/diabetes/php/data-research/index.html#

[59] Ostchega, Fryar, Nwankwo, Nguyen, "Hypertension Prevalence Among Adults Aged 18 and Over: United States, 2017–2018." U.S. Centers for Disease Control and Prevention, https://www.cdc.gov/nchs/products/databriefs/db364.htm

[60] 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

[61] National Association of Community Health Centers, "Closing the Primary Health Gap." 2023. https://www.nachc.org/usa-today-a-third-of-americans-dont-have-a-primary-care-provider-according-to-nachc-report/

[62] The American College of Obstetricians and Gynecologists, "Cervical Cancer Screening." 2023. https://www.acog.org/womens-health/faqs/cervical-cancer-screening

[63] Wilson, Gordon, Mallory, Choi, Badgett, "Health and Socioeconomic Well-being of LBQ Women in the US." Williams Institute, 2021. https://williamsinstitute.law.ucla.edu/wp-content/uploads/LBQ-Women-Mar-2021.pdf

[64] Deutsch, "Screening for Breast Cancer in Transgender Women." Univtersity of California San Francisco Transgender Care. 2016. https://transcare.ucsf.edu/guidelines/breast-cancer-women

[65] Wilson, Gordon, Mallory, Choi, Badgett, "Health and Socioeconomic Well-being of LBQ Women in the US." Williams Institute, 2021. https://williamsinstitute.law.ucla.edu/wp-content/uploads/LBQ-Women-Mar-2021.pdf

[66] Ali, Imperatore, Benoit, O'Brien, Holliday, Echouffo-Tcheugui, McKeever Bullard, "Impact of Changes in Diabetes Screening Guidelines on Testing Eligibility and Potential Yield among Adults without Diagnosed Diabetes in the United States." Diabetes Research and Clinical Practice. 2023. https://pmc.ncbi.nlm.nih.gov/articles/PMC10352955/

[67] Clemens, Brähler, Fegert, "#patientstoo – Professional Sexual Misconduct by Healthcare Professionals towards Patients: A Representative Study." Epidemiology and Psychiatric Sciences. 2021. https://pmc.ncbi.nlm.nih.gov/articles/PMC8220485/

[68] The Trevor Project. https://www.thetrevorproject.org/

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

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

[71] James, Herman, Rankin, Keisling, Mottet, Anafi, "The Report of the U.S. Transgender Survey 2015." The National Center for Transgender Equality. 2016. https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf

[72] Grant, Sewell, "We Never Give Up the Fight: A Report of the National LGBTQ+ Women's Community Survey." 2023. Chapter 6, "Sexual Practices, Resilience and Joy."