

Gender inclusivity survey

This survey reports organizations' experiences providing breast cancer information or services for gender-diverse people. Please note the survey allowed respondents to skip questions, so the number of respondents is indicated for each question.

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BACKGROUND

Q1. Tell us about your organization:

Name of organization

URL of organization

Name of person completing this survey

Job title

Department

Email address

Role in organization	# Respondents	% respondents	Did Not Respond
Total respondents	147		6
administrator	49	36 %	
certified genetic counselors	29	21 %	
patient navigators	17	12 %	
social/psychological service providers	19	14 %	
medical care providers	13	9 %	
educators/advocates	15	11 %	
academics/researchers	3	2 %	
administrative support	2	1 %	

Q2. Before this survey, how familiar were you with each of the following terms? For a good definition of each term visit the glossary on the PFLAG website. 152 respondents

Term	Very familiar	Somewhat Familiar	Not Very Familiar	Not at All Familiar
Assigned sex at birth	144 (95 %)	6 (4 %)	0	2 (1 %)
Gender	146 (96 %)	6 (4 %)	0	0
Cisgender	100 (66 %)	23 (15 %)	12 (8 %)	17 (11%)
Gender Fluid	84 (55 %)	46 (30 %)	9 (6 %)	13 (9 %)
Genderqueer	68 (45 %)	53 (35 %)	17 (11 %)	14 (9 %)
Transgender	129 (85 %)	20 (13%)	0	3 (2 %)
Trans Man	118 (78 %)	23 (15 %)	4 (3 %)	7 (5 %)
Trans Woman	118 (78 %)	23 (15 %)	4 (3 %)	7 (5 %)
Non-binary	105 (69 %)	29 (19 %)	9 (6 %)	9 (6 %)
Two-spirit	30 (20 %)	32 (21 %)	43 (28 %)	47 (31 %)
Pronouns	133 (88%)	15 (10 %)	1 (1 %)	3 (2 %)

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Q3 Does your organization offer direct services, clinical care, support, or programs for people with or at high risk for breast cancer?

Responses	# Respondents	% Respondents	Did Not Respond
total	153		0
yes	144	94%	
no*	9	6%	

* later responses clarified that the organization did serve breast cancer patients for all that were included

Q4 When collecting personal and demographic information, does your organization collect information about people's gender pronouns? (for example: she/her, he/him or they/them)?

Responses	# Respondents	% Respondents	Did Not Respond
total	124		29
not sure	16	13%	
no	30	24%	
yes, some of the time	23	19%	
yes, most of the time	23	19%	
yes, all of the time	32	26%	
yes (at least sometimes)	78	63%	

Q5 Does your organization ask people about their pronouns when they access a program or during appointments?

Responses	# Respondents	% Respondents	Did Not Respond
total	123		30
not sure	23	19%	
no	35	28%	
yes, some of the time	30	24%	
yes, most of the time	17	14%	
yes, all of the time	18	15%	
yes (at least sometimes)*	65	53%	

* Includes respondents who indicated "yes, some of the time," "yes, most of the time," and "yes all of the time."

Q6 Does your organization have a policy for service providers or staff to address people using their pronouns?

Responses	# Respondents	% Respondents	Did Not Respond
total	122		31
yes	35	29 %	
no	47	39 %	
I'm not sure	40	33 %	

Q7 When collecting personal and demographic information, does your organization collect data about gender identity beyond asking people about the sex assigned at birth? (For example, by asking "Are you a cisgender man, transgender man, cisgender woman, transgender woman, non-binary, two-spirit or genderqueer"?)

Responses	# Respondents	% Respondents	Did Not Respond
total	121		32
I'm not sure*	27	22 %	
no**	34	28 %	
yes, some of the time	23	19 %	
yes, most of the time	19	16 %	
yes, all of the time	18	15 %	
yes (at least some of the time)***	60	50 %	

* 70% of respondents who indicated "I'm not sure" also reported at least one place where they did collect this data in Question 8.

