

Breast Health Toolkit for the LGBTQ Community



About the Toolkit

Introduction

Based on research conducted by Susan G. Komen Puget Sound in 2016 on the healthcare experiences of LGBTQ community in Western Washington, there is a need for cultural sensitivity training for healthcare providers.

The LGBTQ community often delays seeking preventive care. When asked for their reasons behind delaying or never seeking preventive care, 83% of transgender men, 67% of gender non-conforming people, and 17% of cisgender women cited lack of cultural sensitivity from healthcare providers.

Furthermore, the LGBTQ community in Western Washington needs more education on breast health that is inclusive of all genders. 50% of transgender women, 33% of transgender men, 22% of gender non-conforming people, and 17% of cisgender women reported a reason they delayed or did not seek preventive care was uncertainty of the recommendations for screening guidelines.

Consequently, only 60% of the LGBTQ community age 50-74 received their recommended mammogram in the past two years. This compares with 76% 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 facet.

This toolkit was designed in response to the indication from 98% of our research participants that healthcare providers in Western Washington need to undergo LGBTQ cultural sensitivity training. Our coalition of researchers, leaders in the LGBTQ community, and healthcare providers created this toolkit based on recommendations from research participants from the LGBTQ community.

How It Should Be Used

This toolkit includes materials on breast health that can be adapted for use with health workers including staff at breast health centers and oncology centers. Ideally, this toolkit will be used in conjunction with a comprehensive LGBTQ cultural sensitivity training for all staff, from first point of patient contact through the continuum of care to ensure that the LGBTQ community is affirmed through their entire healthcare experience.

Because service delivery will vary across settings, providers may choose to alter these materials to make them appropriate for use in their setting. The materials in the “For the LGBTQ Community” section may also be used outside of health care settings, such as part of educational programming for LGBTQ community-based organizations.

Suggestion for Training

We recommend all-staff training sessions be at least one and one-half to two hours long to allow time for exercises and a short question and answer session. The amount of time for training can vary depending upon the need to build a foundational understanding of LGBTQ identities. This should be a repeating cycle training to ensure that all staff, whether onboarding new hires or even after turnover, maintain the ability to provide appropriate, respectful, affirming care to the LGBTQ community.

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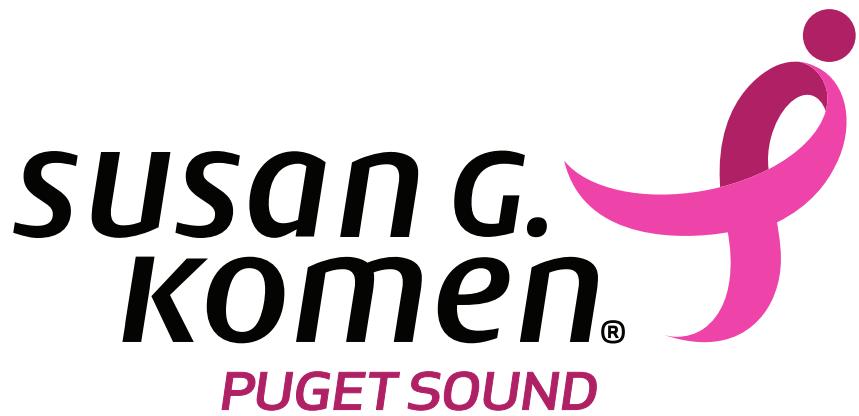
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For Healthcare Providers



Objectives

1. Understand terminology related to gender identity and sexual orientation so that all staff can use affirming language to interact with patients
2. Be able to provide affirming care to patients of all genders and sexualities through comprehensive intake forms and creating welcoming spaces
3. Understand the mammography screening guidelines for people of all genders
4. Be able to identify barriers to health care for the LGBTQ community and engage in appropriate responses
5. Be able to answer frequently asked questions that the LGBTQ community may have about breast health
6. Be able to identify local and national LGBTQ resources

LGBTQ Terminology

Consider posting these definitions on your wall for easy reference. Always use language that folks use for themselves (which you have to ask or provide opportunity to share). Language is dynamic and shifting; when you make a mistake do your best to learn why what you said did not work and then move on.

Natal sex/sex assigned at birth - the assignment and classification of people as female, male, intersex, or another sex assigned at birth often based on physical anatomy at birth and/or chromosomes. Assigned Male at Birth [AMAB] | Assigned Female at Birth [AFAB]

Gender identity - one's innermost concept of self as male, female, gender non-conforming, non-binary, or another gender. Gender identity can be the same or different from someone's natal sex. Since gender identity is internal, it is not necessarily visible to others. Gender identity is an independent identity from sexual orientation.

Gender expression - how a person demonstrates who they are through the way they act, dress, behave, and interact. Gender expression can change from day to day, setting to setting. Gender expression is interpreted by others based on traditional gender roles.

Sexual orientation - one's innermost concept of who they're attracted to or drawn to romantically, emotionally, and sexually.

Transition - a term that describes the processs of "transitioning" from one gender to another. (Although still used, this term is becoming outdated based on its underpinnings within the binary gender concept)

Gender affirmation - a more recently coined term referring to the process of altering one's gendered appearance to better align with one's gender identity. (This term does not enforce a gender binary like the term "transition" does. Physical alterations may be hormonal, surgical, social or any combination of these)

Gender affirming care - refers to providing healthcare that specifically helps patients achieve congruence between their gender identity and physical appearance. Often, but not always, involves varying level of hormones and/or surgical procedures. Highly individualized to each person's desires and gender identity.

Gender Affirming Surgery - any surgery that assists the patient with actualizing their internal gender identity.

Sex Reassignment Surgery (SRS) - typically used to discuss vaginoplasty or phalloplasty, but the term is avoided by some patients and providers because it references a binary sex/gender status and seems antiquated.

Top Surgery - used colloquially by non-providers to refer to gender affirming chest surgeries such as chest reconstruction, breast reduction, and breast augmentation.

Bottom Surgery - used colloquially by non-providers to refer to gender affirming genital surgeries such as vaginoplasty, orchectomy, phalloplasty, orchioplasty.

LGBTQ Terminology

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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 - 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 (AFAB).

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

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.

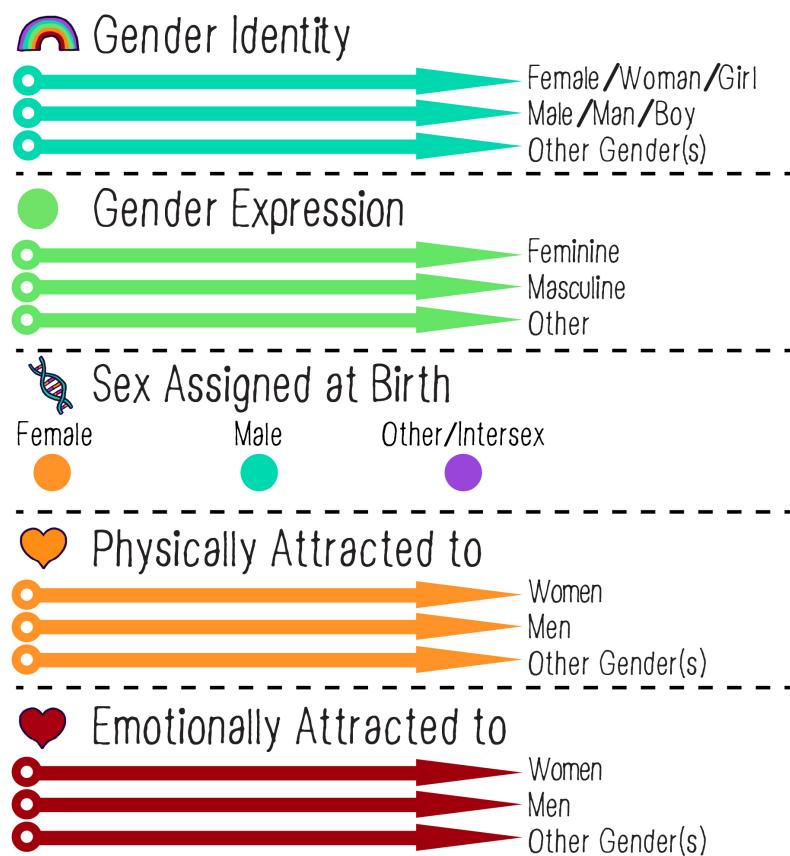
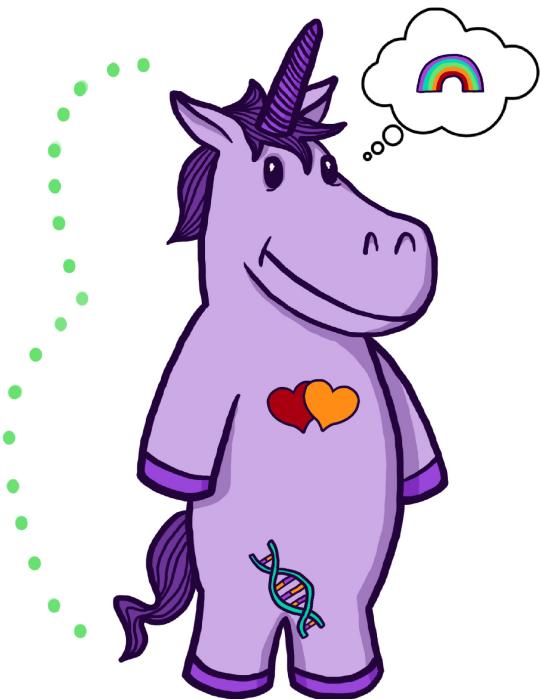
*It is important to note that this list of identities is not comprehensive because language around gender and sexuality continues to evolve.

