OUT WITH CANCER

LGBTIQ+ EXPERIENCES OF CANCER SURVIVORSHIP AND CARE

OVERVIEW OF FINDINGS
FEBRUARY 2025

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LGBTIQ+ HEALTH AUSTRALIA

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CONTENTS

WHAT IS THE OUT WITH CANCER STUDY?

The Out with Cancer study examined the cancer survivorship and care experiences of 430 LGBTIQ+ people with cancer, across a range of age groups, tumour types, sexual and gender identities. The perspectives of 131 LGBTQI+ informal carers and 357 oncology healthcare professionals (HCPs) were also included in the study. Data was collected between September 2019 to September 2021.

The research was conducted at Western Sydney University, in collaboration with the Cancer Council NSW, Breast Cancer Network Australia, Canteen, Prostate Cancer Foundation Australia, ACON, and LGBTIQ+ Health Australia. The Out with Cancer Study was funded by an Australian Research Council Linkage grant. An Advisory Group of LGBTIQ+ people, including some who had cancer, clinicians, community organisations, and researchers collaborated in the research and development of the translational outcomes.

This report provides an overview of the study’s findings. Further details can be found in the research publications listed at the end of this report, which are open-access - free to download and read.

SUMMARY OF FINDINGS

LGBTIQ+ people with cancer experience greater distress than the general cancer population.

Whilst a cancer diagnosis and subsequent treatment is a distressing time for any person, the Out with Cancer Study found that distress in the LGBTIQ+ cancer population was 3 to 6 times higher than in the general cancer population. There are also differences within LGBTIQ+ communities: bisexual people, adolescents and young adults, trans people, people with innate variations in sex characteristics, and those in rural and regional areas reported higher levels of distress.

The factors found to be significantly associated with distress were:

- Minority stress – including:
    - Experiencing discrimination in general life and in cancer care
    - Being uncomfortable with being LGBTIQ+
    - Fear of disclosure of LGBTIQ+ status in life and in cancer care
    - Concealing LGBTIQ+ status in cancer care
- Cancer impacting feelings about being LGBTIQ+ and community connection
- Experiencing more physical and sexual concerns after cancer
- Having less social support
- Fear of cancer recurrence

For LGBTIQ+ carers, having higher distress was also associated with:

- Experiencing more financial and health impacts of caregiving

LGBTIQ+ people are uniquely affected by cancer and treatment impacts.
The physical and sexual impacts of cancer treatment are largely similar for LGBTIQ+ and non-LGBTIQ+ patients. However, for LGBTIQ+ patients these changes may have unique implications for how they understand and express themselves as LGBTIQ+. LGBTIQ+ people with cancer and carers can also have different experiences around social support, exclusion and rejection, and discrimination, which can affect their experiences of cancer and cancer care.

LGBTIQ+ patients and carers are invisible and underserved by health systems.
The unique needs of LGBTIQ+ patients and carers are often not well understood or met by healthcare systems. Healthcare services and professionals may not understand the importance and impact of signalling LGBTIQ+ inclusivity and facilitating disclosure of LGBQ+, Trans and innate variations in sex characteristics. They may assume all patients are cisgender, heterosexual, and do not have innate variations in sex characteristics. Many healthcare professionals do not understand the unique needs and concerns of LGBTIQ+ people with cancer and their carers. This serves to make LGBTIQ+ people invisible and creates anxiety about disclosure and discrimination in healthcare contributing to distress and lower satisfaction with care. Training for healthcare professionals about best practices when working with LGBTIQ+ communities is essential.

Despite these vulnerabilities, many LGBTIQ+ people show resilience and community connection in the face of their cancer experiences. This includes LGBTIQ+ communities and chosen family coming together to support people with cancer and carers, as well as individuals channelling their experiences into advocacy and initiatives to improve the care and support provided to other LGBTIQ+ people in the future.

WHO ARE LGBTIQ+ PEOPLE?

The acronym LGBTIQ+ stands for **L**esbian, **G**ay, **B**isexual, **T**ransgender, **I**ntersex, **Q**ueer, and **+** other identities (e.g. pansexual, asexual, genderqueer). This includes people who:

- Are attracted to the same gender, or to multiple genders (***LGBQ+***)
- Do not identify as the gender associated with the sex that was recorded when they were born (***T****rans and non-binary*). In this report we use the term trans to refer to transgender, non-binary and gender diverse people. When we quote participants, we use the sexuality and gender descriptions provided by participants.
- Have innate variations of sex characteristics, meaning their chromosomes, reproductive organs, reproductive development and/or hormones differ from what is typically expected of female or male bodies (***I****ntersex*).

WHY IS IT IMPORTANT TO UNDERSTAND THE EXPERIENCES OF LGBTIQ+ CANCER PATIENTS?

To provide equitable and inclusive cancer treatment and care to LGBTIQ+ cancer patients, it is essential to understand their unique experiences and needs.

It is estimated that there are currently over 100,000 LGBTIQ+ cancer survivors in Australia. Cancer registries do not collect data on patients' LGBTIQ+ status, meaning that this estimate is based on how many people in the general population say they are LGBTIQ+ (1) and the number of people living after cancer diagnoses (2).

When compared to the general population, LGBTIQ+ people are more likely to get some types of cancer, including anal, breast, gynaecological and lung cancers (3). These disparities are partly explained by higher rates of smoking (4) and alcohol consumption (5) and low rates of cancer screening in LGBTIQ+ communities. Obesity and nulliparity (not having children) are additional risk factors for lesbian and bisexual women, with anal sex and higher rates of HPV infection, as well as the impact of HIV, acting as risks factors for gay men and trans and non-binary people (6). Previous research has found that LGBTIQ+ people with cancer experience higher rates of distress and greater dissatisfaction with cancer care than non-LGBTIQ+ people (3, 7).

Despite this, the specific healthcare needs of LGBTIQ+ people often go unrecognised, resulting in this diverse group becoming a growing and underserved population in cancer care.

Previous research primarily focused on the experiences of cisgender older adults with breast or prostate cancer (3, 7) . There has been a call for large-scale studies exploring the complexities of experiences of cancer amongst LGBTIQ+ communities, across ages, LGBTIQ+ identity groups, and cancer streams, to inform culturally safe cancer care (8-10). This was the aim of the Out with Cancer Study.

STUDY METHODS

Research methods included surveys, interviews, photo-stories, and a review of online Australian cancer information resources (Table 1).

430 LGBTIQ+ people with cancer	These participants represented a range of diagnoses (including people who had medical intervention related to cancer risk), sexual and gender identities, and ages. › **Surveys** included validated measures, closed- and open-ended questions asking about experiences of cancer care, how cancer had impacted their lives, and about their broader wellbeing (including distress, social support, and minority stress) (11). › 104 participants completed **interviews** and 45 completed **photo-story interviews** about their experiences.
131 LGBTIQ+ carers	These carers were LGBTIQ+ people who had cared for LGBTIQ+ and/or non-LGBTIQ+ people with cancer, including partners and ex-partners, family members and friends. › **Surveys** with validated measures, closed- and open-ended questions asked about participants' experiences of caregiving, how being a carer had impacted their lives, and their broader wellbeing (12). › 31 carers completed **interviews** and 10 completed **photo-story interviews** about their experiences.
357 Healthcare professionals	Participating healthcare professionals (HCPs) included medical, nursing and allied health staff working with people with cancer, as well as those involved in clinical leadership and service delivery. › Brief **surveys** including closed- and open-ended questions asked about participants' attitudes, knowledge, practice behaviours and experiences regarding LGBTIQ+ cancer care (13). › 48 of these cancer care professionals also completed **interviews**.
61 Websites of cancer organisations	These websites were audited to assess whether there was any mention of, or specific information for, LGBTIQ+ people with cancer and carers. Content that was **not** specific to LGBTIQ+ individuals was also assessed to determine whether language, imagery and content was inclusive (14).

We will draw on the statistics, interviews, and the photo-stories throughout this report.

PARTICIPANT DEMOGRAPHICS

People with cancer. Participants encompassed a diverse range of sexualities and gender identities (see Figure 1), with the majority identifying as cisgender women (50.2%) and as lesbian, gay or homosexual (73.7%). Ages ranged from 16 to 92 years (M=52.5), with 22.1% being adolescents or young adults (AYAs, 15-39yrs) at the time of participation. Most participants resided in Australia (72.3%) and identifed as white (85.2%). Various cancer diagnoses were represented (Figure 2), with the most common being breast (24.3%) and prostate (15.9%). See Appendix 1 for full details of demographics.

FIGURE 1. Demographics of participating LGBTIQ+ people with cancer.

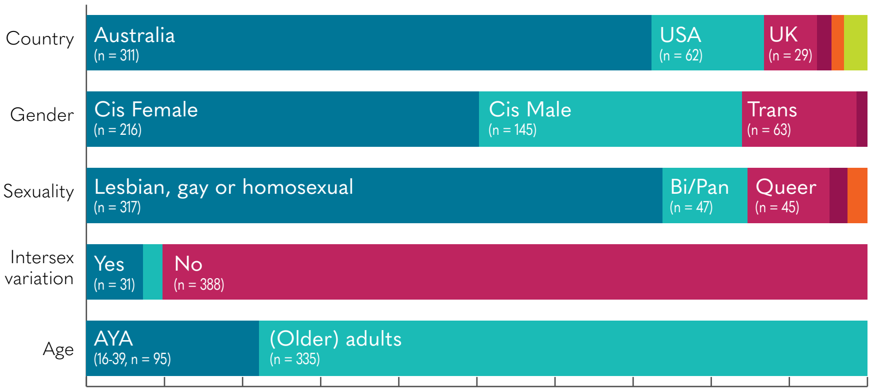
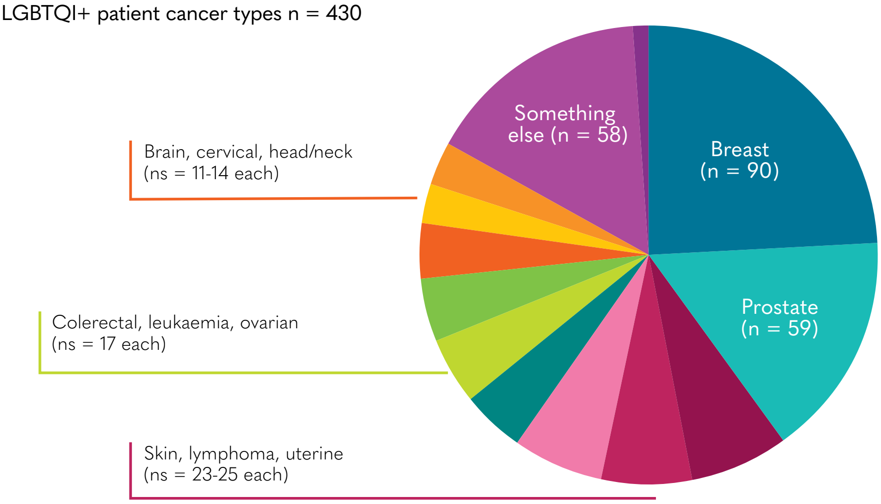
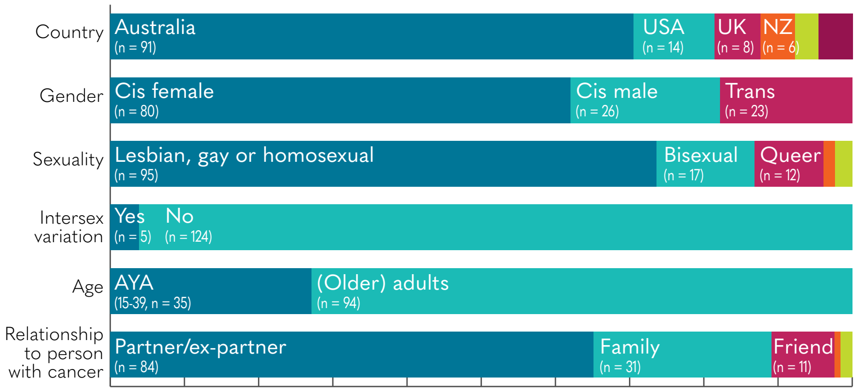


FIGURE 2. Initial cancer diagnoses reported by participating LGBTIQ+ people with cancer.



