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

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Syros Pharmaceuticals

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Suggested citation:
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.

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

CULTURALLY COMPETENT PROVIDERS

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

- 68% All or most primary care providers
- 69% All or most nurses
- 66% All or most healthcare support staff

* 87% cis male
  81% cis female
* 88% cis male
  82% cis female
* 86% cis male
  80% cis female
Environmental indicators of welcoming care are significantly more important for gender expansive folks in identifying safe spaces to receive cancer treatment and care.

“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.”

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

<table>
<thead>
<tr>
<th>Tip</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Seek Support</strong></td>
<td>“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.”</td>
</tr>
<tr>
<td><strong>2. Choose Your Hospital System Wisely</strong></td>
<td>“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.”</td>
</tr>
<tr>
<td><strong>3. Sign And Notarize Power of Attorney</strong></td>
<td>“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.”</td>
</tr>
<tr>
<td><strong>4. Bring Your Whole Self</strong></td>
<td>“Your whole self is impacted by cancer. Bring your whole self to your treatment and care.”</td>
</tr>
<tr>
<td><strong>5. Create Your Own Quick Answers Sheet</strong></td>
<td>“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.”</td>
</tr>
<tr>
<td><strong>6. Ask About Sex</strong></td>
<td>“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.”</td>
</tr>
</tbody>
</table>
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.”

FOR MORE VISIT:
cancer-network.org
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 $\Delta$ 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

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Identity</th>
</tr>
</thead>
<tbody>
<tr>
<td>60%</td>
<td>Male</td>
</tr>
<tr>
<td>32%</td>
<td>Female</td>
</tr>
<tr>
<td>3%</td>
<td>Transgender</td>
</tr>
<tr>
<td>2%</td>
<td>Genderqueer/Gender Non-Conforming</td>
</tr>
<tr>
<td>2%</td>
<td>Non-binary</td>
</tr>
<tr>
<td>1%</td>
<td>Another Gender Identity</td>
</tr>
</tbody>
</table>

### SEX ASSIGNED AT BIRTH

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>28%</td>
<td>Male</td>
</tr>
<tr>
<td>72%</td>
<td>Female</td>
</tr>
<tr>
<td>7%</td>
<td>Intersex</td>
</tr>
</tbody>
</table>

### RACE/ETHNICITY

- 78% White Non-Hispanic
- 8% Multi-Racial Non-Hispanic
- 5% Hispanic
- 4% Another Racial Identity
- 3% Black Non-Hispanic
- 2% Asian

### SEXUAL ORIENTATION

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Orientation</th>
</tr>
</thead>
<tbody>
<tr>
<td>37%</td>
<td>Multiple</td>
</tr>
<tr>
<td>21%</td>
<td>Lesbian</td>
</tr>
<tr>
<td>13%</td>
<td>Queer</td>
</tr>
<tr>
<td>8%</td>
<td>Pansexual</td>
</tr>
<tr>
<td>7%</td>
<td>Bisexual</td>
</tr>
<tr>
<td>5%</td>
<td>Gay</td>
</tr>
<tr>
<td>4%</td>
<td>Straight</td>
</tr>
<tr>
<td>3%</td>
<td>Asexual</td>
</tr>
<tr>
<td>2%</td>
<td>Another Sexual Orientation</td>
</tr>
</tbody>
</table>

### AGE:

MEAN = 49

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Age Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>6%</td>
<td>71 years or older</td>
</tr>
<tr>
<td>20%</td>
<td>61-70 years old</td>
</tr>
<tr>
<td>25%</td>
<td>51-60 years old</td>
</tr>
<tr>
<td>17%</td>
<td>41-50 years old</td>
</tr>
<tr>
<td>19%</td>
<td>31-40 years old</td>
</tr>
<tr>
<td>13%</td>
<td>30 or younger</td>
</tr>
</tbody>
</table>
Participant Characteristics

**State**
41 states represented

**Top 5 States**
- California
- New York
- Washington
- Pennsylvania
- Colorado

**Urbanicity**

- 41% urban
- 43% suburban
- 16% rural

**Health Insurance**

- 97% YES
- 3% NO

**Disability**

- *61% YES 39% NO*

**Type of disability (select all)**
- 31% cis male
- 41% cis female

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

**Education**

- 42% graduate school
- 17% some college
- 39% college degree
- 2% high school or less
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?

