

# THE NATIONAL CANCER SURVEY

## SPECIAL SUB-REPORT: GENDER EXPANSIVE FINDINGS

NOVEMBER 2021



Transgender cancer survivors teach us how to  
improve care for all.

national  
lgbt  
cancer  
network



November 2021

## **OUT: The National Cancer Survey Gender Expansive Sub-Report**

As a trans man, I was very interested to explore how the experiences of gender expansive people may be similar or different to the rest of the Out survey respondents. There is so little data on trans, nonbinary, and other gender expansive people; the biggest theme across my professional career is simply urging people to please collect data on our population. What data points we have can be extremely troublesome. Not only does the National Trans Discrimination Survey portray a population with a much higher level of underlying health disparities but when we get cancer data it often echoes those disparities. A few studies that have stuck with me over the last several years are: how even a very welcoming health center found their trans patients had much lower cancer screening rates (i.e. 50% lower colorectal cancer screening rates than other patients) and a broad study of oncologists showing approximately 80% do not feel educated enough about trans issues.

As some who have heard me speak will realize, I have lived this experience too. Despite running a cancer organization, it took my partner's multiple nudges to get me in to see the dermatologist for something that did turn out to be cancer. I'm lucky that this cancer was easily treatable but it reinforces how hard it is even for health-focused gender expansive people to motivate themselves to go to new providers to take care of routine cancer screenings. Fear of not being treated well is a powerful health deterrent.

For these reasons I am very excited to share the findings from Out:The National Cancer Survey in this special sub report on gender expansive participants. We felt it was only fitting to share this information in acknowledgement of Transgender Awareness Week. Be sure to start your perusal with our Executive Summary, where we highlight some of the themes we see across these data.

As always, a deep thank you to our primary funder, Bristol Myers Squibb, and to all the many partner organizations, led by the Center for Black Equity, who joined us in helping to promote this survey widely across the country. And stay tuned to this channel, the next subreport will be the BIPOC report released in honor of Black History Month.

May we all learn and use this gift of knowledge to create positive change for the 40% of us who will one day face a cancer diagnosis.

**In solidarity**

**Dr. Scout**

Executive Director, National LGBT Cancer Network





# TABLE OF CONTENTS

ACKNOWLEDGEMENTS .....	1
METHODS .....	2
GENDER EXPANSIVE FINDINGS EXECUTIVE SUMMARY .....	3 - 5
TIPS FROM LGBTQI+ SURVIVORS .....	6
TIPS FOR PROVIDERS OF GENDER EXPANSIVE CANCER SURVIVORS.....	7
PARTICIPANT CHARACTERISTICS .....	8
COVID-19 & CANCER .....	9 - 11
CANCER DIAGNOSIS .....	12 - 13
CANCER TREATMENT EXPERIENCE .....	14 - 17
SOCIAL NETWORKS & SUPPORT .....	18 - 20
CANCER SURVIVORSHIP RESOURCES .....	21 - 22
HEALTH & HEALTH BEHAVIORS .....	23 - 26
TIPS FOR PROVIDERS .....	27
CONCLUSION .....	28
KEY PARTNERS .....	29 - 30
PROMOTIONAL PARTNERS .....	31





## ACKNOWLEDGMENTS

### PROJECT SPONSORS

#### **Bristol Myers Squibb**

Genentech

NYC Pride

Syros Pharmaceuticals

### OUT: THE NATIONAL CANCER SURVEY PRINCIPAL INVESTIGATORS

NFN Scout, MA, PhD

Bethany Rhoten, PhD, RN

### ADVISORY COMMITTEE MEMBERS

Denise Batts

Dr. Lauren B. Beach, JD/PhD

E. Dawn Capone, M.Ed., LPC

Ronda Copher, PhD

Dr. Don Dizon, MD

Dr. Jason Domogauer, MD, PhD

Dr. William Jesdale, PhD

Nina Kennedy

Knoll Larkin, MPH

Phoenix Matthews, PhD

Andre D. Singleton

### NATIONAL LGBT CANCER NETWORK STAFF & INTERNS

NFN Scout, MA, PhD

Harold Abrams

Clarke Dalton

Gabe Glissmeyer

Jessica Jordan

Aurea Kasberg

Knoll Larkin, MPH

Reece Lyerly, MS, MPH

Bryce Moore

Kk Naimool

Valeria Servigna

Michelle Veras, MPH

Alice Wu

OUT: The National Cancer Survey approved by WCG IRB (formerly New England IRB) August 2020.

Suggested citation:

The National LGBT Cancer Network Special Sub-Report Gender Expansive Findings <https://cancer-network.org/out-the-national-cancer-survey/> November 2021

## METHODS

>> We administered a web-based survey for LGBTQI+ cancer survivors from September 2020 to March 2021. We promoted the survey via social media outlets in collaboration with over 100 community partners.

### ELIGIBILITY CRITERIA

In order to be eligible for the survey, participants needed to:

- >> **Have been previously diagnosed with cancer**
- >> **Be 18 years or older**
- >> **Self-identify as LGBTQI+**
- >> **Currently live in the US**

### SURVEY

The survey was accessible via a web link and took approximately 30 minutes to complete. Participants completed the survey independently in either English or Spanish. The survey was voluntary and anonymous.

### RECRUITMENT

Throughout the entire seven months, we promoted the survey via paid media ads on various social media outlets including Facebook, Instagram and Twitter. We leveraged the networks of over 100 community partners to reach LGBTQI+ communities from diverse backgrounds and experiences across the US. In particular, we worked closely with partners from Black and Brown pride committees and greek organizations to increase representation in our survey. We also worked with a media buyer to promote the survey online.

### GENDER EXPANSIVE

Gender expansive includes respondents who identify as transgender, genderqueer/gender non-conforming, non-binary, and another gender identity (total = 211). All of the following statistics are specific to gender expansive respondents.

### COMPARISONS

A **red triangle**  is included by all questions where there was a statistically significant difference ( $p < 0.05$ ) between gender expansive survivors and LGBTQI+ cisgender survivors. This means that the responses of gender expansive survivors were unique from LGBTQI+ cisgender survivors. For select questions, there is a callout, in the form of an asterisk (\*) highlighting the findings by sub-group.

**>> IN TOTAL, 2728 LGBTQI+ SURVIVORS COMPLETED THE SURVEY, SHARING THEIR INDIVIDUAL STORIES OF CANCER DIAGNOSIS, TREATMENT, AND SURVIVORSHIP.**

---



# GENDER EXPANSIVE FINDINGS EXECUTIVE SUMMARY

>> This Executive Summary highlights the experiences of gender expansive cancer survivors as compared to cisgender LGBTQI+ survivors. Based upon our analyses, we identified four key themes about cancer diagnosis, treatment and care for gender expansive folks.

# 1

Gender expansive folks experience unique barriers in disclosing their LGBTQI+ identity to healthcare providers due to fears related to less welcoming care.

Gender expansive survivors are **2X** as likely not to disclose their LGBTQI+ identity to cancer healthcare providers compared with cisgender survivors.

Gender expansive survivors who did disclose their LGBTQI+ identity were **3X** as likely to report their care as less welcoming afterwards.

*"I did not want to piss off the person who was treating me."*

# 2

Gender expansive folks are less likely to receive recommended cancer screenings - possibly due to barriers accessing culturally competent healthcare providers.

## CULTURALLY COMPETENT PROVIDERS

About how many of the [insert provider type] that you encountered during your cancer diagnosis and treatment provided culturally competent care? ⚠️



* 87% cis male	* 88% cis male	* 86% cis male
81% cis female	82% cis female	80% cis female

*"As a gender diverse person who was assigned female at birth, it is VERY rare to receive any kind of gender affirming gynecological care."*

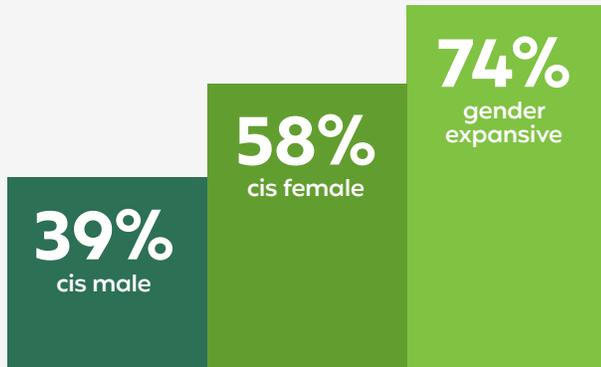




# 3

Environmental indicators of welcoming care are significantly more important for gender expansive folks in identifying safe spaces to receive cancer treatment and care.

Environmental Indicators of Welcoming Care are Somewhat or Very Important 



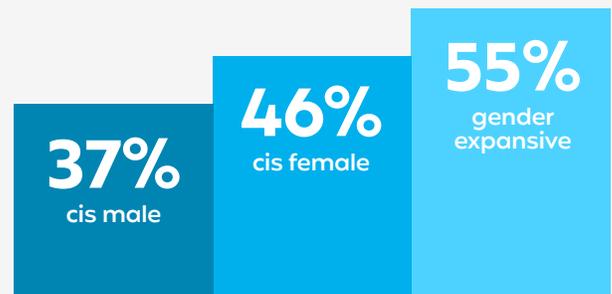
*“Place visual cues that your clinic or practice is a safe place. These can be in the form of a rainbow sticker, gender neutral bathrooms or even on your intake forms.”*

# 4

Navigating disruptions in health care caused by the COVID-19 pandemic exacerbated feelings of pessimism about gender expansive survivors' future health.