Carers. 131 LGBTIQ+ people completed surveys about their experiences caring for someone who had cancer; 31 completed interviews, and 10 completed a photo-story exercise. A diverse range of sexualities and gender identities were represented (see Figure 3), with cisgender women (62.0%) and those identifying as lesbian, gay or homosexual (73.6%) the most common.

FIGURE 3. Demographics of participating LGBTIQ+ carers.

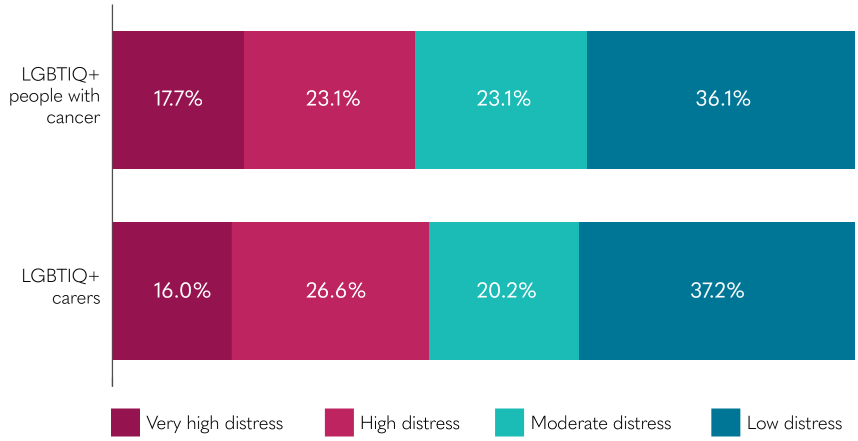


Carer participants were between 15 and 76 years old (M=50.2), with 27.1% being AYAs. Participants had most cared for current/former partners (65.1%) and family members (24.0%) diagnosed with a range of cancers; the most common diagnoses were breast (29.4%) and ovarian (10.3%) cancers. Most lived in Australia (70.5%) and were white (82.2%).

DISTRESS AMONGST LGBTIQ+ PEOPLE WITH CANCER AND LGBTIQ+ CARERS

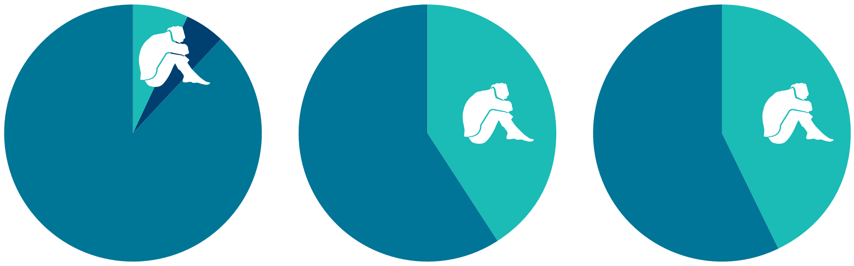
The Out with Cancer study revealed significant levels of distress among both individuals with cancer and their carers. High or very high distress levels, as measured by the Kessler-10, were reported by 41% of LGBTIQ+ people with cancer [11] and 43% of LGBTIQ+ carers [12].

FIGURE 4. Levels of distress for LGBTIQ+ people with cancer and carers



The proportion of LGBTIQ+ people with cancer reporting high or very high distress levels in the Out with Cancer Study (41%) were approximately three to six times higher than previous Australian cancer population studies using the same measure (7-12%).

FIGURE 5. Percentage of LGBTIQ+ people with cancer reporting high or very high distress levels compared to general cancer populatio



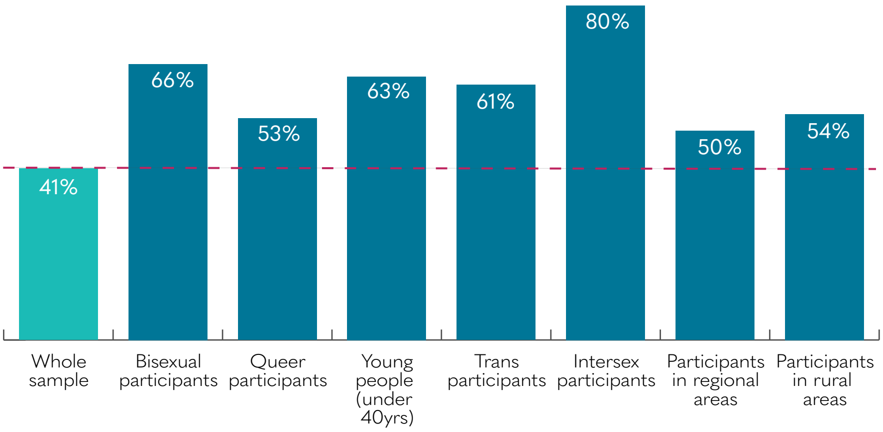
7-12% of the general cancer population reports high/very high distress

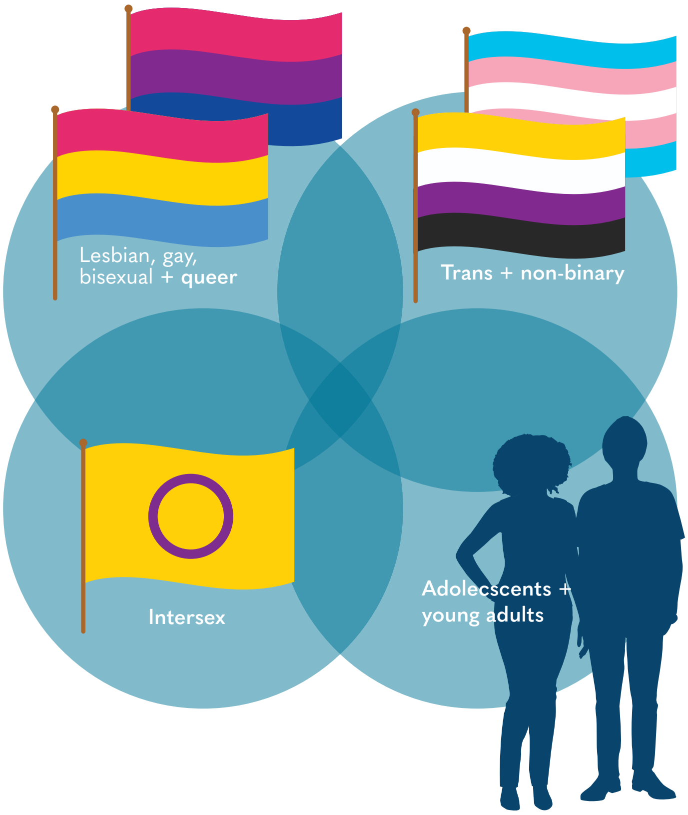
41% of LGBTIQ+ people with cancer report high/very high distress

43% of LGBTIQ+ carers report high/very high distress

Distress levels were found to be higher for bisexual and queer people, adolescents and young adults (AYAs), trans people, those with innate variations in sex characteristics (intersex people), and those in rural and regional areas. The proportion of these groups reporting high/very high distress is shown in Figure 6.

FIGURE 6. Levels of high/very high distress by demographic group





Different identity groups intersect, which means that individuals who hold multiple intersecting identities may be at even greater risk of distress. For example, a young trans bisexual person with cancer may be at higher risk of experiencing distress.

WHAT ARE THE UNIQUE FACTORS LEADING TO DISTRESS?

The factors found to be significantly associated with distress (11) were:

- Minority stress – including:
    - Experiencing discrimination in general life and in cancer care
    - Being uncomfortable with being LGBTIQ+,
    - Fear of disclosure of LGBTIQ+ status in life and in cancer care
    - Concealing LGBTIQ+ status in cancer care
- Cancer impacting feelings about being LGBTIQ+ and community connection
- Experiencing more physical and sexual concerns after cancer
- Having less social support
- Fear of cancer recurrence

For LGBTIQ+ carers, having higher distress was also associated with:

- Experiencing more financial and health impacts of caregiving

MINORITY STRESS AND DISCRIMINATION

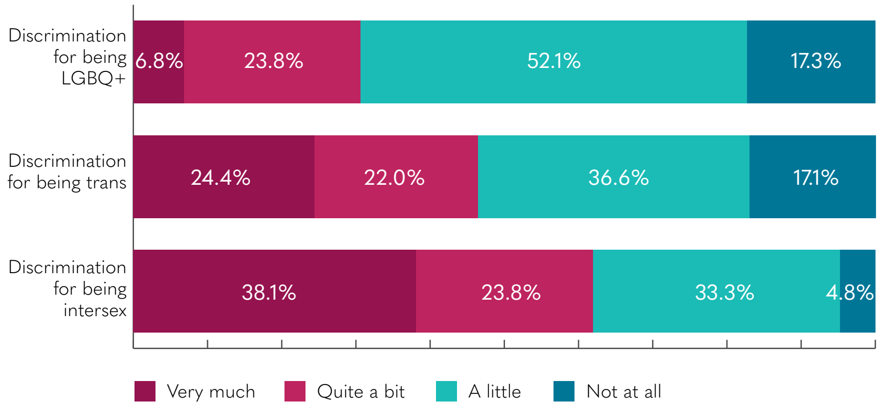
Health inequities reported by LGBTIQ+ people with cancer and their carers can partly be explained by minority stress (15), the experience of chronic stress associated with living with a marginalised LGBTIQ+ identity. This includes experience and anticipation of stigma, exclusion, discrimination, and violence (16). Taking on board anti-LGBTIQ+ sentiment can contribute to negative self-views, identity concealment and expectations of rejection, hostility and potential future victimisation (17). Supporting this theory, distress reported by LGBTIQ+ cancer patients and their carers was found to be significantly associated with experiences of discrimination in life and cancer care (11, 12), accompanied by identity concealment and expectations of future hostility (18, 19).

DISCRIMINATION IN GENERAL LIFE

Experiences of discrimination were common among people with cancer and were associated with higher levels of distress. The majority of LGBTIQ+ people with cancer (83.6%) and carers (69.6%) reported a history of anxiety and distress caused by discrimination experienced in life outside of cancer care. Notably, discrimination for being trans and for having innate variations in sex characteristics was more common than discrimination for being LGBQ+, as shown in Figure 7.

