

More Than Pink: LGBTQ Breast Health

LGBTQ Health Care Experiences in Western Washington



October 2016

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Glossary

Gender Identity

Agender - describes a person who identifies as having no gender

Cisgender - describes a person whose sex and gender identity align. i.e., someone who was assigned male at birth and identifies as male/masculine.

Gender fluid - describes a person whose gender identity is not fixed. A person who is gender fluid may always feel like a mix of female and male, or may feel they are more one gender some days and another gender other days.

Gender non-conforming (GNC) - an umbrella term describing gender expression that differs from a given society's norms of only male and female

Genderqueer - describes a person whose gender identity falls outside the traditional gender binary of male and female.

Non-binary - an umbrella term covering any gender identity that does not fit within the gender binary of male and female.

Transgender man - a transgender person whose gender identity is male. Transgender men were assigned female at birth.

Transgender woman - a transgender person whose gender identity is female. Transgender women were assigned male at birth.

Two-spirit - describes Native American/Alaskan Native LGBTQ people, stemming from language meaning to have both female and male spirits within one person. The term has different meaning in different communities.

Sexual Orientation

Asexual - describes a person who experiences little or no sexual attraction to others.

Bisexual - describes a person who is emotionally and sexually attracted to people of their own gender and people of the other binary gender.

Gay - describes a man who is emotionally and sexually attracted exclusively to other men.

Lesbian - describes a woman who is emotionally and sexually attracted exclusively to other women.

Pansexual - describes a person who is emotionally and sexually attracted to people of gender identities throughout the gender spectrum.

Queer - an umbrella term used by some to describe people who think of their sexual orientation or gender identity as outside of societal norms. Some people view the term queer as more fluid and inclusive than traditional categories of sexual orientation and gender identity. Due to its history as a derogatory term, it is not embraced or used by all of the LGBTQ community.

About Us

Susan G. Komen® Puget Sound was founded in 1992 by CJ Taylor and a group of community volunteers, all of whom shared a vision of ending breast cancer forever. Komen Puget Sound facilitates programs that combat institutional barriers between underserved communities and provide breast health services everyone deserves. We have a new, Bold Goal to reduce the current number of breast cancer deaths in the U.S. by 50% in the next decade.

In 2016 we funded \$750,000 in community grants for local breast cancer programs and \$400,000 in research funding to find a cure. Over the past 23 years, Komen Puget Sound has invested more than \$30 million in local nonprofit, tribal, and government agencies that provide breast health and breast cancer services. We are committed to investing in our community, but recognize that there is a gap in services for the lesbian, gay, bisexual, transgender, and queer (LGBTQ) community.

Every four years, Komen Puget Sound undergoes a research process to determine our programming priorities, outlined in our

Community Profile Report. This research provides an evidence base for targeted investments that empower and educate the community while improving health system access and eliminating disparities. For 2016 until 2020, we identified key underserved communities including the LGBTQ community, the black/African American community, the Hispanic/Latinx community, the Native community, and the Pacific Islander community.

Under our Health Equity Project, we fund a faith-based program, *Worship In Pink*, for education on prevention and early detection for women of color as well as *La Mujer Hispana*, which aims to increase breast cancer awareness and screening among Hispanic women in King and Pierce Counties.

Most recently, we have begun the *LGBTQ Breast Health Initiative*, which aims to increase cultural sensitivity in health care providers and to increase knowledge about breast health in the LGBTQ community. We hope this will empower the community to access preventative care and increase mammogram screening rates.

OUR MISSION

Komen Puget Sound works to eliminate breast health disparities by reducing barriers, increasing knowledge, and improving access to quality breast health services that meet the needs of our community.

OUR PARTNERSHIPS focus on:

- **Funding innovative, scientific research**
- **Empowerment through education and outreach**
- **Increasing early detection and screening rates**
- **Improving health system access through patient navigation**
- **Providing emergency financial assistance**
- **Helping people during and after breast cancer through treatment support and survivorship**

Executive Summary

We asked the local LGBTQ community about their experiences accessing health care.

74 participants in online questionnaire

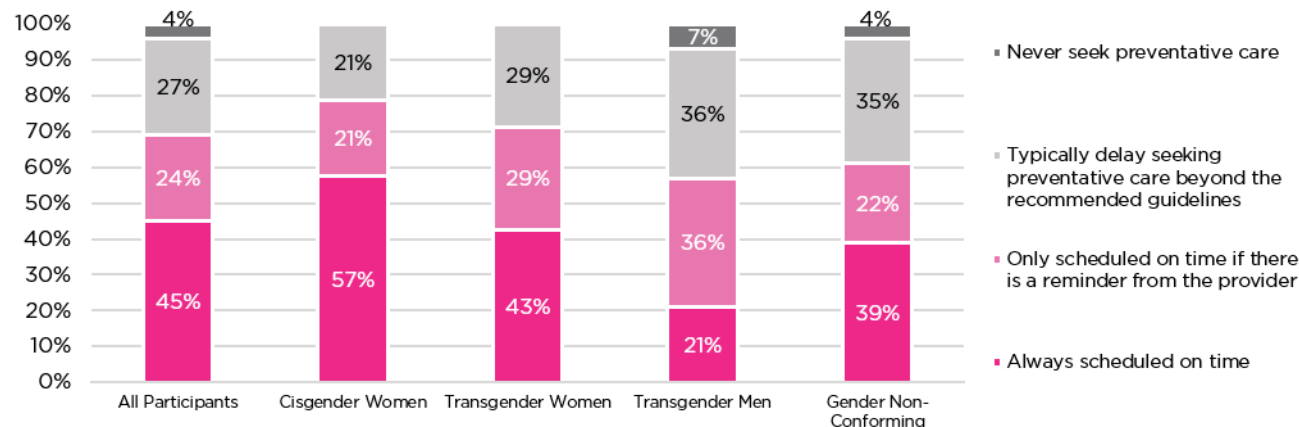


17 participants in interviews



Is the LGBTQ community seeking preventative care?

Transgender men and gender non-conforming people are less likely to schedule preventative care.



Why is the LGBTQ community delaying or never seeking preventative care?



Lack of Cultural Sensitivity from Health Care Providers

- 83%** of transgender men
- 67%** of gender non-conforming people
- 17%** of cisgender women



Uncertainty of Recommendations for Screening Guidelines

- 50%** of transgender women
- 33%** of transgender men
- 22%** of gender non-conforming people
- 17%** of cisgender women

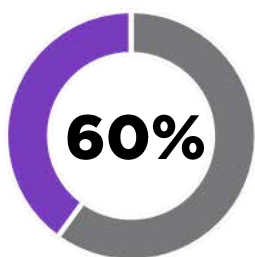


Inability to Afford Cost of Services

- 50%** of cisgender women
- 11%** of gender non-conforming people

Executive Summary

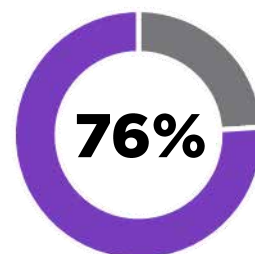
What does this mean for breast health?



LGBTQ Community

Only 60% LGBTQ people age 50-74 have received their recommended mammogram in the past two years.

This compares with 76% of the general population in the Komen Puget Sound service area.



Komen Puget Sound service area

Many people in the LGBTQ community do not understand the risk factors for breast cancer.



6 out of 7 interviewees assigned male at birth received no information on breast health while they were growing up.



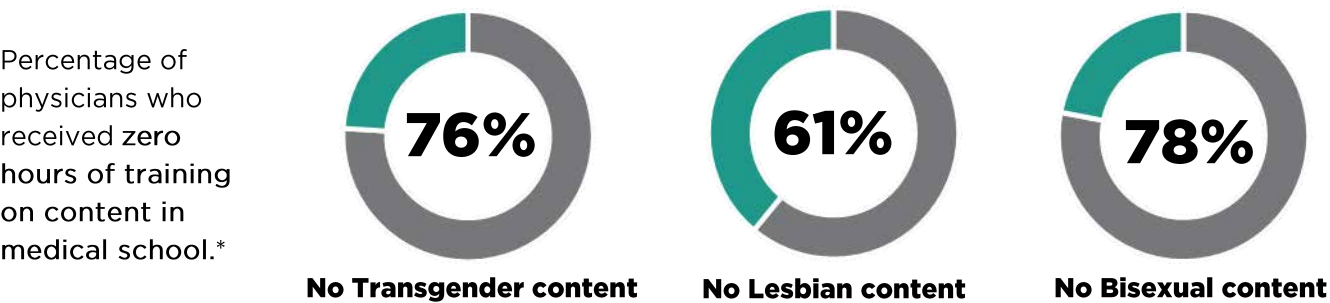
3 out of 10 interviewees assigned female at birth received no information on breast health while they were growing up.

The LGBTQ community needs more education on breast health, inclusive of all genders.

- X** No interviewees knew that self-examinations are no longer part of the screening guidelines. However, it is important to become familiar with the way your chest normally looks and feels, which may help individuals to see or feel changes in their chest.
- X** Only 1 out of the 17 interviewees was able to correctly articulate the guidelines for clinical breast exams.
- X** Only 3 out of the 7 interviewees who were assigned male at birth were able to provide an overview of guidelines for mammography.
- ✓** All 10 interviewees assigned female at birth had a general idea of the age and frequency guidelines for mammography.

Executive Summary

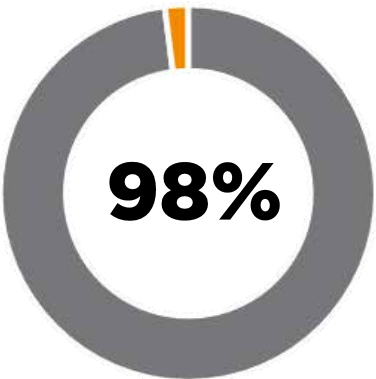
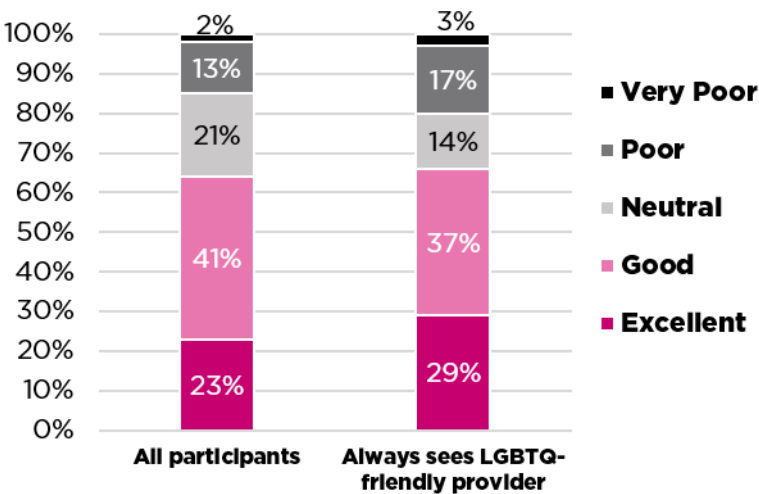
Many physicians receive no training on LGBTQ health or LGBTQ cultural sensitivity while they are in medical school.



Even providers who are LGBTQ-friendly may not be as knowledgeable about LGBTQ health as they intend to be.

Fifty-three percent of the LGBTQ community always go to a provider who specializes in LGBTQ health or who is sensitive to LGBTQ identities.

Still, only 29% rate their provider as “excellent” in the provider’s ability to understand the patient’s gender identity and/or sexual orientation.



Percentage of the LGBTQ community who agrees or strongly agrees that health care providers in Washington need to undergo LGBTQ cultural sensitivity training.

*Eliason, M.J., Dibble S., Robertson, P.A., (2011). Lesbian, Gay, Bisexual, and Transgender (LGBT) Physician's Experiences in the Workplace. See: [http://www.researchgate.net/publications/51747459_Lesbian_Gay_Bisexual_and_Transgender_\(LGBT\)_Physician's_Experiences_in_the_Workplace](http://www.researchgate.net/publications/51747459_Lesbian_Gay_Bisexual_and_Transgender_(LGBT)_Physician's_Experiences_in_the_Workplace)

Needs Assessment

A 2012 Gallup study estimated the Washington state LGBTQ population as one of the highest in the United States at 4% (about 209,670 residents).¹ However, the data captured only those who self-reported or acknowledge same-sex relationships. They likely miss those who are not partnered and those whose sexual and gender identity are characterized by fluidity and change (e.g. bisexual, transgender, intersex, queer/questioning). Thus, gender minorities and sexual minorities may be far more numerous than reported.

Sexual minority women have the densest cluster of risk factors associated with breast cancer.² This includes higher rates of never giving birth, older age at first live birth, higher rates of smoking and substance abuse, and higher rates of elevated BMI. However, because no national cancer registries or databases currently collect information on gender identity or sexual orientation, it is impossible to know incidence rates of breast cancer in the LGBTQ community.³

The LGBTQ community also faces an increased risk of negative health outcomes surrounding cancer because of a lack of cultural sensitivity from health care providers, being less likely to have employer-provided health insurance, and delaying preventative care.⁴

The barriers make optimal medical care for many LGBTQ community members formidable. While Komen Puget Sound has made strides promoting mammography screening among LGBTQ people, much work is critically needed to create a healthier environment for LGBTQ patients.

Increasing knowledge and encouraging informed breast care decision-making among the LGBTQ community can only go so far if the broader health system discourages the LGBTQ community from taking positive action about their health care. Optimal care requires empowering, welcoming clinical and program environments that promote good

communication and allow individuals to feel comfortable and safe to discuss their gender identity, gender expression, sexual orientation, sexual behavior, and any conflicts they may be experiencing that impact their health care.

There is a necessity to understand the experiences of the LGBTQ community when accessing health care in the Komen Puget Sound service area so that the needs of the community can be amplified and systemic barriers to accessing high quality health care can be reduced.

Komen Puget Sound aims to gather this information and use it to develop a comprehensive, tailored LGBTQ cultural sensitivity toolkit for breast health providers and for the LGBTQ community. The toolkit will increase health care providers' awareness, knowledge, and sensitivity to the LGBTQ community and will increase the LGBTQ community's knowledge surrounding breast health. This will supplement existing LGBTQ cultural sensitivity curricula which local health care systems are implementing.

We hope this will empower and encourage LGBTQ individuals to get screened for breast cancer, take action to obtain diagnostic procedures when needed, and seek and complete treatment after a breast cancer diagnosis.



Methodology, Limitations, and Future Research

This study was a three-part mixed methods study that obtained IRB approval through collaboration with the University of Washington.

Literature Review

The first component of this study was a comprehensive literature review of research on the relationship between the LGBTQ community and health care, cultural sensitivity, and cancer. This was done to examine the landscape of research surrounding the LGBTQ community and cancer as well as LGBTQ cultural sensitivity in the health care system. The entirety of the literature review can be found in Appendix H.

Quantitative Data

The second phase of the study was a questionnaire to gather quantitative data. It was disseminated through social media and email listservs to local LGBTQ organizations and social media websites from March, 2016 through May, 2016 and was available in both English and Spanish.

The questionnaire consisted of demographic questions, challenges when accessing health care, experiences while receiving services, and disclosure of identities to health care providers.

Data was collected from participants who identify as a sexual minority and/or gender minority, and are over the age of 18. The questionnaire was open to people who meet that criteria and reside in Western Washington within the Komen Puget Sound 16-county service area: Clallam, Jefferson, Grays Harbor, Mason, Pacific, Wahkiakum, Lewis, Thurston, Pierce, King, Kitsap, Snohomish, Skagit, Whatcom, San Juan, and Island.

Qualitative Data

The third phase of this study was a series of interviews gathering qualitative data to supplement the quantitative data. Seventeen interviews were held from March, 2016 through May, 2016 either over the telephone or in-person with gender minorities and sexual minorities who live in the Komen Puget Sound service area.

The interview questions inquired about knowledge surrounding breast health, experiences when receiving health care, and input on what should be included in an LGBTQ cultural sensitivity toolkit for health care providers, particularly about breast health. The interviews were audio-recorded, transcribed, and then thematically coded.

Limitations

Sample Size

One limitation of this study is that the overall sample size of is fairly small, with 74 participants in the online quantitative questionnaire and 17 people interviewed for qualitative data. This limits the generalizability of findings in this study.

Geography

Furthermore, while there was outreach for participation in the questionnaire in all sixteen counties that Komen Puget Sound serves, eleven counties did not have any LGBTQ participants respond. This may speak to lower population levels compared to urban areas like King County, and it may also speak to the social stigma of LGBTQ identities still more prevalent in rural areas which could lead to less willingness from the LGBTQ community to be “out” and participate in LGBTQ-themed research.

Race/Ethnicity

One significant limitation of the qualitative data is that most participants identified their race as white. The data generally correlates with the racial makeup of King County in that the majority of participants were white (66%). While this does reflect much of the population makeup of the Puget Sound area, it should be noted that systemic racism intersects with sexual and gender minorities who are also people of color, which likely means people of color in the LGBTQ community may have additional or different needs than what has been outlined by these interview participants.

Methodology

Race/ethnicity and other variables like age, ability, and class interact synergistically to impact health care experiences for the LGBTQ community. People of color who also identify as LGBTQ often face multiple and intersecting forms of oppression when accessing health care, and those voices may not be sufficiently represented in this study. There is no one health care narrative for people of color, and many more voices need to be heard.

Medical Transitions

This study did not gather information on transgender or gender non-conforming participants' status in regard to hormone replacement therapy or gender-affirming surgery. This could slightly skew the data, for example, if some transgender men have had chest reconstruction surgery and consequently cannot get mammogram screenings. However, the researchers believe these numbers to be small enough that it does not adversely affect the overall disparity reflected in the data surrounding mammography screening rates.

Next Steps

This research will be used to inform the creation of an LGBTQ breast health toolkit intended to supplement existing, broader LGBTQ cultural sensitivity trainings for health care providers.

Komen Puget Sound will partner with organizations that specialize in human-centered design to create an LGBTQ breast health toolkit. The toolkit will then be vetted through a series of focus groups with both members of the LGBTQ community and health care providers. Komen Puget Sound views the focus groups as an opportunity to incorporate more voices from LGBTQ people of color to create an inclusive toolkit. It will then be adjusted as needed, and piloted in several local health systems.

By engaging with a coalition of breast health experts and LGBTQ community-based organizations, Komen Puget Sound will identify local health systems that have developed LGBTQ

cultural sensitivity trainings and expand our partnerships with them to integrate the toolkit into training programs.

Recommendations for Future Research and Policy Change

National cancer registries and databases need to begin collecting comprehensive information on gender identity and sexual orientation so that satisfactory research can be conducted on incidence rates of breast cancer and other diseases in the LGBTQ community.

There is also a need for more medical research on the effects that hormone usage has on breast health for transgender individuals, both for people taking testosterone therapy and people taking estrogen therapy. Without sufficient data, health care providers cannot accurately guide or treat transgender patients.

This study only included people who identify as LGBTQ. Collecting information on sexual behavior, which for some may be different than sexual identity, is also important in order to create a comprehensive vision of health care access and provider sensitivity.

Findings

Survey Participants At A Glance

Interview Participants

Demographic data from the interview participants will not be incorporated into the findings of this report so that their data is not duplicated because many of the interview participants also anonymously participated in the online questionnaire. Quotes from the interviews will be used to further explore these themes and explain the quantitative data findings. The demographics of the interview participants can be found in Appendix A.

Age

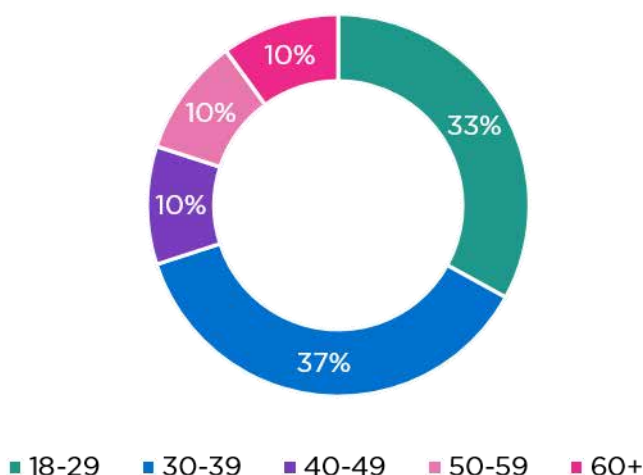
Ten percent of respondents reported that they are age 60 or older, 10% are age 50-59, and 10% are age 40-49. This means that 30% of participants fall in Komen Puget Sound's target demographic of age 40 and older. Another 37% of participants are age 30-39 and 33% of participants are age 18-29.

Geography

The majority (83%) of participants reside in King County. Nine percent of participants reside in Snohomish County, 4% in Whatcom County, 3% in Kitsap County, and 2% in Pierce County.

Outreach efforts were made to local LGBTQ organizations in all 16 of the counties in the Komen Puget Sound service area, but one limitation of this data is that there is insufficient representation from each county. However, the majority of people who identify as LGBTQ in the Komen Puget Sound service area reside in King, Pierce, and Snohomish counties, because those counties are more densely populated.⁵

Figure 1.1. Age of Participants

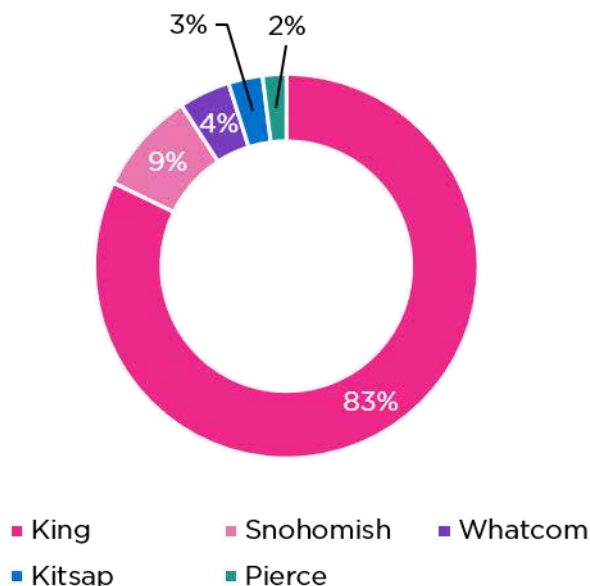


74 participants in online questionnaire



17 participants in interviews

Figure 1.2. County of Residence of Participants



Survey Participants At A Glance

Race/Ethnicity

In order to collect the most accurate information possible, respondents were able to choose any number of identities in the race/ethnicity category. In King County, where most survey participants reside, 61% of people identify as “White alone, not Hispanic or Latino,” and 66% of participants in this study identified as white.⁶ However, the proportions of people of color represented in this survey differs from the representation in King County.

Five percent of study participants identify as Asian/Pacific Islander. Three percent identify as Hispanic/Latino, three percent identify as black/African American, three percent identify as Native American/Alaskan Native, and three percent self-identify as Semitic/Jewish.

Another 17% of participants identify as multiracial. Within the multiracial category, there is a wide range of participant identities.

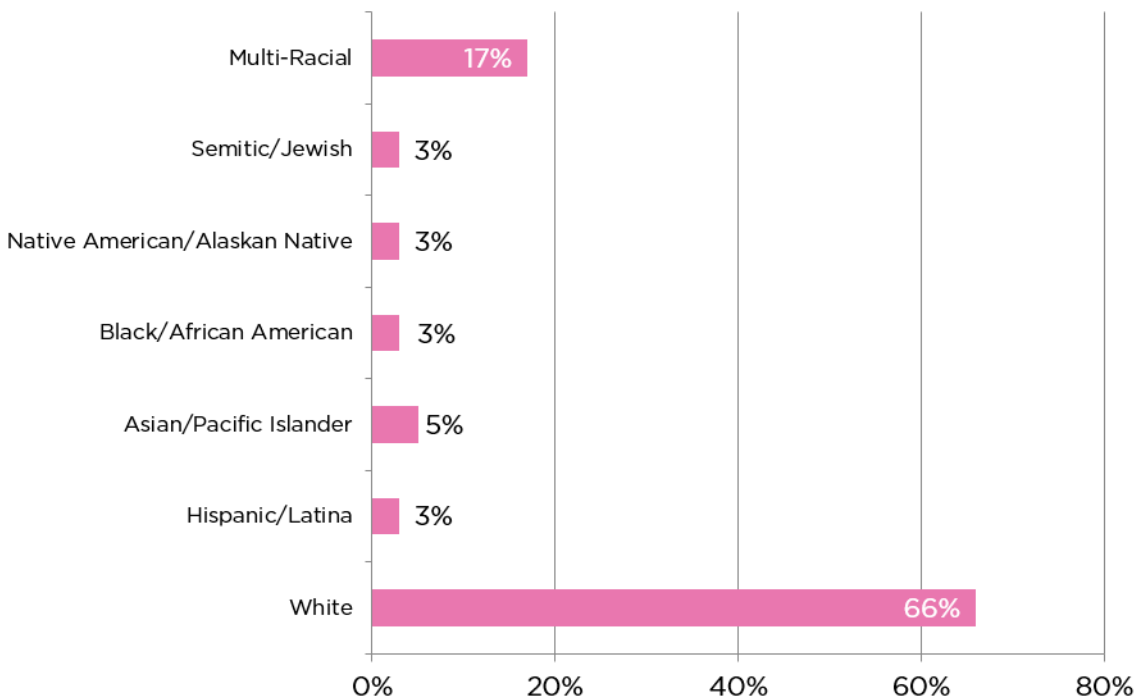
Three participants identify as Asian/Pacific Islander and white. Two participants identify as Native American/Alaskan Native and white. Two participants identify as Hispanic/Latino and black/African American.

