

Breast Health for the LGBTQ Community*

*This resource was adapted from the Susan G. Komen Puget Sound LGBTQ Community Toolkit

**SUSAN G.
KOMEN®**
PUGET SOUND



About the Resource

Introduction

Based on research conducted by Susan G. Komen® Puget Sound in 2016 on the health care experiences of the Lesbian Gay Bisexual Transgender Queer (LGBTQ) community in Western Washington, there is a need for breast health and breast cancer information specifically for the LGBTQ community.

A research study was conducted as a 3-part mixed method study. A literature review was done to look at research on the relationship between the LGBTQ community and health care, cultural sensitivity and cancer. Secondly, a questionnaire was created to gather quantitative data from 74 participants. Thirdly, qualitative data was collected through a series of interviews with 17 people.

Members of the LGBTQ community often delay seeking preventive care. When asked for the reasons behind delaying or never seeking preventive care, 83 percent of transgender men, 67 percent of gender non-conforming people and 17 percent of cisgender women in Western Washington cited lack of cultural sensitivity from health care providers.

Furthermore, the LGBTQ community in Western Washington needs more education on breast health inclusive of all genders. Fifty percent of transgender women, 33 percent of transgender men, 22 percent of gender non-conforming people and 17 percent of cisgender women reported a reason they delayed or did not seek preventive care was uncertainty about the recommendations for screening guidelines.

Consequently, only 60 percent of the LGBTQ community age 50-74 in Western Washington received their recommended mammogram in the past 2 years. This compares with 76 percent of the general population in the Komen Puget Sound service area. The LGBTQ population faces a myriad of health disparities and breast health is only one.

This resource was designed to provide the LGBTQ community with breast health and breast cancer information that can be used for conversations with health care providers.

At the end of this resource, you should be able to:

- State 1 reason sexual minority women may have an increased risk of breast cancer.
- Name at least 1 lifestyle habit that may increase your risk of breast cancer.
- Identify the 8 warning signs of breast cancer which should be reported to a health care provider.
- Name 2 breast cancer screening tests.

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Know Your Risk of Breast Cancer

The best defense against breast cancer is early detection. The earlier breast cancer is found, the easier it is to treat. Know your risk of breast cancer.

Sexual Minority Women (Cisgender)

Sexual minority women (i.e., lesbian, gay, bisexual) who are cisgender (not transgender) may have an increased risk of breast cancer due to:

- Never having children
- Having children later in life
- Higher rates of alcohol use
- Higher rates of obesity¹



Transgender Men

The risk of breast cancer in the transgender community is not well understood (due to the lack of evidence). There have not been significant studies of breast cancer occurrence in transgender or gender non-conforming individuals, but this does not mean transgender people are not at risk.

- Excess testosterone in the body can be converted to estrogen. Excess estrogen increases the risk of breast cancer. Transgender men taking testosterone may be at increased risk of breast cancer.
- Even after chest reconstructive surgery some breast tissue will remain. The remaining tissue is still at risk of breast cancer.²

Transgender Women

The risk of breast cancer in the transgender community is not well understood (due to the lack of evidence). There have not been significant studies of breast cancer occurrence in transgender or gender non-conforming individuals, but this does not mean transgender people are not at risk.

- Data are limited about breast cancer risk in this community. For example, while breast density is a known risk factor for women overall and prevalence of breast density in the general population is unknown, a small Dutch study of 50 transgender women found 60 percent had “dense” or “very dense” breasts on mammography. Breast density is a mammographic finding and not a clinical finding, therefore individuals wouldn’t know if they had dense breasts without a mammogram.³

¹ <https://ww5.komen.org/BreastCancer/Statistics.html>

² <http://www.thecentersd.org/pdf/health-advocacy/breast-cancer-facts-for.pdf>

³ <http://transhealth.ucsf.edu/trans?page=guidelines-breast-cancer-women>

Know Your Risk of Breast Cancer

Do you know your risk of breast cancer?

answers on this side are

AVERAGE RISK



answers on this side are

HIGH RISK

1. How old are you?

(USA) odds: 30's 40's
1 in 217 1 in 67

... most women are diagnosed in these ages ...