- socially connected: 67%
- neither: 11%
- socially isolated: 22%

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

- more socially connected: 8%
- no change: 15%
- more socially isolated: 77%

OPTIMISM ABOUT HEALTH

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

- optimistic: 54%
- neither: 20%
- pessimistic: 26%

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

- more optimistic: 55%
- no change: 34%
- more pessimistic: 11%

*37% cis male
46% cis female

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? ▲

*42% YES 58% NO

*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? ▲

82% YES
18% NO

14% dissatisfied
74% satisfied
12% neither

**LIKELIHOOD OF VACCINE**
Do you plan to get a coronavirus vaccine when one is available? ▲

84% YES
2% NO
14% Not Sure

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

96% all or most of the time
1% some of the time or never
3% do not go to those types of places*

*25% cis male 40% cis female
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

- 9% 20 years or younger
- 18% 21-30 years old
- 19% 31-40 years old
- 21% 41-50 years old
- 23% 51-60 years old
- 8% 61-70 years old
- 2% 71 years old or older

CURRENTLY HAVE CANCER: 27%

- 80% of those with cancer are currently receiving treatment
- 28% more than one cancer diagnosis

TYPES OF CANCER

TOP 5 CANCERS

- Breast cancer
- Skin cancer (including basal, squamous or melanoma)
- Ovarian
- Leukemia
- Colorectal

PERSON WHO DELIVERED CANCER DIAGNOSIS

- 36% oncology health provider
- *45% someone else
- 19% primary care provider
- *Gynecologist Surgeon
- Emergency Room Doctor
- Surgeon
RESPECTFULNESS OF CANCER DIAGNOSIS
How respectful or disrespectful was the notification of your cancer diagnosis? △

<table>
<thead>
<tr>
<th>respectful</th>
<th>neither</th>
<th>disrespectful</th>
</tr>
</thead>
<tbody>
<tr>
<td>76%</td>
<td>9%</td>
<td>*15%</td>
</tr>
</tbody>
</table>

*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)? △

<table>
<thead>
<tr>
<th>YES</th>
<th>71%</th>
</tr>
</thead>
<tbody>
<tr>
<td>NO</td>
<td>*29%</td>
</tr>
</tbody>
</table>

* 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)?

<table>
<thead>
<tr>
<th>YES</th>
<th>79%</th>
</tr>
</thead>
<tbody>
<tr>
<td>NO</td>
<td>21%</td>
</tr>
</tbody>
</table>

*37% cis male 14% cis female

There are no guidelines for cancers that are more prevalent amongst Trans women. I had to fight like hell to have an anoscopy, and sure enough we found HDSC!
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?

- 20% YES
- 80% NO

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

- 37% 15-29 minutes
- 16% less than 15 minutes
- 16% 45-59 minutes
- 8% 30-44 minutes
- 23% one hour or longer

WELCOMING ENVIRONMENT AT CANCER TREATMENT CENTER
How welcoming or unwelcoming was the environment where you received cancer treatment?

- 79% welcoming
- 13% neither
- 8% unwelcoming

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

PROVIDERS AWARE OF LGBTQI+ IDENTITY

76% YES 24% NO

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)

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>34%</td>
<td>allied, complementary and alternative health professionals</td>
</tr>
<tr>
<td>51%</td>
<td>administration and reception staff</td>
</tr>
<tr>
<td>86%</td>
<td>nursing professionals</td>
</tr>
<tr>
<td>89%</td>
<td>medical professionals</td>
</tr>
</tbody>
</table>

>> 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?

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>21%</td>
<td>more welcoming</td>
</tr>
<tr>
<td>67%</td>
<td>no change</td>
</tr>
<tr>
<td>12%</td>
<td>more unwelcoming</td>
</tr>
<tr>
<td>4%</td>
<td>cis male</td>
</tr>
<tr>
<td>4%</td>
<td>cis female</td>
</tr>
</tbody>
</table>

>> 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?

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>78%</td>
<td>safe</td>
</tr>
<tr>
<td>7%</td>
<td>unsafe</td>
</tr>
<tr>
<td>15%</td>
<td>neither</td>
</tr>
</tbody>
</table>
CULTURALLY COMPETENT PROVIDERS
About how many of the [insert provider type] that you encountered during your cancer diagnosis and treatment provided culturally competent care?

- **68%** All or most primary care providers
  - *87% cis male
  - 81% cis female

- **69%** All or most nurses
  - *88% cis male
  - 82% cis female

- **66%** All or most healthcare support staff
  - *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?