Since the start of the COVID-19 pandemic in March 2020, more pessimistic about future health. 

*“I feel less connected to my care team, in a similar way that I feel less connected to my friends.”*



A red triangle  is included by all questions where there was a statistically significant difference ( $p < 0.05$ ) between gender expansive survivors and LGBTQI+ cisgender survivors. This means that the responses of gender expansive survivors were unique from LGBTQI+ cisgender survivors. For select questions, there is a callout, in the form of an asterisk (\*) highlighting the findings by sub-group.



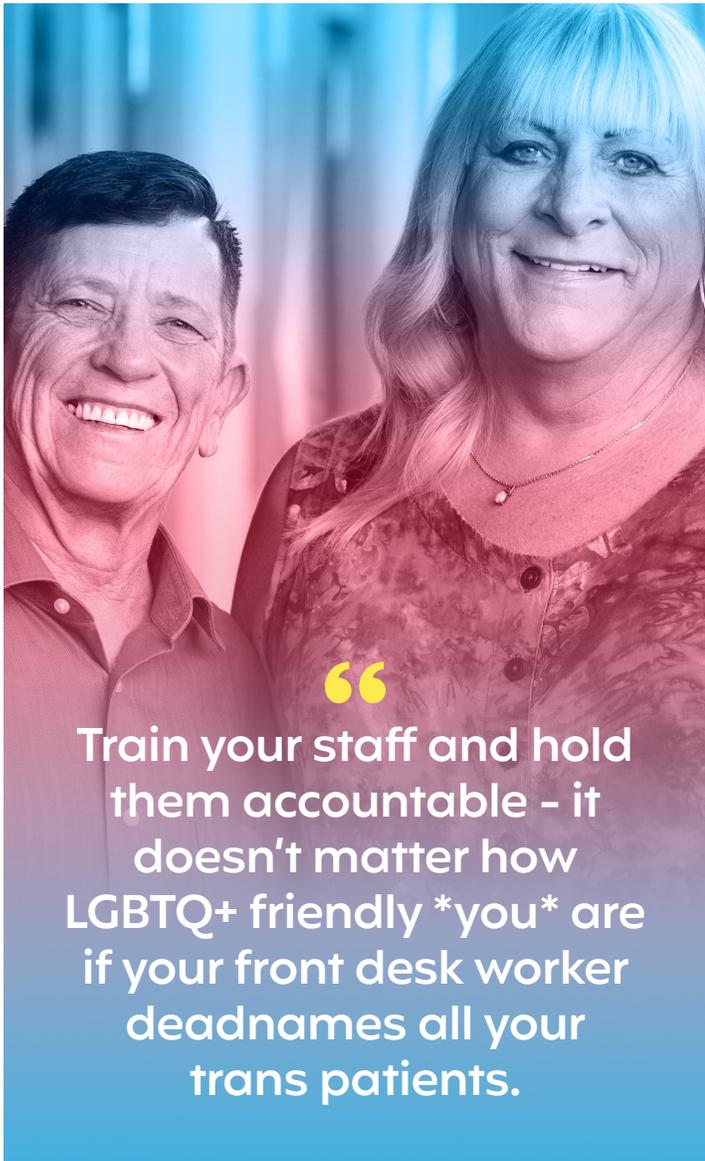
## Recommendations for Providers

### REQUIRE TRAINING FOR ALL STAFF

Provide a clear professional mandate that all staff are expected to provide patient-centered care that acknowledges and affirms the unique experiences of LGBTQI+ survivors, specifically gender expansive folks. Do not require us to educate providers at the same time as we navigate cancer screening, care, or survivorship.

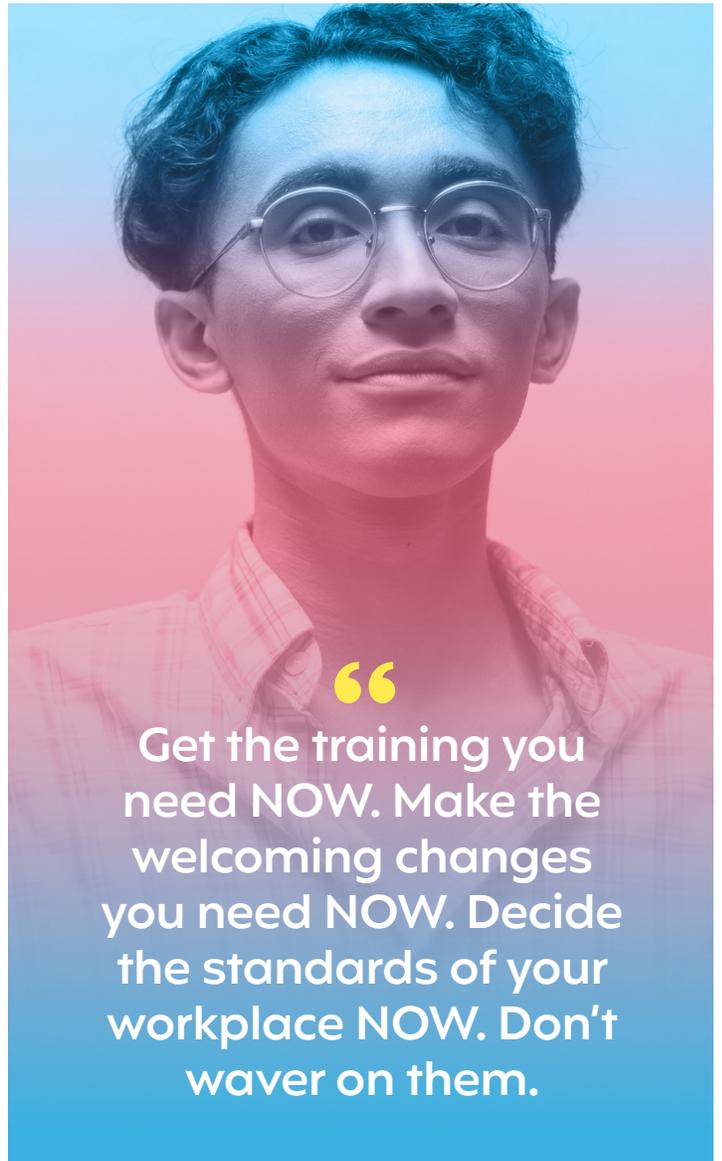
### REMEMBER TO SHOW LGBTQI+ WELCOME BEFORE ASKING US TO DISCLOSE

For example, introduce yourself with your pronouns, include LGBTQI+ in a posted non-discrimination statement, ask about LGBTQI+ status on intake forms.



“

Train your staff and hold them accountable - it doesn't matter how LGBTQ+ friendly \*you\* are if your front desk worker deadnames all your trans patients.



“

Get the training you need NOW. Make the welcoming changes you need NOW. Decide the standards of your workplace NOW. Don't waver on them.



## Tips for LGBTQI+ Cancer Survivors from Gender Expansive Cancer Survivors

1

### Seek Support

"In the hardest moments, you are often reduced to your body parts. Seek support from people that can help you to emotionally navigate this time and advocate for yourself."



2

### Choose Your Hospital System Wisely

"Get to a hospital system that has IN WRITING your identity in its nondiscrimination policy, preferably also with a gender clinic to prove it means it."



3

### Sign And Notarize Power of Attorney

"Get Health POA signed and notarized with the names of who you WANT to make decisions for you if you're not capable, and who should NOT receive info or access."



4

### Bring Your Whole Self

"Your whole self is impacted by cancer. Bring your whole self to your treatment and care."



5

### Create Your Own Quick Answers Sheet

"Create a handout or sheet that you can provide each provider that will give them quick answers about things like pronouns. It is frustrating to have to remind people constantly, but having a card or something simple takes the pressure off."



6

### Ask About Sex

"Ask healthcare providers specific questions about sex after surgery. The guidelines they give are often limited and may not be applicable to your sexual activities."





# Tips for Providers from Gender Expansive Cancer Survivors

1

## Don't Assume

"Don't assume my gender or sexual orientation. Don't assume I want to keep my breasts or hair. Don't assume anything."



2

## Get The Training You Need NOW

"There are already LGBTQI+ people in your establishments who deserve to be treated with the same respect and dignity that your straight, cisgender patients receive."



3

## Earn Our Trust

"Recognize that many of us have had bad experiences with doctors and you may need to earn our trust. This means making an extra effort to listen and affirm our experiences."



4

## Include Us In Your Office Atmosphere

"Make sure we are included in your intake forms. Train all staff members on working with queer and gender diverse communities."



5

## Listen To Us

"We're scared about so much after getting our diagnosis. We don't want to have to fear a reaction from our providers about who is there to support us. You want us to listen to you and trust you - listen to us and trust us too."





# PARTICIPANT CHARACTERISTICS

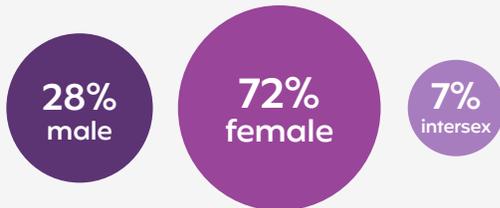
>> Gender expansive includes transgender, genderqueer/gender non-conforming, non-binary, and another gender identity categories (total - 8%, n=211). All of the following statistics are specific to gender expansive respondents.

A red triangle  is included by all questions where there was a statistically significant difference (p<0.05) between gender expansive survivors and LGBTQI+ cisgender survivors. This means that the responses of gender expansive survivors were unique from LGBTQI+ cisgender survivors. For select questions, there is a callout, in the form of an asterisk (\*) highlighting the findings by sub-group.