** 50% of "No" responders indicated at least one place where they did collect this data in Question 8.

*** Includes respondents who indicated "yes, some of the time," "yes, most of the time," and "yes all of the time."

Q8 If yes, please provide examples of how your organization asks people about this information.

Most commonly at intake, on electronic health record, or patient navigation portal. Most who collected this information indicated patients could select from a list or decline to respond. Several indicated that they are in the process of incorporating this information collection.

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Q9 Where does your organization collect this data? (Select all that apply).

Responses	# Respondents	% Respondents	Did Not Respond to Any Options
total	120		33
As part of their medical records/electronic health records (EHR)	70	75 %	
As part of their patient portal	24	26 %	
During appointments	27	29 %	
Satisfaction or user feedback surveys	7	8 %	
Sign-up forms for classes or programs	12	13 %	
Peer support or navigation program user forms	10	11 %	
Research studies	10	11%	
Other: during phone call part of cancer registry via partners via contracted primary care providers email	6	6 %	

Q10 When collecting personal and demographic information, does your organization specifically collect data on whether or not a person is transgender? (For example, do you have a question on any patient form or survey that asks "Are you transgender?")

Responses	# Respondents	% Respondents	Did Not Respond
total	122		31
not sure*	39	32 %	
no**	50	41 %	
yes, some of the time	10	8 %	
yes, most of the time	6	5 %	
yes, all of the time	17	14 %	
yes (at least sometimes)***	33	27 %	

*1 respondent who indicated "I'm not sure" stated "I see the end result of gender identity, sex assigned at birth, preferred name, and pronouns as well as an organ inventory." Another indicated that they ask for sex assigned at birth and current gender but not transgender per se.

** 2 respondents who indicated "no" also noted that they do ask for sex assigned at birth and current gender but not transgender per se. 1 respondent indicated there was no form but there was a discussion.

***** Includes respondents who indicated "yes, some of the time," "yes, most of the time," and "yes all of the time."

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Q11 If yes, please provide examples of how your organization asks for this information.

Most indicated that this information was collected on intake or admission forms. In some cases, respondents indicated these were discussions rather than forms; one person mentioned that they emphasize this is optional.

Some organizations reported asking patients for their gender identity information with open-ended questions. Others provide categories such as “trans female to male,” “genderqueer,” and “gender diverse” on forms that collect demographic data.

Q12 Does your organization provide any of the following visual signs of welcome for gender-diverse patients or clients?

Sign of Welcome	Yes	No	Unsure	Not Applicable	Total Responses
gender neutral or gender-inclusive restrooms	38 (32%)	42 (36%)	14 (12%)	24 (20%)	118
gender neutral or gender-inclusive signage	33 (28%)	41 (35%)	26 (22%)	18 (15%)	118
gender neutral or gender-inclusive hospital gowns	31 (26%)	22 (19%)	26 (22%)	38 (32%)	117
patient information depicting a variety of genders or specifically geared toward the LGBTQ+ community	48 (41%)	30 (25%)	33 (28%)	7 (6%)	118
staff badges with pronouns or other signs of inclusion for the LGBTQ+ community	36 (30%)	63 (53%)	7 (6%)	12 (10%)	118
posted non-discrimination statements or patient bill of rights, including sexual orientation/gender identity	48 (41%)	22 (19%)	30 (25%)	18 (15%)	118
online accessible information about being a safe space for people of all sexual orientations/gender identities	48 (41%)	31 (26%)	34 (29%)	5 (4%)	118

GENDER INCLUSIVE LANGUAGE

Q13 Does your organization develop educational materials for people with or at high risk for breast cancer?

Response	# Respondents	% Respondents	Did Not Respond
total	129		24
yes	106	82 %	
no	25	18 %	

Q14 Does your organization use gender-inclusive language in your educational resources? (This may include avoiding gendered terms like "men" and "women" or including statements about "sex assigned at birth" and "gender.")