> It's taken me a long time [to embrace my sexual identity] because I grew up in the 70s seeing my friends who were gay being targeted. One guy I worked with took his own life. He had a record because he was involved in a sexual act and that was illegal at that stage. So, seeing all of these things, all of these repercussions, I sort of thought I need to squash the gay side of me.
>
> CIS WOMAN, BISEXUAL, AGE 56, CERVICAL CANCER

FIGURE 7. Discrimination in general life



These experiences of discrimination took many forms (17). Many participants described growing up or living through times when:

- Homosexuality was criminalised, with participants experiencing and witnessing police violence and criminal convictions against lesbian and gay people
- LGBTQ+ identities were pathologised as mental illnesses, justifying "correction" through conversion therapy
- In this era of criminalisation and pathologisation, there was also increased threat of losing jobs or housing if found to be LGBTIQ+, resulting in pressure to remain closeted
- The HIV/AIDS epidemic disproportionately impacted LGBTIQ+ people (particularly gay men) resulting in stigma in society and in healthcare, and harming queer communities

While society has become gradually more accepting of LGBTIQ+ communities, prejudice, discrimination, and exclusion of LGBTIQ+ people continues to this day. These ongoing experiences included:

- Innate variations in sex characteristics continue to be seen as dysfunctional, leading to surgical procedures to "correct" these variations, often without informed consent (20). Cancer risks were often used to justify these interventions, although evidence for innate variations in sex characteristics causing cancer is unfounded (21).
- Prejudice, hostility, and rejection from family of origin means that LGBTIQ+ people are less likely to have family support, impacting housing or financial security, or this support may be contingent on hiding identities or relationships (17).
- Participants noted an "ominous" increase in anti-LGBTIQ+ (and particularly transphobic) public commentary in recent years, and worried about erosion of LGBTIQ+ rights (17).

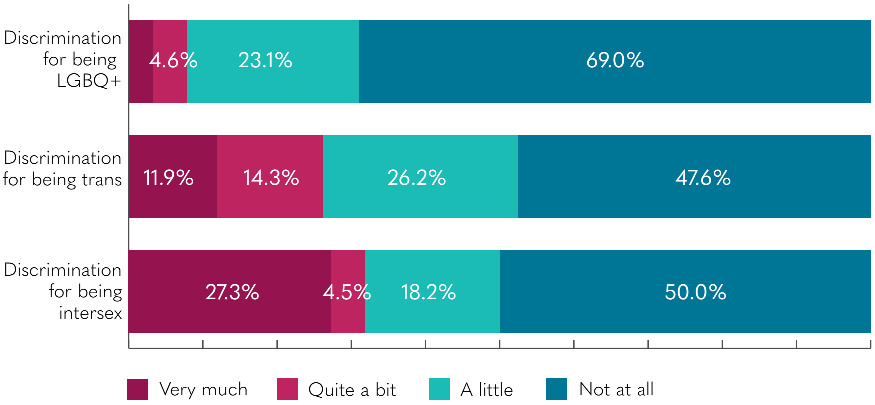
> I've been assaulted seriously in the last 24 months, six times. Last year, someone attacked me in my own front yard in daylight. Bathroom use has also been 'problematic'. I have been verbally abused and physically assaulted on several occasions inside my local shopping centre.
>
> TRANS WOMAN, AGE 53, SOFT TISSUE CANCER

> Being more effeminate I am easily spotted as gay. This can place me at greater social risk. I would say I am fearful of violence.
>
> CIS MAN, GAY, AGE 67, SKIN CANCER

DISCRIMINATION IN CANCER CARE

A third (33%) of LGBTIQ+ people with cancer and a fifth (21%) of LGBTIQ+ carers reported that they had experienced discrimination in cancer care. These individuals were more likely to report distress. Rates of discrimination in cancer care were higher for trans (52%) and intersex participants (50%), compared to LGBQ+ people (31%). Figure 8 shows rates of discrimination in cancer care reported by LGBTIQ+ people with cancer.

FIGURE 8. Discrimination in cancer care



This discrimination is experienced in many ways.

Being judged as perverse, sick or abnormal

> While in hospital I heard them talking about me as if I was a freak, being described as high-risk need for extra care and identified as trans in discussions by my bed for everyone to hear.

TRANS, NON-BINARY, AGE 66, PANCREATIC CANCER

Bodies being judged as deficient or deviant

> I was treated like a freak by the woman who did the mammography, and the technicians who did the fine needle biopsy giggled continuously through the entire, painful experience.

CIS WOMAN, LESBIAN, AGE 67, INTERSEX, BRAIN CANCER

Not having treatment choices respected

> It felt like they were thinking 'Why would a female not want to have breasts, let's collectively gawk at the patient until they agree to save them'. Why couldn't they just listen to me?

NON-BINARY, BISEXUAL, AGE 36, BREAST CANCER

Having partners or chosen family excluded

> My radiation oncologist clearly thought my life was absolutely disgusting, refused to acknowledge my partner. If she was in an appointment with me, he'd just completely ignore her. I had ticked the de facto box and he scribbled out my tick on that box and put single.

CIS WOMAN, LESBIAN, AGE 41, VULVAL CANCER

> When you grow up as a lesbian and the age group that I grew up, your attitudes and the way you deal with the world because of the condemnation, you had to hide yourself or not be yourself. Or you'd be yourself, but you've got to be prepared for hostility. I think to understand your response to the world, people do need to understand that you are very much affected by that feeling of derision, hatred, whatever, that you've blocked out.
>
> CIS WOMAN, LESBIAN, AGE 61, DIAGNOSED WITH BREAST CANCER

COMFORT IN BEING LGBTIQ+

The majority (91.0%) of the LGBTIQ+ people with cancer we heard from were comfortable being LGBTIQ+. LGBQ+ people were more likely to report being comfortable in their sexuality (93.0% people with cancer, 91.7% carers), than participants reported being comfortable with being trans (83.3%*)[1] or having innate variations in sex characteristics (69.6%*). A small proportion of participants wished they were not LGBTIQ+, which was more common for trans (19.0%*) and intersex (17.4%*) participants than for LGBQ+ participants (5.4% people with cancer, 6.3% carers).

Discomfort in being LGBTIQ+ was associated with higher levels of distress, and is a legacy of prejudice, discrimination, criminalisation, pathologisation, and exclusion, which was both historic and ongoing.

FEAR OF DISCLOSURE IN LIFE AND IN CANCER CARE

As a result of being mistreated for being LGBTIQ+, almost a third of patients (30.8%) and carers (32.7%) kept careful control over who knew they were LGBTIQ+ in general life - this included over half of trans participants (54.8%*) and those with innate variations in sex characteristics (52.2%*) [10].

This was carried into cancer treatment and caregiving experiences, with participants describing being reluctant to disclose and worrying about the potential for discrimination and mistreatment for being LGBTIQ+. These fears and anxieties acted as additional stressors during the already stressful experiences of a cancer diagnosis, treatment, survivorship, and caregiving (19).

> I don't feel safe. I have to think ALL THE TIME in medical situations if it's safe to come out. Correcting, educating, making formal complaints – I am enraged that my energy has been taken up by this my whole life when I'm in pain; very sick; recovering; scared.
>
> FEMME, QUEER, AGE 39, MEDICAL INTERVENTION RELATED TO CANCER RISK

LGBTIQ+ people described being constantly alert to the potential threat of hostility and discrimination from healthcare professionals (18). This caused distress, distrust and feelings of invalidation and fear for safety. As a result, navigating cancer care as a LGBTQI+ person was described as walking in an area that has "landmines".

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[1] *Numbers of trans and intersex carers too low to report

> It’s like walking in an area that has landmines. You’re always cautious. You don’t know if you’re going to step on a landmine, so you have to walk gingerly. This is what it means to navigate the health system as a lesbian woman.

CIS WOMAN, LESBIAN, AGE 36, UTERINE CANCER

PARTICIPANT PHOTOGRAPH

> It is easier to not be out in the medical setting. In not being out, you get treated better. I do not mean medical treatment here, just interactions.
>
> CIS WOMAN, LESBIAN, AGE 63, BREAST CANCER

> I feel it’s nobody’s business what I do outside work or in my private life. I wasn’t out to anybody at that stage, not even my brother.
>
> GAY, CIS MAN, GAY, AGE 63, PROSTATE CANCER

CONCEALING LGBTIQ+ STATUS IN CANCER CARE

For most participants, disclosure of LGBTIQ+ status was one of the most difficult aspects of cancer care (18, 19). Participants described having to constantly weigh up the potential benefits of disclosure against the possibility of:

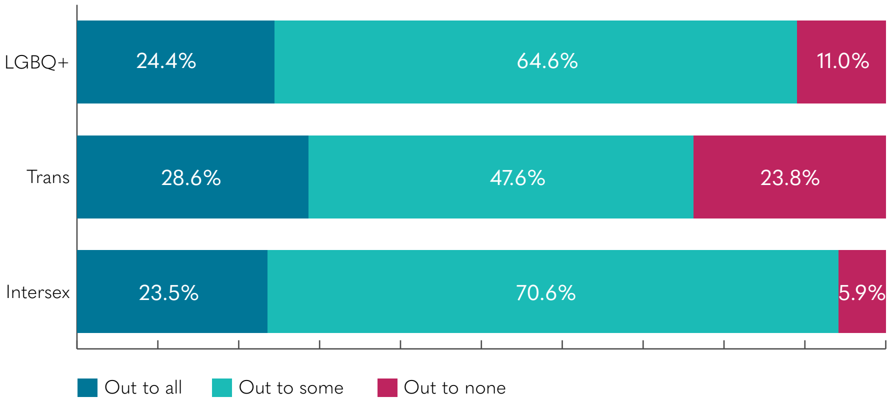
- Awkwardness when correcting clinicians’ assumption about sexuality, gender, or anatomy
- Clinicians not understanding the relevance of being LGBTIQ+, or not knowing how to tailor their cancer care and information
- Needing to educate clinicians about what it means to be LGBTIQ+
- Encountering prejudiced healthcare professionals who would mistreat or discriminate against them for being LGBTIQ+
- Sharing private information about sexuality, gender or innate variations in sex characteristics

> I don’t want them to know I’m gay because I don’t want them to treat me different. If they realise I’m gay… if they’re religious are they going to have less motivation to treat me, cure me?
>
> CIS MAN, GAY, AGE 27, LYMPHOMA

> It is just absolutely not worth it to me to identify as anything other than cis in the health system because people make a mockery of trans bodies.
>
> QUEER NON-BINARY, AGE 37, BRCA

A minority of participants did not disclose LGBTIQ+ status to any healthcare professionals (11.9% LGBQ+, 23.8% trans, 6.3% intersex) (19). Some people feel it is easier to pass as straight, cisgender and/or endosex (not intersex) in the medical system (18). Other people are not out in life - or not out in all aspects of life - and, for this reason, do not want to be out in cancer care. They may consider that their LGBTIQ+ status is private and not relevant to medical care. People may fear that openly identifying as trans (22) or intersex (20) will be treated as a point of curiosity. Living in rural areas or small towns can make disclosure more difficult (19). Young people who have limited experience with the healthcare system (and potentially limited health literacy) may find it harder to come out to healthcare professionals, especially if they are accompanied by family or carers who they are not out to (23).

FIGURE 9. Disclosing LGBTIQ+ identities in cancer care



Even participants who were comfortable and open about being LGBTIQ+ described disclosure as “never easy”, “quite scary”, “shaming”, and requiring careful planning. As a result, most participants (LGBQ+ 56.6%, trans 47.6%, intersex 70.6%) were only out to some of their healthcare professionals, based on case-by-case decisions about the relevance, and potential risks and benefits of disclosure.