Gender and Sexuality Spectrums

Gender identity, gender expression, and sexuality all occur on spectrums, as illustrated by this image from Trans Student Educational Resources (TSER).

The Gender Unicorn

Graphic by:
TSER
Trans Student Educational Resources



To learn more, go to:
www.transstudent.org/gender

Design by Landyn Pan and Anna Moore

LGBTQ Terminology

Try covering up one column at a time and practicing defining the terms,

Natal Sex/Sex Assigned At Birth	The assignment and classification of people as female, male, intersex, or another sex assigned at birth often based on physical anatomy at birth and/or chromosomes. Assigned Male at Birth [AMAB] Assigned Female at Birth [AFAB]
Gender Identity	One's innermost concept of self as male, female, gender non-conforming, non-binary, or another gender. Gender identity can be the same or different from someone's natal sex. Since gender identity is internal, it is not necessarily visible to others. Gender identity is an independent identity from sexual orientation.
Gender Expression	How a person demonstrates who they are through they act, dress, behave, and interact. Gender expression can change from day to day, setting to setting. Gender expression is interpreted by others based on traditional gender roles.
Sexual Orientation	One's innermost concept of who they're attracted to or drawn to romantically, emotionally, and sexually.
Transition	A term that describes the process of "transitioning" from one gender to another. (Although still used, this term is becoming outdated based on its underpinnings within the binary gender concept.)
Gender Affirmation	A more recently coined term referring to the process of altering one's gendered appearance to better align with one's gender identity. (This term does not enforce a gender binary like the term "transition" does. Physical alterations may be hormonal, surgical, social or any combination of these.)

LGBTQ Terminology

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Gender Affirming Care

Refers to providing healthcare that specifically helps patients achieve congruence between their gender identity and physical appearance. Often, but not always, involves varying level of hormones and/or surgical procedures. Highly individualized to each person's desires and gender identity.

Gender Affirming Surgery

Any surgery that assists the patient with actualizing their internal gender identity.

Sex Reassignment Surgery (SRS)

Typically used to discuss vaginoplasty or phalloplasty, but the term is avoided by some patients and providers because it references a binary sex/gender status.

Top Surgery

Used colloquially by non-providers to refer to gender affirming chest surgeries such as chest reconstruction, breast reduction, and breast augmentation.

Bottom Surgery

Used colloquially by non-providers to refer to gender affirming genital surgeries such as vaginoplasty, orchectomy, phalloplasty, orchioplasty.

LGBTQ Terminology

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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	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. The term "queer" can be offensive to some in the community.
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 [AFAB].
Transgender Woman	A transgender person whose gender identity is female. Transgender women were assigned male at birth [AMAB].
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.

Adapted from <http://www.transstudent.org/gender> and <http://www.hrc.org/resources/sexual-orientation-and-gender-identity-terminology-and-definitions>

LGBTQ Terminology

Try covering up one column at a time and practicing defining the terms.

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 someone who is emotionally and sexually attracted exclusively to their same gender. Often the term refers to men who are attracted to men. Some women also identify as “gay” and “lesbian” interchangeably, and some prefer the term “gay.”

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.

Match the Definition

Practice your knowledge of this terminology by matching the correct definition to the term.

- | | |
|-------------------------------|---|
| 1. Agender | A. describes a person who is emotionally and sexually attracted to people of their own gender and people of the other binary gender |
| 2. Asexual | B. describes a person whose gender identity is not fixed. A person 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 |
| 3. Bisexual | C. one's innermost concept of self as male, female, gender non-conforming, or another gender |
| 4. Cisgender | D. describes a person who is emotionally and sexually attracted to people of gender identities throughout the gender spectrum |
| 5. Gay | E. describes a person who identifies as having no gender |
| 6. Gender expression | F. a transgender person whose gender identity is female |
| 7. Gender fluid | G. an umbrella term used to describe people who think of their sexual orientation or gender identity as outside of societal norms. Some view the term 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 by all of the LGBTQ community |
| 8. Gender identity | H. the assignment and classification of people as female, male, intersex, or another sex assigned at birth often based on physical anatomy at birth and/or chromosomes |
| 9. Gender non-conforming | I. describes a person whose gender identity falls outside the traditional gender binary of male and female |
| 10. Genderqueer | J. describes Native American/Alaskan Native LGBTQ people, stemming from language meaning to have both female and male spirits within one person |
| 11. Lesbian | K. describes a person whose sex and gender identity align |
| 12. Non-binary | L. describes a person who experiences little or no sexual attraction to others |
| 13. Pansexual | M. an umbrella term covering any gender identity that does not fit within the gender binary of male and female |
| 14. Queer | N. an umbrella term describing gender expression that differs from a given society's norms of only male and female |
| 15. Sex/sex assigned at birth | O. how a person demonstrates who they are through they act, dress, behave, and interact |
| 16. Transgender man | P. describes a woman who is emotionally and sexually attracted exclusively to other women |
| 17. Transgender woman | Q. a transgender person whose gender identity is male |
| 18. Two-spirit | R. describes a man who is emotionally and sexually attracted exclusively to other men |

Recommendations for Best Practices for Healthcare Providers to Affirm LGBTQ Identities

(1) Health care institutions and offices should actively convey that LGBTQ-welcoming behavior is a core expectation of all staff.

- Prioritize regular and consistent mandatory staff trainings, preferably led by external trainers.
- Reinforce such inclusiveness through the actions of management and public relations staff.
For example, an article could be written on LGBTQ diversity for an employee newsletter.
- Train your staff and recognize that:
 - * Front-line staff are the first impression your LGBTQ patients will have of your practice.
 - * LGBTQ health can be confusing and uncomfortable for those not familiar with the LGBTQ community. This must be addressed in trainings, NOT with patients.
 - * Staff will need a safe space to ask uncomfortable questions about sex, gender, identity, pronouns, and language.
- Learn about navigating pharmacy and insurance systems to ensure appropriate coverage of care and medications, particularly for transgender patients. If you are unsure, know who to contact with questions.

(2) Health care institutions and offices should convey a zero-tolerance environment for any discriminatory behavior on the part of the staff.

- Include scenarios and possible responses in staff trainings.

(3) Health care institutions and offices need to broadcast their LGBTQ-welcoming policies and training to potential and current patients.

- Include LGBTQ measures and nondiscrimination protections on intake forms.
 - * Prominently display LGBTQ protections/welcome on website and in waiting room.
 - * Partner with local LGBTQ community-based organizations for public events.
 - * Tailor ads to LGBTQ media outlets.
- Participate in and display the results from the Human Rights Campaign Healthcare Equality Index report card.
- Display publications that make commitment to diversity clear in other ways (recognizing the intersectionality of sexuality, gender, race, ability, etc.)

(4) Collect evidence to see if LGBTQ patients feel safe coming out at your institution and use evidence to build safety.

- Ask about LGBTQ status on patient satisfaction surveys.
- Ask about LGBTQ status on general employee satisfaction surveys.
- Include LGBTQ people on community advisory bodies to provide a constant source of feedback.
- Conduct an environmental scan of the facility to check how and when safety is conveyed to LGBTQ patients.

(5) Health care institutions and offices should ensure that a patient's family-of-choice and health care proxies are designated and respected.

- Prominently display policies ensuring family-of-choice is respected during care. For LGBTQ people, families of choice are often more significant than families of blood relations.
- Train staff in the steps to comply with the early designation of health care proxy.
 - * Include designation of health care proxy materials in routine intake forms.
- Allow patient to designate important support team members as well as health care proxy on forms and/or patient records.

Creating a Welcoming Environment: Sample Intake Form Data

Create comprehensive intake forms that gather information on your patients' gender identity, sexual orientation, and sexual activity without making assumptions.

Develop a method for distinguishing between natal sex and gender identity in your health records to ensure both appropriate screening and respect for current identity.

Ensure that electronic medical record systems can capture essential data like gender identity, sexuality, and pronouns in a way that is flexible as LGBTQ language continues to evolve.