Other participants identify as: Hispanic/Latino and Asian/Pacific Islander; Hispanic/Latino, Native American/Alaskan Native, and white; multiracial Hispanic/Latino; multiracial black/African American; and black/African American and white.

While fewer participants identify as a racial or ethnic minority than we aimed to reach, the participants do represent a variety of racial and ethnic identities.

It is important to note the need to amplify voices from communities of color and that an inability to fully represent the makeup of racial identities of the Komen Puget Sound service area is a limitation in the study.

Figure 1.3. Race/Ethnicity



Survey Participants At A Glance

Education

Participants represent a wide range of educational attainment levels. Six percent of respondents hold a professional degree and 38% of respondents hold a master's degree. Another 37% hold a bachelor's degree and 12% hold an associate's degree. One percent of respondents have completed trade or technical school.

Four percent of respondents have completed some college credit but do not have a degree and 1% of respondents hold a high school diploma or GED.

Employment

Fifty-three percent of respondents are employed full-time. Sixteen percent work part-time and 17% are students. Five percent of respondents report that they are retired. Five percent of respondents are unemployed, and an additional 4% of respondents are unemployed and unable to work.

Figure 1.5. Employment Status

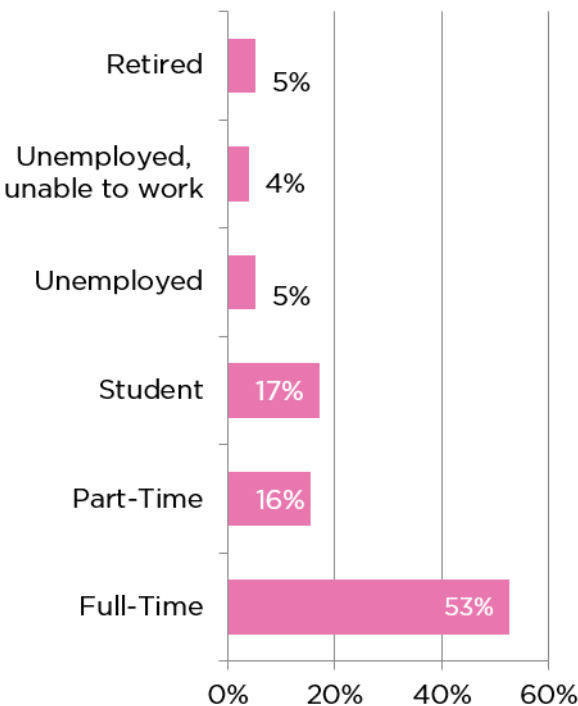
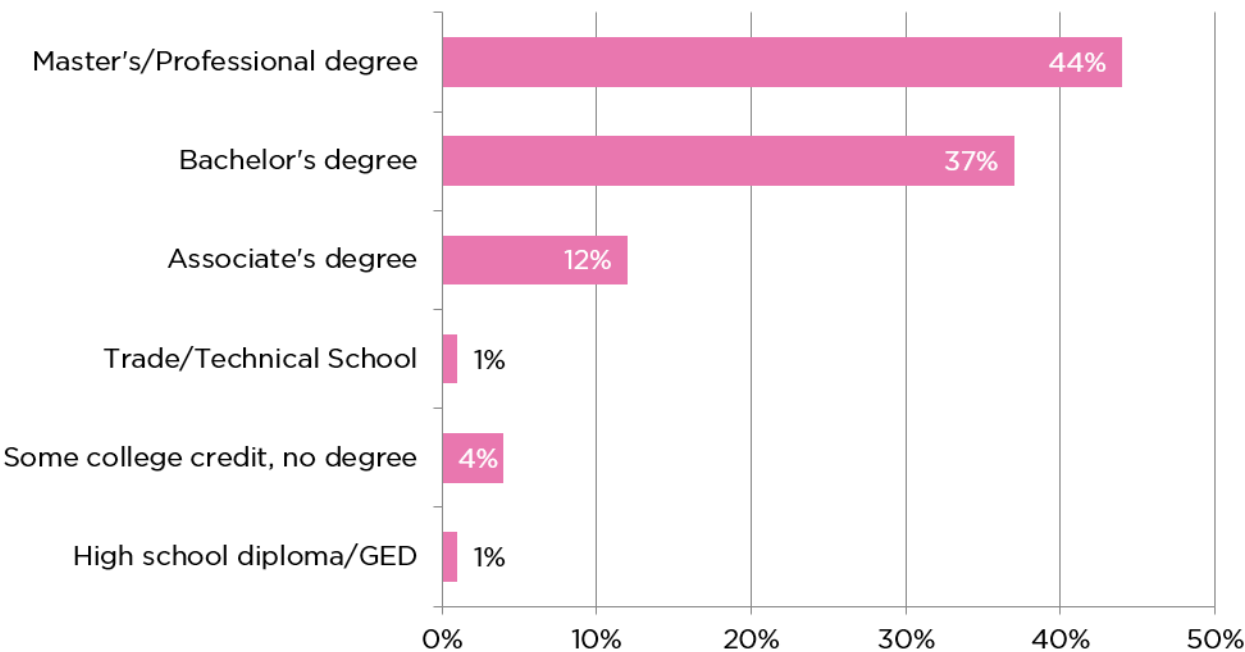


Figure 1.4. Educational Status



Survey Participants At A Glance

Income

The annual household income of respondents varies greatly. It should be noted that this study did not ask how many people contribute to the annual household income, so this does not necessarily represent the participant's individual income.

Eleven percent of respondents reported that their annual household income is less than \$10,000 per year. This means that over 11% of respondents are living below the Federal Poverty Level (FPL), which is \$11,880 for individuals.⁷ The number living below the FPL is potentially much higher, but cannot be accurately determined because the study did not ask about the number of people living in the respondents' households. In 2013, the poverty rate in Washington state was 14.1%.⁸ This report does not fully analyze the impact of income on breast health, but other research indicates that lower income correlates with adverse health outcomes.⁹

Fifteen percent of questionnaire participants reported their annual household income between \$10,000-19,999. Another eight percent reported between \$20,000-29,999.

Thirty-two percent of participants indicated that their income is between \$30,000-59,999. Eleven percent of participants' annual household income is between \$60,000-89,999. Twenty-three percent of participants reported that their annual household income is \$90,000 or greater.

Insurance

Furthermore, all respondents reported that they have health insurance. Seventy percent of participants indicated that they utilize private insurance and 30% of participants use Medicaid, known in Washington state as Apple Health. This means that all participants have access to free mammography, though follow-up and diagnostic care may not be covered.

Figure 1.6. Annual Household Income

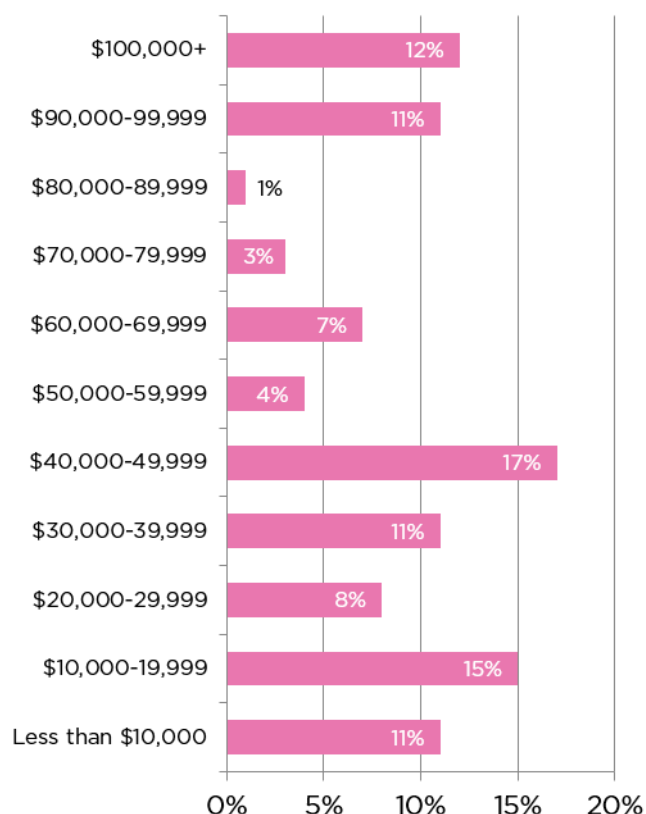
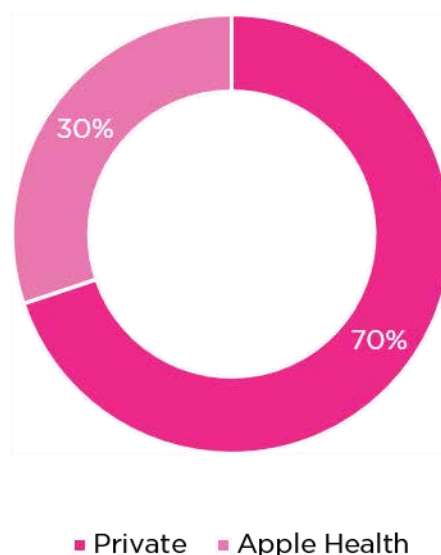


Figure 1.7. Insurance Provider



Survey Participants At A Glance

Gender Identity

This study recognizes that gender and sexuality occur on a spectrum and are not fixed categories, but are fluid and can shift throughout the life course. Given that, this study still collected data on how participants identified so that possible differences in data could be explored.

In order to capture the most accurate data regarding identities, participants were allowed to select all the gender identities with which they identify. Several participants identify with more than one term.

Thirty-nine percent of respondents identify as a cisgender woman. Nine percent of respondents identify as a cisgender man.

Thirty-one percent of respondents identify either as genderqueer, gender fluid, gender non-conforming (GNC), or non-binary. This category encompasses a broad range of identities across the spectrum, but for the sake of brevity, the report will use the acronym “GNC” when referring to this category of identities.

Eighteen percent of respondents identify as a transgender man. Nine percent of respondents identify as a transgender woman. Another five percent self-identified, including identities such as agender, two-spirit, and butch. See Appendix B for a deeper breakdown of gender identity.

Glossary

Cisgender - describes a person whose sex and gender identity align. i.e., someone who was assigned male at birth and identifies as male/masculine.

Genderqueer - describes a person whose gender identity falls outside the traditional gender binary of male and female.

Gender fluid - describes a person whose gender identity is not fixed. A person who is gender fluid may always feel like a mix of female and male, or may feel they are more one gender some days and another gender other days.

Gender non-conforming (GNC) - an umbrella term describing gender expression that differs from a given society's norms of only male and female

Non-binary - an umbrella term covering any gender identity that does not fit within the gender binary of male and female.

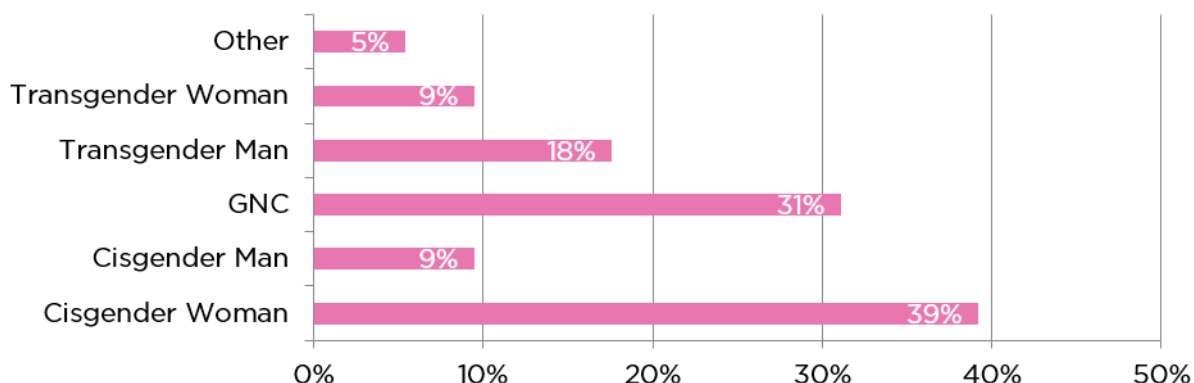
Transgender man - a transgender person whose gender identity is male. Transgender men were assigned female at birth.

Transgender woman - a transgender person whose gender identity is female. Transgender women were assigned male at birth.

Agender - describes a person who identifies as having no gender

Two-spirit - describes Native American/Alaskan Native LGBTQ people, stemming from language meaning to have both female and male spirits within one person. The term has different meaning in different communities.

Figure 1.8. Gender Identity



Survey Participants At A Glance

Sexual Orientation

Participants were asked to identify their sexual orientation. It should be noted that the participants identifying their sexual orientation encompass many gender identities, as previously outlined in Figure 1.8.

For example, this means that someone who identifies as straight may also identify as a transgender man because gender identity and sexual orientation are two separate identities. Similarly, someone who identifies as lesbian may also identify as a transgender woman.

Forty-three percent of respondents identify as queer. Eighteen percent of respondents identify as lesbian and 15% of respondents identify as gay. Eleven percent of respondents identify their sexual orientation as bisexual and eight percent of respondents identify as pansexual. Four percent of respondents identify as straight and one percent of respondents self-identified as both queer and gay.

Glossary

Lesbian - describes a woman who is emotionally and sexually attracted exclusively to other women.

Gay - describes a man who is emotionally and sexually attracted exclusively to other men.

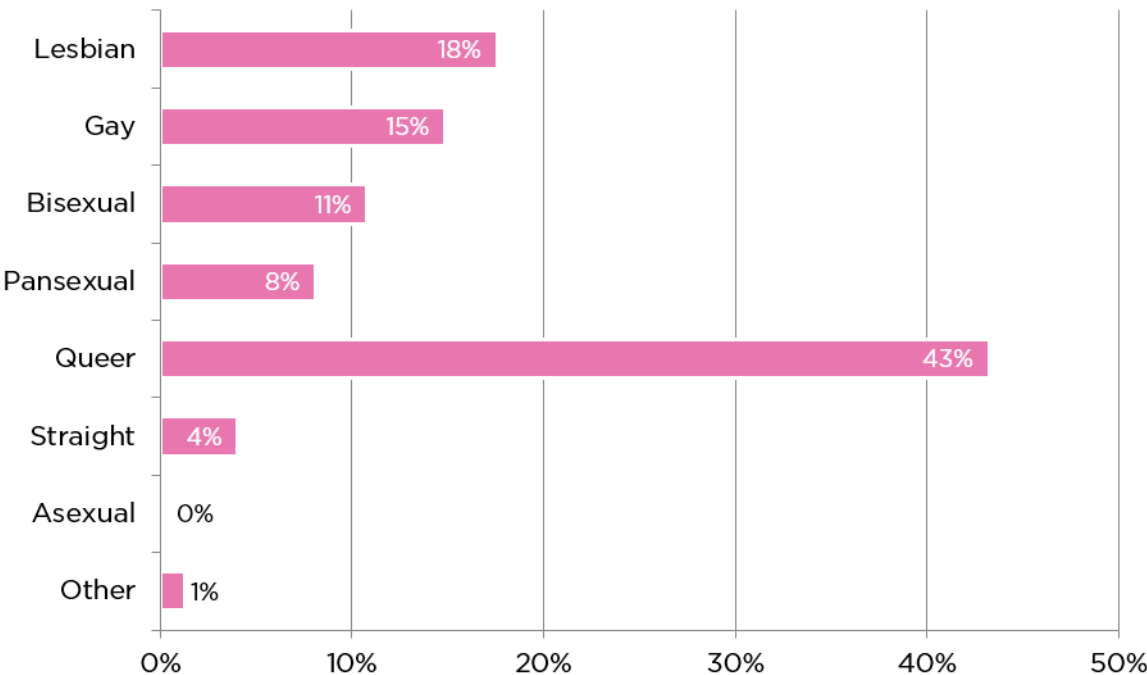
Bisexual - describes a person who is emotionally and sexually attracted to people of their own gender and people of the other binary gender.

Pansexual - describes a person who is emotionally and sexually attracted to people of gender identities throughout the gender spectrum.

Queer - an umbrella term used by some to describe people who think of their sexual orientation or gender identity as outside of societal norms. Some people view the term queer as more fluid and inclusive than traditional categories of sexual orientation and gender identity. Due to its history as a derogatory term, it is not embraced or used by all of the LGBTQ community.

Asexual - describes a person who experiences little or no sexual attraction to others.

Figure 1.9. Sexual Orientation



Accessing Health Care

Avoidance of and delay in seeking preventative care is a consistent disparity in the LGBTQ community, regardless of age and location, as found in multiple studies in the United States.

The LGBTQ community has lower rates of cancer screenings and higher rates of some cancer diagnoses.¹⁰ More specifically, the transgender community is less likely to have routine cancer screenings or to get testing if symptoms arise.¹¹ Research by the National LGBT Task Force, an LGBTQ advocacy group, reported that either previous negative experiences or fear of stigmatization within the health care system caused 28% of transgender respondents to postpone or forego medical care when they were either sick or injured.¹² In another national study, transgender people (72.5%) were significantly less likely than their cisgender counterparts (83%) to have had a routine checkup.¹³

When this increased risk is paired with delay in seeking preventative care, health outcomes for the LGBTQ community decline.

Service Provider

There does not seem to be one or two locations that the local LGBTQ community embraces when accessing health care.

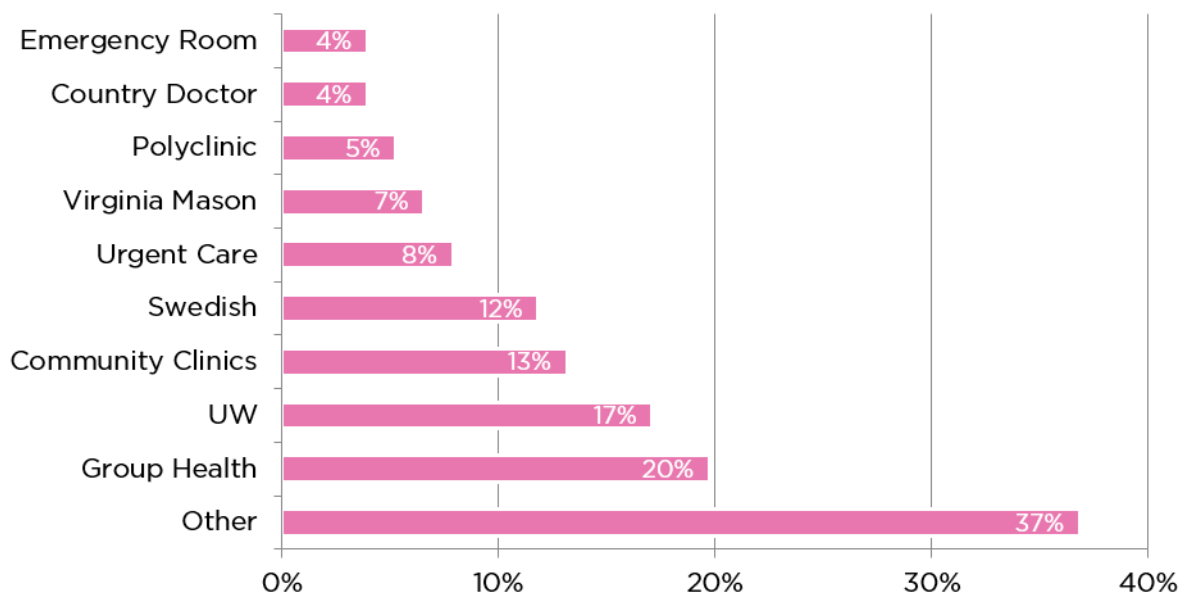
Twenty percent reported that they go to Group Health and 17% go to the University of Washington. Twelve percent reported that they go to Swedish Medical Center. Seven percent reported that they go to Virginia Mason. Five percent go to the Polyclinic and four percent go to Country Doctor.

Thirteen percent utilize community clinics and eight percent utilize urgent care centers. Four percent go to the emergency room when they need health care.

Another 37% of respondents specified other organizations including: Capitol Hill Medical, Queen Anne Medical Services, Family Care, Neighborcare, the Veteran Hospital, Bastyr Cedar River Clinics, Everett Clinic, the Institute of Natural Medicine, and Pac Med.

A comprehensive look at where the LGBTQ community seeks health care can be found in Appendix C, Figure 7.8.

Figure 2.1. Where the LGBTQ community goes for health care



Accessing Health Care

Fifty-three percent of respondents reported that they always seek out a health care provider who either specializes in serving the LGBTQ community or who is sensitive to LGBTQ identities. Another 28% of respondents stated that they sometimes seek providers sensitive to LGBTQ identities. Only 19% reported that they do not ever actively seek health care providers sensitive to LGBTQ identities. This highlights that the general medical field is not perceived to be well-trained on LGBTQ health.

The LGBTQ community largely finds LGBTQ-friendly health care providers through word of mouth (82%). Forty-five percent of respondents reported that they read online reviews of health care providers to determine cultural sensitivity. Forty percent utilize a social media site called the Seattle Queer Exchange on Facebook. Twenty-six percent call the health care provider and ask about sensitivity. Twenty-one percent seek information on culturally sensitive providers from the Ingersoll Gender Center and 13% utilize the King County Trans Resource Guide.

Another 13% chose “other” and reported seeking information from the Gender Justice League, using the Group Health online directory, searching for “LGBT” on their insurance company’s list of providers, and suggestions from other providers.

Figure 2.2. Percentage that actively seek a health care provider specializing in serving the LGBTQ community or is sensitive to LGBTQ identities

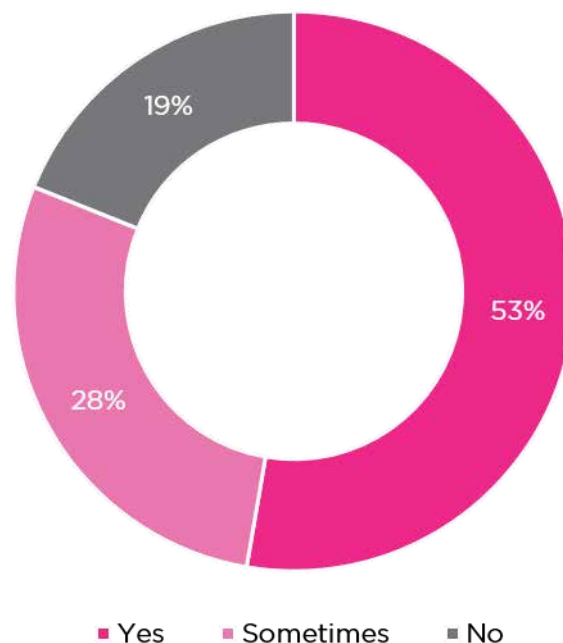
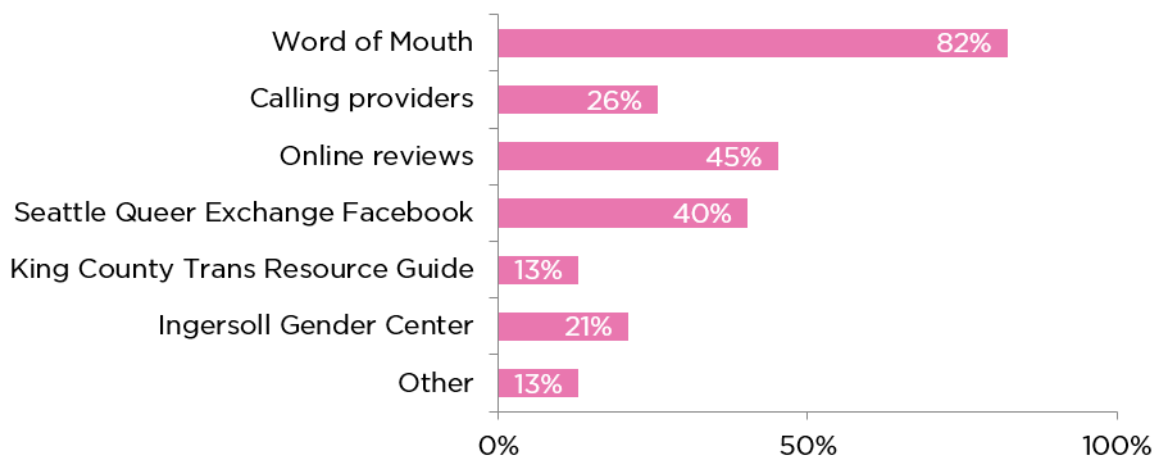


Figure 2.3. How the LGBTQ community finds LGBTQ-friendly health care providers



Accessing Health Care: By Gender Identity

Preventative Care

Participants were asked whether or not they seek routine preventative care, which included examples of services such as immunizations, annual pap tests, mammograms, HPV vaccinations, eye exams, and STI/HIV testing.