> I've always called coming out that sweating moment, you know, whether it's to somebody that you're friends with or want to be friends with, or it's a provider. I do think carefully about the strategy. I want to always be in a good mood when I do it, I don't want to be angry. I don't want to feel particularly vulnerable. I want to be… sort of casually confident. Sometimes I pull it off better than others.
>
> CIS WOMAN, LESBIAN, AGE 76,
> BRAIN CANCER

> Coming out over and over again, because of multiple doctors and specialists is hard. No matter how strong I am, how resilient, how proud, I am still scared of how medical people and fellow patients in hospital will treat me. This is based on a valid fear due to past negative experiences and the fact that I read the news and listen to negative comments about my community.
>
> QUEER FEMME, AGE 38,
> COLORECTAL AND OVARIAN
> CANCER

> This photo reflect[s] me attempting to look like I belonged in some kind of normal, hetero kind of world. It's so foreign to me, the whole thing is so foreign… looking back on it in relation to what we've spoken about and my experience of cancer. This reflects that feeling of being vacant and empty.
>
> CIS WOMAN, LESBIAN, AGE 65,
> DIAGNOSED WITH UTERINE
> CANCER

PARTICIPANT PHOTOGRAPH

BEING PRESSURED TO DISCLOSE - THE GLASS CLOSET

Some LGBTIQ+ people feel they must disclose to ensure their partners are included in their cancer care and decision-making (19). For trans people and intersex people, a physical examination or hormonal treatment means they may not have the choice of non-disclosure. If people present as visibly trans or non-passing, or want people to use correct pronouns, they feel they must disclose (22).

DISCLOSURE WITHOUT DISCRIMINATION IS ASSOCIATED WITH SATISFACTION WITH CARE

Being able to disclose LGBTIQ+ status and include partners and other chosen family without experiencing discrimination was associated with satisfaction with cancer care (19).

For a subset of participants, disclosure was "non-negotiable" and an important part of their authentic self-presentation, with some also choosing to be visible to create positive change in healthcare systems. Approximately a quarter of participants described being open to all their healthcare professionals about being LGBQ+ (25.0%), trans (28.6%) or intersex (18.8%).

Disclosure of LGBTIQ+ status to healthcare professionals was for many LGBTIQ+ participants an important step in ensuring they received appropriate medical care and relevant information about cancer and treatment impacts. It also allowed them to more freely raise questions and concerns related to being LGBTIQ+, and to have their partners and chosen support people recognised.

> Getting cancer while lesbian is like forcing you into a glass closet. Prior to diagnosis, only our families, friends, and select people at work knew. When you get cancer, you have to tell your health professionals.
>
> CIS WOMAN, LESBIAN, AGE 36, UTERINE CANCER

> Everywhere you go, you are asked who this person is with you, and eventually, you have to say "my partner", so it gives it away. You can only lie so long. Saying they are just a friend means they do not get access to many places or the information to help with decision-making.
>
> TRANS MAN, ASEXUAL, AGE 57, MEDICAL INTERVENTIONS FOR CANCER RISK

> It's important for me to get it off my chest so they can understand me and how I operate. I basically do it so that they can give me appropriate care.
>
> CIS MAN, GAY, AGE 60, OESOPHAGEAL CANCER

> I usually introduce Ellen as my wife, and we haven't had anyone flinch or look twice or nothing. We've both been included in everything, so they'll just call us in and just take both our hands on every occasion. Last time when we left the oncologist because my results were really promising he grabbed both of us and gave us a big hug and said 'you are such a good team'.
>
> CIS WOMAN, LESBIAN, AGE 48, BOWEL CANCER

> “The white tennis shoe has a rainbow stripe around the shoe. He loved the shoes and he wore them to almost every treatment session we were going to. It doesn’t say you Trans, it says LGBTI, and if it doesn’t say that to someone, it says Gay. You’d have people smile and you could tell by the smile you’d have people smile nicely and say love your shoes. And it was a way of connecting, we had lots of happy connections because of the shoes and if it doesn’t say that to someone, it says Gay.”

TRANS MAN, GAY, AGE 55, CARER OF PARTNER WITH MULTIPLE CANCERS

PARTICIPANT PHOTOGRAPH

BURDEN OF DISCLOSURE IS ON LGBTIQ+ PEOPLE

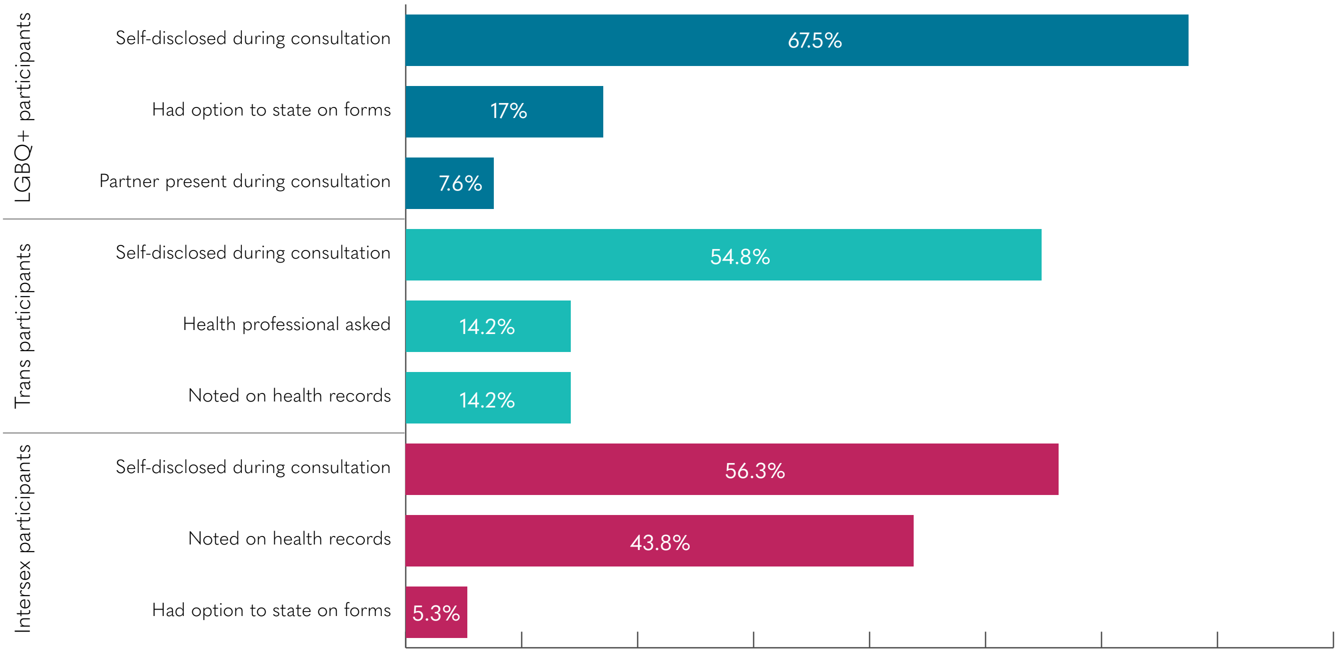
Overwhelmingly, the burden of disclosure was placed on LGBTIQ+ patients and carers; very few were asked about their sexual orientation or gender identity by healthcare professionals or had the option to state that they were LGBTIQ+ on forms.

This is reflected in the most common means of disclosure of LGBTIQ+ status being patient disclosure.

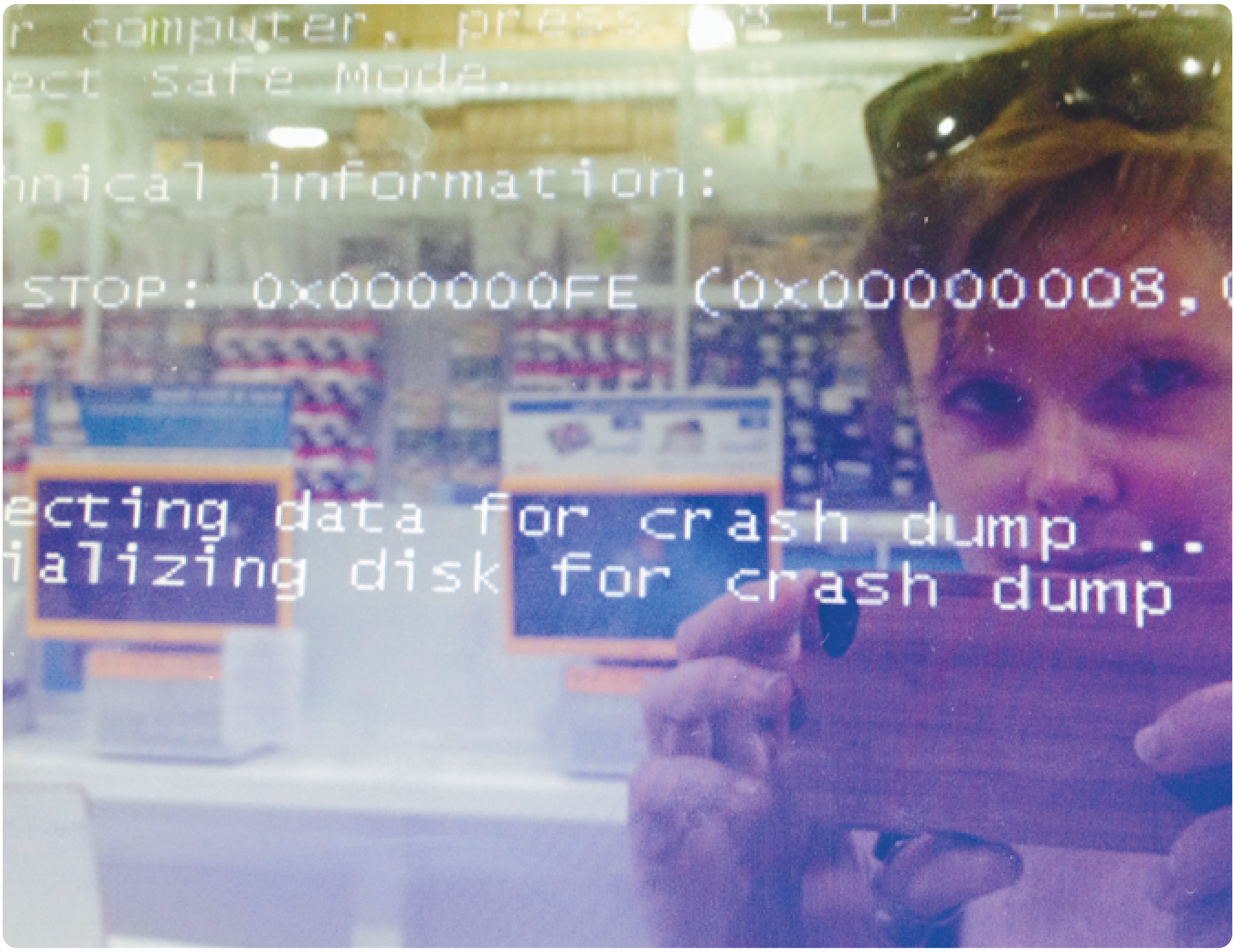
> The only options for my oncology office forms are male and female.
>
> QUEER, NON-BINARY, AGE 38, OVARIAN CANCER

> Nobody said anything- and so neither did I. It's not my job, that's their job. I'm already in a heightened state of anxiety and, you know, not coping. It's their job to put you at ease, not the other way around.
>
> CIS WOMAN, LESBIAN, AGE 54, BREAST CANCER

FIGURE 10. Methods of disclosure of LGBTIQ+ status



When there was no indication that healthcare professionals or systems are LGBTIQ+ inclusive, reflected in the failure to enquire about patients' gender, sexuality, and or innate variations in sex characteristics, some participants were deterred from disclosing that they were LGBTIQ+, or avoided seeking health care.