It may be helpful for you to adapt this template:

Legal Last Name	Legal First Name	MI
Is there a different name we should use to address you?		
Your pronouns are (circle all that apply): She/Her/Hers He/Him/His They/Them/Theirs Something else: _____		
Address _____		
The sex I was assigned at birth was (circle one): Male Female Intersex		
Gender identity (circle all that apply): Man Woman Transgender Man Transgender Woman Gender Non-Conforming Non-Binary Genderfluid Genderqueer Agender Something else (explain) _____		
Sexual orientation (circle all that apply): Straight Lesbian Bisexual Pansexual Queer Gay Questioning Asexual Something else (explain) _____		
In the past year, my sexual partners include (circle all that apply): Men Women Both Men and Women None Transgender partners Gender Non-Conforming Partners Non-Binary Partners Something else (explain) _____		

Creating a Welcoming Environment: Do's & Don'ts

Consider prominently displaying these do's and don't in your office as a reminder.

- ✓ **DO** post a non-discrimination policy that includes gender identity and sexual orientation
- ✓ **DO** provide all-gender restrooms
- ✓ **DO** use gender neutral language and inclusive language in waiting rooms and exam rooms
- ✓ **DO** use terms like "partner" or "significant other"
- ✓ **DO** create inclusive intake forms that don't make assumptions about gender identity or sexual orientation
- ✓ **DO** incorporate questions about pronouns onto intake forms and in medical records
- ✓ **DO** create a method for distinguishing between natal sex and gender identity in your health records to ensure both appropriate screening and respect for current identity
- ✓ **DO** ask "Are you seeing someone?" or "Are you in a relationship?" rather than "Do you have a boyfriend?" or "Do you have a girlfriend?"
- ✓ **DO** listen to what a person has to say
- ✓ **DO** be honest when you don't understand something
- ✓ **DO** ask them about the confidentiality of their identities and relationships and reassure them of your confidence
- ✓ **DO** use pronouns that someone asks you to use. When you mess up the pronoun, correct yourself, apologize, and move on
- ✓ **DO** respect an individual's identity and use the terms that someone uses for themselves. Mirror a person's language.
- ✓ **DO** accept a person's identity

- ✗ **DON'T** make assumptions about a person's gender identity or sexual orientation
- ✗ **DON'T** assume and use the term "boyfriend/girlfriend" or "husband/ wife"
- ✗ **DON'T** interject or interrupt
- ✗ **DON'T** be disrespectful when asking questions or make assumptions about what a patient's answer to a question will be
- ✗ **DON'T** "out" someone's sexual orientation or gender identity
- ✗ **DON'T** ignore the importance of using the correct pronouns
- ✗ **DON'T** use language like "he says he's a girl, but he's really a boy" or "she's not a real girl; she's a transgender"
- ✗ **DON'T** use "it" as a pronoun
- ✗ **DON'T** ask invasive questions about someone's body that are not relevant to their health care needs

Practice Affirming LGBTQ Identities

Scenario: A Transgender Man Getting A Mammogram

Mikhal (preferred name; legal name, Michelle) Brown is a 65-year-old transgender man who presents alone to the breast health center after feeling a lump in his chest.



**Mikhal, 65
Transgender Man**

In preparation for the visit, you review his available medical records and learn that Mikhal came out as transgender in his late 40s and has been receiving testosterone ever since from an outside endocrinologist. He has not had any gender-affirming surgeries.

In spite of the fact that Mikhal retains natal pelvic anatomical structures (vagina, cervix, uterus, and ovaries) and has been encouraged to undergo routine preventive screenings by his endocrinologist, he has not had a Pap test in more than 20 years, because pelvic exams re-awaken the trauma of an adolescent sexual assault, and because he is loath to reveal genitalia discordant with his gender identity. He has never had mammograms or a colonoscopy.

The remainder of his personal medical history is unremarkable. Other than transdermal testosterone, he takes no other medications and has no allergies. The family history is notable for a mother with postmenopausal breast cancer. He was in a long-term, self-identified lesbian relationship for many years, but his ex-partner ended the relationship when he came out as transgender, and he has been single ever since. He has smoked one pack of cigarettes a day for 50 years but does not drink alcohol or use illicit drugs.

Before you knock on the exam room door, the medical assistant tells you the patient declined to remove "his, I mean, her" coat for a blood pressure check and "she, I mean he, seems upset". On entering the room, you encounter a visibly anxious, bearded man standing by the door.

After inviting him to sit down and inquiring as to the source of his distress, he recounts his experience on arrival to the clinic. The receptionist looked him up and down during check-in, appearing confused, and said, "This is mammography clinic, and we only see women here." After insisting that he was in the right place, he took a seat in the waiting room, feeling intensely embarrassed and fearful that the women sitting there were scrutinizing him.

Minutes later, a similar situation occurred when the medical assistant called out his legal name; as he rose in response, she said, "I don't think you heard me correctly... I'm looking for Michelle...You're not Michelle, are you?" Once again, he had to explain himself publicly, and once again he felt mortified.

He now says he isn't sure he wants to stay to complete the mammogram.



a

"She, I mean he, seems upset... he isn't sure he wants to stay to complete his mammogram."

Practice Affirming LGBTQ Identities

Scenario Discussion Points

- Identify health disparities and barriers to care experienced by LGBTQ people.
- Inspect a health care environment through the eyes of a transgender patient seeking care and formulate a plan to make it feel more welcoming and safe. Include attention to intake forms, signage, educational materials, bathrooms, and staff training.
- Role-play taking a history inclusive of gender identity and sexual orientation, taking care to explicitly discuss the patient's preferences regarding means of address (e.g., name and pronouns).
- Propose a preventive screening strategy for a transgender man (via role-play or use of a standardized patient) that is appropriate to his age, genetic and behavioral risk factors, hormone status, presence or absence of natal anatomical structures, and personal preferences.
- Perform a mammogram on a transgender man (using simulation or a standardized patient) in a manner that is respectful of his body, sense of autonomy and control, and physical comfort.
- Debate the value of creating culture-specific vs. one-size-fits-all patient educational materials and evaluate breast health resources that have been developed for LGBTQ patients.
- Describe the importance of designated support services for LGBTQ people who are living with cancer and/or who are elderly and prepare a list of resources that are welcoming to LGBTQ patients.
- Design and deliver a peer teaching session that aims to enhance the sensitivity with which your colleagues interact with LGBTQ patients.

Practice Affirming LGBTQ Identities

Mythbusting

Seemingly small signs of respect mean a lot coming from the medical community. If you want LGBTQ people to trust you enough to give you an accurate history so you know what kind of medical care they need, then taking the time to show you care enough to refer to them the way they want to be referred makes a big difference.

These are some examples of common thoughts that healthcare providers or staff may have when interacting with a transgender patient and responses that may prompt someone to reconsider their viewpoint. Have two people act out these scripts.

“So, are you a man or a woman?”

“I may have been born with male sex organs, but I am a woman.”

“You mean you’re a transgender woman?”

“I might identify myself as a transgender woman, or maybe I just prefer to identify as a woman.”

“But have you had ‘the surgery’?”

“There are many surgeries, and I don’t have to have any of them or tell you which ones I’ve had to identify as a woman and to be deserving of your professional respect as you’re checking me in.”

“But how do I know you’re really a woman?”

“You believe me.”

“Pronouns don’t really matter.”

“If I refer to you by the wrong pronoun, would you make it past 2 sentences without feeling disrespected and frustrated?”

“They/them is clunky/hard/weird to use as pronouns for one person.”

“You use it all the time in the plural or if you are uncertain of someone’s gender (like when referring to a name that is gender neutral, such as Alex or Sam). If you care more about showing respect to the individual in front of you than the grammar rules you were taught in grade school you will adapt to this.”

How to Be an Ally

The Three Rules of Being an Ally

- (1) Be quiet and listen.
- (2) Don't add your voice to the mix; amplify theirs.
- (3) When you mess up, own it.



How to Mess Up:

Step 1: Acknowledge you messed up. Say, "I messed up."

Step 2: Apologize for messing up. "I'm sorry, I messed up."

Step 3: Make amends.

"I'm sorry I did/wrote/said this thing. What can I do to make up for messing up?"

And lastly, act on your mistake.

"Well, I don't want to mess up like that again. I need to come up with a plan for how not to mess up."

Because it's not a question of if we'll mess up, it's a question of when.



Practice Affirming LGBTQ Identities

Written Exercise

The entire staff, from first point of patient contact all the way through the health system, needs to be able to affirm LGBTQ identities. Sometimes staff can be caught off guard when a patient discloses their identity and unintentionally say something harmful or discriminatory to the patient. While the intent may not be there, the impact is certainly felt by LGBTQ patients.

"Physicians could plan out 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 [after that], the first moment where they're taking in what you just said - there's this dread about how the physician is going to react."

--LGBTQ participant in Komen Puget Sound research

To practice affirming LGBTQ identities, think through and then write out what you will say when a patient discloses their gender identity or sexual orientation. This will allow you to be prepared with an affirming response rather than not reacting at all or reacting negatively.

It may be helpful to practice saying these responses out loud. Keep in mind that your non-verbal communication carries weight, too. Be mindful of your body language when responding.

Examples of responses include:

"Thank you for trusting me with this information. Of course, we'll maintain the confidentiality of your sexuality/gender identity."

"As your doctor, how can I support you?"

