# Breast Health Toolkit for Health Care Providers caring for the LGBTQ Community

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



#### About the Toolkit

#### Introduction

Based on research conducted by Susan G. Komen<sup>®</sup> 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 toolkit was designed in response to the indication from 98 percent of our research participants that health care providers in Western Washington need to undergo LGBTQ cultural sensitivity training. Our coalition of researchers, leaders in the LGBTQ community and health care 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 care 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 the LGBTQ community is affirmed through their entire health care 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 "Breast Health for the LGBTQ Community" resource 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 run from 45 minutes to 2 hours, depending on the need to build a foundational understanding of LGBTQ identities. This should be a continual training to ensure all staff, even after turnover and especially new hires, maintain the ability to provide affirming care to the LGBTQ community.

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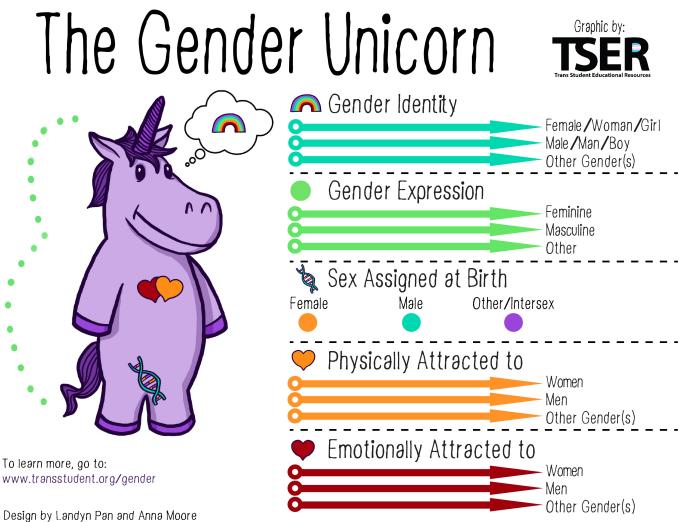
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### **Objectives**

- 1. State the difference between sexual orientation and gender identity.
- 2. Create at least 1 comprehensive intake form to provide affirming care to patients of all genders and sexualities.
- 3. State the screening guidelines for people of all genders.
- 4. Identify at least 2 barriers to health care for the LGBTQ community and demonstrate appropriate responses.
- 5. Answer frequently asked questions the LGBTQ community may have about breast health.
- 6. State at least 2 local and national LGBTQ resources.

#### 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).



### LGBTQ Terminology

Consider posting these definitions on your wall for easy reference. Always use language people 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. It is a good idea to gather how an individual identifies in terms of their gender identity, sexual orientation and pronouns on their patient intake forms. This list of terms is not exhaustive. The <u>Glossary of LGBT Terms</u> for Health Care Teams provided by the Fenway Insititute provide the most common terms Additional terms can be foundTo all

**Natal sex/assigned sex at birth** (noun) - the sex (male or female) assigned to a child at birth, most often based on the child's external anatomy. Also referred to as birth sex, natal sex, biological sex or sex.

**Gender identity** (noun) - a person's inner sense of being a boy/man/male, girl/woman/female, another gender or no gender.

**Gender expression** (noun) - describes the ways (e.g., feminine, masculine, androgynous) in which a person communicates their gender to the world through their clothing, speech, behavior, etc. Gender expression is fluid and is seperate from assigned sex at birth or gender identify.

Sexual orientation (noun) - how a person characterizes their emotional and sexual attraction to others.

**Transition** (noun) - for transgender people, this refers to the process of coming to recognize, accept and express one's gender identity. Most often, this refers to the period when a person makes social, legal and/or medical changes, such as changing their clothing, name, sex designation and using medical interventions. Sometimes referred to as gender affirmation process.

**Gender affirmation** (noun) - 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** (noun) - refers to providing health care that specifically helps patients achieve congruence between their gender identity and physical appearance. Often, but not always, this involves varying levels of hormones and/or surgical procedures. This is highly individualized to each person's desires and gender identity.

**Gender affirming surgery (GAS)** (noun) - surgeries used to modify one's body to be more congruent with one's gender identify. Also referred to as sex reassignment surgery (SRS) or gender confirming surgery (GCS).

**Sex Reassignment Surgery (SRS)** (noun) - 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** (noun) - colloquial way of describing gender affirming surgery on the chest.