> Since I've had to be more and more involved in the health system personally, I've had to keep ticking male/female boxes, like no queer or intersex box available.
>
> I miss the way I got to move through the world and be more myself. Since cancer influenced my journey, I am just so used to conforming more… I almost had to sacrifice that part of my identity just to get treatment in the health system. And I've definitely come to a point in my life where I've avoided help-seeking or opted out of the health system just because I couldn't be a binary person that day.

GENDERFLUID, QUEER, AGE 37, MEDICAL INTERVENTION AND BREAST CANCER

PARTICIPANT PHOTOGRAPH

SPOTLIGHT

INTERSEX PEOPLE WITH INNATE VARIATIONS IN SEX CHARACTERISTICS

Many intersex people with innate variations in sex characteristics have had negative experiences in healthcare, such as the removal of gonads or sexual anatomy in childhood without consent. This is often justified by poorly evidenced risk of cancer associated with innate variations in sex characteristics. (24)

> Cancer was the excuse to perform "normalising" surgeries on my genitals and to give me hormone treatment .
>
> INTERSEX WOMAN, AGE 49

> Cancer risks are often used to assimilate intersex people into the gender binary regardless of the variation.
>
> INTERSEX, NON-BINARY WOMAN, AGE 43

This form of medical intervention of intersex bodies is now recognised as a human rights violation (21) and is no longer recommended but remains an ongoing practice. Intersex people may struggle to trust healthcare professionals, because of traumatic or non-consensual medical interventions done to modify their innate variations in sex characteristics.

> I have a lifelong phobia of hospitals, medical people, and ongoing physical issues from what was done to me as a child. It's hard to trust medical people in general for me.
>
> INTERSEX, QUEER, AGE 45, MEDICAL INTERVENTION IN CHILDHOOD

> Unsurprisingly, many intersex people often have trust issues regarding medical and legal issues.
>
> INTERSEX, NONBINARY, AGE 30'S.

Secrecy surrounds innate variations in sex characteristics and medical interventions. Many people only find out about their intersex variations in adulthood, as parents are told not to talk about their child being intersex, or about medical interventions conducted in infancy or childhood.

> I had stomach cramps (as a child) that were extremely painful. I was told that I was struggling with constipation but instead, my testes were pulled down. Neither I nor my parents were officially informed of what that surgery was about. It wasn't until I turned 35 that I learned what truly happened to me at seven years of age.
>
> INTERSEX, NONBINARY, AGE 40

The social stigma and secrecy surrounding intersex bodies can cause feelings of internalised shame and stigma, leading to lack of disclosure of intersex variations in social and healthcare interactions.

> There is so much internalised shame tied into the experience of being intersex. It's hard to disclose. I've also disclosed in the past and had medical professionals respond negatively or even Google my variation in front of me. I'm very careful about who I disclose to now.
>
> NON-BINARY, BISEXUAL, INTERSEX, AGE 20'S

Many intersex people have a heightened fear of cancer, even if they have undergone medical interventions.

> I've had constant fears that I'll get cancer. I had surgery 10 years ago.
>
> INTERSEX WOMAN, AGE 27

> The word alone cancer is enough to strike fear into anyone's heart. I've had counselling to learn how to not live in fear that I may wind up with cancer in the future, even though I've had multiple preventative surgeries.
>
> INTERSEX, NONBINARY, AGE 40

A cancer diagnosis may confirm the worst fears and add to the trauma of medical intervention and its consequences for intersex people. It is essential to acknowledge these concerns, provide trauma-informed care, and ensure that intersex patients feel supported, understood, and empowered in their treatment choices (20).

> We need health professionals to understand our needs, unlike my local hospital that just whacked up a few rainbow stickers showing support when there has been zero specific training and they don't even know what intersex is. I think the public and health pros need to realise there has been a LOT of trauma involved in the intersex person, particularly those diagnosed with cancer or any medical challenge on top of what they already have to live with.
>
> INTERSEX, NON-BINARY, PANSEXUAL, AGE 55, SKIN CANCER

However, many intersex participants who were able to be open about having innate variations in sex characteristics, connect with intersex communities, and engage in advocacy, finding these experiences to be empowering and rewarding.

> I love who I am. I do not love society's stance on intersex people.
>
> INTERSEX WOMAN, AGE 27

> I wish I didn't have all the social baggage and medical complications that go with my intersex person, but if I didn't have it I wouldn't have the same personality - I wouldn't be me.
>
> INTERSEX, NON-BINARY, AGE 42

END-OF-LIFE CARE

Experiences of prejudice and discrimination in cancer care and broader life gave rise to concerns that their wishes would not be respected in end-of-life care. Almost a third of LGBTIQ+ people with cancer participants were not confident that they would be treated with dignity and respect (28.5%), respected as a LGBTIQ+ person (30.6%), and that their partners would be acknowledged (28.4%) in end of life care. Similarly, 21.8% were not confident that their chosen support people would be able to make decisions for them if necessary, and 17.7% were not confident that their wishes regarding financial matters would be respected.

Some participants with families who were unaccepting of them being LGBTIQ+ expressed concern that relatives may attempt to override their wishes at end-of-life, or after their death.

> My wife and I have very clear health directives, wills etc., that we have put in place for a long time. Our families are very aware of our wishes. However, even though we are married, there is still some uncertainty how individuals, family or professionals may respond at this time...That's why we've always been very clear and spent plenty of money to make everything as legal and binding as we can.
>
> CIS WOMAN, LESBIAN, AGE 57, BREAST CANCER

> My partner and I have Enduring Guardianship and Power of Attorney to ensure our medical wishes and financial matters are secure. We put this in place because we were not confident that as a lesbian couple our wishes would necessarily be respected.
>
> CIS WOMAN, LESBIAN, AGE 57, MEDICAL INTERVENTION FOR CANCER RISK

Trans and intersex people with cancer also expressed additional concerns about the potential for inconsistencies in gender and sex markers across documentation to prevent their financial wishes from being enacted, and about the potential for being misgendered after their death.

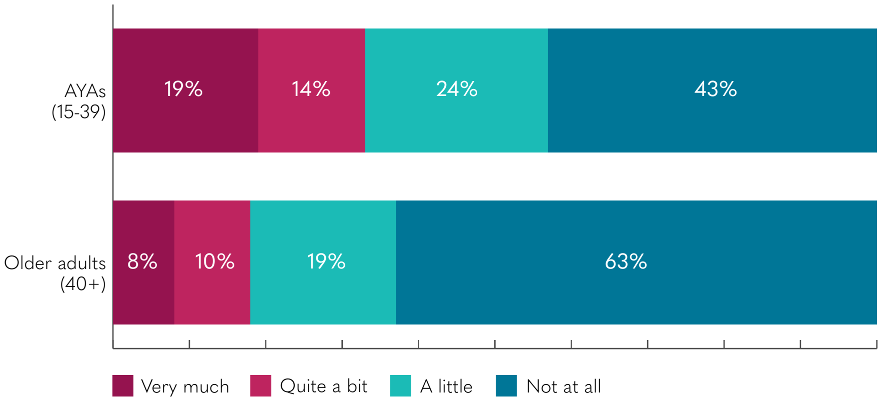
> I worry about my super being released to my disabled son. As my sex on my birth certificate is still female, I have kept my super gender as female so it will match my death certificate. The law has only changed on May 1st 2020 to allow me to change it without surgery. But if I change it, I am worried about the impact on my life insurance in the super fund. As I have very little super the insurance is an important component. You can see it is not straightforward and gets put on the back burner when you are physically exhausted from treatment.
>
> TRANS MAN, ASEXUAL, AGE 55, MEDICAL INTERVENTIONS FOR CANCER RISK

> I worry that I will die before intersex birth certificates and sex markers are available for all intersex people who would choose to have one. I do not want the word 'female' to be entered on my death certificate. I feel that allowing this is being complicit with the lie we tell ourselves about our true human footprint. I fear that I will not be able rest in peace until the certificate shows an intersex person lead the life recorded.
>
> NON-BINARY INTERSEX WOMAN, AGE 43, MEDICAL INTERVENTION FOR CANCER RISK

CANCER IMPACT ON FEELINGS ABOUT BEING LGBTIQ+ AND COMMUNITY CONNECTION

A large proportion of LGBTIQ+ people with cancer (11) and carers (12) reported that cancer and cancer treatment had impacted how they felt about being LGBTIQ+ (patients 41.3%, carers 28.8%), how open they were about being LGBTIQ+ (patients 66.7%, carers 61.5%), and how involved they were with LGBTIQ+ communities (patients 59.4%, carers 59.6%) These impacts were more likely to be reported by younger LGBTIQ+ people who were newly exploring or expressing their identities (23) – (see spotlight: adolescents and young adults).

FIGURE 11. Impact of cancer on LGBTQI+ identities



> I feel that my ability to explore my sexuality has been so severely impacted by my cancer treatment, feeling left behind and excluded from my peers. Even when I have attempted to find my place in the queer community, I have felt excluded by my physical disabilities after cancer treatment. So much of queer sexuality and identity forming happens in spaces that I find difficult or impossible to access.
>
> CIS WOMAN, QUEER, AGE 26, SARCOMA

Identity exploration, acceptance and expression are not limited to younger patients. Many adults realise they are sexuality or gender diverse later in life and start exploring this aspect of themselves.

> It was thrilling and scary coming out because you didn't know what you were doing. I didn't know what the basics were. There was no degree in gay male sex. The only thing you could do was look at the porn and say, "Is that what you do?" It was very difficult at an older age. And then it just all crashed before I'd even got there, it was devastating. The whole thing had gone before it had even started [because of cancer].
>
> CIS MAN, GAY, AGE 72, PROSTATE CANCER

There may be complex emotional reactions for people diagnosed with cancer after coming out later in life. These can include regret about not embracing their sexuality or gender identity earlier, as well as anger and disappointment at having been deceived or misinformed about their bodies.

> My diagnosis came just 7 months after transitioning. I was so upset about how for three decades of my life leading up to my transition I had wanted to be dead, and suddenly I was happy and had found a new lease on life and BAM! - there's cancer, at the worst possible time!
>
> TRANS WOMAN, LESBIAN, AGE 46, MELANOMA

Some of these identity impacts were related to physical and sexual changes; others were related to the existential threat of cancer, interactions with healthcare professionals and support people, caregiving demands, or changed outlooks on life brought about by the cancer experience.

This included:

- LGBQ+ participants who felt that sexual changes challenged or undermined their sexual identity, or disrupted their connections with other LGBTIQ+ people (25)
- Trans participants experiencing dysphoria associated with gendered cancer care, attention to gendered body parts, or physical changes (22)
- Trans participants having gender-affirming procedures interrupted or delayed by cancer treatment or caregiving responsibilities (22)
- Intersex people finding out about innate variations in sex characteristics later in life (20)
- Patients and caregivers who felt pressured to hide the fact that they were LGBTIQ+ to avoid discrimination in healthcare, preserve social support networks, or preserve important relationships (12)
- Participants who felt that LGBTIQ+ social spaces and events were inaccessible or alienating because of the physical, sexual, and emotional impacts of cancer, treatment, or caregiving (12, 17).

> “[It’s a] constant struggle to not feel broken and disconnected from the wonderful sex cultures I used to be such a big part of. It contributes to the sense of cultural / social isolation AND the sense of not - belonging in my own body. A lack of connection to my body and to other people – it’s a unique form of grief and I wish I had a space to talk to other queer people about it more.”
>
> FEMME, QUEER, AGE 39, MEDICAL INTERVENTION RELATED TO CANCER RISK

For some people, cancer affirmed their LGBTIQ+ identities, and their desire to be “out there”.