"What would you like me to call you?" or "How would you like me to refer to you?"

"What pronouns would you like me to use?"

Screening Guidelines

Expert recommendations for breast cancer screening guidelines vary by organization. The table below illustrates breast cancer screening recommendations for cisgender women at average risk.

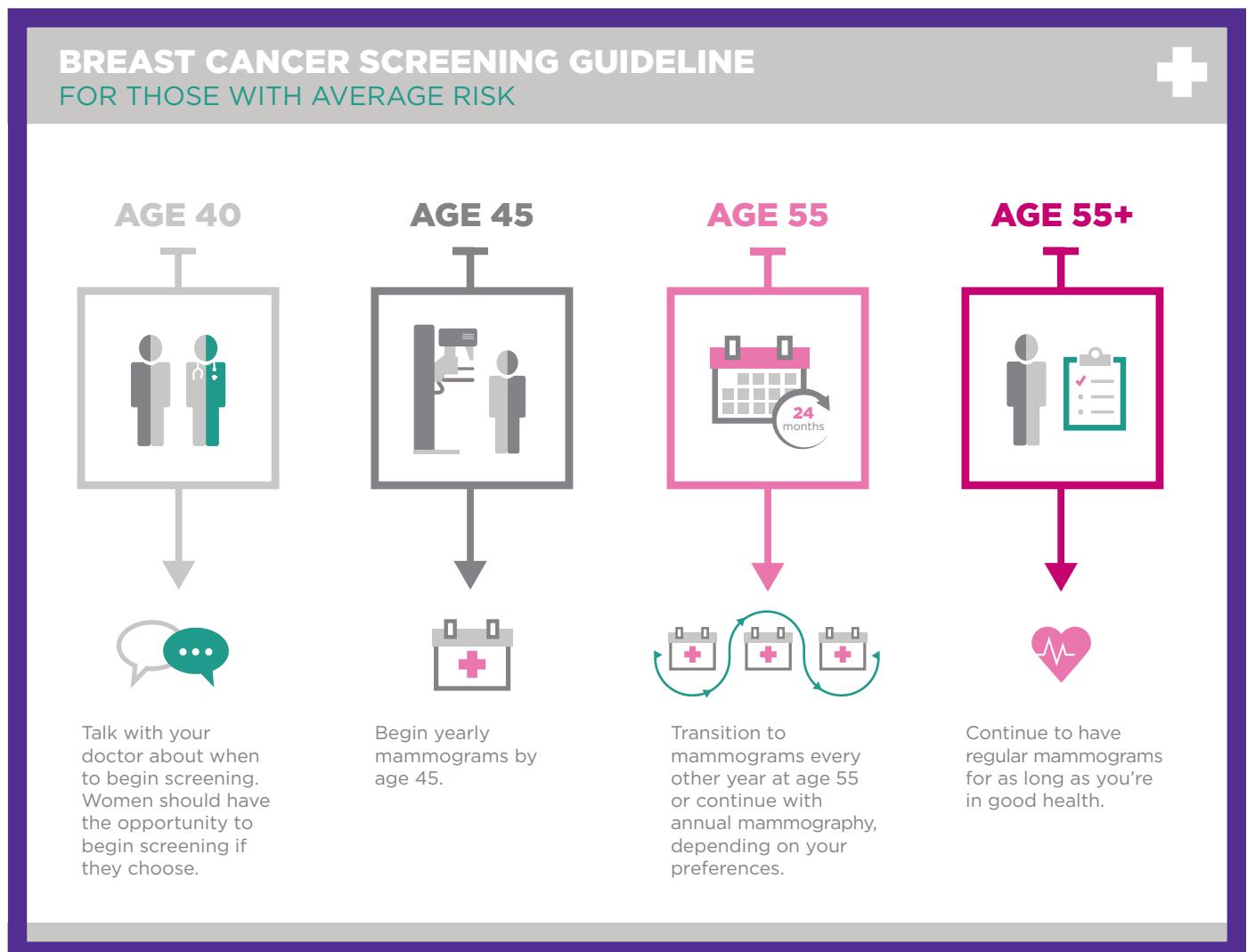
Breast Cancer Screening Recommendations for Cisgender Women at Average Risk		
American Cancer Society	National Comprehensive Cancer Network	U.S. Preventive Services Task Force
Mammography		
Informed decision-making with a health care provider ages 40-44 Every year starting at age 45-54 Every 2 years (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

Cisgender Women

While there is still conjecture on the best screening guidelines, we have chosen to adapt and visualize the American Cancer Society's recommendations for cisgender women at average risk.



Adapted from <https://www.cancer.org/content/dam/cancer-org/images/galleries/infographics/new-breast-cancer-screening-guidelines-infographic.pdf>

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 toolkit 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

Transgender women have a high prevalence of dense breasts, which is an independent risk for breast cancer and also a predictor of increased rates of false negative mammograms.

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, it may be recommended that she begin mammograms earlier than age 50.

Transgender Men

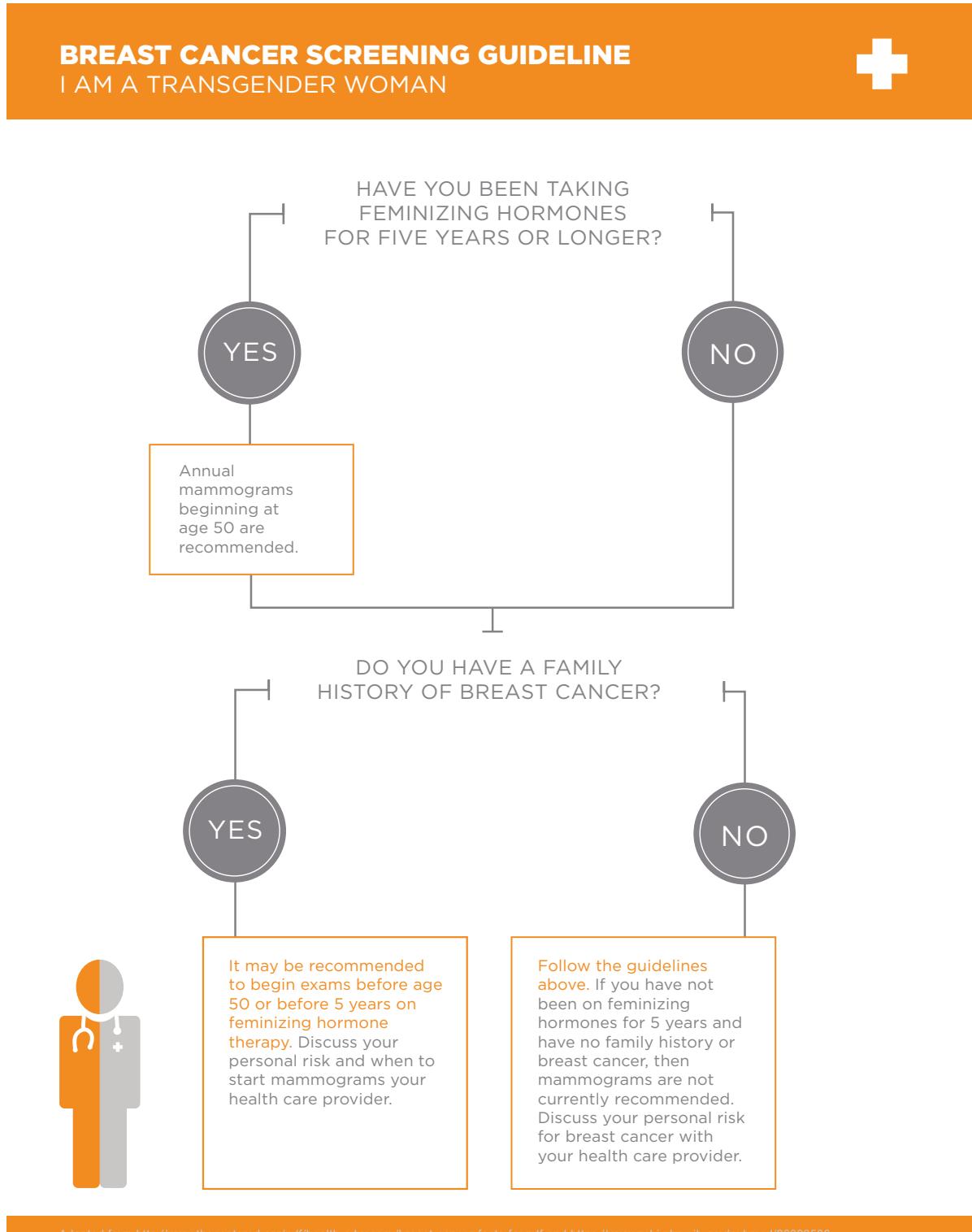
Excess testosterone in the body can be converted to estrogen. Excess estrogen increases the risk of breast cancer. Transgender men taking testosterone may be at increased risk for breast cancer. Even after chest reconstructive surgery some chest tissue will remain. The remaining tissue is still susceptible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

Among many other barriers to receiving healthcare, 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.