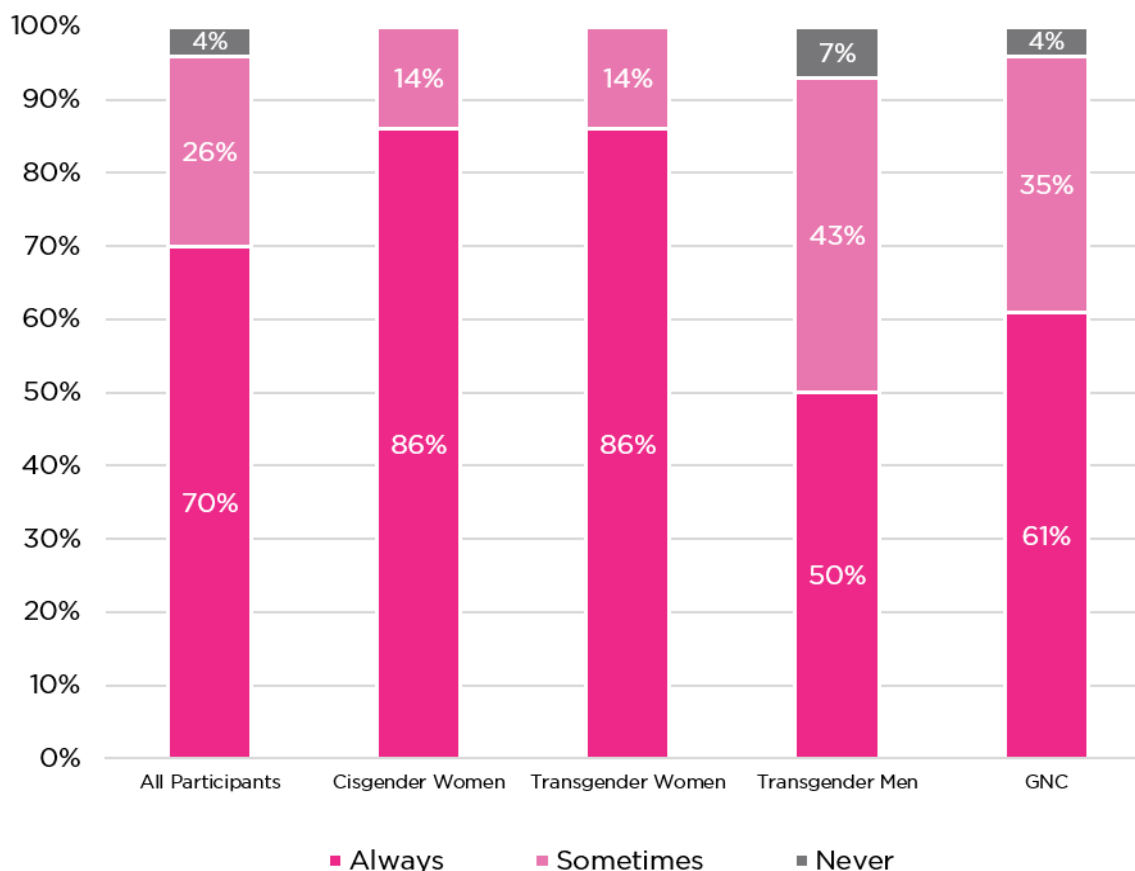
All participants combined, 70% reported that they always seek routine preventative care. Another 26% reported that they sometimes seek routine preventative care and four percent said that they never seek it.

However, when broken down by gender identity, there are stark differences. Only 50% of transgender men and 61% of GNC* individuals reported that they always seek preventative care. This compares with 86% of cisgender women and 86% of transgender women who reported that they always seek preventative care.

It should also be noted that transgender men and GNC individuals were the only gender identities in which some participants reported that they never seek routine preventative care; all cisgender women and transgender women participants reported that they either always or sometimes seek routine preventative care.

This may be because routine preventative care for transgender women, such as a mammogram, is seen as affirming of their gender identity whereas transgender men and GNC individuals often feel distress or dysphoria related to health care such as a mammogram or pap test because those tests are reminders that their bodies do not always match their identities.

Figure 2.4. Percentage that seeks routine preventative care



*encompasses all gender non-conforming identities, including but not limited to people who identify as gender fluid, genderqueer, and non-binary.

Accessing Health Care: By Gender Identity

Participants were asked how often they seek routine preventative care according to the recommended guidelines. Overall, 45% of participants reported that they always seek it on time. Another 24% rely on a reminder from their health care provider in order to schedule it on time. Twenty-seven percent typically delay scheduling preventative care and four percent never seek preventative care.

This means that 31% of LGBTQ respondents are not receiving their necessary preventative care in a timely manner, though that number could be even higher if providers are not reminding patients that preventative care is due.

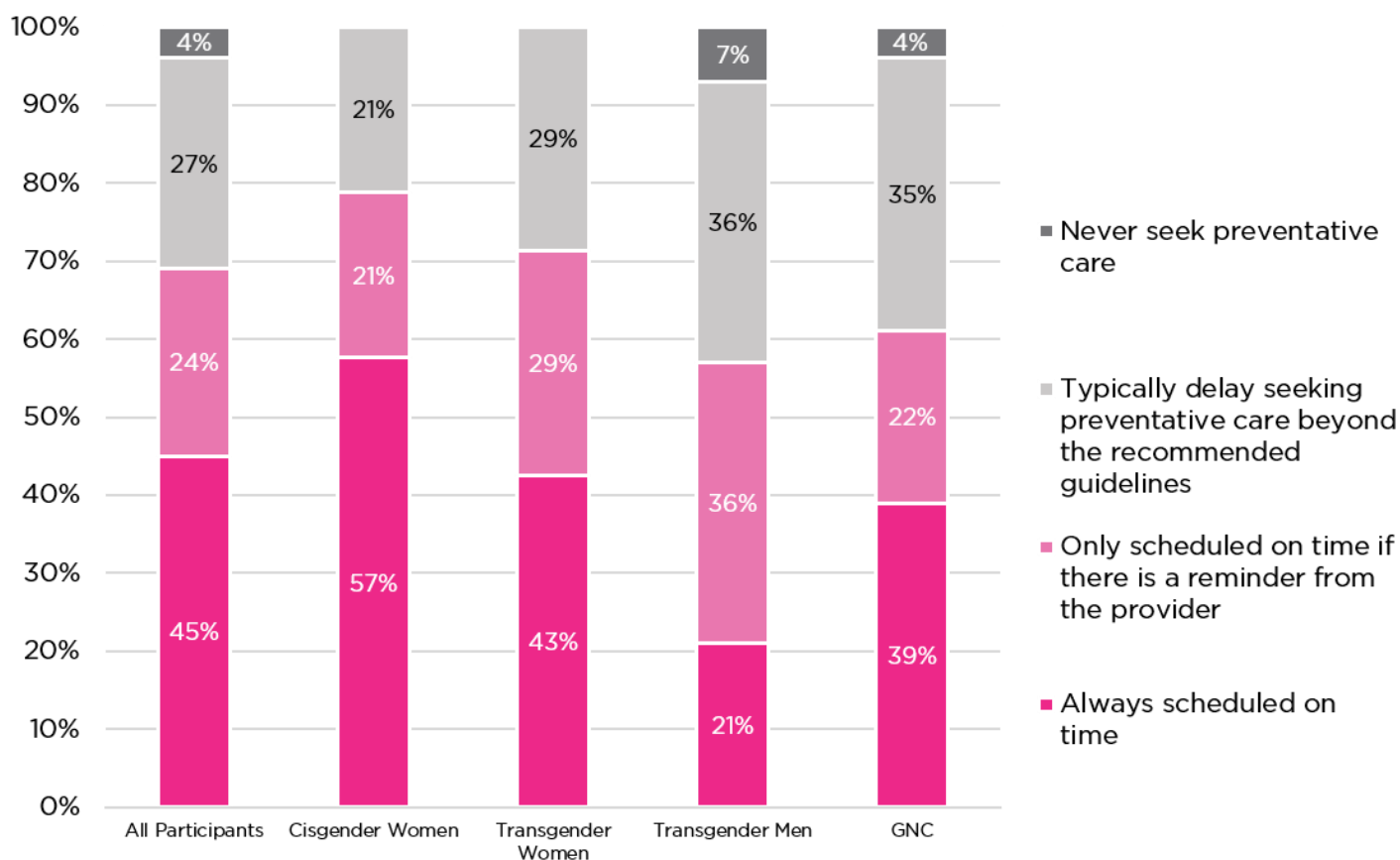
Furthermore, there are notable differences when the participant responses are broken

down by gender identity. Cisgender women are much more likely to schedule preventative care on time (57%) whereas only 21% of transgender men and only 39% of GNC individuals schedule it on time. Forty-three percent of transgender women schedule preventative care on time.

Transgender men are more likely to rely on a provider to remind them to schedule preventative care (36%) compared to cisgender women (21%), transgender women (29%) and GNC individuals (22%).

Most notably, 43% of transgender men and 39% of GNC individuals typically delay or never seek preventative care. This compares with just 21% of cisgender women and 29% of transgender women.

Figure 2.5. Percentage that schedule preventative care according to the recommended guidelines



Accessing Health Care: By Gender Identity

In addition to differences in delaying care, it is apparent that reasons behind delaying or never seeking preventative care vary based on gender identity, too.

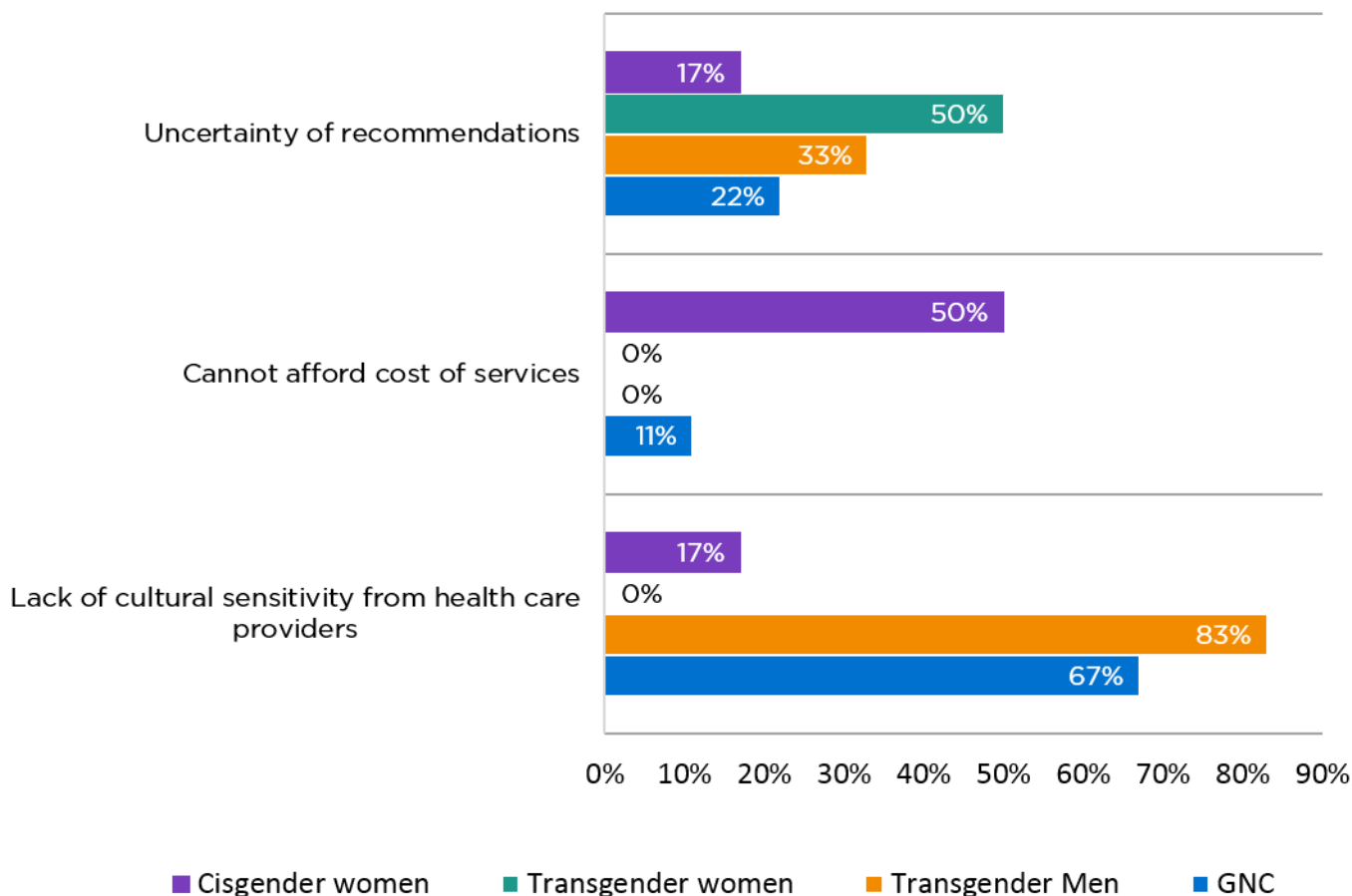
The most common reason that cisgender women delay seeking preventative care is that they cannot afford the cost of services (50%). Eleven percent of GNC individuals also reported they could not afford cost of preventative care.

Transgender women are most likely to delay simply because they are uncertain what the recommendations are for seeking routine preventative care (50%). Thirty-three percent of transgender men and 22% of GNC individuals also delay or do not seek care because of this. Only 17% of cisgender women delay seeking preventative care because of uncertainty around guidelines.

The most notable difference is that transgender men (83%) and GNC individuals (67%) largely delay or never seek preventative care because they do not feel that health care providers are culturally sensitive to LGBTQ identities. No transgender women and only 17% of cisgender women reported that they delay or never seek preventative care because of lack of cultural sensitivity from health care providers.

It seems that lack of cultural sensitivity is a significant deterrent for seeking preventative care, as evidenced by markedly lower rates of transgender men and GNC individuals seeking preventative care and scheduling it on time, illustrated by Figures 2.4, 2.5, and 2.6.

Figure 2.6. Reasons for delaying or never seeking preventative care



Accessing Health Care: By Sexual Orientation

Preventative Care

The same data used to examine access to routine preventative care by gender identity was also categorized by sexual orientation. Participants were asked about routine preventative care, which included examples of services such as immunizations, annual pap tests, mammograms, HPV vaccinations, eye exams, and STI/HIV testing.

All participants combined, 70% reported that they always seek routine preventative care. Another 26% reported that they sometimes seek routine preventative care and four percent said that they never seek it.

However, when broken down by sexual orientation gay men (64%) and queer individuals (66%) were less likely to always seek preventative care. Eighty-five percent of lesbian women always seek preventative care.

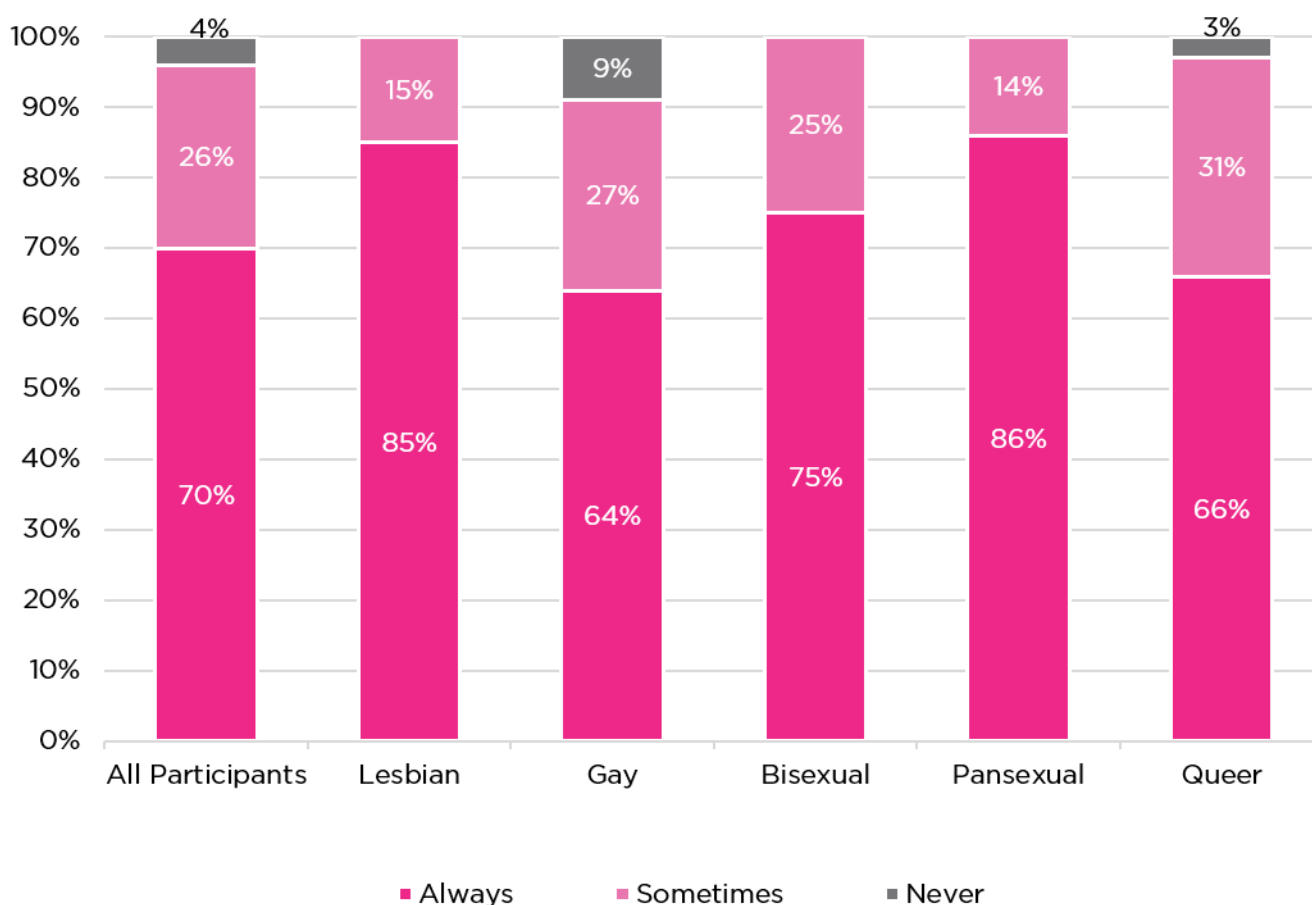
Seventy-five percent of bisexual individuals and 85% of pansexual individuals always seek preventative care.

Fifteen percent of lesbian women and 27% of gay men reported that they sometimes seek preventative care. Twenty-five percent of bisexual individuals and 14% of pansexual individuals sometimes seek preventative care. 31% of queer individuals sometimes seek preventative care.

Nine percent of gay men never seek preventative care and three percent of queer individuals never seek preventative care.

It should be noted that in this study, most gay men identify as transgender men, and intersecting identities may play different roles in an individual's decision to seek or not seek preventative care.

Figure 2.7. Percentage that seeks routine preventative care



Accessing Health Care: By Sexual Orientation

Participants were asked how often they seek routine preventative care according to the recommended guidelines. Overall, 45% of participants reported that they always seek it on time. Another 24% rely on a reminder from their health care provider in order to schedule it on time. Twenty-seven percent typically delay scheduling preventative care and four percent never seek preventative care.

This means that 31% of LGBTQ respondents are not receiving their necessary preventative care, though that number could be even higher if providers are not reminding patients that preventative care is due.

When broken up into sexual orientations, there are stark differences in percentages that always seek preventative care on time.

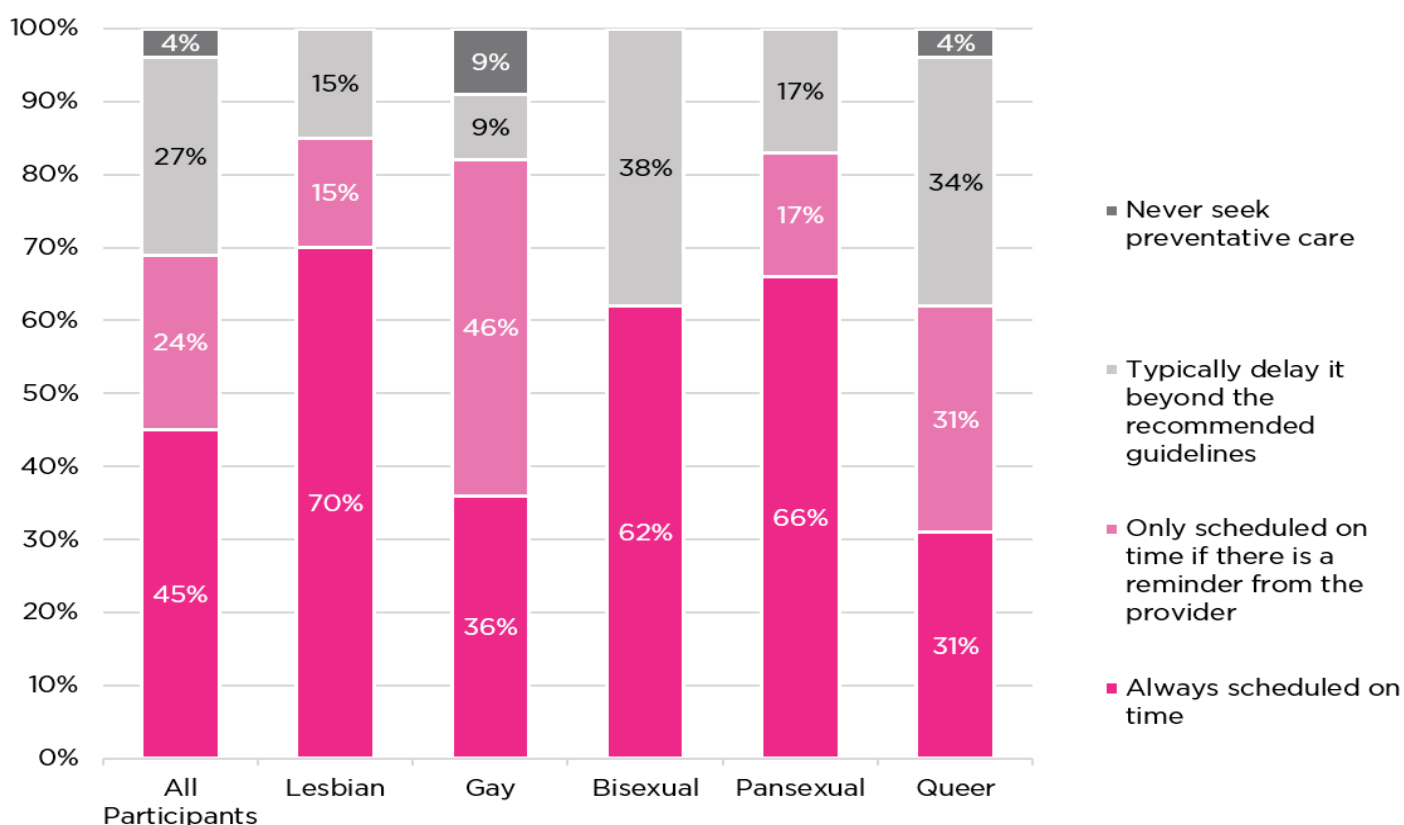
Only 31% of people who identify as queer and only 46% of gay men always seek preventative

care on time. It should be noted that four out of 11 people who identified as gay also identified as a transgender man or GNC. These rates compare with 70% of lesbian women always seeking preventative care on time. Sixty-two percent of bisexual individuals and 66% of pansexual individuals always seek preventative care on time.