> “Most of my life, I’ve been pretty out there and I felt like I also needed to be pretty out there with my health as well and with what was happening to me and not try and hide behind some kind of screen or a wig. So each time I have chemo, I had a friend or a couple of friends come over and do my head for me with a henna design of their choosing. And I guess this is about being, out there, a little bit in your face and keeping my identity and not try to cover up.”
>
> CIS WOMAN, LESBIAN, UTERINE CANCER

PARTICIPANT PHOTOGRAPH

SPOTLIGHT

IMPACT OF CANCER ON DEVELOPING IDENTITIES FOR ADOLESCENTS AND YOUNG ADULTS

Adolescence and young adulthood are critical developmental stages for exploring, establishing, and articulating sexuality and gender identities, relationships, and communities. These processes are vulnerable to disruption by cancer and treatment demands, or by caring for someone with cancer (12, 23).

> I remember questioning my sexuality, like, 'Hmm I don't entirely feel straight', but I'm already dealing with so much, I have no emotional energy left to deal with this. So, I just kind of ignored it.
>
> NONBINARY, BISEXUAL, AGE 20, CARING FOR FATHER WITH BRAIN CANCER

Some young people delay exploration of their sexuality or gender identity, including forming intimate relationships and becoming involved with LGBTIQ+ communities, because of the demands of treatment. Others choose to conceal their sexuality and gender identities because they are dependent on family caregivers who are not accepting of LGBTIQ+ people.

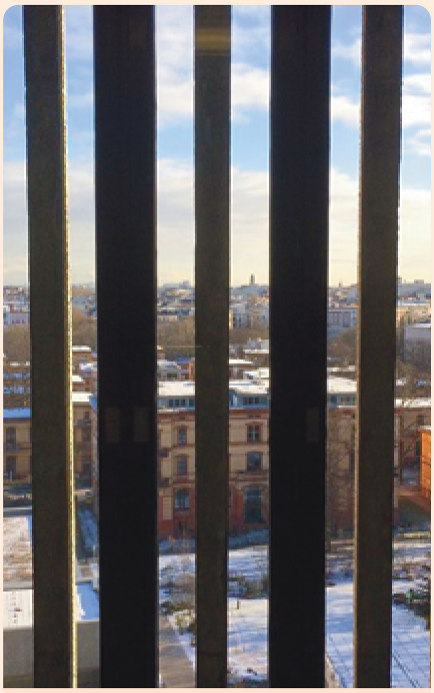
> It's kind of rough. My partner and I were planning on coming out to our families much sooner, but then cancer happened. It would be nice to live life the way we want to, but I don't want to rock the boat right now because I don't think my parents are going to be very accepting. And if anyone that is supporting me right now decides that they want to stop supporting me, I'm going to be in a lot of trouble.
>
> CIS WOMAN, QUEER, ASEXUAL, AGE 26, LYMPHOMA

Some younger participants reported that their social support networks were limited due to anti-LGBTIQ+ prejudice – including those who experienced family rejection or ostracism from peers (17). Additionally, many younger people were yet to find partners or supportive LGBTIQ+ community, meaning they lacked key social supports that helped older LGBTIQ+ people to adjust to their cancer diagnosis (17). Coupled with a lack of support services and peer networks designed for young LGBTIQ+ people with cancer, this left the population particularly vulnerable to experiencing high distress (11).

For these young people, it can be hard to find LGBTIQ+ community after treatment because of lasting impacts that make social spaces inaccessible, such as fatigue and physical and sexual changes. After treatment, young people may struggle to connect with the LGBTIQ+ community due to lasting impacts.

> At this age, queer life is based around nightlife. And when you can't be in those spaces any more, it's really hard to have an active social life, or dating life.
>
> NON-BINARY, GAY, AGE 32, LEUKEMIA

This also meant it could be difficult to come out to cancer care professionals, and to challenge assumptions and perceived discrimination – particularly for those who were not openly LGBTIQ+ or had limited experience navigating the healthcare system (18, 23).



> I grew up really distant from the queer community, and almost scared to be involved in it... so I'd moved [overseas], was trying to have a more kind of open and queer life, and kind of got a taste of it there, that was great.
>
> But the view from the hospital was almost like a visual metaphor for a prison of seeing my life, oh boy, it was about to become being stuck inside healthcare and then also seeing what I wanted from this life I tried to start and seeing it through these bars and realizing that like there was always now going to be this thing in between.
>
> NON-BINARY, GAY, AGE 32, LEUKEMIA

PARTICIPANT PHOTOGRAPH

Conversely, some participants described how cancer helped them to affirm or explore their identity, to become involved in LGBTIQ+ communities, or made them want to be more open about being LGBTIQ+.

PRIDE.

> When I got diagnosed with cancer, it made me focus on who am I, and how do I want to continue, and at what point am I going to ignore these parts of myself.

NONBINARY, GAY, AGE 32, LEUKEMIA

PARTICIPANT PHOTOGRAPH

> “I try and repurpose all of the medicines jars that I have and grow things in them. They represent the **new growth that comes from the difficult times**. I was thinking about with newness and growth in the context of cancer, like maybe the new me or the **new growth or the new version of myself just needs to be grounded in the identity that I already hav**e and I’ve fought for since I was born and **can’t be persuaded or conditioned by this mainstream landscape of heteronormativity.**”

NON-BINARY, QUEER, AGE 37, MEDICAL INTERVENTION AND BREAST CANCER

PARTICIPANT PHOTOGRAPH

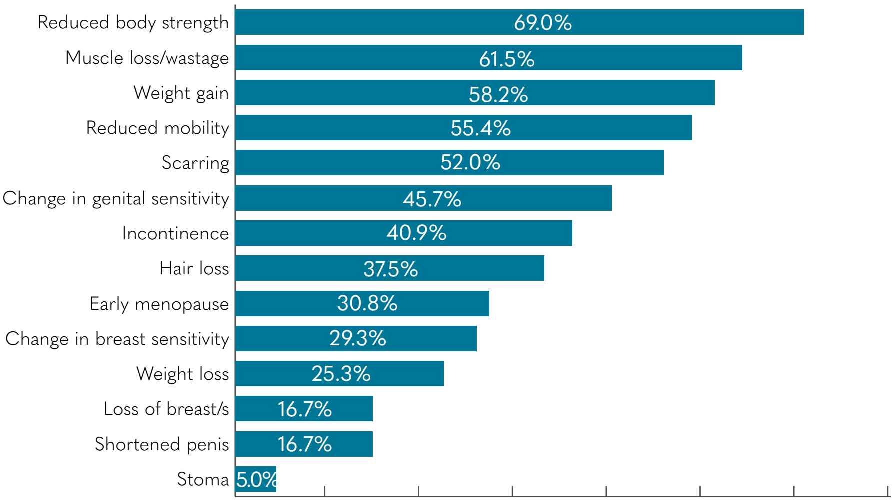
PHYSICAL AND SEXUAL CHANGES AFTER CANCER

PHYSICAL CHANGES

Almost all (94.1%) LGBTIQ+ people in this study experienced physical changes associated with cancer and cancer treatment, reporting 5.3 physical concerns on average. People reporting more physical changes reported higher distress.

These physical changes had unique implications for LGBTIQ+ people because of how LGBTIQ+ identities and relationships were embodied. For example, changes in hair, appearance or shape, breasts, or sexual organs could affect how LGBTIQ+ patients understood, communicated and enacted their identities.

FIGURE 12. Physical changes after cancer



> This is rock bottom. When I look at this, I can see the pain on my face. I don't know how to explain it. But from being inside, being the person who's experiencing it, I couldn't quite match up how much pain I was feeling with how I looked. When I looked down it just looked a black line which is the dried blood from where I'd been stitched back together.

CIS WOMAN, GAY, AGE 41, BREAST CANCER

PARTICIPANT PHOTOGRAPH

> 30 years worth of looking good and people going, "look at you and you're looking good for your age and all that". When it wasn't necessarily losing my hair, what got me was putting on 16 kilos in weight, the drugs were making me so hungry for food. I had to have three of my teeth taken out because of the chemotherapy. And I've had nice teeth before and that really upsets me. So it's not my hair. It was weight and and how I looked.

CIS MAN, GAY, AGE 66, PROSTATE CANCER

PARTICIPANT PHOTOGRAPH

BODY DYSPHORIA AND EUPHORIA

Cancer and cancer treatment can affect embodied gender in different ways, particularly for trans people (22). This can include:

- **Body dysphoria**: When people experience changes that make their bodies less congruent with their gender identities, which they find distressing.
- **Body euphoria**: When people experience changes that make their bodies more congruent with their gender identities.

Gendered cancers such as breast cancer and cancers of the reproductive organs can be dysphoric for trans and non-binary people.

> The type of cancer I have had, which relates to my sex assigned at birth, can be distressing and is hard to cope with and brings about a lot of dysphoria. It's more having a stupid cancer associated with my organs I don't want and were taken out but still I have to deal with, when I just want to forget they even existed and don't want to think about that stuff ever.
>
> TRANS MAN, QUEER, AGE 34, UTERINE CANCER

PARTICIPANT PHOTOGRAPH

Weight gain and lymphoedema can be experienced as feminising and may cause dysphoria for trans men and trans masculine people. Compression garments used to manage lymphoedema may also cause dysphoria by displacing packers (realistic-looking penis made of silicone or other material) used to affirm gender.

> If top surgery is more like masc-presenting, lymphedema is ultra-femme because you get swollen and you get curvy and you get lumps in different areas. And all of the lymphedema stuff is like ultra-femme, it's like pink or tan.
>
> NON-BINARY, QUEER, AGE 37, MULTIPLE CANCERS

> The lymphedema causes me gender dysphoria because it feminises my abdomen/hips. The compression garments push down my packer to the point it causes me gender dysphoria.
>
> TRANS MAN, STRAIGHT, AGE 47, OVARIAN CANCER.

Mastectomy, menstruation stopping, removal or change in size of testicles or penis, was experienced as euphoric for some participants because this affirmed their gender identity (22).

> Having a shorter and non-erect penis is a positive for me, as is reduced muscle mass and strength and breast sensitivity - at least now I have breasts that are sensitive.
>
> TRANS WOMAN. GAY, AGE 63, PROSTATE CANCER

It's important not to make assumptions about how treatments will affect people. Sometimes, trans people may experience relief and grief at the loss of gendered body parts.

> "When people think about transgender men, I don't think they think about ovaries or people do assume that, "oh, well, they're a man, they wouldn't want those parts anyway". But there still is some grief about the loss of those parts. They were still a part of me. That doesn't affect my masculinity, but I still grieve them. And where do you go for counselling services? The symptoms both brought me relief (lack of periods) and torment (years of being misdiagnosed, having constant focus on my 'womanhood'). It was like a million bricks flying off my shoulders when I woke up from surgery. And I didn't have these parts in me anymore. I felt more whole than I had in my entire life. Being diagnosed with cancer was actually a gift to me. The surgery alleviated me of some of the parts that were at the core of my gender dysphoria symptoms at the time."
>
> TRANS MAN, AGE 47, OVARIAN CANCER

SPOTLIGHT

LOSS AND RECONSTRUCTION OF BREASTS FOR LESBIAN, TRANS AND NONBINARY PEOPLE

LGBTIQ+ people's responses to breast cancer treatment-related bodily changes vary widely. Each patient will assign a different meaning to their breasts/chest.