Screening Guidelines for Transgender Women

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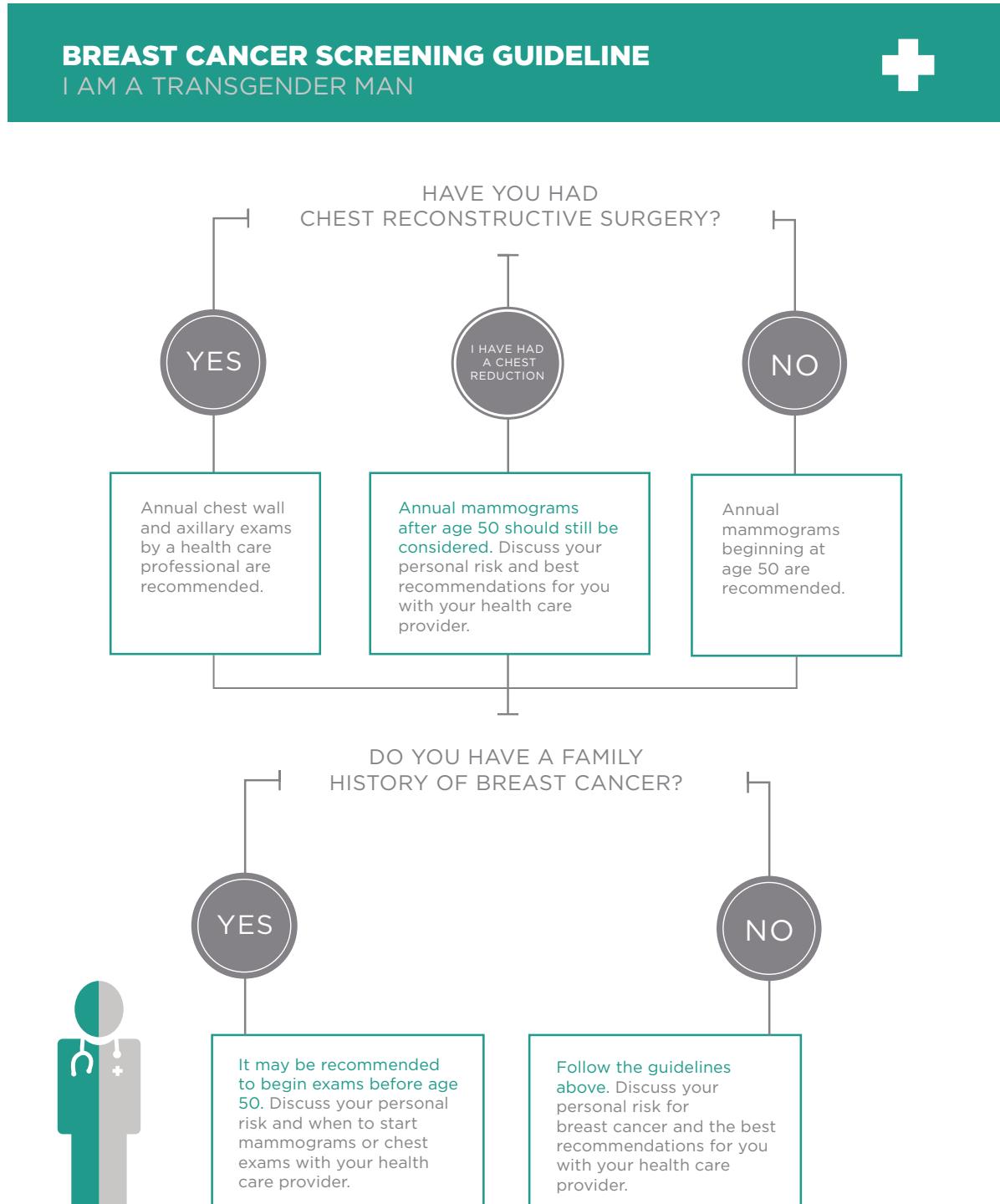


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Screening Guidelines for Transgender Men

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



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Barriers and Suggested Responses

Try covering up the right column and practicing responses to these frequent barriers to care.

I'm a transgender man and I have had chest reconstruction surgery, so I'm not at risk for breast cancer.

Even after chest reconstructive surgery some chest tissue will remain. The remaining tissue is still susceptible to breast cancer. Transgender men should get chest wall and axillary exams from a health care provider annually.

Excess testosterone in the body can be converted to estrogen, and excess estrogen increases the risk of breast cancer. Transgender men taking testosterone may be at increased risk for breast cancer. Discuss your personal risk for breast cancer and the best recommendations for you with your health care provider.

I'm a transgender woman, and only cisgender women get breast cancer, so I don't need to get mammograms.

People of all genders can get breast cancer. Transgender women have a high prevalence of dense breasts, which is an independent risk for breast cancer and also a predictor of increased rates of false negative mammograms.

Transgender women over the age of 50 who have been taking feminizing hormones for 5 years or more should get a mammogram annually. Discuss your personal risk for breast cancer and the best recommendations for you with your health care provider.

I cannot afford the cost of a mammogram OR I don't have health insurance.

Reassure them that there are options to help pay for the mammograms or clinical breast exams, and assistance if they need follow-up exam tests.

Medicare pays for most of the cost of a mammogram. If they have insurance, they can call the number on the back of their card to find out if they will cover the cost of a mammogram.

I don't have enough time to get a mammogram. I'm too busy.

The mammogram itself usually takes about an hour from the time you walk into the facility until the time you walk out. You might check in with the imaging center to learn what days and times are usually less busy and try to schedule your appointment then.

A mammogram is important. It is the best screening tool used today to find breast cancer. Mammography can find cancers at an early stage, when they are small (too small to be felt) and most responsive to treatment. Getting regular screening tests is the best way for people to lower their risk of dying from breast cancer.

Barriers and Suggested Responses

Try covering up the right column and practicing responses to these frequent barriers to care.

I am afraid or anxious to get a mammogram.

It is understandable that you are nervous about having a mammogram. For some people, thinking about breast cancer screening reminds them about the possibility that they could get breast cancer. This is very upsetting, it makes it difficult for them to do what they need to do - get a mammogram. Often, once they have a mammogram, they can usually stop worrying. Does this sound familiar?

Some people find it makes them feel less anxious if they take a friend or loved one to their appointments. And, before the exam, they could let the technologist know about their concerns. You might ask, "What do you think will help you feel less anxious about having a mammogram?"

I don't have reliable transportation to a breast health center.

Getting around is difficult if you don't have a car or anyone to take you places, and this can be frustrating. This problem makes scheduling your mammogram difficult.

Fortunately, your local Susan G. Komen® Affiliate may provide you with information about grantees who may be able to assist you with transportation to and from the mammogram facility.

Or you can call the Susan G. Komen® Breast Care Helpline at 1-877 GO KOMEN (1-877-465-6636) learn about possible sources of assistance in your area.

My doctor examines my chest every year when I go for a check-up, so I don't need to get a mammogram.

Having a yearly breast exam by a health professional is important and so is a mammogram. Mammograms can find most breast cancer before either you or your doctor can feel a lump. Although mammography is the best screening tool for breast cancer today, it is not perfect. So, combining mammography with clinical breast exams may improve the ability to find cancer earlier.

Screening tests can find breast cancer early, when it is most treatable. Getting regular screening tests is the best way for women to lower their risk of dying from breast cancer.

I am, or someone in my family is, an undocumented immigrant and I am scared of being reported.

It is not the policy of health care programs to report undocumented immigrants. In fact, some organizations prohibit its employees from sharing immigrant status information.

There are federally funded public health programs, federally qualified health centers, and migrant health clinics that can provide you with a mammogram regardless of your citizenship status. Let's work together to find an organization that will provide you a mammogram without fear of your immigration status being reported.

Barriers and Suggested Responses

Try covering up the right column and practicing responses to these frequent barriers to care.

I don't have a doctor, so I can't get a mammogram.

You may qualify for a low or no-cost mammogram.

Call the Susan G. Komen® Breast Care Helpline at 1-877 GO KOMEN (1-877-465-6636) to learn about possible sources of care in your area.

Last time I went to a health care provider for a mammogram the staff were insensitive to my gender identity or sexuality.

I hope you will tell your doctor how you feel so he/she can communicate with the technologist how it made you feel. In the meantime, you may want to request a different technologist when you make your appointment or call another facility that covers your mammograms. Does this sound like something you could do?

My chest feels fine and I have no symptoms, so I don't need to keep going for mammograms.

In the case of breast cancer, it's not always easy to tell whether or not something is broken, that is, whether or not you have breast cancer. People can have breast cancer without having any symptoms. In fact, the best time to get a mammogram is when you feel fine and do not have any symptoms.

Mammograms can find breast cancer early before there are any symptoms and when it's most treatable. Getting regular screening tests is the best way for people to lower their risk of dying from breast cancer.