## GENDER IDENTITY

- 60%** Male
- 32%** Female
- 3%** Transgender
- 2%** Genderqueer/Gender Non-Conforming
- 2%** Non-binary
- 1%** Another Gender Identity

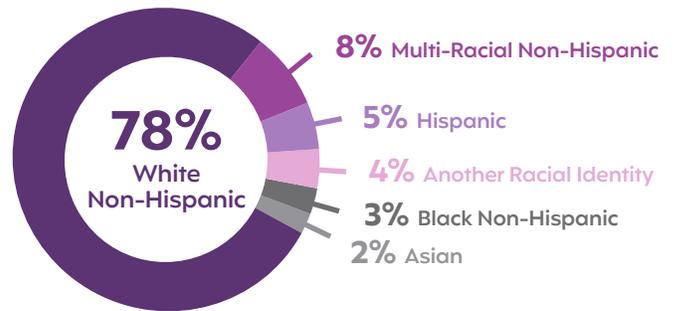
## SEX ASSIGNED AT BIRTH



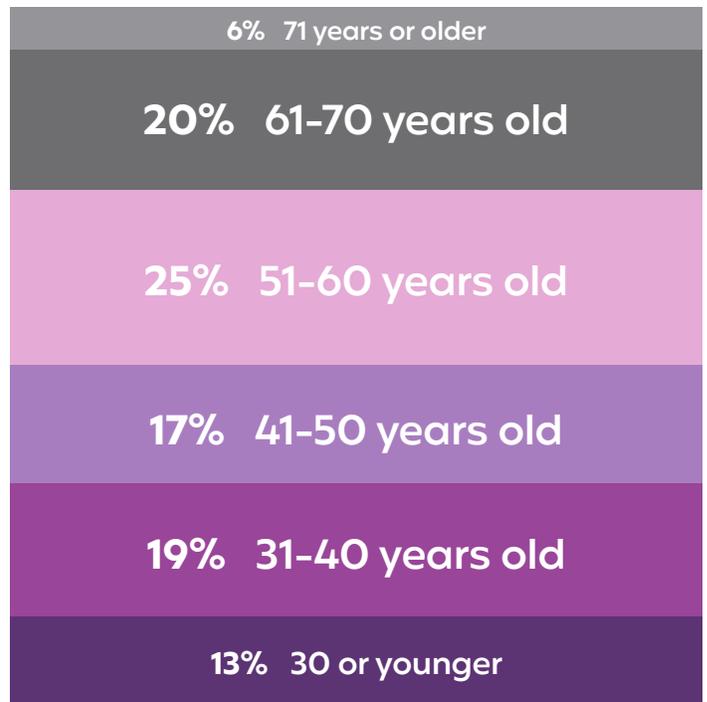
## SEXUAL ORIENTATION

- 37%** Multiple
- 21%** Lesbian
- 13%** Queer
- 8%** Pansexual
- 7%** Bisexual
- 5%** Gay
- 4%** Straight
- 3%** Asexual
- 2%** Another Sexual Orientation

## RACE/ETHNICITY



AGE:  
MEAN = 49





### STATE

41 states represented

#### TOP 5 STATES

California

New York

Washington

Pennsylvania

Colorado

### URBANICITY ⚠



### HEALTH INSURANCE



### DISABILITY ⚠

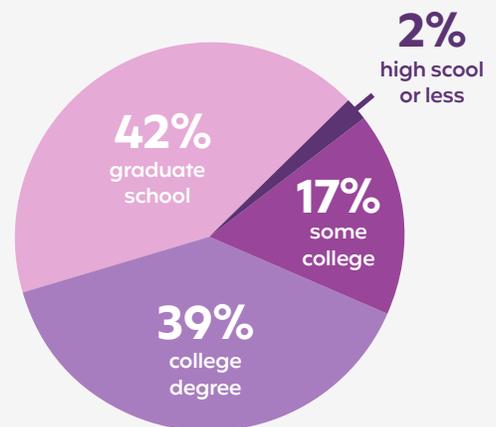


\*31% cis male 41% cis female

>> IF YES Type of disability (select all)

- 70% mental disability
- 44% cognitive/learning disability
- 42% mobility
- 23% developmental disability
- 8% visual impairment
- 5% deafness

### EDUCATION ⚠

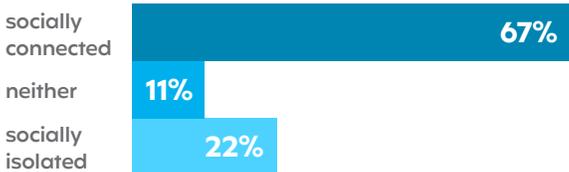


## COVID-19 & CANCER PAGE

>> The COVID-19 pandemic has greatly impacted our daily lives, particularly for cancer survivors. Due to increased risk of exposure and severity, many survivors experienced social isolation throughout the pandemic. This also impacted healthcare screening and treatment, with many delaying appointments, shifting to telemedicine, and attending treatments without their primary support team. For gender expansive cancer survivors, navigating the COVID-19 pandemic exacerbated feelings of loneliness and pessimism about their future health.

### SOCIAL CONNECTEDNESS

Before COVID-19, how socially connected or isolated would you say you were?

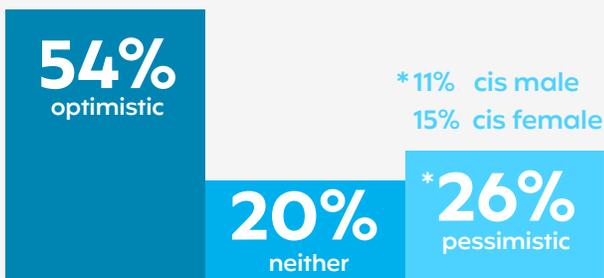


Since the start of the COVID-19 pandemic in March 2020, how has your level of social connection or isolation changed?

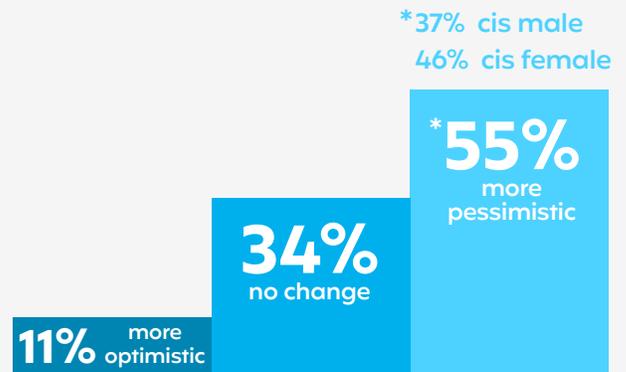


### OPTIMISM ABOUT HEALTH

Before COVID-19, how optimistic or pessimistic were you about your future health? ⚠️



Since the start of the COVID-19 pandemic in March 2020, how has your level of optimism or pessimism about your future health changed? ⚠️



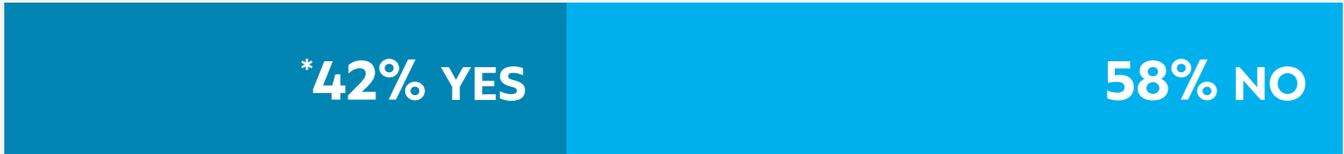
“

I only found out I had cancer because I went to the ER thinking I had covid. Only then did they discover the massive tumor in my chest pushing on my lungs and heart.



### DELAYED SCREENINGS OR TREATMENT

Since the start of the COVID-19 pandemic in March 2020, have you or your doctors delayed any cancer screenings, follow-ups, or treatments?



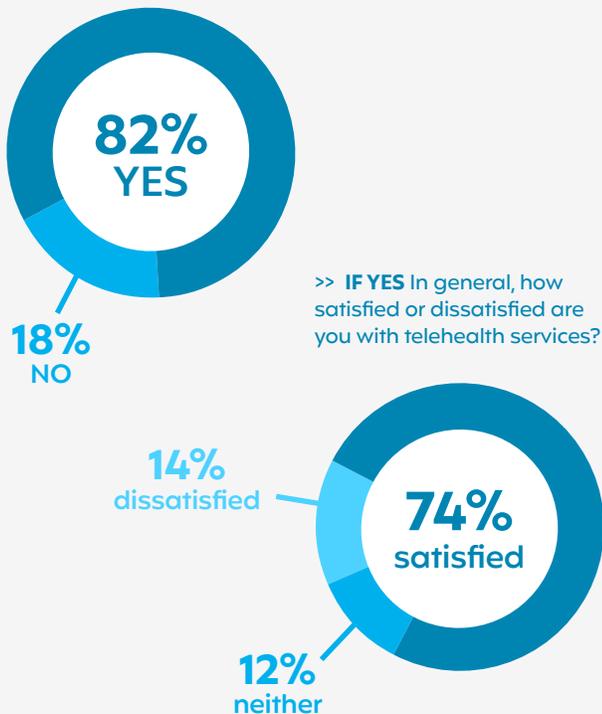
\*25% cis male    40% cis female



I was in active treatment from March until May [2020]. Chemotherapy was hard to begin with, but having to go without my support system made it deeply difficult.