Bottom surgery (noun) - colloquial way of describing gender affirming genital surgery.

Adapted from https://www.lgbthealtheducation.org/wp-content/uploads/2018/03/Glossary-2018-English-update-1.pdf and http://www.hrc.org/resources/sexual-orientation-and-gender-identity-terminology-and-definitions

#### **Gender Identity**

Agender (adj.) - describes a person who identifies as having no gender.

**Cisgender** (adj.) - a person whose gender identity and assigned sex at birth correspond (i.e., a person who is not transgender).

**Gender fluid** (adj.) - describes a person whose gender identity is not fixed. A person who is gender fluid may always feel like a mix of the two traditional genders, but may feel more one gender some of the time, and another gender at other times.

**Gender non-conforming** (adj.) - describes a gender expression that differs from a given society's norms for males and females.

**Genderqueer** (adj.) - describes a person whose gender identity falls outside of the traditional gender binary structure. Other terms for people whose gender identify falls outside the tranditional gender binary include gender variant, gender expansive, etc. Sometimes written as two words (gender queer).

**Non-binary** (adj.) - describes a person whose gender identity falls outside of the traditional gender binary structure. Sometimes abbreviated as NB or "enby."

**Transgender man/Trans man/female-to-male (FTM)** (noun) - a transgender person whose gender identity is male may use these terms to describe themselves . Some will just use the term man.

**Transgender woman/Trans woman/male-to-female (MTF)** (noun) - a transgender person whose gender identity is female may use these terms to describe themselves. Some will just use the term woman.

**Two-spirit** (adj.) - describes a person who embodies both a masculine and a feminine spirit. This is culture-specific term used among Native American, American Indian and First Nations people.

#### **Sexual Orientation**

**Asexual** (adj.) - describes a person who experiences little or no sexual attraction to others. Asexuality is not the same as celibacy.

**Bisexual** (adj.) - describes a person who is emotionally and sexually attracted to people of their own gender and people of other genders.

**Gay** (adj.) - describes a person who is emotionally and sexually attracted to people of their own gender. It can be used regardless of gender identity, but is more commonly used to describe men.

Lesbian (adj., noun) - describes a woman who is emotionally and sexually attracted to other women.

**Pansexual** (adj.) - describes a person who is emotionally and sexually attracted to people of all gender identities.

**Queer** (adj.) - 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 for 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 is highly personal and continues to evolve.

### LGBTQ Terminology

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

| Natal Sex/Assigned Sex<br>At Birth | The sex (male or female) assigned to a child at birth,<br>most often based on the child's external anatomy. Also<br>referred to as birth sex, natal sex, biological sex or sex.   |
|------------------------------------|---|
|                                    |   |
| Gender Identity                    | a person's inner sense of being a boy/man/male, girl/<br>woman/female, another gender or no gender.   |
|                                    |   |
| Gender Expression                  | The ways (e.g., feminine, masculine, androgynous) in<br>which a person communicates their gender to the world<br>through their clothing, speech, behavior, etc. Gender<br>expression is fluid and is seperate from assigned sex at<br>birth or gender identify.   |
|                                    |   |
| Sexual Orientation                 | How a person characterizes their emotional and sexual attraction to others.   |
|                                    |   |
| Transition                         | For transgender people, this refers to the process of<br>coming to recognize, accept and express one's gender<br>identity. Most often, this refers to the period when a<br>person makes social, legal and/or medical changes,<br>such as changing their clothing, name, sex designation<br>and using medical interventions. Sometimes referred to<br>as gender affirmation process. |
|                                    |   |
| Gender Affirmation                 | A more recently coined term referring to the process<br>of altering one's gendered appearance to better align<br>with one's gender identity. (This term does not enforce<br>a gender binary like the term "transition" does. Physical<br>alterations may be hormonal, surgical, social or any<br>combination of these).   |

Adapted from https://www.lgbthealtheducation.org/wp-content/uploads/2018/03/Glossary-2018-English-update-1.pdf and http://www.hrc.org/resources/sexual-orientation-and-gender-identity-terminology-and-definitions