Also of note, bisexual individuals (38%) and queer individuals (34%) are much more likely to delay seeking preventative care beyond the recommended guidelines. Reasons for delaying or not seeking preventative care are found in Appendix D, Figure 7.9.

In 2015, another study found that lesbian and bisexual women are more likely than heterosexual women to delay seeking routine care such as breast exams and mammograms.¹⁴

Figure 2.8. Percentage that schedule preventative care according to the recommended guidelines



Health Care Provider Cultural Sensitivity

Ninety-eight percent of participants indicated that they either strongly agree or agree that there is a need for health care providers to undergo LGBTQ cultural sensitivity training. No participants strongly disagreed.

When disaggregated by gender identity, it is apparent that the transgender community feels this more strongly than cisgender sexual minorities.

One hundred percent of transgender men, 96% of GNC* individuals, and 86% of transgender women strongly agreed that there is a need for health care providers to have LGBTQ cultural sensitivity training.

This compares with only 66% of cisgender men and 65% of cisgender women strongly agreeing that there is a need, highlighting a significant gap in provider knowledge about gender identities when learning about the LGBTQ community.

Figure 3.1. Belief that health care providers in Washington state need to undergo LGBTQ cultural sensitivity training

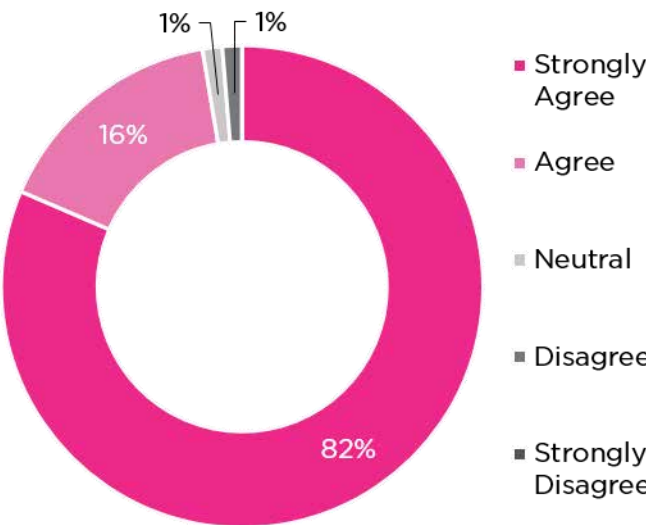
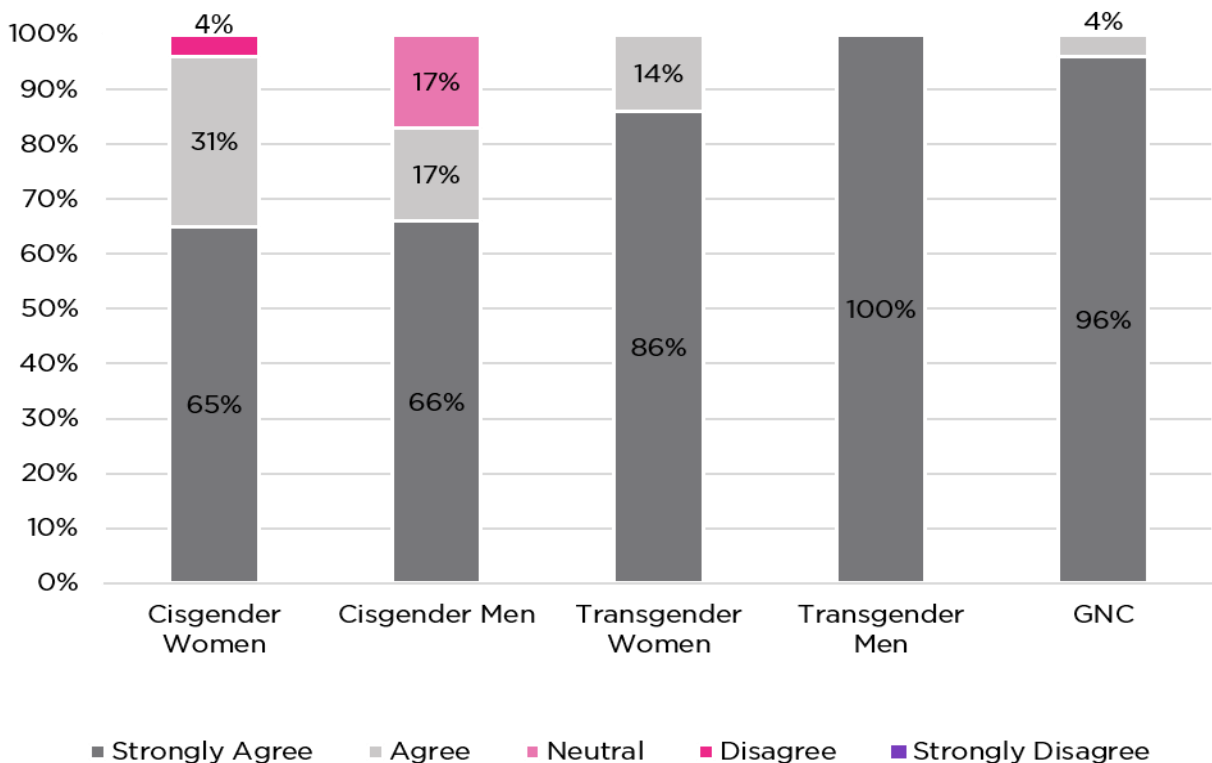


Figure 3.2. Belief that health care providers in Washington state need to undergo LGBTQ cultural sensitivity training, broken down by gender identity



*encompasses all gender non-conforming identities, including but not limited to people who identify as gender fluid, genderqueer, and non-binary.

Health Care Provider Cultural Sensitivity

Understanding of Gender Identity and Sexual Orientation

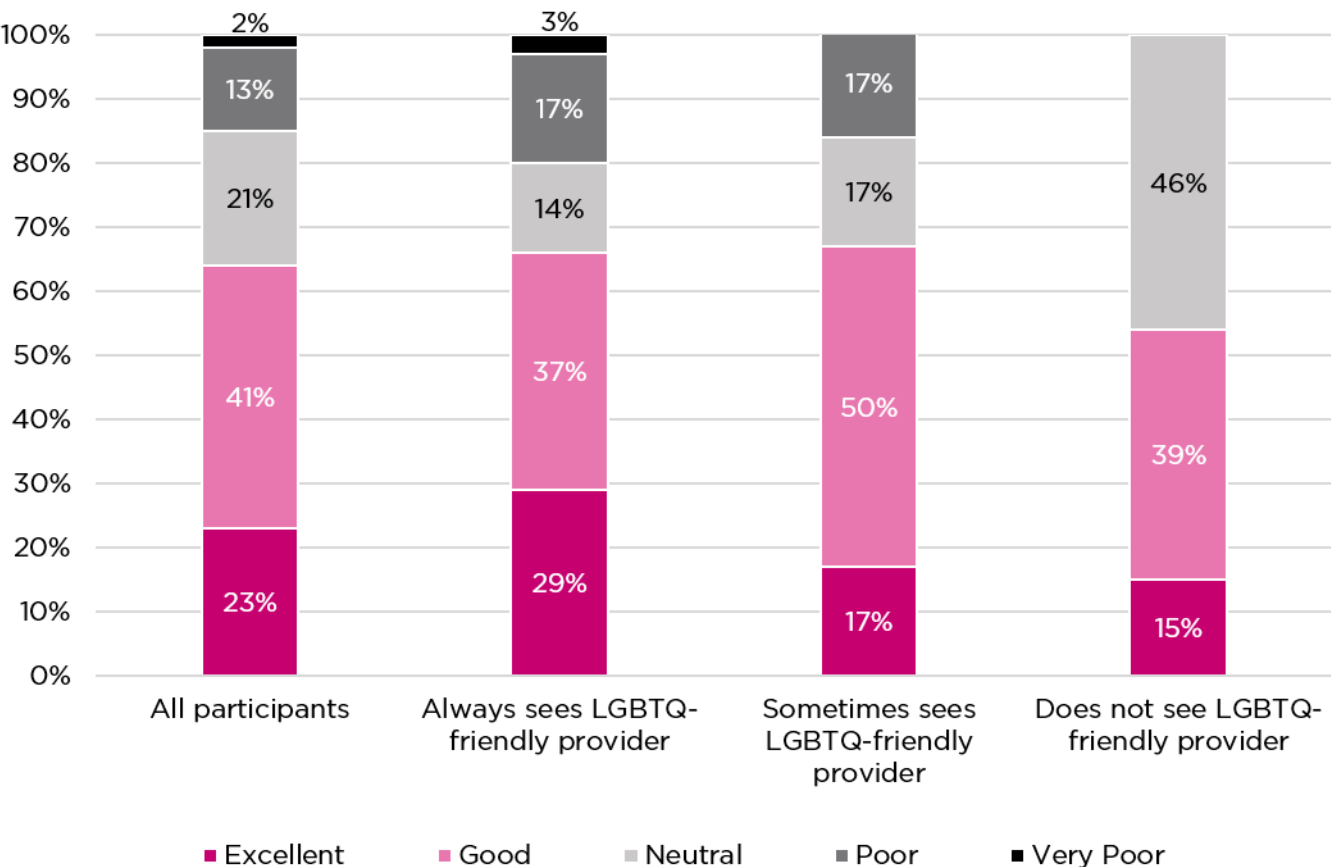
Figure 2.2 highlighted that 53% of participants see a health care provider who specializes in or is sensitive to LGBTQ identities. Figure 3.3 disaggregates data from the participants that indicated that they see a provider sensitive to LGBTQ identities to visualize how LGBTQ-friendly health care providers' cultural sensitivity is actually perceived by the LGBTQ community.

Only 29% of respondents who always see a provider sensitive to LGBTQ issues indicated that their provider is excellent in understanding their gender identity and/or sexual orientation. Another 37% rated their providers as "good." However, 34% of those participants rated their provider as either neutral, poor, or very poor.

This means that while health care providers may believe that they are open-minded and accepting of the LGBTQ community, they may not actually be as knowledgeable or sensitive to LGBTQ identities and LGBTQ health as they believe themselves to be.

This may partly be because health care providers do not learn about LGBTQ health while in medical or nursing school. Literature suggests that nearly 80% of physicians receive zero hours of training on transgender health in medical school, nearly 80% receive zero hours of training on bisexual health, over 60% receive zero training on lesbian health, and nearly 50% receive no training on gay men's health.¹⁵

Figure 3.3. How the LGBTQ community rates how well their providers understand their gender identity and/or sexual orientation overall.



Health Care Provider Inclusivity

Assumptions

Seventy-four percent of respondents reported that they have had health care providers make assumptions about their gender identity and/or sexual orientation, as illustrated in Figure 4.1.

This means, for example, that a provider assumed a respondent to be cisgender or assumed that a patient's partner identified as the opposite sex. Another 10% of respondents were unsure if their health care providers had done this. Only 16% reported that their provider has never made assumptions about gender identity and/or sexual orientation.

Inclusive Language

Figure 4.2 shows that only 38% of respondents indicated that their health care provider always uses inclusive language when speaking to the patient, such as "spouse" or "partner" rather than gendered terms like "husband" or "boyfriend." Another 41% indicated that their provider sometimes does this. Fourteen percent reported that their provider rarely does this and seven percent reported that their provider never does this.

Figure 4.1. How often health care providers use inclusive language

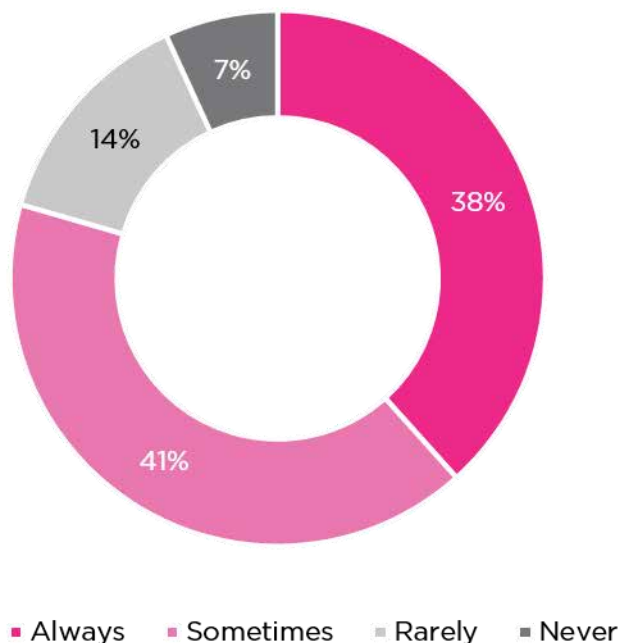
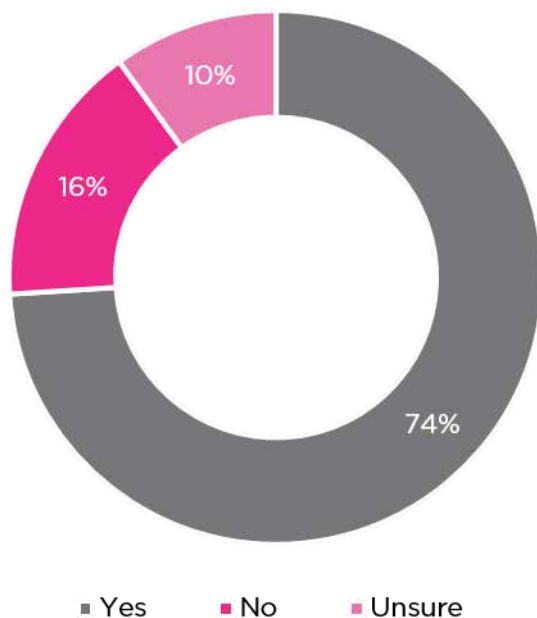


Figure 4.2. Percentage of respondents who have had health care providers make assumptions about their gender identity and/or sexual orientation



Health Care Provider Inclusivity

LGBTQ-Friendly Providers

When examining data only from participants who indicated that they always see a provider that specializes in LGBTQ health or that is sensitive to LGBTQ identities, the findings indicate that even those providers can improve their inclusivity.

According to Figure 4.3, only 45% of participants who always see an LGBTQ-friendly provider reported that their provider always uses inclusive language. Another 45% reported that their provider sometimes uses inclusive language. Ten percent stated that their provider either rarely or never uses inclusive language, despite that they go to a provider who is supposed to be sensitive to LGBTQ identities.

Figure 4.4 further illustrates that providers who consider themselves inclusive of LGBTQ identities may not be as inclusive as they believe. Forty-four percent of LGBTQ-friendly providers do not ask their patients what pronouns to use. Twenty-three percent do not ask if they should use a name other than the patient's legal name. Twenty-one percent do not ask the patients gender identity and 18% do not ask the patients sexual orientation. While these rates are better than the overall rates of

health care providers (Appendix E, Figure 8.2), there is clearly room to increase inclusivity.

This finding underscores other research which reported that only 34.3% of health care providers reported that their intake forms contained a place to disclose sexual orientation and only 11.5% contained a place to disclose gender identity.¹⁶

Figure 4.3. How often health care providers use inclusive language (LGBTQ-friendly providers only)

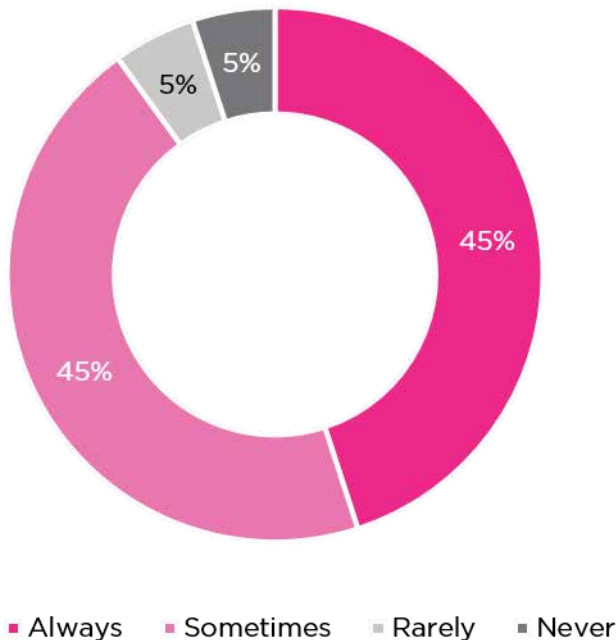


Figure 4.4. Where participants reported health care providers ask about name, pronouns, gender identity, and sexual orientation (LGBTQ-friendly providers only)

	On Forms	In Person	Unsure	Does Not Ask
Name used other than legal name	44%	38%	18%	23%
Pronouns	23%	33%	13%	44%
Gender Identity	49%	33%	15%	21%
Sexual Orientation	51%	38%	18%	18%

Health Care Provider Inclusivity

Disclosure of Identity

While the sample size of transgender and GNC people was small, it is still indicative that many in the LGBTQ community do not disclose their gender identity to their health care provider. This means that a provider may not gather the entire picture about a patient's health needed for comprehensive, accurate treatment.

Only about 43% of trans and gender non-conforming individuals always disclose their gender identity to health care providers. Thirty-seven percent sometimes tell their provider their gender identity, but 19% rarely or never disclose their gender identity to their provider. Figure 5.1 breaks this down by gender identity.

Figure 5.2 indicates that if a provider asks a patient, they are more likely to disclose. When asked how they disclose their gender identity, 62% of respondents indicated that they tell the provider if they ask in person, and 56% tell their provider if they ask on intake forms. However, only 31% of participants write it on an intake form if the form does not ask and only 33% of participants tell their provider if the provider does not ask.

Other research suggests that members of the LGBTQ community are even less likely to disclose their gender identity or sexual orientation during cancer treatment.¹⁷

Figure 5.1. Number of participants that typically disclose their gender identity to their health care provider

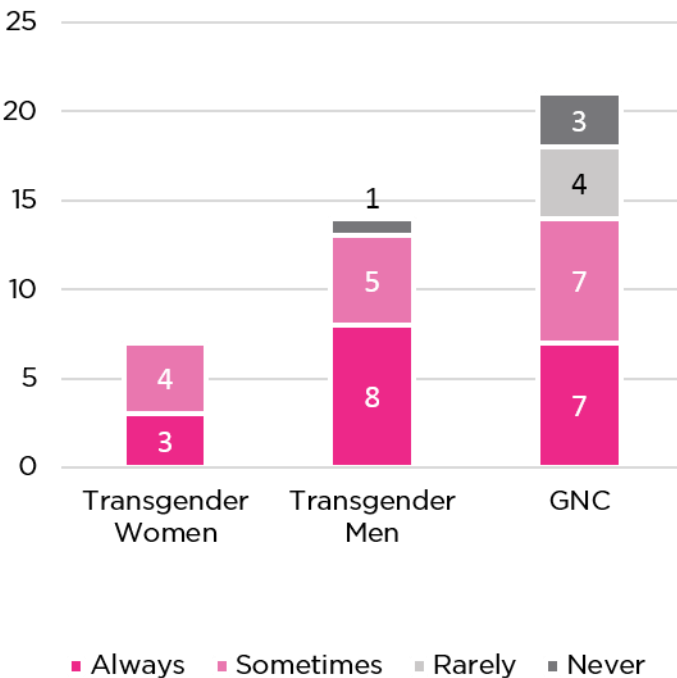
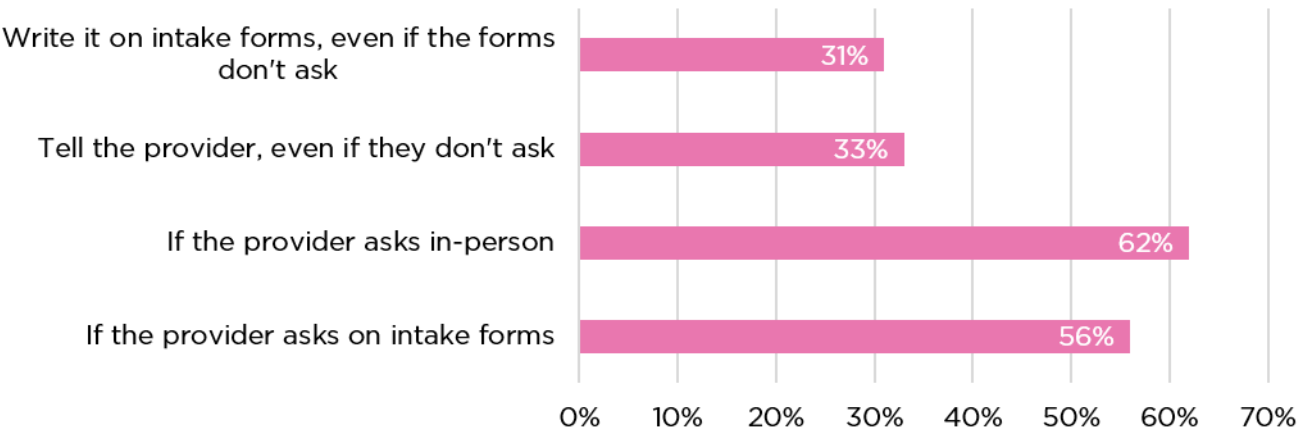


Figure 5.2. How participants disclose their gender identity to health care providers



Health Care Provider Inclusivity

Similarly to the findings surrounding gender identity, only about 40% of sexual minorities report that they typically disclose their sexual orientation to their health care provider. A breakdown by sexual orientation is illustrated in Figure 5.3. Another 41% of sexual minorities sometimes disclose their sexual orientation to their health care provider, but 16% either rarely or never disclose their sexual orientation to their provider.

Similarly to participants who disclose their gender identity to health care providers, people who are sexual minorities are also more likely to tell their provider if they ask in-person (67%) or on intake forms (54%). Another 31% of respondents reported that they tell their health care provider if the provider does not ask, but only seven percent reported that they write it on intake forms even if the forms do not ask.

This points to the need for providers to be able to have conversations with their patients and gather information surrounding gender identity and sexual orientation to provide comprehensive treatment.