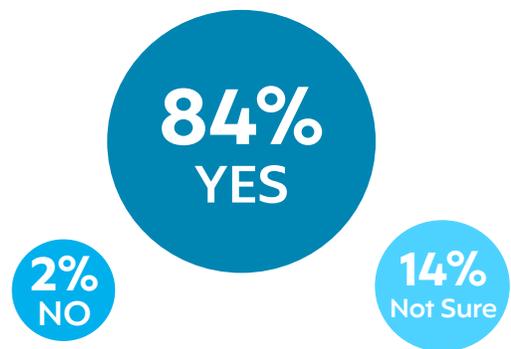
### SATISFACTION WITH TELEHEALTH

Since the start of the COVID-19 pandemic in March 2020, have you had any telehealth medical appointments?



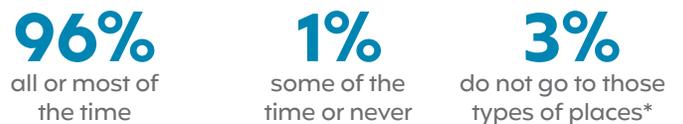
### LIKELIHOOD OF VACCINE

Do you plan to get a coronavirus vaccine when one is available?



### MASK PRACTICES

In the past month, how often, if ever, have you worn a mask or face covering when in stores or other businesses?





## LOST EMPLOYMENT

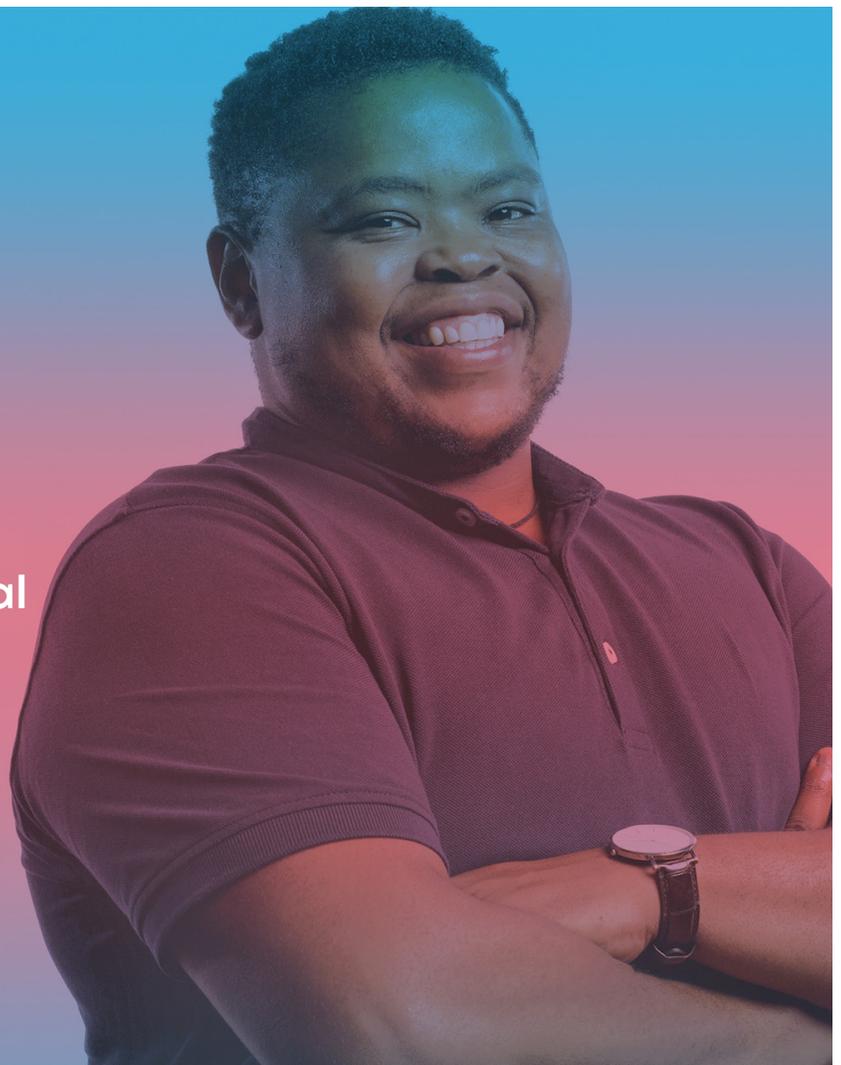
Since the start of the COVID-19 pandemic in March 2020, did you lose any form of employment or paid work?

**30%**  
YES

**70%**  
NO

“

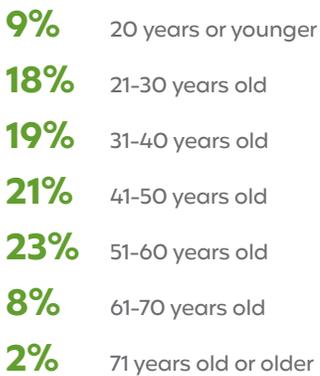
If it weren't for covid, I may have died from cancer because of my fears of seeking medical attention unless absolutely necessary.



## CANCER DIAGNOSIS

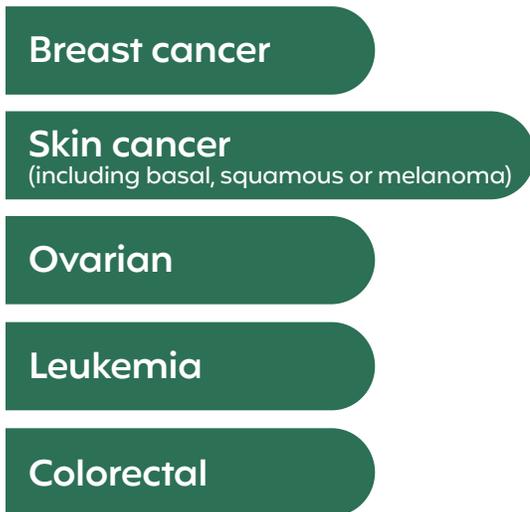
>> Learning that you have cancer is a difficult life event, regardless of one's age or background. Gender expansive survivors were almost twice as likely to report their cancer diagnosis as disrespectful compared to LGBTQI+ cisgender males. Moreover, gender expansive folks are less likely to receive recommended cancer screenings due to barriers accessing culturally competent healthcare.

### MEAN AGE AT DIAGNOSIS: 42 YEARS OLD

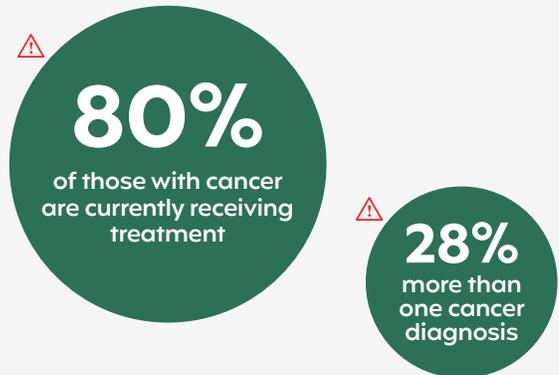


### TYPES OF CANCER

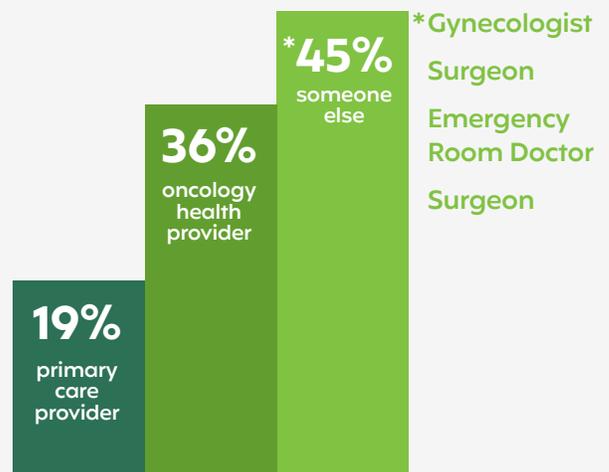
#### TOP 5 CANCERS



### CURRENTLY HAVE CANCER: 27%



### PERSON WHO DELIVERED CANCER DIAGNOSIS



## RESPECTFULNESS OF CANCER DIAGNOSIS

How respectful or disrespectful was the notification of your cancer diagnosis? ⚠️

\*8% cis male 13% cis female



“

My providers who have offered cancer screenings have rarely been well informed about trans-specific health needs which makes it VERY hard to convince myself to go, even when I KNOW I need them.

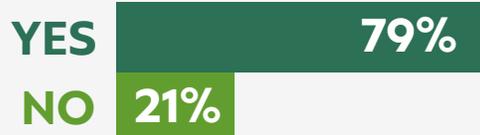
### COMPLETED CANCER SCREENINGS

Before being diagnosed with cancer, did you receive any scheduled cancer screening tests (e.g., pap smear, colonoscopy, lung cancer screening)? ⚠️



\* 37% cis male 14% cis female

Since being diagnosed with cancer, have you received any scheduled cancer screening tests (e.g. pap smear, colonoscopy, lung cancer screening)?