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

| Gender Affirming Care             | Refers to providing health care that specifically helps<br>patients achieve congruence between their gender<br>identity and physical appearance. Often, but not always,<br>involves varying levels of hormones and/or surgical<br>procedures. Highly individualized to each person's<br>desires and gender identity. |  |
|-----------------------------------|--|--|
|                                   |  |  |
| Gender Affirming<br>Surgery (GAS) | Surgeries used to modify one's body to be more<br>congruent with one's gender identify. Also referred to as<br>sex reassignment surgery (SRS) or gender confirming<br>surgery (GCS).   |  |
|                                   |  |  |
| Sex Reassignment<br>Surgery (SRS) | Typically used to discuss vaginoplasty or phalloplasty,<br>but the term is avoided by some patients and providers<br>because it references a binary sex/gender status.   |  |
|                                   |  |  |
| Top Surgery                       | Colloquial way of describing gender affirming surgery on the chest.  |  |
|                                   |  |  |
| Bottom Surgery                    | Colloquial way of describing gender affirming genital surgery.   |  |

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

| Agender                  | Describes a person who identifies as having no gender.  |
|--------------------------|---|
| Cisgender                | Describes a person whose sex and gender identity<br>align. i.e. someone who was assigned male at birth and<br>identifies as male/masculine.   |
| Gender Fluid             | Describes a person whose gender identity is not fixed.<br>A person who is gender fluid may always feel like a<br>mix of female and male, or may feel they are more one<br>gender some days and another gender other days. |
| Gender<br>Non-Conforming | An umbrella term describing gender expression that<br>differs from a given society's norms of only male and<br>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.<br>Men were assigned female at birth.   |
| Transgender Woman        | A transgender person whose gender identity is female.<br>Transgender women were assigned male at birth.   |
| Two-Spirit               | Describes Native American/Alaskan Native LGBTQ<br>people, stemming from language meaning to have both<br>female and male spirits within one person. The term has<br>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

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

| Asexual   | Describes a person who identifies as having no gender.   |
|-----------|--|
| Bisexual  | Describes a person who is emotionally and sexually<br>attracted to people of their own gender and people of<br>other genders.  |
| Gay       | Describes a person who is emotionally and sexually<br>attracted to people of their own gender. It can be used<br>regardless of gender identity, but is more commonly<br>used to describe men.  |
| Lesbian   | Describes a woman who is emotionally and sexually attracted to other women.  |
| Pansexual | Describes a person who is emotionally and sexually attracted to people of all gender identities.   |
| Queer     | An umbrella term used by some to describe people<br>who think of their sexual orientation or gender identity<br>as outside of societal norms. Some people view the<br>term "queer" as more fluid and inclusive than traditional<br>categories for sexual orientation and gender identity.<br>Due to its history as a derogatory term, it is not<br>embraced or used by all of the LGBTQ community. |

#### **Match the Definition**

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

| 1.  | Agender                   | <b>A.</b> a person who is emotionally and sexually attracted to people of their own gender and people of other genders  |
|-----|---------------------------|---|
| 2.  | Asexual                   | <b>B.</b> a person who is gender fluid may always feel like a mix of the two traditional genders, but may feel more one gender some of the time, and another gender at other time   |
|     | Bisexual                  | <b>C.</b> a person's inner sense of being a boy/man/male, girl/woman/<br>female, another gender or no gender  |
|     | Cisgender                 | <b>D.</b> a person who is emotionally and sexually attracted to people of all gender identities   |
| 5.  | Gay                       | <b>E.</b> a person who identifies as having no gender   |
| 6.  | Gender expression         | <b>F.</b> a transgender person whose gender identity is female  |
| 7.  | Gender fluid              | <b>G.</b> people who think of their sexual orientation or gender identity<br>as outside of societal norms. Some people view the term "queer"<br>as more fluid and inclusive than traditional categories for sexual<br>orientation and gender identity |
|     | Gender identity           | <b>H.</b> the sex (male or female) assigned to a child at birth, most often based on the child's external anatomy   |
| 9.  | Gender non-conforming     | I. a person whose gender identity falls outside of the traditional  |
| 10. | Genderqueer               | gender binary structure   |
| 11. | Lesbian                   | J. a person who embodies both a masculine and a feminine spirit. This is culture-specific term used among Native American, American Indian and First Nations people   |
| 12. | Non-binary                | <b>K.</b> a person whose gender identity and assigned sex at birth correspond (i.e., a person who is not transgender)   |
| 13. | Pansexual                 | L. a person who experiences little or no sexual attraction to others  |
|     |                           | <b>M.</b> a person whose gender identity falls outside of the traditional gender binary structure   |
| 14. | Queer                     | <b>N.</b> a gender expression that differs from a given society's norms for   |
| 15. | Sex/assigned sex at birth | males and females   |
| 16. | Transgender man           | <b>O.</b> describes the ways (e.g., feminine, masculine, androgynous) in which a person communicates their gender to the world through their clothing, speech, behavior, etc.   |
| 17  | Transgender woman         | P. a woman who is emotionally and sexually attracted to other women   |
|     | Hansgehaer wornan         | <b>Q.</b> a transgender person whose gender identity is male  |
| 18. | Two-spirit                | <b>R.</b> describes a person who is emotionally and sexually attracted to people of their own gender. It can be used regardless of gender identity, but is more commonly used to describe men   |