50's 60's 70's
1 in 43 1 in 29 1 in 25

Lifetime risk 1 in 8⁴

2. How much estrogen have you been exposed to?⁵

I got my period during/after age 12.
I gave birth before age 35 and had several pregnancies.⁶
I have breastfed.
I entered menopause before age 45.
I was a normal weight after menopause.
I have not used birth control pills for 10 years or so or have not used them at all.
I have not used menopausal hormone therapy (estrogen/hormone pills).

I got my period before age 12.
I have never had children, or did so after age 35.
I have not breastfed.
I entered menopause after age 55.
I was overweight after menopause.
I'm taking birth control pills now.
I have used menopausal hormone therapy.

3. Do you have a relative who has had breast cancer?

No.
More than 80 percent of women diagnosed with breast cancer have no family history.

Yes.
My mother, sister or daughter has had breast cancer. (This doubles your risk.)

4. Have you been diagnosed with a benign breast condition?

No.
I just have fibrocystic (lumpy) breasts.

Yes.
I've had a biopsy before that found atypical hyperplasia.

5. What did your mammogram show?

I have low breast density.

I have high breast density.

6. What are your lifestyle habits?

I do not consume alcohol.
I exercise regularly.

I drink more than one alcoholic beverage a day.
I am rarely physically active.

Talk with your doctor about your screening plan.
Decide how often you should have the following and at what age:

Clinical Breast Exam

Mammogram

Breast MRI
(for people at higher risk)

Adapted from <https://www.worldwidebreastcancer.org/>

⁴ <https://ww5.komen.org/Breastcancer/Understandingrisk.html>

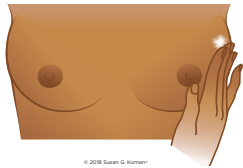
⁵ <https://ww5.komen.org/AboutBreastCancer/RiskFactors/FactorsAffectingBreastCancerRisk/FactorsAffectingBreastCancerRisk.html>

⁶ <https://ww5.komen.org/BreastCancer/NotHavingChildrenorHavingFirstAfterAge35.html>

Know What To Look For

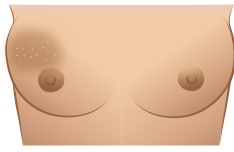
Warning signs of breast cancer are not the same for everyone. The important thing to know is if you notice a change, see a health care provider.

- Lump, hard knot or thickening inside the breast, chest or underarm area



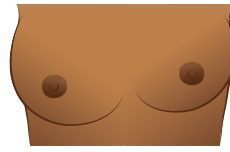
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- Swelling, warmth, redness or darkening of the breast



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- Change in the size or shape of the breast



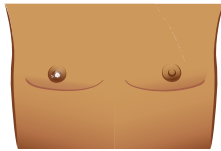
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- Dimpling, puckering or redness of the skin of the breast



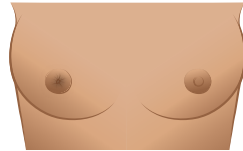
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- Itchy, scaly sore or rash on nipple



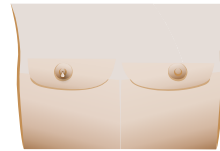
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- Pulling in of your nipple or other parts of the breast



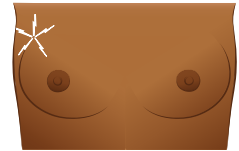
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- Nipple discharge that starts suddenly



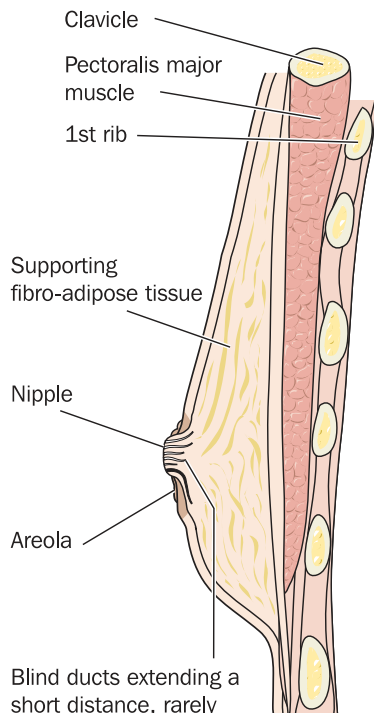
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- New pain in one spot that does not go away