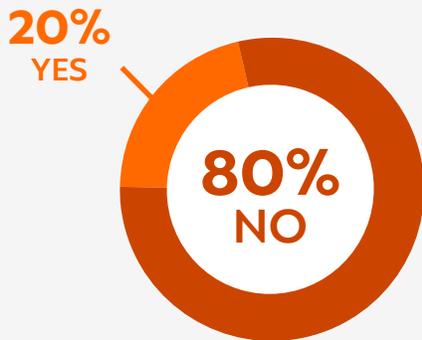


## CANCER TREATMENT EXPERIENCE

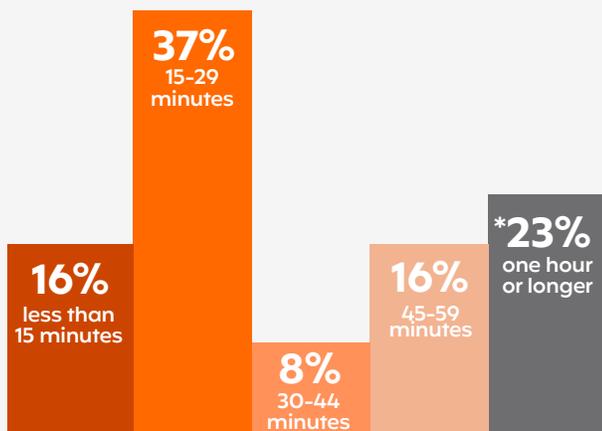
>> Gender expansive survivors experienced significant difficulties identifying welcoming and culturally competent providers for cancer treatment, often relying upon referrals from others in their network. For those who disclosed their LGBTQI+ identity, they were three times as likely to report their care as less welcoming afterwards compared to cisgender survivors. As such, environmental indicators of welcoming care (e.g. rainbow flag) are significantly more important for gender expansive folks.

### SOUGHT TREATMENT AT WELCOMING CANCER CARE CENTER

Did you intentionally seek treatment from a cancer care center or provider that was potentially welcoming for LGBTQI+ patients?



>> **IF YES** Travel time to welcoming provider  
How far did you travel (in minutes) to receive treatment from this cancer care center or provider? ⚠️



### WELCOMING ENVIRONMENT AT CANCER TREATMENT CENTER

How welcoming or unwelcoming was the environment where you received cancer treatment? ⚠️



“  
I was scared speaking up for myself regarding my orientation and gender identity would put my cancer care in jeopardy.”

## PROVIDERS AWARE OF LGBTQI+ IDENTITY ⚠️



### PROVIDERS AWARE OF LGBTQI+ IDENTITY (continued)

>> Types of disclosure (select all)

- 76%** Self-disclosure during consultation
- 33%** Obvious from appearance
- 32%** Medical forms provided option to disclose
- 32%** Embedded in medical information
- 20%** Something else (typically related to having a partner present)
- 13%** Health professional asked
- 4%** Disclosed by someone else

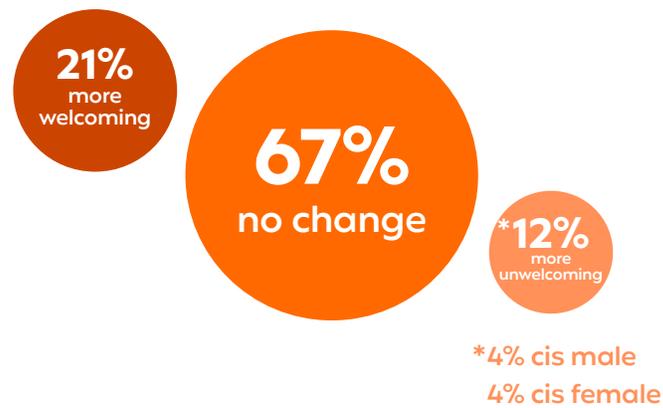
>> Types of providers aware of identity

In general, which staff and healthcare professionals were aware of your LGBTQI+ identity during your cancer diagnosis and treatment? (select all)



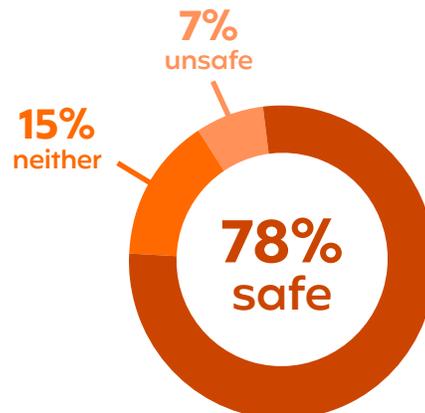
>> Change in environment after disclosure

After disclosure of your LGBTQI+ identity, would you describe the environment at the place where you received cancer treatment as more or less welcoming? ⚠️



>> Feelings of safety with disclosure

How safe or unsafe did you feel about staff and healthcare professionals knowing your LGBTQI+ identity during your cancer diagnosis and treatment? ⚠️





### CULTURALLY COMPETENT PROVIDERS

About how many of the [insert provider type] that you encountered during your cancer diagnosis and treatment provided culturally competent care?



\* 87% cis male  
81% cis female



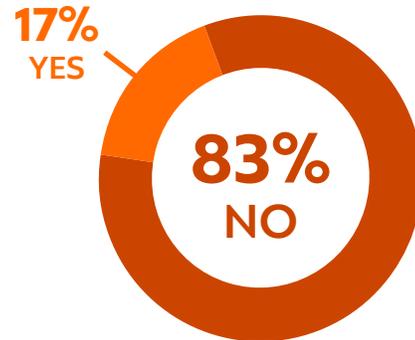
\* 88% cis male  
82% cis female



\* 86% cis male  
80% cis female

### ENVIRONMENTAL INDICATION OF WELCOMING CARE

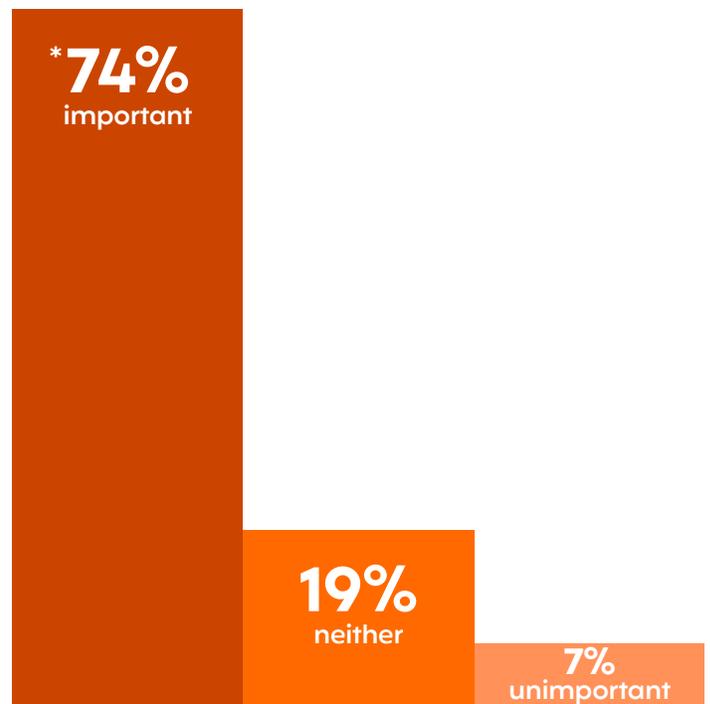
Was there any environmental indication (e.g. rainbow flag, affirming messaging) of welcoming care at the place where you received cancer treatment?



### IMPORTANCE OF ENVIRONMENTAL INDICATOR

How important or unimportant is it to you that there are environmental indicators (e.g. rainbow flag, affirming posters, flyers or leaflets, etc.) of welcoming care for LGBTQI+ patients at the places where you receive cancer treatments?

\* 39% cis male  
58% cis female





### SATISFACTION WITH CANCER TREATMENT EXPERIENCE

How satisfied or dissatisfied were you with your overall cancer treatment experience? 

**84%**

satisfied

**4%**

neither

**12%**

dissatisfied

### DISCUSSED FERTILITY OPTIONS

Did your cancer care provider share possible options for fertility preservation? 

**73%**  
NO

**27%**  
YES

“

During cancer treatment I intentionally hid my LGBTQ identity because I lived in a state that was known in the community for doctors refusing treatment.



## SOCIAL NETWORKS & SUPPORT

>> Social support and networks are a vital resource for navigating cancer survivorship. For gender expansive survivors, their diverse support networks were more likely to become weaker through the experience of cancer treatment and survivorship. Few LGBTQI+ survivors have participated in cancer support groups, with many describing difficulty finding welcoming spaces for their intersectional identities, including their cancer diagnosis.

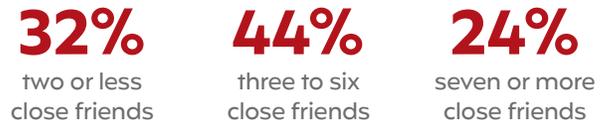
### # OF PEOPLE AWARE OF LGBTQI+ IDENTITY

In general, how many people in your life know you are LGBTQI+? ⚠️



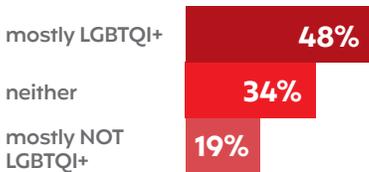
### # OF CLOSE FRIENDS

How many people in your life would you describe as close friends (friends you speak with at least once a week)? ⚠️



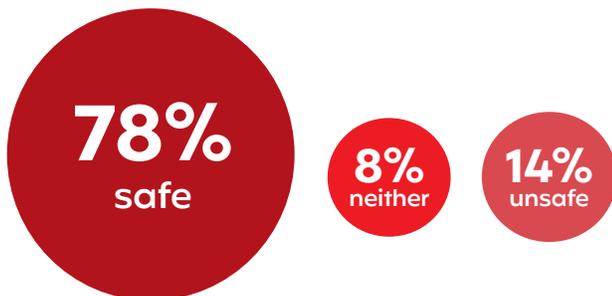
### SEEN AS LGBTQI+ IN PUBLIC

In general, how often do people identify you as LGBTQI+ or not LGBTQI+ in public? ⚠️



### FEELINGS OF SAFETY WITH DISCLOSURE TO OTHERS

Aside from healthcare professionals, how safe or unsafe do you feel disclosing your LGBTQI+ identity to people in your life? ⚠️

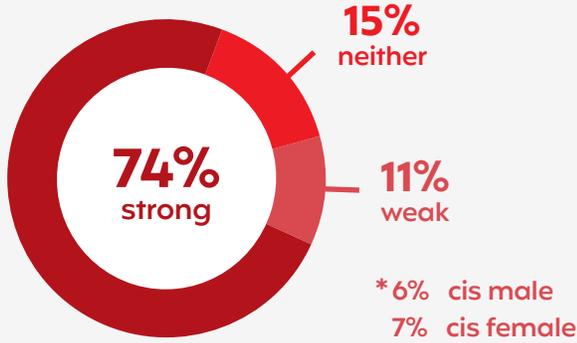


“It's important for support groups to find ways to include survivors who are unable to speak verbally and survivors who have severe mobility disabilities. I feel we are often left out.”