### **Recommendations for Best Practices for Health Care 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:
  - \* 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.
  - \* Gather information about sex, gender identify, pronouns and language on intake forms as it is an easy, immediate/upfront, and "quiet" way to show those in the LGBTQ community that your clinic is a safe space.
- 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 boards 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 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 for 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. It is a good idea to have the preferred pronouns front and center on a patient's chart in a way to ensure providers use the correct pronouns with the patient.

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 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 N  | ame                                     | Legal First Name            |                | МІ              |
|---------------|---|-----------------------------|----------------|-----------------|
|               |   |                             |                |                 |
| What is you   | r preferred name?                       |                             |                |                 |
|               | ns are (circle all that a               | annly):                     |                |                 |
| _             |   |                             | Theirs         | Something else: |
| Address:      |   |                             |                |                 |
| The ear lune  |   |                             |                |                 |
| Male          | <b>s assigned at birth wa</b><br>Female | s (circle one):<br>Intersex |                |                 |
|               | T emaie                                 | Intersex                    |                |                 |
| Gender iden   | tity (circle all that app               | oly):                       |                |                 |
| Man           | Woman                                   | Transgender Man             | Transg         | gender Woman    |
| Gender Non-   | Conforming                              | Non-Binary                  | Genderfluid    | Genderqueer     |
| Agender       | Something else (expl                    | ain)                        |                |                 |
| Sexual orien  | tation (circle all that a               | pply):                      |                |                 |
| Straight      | Lesbian Bisexu                          | al Pansexual                | Queer          | Gay             |
| Questioning   | Asexual                                 | Something else (exp         | olain)         |                 |
| In the past y | ear, my sexual partne                   | rs include (circle all t    | that apply):   |                 |
| Men           | Women                                   | None Trans                  | gender partner | S               |
| Something e   | lse (explain)                           |                             |                |                 |

## **Creating a Welcoming Environment: Dos & Don'ts**

Consider prominently displaying these dos and don'ts 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

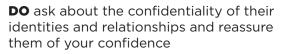


**DO** ask "Are you seeing someone?" or "Are you in a relationship?" rather than "Do you have a boyfriend?" or "Do you have a girlfriend?"



**DO** listen to what a person has to say

**DO** be honest when you don't understand something



**DO** use pronouns 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 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

#### 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.



In preparation for the visit, you review his available medical records and learn 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.

#### Mikhal, 65 Transgender Man

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 a mammography clinic, and we only see women here." After insisting 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.



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

#### **Scenario Discussion Points**

- Identify health disparities and barriers to care experienced by LGBTQ individuals.
- Inspect a health care environment through the eyes of an 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 on how they prefer to be addressed (e.g., name and pronouns).
- Propose a screening strategy for a transgender man (via role-play or use of a standardized patient) that is appropriate to their 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 their body, sense of autonomy and control and physical comfort.
- Discuss 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. Susan G. Komen has a Facts for Life educational material specific to Lesbian, Gay, Bisexual, Transgender and Questioning/Queer People. This resource can be found <u>here</u>.
- Describe the importance of designated support services for LGBTQ patients who are living with cancer and/or who are elderly. 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.

#### **Mythbusting**

Seemingly small signs of respect mean a lot coming from the medical community. If you want LGBTQ individuals to trust you enough to give you an accurate medical history, take time to show you care by referring to them the way they prefer to be addressed.