Some patients find breast removal very distressing. For them, reconstruction is important for body shape, identity or maintaining sex and intimacy after cancer (25).

> I am a cis woman and had a single mastectomy. Subsequent surgeries left me with many scars and only one working breast and nipple. This greatly affected my image as a woman and gave me extreme body issues.
>
> CIS WOMAN, QUEER, AGE 33,
> BREAST CANCER

Other individuals found the removal of breasts an empowering experience, and for some people it can create gender euphoria. They choose not to reconstruct. This choice can be called 'staying flat', 'being flat', or 'aesthetic flat disclosure' (22).

> I never wanted the shape of a female body, especially not breasts. I would hide and flatten my breasts and researched top surgery from time to time. Then, I was diagnosed with breast cancer, and it allowed me to state what surgery I would prefer – a bilateral mastectomy. I didn't want to get cancer. But I'm happier without breasts. It's freeing.
>
> CIS WOMAN, LESBIAN, AGE 53,
> BREAST CANCER

Some participants were disappointed that a mastectomy is not the same as top surgery conducted as part of gender affirmation (22).

> Double mastectomy itself is a very different procedure. They remove every bit of breast tissue. You don't get pecs, you don't get nipples. You don't get to have a body that resembles any mainstream body. You just have to take whatever comes out at the other end of that surgery, and for some people, that means they have lumpy bits here and there or dog ears or concaved chests, and for other people, that means that they get really flat smooth chests.
>
> NON-BINARY, QUEER, AGE 27,
> BREAST CANCER

Some participants reported that healthcare professionals did not always understand or appreciate how mastectomy could help to affirm gender or queer identity. Several had their surgical choices disregarded. This was distressing and disempowering.

> I was really excited about having small breasts and not having to wear a bra at the time. Before the surgeon stepped in and said "we just didn't quite reduce them". He said that they would not suit my body type. That he knew women and their bodies. And so he knew what would suit my body type. And at one point, he actually said that he thought it was chemo brain talking... And after surgery, he'd given me like C cups, which was a reduction from what I'd had ... [but] not what I asked for.

CIS WOMAN, QUEER, AGE 50,
BREAST CANCER

PARTICIPANT PHOTOGRAPH

SPOTLIGHT

HAIR AS IDENTITY, AND THE SIGNIFICANCE OF HAIR LOSS FOR LGBTIQ+ PEOPLE

Hair loss was often a distressing side effect of cancer treatment, that disrupted how participants experienced their gendered bodies, interacted with others, and made sense of their sexual identity after treatment.

> That was done on the night after I had my last chemo because I'd lost my beard and I do miss it – like people who lose their top hair and they'll miss that, it's the same thing if you've wanted a beard, if you like it. I felt it suited me better than my goatee features. At that time of that photo I had no hair. So I thought I'll do this as an art therapy thing but through makeup. It's not a drag queen thing, I see me more like a drag king, and they're around but they're usually lesbians dressing up as men not the other way around... So I thought I'd give that a go.

CIS MALE, GAY, AGE 54,
PROSTATE CANCER

PARTICIPANT PHOTOGRAPH

The loss of facial hair can threaten the masculinity of trans men and gay men who identified as "bears", and in some cases lead to them being misgendered. However, these men have little support to manage the impact of this loss, in contrast to the services available to women experiencing hair loss (22).

This was also true of some queer women and non-binary people, for whom cutting and styling hair was an important part of making identities visible.

> He's a trans man. To have facial hair matters so much. There's no grief counselling, there's no support group, there's no community. There's nothing. You just sit there and wear it. And that's what the photo means. It's a reminder, that he can't get back to there, but it shows who he is inside and the pain that is carried, emotional pain that doesn't have a place in the medical profession anywhere.

TRANS MAN, GAY AND ASEXUAL, AGE 55, MULTIPLE CANCERS; CARER OF TRANS PARTNER WITH LUNG CANCER

PARTICIPANT PHOTOGRAPH

> I've always had really good hair, like when I was a younger lesbian I used to get it cut really short and spikey. It was always really neat and it always looked really good. So it just meant a lot to me to have hair and when it wasn't there it was very confronting... It was like losing my identity on some level.

CIS WOMAN, LESBIAN, AGE 61, OVARIAN CANCER

PARTICIPANT PHOTOGRAPH

SEXUAL WELLBEING

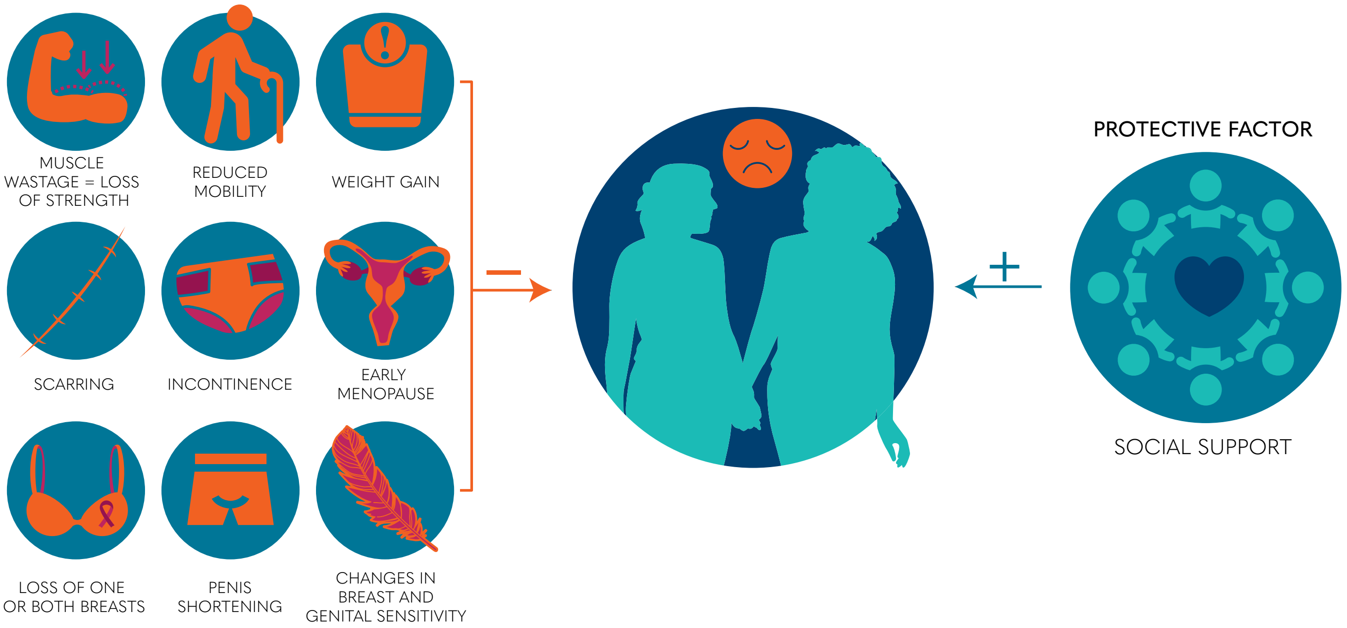
Sexual wellbeing can be affected by the physical and psychological impacts of cancer diagnosis and treatment, and these effects can persist long after treatment ends. These may include reductions in sexual desire and satisfaction; sexual pain; erectile and ejaculation changes; changes in penis size; vaginal dryness, tightness and narrowing; and incontinence during sex.

For some people, sexual changes are the most distressing long-term effect of cancer. This can occur not only with reproductive cancers but also with any type of cancer and its treatment that impacts the body's structures and sexual functioning, as well as body image, fatigue, relationships and fertility. These factors can all contribute to changes in how a person views themselves as a sexual being.

Sexual and other embodied changes can have a negative impact on gender identity and sexual identity, affecting LGBTIQ+ identity and causing psychological distress.

Almost three-quarters (71.3%) of LGBTIQ+ people with cancer in this study reported sexual concerns since cancer, with many reporting multiple concerns (3.6 concerns on average)(25). This included decline in physical intimacy, sexual desire, enjoyment of sexual activity, ability to reach orgasm, communication about sexual issues, and satisfaction with sex life from pre- to post-cancer. Poorer sexual well-being after cancer was associated with distress, and with more physical concerns, but buffered by social support, as summarised below:

RISK FACTORS FOR POORER SEXUAL WELLBEING



The specific sexual concerns reported were like those seen in general cancer populations (26). These included (25):

- **Decreased satisfaction with level of sexual desire (48.5%):** The loss of desire and libido associated with cancer and treatment commonly resulted in a reduction or cessation of sexual activity, which left many participants frustrated and in "psychological mourning".
- **Decreased satisfaction with sex life (43.8%):** Body changes, particularly those affecting body image and sexual activity (e.g. scarring; oral, breast, penile and vaginal changes; incontinence), left some participants feeling "broken", frustrated and disappointed with their inability to engage in their previous sexual activities.
- **Fatigue/lack of energy affecting sex life (53.1%)** was also commonly reported.

However, these concerns may have unique implications for LGBTIQ+ patients, given the difference in sexual practices amongst queer communities.

Incontinence: Amongst the physical and sexual concerns reported by LGBTIQ+ participants, 40.9% reported incontinence. This was a distressing experience for the majority.

> These things are real sort of horror things, like the first week after I had the catheter removed, just that whole, it's termed 'leakage'. But it's actually like gushing. I didn't realise how much urine a person could make in a matter of a couple of hours. I mean, it was just horrendous. It was a bit like being a helpless person. You're an independent grown up and then suddenly your pants are wet or the pad in your pants is wet all the time.
>
> CIS MALE, GAY, AGE 67, PROSTATE CANCER

PARTICIPANT PHOTOGRAPH

Penetrative sex: Some LGBTIQ+ people do enjoy penetrative sex, with fingers, penis, tongue, or dildos. This can be difficult or painful after cancer, resulting in feelings of loss and grief, particularly where sex is no longer spontaneous.

> I really enjoyed penetration and now I get really nervous about penetration. I can take a finger or two, but I certainly couldn't take a dildo anymore, which is disappointing because I used to really enjoy that. I used to really enjoy a very uninhibited creative varied sex life. And so, it's made it all just a little bit more precarious. We need to think things through and have the lube available so it's a little bit less spontaneous.
>
> CIS WOMAN, LESBIAN, AGE 61
> CERVICAL CANCER

Gay and bisexual men: Many sexual changes have particular significance in the context of gay male sex and gay identities (25).

> My physio talks about my throat and swallowing and all sorts of things, but doesn't actually say, "Hey, how you going with oral sex?" That might make a difference. I don't think it's a factor that the throat cancer would impact my ability to have oral sex ever came up.
>
> CIS MAN, GAY, AGE 56, HEAD/ NECK CANCER

- A firmer erection is needed for anal sex. Some gay men with cancer lose the ability to have a firm erection, and this can cause distress and loss of identity as a "top" (insertive partner).
- Receptive anal sex may be hindered by radiation and other treatments, resulting in a loss of pleasure and identity as a "bottom" (receptive partner).
- Ejaculate is a visible signal of desire and pleasure in gay male sex, and its loss following prostate cancer treatment can be devastating (27)
- Many gay men have casual sexual partners. Explaining loss of erections and ejaculate in a casual sexual encounter can be difficult and can lead to the avoidance of sex.
- Visibility and comparison of penis size between gay men is common. Penis size reduction following cancer treatment can be a significant cause of distress.
- Urinary incontinence, post-surgical scarring, changes in anal sensitivity and penis shrinkage, can all affect gay male sexual identity.