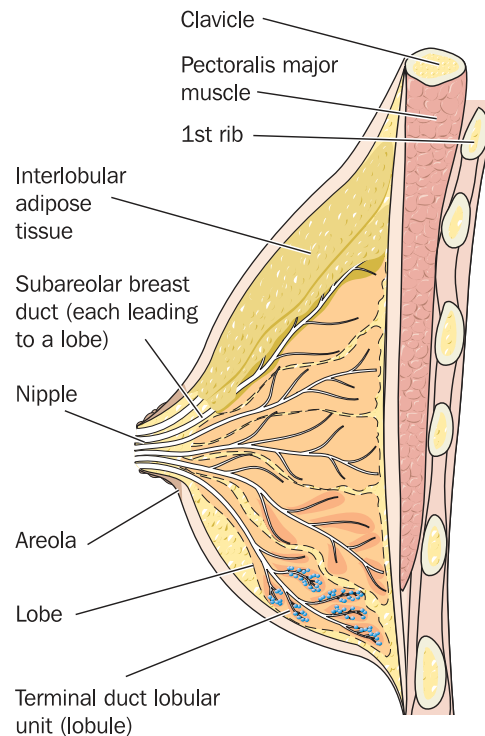


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Male breast

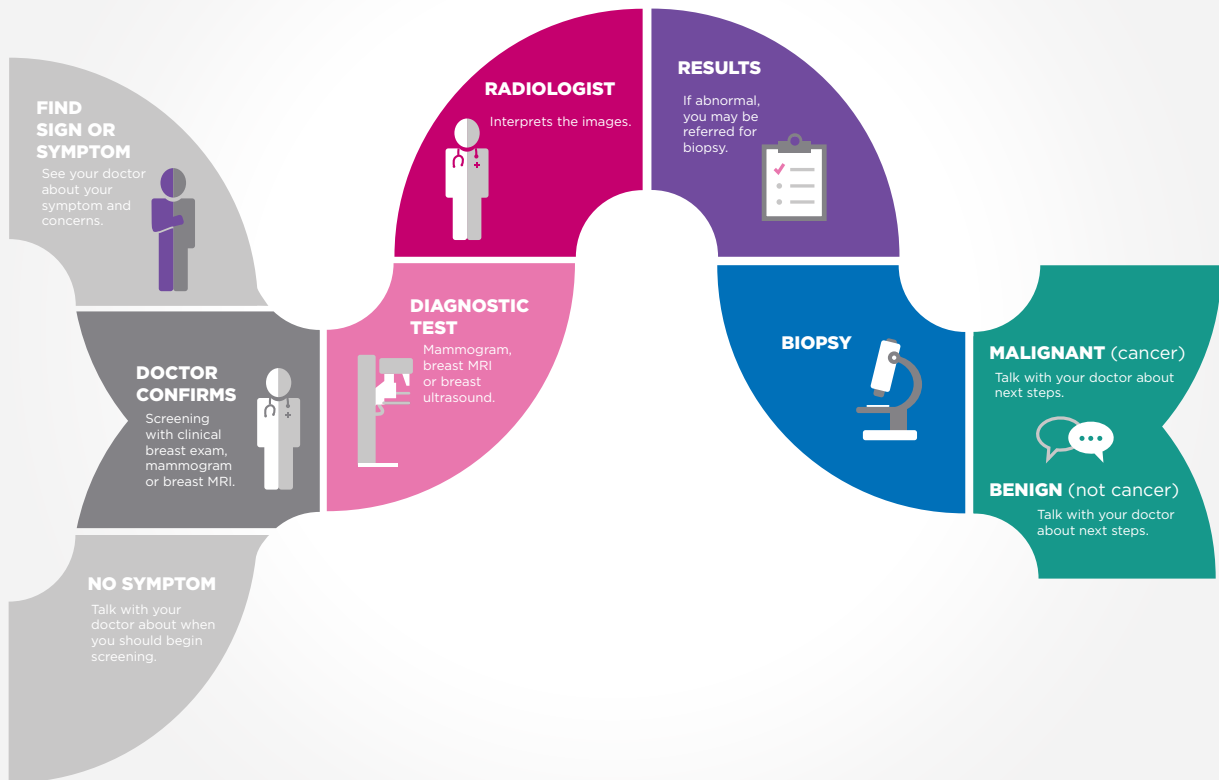


Female breast



HOW TO FIND BREAST CANCER

Knowing these steps will help you be more confident in taking charge of your health and seeking answers.