Figure 5.3. Number of participants that typically disclose their sexual orientation to their health care provider

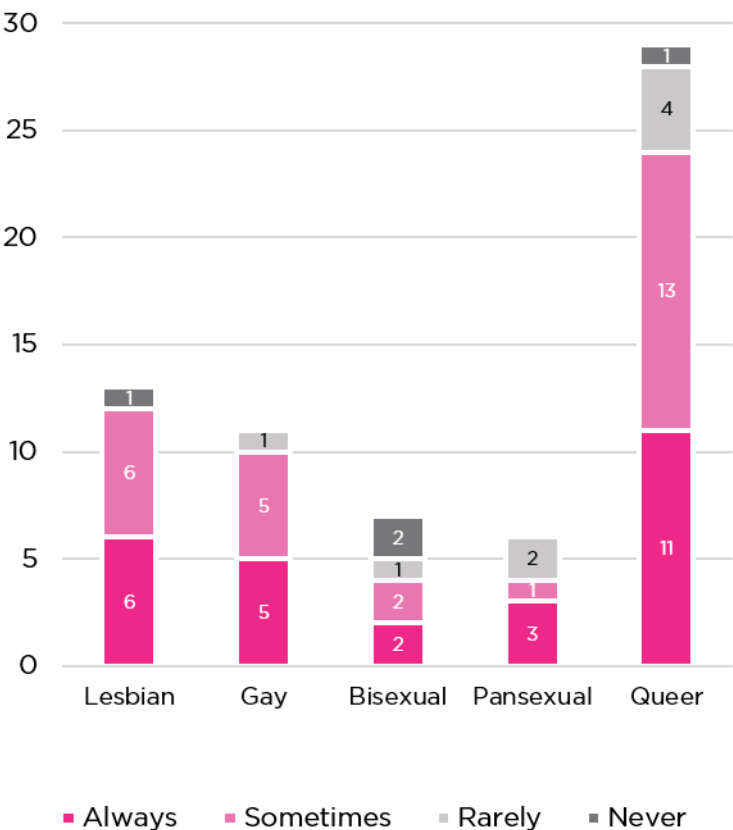
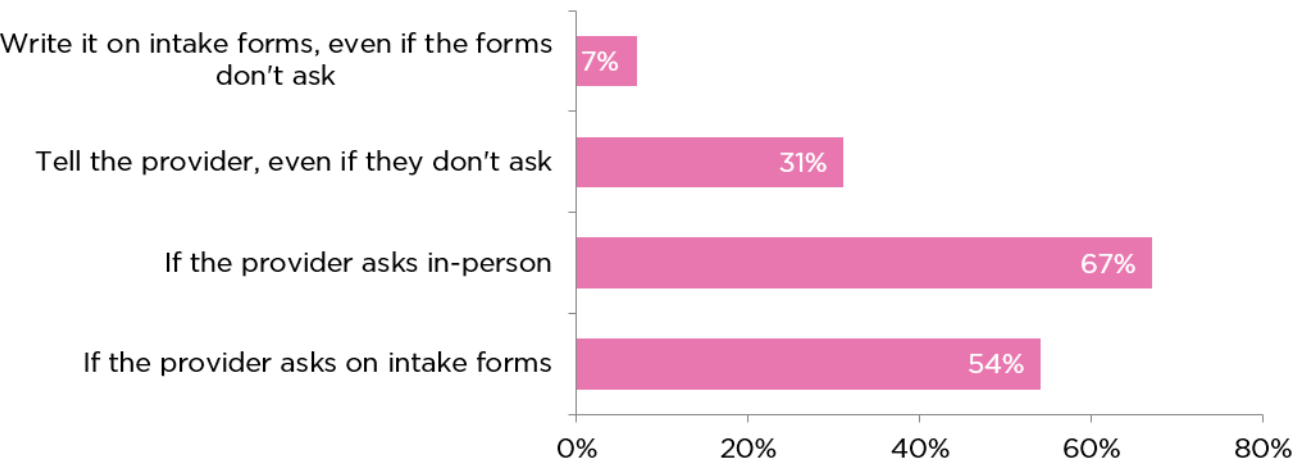


Figure 5.4. How participants disclose their sexual orientation to health care providers



Health Care Provider Inclusivity

Affirmation

Figure 5.5 shows the percentage of respondents who have ever had a health care provider react with immediate affirmation after disclosure of their gender identity or sexual orientation, such as reflecting back someone's identity through language.

Transgender men (21%), gender non-conforming individuals (26%), and queer individuals (28%) have the lowest rates of affirmation. This gap likely contributes to lower rates of seeking preventative care, as well as the perception that health care providers need to undergo LGBTQ cultural sensitivity training.

Providers do not always acknowledge the need to learn more about gender identities or sexual orientations. Figure 5.6 highlights that only 22% of gender non-conforming people, 25% of bisexual people, and 25% of queer people reported that their provider acknowledged a need to learn more after disclosure of gender identity or sexuality. Appendix F has more information on provider reactions to disclosure.

While perhaps providers do not believe that they need to learn more about gender identity or sexual orientation, perceptions from the LGBTQ community indicate that providers do need to increase their knowledge.

Figure 5.5. Percentage of respondents who have ever had a health care provider react with immediate affirmation after disclosure of gender identity or sexual orientation

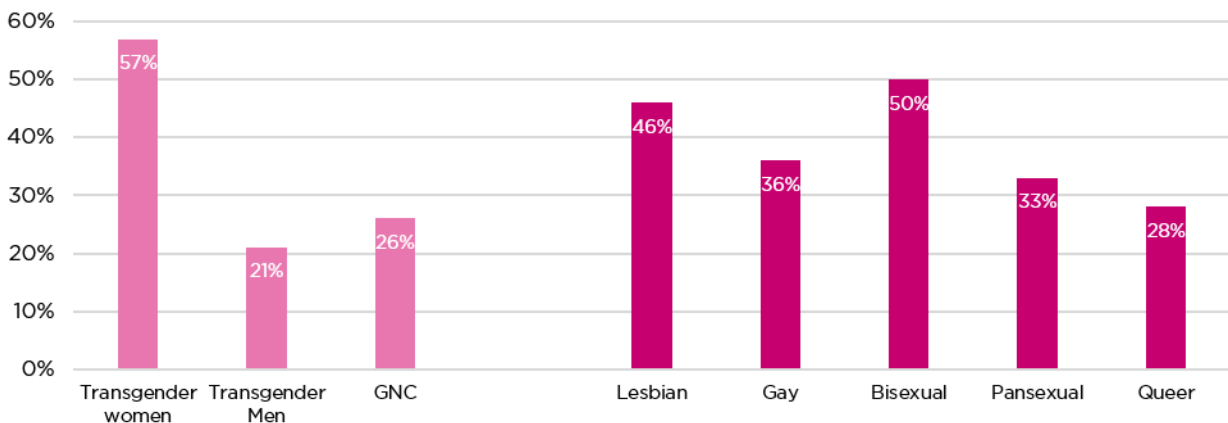
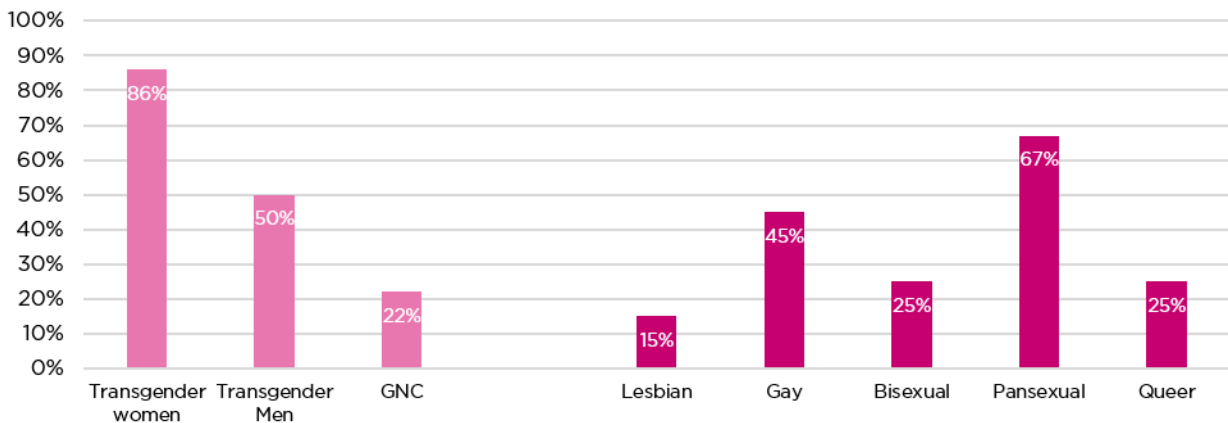


Figure 5.6. Percentage of respondents who have had a health care provider acknowledge their need to learn more after disclosure of gender identity or sexual orientation



Mammography

It is important to note limitations within the data that this study gathered about mammography and the LGBTQ community. This study did not ask for information surrounding hormone usage and surgery status, which affects the need for mammogram screenings in the transgender community. The researcher chose to make the assumption that all respondents who are transgender women are taking estrogen, that respondents who are transgender men have not had chest reconstruction surgery, and that respondents who are members of the community who were assigned male at birth and identify elsewhere on the gender spectrum are taking estrogen.

This means that the data for this section includes only the people who the researcher presumed need mammograms, which means it excludes cisgender men and includes responses from cisgender women and all other people across the gender spectrum.

Fifteen percent of respondents age 40 and older reported that they have *never* had a mammogram. Given that information, it can be

inferred that even fewer people have had a mammogram screening according to the recommended guidelines.

Data gathered by the Department of Health reports that 77.5% of women age 50-74 in the U.S. and 76.3% of women age 50-74 in the Komen Puget Sound service area have had a mammogram in the past two years.¹⁸ Komen Puget Sound gathered data on mammogram screening rates for the LGBTQ community at the Rainbow Health Fair in Seattle on June 25, 2016, illustrated by Figure 6.2.

Out of ten LGBTQ respondents age 50 and older who fit the criteria outlined at the beginning of this section, only 60% had a mammogram within the past two years. Out of 13 respondents age 40 and older, still only 66% had a mammogram in the past two years.

In another study using seven different surveys of sexual minority women, only 73% of women age 40-49 reported ever receiving a mammogram, compared with 87-90% of women in the U.S. general population.¹⁹

Figure 6.1. Percentage of respondents (age 50-74) who have had a mammogram in their lifetime

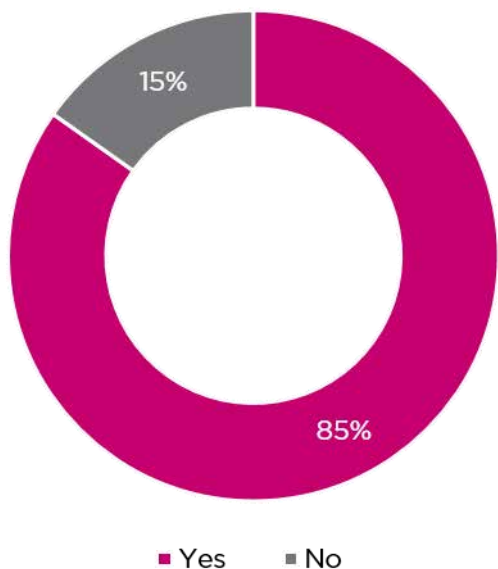
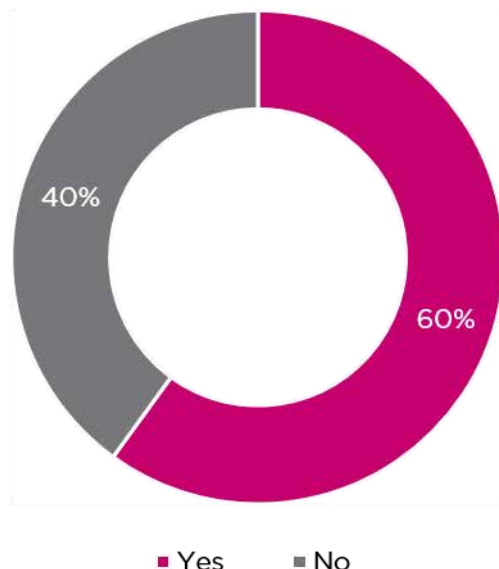


Figure 6.2. Percentage at the 2016 Rainbow Health Fair (age 50-74) who have had a mammogram in the past two years



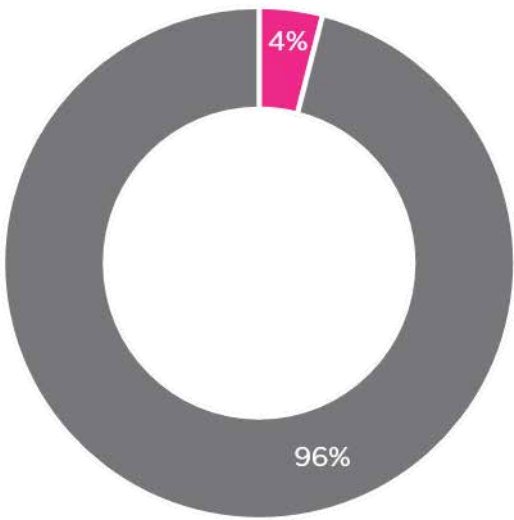
Mammography

The data indicates that members of the LGBTQ community seek mammogram screenings from many different health care providers. Figure 6.3 illustrates where the LGBTQ community goes for their mammograms.

Nineteen percent of respondents indicated that they go to Group Health, 10% go to The Polyclinic, 10% go to Seattle Cancer Care Alliance, and 10% go to Swedish Medical Center. Forty-three percent of respondents indicated they get screened through a provider other than the options provided in the questionnaire, but the locations identified varied widely. See Appendix C, Figure 7.7 for a breakdown of the responses in the “other” category.

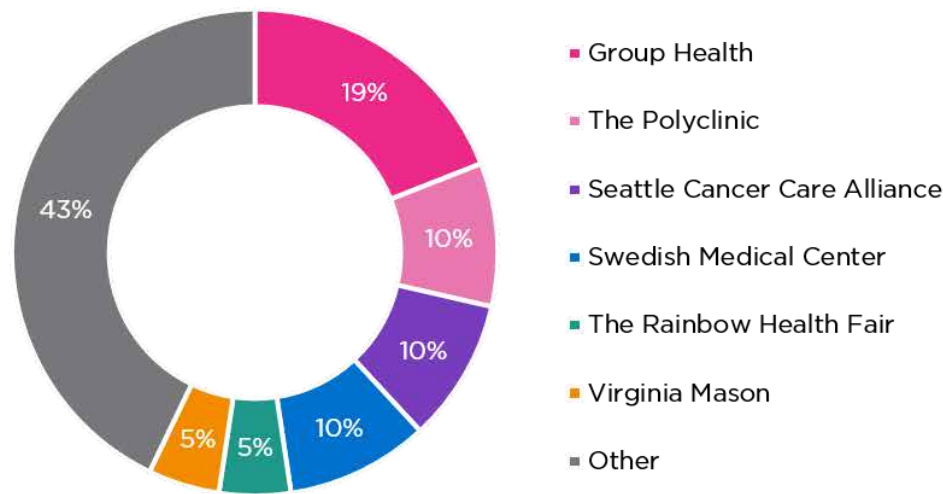
Out of all of the respondents, only two people indicated that they have ever been diagnosed with breast cancer, representing four percent of the pool of respondents age 30 and older.

Figure 6.4. Percentage of breast cancer diagnoses in the LGBTQ community, age 30 and older



- Breast Cancer Diagnosis
- No Breast Cancer Diagnosis

Figure 6.3. Where the LGBTQ community goes for mammography



Breast Health Knowledge

As part of this study, we conducted 17 interviews and asked about knowledge surrounding breast health. The findings are outlined in this section. It is apparent that participants who were assigned female at birth were more likely to receive breast health information than people who were assigned male at birth. Only one out of seven people assigned male at birth recalled learning about breast health while growing up or as an adult.

Interview participants who were assigned female at birth provided feedback that they received a general sense of the importance of mammogram screenings and self-exams from their family. However, three out of the ten interview participants assigned female at birth did not receive any information on breast health from their family while growing up or as an adult.

A common theme throughout the interviews was that if a participant received education surrounding breast health as they were growing up or as an adult, they often had a family member or close friend of the family who had a breast cancer diagnosis. Because most breast cancer diagnoses are not linked to genetics, this speaks to the need for broader education on risk and screening guidelines for everyone, regardless of gender.

Breast Cancer Risk Factors

Ten participants in the interviews cited genetics as a risk factor, either reporting that they knew they had a high risk due to family history of breast cancer or dismissing their risk for breast cancer because they did not have a family history. This initial reaction to breast cancer risk seems to indicate that there is a misconception that breast cancer is largely a genetic disease, when in reality only five to ten percent of all breast cancer cases are due to genetic mutations.²⁰

Only two participants out of seventeen identified age as a risk factor, meaning that risk for breast cancer increases the older a person becomes. This is significant to note, since the two biggest risk factors for breast cancer are simply “being a woman” and “getting older.”²¹

Three participants were able to identify environmental factors as a risk for breast cancer, but did not specify what those might be. One participant accurately noted that smoking and drinking alcohol also increases risk for breast cancer.

Four participants who identified as transgender women did understand that their personal risk may increase when they take hormone medications.²² Participants commented on the complexity of hormone usage and age in relation to breast health, since several of the transgender women who participated began their transition later in life. However, there is not enough research completed to indicate how transitioning from male to female or how transitioning from female to male might affect risk for breast cancer as well as how that risk might change based on age at the start of transitioning.

Breast Cancer Risk for the LGBTQ Community

The LGBTQ community largely does not appear to be aware that research indicates sexual minority women, which for that particular study meant cisgender women, have the densest cluster of risk factors associated with breast cancer.²³ None of the interview participants in this study were able to provide any knowledge of risk specifically for the LGBTQ community.

“I have next to no understanding about stuff like breast care or breast health [because of assumption that I am male].”

-- Genderqueer person

Breast Cancer Screening Knowledge

It is clear that the LGBTQ community needs a greater understanding of the guidelines for breast cancer screening, and particularly a comprehensive set of guidelines for people who are not cisgender.* The recommendations can vary depending upon hormone usage, age when hormone usage began, and whether or not someone has had gender-affirming surgery, which makes the development of screening guidelines challenging.

Self-Exams

No participants knew the correct guidelines for self-examination for breast cancer, which are that self-exams are no longer recommended as a breast cancer screening because studies have shown that they do not offer the early detection and survival benefits of other screening tests and are linked to more false positive results.²⁴ However, it is important to become familiar with the way your chest normally looks and feels, which may help individuals to see or feel changes in their chest.

Most participants who answered the question about guidelines for self-examination believed that it should be done monthly or every few months. Several more participants identified that the self-exams should begin at puberty or when a transgender person begins taking estrogen. Six out of the 17 participants did not have any information to share about self-examinations, and one participant incorrectly stated that *“a lot can be detected with self-breast checks.”*

Clinical Breast Exams

Similarly, participants had little and varying information on guidelines for clinical breast examinations. Only four out of 17 participants were able to provide an answer about the guidelines.

One participant believed that clinical breast exams should occur annually. Two participants believed that the guidelines are for every one to three years. One participant said that they are *“not sure if a clinical breast exam is that helpful.”*

Mammograms

Participants who were assigned male at birth were less likely to have knowledge surrounding guidelines for mammograms. Each of the ten participants who were assigned female at birth had a general idea of the age and frequency guidelines, but only three out of the seven respondents assigned male at birth were able to provide an overview of the guidelines.

Overall, respondents understood that they should seek mammogram screening beginning either in their forties or their fifties, and believed they should be screened annually to every few years. Most respondents recognized that the guidelines have changed in recent years, and that different organizations provide different screening guidelines, which can be confusing. *“I’m not really clear on what is the age, what is the frequency. A lot of contradicting information.”*

*cisgender describes a person whose sex and gender identity align. i.e., someone who was assigned male at birth and identifies as male/masculine

Conclusion

Preventative Care

Our findings indicate that many people in the LGBTQ community, particularly transgender people, delay or do not access preventative health care. For instance, only 21% of transgender men and 39% of gender non-conforming (GNC) people always schedule preventative care on time. By comparison, 57% of cisgender women always schedule preventative care on time.

Delaying or never seeking preventative care means that many people in the LGBTQ community who should be having mammogram screenings are not getting them according to the recommended guidelines. This study indicates that 40% of the LGBTQ community age 50-74 has not had their recommended mammogram in the past two years. This could lead to poorer health outcomes, such as advanced stage breast cancer diagnosis.

Cultural Sensitivity

The reasons behind delaying or not seeking preventative care vary by identity. Eighty-three percent of transgender men and 67% of GNC people delay or never seek preventative care because of health care providers' lack of cultural sensitivity. However, only 17% of cisgender women indicated that poor sensitivity was a barrier for them. Instead, 50% of cisgender women identified inability to afford the cost of services as why they delay or do not seek preventative care.

Even though some participants did not indicate lack of cultural sensitivity from health care providers as a reason for why they delay preventative care, 98% of participants indicated there is a need for health care providers to undergo LGBTQ cultural sensitivity training. Furthermore, data shows that while providers may consider themselves to be affirming of LGBTQ identities, there is room for growth; only 29% of participants who always see an LGBTQ-friendly provider rated their provider as "excellent" in their ability to understand the patient's gender identity and/or sexual orientation. Recommendations from interviewees on best practices for LGBTQ cultural sensitivity are included in the next section.

Breast Health Education

Seventeen percent of cisgender women, 50% of transgender women, 33% of transgender men, and 22% of gender non-conforming people cited uncertainty of preventative health recommendations as a reason why they delay or never seek preventative care. In regard to breast health, interview participants highlighted gaps in knowledge surrounding risk for breast cancer as well as screening guidelines. It is apparent that there is a need for education and outreach to improve community understanding of risk factors for breast cancer and breast health screening guidelines.

In response to these findings, Susan G. Komen Puget Sound will use this report to inform the creation of an LGBTQ breast health toolkit using human-centered design. Recommendations from interview participants about the components of an LGBTQ breast health and cultural sensitivity toolkit can be found in Appendix G. The toolkit will be vetted through a series of focus groups with breast health experts and the LGBTQ community, allowing the opportunity for more voices to be heard, particularly amplifying experiences of people of color in order for this project to increase intersectionality with the priority populations outlined in Susan G. Komen Puget Sound's 2015 [Community Profile Report](#).

This toolkit will supplement existing LGBTQ cultural sensitivity curricula in local health systems and also have a component geared toward empowering the LGBTQ community with relevant information about breast health. We hope that by increasing provider knowledge about the LGBTQ community we will help bridge trust between the community and the health care system, thereby increasing the rate that the LGBTQ community accesses preventative care such as mammography. This is one component of the larger goal of increasing health equity for the LGBTQ community.

Recommendations for Health Care Providers

Respectfulness

Being compassionate and respectful are always essential practices for health care providers, particularly when working with the LGBTQ community. Basic respect was something that many of the participants in the interviews highlighted as something they need from health care providers.

Health care providers should understand the dignity and worth of the person and treat each person in a caring and respectful fashion, being mindful of individual differences.²⁶ The following recommendations should be grounded in the values of respect, dignity, and worth of a person.

"What they did was treat me like a normal human being. Respect, respect, respect."

-- Bisexual Transgender Woman

"My biggest statement is just to be respectful. When they're respectful to me, it's a lot easier to have that conversation and get medical information that they need to them."

-- Queer Transgender Woman

1. Ask Name and Pronouns

Many health systems do already have a location either on their intake forms or within their digital database for a name or nickname other than a patient's legal name. However, it is clear that the majority of health systems do not ask for the pronouns that the patient uses. Making changes to the software used by a health system may prove challenging and time-consuming, but there are temporary solutions until those changes happen, such as either making a note in the physical chart or a note in the digital chart about pronouns.

"Having a form that asks 'What's your preferred name and pronouns' was just, like— I think I stared at it for five minutes. It was just so cool. It wasn't even like to check a box; it was to fill out. And that— it was a really nice experience."

-- Queer Non-Binary Person

"I think it would be really great if health care providers, whether in-person or on forms or both, include a thing about pronouns. So that when they have a patient, they don't just walk in and immediately assume a gender and misgender a person."

-- Bisexual/Pansexual Agender Person

2. Create Comprehensive Intake Forms

Health systems need comprehensive intake forms that gather necessary health information using inclusive language in a way that is non-pathologizing and without judgement. Intake forms should have space for a name other than the patient's legal name and what pronouns to use. They should have as many options as possible for both gender identity and sexual orientation, including space for patients to self-identify.

When providers do include a space on forms for the patient's pronouns, it is an affirming experience for members of the LGBTQ community and sets the tone for the rest of the visit. By asking about pronouns, the patient can infer that the provider will be sensitive to LGBTQ identities, so the patient may be more open in sharing personal health information or more likely to continue to seek care when needed. *"One provider that I went to had checkboxes for literally 'I identify as something else' and it literally had a checkbox for 'I'm transgender.' Just having a checkbox for being transgender means I can start that conversation easier about what I have and what I don't have and who I am seeing."*

Often intake forms ask about sex or gender, but in a way that is not fully inclusive of the spectrum, and in a way that assumes that sex assigned at birth and gender identity align. One respondent discussed what a transgender nurse advocates that intake forms should include: *"He was talking about asking gender assigned at birth and asking if your gonads are intact. And if you say your gonads are not intact, asking what surgeries you've had and when. Because asking if your gonads are intact does not only get to if you had gender affirming surgery, but also information about cancers, too, because that's another common reason why those things are removed."*

Asking open-ended questions is another way for health care providers to gather information about their patients rather than through an intake form. *"I think there can be maybe on a general intake form, something like 'Is there something the doctor needs to know about you that would help us bring you health care?'"*

"One thing that I did not like about any of those places was that they just had a questionnaire asking if you were female or male and I always had write in the corner that I was transitioning."

-- Gay/Queer Transgender Man

"Have a sheet of paper that asks people what their sexuality is and allows them to have any option from polyamorous, to pansexual, to queer, to gay, to having all that instead of just gay or straight."