These are some examples of common thoughts health care providers or staff may have when interacting with a transgender patient and responses that may prompt someone to reconsider their viewpoint. Have 2 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."

#### 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 there's not that moment of 'Oh. Oh my God!' 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 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. As your doctor, how can I support you?"

"What pronouns would you like me to use?"

### 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?"

Step 4: 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.

### **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<br>Cisgender Women at Average Risk  |  |   |
|---|--|---|
| American Cancer Society   | National Comprehensive<br>Cancer Network                                       | U.S. Preventive Services<br>Task Force  |
| Mammography   |  |   |
| Informed decision-making with a<br>health care provider ages 40-44<br>Every year starting at age 45-54<br>Every 2 years (or every year if a<br>woman chooses to do so) starting<br>at age 55, for as long as a woman<br>is in good health | Every year starting at age<br>40, for as long as a woman<br>is in good health* | Informed decision-making<br>with a health care provider<br>ages 40-49<br>Every 2 years ages 50-74 |
| Clinical Breast Exam  |  |   |
| Not recommended   | Every 1-3 years ages 25-39<br>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.<sup>1</sup>

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.<sup>2</sup>

#### **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.<sup>3</sup> Even after chest reconstructive surgery some breast tissue will remain. The remaining tissue is still susceptible to breast cancer.<sup>4</sup>

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.

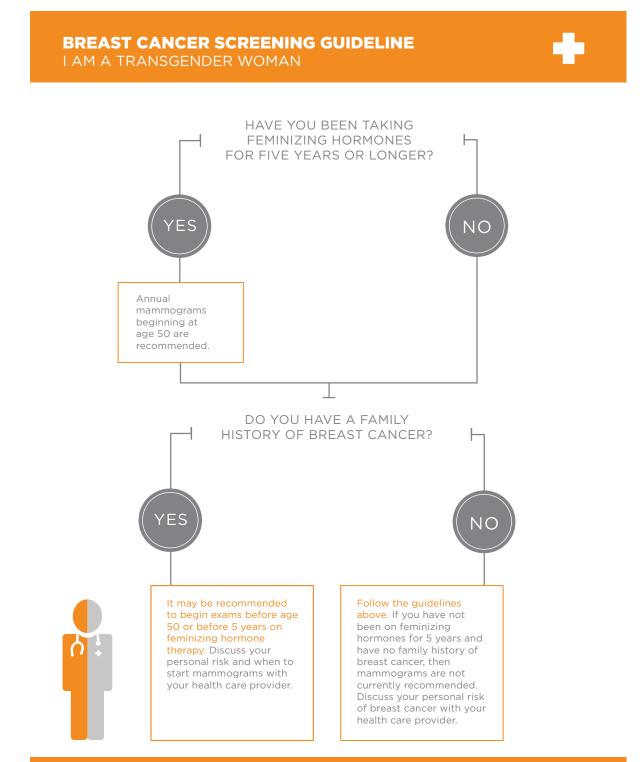
- Transgender men who have had chest reconstructive surgery should still receive annual chest wall and axillary exams beginning at age 50.
- Transgender men who have had a chest reduction may still be recommended to have annual mammograms beginning at age 50.
- Transgender men who have not had chest 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.<sup>5</sup>

- <sup>1</sup> 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
- <sup>2</sup> http://www.thecentersd.org/pdf/health-advocacy/breast-cancer-facts-for.pdf
- <sup>3</sup> http://www.thecentersd.org/pdf/health-advocacy/breast-cancer-facts-for.pdf
- <sup>4</sup> http://lgbthealtheducation.org/wp-content/uploads/COM-2245-The-Medical-Care-of-Transgender-Persons.pdf
- <sup>5</sup> http://www.thecentersd.org/pdf/health-advocacy/breast-cancer-facts-for.pdf