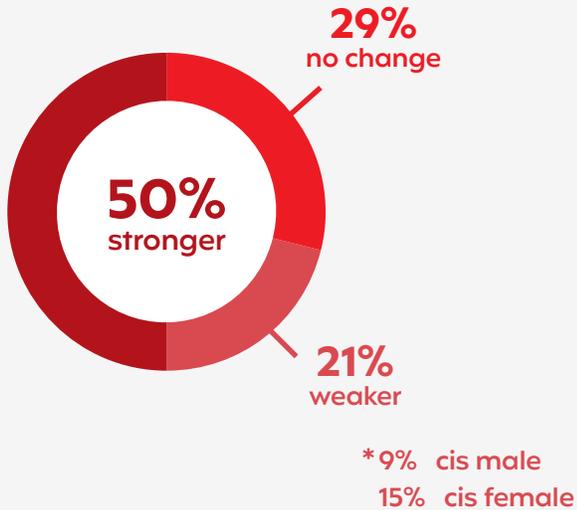


### STRENGTH OF SOCIAL NETWORK

Prior to being diagnosed with cancer, how would you describe the strength of support provided by your social network? ⚠️



After being diagnosed with cancer, how has the strength of support provided by your social network changed? ⚠️



### PRIMARY SUPPORT PEOPLE

Did you have primary support people during your cancer? ⚠️



Instagram and Reddit were vital to me throughout treatment to connect with other people going through the same thing.

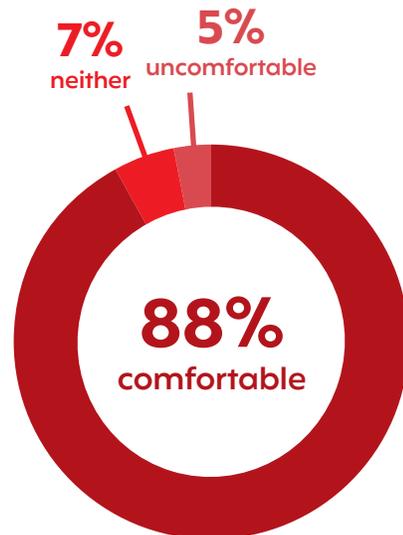
### PRIMARY SUPPORT PEOPLE (continued)

>> Who were your primary support people, select all



>> Comfort bringing support people to healthcare visits

In general, how comfortable or uncomfortable did you feel bringing your support people to your healthcare visits during cancer treatment?



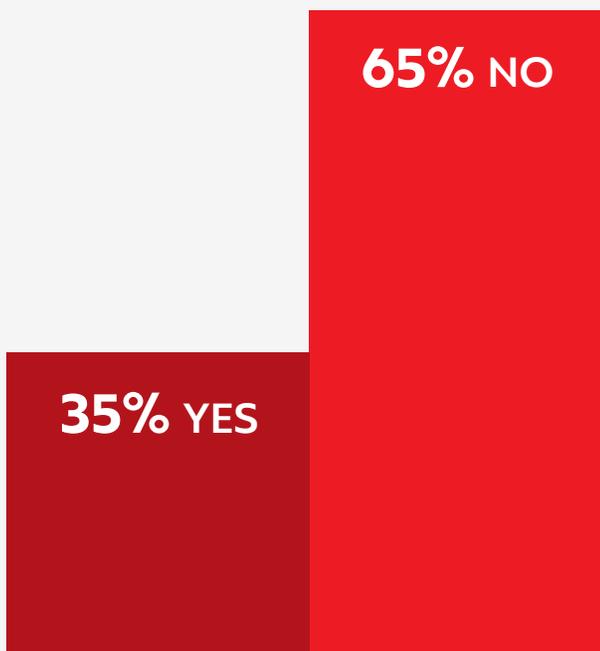


### CANCER SOCIAL SUPPORT GROUP

Have you ever received cancer survivor social support? ⚠️

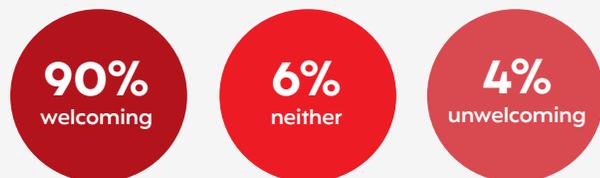
>> **IF YES** from where did you receive cancer survivor social support?

- 63% from a peer group
- 46% from a professional
- 28% peer to peer direct connection



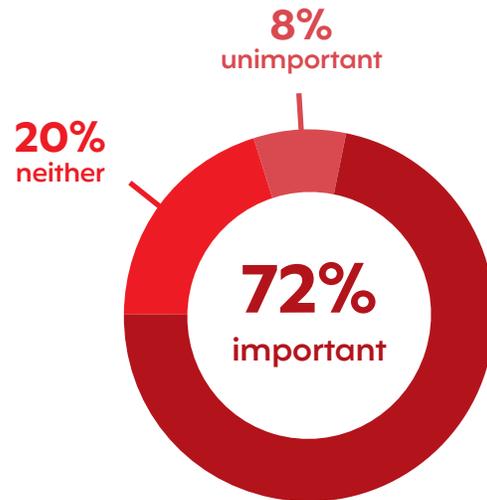
How welcoming or unwelcoming was this cancer survivor social support? ⚠️

>> **IF YES** Welcoming environment at support group



### IMPORTANCE OF WELCOMING ENVIRONMENT

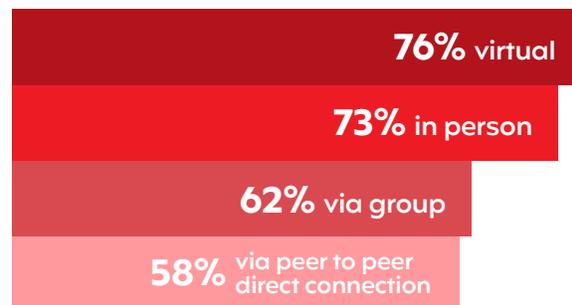
How important or unimportant is it to you to be able to access LGBTQI+ welcoming cancer survivor social support? ⚠️



“  
If I could have talked to other queer people about my cancer that would have been amazing. I never saw that as an option.”

### PREFERENCE FOR TYPE OF SUPPORT GROUP

If you needed it again, what options would you consider related to cancer survivor social support? (select all)





## CANCER SURVIVORSHIP RESOURCES

>> Despite the abundance of resources available online, many LGBTQI+ survivors describe difficulty finding resources specific to the LGBTQI+ community. This includes many post-treatment care plans excluding information specific to their LGBTQI+ identity, which is considered significantly more important among gender expansive survivors.

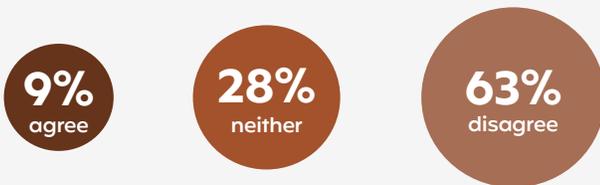
### ABLE TO FIND RESOURCES ABOUT CANCER SURVIVORSHIP

During my cancer treatment, I could find helpful information about my cancer ⚠️



### ABLE TO FIND RESOURCES FOR LGBTQI+ CANCER SURVIVORSHIP

During my cancer treatment, I could find helpful information about being a LGBTQI+ person with cancer ⚠️



### ABLE TO ACCESS RESOURCES NEEDED TO MAINTAIN HEALTH

I am able to access the resources I need to maintain or improve my health. ⚠️



Please include experts as well as survivors who are LGBTQIA+. Any support group can provide valuable information, but only queers or allies can promote hope.

### TALKED WITH PROVIDER ABOUT POST-TREATMENT CARE PLAN

Has your provider talked to you about your post-treatment care plan (also referred to as a cancer survivorship plan), including things such as referrals to community services, reminders for future cancer screenings, and psychological support for adapting to life as a cancer survivor?