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/>

Cancer Organizations

Susan G. Komen - National

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/>

Audience Assessment

This assessment may be a useful tool for LGBTQ healthcare trainers to use in order to gauge the level of knowledge that the audience holds before undergoing training. This document can also be used as a tool to find out how much the audience retained or learned when compared to their answers on this same document presented prior to the training. It can also be simply used as a post test.

Circle all letters which apply or check the best answer.

- 1. Providing culturally-sensitive care has the potential to increase access in services for the LGBTQ population.**
 True False
- 2. The LGBTQ community seeks preventative care at lower rates than the general population.**
 True False
- 3. What are some reasons why the LGBTQ community delays or never seeks preventative care?**
 - a. Lack of cultural sensitivity in health care settings in addressing gender and/or sexual identities
 - b. Uncertainty of recommendations for screening guidelines for trans and non-binary clients
 - c. Inability to afford services
 - d. All of the above
- 4. What percentage of the LGBTQ aged 50-74 have received their recommended mammogram in the past two years?**
 - a. 50%
 - b. 60%
 - c. 70%
 - d. 80%
- 5. What percentage of the LGBTQ community agrees or strongly agrees that health care providers in Washington need to undergo LGBTQ cultural sensitivity training?**
 - a. 70%
 - b. 87%
 - c. 92%
 - d. 98%
- 6. What barriers face the LGBTQ community when shopping for gender affirming care?**
 - a. Finding proficiency among providers/staff/facilities in affirming LGBTQ identities
 - b. Lacking knowledge about breast health practices, risks and screening guideline recommendations
 - c. Updating universal health system policies to recognize partner/spousal rights and differing sexual identities
 - d. Lacking trust and a feeling of safety to disclose gender identity or sexuality
 - e. Experiencing trauma/anxiety from abusive or uncomfortable social encounters making it difficult to seek help
- 7. What is the difference between gender identity and sexual orientation?**
- 8. Higher incidences of never giving birth increases the risk of breast cancer for cis lesbians, cis straight, trans and non-binary men and women.**
 True False
- 9. Taking cross-gender hormones long-term decreases the risk for breast cancer among trans and non-binary individuals.**
 True False
- 10. Transgender men and non-binary people who have had chest reconstruction surgery no longer need mammograms.**
 True False



For the LGBTQ Community



Know Your Risk for Breast Cancer

The best defense against breast cancer is early detection. The earliest breast cancer is detected, the easier it is to treat. Know your risk for breast cancer.

Sexual Minority Women (Cisgender)

Sexual minority women who are cisgender (not transgender) have a high risk of breast cancer due to:

- Higher rates of never giving birth
- Older age at first live birth
- Higher rates of smoking
- Higher rates of alcohol abuse
- Higher rates of elevated BMI



Transgender Men

The risk of breast cancer in the transgender community is not well known. There have not been significant studies of breast cancer occurrence in transgender or gender non-conforming individuals, but this does not mean that 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 for breast cancer.
- Even after chest reconstructive surgery some chest tissue will remain. The remaining tissue is still at risk for breast cancer.

Transgender Women

The risk of breast cancer in the transgender community is not well known. There have not been significant studies of breast cancer occurrence in transgender or gender non-conforming individuals, but this does not mean that transgender people are not at risk.

- Transgender women have a high occurrence of dense breasts, which is an independent risk for breast cancer and also a predictor of increased rates of false negative mammograms.

Know Your Risk for Breast Cancer

Do you know your risk for breast cancer?

answers on this side are

AVERAGE RISK

answers on this side are

HIGHER RISK



1. How old are you?

(USA) odds:

30's
1 in 233

40's
1 in 69

50's
1 in 38

60's
1 in 27

70's +
1 in 8

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

2. How much estrogen have you been exposed to?

I got my period during/after age 12. I got my period before age 12.

I gave birth before age 30 and had several pregnancies. I have never had children, or did so after age 30.

I have breast fed. I have not breast fed.

I entered menopause before age 55. I entered menopause after age 55.

I was a normal weight after menopause. I was overweight after menopause.

I've not used birth control pills for 10 years or so. I'm taking birth control pills now.

I have not used HRT (estrogen/hormone pills). I have used HRT.

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

No.

Still at risk, as 80% of women diagnosed with breast cancer have no family history.

Yes.

Mother's or father's side still counts.

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

4. Any breast conditions?

I have fibrocystic (lumpy) breasts or dense breasts.

I've had a biopsy before, or found atypical hyperplasia.

5. Lifestyle habits?

I do not consume alcohol.

I occasionally have an alcoholic beverage.

I drink more than one alcoholic beverage a day.

I exercise regularly.

I am somewhat physically active.

I am rarely physically active.

TALK WITH YOUR DOCTOR ABOUT YOUR SCREENING PLAN.

Decide how often you should do the following and at what age:

self-exam:

clinical exam:

mammogram:

*If you are at a higher risk, ask about other diagnostic tools such as mri, ultrasound, etc.



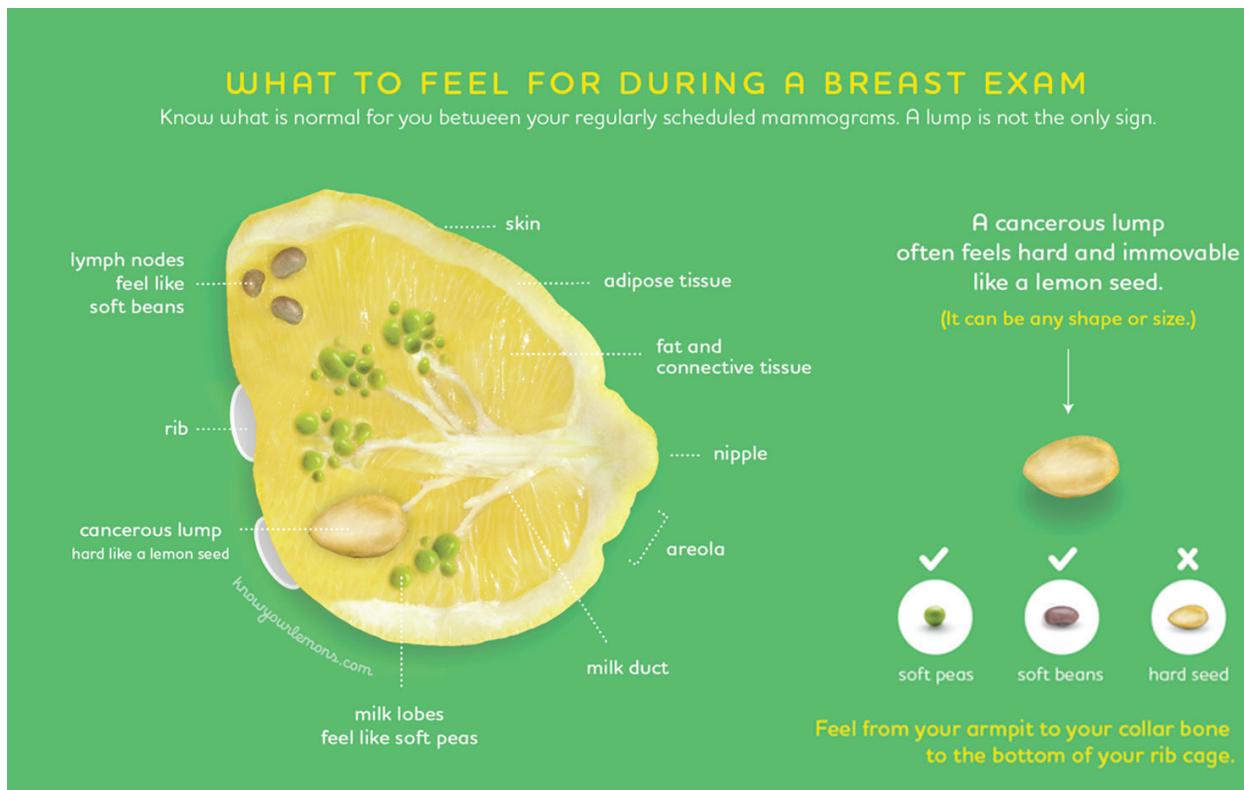
worldwide
breast cancer

Risk form by worldwidebreastcancer.org
Based on the NCI Risk Calculator (cancer.gov/bcrisktool).

Research indicates that self-exams are not effective in early detection of breast cancer. Self-exams are not recommended in place of mammography. However, self-exams can be helpful in understanding what your body looks and feels like, which can help you recognize what is normal for you and if there changes in your body that mean you should speak with a health care providers.