Response	# Respondents	% Respondents	Did Not Respond
total	127		26
not sure	24	19 %	
no	31	24 %	
yes, some of the time	40	31 %	
yes, most of the time	20	16 %	
yes, all of the time	12	9 %	
yes (at least sometimes)*	72	57 %	

* Includes respondents who indicated "yes, some of the time," "yes, most of the time," and "yes, all of the time."

Q15 If yes, please provide specific examples of how and where your organization uses these terms.

How:

Using updating wording to be more gender-inclusive:

- Using phrase "people at risk of breast cancer"
- Any place where "people" or Washingtonians/Alaskans/Virginians can be used, we do.
- "Individuals affected by breast cancer" instead of just women with breast cancer like we used to many years ago
- We use language to say we support all
- We have moved away from saying "young women" and towards "young adults"
- When talking about cancer screening, we talk about body parts versus gender. We use "breast/chest" where possible
- We say "members we serve," instead of "women and men we serve"
- We try to use the term "people" where appropriate, but when citing sources, we use the term used in the reference. We also use "they" or "them," if applicable
- We say "people of all genders"
- We use breast cancer (assigned female at birth) and breast cancer (assigned male at birth)

- Our high-risk breast cancer clinic page uses "women" mostly to describe patients, but sometimes uses "patients" in a more general sense (like when referring to types of screenings people can have)
- Example: "People assigned female at birth and who have a BRCA1 mutation are recommended to remove their ovaries preventatively"

Developing policies and strategies

- We are working to develop policies and strategies to equally view all the population, including the LGBTQIA+ Community.
- Sometimes we have to be specific, due to the nature of the program and funding. Terms like "sex assigned at birth" can help when trying for that specificity.
- We consult with a non-binary advisor to lead staff discussions.

where, when, in what materials:

- during assessment and hospitalization
- in all of our collateral material
- marketing materials: redesigning organization's logo
- imagery website
- program brochure
- patient handouts
- template letters
- gender-affirming surgery/treatment educational resources
- sexual health and wellness materials
- test requisition forms and reports list sex assigned at birth, with an explanation of what that means.
- social media message toolkits
- within our genetic counseling information
- in our gene-specific handouts (list cancer risks by organ and not by sex assigned at birth/gender)
- blogs

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Q16 How high a priority is using inclusive language in your organization?

Response	# Respondents	% Respondents	Did Not Respond
total	119		34
very low	3	3 %	
somewhat low	16	13 %	
somewhat high	43	36 %	
very high	36	30 %	
I'm not sure	21	18 %	

Q17 How high a priority is collecting data on gender-diverse individuals for your organization?

Response	# Respondents	% Respondents	Did Not Respond
total	118		35
very low	7	6 %	
somewhat low	18	15 %	
somewhat high	38	32 %	
very high	22	19 %	
I'm not sure	33	28 %	

Q18 Has your organization implemented the National Academies of Science, Engineering and Medicine recommendations on measuring sex, gender identity, and sexual orientation? <https://nap.nationalacademies.org/catalog/26424/measuring>

Response	# respondents	% respondents	did not respond
total	117		36
yes (please share more details about the barriers below)	4	3 %	
no, but we plan to	11	9 %	
no, and we don't plan to	8	7 %	
I'm not sure	94	80 %	

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Q19 To what degree has your organization experienced any barriers to using gender-inclusive language in your resources?

Response	# Respondents	% Respondents	Did Not Respond
total	118		35
no barriers encountered	28	24 %	
small amount	19	16 %	
medium amount	15	13 %	
large amount	6	5 %	
I'm not sure	45	38 %	
not applicable	5	4 %	

What are the barriers that you see?