>> IF YES post-treatment care plan included resources for LGBTQI+ cancer survivors

Does your post-treatment care plan include resources for LGBTQI+ individuals? ⚠️

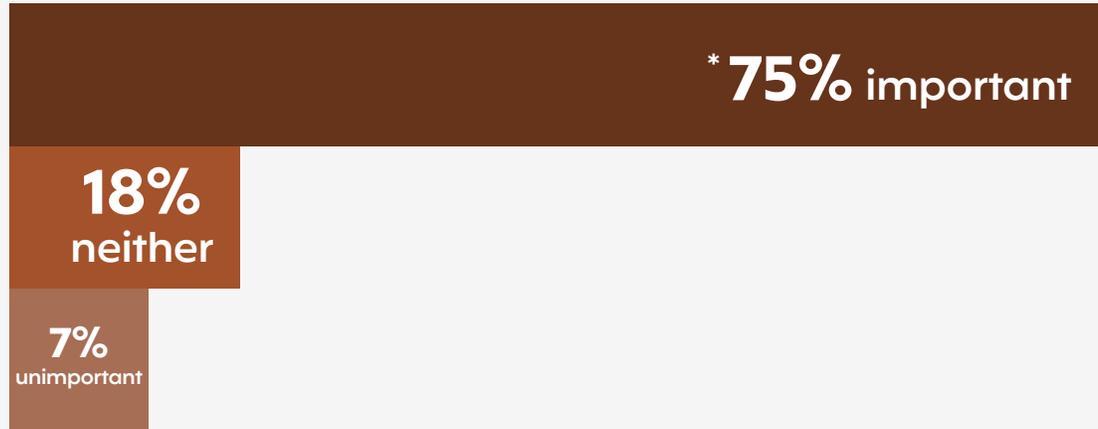




## IMPORTANCE OF LGBTQI+ RESOURCES IN POST-TREATMENT CARE PLANS

How important or unimportant is it to you that your post-treatment care plan includes information helpful to LGBTQI+ individuals? 

\* 54% cis male    61% cis female



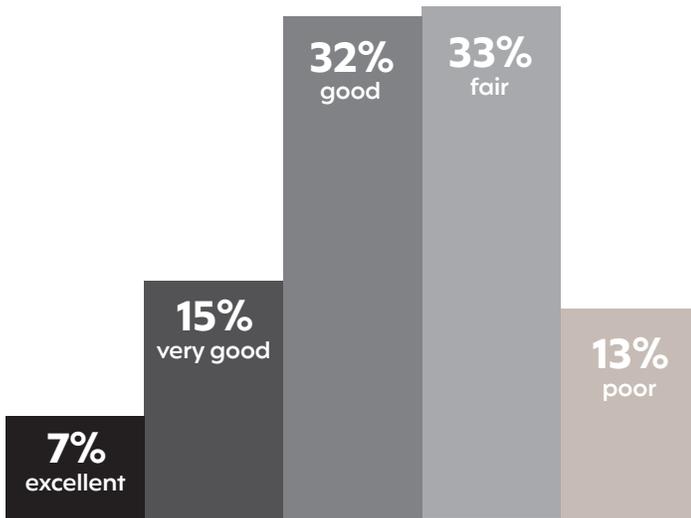


## HEALTH & HEALTH BEHAVIORS

>> Previous research demonstrates that many health risk behaviors, including tobacco and alcohol consumption are higher among the LGBTQI+ community. Even so, very few survivors have received tailored information, highlighting this gap in resources. For gender expansive survivors, the burden of mental health affects more than one in three, making tailored resources even more important for this vulnerable population.

### CURRENT HEALTH STATUS

How would you describe your current health? ⚠️



### CURRENT TOBACCO USE

Do you currently use any of the following tobacco products (select all that apply)?

**82%** Do NOT currently use tobacco products

**55%** have previously used tobacco products

**45%** have NEVER used tobacco products

**13%** Cigarettes

**5%** E-cigarettes or vapes

**4%** Hookah or chewing tobacco

**2%** Cigars or cigarillos

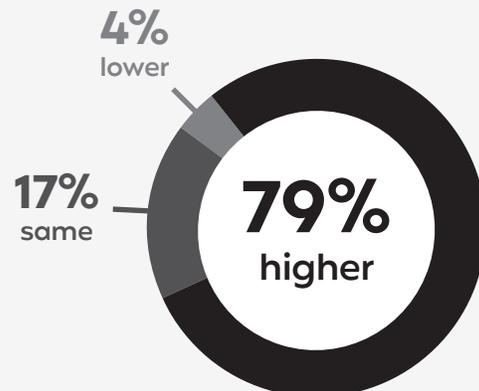
### RATES OF TOBACCO USE AMONG LGBTQI+ COMMUNITIES

Do you think the LGBTQI+ communities use tobacco products at rates that are higher or lower than the general population?

### TOBACCO

#### 100+ CIGARETTES IN LIFETIME

Have you smoked 100 or more cigarettes in your life? ⚠️





### EVER RECEIVED LGBTQI+ TAILORED TOBACCO RESOURCES

Have you ever received resources to help you stop using tobacco that were developed for LGBTQI+ individuals?



### IMPORTANCE OF TAILORED TOBACCO RESOURCES

How valuable would tobacco resources developed for LGBTQI+ individuals be to you?



## ALCOHOL

### DAILY ALCOHOL CONSUMPTION

On average, how many alcoholic drinks do you drink on an average day? One drink is equivalent to a 12-ounce beer, a 5-ounce glass of wine, or a drink with one shot of liquor. ⚠️

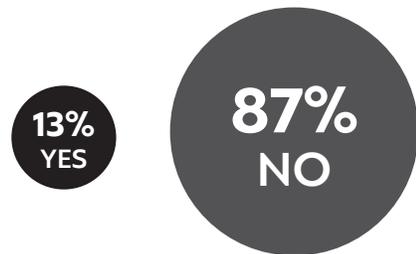
77%  
none

22%  
1-2 drinks/day

1%  
3-4 drinks/day

### EVER RECEIVED LGBTQI+ TAILORED ALCOHOL RESOURCES

Have you ever received resources related to alcohol consumption developed for LGBTQI+ individuals?



How valuable would alcohol resource developed for LGBTQI+ individuals be to you?

### RATES OF ALCOHOL USE AMONG LGBTQI+ COMMUNITIES

Do you think the LGBTQI+ communities drink alcohol at rates that are higher or lower than the general population? ⚠️

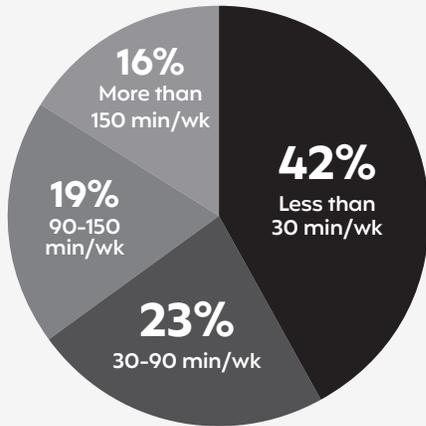




## PHYSICAL ACTIVITY

### CURRENT PHYSICAL ACTIVITY

In general, how many minutes per week do you engage in moderate to vigorous aerobic activity (e.g. brisk walking, jogging, cycling, heavy yard work, etc.)?



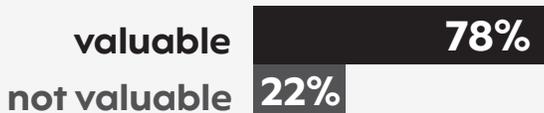
### EVER RECEIVED LGBTQI+ TAILORED ALCOHOL RESOURCES

Have you ever received resources related to alcohol consumption developed for LGBTQI+ individuals? ⚠️



### IMPORTANCE OF TAILORED PHYSICAL ACTIVITY RESOURCES

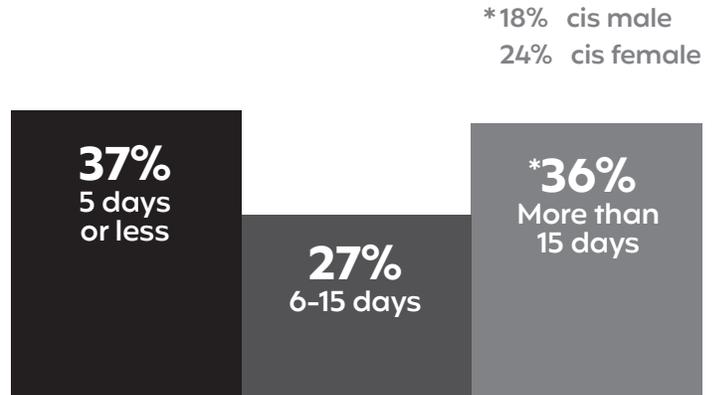
How valuable would physical activity resources developed for LGBTQI+ individuals be to you? ⚠️



## MENTAL HEALTH

### # OF DAYS WITH POOR MENTAL HEALTH

Now, think about your mental health, which includes stress, depression, and problems with emotions. In the past 30 days, for how many days was your mental health poor? ⚠️



### EVER RECEIVED LGBTQI+ TAILORED MENTAL HEALTH RESOURCES

Have you ever received resources related to mental health developed for LGBTQI+ individuals? ⚠️