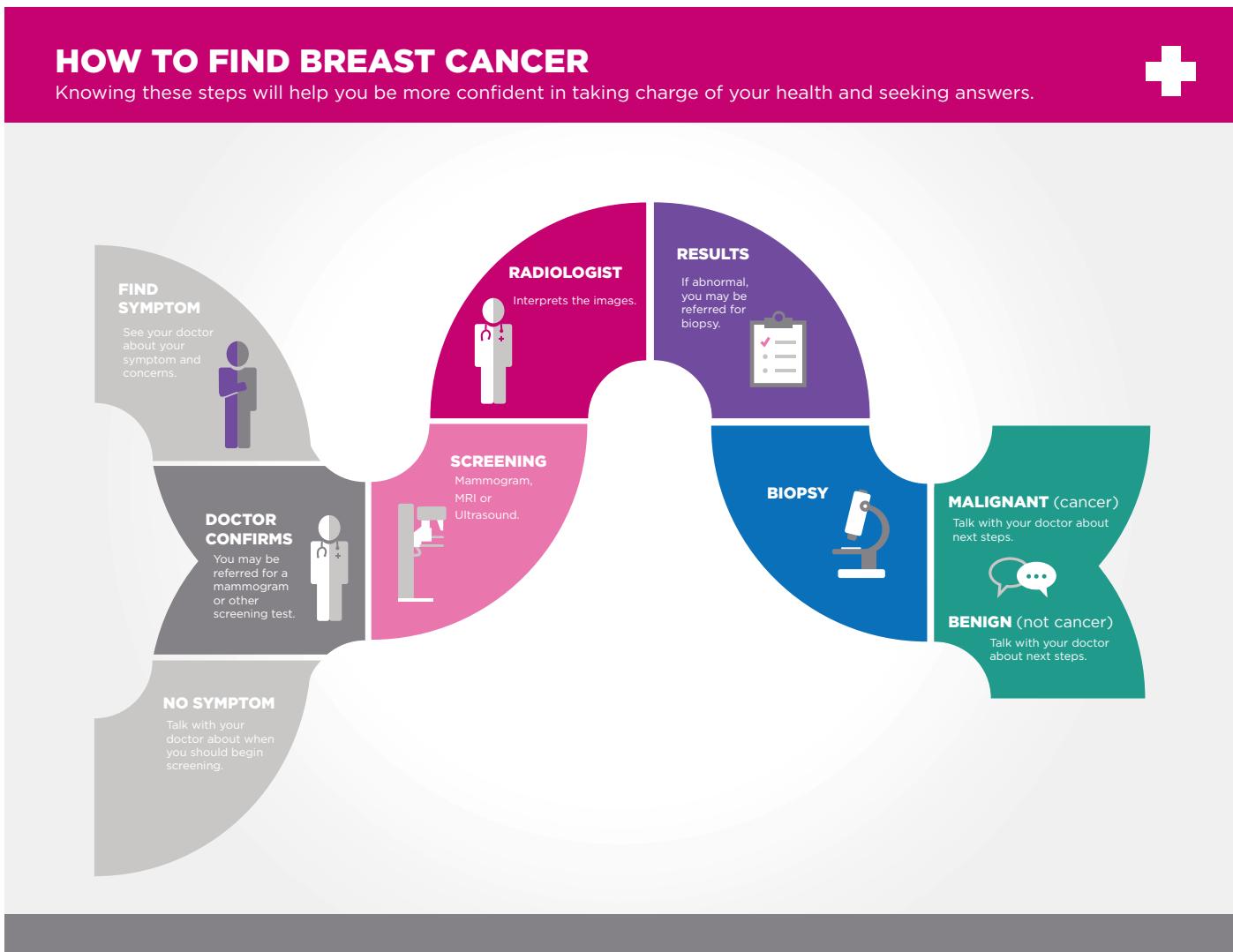
Know What To Look For

Research indicates that self-exams are not effective in early detection of breast cancer. Self-exams are not recommended in place of mammography. However, self-exams can be helpful in understanding what your body looks and feels like, which can help you recognize what is normal for you and whether there are changes in your body that mean you should speak with a health care provider.



What To Do If You See or Feel Something

Research indicates that self-exams are not effective in early detection of breast cancer. Self-exams are not recommended in place of mammography. However, self-exams can be helpful in understanding what your body looks and feels like, which can help you recognize what is normal for you and whether there are changes in your body that mean you should speak with a health care provider.



Screening Guidelines

Expert recommendations for breast cancer screening guidelines vary by organization. The table below illustrates breast cancer screening recommendations for cisgender women at average risk.

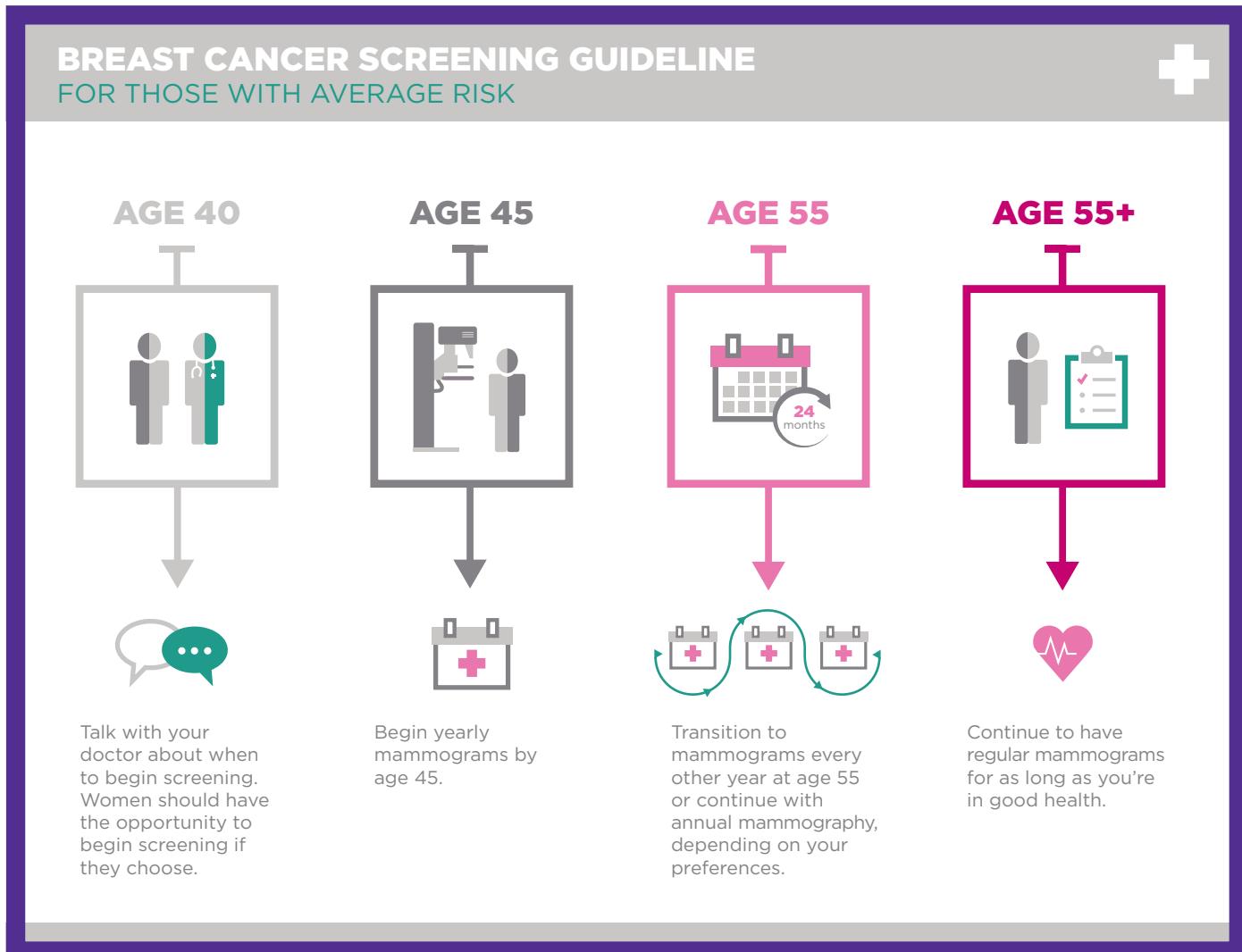
Breast Cancer Screening Recommendations for Cisgender Women at Average Risk		
American Cancer Society	National Comprehensive Cancer Network	U.S. Preventive Services Task Force
Mammography		
Informed decision-making with a health care provider ages 40-44 Every year starting at age 45-54 Every 2 years (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