Allow people to have a gender that's not just female or male to fit in that binary box – it can have trans female, trans male, androgynous, agender, be able to check as many options as they want. Even a pronoun box that says he/him, she/her, they/them, ze/zir, all that in there so that you've got the person's gender identity, the person's pronouns, and their age, and then their sexual orientation so when you go in and have all those invasive questions around somebody's sexual activity that somebody doesn't assume that you're having penis-in-vagina sex or whatnot."

You could even have a blank for 'What do you call 'down there'?' if that's not too many questions."

-- Gay/Queer Transgender Man

3. Ensure Staff Reads Charts or Intake Forms

While many in the LGBTQ community identified ways that intake forms can be used to create an inclusive environment, the forms are only effective if all staff members involved across the continuum of care read the chart, absorb the information, and react accordingly.

According to participants, especially transgender participants, even if providers ask questions around gender identity and sexual orientation, often staff do not take the time to read the chart thoroughly enough to understand the patients' needs. One transgender man spoke about needing an STI test. *"Then the test that they brought out was not appropriate for me. And I said 'Did you read my chart?' Because it was like in this big colorful, like, something different. And I was like, 'Really, did you not read that? Because it's not going to work for me.' You know, that piece of equipment isn't going to work. I think you'll need a swab."* Reading charts and intake forms is important not just for cultural sensitivity, but also in providing accurate care for patients.

Often health care providers within a larger health system do not have the autonomy to make changes in an online system that allow for greater inclusivity. Regardless of the health system's ability to make a note in their online charts of something like pronoun usage or gender identity, staff can take action to address patients the way that the patients identify.

"I don't care about the intake forms so much, because intake forms don't even get looked at. That was the problem with the first person I had. She didn't even address why I was there based on my intake form."

-- Queer Genderqueer Person

"I said I use they/them pronouns. And she looked at my chart and said 'There's no way for me to put that in here.' I said, 'That's not the problem. You and I are having the conversation. You can use those pronouns.'"

-- Queer Genderqueer Person

4. Experiences in the Waiting Room

Often health care departments or offices for gynecology or other similar services are named as a “Women’s Health Center.” This can be ostracizing to members of the LGBTQ community who do not identify as women but who need health care services for anatomy that society associates with women.

Waiting rooms for services like a mammogram or pap smear can be particularly uncomfortable for transgender and gender non-conforming individuals, especially when staff does not listen to the patient’s needs or read the patient’s chart that indicates what name to call.

Several transgender people recounted their experiences trying to receive a mammogram screening. This happens both for transgender men who need services that are typically associated with the female gender and for transgender women who are still perceived as male by staff.

“Their waiting room is equally, um, daunting because it’s called the ‘Women’s Health Center.’”

-- Gay Transgender Man

“I’d be waiting in the lobby and they’d say [my name] and I would stand up and walk over and they’d say ‘No, no. [My name].’ And I’d say ‘That’s me.’ And I’d have to explain that I’m transgender.”

-- Lesbian Transgender Woman

“Then when the person from the desk came to get me to go back, she kept reading the name on the chart as [my former female name].... Another couple minutes she comes back out, ‘[My former female name]?’

So I went up to her and said, ‘I think you’re trying to say my name. It’s [my male name]. Is that who you’re looking for?’ And she looks down at her chart, looks at what needs to be done, and looks back up at me and says, ‘Oh, I don’t think this is for you. It isn’t for you.’ And I said, ‘I’m fairly sure it is.’

And she says no, closes the door, runs to the back, some sort of conversation happens. So she comes back into the waiting room, she has the chart in her hand, and she talks to my advocate and says ‘Okay, here’s what we’re going to do next.’”

-- Gay Transgender Man

5. Don't Make Assumptions About Gender Identity and Sexual Orientation

Overall, participants reported that health care providers often made assumptions about their patients' sexual orientation and gender identity, as well as the identities of patients' partners. Asking open-ended questions surrounding gender and sexual behavior can be important depending upon what health care services the patient is seeking. Many providers assume what anatomy that the patient and/or the patient's partner(s) have, which can affect recommendations for testing or preventative care.

Just like many health care providers make assumptions about gender identity and anatomy, they also make assumptions about the sexual orientation of their patients. When related to assessing risk or treatment needs, providers should be asking questions about sexual orientation as well as sexual behavior, with an understanding that there can be a difference between identity and behavior.

"It's very frustrating to have it assumed that I am a cis, AFAB [assigned female at birth] woman every time I go into the doctor's office."

-- Bisexual/Pansexual Agender Person

"Before I out myself to providers they always assume my gender identity is female, and it is not. And even after I tell people that I identify as trans, they still mess up and call me 'she' and 'her' and a 'woman' and assume my gender identity in that way."

-- Queer Gender Non-Conforming/Transgender Person

"I don't actually know that anybody has ever asked me about my sexuality....I thought it was rather humorous when [my same-sex partner] and I first got together as partners, I did go into the doctor and asked to be checked for STDs. She gave me this eye roll comment 'Oh you single women.' ... I just thought her comment was funny about me being single and promiscuous."

"But she didn't, nor has anybody, ever asked me if I have an active sex life with women. I guess, they just never asked. Nope. Nobody, I don't think, has ever asked me that question."

-- Bisexual Transgender Woman

"Having this cis straight guy doctor assume that I was straight, I didn't feel like I could correct him. And he wanted to do pap smears and I was like 'Uhm.....' and so I kind of stopped seeing a doctor, I kind of like refused to go to a doctor for many years."

-- Queer Gender Non-Conforming/Transgender Person

6. React to Disclosure in an Affirming Way

A visibly negative reaction from a health care provider when a patient corrects assumptions about gender identity or sexual orientation can be traumatic for the patient and can impact the current visit as well as have a lasting impact on whether or not a patient seeks health care and preventative care in the future.

For example, a patient whose provider reacted negatively to the patient's queer identity and did not ask any questions about the patient's sexual behavior but also did not want to perform a pap smear test. *"And then when I finally got her to give me a pap smear it was a very uncomfortable experience because she seemed uncomfortable with me."* This resulted in the patient delaying preventative care in the future.

The experiences that participants spoke about during their interviews highlight the need for health care providers to think through their reactions to disclosure of gender identity and sexual orientation so that they can affirm the identities of their patients, rather than giving an impression of discomfort, disapproval, or judgement.

"There is usually kind of a blank look on the person's face. Most people – increasingly, people are aware of binary trans identities, but the non-binary identities are still basically just another language to most people. So talking to health care providers and saying 'I'm agender, please use 'they' pronouns,' they don't really know what that means or how to deal with that. So that has been a struggle."

-- Bisexual/Pansexual Agender Person

"So they went down the current medication list and she was like, 'Oh, you're taking testosterone. Are you a trans?' And I was just like 'Uhhhhh. Yes?' And she was like, 'Do you want me to add this to your problems list?'"

-- Queer Non-Binary Person

"And everybody looked at me funny because I was a big fat old man with a beard and a hat. And they said 'You know, this is for ladies. This is for a mammogram.' And I said 'I know, I'm here for a mammogram.'"

-- Lesbian Transgender Woman

7. Be Mindful When Asking Questions

While participants want health care providers to continue to learn about LGBTQ health, they do not necessarily want to be the source of that education when in a providers' office for a visit. Health care providers should be mindful of whether they are asking questions to provide quality care for the patient or whether they are asking questions for their own education or curiosity. One participant suggested: *"And then keeping their questions to themselves until they can look it up later – there's a human on the other end of their questions."* Patients come to health care providers for care, not to educate the provider on an identity.

However, there are questions particular to each individual patient that are crucial for a health care provider to ask in order to gather the most accurate health information. Regardless of whether or not an intake form asks inclusive questions about sexual orientation or gender identity, the health care provider should be able to ask questions surrounding identities and behaviors.

Appropriate timing is also important when health care providers ask their patients questions about gender identity and sexual orientation. Staff asking questions about gender identity or sexual orientation while in the process of performing invasive procedures tends to be an uncomfortable time for the patient to have that discussion. Ideally, questions surrounding gender identity and sexual orientation should be asked before or after medical procedures instead of during them.

"The nurse practitioner who did [the pap test] was quizzing me about my gender identity while inserting it. And I was just like 'I'm not really comfortable having this conversation with your hand up my vagina.'"

-- Queer Non-Binary Person

"So providers instead of making assumptions about what taking testosterone means, they could say 'So what does that mean for you?'"

-- Queer Non-Binary Person

"He just got very quiet and kind of leaned in, and just immediately came out with 'Well, what would you like me to call you?'"

-- Bisexual Transgender Woman

"He asked about my sex life in really affirming ways of asking what anatomy my partner has, how my partner identifies and whether we describe our union as a marriage. A ton of really good questions of other intersecting things, like what other health problems I had, a ton of stuff about how my relationship was. It was a really holistic, like let's get the entire picture of your life kind of thing."

-- Pansexual Transgender Woman

8. Stay On Topic

The recommendation of staying on topic was a theme that emerged in the interviews that the study did not touch on through the quantitative data. While holistic care is important, some LGBTQ participants felt that questions unrelated to the purpose of that particular visit to the provider were intrusive and often insensitive to the patient's health history. For example, when a patient is at an urgent care center for a cold, the person's long-term plans for transitioning are not relevant to treatment, nor does that physician need to know the details since they are not the patient's primary care physician.

“Then the doctor was like ‘So what are your plans for surgery?’ And I was like ‘I have a cold.’”

-- Queer Non-Binary Person

“I went to the doctor for a kidney infection, and in so much pain that I was throwing up because of this kidney infection and I wanted antibiotics and anti-nausea medication. And she left for a while and came back and she was like ‘Well, you know, you are overweight, so we can get you set up on a diet and exercise plan.’

And ignores the fact that I had an eating disorder growing up. I spent 15 years being anorexic. [They didn’t ask any history around that.] So there’s a lot of room for sensitivity and improvement in a lot of areas.”

-- Bisexual/Pansexual Agender Person

“Keep it straightforward to what you’re examining, what you’re doing, what your purpose is. I’m fully tattooed on my body and I’ve been commented on those things. I’ve been commented on size, when I was larger to when I was smaller. I was either underweight or overweight, but that wasn’t what I was in there for.

I understand that it’s a whole health thing, but when you sprain your foot or cut your finger open your weight doesn’t matter. I’d like to stay focused on the issue. If my finger is bleeding and you need to be sewing it, my weight shouldn’t matter in the conversation.”

-- Queer Genderqueer Person

APPENDICES

Appendix A: Qualitative Research Demographics

The researcher was mindful of ensuring that the demographic makeup of interview participants represented as many genders, sexualities, and racial/ethnic identities as possible. Demographics of the interview participants quoted in this report are outlined below:

Gender Identity

Two interview participants identified as cisgender women. Four interview participants identified as genderqueer and one person as non-binary. Three participants identified as transgender men. Five participants identified as transgender women. An additional participant identified as a transgender woman who is non-binary. One participant identified as agender.

Sexual Orientation

Three participants categorized their sexual orientation solely as bisexual. Another participant identified as bisexual or pansexual. One

participant identified as gay, and one participant identified as gay and queer. Three participants categorized their sexual orientation as lesbian. Six participants categorized their sexual orientation solely as queer. One participant identified as queer and pansexual, and one participant identified solely as pansexual.

This sample size clearly represents a variety of identities throughout the spectrum of gender and the spectrum of sexuality.

Race/Ethnicity

One participant identified as biracial (half white and half Hispanic/Latino). One participant identified as biracial (half Hispanic/Latino and half black/African American). Another participant identified as mixed race and Hispanic/Latino. Fourteen of the 17 participants identified as white.

Figure 7.1. Gender identity of interview participants

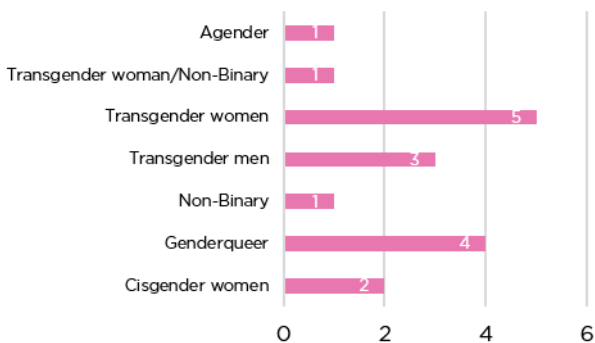


Figure 7.2. Sexual orientation of interview participants

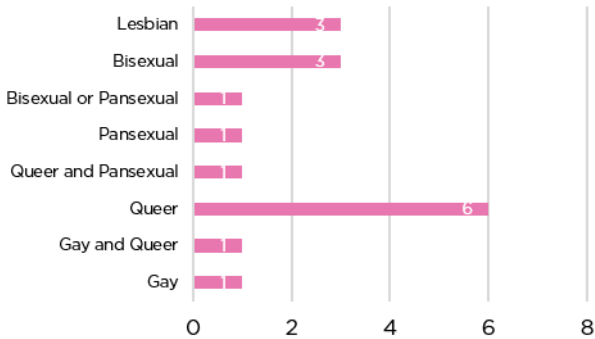
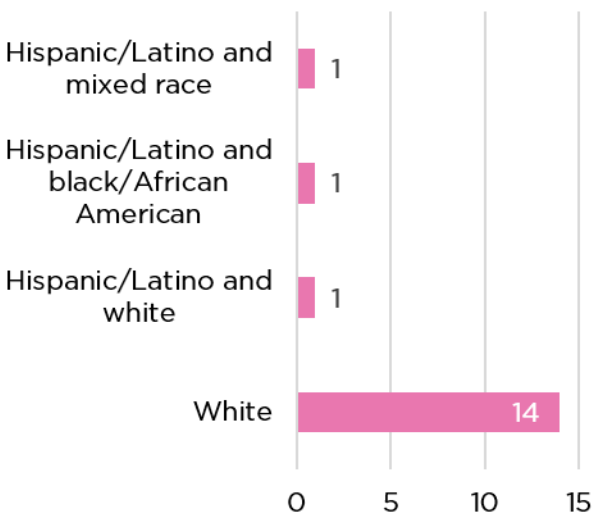


Figure 7.3. Race/Ethnicity of interview participants



Appendix B: Gender Identity

Figures 7.4 and 7.5 break down the gender identities of participants based on the sex each was assigned at birth. This was done to gain a deep understanding of participants' identities because people who are genderqueer, gender fluid, gender non-conforming or non-binary may have different health care needs based upon how their assigned sex at birth intersects with whether they use hormone therapy and whether they have had gender-affirming surgery.

Figure 7.4. Gender identity of participants who were assigned female at birth

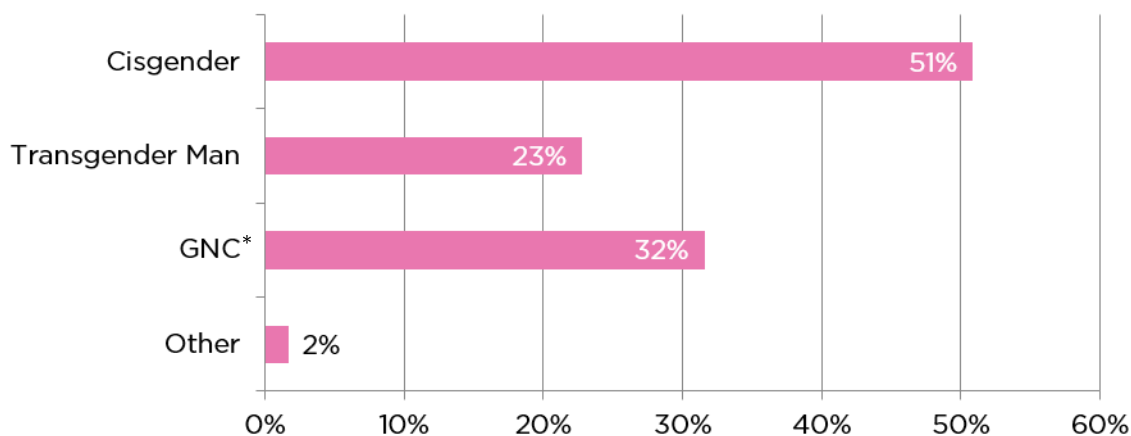
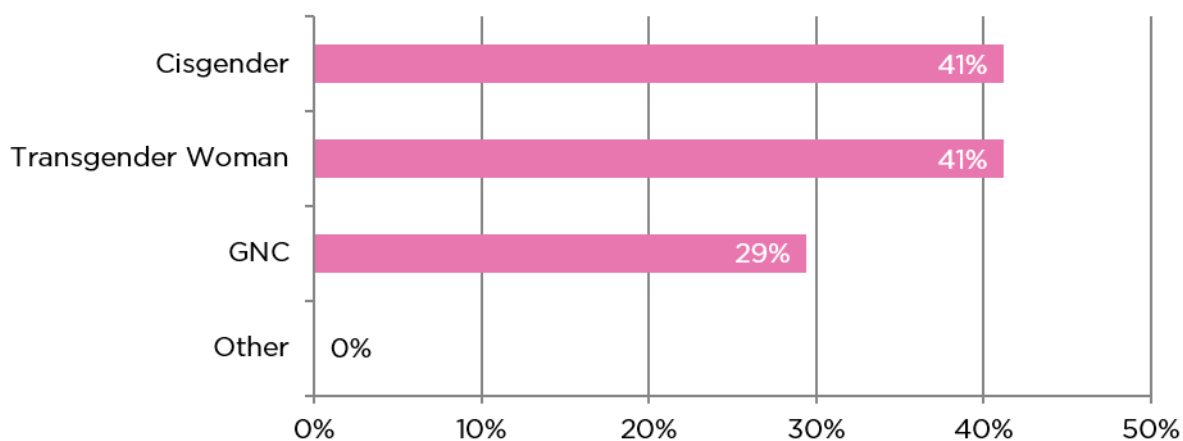


Figure 7.5. Gender identity of participants who were assigned male at birth



Appendix C: Provider Locations

Figure 2.1 indicated that when asked where they typically seek health care, 37% of respondents chose “other” and wrote in answers. Figure 7.6 outlines how many participants seek health care at each location in the “other” category.

Figure 7.6. Responses in the “other” category for where participants typically seek health care

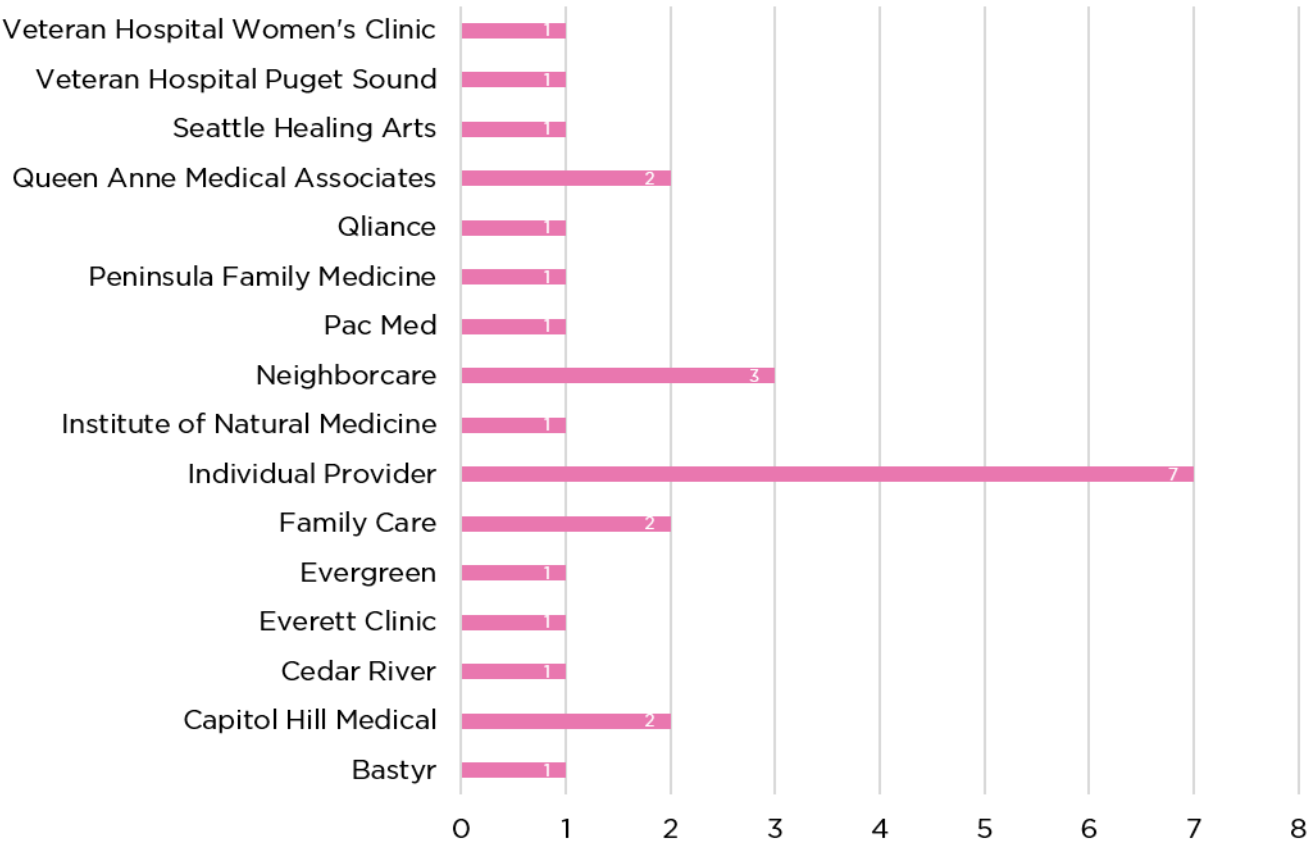
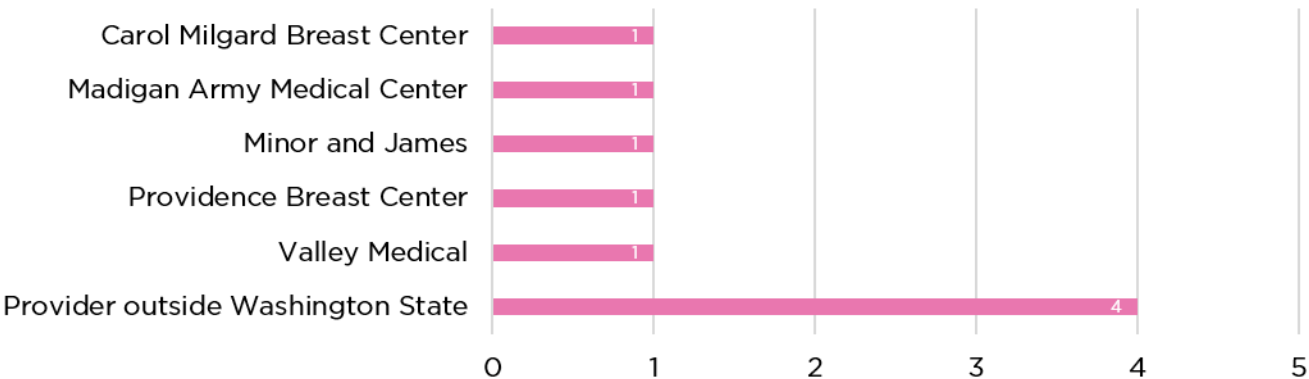


Figure 6.3 indicated that 43% of LGBTQ community members who received a mammogram went to a location other than the choices listed in the questionnaire. Figure 7.7 illustrates how many people went to each location identified in the “other” category.