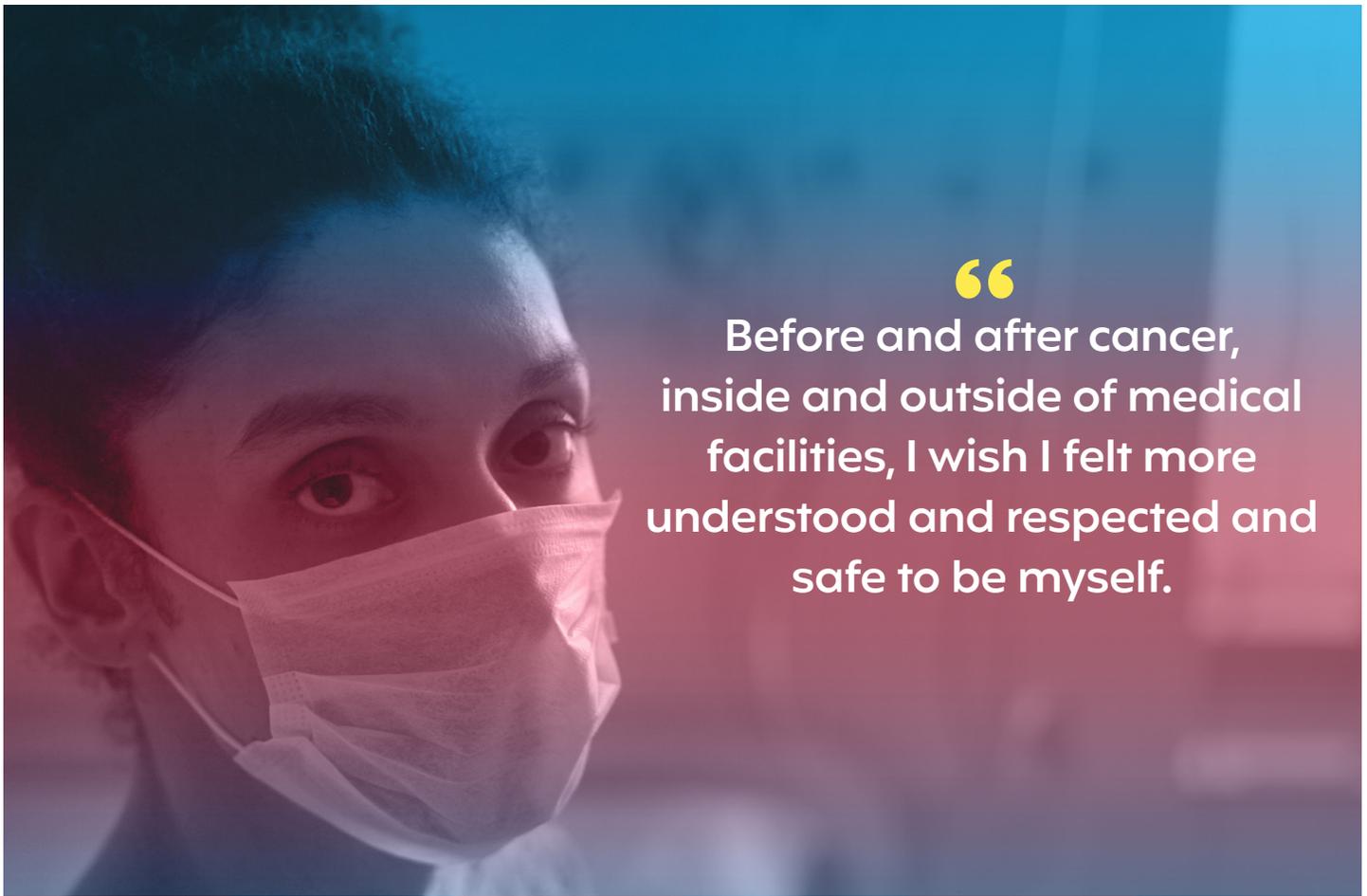


“

It is helpful and more meaningful to visually see people like me in resources offered.

### IMPORTANCE OF TAILORED MENTAL HEALTH RESOURCES

How valuable would mental health resources developed for LGBTQI+ individuals be to you? ⚠️



“

Before and after cancer, inside and outside of medical facilities, I wish I felt more understood and respected and safe to be myself.



# Tips for Providers from Gender Expansive Cancer Survivors

1

## Don't Assume

"Don't assume my gender or sexual orientation. Don't assume I want to keep my breasts or hair. Don't assume anything."



2

## Get The Training You Need NOW

"There are already LGBTQI+ people in your establishments who deserve to be treated with the same respect and dignity that your straight, cisgender patients receive."



3

## Earn Our Trust

"Recognize that many of us have had bad experiences with doctors and you may need to earn our trust. This means making an extra effort to listen and affirm our experiences."



4

## Include Us In Your Office Atmosphere

"Make sure we are included in your intake forms. Train all staff members on working with queer and gender diverse communities."



5

## Listen To Us

"We're scared about so much after getting our diagnosis. We don't want to have to fear a reaction from our providers about who is there to support us. You want us to listen to you and trust you - listen to us and trust us too."





## CONCLUSION

>> Thank you to the 2700+ LGBTQI+ cancer survivors who shared their stories and experiences with us on the OUT Survey. As a follow-up to the OUT National Cancer Survey, we invited participants to join an LGBTQI+ survivors panel, with over 1,200 members and growing. Through this panel, we offer virtual support groups, opportunities for speaking engagements, early release of data reports, and more. If you are an LGBTQI+ cancer survivor, we invite you to join our survivor panel: <https://cancer-network.org/programs/support-groups-for-survivors/>.



## KEY PARTNERS

>> The National LGBT Cancer Network thanks the many community and state partners that worked to promote OUT: The National LGBT Cancer Survey. With the support of these partners, we were able to recruit over 2,700 respondents, making this the largest-ever survey of LGBTQI+ cancer survivors.

We are especially grateful for our partnership with the Center for Black Equity; the Center for Black Equity works to improve the lives of Black LGBTQI+ people globally. This partnership helped us elevate the voices and experience of Black LGBTQI+ cancer survivors. Look for the release of a special report on these experiences in the Spring of 2022.





# KEY PARTNERS





## PROMOTIONAL PARTNERS

Adagio Health	Advancing LGBTQ Equality	Nebraska Cancer Coalition	Center of Chase Brexton Health Care
AIDS Alabama / BHAM Black Pride	GUMDROP (Genito-Urinary Multi-Disciplinary D.C. Regional Oncology	North Carolina Oncology Navigator Association - NCONA	The PAIGE
AIDS Services Coalition	Health Care Improvement Foundation	Northwestern: Evaluation, Data Integration and Technical Assistance (EDIT) Program	Tobacco Control of Elkhart County
Alliance (Alliance to Advance Patient-Centered Care )	Health Equity Alliance for LGBTQ+ New Mexico	Nu Phi Zeta Fraternity	Trans Empowerment Project
Alpha Omega Kappa Fraternity Inc	HIV Ohio	Nu Tau Beta Fraternity	Transgender District
Ann's Place	Imperial Valley LGBT Resource Center	Oakland LGBTQ Community Center	Twin Oaks Queer Gathering
APNH: A Place to Nourish Your Health	Indiana Cancer Consortium	Omicron Epsilon Pi Sorority	Ulman Foundation
Arkansas Black Gay Men's Forum / Little Rock Black & Brown Pride	Inside Out Youth Services	One Iowa	University Of Maryland Greenebaum Cancer Center
Arnold School of Public Health	Institute for SGM Health and Wellbeing	Open Door Health	University of Michigan Spectrum Center
Asheville Gay Men's Chorus	interACT: Advocates for Intersex Youth	Open House SF	USC Norris Comprehensive Cancer Center
Breast Advocate	JASMYN	Oregon Health & Science University (OHSU)	Vanderbilt LGBTQ Health
Cal Poly Pride Center	Kansas Cancer Partnership	Out Boulder	VCU Health and Behavior/ Massey Cancer Center
Cancer and Careers	Kansas Department of Health and Environment	Pennsylvania Equality Project	Virginia Cancer Patient Navigator Network
Cancer Support Community, San Francisco Bay Area	Kappa Psi Theta	People Against Biphobia	Well Beyond Ordinary
Cancer Today	Kentucky Black Pride Inc.	Personal Stories Project	West Virginia University LGBTQ Center
Carolina Rainbow News (CRN)	Kween Culture Initiative	PFLAG Woodstock	Winship Cancer Institute of Emory University
Central Alabama Pride	Lacuna Loft	Philadelphia Black Pride	Wisconsin Comprehensive Cancer Program
Connections IN Health	Latinos in the Deep South	POCAAN Pacific Northwest Black Pride	Alpha Pi Delta Sorority
CURE Magazine	Leukemia and Lymphoma Society	Positively Aware	Engage; Collaborative Care and Community Engagement
David's Dream & Believe Cancer Foundation	LGBT Detroit	Pride CC	Erie County HIV Task Force
Delta Zeta Phi Fraternity	LGBTQ Northwest Indiana	Pride Center of Staten Island	Oklahoma's Take Charge! & Comprehensive Cancer Control Program
Desert AIDS Project	Living Beyond Breast Cancer	Project Koru	South Carolina Tobacco Control
Equality NC	Magic City Equality	PT Proud	Pennsylvania Comprehensive Cancer Program
Erie County Health Department	Markey Cancer Center	Queer Resource Center (City College San Francisco)	Texas Comprehensive Cancer Program
Eta Theta Psi Sorority	Methodist Federation for Social Action	Rainbow Health Coalition at TouroCOM - Harlem	Howard Brown Health
Friend for Life Cancer Support Network	MGH Cancer Center	Rockland County Pride Center	Idaho Tobacco Control
Friendly "Virtual" Visiting Program	Montgomery County Office of Public Health	SAGE USA	Kappa Iota Sigma
Gala Pride and Diversity Center	Movement Advancement Project	SAGE - Staten Island	Alpha Zeta Gamma
Gay City: Seattle's LGBTQ Center	My Breast Choice	Sidney Kimmel Cancer Center	
Gay Web Source	National Alliance for Hispanic Health	Sigma Nu Psi Sorority	
Gender Benders	National Queer Asian Pacific Islander Alliance (NQAPIA)	Smillow Cancer Center	
Get Healthy Philly		Socially Centered	
GLMA: Health Professionals		Stupid Cancer	
		The LGBT Health Resource	