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Transgender Men

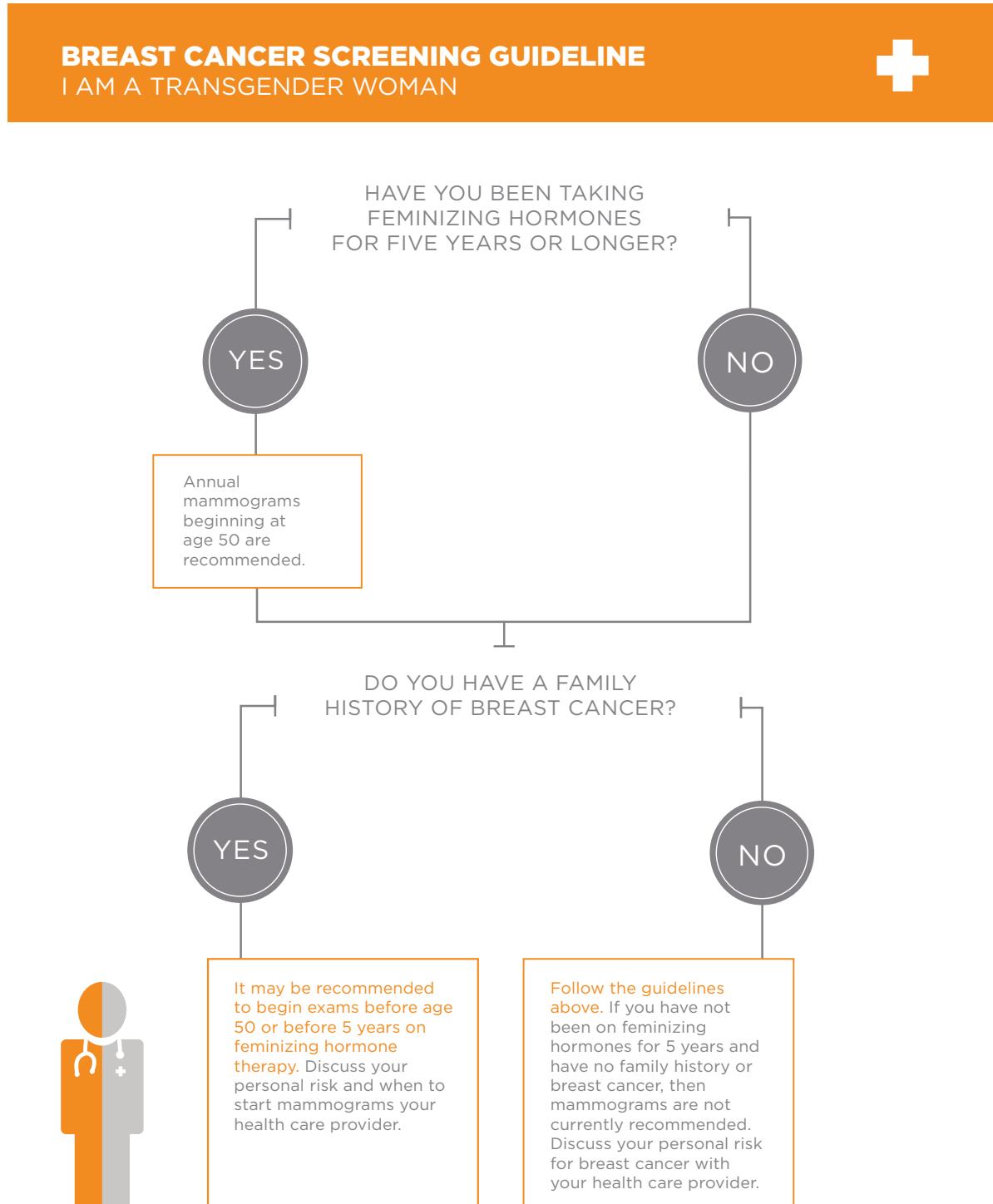
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Among many other barriers to receiving healthcare, transgender men may feel disconnected from their chest, or assume chest reconstructive surgery protects them, and therefore do not see a health care provider for clinical chest exams.

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.

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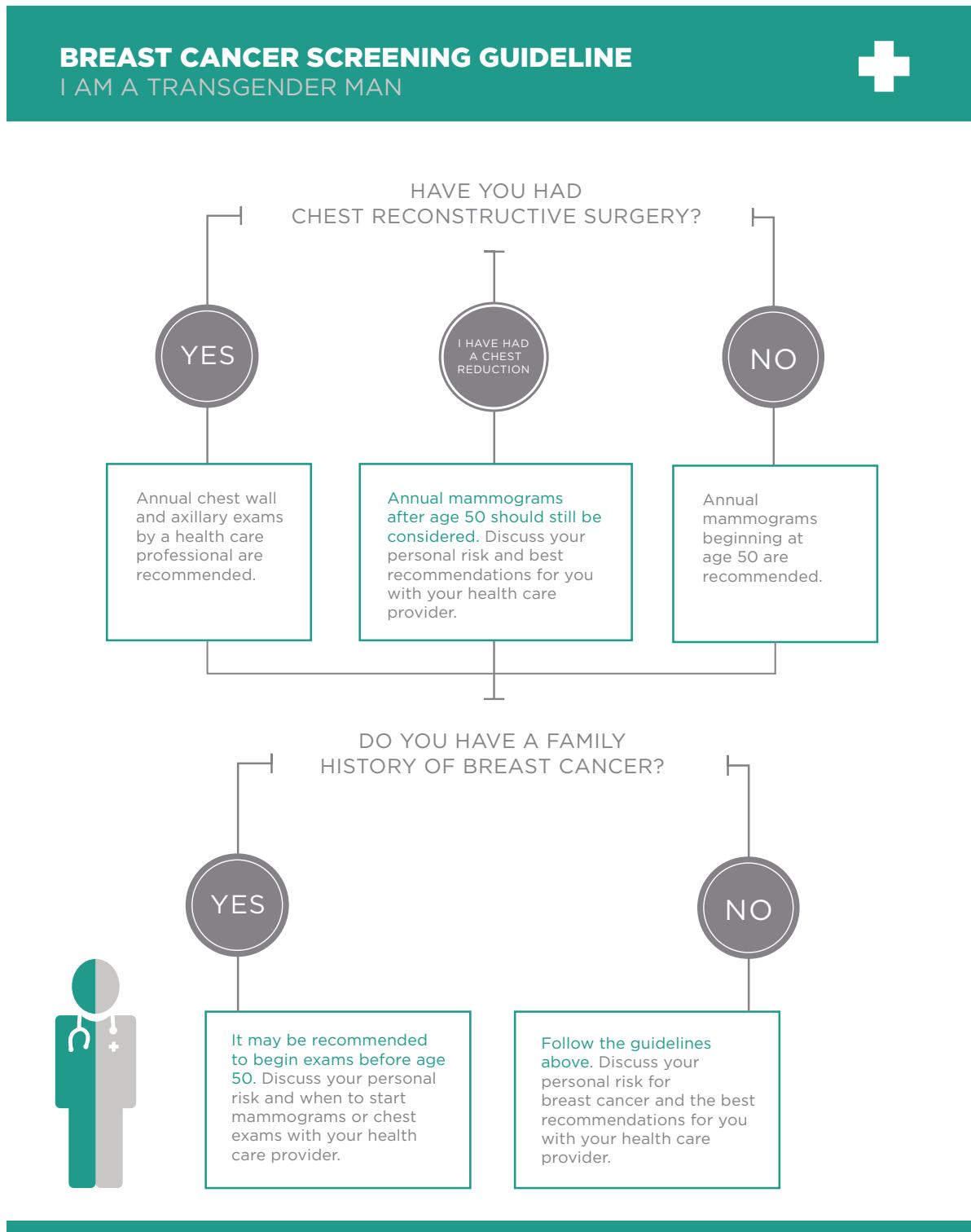


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FAQs for LGBTQ Patients

For Transgender Women

How do feminizing hormones affect breast health?

It is recommended that transgender women over the age of 50 who have used feminizing hormones for 5 years or more should get a mammogram annually.

Transgender women have a high prevalence of dense breasts, which is an independent risk for breast cancer and also a predictor of increased rates of false negative mammograms.

Talk with your health care provider about your personal risk for breast cancer and the best recommendations for you.

How does age at the start of hormone usage affect when to start getting a mammogram?

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.

Talk with your health care provider about your personal risk for breast cancer and the best recommendations for you.

How do implants affect mammography?

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 two).

If you can, choose a center with technologists and radiologists who are experienced in mammography for women with breast implants.

For Transgender Men

Does binding my chest have an impact on the risk for breast cancer?

Permanent tissue changes can result from long-term compression of the chest. There is not substantial research to indicate whether this can increase the risk for breast cancer.

How do masculinizing hormones affect chest health?

While there has not been substantial research on transgender men and breast health, it is known that 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 for breast cancer.

If I've had chest reconstructive surgery, do I still need to get a mammogram?

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.

If a transgender man has family history of breast cancer, then the recommendations may be different.

Talk with your health care provider in order to assess your personal risk for breast cancer and the best recommendations for you.

FAQs for LGBTQ Patients

For Gender Non-Conforming People

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

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

For Cisgender Women

How often should I get a mammogram?

Discuss your personal risk for 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 for breast cancer, your screening guidelines may be different.

How can I 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

FAQs for the Transgender Community

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If you can, choose a center with technologists and radiologists who are experienced in mammography for women with breast implants.

FAQs for Non-Binary People

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

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

FAQs for Cisgender Women

How often should I get a mammogram?

Discuss your personal risk for 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 scheduling mammograms every other year after age 55 but some recommend continuing annual mammograms.

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- Limit menopausal hormone use
- If you have children, breastfeed, if you can

Thank You To Our Partners

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Mitchell C. Hunter

World Wide Breast Cancer

All LGBTQ participants in Susan G. Komen Puget Sound's research study. This toolkit would not have been possible without your feedback.

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