- **17%** YES
- **83%** NO

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

- **74%** important

- **19%** neither

- **7%** unimportant
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+? △

- All or most people: 80%
- Half or less: 20%

# OF CLOSE FRIENDS
How many people in your life would you describe as close friends (friends you speak with at least once a week)? △

- Two or less close friends: 32%
- Three to six close friends: 44%
- Seven or more close friends: 24%

SEEN AS LGBTQI+ IN PUBLIC
In general, how often do people identify you as LGBTQI+ or not LGBTQI+ in public? △

- Mostly LGBTQI+: 48%
- Neither: 34%
- Mostly NOT LGBTQI+: 19%

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? △

- Safe: 78%
- Neither: 8%
- Unsafe: 14%

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?

- 74% strong
- 11% weak
- 15% neither

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

- 50% stronger
- 21% weaker
- 29% no change
- 15% neither

PRIMARY SUPPORT PEOPLE
Did you have primary support people during your cancer?

- YES 85%
- NO 15%

PRIMARY SUPPORT PEOPLE (continued)
Who were your primary support people, select all

- 58% friend
- 45% current partner
- 45% parent
- 34% sibling
- 20% former partner
- 12% someone else

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?

- 88% comfortable
- 7% neither
- 5% uncomfortable

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

* 6% cis male
* 7% cis female
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

65% NO
35% YES

How welcoming or unwelcoming was this cancer survivor social support?

>> IF YES Welcoming environment at support group

90% welcoming
6% neither
4% unwelcoming

IMPORTANCE OF WELCOMING ENVIRONMENT
How important or unimportant is it to you to be able to access LGBTQI+ welcoming cancer survivor social support?

8% unimportant
20% neither
72% important

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)

76% virtual
73% in person
62% via group
58% via peer to peer direct connection
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.

“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.”

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

*75% important

18% neither

7% unimportant

My experience with the plastic surgeon could have felt more tailored to my identity. For example, I was sent home with two pink postop bras instead of a postop compression vest.
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?

- 32% good
- 33% fair
- 15% very good
- 7% excellent
- 13% poor

TOBACCO

100+ CIGARETTES IN LIFETIME

Have you smoked 100 or more cigarettes in your life?

- 49% YES
- 51% NO

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?

- 4% lower
- 17% same
- 79% higher
## EVER RECEIVED LGBTQI+ TAILORED TOBACCO RESOURCES
Have you ever received resources to help you stop using tobacco that were developed for LGBTQI+ individuals?

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>7%</td>
<td>93%</td>
</tr>
</tbody>
</table>

## IMPORTANCE OF TAILORED TOBACCO RESOURCES
How valuable would tobacco resources developed for LGBTQI+ individuals be to you?

<table>
<thead>
<tr>
<th>valuable</th>
<th>not valuable</th>
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</thead>
<tbody>
<tr>
<td>39%</td>
<td>61%</td>
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</table>

## 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

### 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?

- 86% higher
- 14% same
- 0% lower

### EVER RECEIVED LGBTQI+ TAILORED ALCOHOL RESOURCES
Have you ever received resources related to alcohol consumption developed for LGBTQI+ individuals?

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>13%</td>
<td>87%</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>valuable</th>
<th>not valuable</th>
</tr>
</thead>
<tbody>
<tr>
<td>51%</td>
<td>49%</td>
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</tbody>
</table>
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.)?

- 16% More than 150 min/wk
- 19% 90-150 min/wk
- 42% Less than 30 min/wk
- 23% 30-90 min/wk

EVER RECEIVED LGBTQI+ TAILORED ALCOHOL RESOURCES
Have you ever received resources related to alcohol consumption developed for LGBTQI+ individuals?

- 88% NO
- 12% YES

IMPACT OF TAILORED PHYSICAL ACTIVITY RESOURCES
How valuable would physical activity resources developed for LGBTQI+ individuals be to you?

- valuable 78%
- not valuable 22%

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?

- 37% 5 days or less
- 27% 6-15 days
- *36% More than 15 days

*18% cis male
*24% cis female

EVER RECEIVED LGBTQI+ TAILORED MENTAL HEALTH RESOURCES
Have you ever received resources related to mental health developed for LGBTQI+ individuals?

- *45% YES
- *30% cis male
- *25% cis female

55% NO
It is helpful and more meaningful to visually see people like me in resources offered.

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.”

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