Summary of barriers observed:

- lack of awareness around gender-inclusive terminology. Lack of scientific/health literacy
- lack of buy-in or education of staff or leadership
- limitations of grant funding that is directed by gender
- cost to update existing materials with gender-inclusive language
- limitations of scientific sources. Grants and studies still use gendered language. Most research on [breast cancer] is about "women" without paying attention to trans/gender nonconforming. Sometimes it's harder to be inclusive when the information you are going off of isn't.
- need to develop materials in Spanish
- coordination with other departments can be difficult: materials have to go through Marketing, so [they] lack final say in how information is presented, time needed to work with tech team to change online materials or inconsistency between departments
- staff uncomfortable asking gender questions
- time needed to update materials
- difficulty getting multiple collaborators to agree on wording
- lack of larger policies about gender-inclusive language
- concern of about others outside the organization: providers' concern that the use of inclusive language will offend or confuse our cisgender patients, concerns about our very religious callers or political pressures.

Q20 To what degree has your organization experienced any barriers to implementing the recommendations from the National Academies of Science, Engineering and Medicine on measuring sex, gender identity, and sexual orientation?

Response	# Respondents	% Respondents	Did Not Respond
total	117		36
no barriers encountered	12	10 %	
small amount	2	2 %	
medium amount	2	2 %	
large amount	3	3 %	
I'm not sure	71	61 %	
not applicable	27	23 %	

What are the barriers that you see?

- staff get confused by medical terminology
- lack of clarity about which recommendations to follow
- lack the ability to capture data
- staff or leadership buy-in

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Q21 Has your organization experienced or do you foresee any future barriers to your organization using gender-inclusive language in your resources?

Response	# Respondents	% Respondents	Did Not Respond
Total	117		36
yes (please share more details about the barriers below)	20	17 %	
no	43	36 %	
I'm not sure	49	42 %	
not applicable	5	4 %	

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Q22 What resources or information could we provide to help you overcome these barriers? (open answer)

Summary of responses:

- Training for staff, employees, and those who help develop policies for the organization
- Materials:
 - printed information for all genders and gender identities
 - educational material in Spanish
 - examples of data-collecting categories
 - free resources
 - publicly available educational resources that are inclusive
 - definition of terms, included as a preface in relevant materials
- Education on:
 - appropriate language and definitions
 - phrasings for coping with limitations in research data, e.g., when research is done on "women"
 - more information on trans/nonbinary risk
 - suggestions for gender-inclusive language for cancer management recommendations based on gene
 - detailed information on the risk factors for individuals of all genders
 - information on National Academies of Science, Engineering and Medicine on measuring sex, gender identity, and sexual orientation
 - a list of possible places to be more inclusive
 - examples of strategies other locations have utilized
- Continue to share and discuss why it is so important to adopt these methods of data collection and inclusive language

Q23 Which of the following best describes your organization's focus?

Response	# Respondents	% Respondents	Did Not Respond
total	116		37
we focus on multiple diseases or conditions, including cancer	41	35 %	
we focus on all types of cancers	36	31%	
we focus on a few or certain types of cancer	12	10 %	
we focus on one type of cancer	23	20 %	
we do not have a disease focus	2	2 %	
other (please describe)	2	2 %	
public health agency	1	1 %	
unsure	1	1 %	

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Q24 What is your geographic reach? (Indicate if national, or name specific state(s), city/ies or region(s), and estimate the number of people your organization reaches.)

Collectively, respondents' organizations served all 50 states and seven U.S. territories (American Samoa, Cherokee Nation of Oklahoma, District of Columbia, Guam, Northern Mariana Islands, Puerto Rico, Virgin Islands).

Response	# Respondents	% Respondents	Did Not Respond
Total	111		60
international (not including the U.S.)	1	1 %	
global or international (including the U.S.)	19	17 %	
national (all states and territories in the U.S.)	11	10 %	
regional	48	44 %	
local	31	28 %	

91 of 111 (82%) had clients only within the U.S.

Q25 In which states or territories do you provide programs or services?