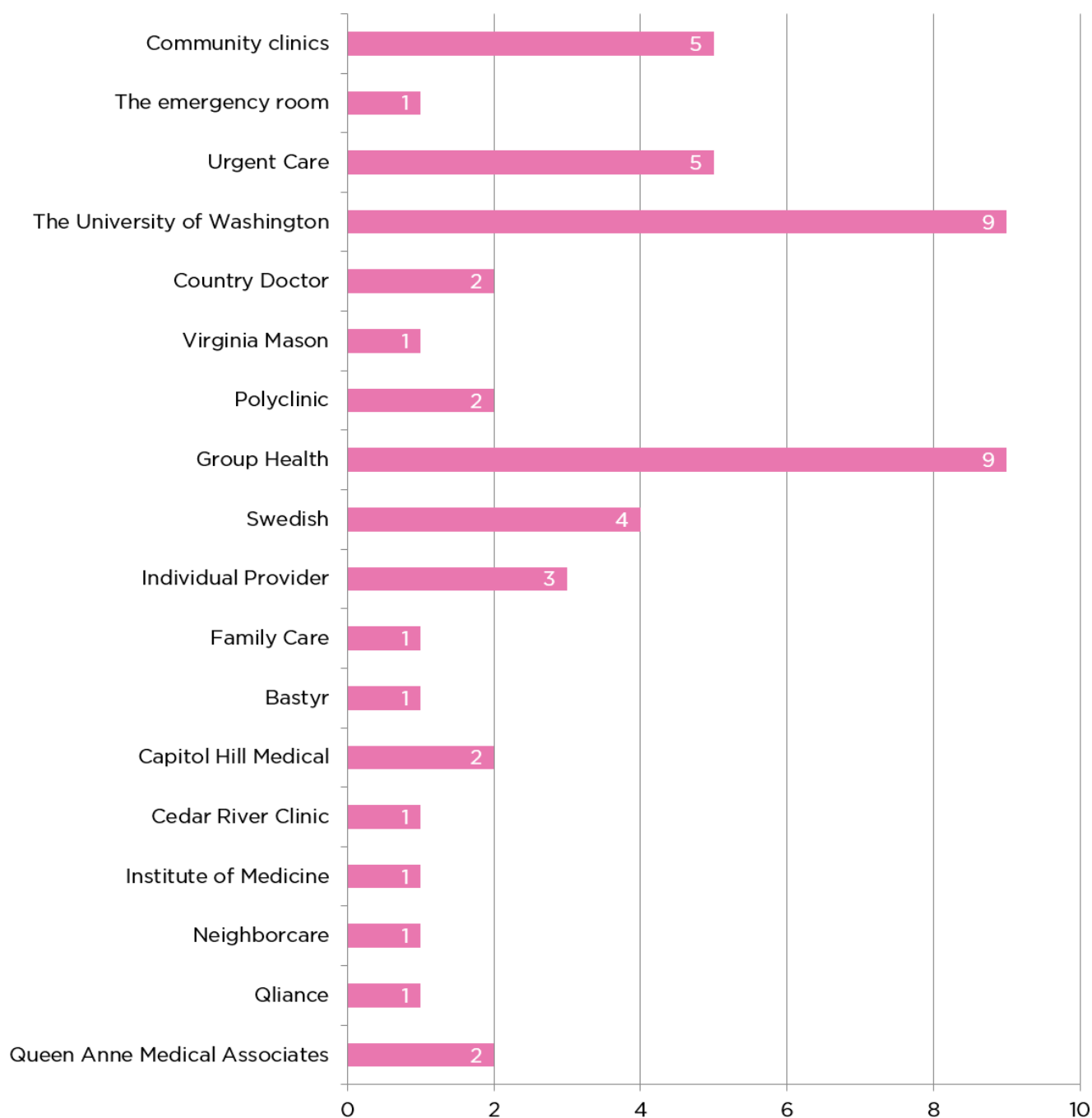
Figure 7.7. Responses in the “other” category for where participants go for mammography



Appendix C: Provider Locations

Fifty-three percent of respondents indicated that they always seek health care providers that either specialize in LGBTQ health or who are sensitive to LGBTQ identities. Figure 7.8 is a breakdown of where those participants seek health care. Nine people indicated that they go to the University of Washington and nine people indicated that they go to Group Health. Five people indicated that they go to community clinics, five people indicated that they go to urgent care centers, and four people indicated that they go to Swedish Medical Center.

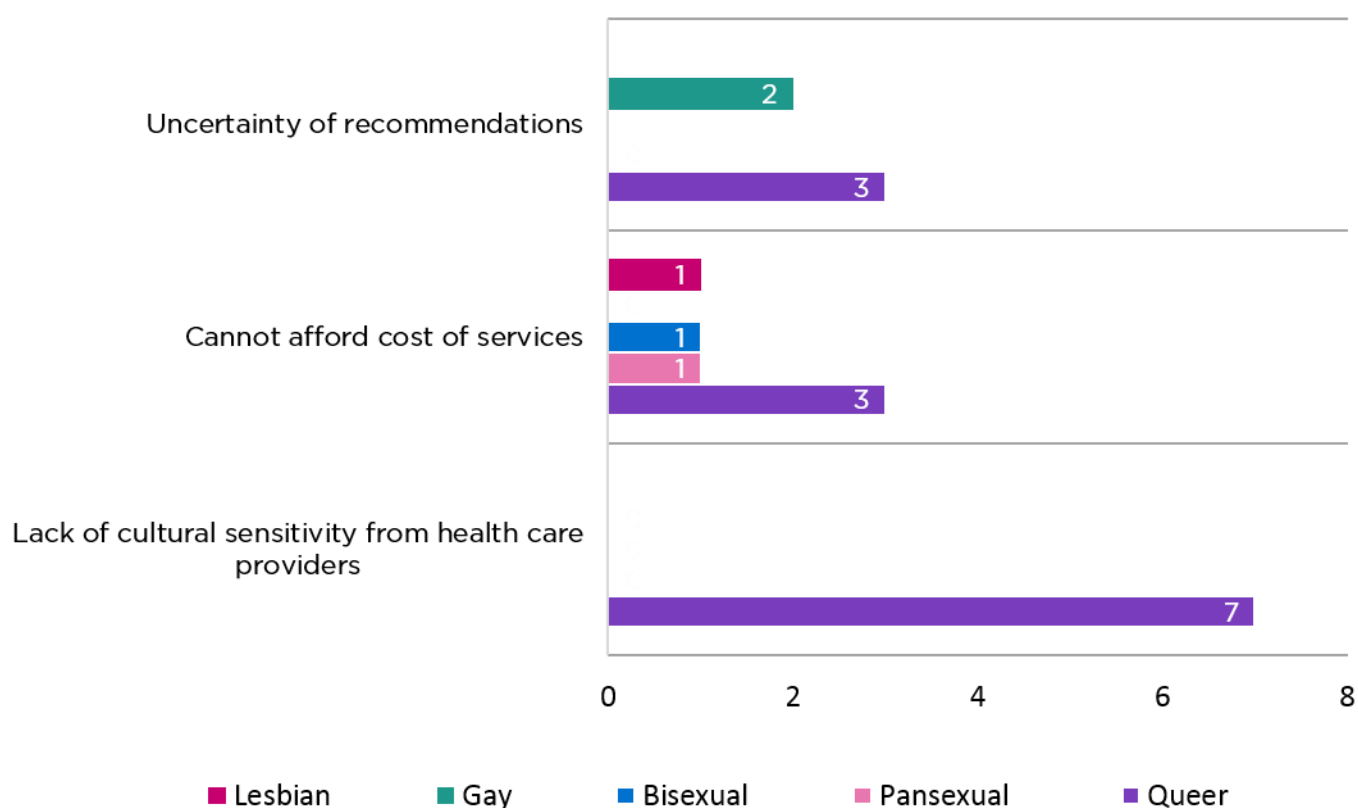
Figure 7.8. Breakdown of the health systems where participants go who seek a provider that specializes in LGBTQ health or who is sensitive to LGBTQ identities



Appendix D: Preventative Care By Sexuality

Figure 7.9 illustrates the reasons why sexual minorities delay or do not seek preventative care. Of the 12 people who identify as queer and reported that they either delay or do not seek preventative care, seven said that it is because health care providers are not sensitive to LGBTQ identities. No other sexual minorities reported this as a reason for delaying or not seeking care, highlighting a gap in provider knowledge about the many identities within the spectrum of sexuality other than lesbian and gay identities.

Figure 7.9. Reasons for delaying or never seeking preventative care



Appendix E: Health Care Provider Inclusivity

Figure 8.1 shows the breakdown by gender identity of how often participants' health care providers used inclusive language when speaking with them. Only five cisgender women, four cisgender men, four transgender women, four transgender men, and eight gender non-conforming people reported that their provider always uses inclusive language.

Figure 8.2 illustrates the overall breakdown of whether participants' health care providers ask what name to use other than a legal name, what pronouns to use when referring to the patient, the patient's gender identity, and the patient's sexual orientation. It shows that 62% of providers do not ask what pronouns to use, 45% do not ask about gender identity, 37% do not ask about sexual orientation, and 37% do not ask what name the patient would like to be called.

Figure 8.1. How often health care providers use inclusive language when speaking with the LGBTQ community, broken down by gender identity

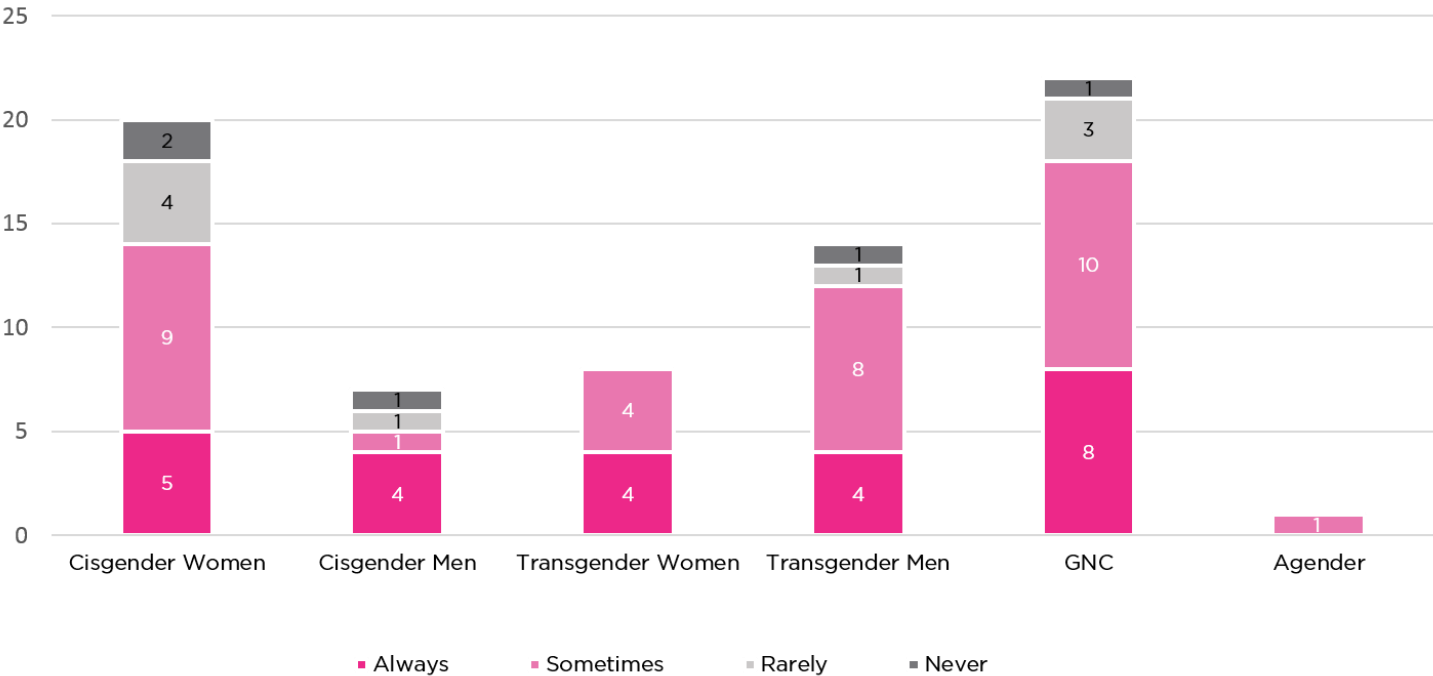


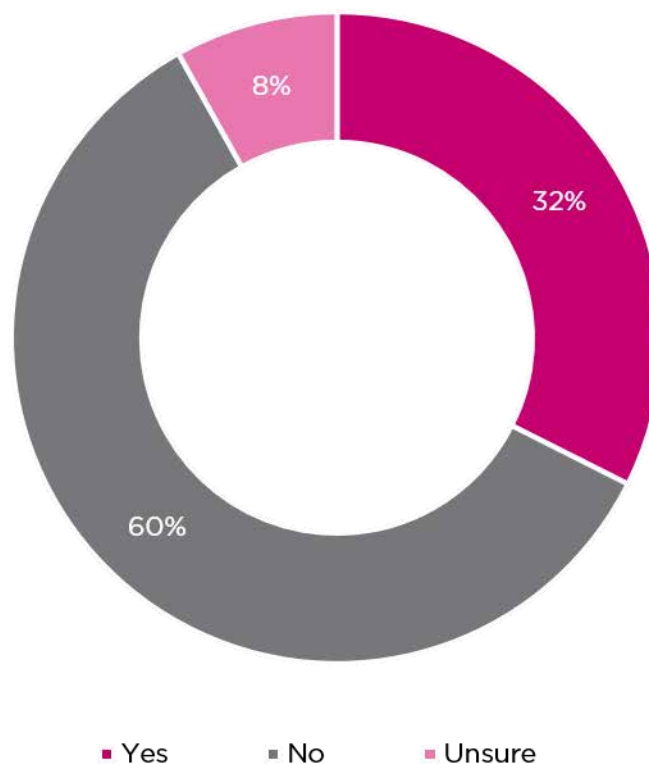
Figure 8.2. Where health care providers ask about preferred name, pronouns, gender identity, and sexual orientation

	On Forms	In Person	Unsure	Does Not Ask
Name used other than legal name	38%	34%	14%	37%
Pronouns	14%	26%	10%	62%
Gender Identity	34%	55%	14%	45%
Sexual Orientation	33%	28%	15%	37%

Appendix E: Health Care Provider Inclusivity

Participants were asked whether their health care provider has ever asked about their experiences with intimate or sexual partner violence. This includes providers asking questions such as “Does a partner or anyone at home hurt, hit, or threaten you?” Only 32% of respondents indicated that a provider has asked them about intimate partner violence, and another eight percent were unsure if a provider had asked. Sixty percent reported that a provider has *never* asked about intimate partner violence.

Figure 8.3. Has a health care provider ever asked about your experiences with intimate/sexual partner violence?



Appendix F: Health Care Provider Sensitivity

Participants were asked about reactions from their health care provider upon disclosure of their gender identity and/or sexual orientation. Figure 8.4 outlines the percentage of people based on identity who have had a health care provider give a blank stare or look confused upon patient disclosure of identity. Figure 8.5 outlines the percentages of people based on identity who have had a health care provider act embarrassed after disclosure of the patient’s gender identity and/or sexual orientation.

Figure 8.4. Upon disclosure of sexual orientation or gender identity, has a health care provider ever given a blank stare or looked confused?

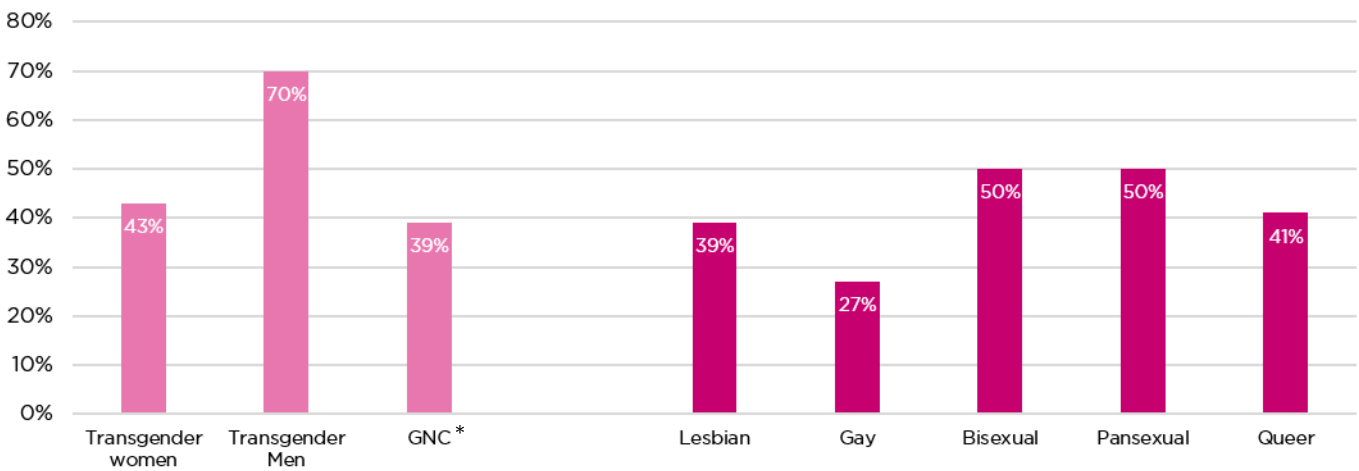
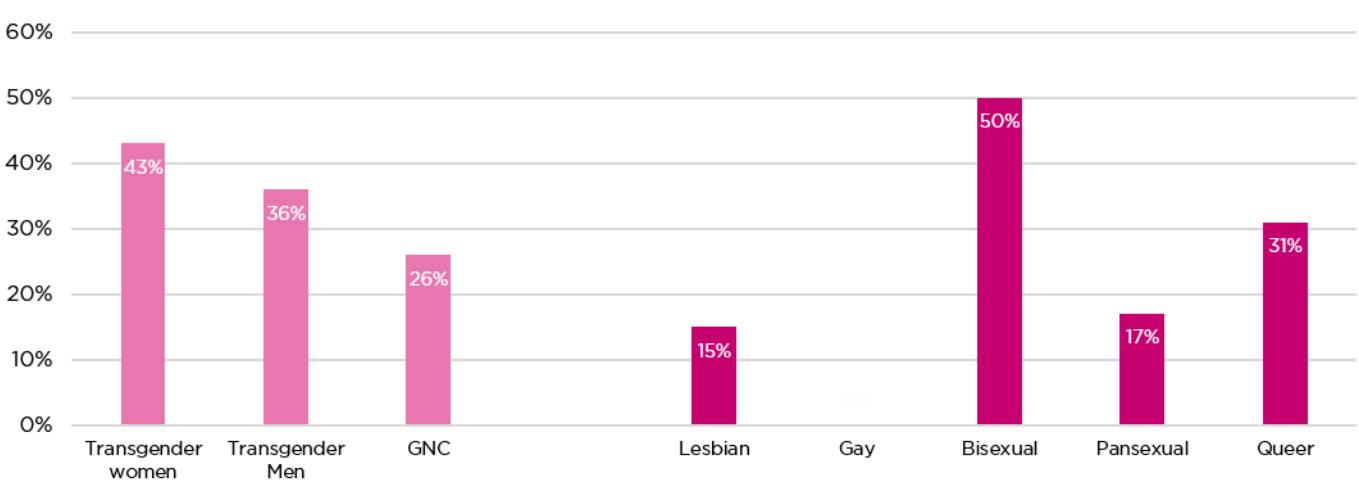


Figure 8.5. Upon disclosure of sexual orientation or gender identity, has a health care provider ever acted embarrassed?



*encompasses all gender non-conforming identities, including but not limited to people who identify as gender fluid, genderqueer, and non-binary.

Appendix F: Health Care Provider Sensitivity

Figure 8.6 outlines the percentage of people based on identity who have had a health care provider make a face of disgust or disapproval after the disclosure of a patient's gender identity and/or sexual orientation. Figure 8.7 outlines the percentage of people based on identity who have heard a health care provider make a statement similar to "I treat all my patients the same" after disclosure of the patient's gender identity and/or sexual orientation. While many providers believe this response is appropriate, it does not actually affirm the identities of patients nor does it acknowledge the particular health needs of the LGBTQ community.

According to another researcher, providers stating "I treat all my patients the same" highlights the need for cultural sensitivity training because quality health care should be about equity rather than equality. As they wrote, "Heteronormative assumptions are the very reason why LGBTQI individuals do not want to be treated 'the same.'"²⁷

Figure 8.6. Upon disclosure of sexual orientation or gender identity, has a health care provider ever made a face of disgust or disapproval?

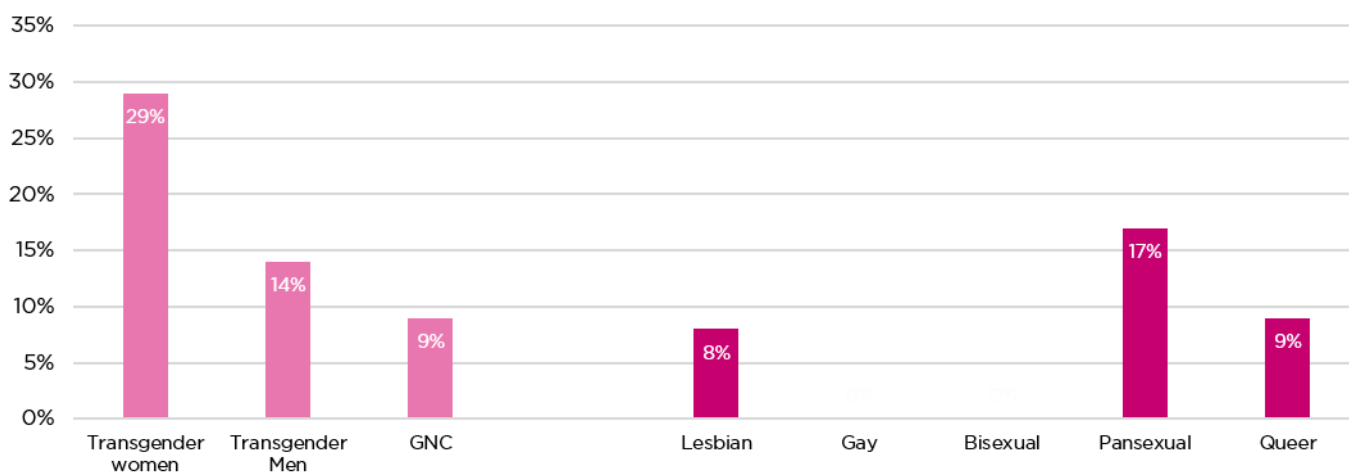
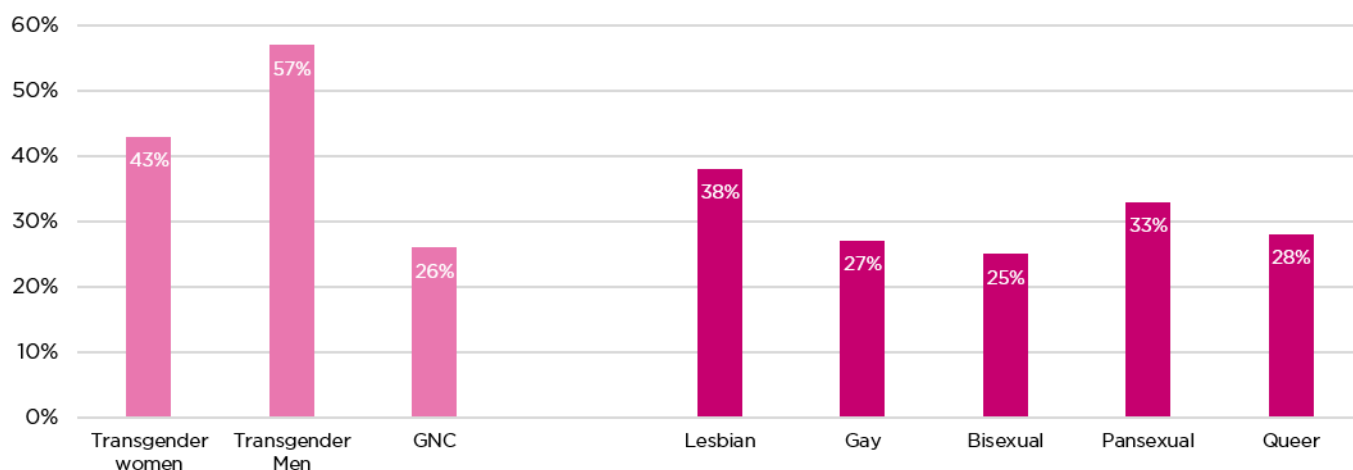


Figure 8.7. Upon disclosure of sexual orientation or gender identity, has a health care provider ever made a statement similar to "I treat all my patients the same"?



Appendix G: LGBTQ Breast Health Toolkit Components

1. Definitions of Sex and Gender

A common theme throughout interviews with the LGBTQ community was the need to ensure that health care providers understand the differences among definitions of sex and gender. Those differences should be clearly defined in the toolkit.

“Understanding the difference between gender identity, anatomical sex, gender expression, and sexual identity, and behaviors. They’re all different things. Sometimes they align, sometimes they don’t, and you can never assume that they do.”

-- Queer Gender Non-Conforming/Trans Person

2. Information on Non-Binary Identities

Many participants in the interviews expressed the need for health care providers to have a deeper understanding about the gender identities that fall outside of the binary of female and male.