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

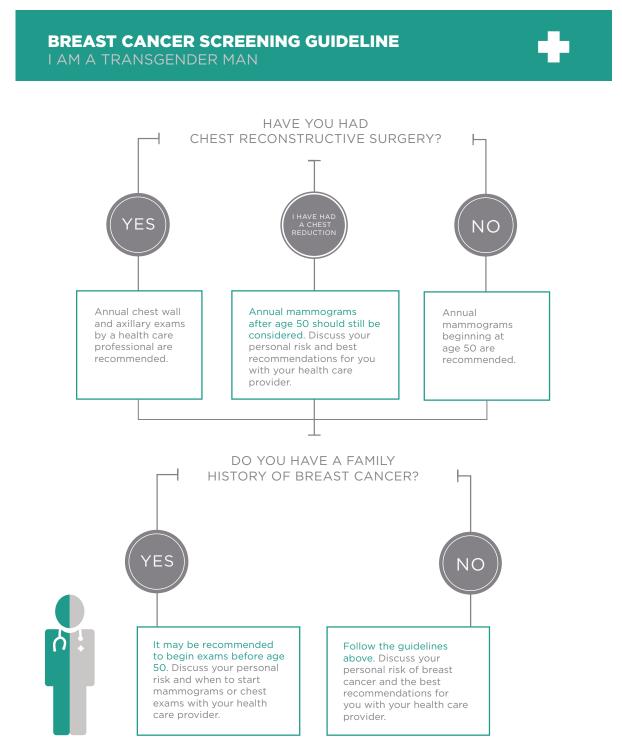
### **Screening Guidelines for Transgender Women**

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.



### **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.



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

### **Barriers and Suggested Responses**

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

| I'm a transgender man<br>and I have had chest<br>reconstruction surgery,<br>so I'm not at risk of<br>breast cancer. | Even after chest reconstructive surgery some breast tissue will<br>remain. The remaining tissue is still susceptible to breast cancer.<br>Transgender men should get chest wall and axillary exams from a<br>health care provider annually. <sup>6</sup><br>Excess testosterone in the body can be converted to estrogen, and<br>excess estrogen increases the risk of breast cancer. Transgender<br>men taking testosterone may be at increased risk of breast<br>cancer. Discuss your personal risk of breast cancer and the best<br>recommendations for you with your health care provider.   |
|---|--|
|   |  |
| I'm a transgender woman,<br>and only cisgender<br>women get breast cancer,<br>so I don't need to get<br>mammograms. | People of all genders can get breast cancer.<br>According to Fenway Health, Transgender women over the age of<br>50 who have been taking feminizing hormones for 5 years or more<br>should get a mammogram annually. Discuss your personal risk of<br>breast cancer and the best recommendations for you with your<br>health care provider. <sup>7</sup>   |
|   |  |
| I can't afford the cost of<br>a mammogram OR I don't<br>have health insurance.                                      | There are options to help pay for the mammograms or clinical<br>breast exams, and assistance if you need follow-up tests.<br>Medicare pays for most of the cost of a mammogram. If you have<br>insurance, you can call the number on the back of your card to find<br>out if they will cover the cost of a mammogram.  |
|   |  |
| I don't have enough time<br>to get a mammogram.<br>I'm too busy.  | The mammogram itself usually takes about an hour from the time<br>you walk into the facility until the time you walk out. You might<br>check in with the imaging center to learn what days and times are<br>usually less busy and try to schedule your appointment then.<br>A mammogram is important. It is the best screening tool used<br>today to find breast cancer. Mammography can find cancers at an<br>early stage, when they are small (too small to be felt) and most<br>responsive to treatment. Getting regular screening tests along with<br>effective treatment is the best way for people to lower their risk of<br>dying from breast cancer. |

Adapted from http://komentoolkits.org/wp-content/uploads/2013/11/Barriers-and-Responses.pdf

 $^{6}\ http://lgbthealtheducation.org/wp-content/uploads/COM-2245-The-Medical-Care-of-Transgender-Persons.pdf$ 

<sup>7</sup> http://www.thecentersd.org/pdf/health-advocacy/breast-cancer-facts-for.pdf