Adapted from <https://www.worldwidebreastcancer.org/>

Screening Guidelines

There's a lack of agreement among professional societies as to when to start screening for breast cancer. So breast cancer screening guidelines vary by organization. The table below illustrates breast cancer screening recommendations for cisgender women at average risk.

As an advocacy organization, we believe people should be able to make informed decisions about breast cancer screening with their health care provider based on their risk and preference.

Breast Cancer Screening Recommendations for Cisgender Women at Average Risk		
American Cancer Society	National Comprehensive Cancer Network	U.S. Preventive Services Task Force
Mammography		
Informed decision-making with a health care provider ages 40-44 Every year starting at age 45-54 Every 2 years (or every year if a woman chooses to do so) starting at age 55, for as long as a woman is in good health	Every year starting at age 40, for as long as a woman is in good health*	Informed decision-making with a health care provider ages 40-49 Every 2 years ages 50-74
Clinical Breast Exam		
Not recommended	Every 1-3 years ages 25-39 Every year starting at age 40	Not enough evidence to recommend for or against
* Breast tomosynthesis (3D mammography) may be considered.		

Screening Guidelines for the Transgender Community

While there is not sufficient research on breast cancer and the transgender community to provide adequate evidence-based screening guidelines, this page illustrates guidelines indicated by Fenway Health, a reputable transgender health clinic, and cites risk factors indicated in the Clinical Journal of Oncology Nursing.

Transgender Women

Data are limited about breast cancer risk in this community. For example, while breast density is a known risk factor for women overall and prevalence of breast density in the general population is unknown, a small Dutch study of 50 transgender women found 60 percent had “dense” or “very dense” breasts on mammography. Breast density is a mammographic finding and not a clinical finding, therefore individuals wouldn’t know if they had dense breasts without a mammogram.⁷

According to Fenway Health, Transgender women over the age of 50 who have been using feminizing hormones for 5 years or more should get a mammogram annually. If a transgender woman has a family history of breast cancer, mammograms may be recommended before age 50.⁸

Transgender Men

Excess testosterone in the body can be converted to estrogen. Excess estrogen increases the risk of breast cancer. Transgender men taking testosterone may be at increased risk of breast cancer.⁹ Even after chest reconstructive surgery some breast tissue will remain. The remaining tissue is still susceptible to breast cancer.¹⁰

According to Fenway Health, among many other barriers to receiving health care, transgender men may feel disconnected from their chest, or assume chest reconstructive surgery protects them, and therefore do not see a health care provider for clinical chest exams.

- Transgender men who have had chest reconstructive surgery should still receive annual chest wall and axillary exams beginning at age 50.
- Transgender men who have had a chest reduction may still be recommended to have annual mammograms beginning at age 50.
- Transgender men who have not had chest reconstructive surgery should follow the same guidelines as cisgender women.
- If a transgender man has a family history of breast cancer, these recommendations may be different.¹¹

Adapted from <https://www.ncbi.nlm.nih.gov/pubmed/26000586>

⁷ Weyers S, Villeirs G, Vanherreweghe E, Verstraelen H, Monstrey S, Van den Broecke R, et al. Mammography and breast sonography in transsexual women. *Eur J Radiol.* 2010 Jun;74(3):508-13.