“I think everybody, including the medical community, has a very binary sense of what it means to be transgender. You’re going from male to female or vice versa, but there’s a thousand shades of gray in between. And most of them don’t know all the other terms like non-binary, it’s just the three: male, female, and trans.”

-- Bisexual Transgender Woman

“I feel like it’s really important to find ways in the toolkit to move beyond the binary, which is very hard in health care, because it’s very like “Okay, you have these chromosomes, okay you have these gonads, you have a penis or a vagina. This or that.” It’s important to move beyond that. I also feel it’s really important to have some stuff in the toolkit about how to go about breast health across the gender spectrum.”

-- Pansexual Transgender Woman

Appendix G: LGBTQ Breast Health Toolkit Components

3. Intake Forms

The toolkit should include sample intake forms that provide comprehensive options for sex, gender, and sexual orientation. Depending upon the relevance to the services being provided, the intake forms should ask the same information about the patient's partner(s). The intake forms should include space for the patient to identify the name that they would like to be called if it is different from their legal name, and the pronouns that staff should use to address the patient.

4. Screening Guidelines

The toolkit should include a comprehensive compilation of guidelines for mammogram screenings, clinical breast exams, and self-exams. This should include as many gender variations as possible, as well as varying stages of physical transition (including hormone usage and surgery status). Ideally, if enough information is available, the guidelines should consider how age at the start of hormone use may affect the need for mammograms. The toolkit should also answer common questions, like whether or not a transgender woman who is still in the stage of breast development but over the age of 50 should have a mammogram screening.

5. Medical Terminology

It seems it may be helpful if providers are able to find language to talk about breast health in a way that does not depend upon medical terminology, particularly when providers are speaking with transgender or gender non-conforming patients. The toolkit should also find other language or metaphors to help convey breast health guidelines in an inclusive way that does not exacerbate gender dysphoria.

“There are a lot of trans men in particular who feel very uncomfortable talking about any of this, much less being examined with any of this. And I’m quite open with all of it. And I think it would be helpful when talking about breast stuff to actually call it ‘chest’ stuff. It just puts it a little bit more at ease. Yes, I know they’re breasts. It draws a point, for me, it draws to the fact that I haven’t had chest surgery yet and it’s an uncomfortable enough situation.”

-- Gay Transgender Man

Appendix G: LGBTQ Breast Health Toolkit Components

6. Exercises

Written Responses

It may be helpful for LGBTQ cultural sensitivity trainings to include time for providers to write out what they will say when a patient discloses their gender identity or sexual orientation. This will allow the provider to be prepared with an affirming response rather than not reacting at all or reacting negatively.

“It probably couldn’t hurt for physicians to have kind of like their go-to response when a patient comes out to them so that there’s not that moment of “Oh. Oh my god!” Because regardless of what their reaction is, that first moment where they’re taking in what you just said – there’s this sort of dread about how they’re going to react.”

-- Bisexual Transgender Woman

“Or what if they, like, thoughtfully wrote down how they would answer a question. Like a paragraph. Like, actual – them doing homework.”

-- Queer Genderqueer Person

Appendix G: LGBTQ Breast Health Toolkit Components

Role Playing

Interview participants indicated that it would be valuable to include within the toolkit activities for health care providers to practice what they hear during an LGBTQ cultural sensitivity training. That way, when the providers do interact with the LGBTQ community, they may find it easier to use affirming language.

“I feel like, and I don’t know what form the toolkit is going to take, but like some sort of role-playing thing might be useful. Because the one health care provider who asked me if I was ‘a trans’ like, later she was like ‘Oh, I just remembered! It’s ‘trans man!’ and I was just like ‘Oh you’re just reading off a script that someone showed you in a Powerpoint at one point.’

And I think practicing the vocabulary and actually saying it and not just looking at a screen and trying to remember it would probably be useful. Because I think if she’d practiced saying ‘trans man, trans man, trans man’ it wouldn’t have come out ‘Are you a trans?’”

-- Queer Non-Binary Person

“Being able to practice pronouns and have that conversation of, especially if you’re focusing on breast cancer, being able to have that conversation with a trans person who doesn’t have breasts anymore and still say okay this is what we know – there’s possibilities and we need to have this conversation. And being able to bring it up even though the patient may not bring it up.”

-- Queer Genderqueer Person

Appendix G: LGBTQ Breast Health Toolkit Components

Understanding Privilege

The toolkit should include thoughtful exercises for health care providers to reflect upon and understand their own positionality and how privilege affects access to health care. One survey participant provided an excellent example of how to be an ally when learning new information about the LGBTQ community.

“So certainly, exploration of privilege... That they should be mindful of those things. And that the nasty thing about privilege is that it centers you as the default and you generally don’t see it unless you go looking for it. And then when you go looking for it, you sometimes think you’re a horrible person for it. You know, I’m in several social justice groups online... And so I have a meme out there which is the three rules of being an ally and how to f--- up.

The first rule is: Shut up and listen.

The second rule is: Don’t add your voice to the mix; amplify theirs.

And the third rule is: When you f--- up, own it.

And then, of course, how to f--- up is:

Step one: Acknowledge your f--- up. Say ‘I f---ed up.’

Step two: Apologize for your f--- up. ‘I’m sorry, I f---ed up.’

Step three: Make amends. ‘I’m sorry I did/wrote/said this thing and caused you to waste your afternoon. What can I do to make up for this f--- up?’

And lastly, act on your f--- up. ‘Well, I don’t want to f--- up like that again. I need to come up with a plan for how not to f--- up.’ Because it’s not a question of if we’ll f--- up, it’s a question of when.’

-- Queer/Pansexual Transgender Woman

Appendix G: LGBTQ Breast Health Toolkit Components

7. Resource List

Interview participants indicated that the toolkit should include a list of resources for health care providers if they need more information about the LGBTQ community or identifying what the breast health guidelines are for a particular patient.

“Another thing to include is different resources around the city.”

-- Gay/Queer Transgender Man

“Contact information where they can call for help.... And if they have somebody that they could reach out to and say ‘I have this patient, and I need some assistance.’ I think that would be really helpful. Probably local would be better. Although, both [local and national]. Having both would be good.”

-- Bisexual Cisgender Woman

8. Continued Learning

The LGBTQ community continues to evolve and develop new language for identities and behaviors. Even people within the LGBTQ community are continually learning about LGBTQ identities, and health care providers must also continue to learn.

As one participant said, *“Sometimes we forget that so much has changed and the vocabulary has changed.”* This is why it is important that health care providers continue to learn about LGBTQ identities, not just through one workshop or training activity.

Suggestions from participants on how to ensure that health care providers have a continuing education on LGBTQ matters included: *“Some workshops that have continuing education hours attached to them. You know, that will count toward their license renewal, so they’ll go to it.”*

“You do have to have some sort of formal training or conversation and it can’t be just like a two-hour training, it has to be somehow in a bigger better workshop. It needs to be continual.”

-- Queer Genderqueer Person

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A Note on Language

The researcher on this project strives to use language that is as inclusive as possible. For this reason, the researcher will use the term “sexual and gender minorities” to encompass all identities along the gender and sexuality spectrums which language such as “LGBT” or “LGBTQ” does not fully encompass. However, when citing other work, this report will use the terminology that those authors used in order to portray the most accurate description of the data analyzed within those studies, which often does not include the queer or non-binary community.

Introduction

I. Health Outcomes

The sexual and gender minorities face an increased risk of negative health outcomes surrounding cancer through delaying preventative care, lack of cultural sensitivity, and other risk factors. Lesbian, gay, bisexual, and transgender (LGBT) cancer survivors are more likely to report fair or poor health compared to heterosexual cancer survivors.²¹ In particular, there are three main factors which contribute to significant negative health outcomes for LGBT people: lack of cultural sensitivity in the healthcare system, reduced access to employer-provided health insurance, and the social stigma that exists against LGBT people.²⁸ For these reasons the U.S. Department of Health and Human Services has elevated sexual orientation from a noted disparity in their Healthy People 2010 objective to a target group for concern and improvement in Healthy People 2020.²⁹

Specifically in regard to negative health outcomes related to breast cancer, lesbian women who are newly diagnosed with breast cancer are significantly less likely to express their anger and significantly less likely to report that they have a fighting spirit.³⁰

II. Risk

Out of any population, cisgender lesbian women have the “*densest cluster of breast cancer risks*.”³¹ This includes higher rates of nulliparity, older age at first live birth, smoking, elevated BMI, and alcohol use. In 2015, the first study was completed that assessed and compared Gail breast cancer risk scores among sexual minority women and heterosexual women in a clinical setting, rather than using self-reported data from participants. This study found that the mean lifetime Gail score for sexual minority women was significant higher (10.7%) than the score for heterosexual women (8.9%).³²

In a project funded by the Susan G. Komen Foundation, a study found that many sexual and gender minority participants did not have anyone in their family talk to them about breast cancer risk, but nearly all participants had been directly or indirectly affected by breast cancer.³³ Despite the increased risk of breast cancer, many in the LGBTQ community do not learn about their risk and then delay seeking or do not seek routine preventative care according to recommended guidelines, which theoretically results in higher rates of later stage diagnosis and lower 5-year survival rates for the community.

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III. Incidence Rates

Despite evidence that sexual and gender minorities are at an increased risk of cancer, to date no cancer registries collect information on gender identity or sexual orientation.³⁴ This makes it nearly impossible to access generalizable data about actual incidence rates of breast cancer in the LGBTQ community. However, according to one national survey of the LGBTQ community, 7% of women in the survey who were ages 50-95 reported having a breast cancer diagnosis.³⁵

One researcher searched for articles about “breast cancer” in 2002, and out of 26,554 articles only six considered LGBT individuals as a separate part of their analysis.³⁶ As one researcher wrote, *“data are a cornerstone of any public health system, and the lack of data on sexual minorities correlates with the failure of public health to address this group’s needs.”*³⁷ Since 2002, more research has been conducted around breast cancer and sexual and gender minorities, yet significant gaps in data remain, making it difficult to assess the needs of the community.

Access to Healthcare

I. Insurance and Decision-Making

Sexual and gender minorities are less likely to have employer-provided health insurance than heterosexual and cisgender individuals.³⁸ Research that assessed breast cancer survivors who were alive five years after their diagnosis concluded that there were no differences in insurance status by sexual orientation, which suggests that sexual minority women who are able to survive breast cancer have gained or maintained access to health insurance.³⁹ Increasing access to affordable insurance coverage and affordable health care could increase survival rates of sexual and gender minorities living with breast cancer.

On another note, if transgender men have undergone chest reconstruction surgery as part of their transition and have changed the gender marker on their government-issued identification to male, then obtaining insurance coverage for mammography for remaining breast tissue may be a challenge.⁴⁰ This reduces access to preventative care measures that lead to early detection of breast cancer. Furthermore, insurance providers may sometimes deny transgender patients coverage for gender-specific cancers, which obviously reduces access to affordable health care.⁴¹

According to one researcher, the majority of sexual minority participants in their study on sexual minorities and end-of-life care were more likely to know about living wills and healthcare proxies, but were less likely to have completed any.⁴²

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II. Cultural Sensitivity

Perceptions in King County, WA

Recently an organization called *Aging with Pride* conducted a Town Hall meeting and a study about the needs, experiences, and feelings that the aging sexual and gender minority population has about health care in King County in Washington state and the need for cultural sensitivity training. One individual stated, “*There’s not a lot of training out there for that kind of thing right now so I think that is something we have to consider.*” The need for provider-level training was raised numerous times in a Seattle Town Hall meeting in 2015, where over 100 people gathered for the *Aging with Pride* Town Hall meeting to discuss the future of aging for the LGBTQ community in the Pacific Northwest.⁴³

While there is limited data specific to the health care disparities of sexual and gender minorities in Western Washington, *Aging with Pride* identified some barriers. According to their research, 16% of LGBTQ older adults in King County, Washington have experienced inferior healthcare and/or were denied care. 15% fear accessing health care services outside of the LGBTQ community, and the number is much higher for transgender individuals (29%).⁴⁴ 30% of those respondents did not have a routine annual checkup in the past year, and only 21% are currently utilizing services.⁴⁵ This points to a growing population of older sexual and gender minorities in the Pacific Northwest who are not accessing preventative care, which could lead to higher rates of late-stage diagnosis of breast cancer and/or lower 5-year survival rates.

Avoidance of Preventative Care

Avoidance of and delay in seeking preventative care appears to be a consistent disparity in the LGBTQ community, regardless of age and location, as found in multiple studies in the United States. According to the Joint Commission, the LGBT community has lower rates of cancer screenings and higher rates of some cancer diagnoses.⁴⁶

More specifically, the transgender community is at particular risk of delaying or not seeking any preventative health care. “*Transgender people are less likely to have routine cancer screenings and may not undergo testing if symptoms develop.*”⁴⁷ According to the LGBT Task Force in their study entitled “Injustice at every turn: A report of the National Transgender Discrimination Survey, either previous negative experiences or fear of stigmatization within the healthcare system caused 28% of transgender respondents to postpone or forego medical care when they were either sick or injured.⁴⁸

Transgender individuals are less likely to have routine cancer screenings and may not follow through with testing if symptoms develop.⁴⁹ In another national study, transgender people (72.5%) were significantly less likely than their cisgender counterparts (83%) to have had a routine checkup.⁵⁰ When this increased risk is paired with delay in seeking preventative care, health outcomes for the LGBTQ community decline.

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The LGBTQ community is also less likely to have received recommended preventative care for breast health. For example, in a sample of nearly 12,000 women from seven U.S. surveys of sexual minority women, only 73% of women age 40-49 reported ever receiving a mammogram, compared with 87-90% of women the same age in the U.S. general population.⁵¹ In 2015, researchers found that lesbian and bisexual women are more likely to delay seeking routine care such as breast exams and mammograms⁵². In a survey conducted by U.C. Davis, only 32% of female respondents had their recommended mammogram.⁵³

III. Health Care Providers and Cultural Sensitivity

Understanding Identities

According to existing recent research, overall the LGBTQ community does not believe that health care providers understand the identities and needs of the LGBTQ community. In a study about disparities in cancer care, it was found that only 25% of lesbian, gay, bisexual, and transgender respondents rated their health care providers as “excellent” in relating to them in terms of their sexual orientation. Furthermore, in that same study only 17% of respondents rated their provider as “excellent” in relating to them in terms of their gender identity.⁵⁴

Provider Knowledge

Health care providers rarely learn about LGBTQ identities and specific health care needs, risks, and barriers during their time in medical school or residency. Because providers do not learn about LGBTQ issues, they may tell LGBTQ patients that they do not feel comfortable treating LGBTQ patients or that they do not know the recommendations for preventative health care.

In a survey of 141 obstetrics and gynecology providers, only 35% were comfortable caring for male-to-female transgender patients and only 29% were comfortable caring for female-to-male transgender patients. About 59% of those obstetrics and gynecology providers did not know the recommendations regarding breast cancer screening for the transgender population.⁵⁵

*“When lesbian women were compared to bisexual women with breast cancer, bisexual women reported significantly less trust in their providers.”*⁵⁶ This alludes to a gap in understanding the identities and needs of *all* members of the LGBTQ community; it seems that most trainings on LGBTQ identities focus on gay and lesbian identities, but omit gender identity and the spectrum of identities that fall within sexual orientation such as pansexuality, asexuality, aromanticism, queer, etc. This perpetuates a barrier to care for many in the LGBTQ community who do not identify as gay or lesbian.

Many in the LGBTQ community fear that coming out to a health care provider may negatively affect the health care that they receive because providers do not have knowledge around LGBTQ identities or have an individual bias against LGBTQ people. According to a national study of LGBT older adults ages 45-75, 20% of LGBT older people feel that their relationships with health care providers would be “adversely affected” if their sexual orientation or gender identity was known.⁵⁷ The same study reports that 65% of transgender older people believe their health care will be “limited as they age,” and 55% believe healthcare will be “denied as they age.”⁵⁸

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Even when health care providers feel they are being sensitive to LGBTQ identities, they may not be perceived that way by patients. Providers commonly state “I treat all my patients the same.” This highlights the need for cultural sensitivity training, because quality health care should be about equity instead of equality; *“heteronormative assumptions are the very reason why LGBTQI individuals do not want to be treated ‘the same.’”*⁵⁹ Sometimes health care providers may think that not reacting to someone disclosing their sexuality or gender identity is the appropriate way to respond. However, according to one researcher, when lesbian women with cancer disclosed their sexuality to their provider and received a neutral reaction they perceived it negatively.⁶⁰

Treatment

LGBTQ cancer patients face even more challenges around disclosure of identity than LGBTQ patients simply seeking preventative care. If a patient comes out to their health care provider, they often have to wonder if their identity has been recorded or passed on to their oncology team upon diagnosis, or whether they will have to continually disclose their identity to their treatment team.⁶¹

Even when “out” to their treatment team, LGBTQ individuals’ partners may not be as involved in treatment as cisgender heterosexual patients’ partners. According to Harding et al., lesbian women wished that their partners were more included in decision making and treatment planning, yet most participants were not asked by their provider who should make medical decisions if they were unable.⁶²

Fear of receiving substandard care for a harrowing disease may contribute to LGBTQ cancer patients’ failure to disclose their sexuality or gender identity to providers. *“Our research also showed that while 88% were out to their primary care physicians, they were more closeted during cancer treatment. In addition, many respondents wrote about the stress of repeatedly having to decide whether to come out or not to each member of their healthcare team.”*⁶³ Many patients expressed fear of a lower quality of care if they came out.

These fears may be perpetuated by the assumptions that cancer care providers make by omitting inclusive options on intake forms and in conversation. In a study of 311 LGBT cancer survivors, only 19% of patients’ forms gave the opportunity to specify one’s sexual orientation and gender identity. 58% of patients brought up their sexuality only to correct a mistaken assumption that they were heterosexual, and only 17% were asked a direct question about their sexual orientation or gender identity.⁶⁴

RECOMMENDATIONS

I. Increase Cultural Sensitivity

Health care providers should be collecting information around sexual orientation and gender identity in order to best treat patients. If providers are not aware of their patients’ sexual orientation or gender identity, and the lack of information is due in part to fear of bias or discrimination, then the integrity of the patient-provider relationship has been compromised. *“LGBT patients deserve professional interactions that affirm their sexual and gender identities at all ages. Without these norms, LGBT*

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*people will be left behind in any national initiative meant to improve the country's overall health and wellbeing.*⁶⁵

When a patient discloses their sexual orientation or gender identity, health care providers should keep this in mind: *"An LGBT identity is a positive outcome that should be met with acceptance and nonjudgmental recognition; or a physician should make proactive commitments to deal with his or her homophobic feelings or heterosexist bias if and when they occur."*⁶⁶

Intake Forms

Incorporating a range of sexual and gender identity options into medical history forms and intake forms symbolizes that the health care provider is knowledgeable and open to discussing concerns related to sexuality and gender identity. Using broad questions, like "Are you currently active with men, women, both, or any other gender identity" and gender neutral language such as "partner" or "significant other" is also recommended. Ask patients what name and pronoun they use, then use them.⁶⁷

Create Open Dialogue

Open dialogue to gather information is important. A great example is *"I am going to ask you some questions about your sexual health and sexuality that I ask all my patients. The answers to these questions are important for me to know to help keep you healthy. Like the rest of this visit, this information is strictly confidential."*⁶⁸ In taking a medical history, it is important to distinguish sexual identity from sexual behavior.

*"Out of respect for my clients' rights to self-identify, I ask all clients what gender pronoun they'd prefer I use for them. What pronoun would you like me to use for you?"*⁶⁹ Even if you make an incorrect assumption, you can always apologize and ask which term the patient prefers.⁷⁰ In general, it is best to mirror a patient's language.⁷¹

Health care providers understanding and listening to sexual minority, cisgender women who are not engaging in sex with anyone with a penis, is a cultural sensitivity value expressed often. According to a thematic analysis of lesbian breast cancer survivors, one woman wrote, *"I signed up for a clinical trial that will cover the cost of my Oncotype [diagnostic] test, but my tumor got sent off a week later than I had anticipated because the oncologist's office called me and told me I'd have to have a pregnancy test first!!! It was super annoying to have to drive 60 mins [round trip] to pee in a cup to prove that I'm not pregnant – because being a lesbian who was currently menstruating at the time wasn't proof enough!!"*⁷² Having conversations with patients around sexual behavior and implementing guidelines that reflect someone's identity and behavior is valued by the LGBTQ community.

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Cultural Sensitivity During Cancer Treatment

*“For LGBT people diagnosed with cancer, the first thing to ask is what kind of support network do you have and can I offer you information about LGBT-friendly networks.”*⁷³ The next step should be ensuring that a patient’s family of choice is involved in treatment as much as the patient would like. *“Allow the patient to say who they want with them and at what time.”*⁷⁴ *“In LGBT people, families of choice are often more significant than families of blood relations.”*⁷⁵ In a survey of 311 LGBT cancer survivors, 77% consider friends and 62% consider their partner to be part of their personal emotional support team at time of diagnosis. Only 40% identified parents, 40% identified siblings, and 28% identified other family members as part of their personal emotional support team.⁷⁶ This highlights the need for policy change around who is allowed to be involved in decision-making on care, and a shift in how providers ask about involving support networks during treatment.

Often gender-conforming and heterosexist assumptions are made about body image changes after cancer treatment, but LGBTQ people would prefer if health care providers simply asked what the patient would like rather than assuming that a patient needs or does not need certain information. *“It would be good if they did not assume you were concerned about how ‘men’ would see you in the future.”*⁷⁷ Another individual in the same study wrote, *“Please offer us fertility options,”* referring to the often incorrect assumption that LGBTQ individuals do not want to have children.⁷⁸ *“It irked me that I was automatically referred to a plastic surgeon at the time of my mastectomy. It irked me that reconstruction was so pushed in the patient ed materials.”*⁷⁹ Similarly, in one researcher’s thematic analysis of lesbian breast cancer survivors, there was a focus on survival over appearance. One woman wrote, *“I never experienced the mourning the loss of my breasts; I was just thrilled to have the cancer gone.”*⁸⁰ Another wrote, *“When I see my chest all I see is an absence of cancer and that to me is beautiful,”* illustrating how treatment plans for reconstruction for sexual minority women has potential to be different than the norm for heterosexual breast cancer patients⁸¹. *“[Audrey Lorde] wrote a lot about how a fake breast would make other people more comfortable to be around her, but how it was not comfortable for HER, and that’s what really matters – what YOU want for YOUR body!”*⁸²

Continued Learning

As identities and best practices evolve, it is important that health care providers continue to learn about health. Health care providers should consider enrolling in continuing education courses that address the needs of the LGBTQ community.⁸³

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II. Establish Comprehensive Guidelines for Screenings for Breast Cancer

For Gender Non-Conforming Individuals

For gender non-conforming individuals and all people who do not identify with the binary of “male” or “female,” it is important to consider factors such as sex assigned at birth, hormone usage, status of chest reconstruction, and of course family history.

For Transgender Men

Transgender men who have not had chest reconstruction surgery should follow the same guidelines for mammography as cisgender women. Even after chest reconstruction surgery, transgender men should receive a chest wall/axillary exam annually.⁸⁴

For Transgender Women

Transgender women who have taken or are taking estrogen should follow the same guidelines for mammography as cisgender women.⁸⁵ However, those who started hormone replacement therapy late in life may not be recommended to receive mammograms immediately.

III. Future Research

There is currently incredibly limited research on incidence rates of breast cancer within the LGBTQ community. Because no national cancer databases or registries collect information on sexual orientation or gender identity, research around incidence rates is very difficult. The first step toward accurate research is ensuring that cancer databases and registries are asking the right questions so that researchers can analyze accurate, comprehensive data. According to the Report on the Health of LGBT Individuals issued by the Institute of Medicine, data on sexual orientation and gender identity should be collected in electronic health records.⁸⁶ Furthermore, they stated that the National Institute of Health should support methodological research on LGBT health.⁸⁷

Particular subgroups of the LGBTQ community have been repeatedly omitted from conversations and research around LGBTQ cultural sensitivity and health care. *“LGBT elder subgroups such as older people of color and transgender older people, as two examples, remain notably understudied.”*⁸⁸

Finally, one researcher points to gaps in research about LGBT people within the cancer continuum: gaps in research reducing the risk of cancer, gaps in research in screening for and early detection of cancer, gaps in research of cancer survivorship, and gaps in research on cross-cutting issues.⁸⁹ They recommend more funding for research in these areas and for national and state surveillance data collection.⁹⁰

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