### Barriers and Suggested Responses (cont.)

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

| l am afraid or anxious<br>to get a mammogram.  | It is understandable you are nervous about having a mammogram.<br>For some people, thinking about breast cancer screening reminds<br>them about the possibility they could get breast cancer. This is<br>very upsetting, it makes it difficult for you to do what you need to<br>do - get a mammogram. Often, once you have a mammogram, you<br>can usually stop worrying. Does this sound familiar?<br>Some people find it makes them feel less anxious if they take a<br>friend or loved one to their appointments. And, before the exam,<br>you could let the technologist know about your concerns.<br>You might ask, "What do you think will help you feel less anxious<br>about having a mammogram?" |
|--|--|
| I don't have reliable<br>transportation to a<br>breast health center.  | Getting around is difficult if you don't have a car or anyone to<br>take you places, and this can be frustrating. This problem makes<br>scheduling your mammogram difficult.<br>Fortunately, your local Susan G. Komen® Affiliate may provide you<br>with information about grantees who may be able to assist you<br>with transportation to and from the mammogram facility.<br>Or you can call the Susan G. Komen® Breast Care Helpline at<br>1-877 GO KOMEN (1-877-465-6636) learn about possible sources<br>of assistance in your area.  |
| My doctor examines my<br>chest every year when<br>I go for a check-up, so<br>I don't need to get a<br>mammogram. | <ul> <li>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.</li> <li>Screening tests can find breast cancer early, when it is most treatable. Getting regular screening tests along with effective treatment is the best way for women to lower their risk of dying from breast cancer.</li> </ul>   |
| I am, or someone<br>in my family is an<br>undocumented<br>immigrant and I<br>am scared of being<br>reported.     | It is not the policy of heath care programs to report undocumented<br>immigrants. In fact, some organizations prohibit its employees<br>from sharing immigrant status information.<br>There are federally funded public health programs, federally<br>qualified health centers and migrant health clinics that can provide<br>you with a mammogram regardless of your citizenship status.<br>Let's work together to find an organization that will provide<br>a mammogram without fear of your immigration status being<br>reported.   |

Adapted from http://komentoolkits.org/wp-content/uploads/2013/11/Barriers-and-Responses.pdf

### Barriers and Suggested Responses (cont.)

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

| l don't have a doctor, so l<br>can't get a mammogram.  | You may qualify for a low or no-cost mammogram.<br>Call the Susan G. Komen® Breast Care Helpline at 1-877 GO KOMEN<br>(1-877-465-6636) to learn about possible sources of care in<br>your area.  |
|--|--|
| Last time I went to a<br>health care provider<br>for a mammogram the<br>staff were insensitive to<br>my gender identity or<br>sexuality. | I hope you will tell your doctor how you feel so he/she can<br>communicate with the technologist how it made you feel.<br>In the meantime, you may want to request a different technologist<br>when you make your appointment or call another facility that<br>covers your mammograms. Does this sound like something you<br>could do?   |
| My chest feels fine and I<br>have no symptoms, so I<br>don't need to keep going<br>for mammograms.                                       | In the case of breast cancer, it's not always easy to tell whether<br>or not something is broken, that is, whether or not you have<br>breast cancer. People can have breast cancer without having any<br>symptoms. In fact, the best time to get a mammogram is when you<br>feel fine and do not have any symptoms.<br>Mammograms can find breast cancer early before there are any<br>symptoms and when it's most treatable. Getting regular screening<br>tests along with effective treatment is the best way for people to<br>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/

#### **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 91809 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/

### **Audience Assessment**

This assessment may be a useful tool for LGBTQ health care trainers to use to gauge the level of knowledge the audience holds before undergoing training. This document can also be used as a tool to find out how much the audience retained when compared to the document presented prior to the training or simply as a post test.

Circle all letters which apply or check the best answer.



- Providing culturally-sensitive care has the potential to increase services for the LGBTQ population.
   True
   False
- 2. The LGBTQ community seeks preventive care at lower rates than the general population.
- 3. What are some reasons why the LGBTQ community delays or never seeks preventive 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 barriers do the LGBTQ community face when looking 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
  - f. All of the above

#### 5. What is the difference between gender identity and sexual orientation?

6. Higher incidence of never giving birth increases the risk of breast cancer of cis lesbians, cis straight, transgender and

non-binary men and women.

□ True □ False

7. Taking cross-gender hormones long-term decreases the risk of breast cancer among transgender and non-binary individuals.

□ True □ False

8. Transgender men and non-binary people who had chest reconstruction surgery no longer need mammograms.



LGBTQ Breast Health Toolkit Assessment

### **Thank You to Our Partners**

#### **The Advisory Board**

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#### **Special Thanks To:**

Cedar River Clinics

**Diverse & Resilient** 

Elijah Grossman, MSW

Mitchell C. Hunter

World Wide Breast Cancer

This toolkit 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/