⁸ <http://www.thecentersd.org/pdf/health-advocacy/breast-cancer-facts-for.pdf>

⁹ <http://www.thecentersd.org/pdf/health-advocacy/breast-cancer-facts-for.pdf>

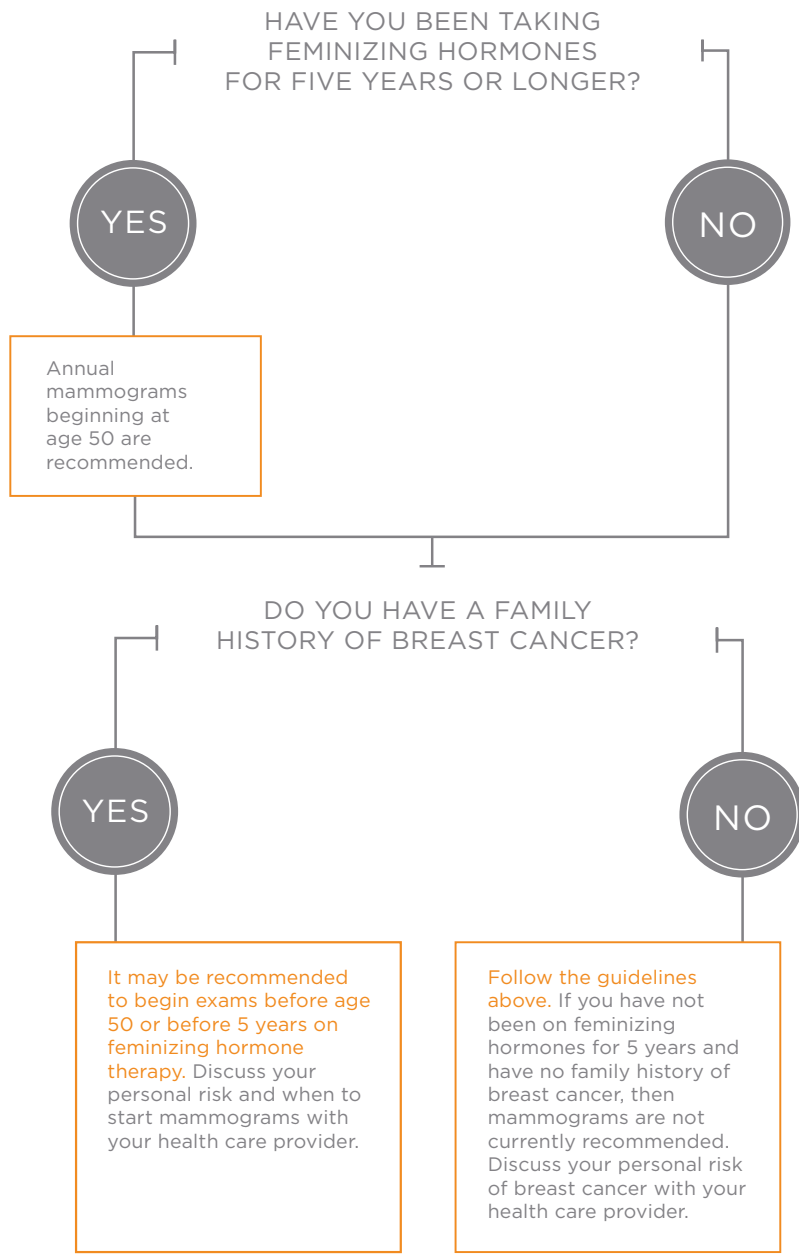
¹⁰ <http://lgbthealtheducation.org/wp-content/uploads/COM-2245-The-Medical-Care-of-Transgender-Persons.pdf>