State or Territory	Local or Regional Reach Only	National or Global Reach	All Reach	%
Alabama	3	30	33	30 %
Alaska	2	30	32	29 %
American Samoa	0	30	30	27 %
Arizona	1	30	30	27 %
Arkansas	2	30	32	29 %
California	8	30	34	31 %
Colorado	3	30	33	30 %
Connecticut	4	30	34	31 %
Delaware	1	30	31	28 %
District of Columbia (DC)	1	30	31	28 %
Florida	4	30	33	30 %
Georgia	6	30	36	33 %
Guam	0	30	30	27 %
Hawaii	0	30	30	27 %
Idaho	1	30	31	28 %
Illinois	11	30	41	37 %
Indiana	7	30	36	33 %
Iowa	2	30	32	29 %
Kansas	3	30	33	30 %
Kentucky	3	30	33	30 %
Louisiana	3	30	33	30 %
Maine	3	30	33	30 %

Maryland	0	30	30	27 %
Massachusetts	4	30	33	30 %
Michigan	4	30	34	31 %
Minnesota	5	30	35	32 %
Mississippi	1	30	31	28 %
Missouri	3	30	33	30 %
Montana	1	30	31	28 %
Nebraska	0	30	30	27 %
Nevada	1	30	31	28 %
New Hampshire	4	30	33	30 %
New Jersey	6	30	35	32 %
New Mexico	0	30	30	27 %
New York	2	30	31	28 %
North Carolina	4	30	34	31 %
North Dakota	1	30	31	28 %
Northern Marianas Islands	0	30	30	27 %
Ohio	7	30	37	34 %
Oklahoma	3	30	33	30 %
Oregon	2	30	32	29 %
Pennsylvania	7	30	37	34 %
Puerto Rico	2	30	32	29 %
Rhode Island	3	30	33	30 %
South Carolina	2	30	32	29%
South Dakota	0	30	30	27 %
Tennessee	1	30	31	28 %
Texas	9	30	38	35 %
Utah	1	30	31	28 %
Vermont	2	30	32	29 %
Virginia	6	30	36	33 %
Virgin Islands	0	30	30	27 %
Washington	4	30	34	31 %
West Virginia	2	30	32	29 %
Wisconsin	5	30	35	32 %
Wyoming	0	30	30	27 %

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Q26 If your organization provides clinical care for breast cancer patients, please indicate the type of services provided. (Please choose all that apply)

Eighty organizations indicated that they provide clinical care for breast cancer patients.

Services Offered	# Respondents	% Respondents
Primary care	54	74%
Breast imaging	69	95%
Genetic counseling and testing	68	93%
Ob/gynecology services	56	77%
Oncology care	67	92%
Fertility preservation	31	42%
Mental health care	58	79%
Breast surgery	65	89%
Breast reconstruction	58	79%
Menopause care	39	53%
Other (please specify)	17	23%

Other service areas included psychosocial support, palliative care, patient navigation, advocacy, education, high-risk breast clinic, and biopsy services.

Q27 Which of the following best describes your organization?

Response	# Respondents	% Respondents	Did Not Respond
Total	116		37
hospital or healthcare provider	72	62 %	
nonprofit or advocacy organization	34	29 %	
for-profit or commercial organization	3	3 %	
other (please specify):	7	6 %	
state or public health department	6	5 %	
tribal health department	1	1 %	

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Q28 If your organization is an advocacy organization, what type of services does your organization provide? (Please choose all that apply)

respondents	# Respondents	% Respondents
total	61	
peer support	61	
education	27	44 %
navigation/referral to services	58	87 %
advocacy training	45	67 %
research matching	19	28 %
public policy work	17	26 %
financial assistance	18	25 %
other (please specify)	29	46 %

Other areas of support included research funding, psychosocial support, genetic counseling, survivorship services, organizational training and technical assistance, and integrative services.

Q29. May we contact you for a short (15-minute) call to clarify any of your responses?

Response	respondents	% respondents	did not respond
total	106		38
yes	62	54 %	
no	44	38 %	

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