¹¹ <http://www.thecentersd.org/pdf/health-advocacy/breast-cancer-facts-for.pdf>

Screening Guidelines for Transgender Women

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BREAST CANCER SCREENING GUIDELINE I AM A TRANSGENDER WOMAN

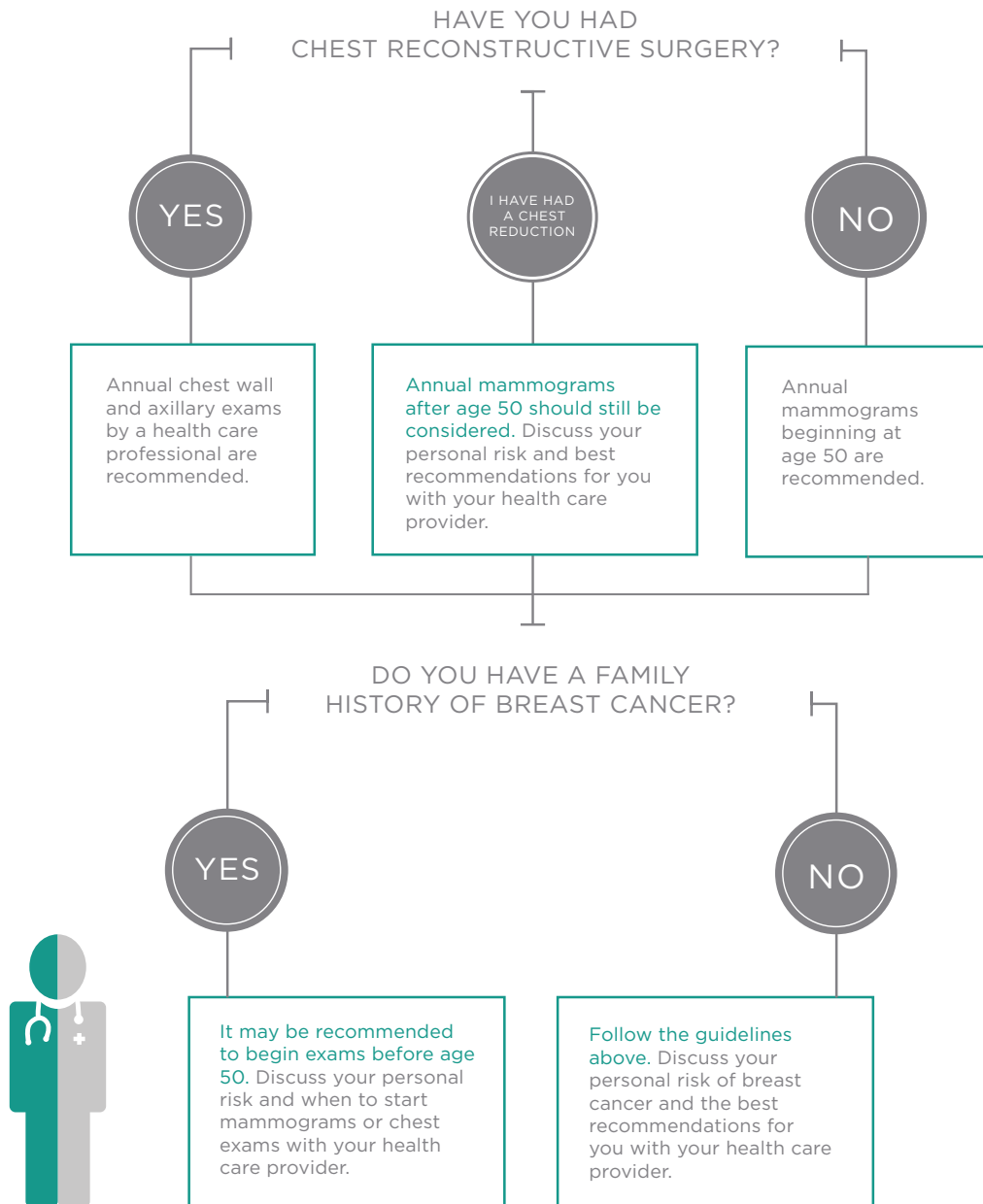


Adapted from <http://www.thecentersd.org/pdf/health-advocacy/breast-cancer-facts-for.pdf> and <https://www.ncbi.nlm.nih.gov/pubmed/26000586>

Screening Guidelines for Transgender Men

While there is not sufficient research on breast cancer and the transgender community to provide adequate evidence-based screening guidelines, this page illustrates guidelines indicated by Fenway Health, a reputable transgender health clinic, and cites risk factors indicated in the Clinical Journal of Oncology Nursing.

BREAST CANCER SCREENING GUIDELINE I AM A TRANSGENDER MAN



Adapted from <http://www.thecentersd.org/pdf/health-advocacy/breast-cancer-facts-for.pdf> and <https://www.ncbi.nlm.nih.gov/pubmed/26000586>

FAQs for the Transgender Community

Does binding my chest have an impact on the risk of breast cancer?	There are no peer-reviewed studies that directly assess the health impact of chest binding, yet transgender community resources commonly discuss symptoms such as pain and scarring. ¹²
How do masculinizing hormones affect chest health?	<p>While there has not been substantial research on transgender men and breast health, it is known excess testosterone in the body can be converted to estrogen.</p> <p>Excess estrogen increases the risk of breast cancer. Transgender men taking testosterone may be at increased risk of breast cancer.¹³</p>
If I've had chest reconstructive surgery, do I still need to get a mammogram?	<p>According to Fenway Health, Transgender men who have undergone chest reconstruction surgery do not need annual mammograms after age 50, but should ensure a health care provider performs an annual chest wall and axillary exam. If a transgender man has had a chest reduction rather than a mastectomy then mammograms may be recommended.¹³</p> <p>If a transgender man has family history of breast cancer, then the recommendations may be different. Talk with your health care provider to assess your personal risk of breast cancer and the best recommendations for you.</p>
How do feminizing hormones affect breast health?	<p>According to Fenway Health, Transgender women over the age of 50 who have used feminizing hormones for 5 years or more should get a mammogram annually.¹³</p> <p>Talk with your health care provider about your personal risk of breast cancer and the best recommendations for you.</p>
How does age at the start of feminizing hormone usage affect when to start getting a mammogram?	<p>According to Fenway Health, Transgender women who are age 50 or older and who have been using feminizing hormones for 5 years or longer are recommended to get a mammogram annually.¹³</p> <p>Talk with your health care provider about your personal risk of breast cancer and the best recommendations for you.</p>
How do implants affect mammography?	<p>Mammography is a safe and effective screening tool for people who have breast implants. However, implants can make it harder to read a mammogram. If you have implants, it is important to tell the technologist before your mammogram. The mammography machine must be adjusted to get the best image of the natural breast tissue. Special positioning of the breast may also be needed. Four views of each breast will be taken (instead of the standard 2).</p> <p>If you can, choose a center with technologists and radiologists who are experienced in mammography for women with breast implants.</p>

¹² <https://www.tandfonline.com/doi/full/10.1080/13691058.2016.1191675>

¹³ <http://www.thecentersd.org/pdf/health-advocacy/breast-cancer-facts-for.pdf>

FAQs for Non-Binary Individuals

What if I have been on hormone therapy (either feminizing or masculinizing) and stopped? How does that affect my risk of breast cancer and whether or not I need a mammogram?

Talk with your doctor about your personal risk of breast cancer and the best recommendations for you.

FAQs for Cisgender Women

How often should I get a mammogram?

Discuss your personal risk of breast cancer with your health care provider. Some experts recommend starting annual screenings at age 40: some experts recommend starting annual screenings at age 45. Some experts recommend switching to having mammograms every other year after age 55, but some recommend continuing annual mammograms.

If you are at a higher risk of breast cancer, your screening guidelines may be different.

How can I do that may reduce my risk of breast cancer?

You can do things that are good for your health and might also lower your risk of getting breast cancer, such as:

- Maintain a healthy weight
- Add exercise to your routine
- Limit alcohol intake
- Limit menopausal hormone use
- If you have children, breastfeed, if you can

Local & National Resource List

Financial Assistance

Breast, Cervical and Colon Health Program

1-888-438-2247 | www.doh.wa.gov/bcchp

Cancer Lifeline

206-297-2100 | <http://www.cancerlifeline.org/>

Organizations

Susan G. Komen

1-877-GO KOMEN (1-877-465-6636) | <http://ww5.komen.org/>

Susan G. Komen Puget Sound Affiliate

112 5th Ave N, Seattle, WA 98109

206-633-0303 | info@pskomen.org | <http://komenpugetsound.org/>

American Cancer Society

1-800-227-2345 | <https://www.cancer.org/>

LGBT Cancer Network

212-675-2633 | liz@cancer-network.org | <http://cancer-network.org/>

Seattle Cancer Care Alliance

825 Eastlake Ave E, Seattle, WA 98109

206-288-SCCA (7222) | contactus@seattlecca.org | <https://www.seattlecca.org/>

Fred Hutchinson Cancer Research Center

1100 Fairview Ave N, Seattle, WA 98109

206-667-5000 | communications@fredhutch.org | <http://www.fredhutch.org/>

Fenway Health

617-927-6354

<https://fenwayhealth.org/the-fenway-institute/education/the-national-lgbt-health-education-center/>

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World Wide Breast Cancer

This resource would not have been possible without the feedback of ALL LGBTQ participants in Susan G. Komen Puget Sound's research study.

For more information on the research conducted by Susan G. Komen Puget Sound on LGBTQ health care experiences in Western Washington, visit our website: komenpugetsound.org/lgbtq-health-care-initiative/