> I thought I would have been okay after the surgery, but I never got an erection, and I didn't realise the importance of ejaculate during sex. I felt that our relationship had changed from being sexual partners to just being friends. This and the persistent urinary incontinence made me feel suicidal.
>
> CIS MAN, GAY, AGE 59, PROSTATE CANCER

Many participants felt inadequately forewarned and prepared for these sexual changes and were left to manage the impacts on their own or with their partners (25).

> I'm having my Zoladex implant and when somebody says, how are you? There's no conversation going on. So if a health professional says, how are you? And nothing comes back, well, that's the end of the interview. Most men, I think, don't know what's going on. Don't know how to talk about it. And a health professional isn't going to waste the time in probing somebody who does know how to talk about it. So that picture to me represents the scary bit.

CIS MAN, GAY, AGE 66, PROSTATE CANCER

PARTICIPANT PHOTOGRAPH

ADDRESSING SEXUAL CONCERNS IN CANCER CARE AND RENEGOTIATING SEX

Many participants were dissatisfied with the information and care they had received about sexual impacts of cancer. Just 50% of participants had talked to their healthcare team about sexual concerns, with only 37.2% reporting that this was helpful (25).

The routine use of vaginal dilators after radiation therapy to the pelvis can be confronting and distressing for LGBTIQ+ people with a vagina, who do not engage in penetrative sex.

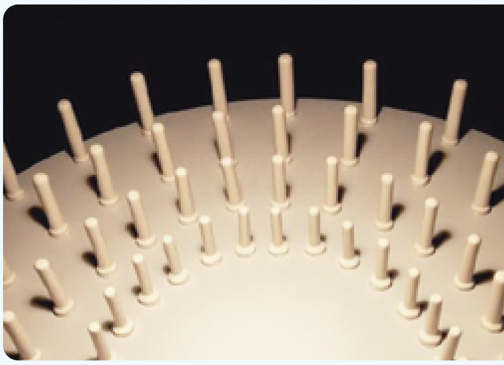
> Every six months I'm told to maintain this vaginal vault. Every six months, I have to present back at the hospital so that someone can inspect this vault. Did anyone ask me if I was going to use this vault? Maybe I don't use my body in that way. That would be my choice. But no one asked me.

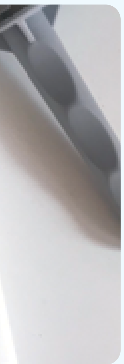
CIS WOMAN, LESBIAN, AGE 46, UTERINE CANCER

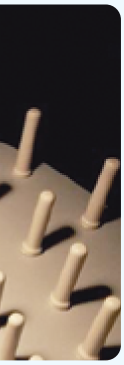
Access to relevant advice during cancer care can be challenging for intersex patients due to a lack of understanding about intersex bodies and the long-term impacts of previous medical interventions.

> It was difficult for me to get appropriate advice relevant to my genital differences. I didn't suffer any further damage as a result of examinations, but it added to the stress of the procedure. I also found that advice given assumed I would be heterosexual and having PIV [penis in vagina] sex.

NON-BINARY, QUEER, INTERSEX, AGE 48







They give you these dilators and say you have to maintain this vault in your body- This hole in your body with these plastic things. And they're so cheap. They're so cheaply made, I know I get it. It doesn't matter for its function. But they're so cheap. And so I made some out of porcelain just as an investigation into the whole thing.

CIS WOMAN, LESBIAN, AGE 46, ENDOCRINE CANCER

PARTICIPANT PHOTOGRAPHS

Many LGBTIQ+ people have positive sex lives after cancer through renegotiating sex and intimacy (25).

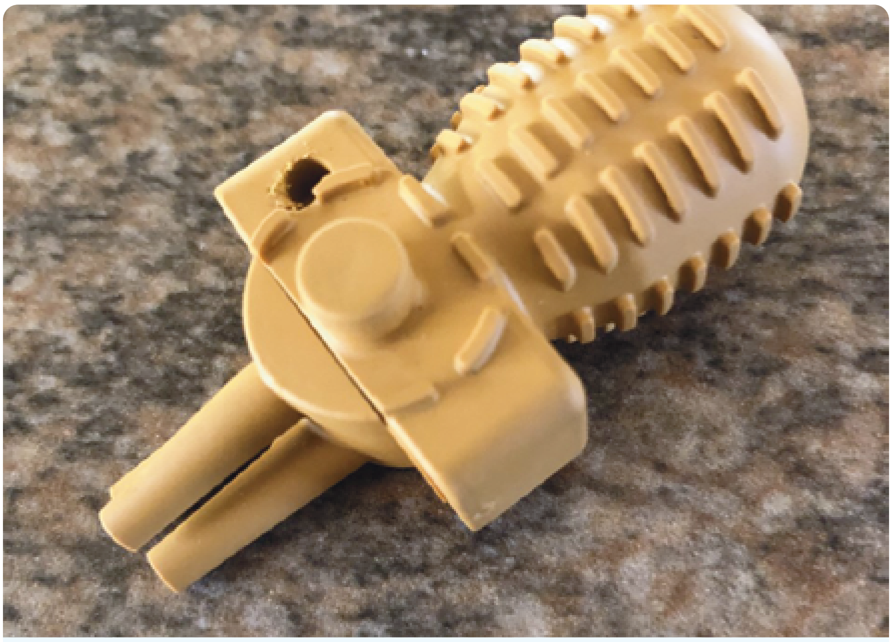
Renegotiated sexual intimacy after cancer can include:

- non-genital intimacy such as kissing, cuddling, and touching
- non-penetrative sexual practices such as oral sex, and mutual masturbation
- penetrative sex aided by lubricant, which can occur digitally or with a dildo
- changing sexual roles and practices.

Participants reported using various coping strategies to manage sexual concerns related to cancer, although there was variability in how helpful they found these strategies (Table 1)..

TABLE 1. Strategies to cope with sexual changes after cancer

	USED BY	HELPFUL FOR
Looking for information online	61.9%	56.2%
Talking to healthcare professional	49.8%	37.2%
Using sex aids	48.3%	61.4%
Changing sexual practices	42.6%	49.6%
Counselling	38.9%	54.7%
Medical interventions	33.4%	44.9%
Accessing support groups	32.5%	40.6%



> That is a penile pump. It is totally outstanding. It's very fulfilling. Probably more so than before. Because not only do you still have orgasms, which are three times as strong, they might take a little longer, but that means you can still have penetration with this penile pump. Life's good.

CIS MAN, GAY, AGE 77, PROSTATE CANCER

PARTICIPANT PHOTOGRAPH

In anal sex, a person may be the top (insertive partner), bottom (receptive partner), or versatile. Some may change from top to bottom or become versatile after cancer.

> My role has changed from versatile to having to be bottom and the receptive partner. I guess, that can overcome the issue of being able to get an erection.
>
> CIS MAN, GAY, AGE 68, PROSTATE CANCER

However, this change is not an acceptable option for all people.

> Changing to bottom it doesn't appeal to me at all.
>
> CIS MAN, GAY, AGE 51, PROSTATE CANCER

> In my recovery stage I had to be very careful about being a receptive partner because I found that could be quite painful.
>
> CIS MAN, GAY, AGE 61, BOWEL CANCER

Many people explore new sexual practices and are more open about sex after cancer, including new forms of intimacy, oral sex, or sex toys.

> Not having a clitoris is a huge thing but we've worked around that. So, things are different. We still have an awesome sex life, but it's not what it was. But that is changing and evolving too.
>
> CIS WOMAN, BISEXUAL, AGE 61, VULVAL CANCER

> I love her skin; we both love each other's skin. It's that good old definition of 'what's sex?' We haven't lost that throughout this whole process.
>
> CIS WOMAN, LESBIAN, AGE 53, OVARIAN CANCER

Gay men are more likely to seek information about sexual changes after cancer and to use medical sexual rehabilitation aids, (28) such as injections, penis pumps, or Viagra.

> I have to inject myself so I can get an erection – that will give me a really good strong erection for hours. So while I've got that erection I can have really amazing sex that just blows all the buttons all over the shop.
>
> CIS MAN, BISEXUAL, AGE 66, PROSTATE CANCER

> There is no shame in using interventions, aids, prosthetics and anything else that is legal and consenting.
>
> TRANS MAN, QUEER, AGE 52, THYROID CANCER

However, medical aids do not work for everyone, due to discomfort, lack of spontaneity in sex, and physical side effects.

> Nothing could be spontaneous; you had to plan if you were going to have sex, because you needed to do that about 15 minutes to 30 minutes before. And sitting in the bathroom, trying to put an injection in your penis was very, very difficult, and, also the fact that I would bruise myself quite often and the tip was all black and blue then.
>
> CIS MAN, GAY, AGE 27, PROSTATE CANCER

> I often have to take a pill to be visibly sexually aroused. So it takes away that kind of spontaneity. And I think that makes both of us feel slightly uneasy and slightly sad at times.
>
> CIS MAN, GAY, AGE 57, PROSTATE CANCER

Talking about sexual health and intimacy is the key to positive outcomes and keeping people engaged in optimal cancer care. Healthcare professionals can also facilitate patients talking to their partners about sexual concerns.

> Cancer made us talk about so much stuff that we did sex and orgasms and bodily intimacy brilliantly, even though it was different.
>
> TRANSMAN, QUEER, AGE 52
> THYROID CANCER

> It is something we've had to negotiate and be really open with each other about and talk about. If it's not something that you can talk about, then it's harder to have physical intimacy with your partner.
>
> CIS WOMAN, LESBIAN, AGE 48, ENDOMETRIAL CANCER

FERTILITY CONCERNS

For LGBTIQ+ people who want to become parents, difficulties with fertility due to cancer and its treatment can be very distressing. This distress can be compounded by additional challenges, such as healthcare professionals being hostile or making inappropriate assumptions, lack of information about fertility options, and challenges accessing fertility treatments.

> Sometimes I fear for same-sex couples that there's sort of an assumption that if one person is having difficulty, then at least the other person can carry [the pregnancy]. That's the way that the cancer and having the hysterectomy was dealt with, that it maybe it wasn't as significant because you've got another female in the relationship.
>
> CIS WOMAN, LSBIAN, AGE 45, UTERINE CANCER

Fertility treatments can also interfere with gender affirmation for trans people.

> I was suffering terrible gender dysphoria and so all the "we need to collect your eggs and freeze his sperm and if you both survive your cancers we will help you do IVF to achieve pregnancies" triggered catastrophic depression and eventually when I was given steroids to provoke hyper-ovulation, I attempted suicide because of how fucked up ...my transbrain responded to even more estrogen.
>
> TRANS MAN, QUEER, AGE 34, THYROID CANCER WHOSE PARTNER ALSO HAD CANCER

It is important for health care professionals to use the language patients use to describe their bodies, and to be aware that discussion of pregnancy and fertility preservation may result in gender dysphoria for trans and non-binary patients.

Intersex people may face fertility challenges due to underdeveloped gonads, reproductive organs, or due to the removal of reproductive tissue due to potential cancer risk. These issues can cause infertility, limit fertility treatment options, and be a significant cause of distress alongside the potential risk of cancer.

> When the diagnosis was first made and I discovered I could not continue my bloodline through procreation I became severely depressed. It was revealed that I have impubescent sex characteristics and that for me to have a child would involve a donated egg and for my womb to be readied for action with 6 months of induced womb shedding. I would also need a donated egg and this was the deal-breaker. I did not want to be an incubator for somebody else's genes.

NON-BINARY, INTERSEX WOMAN, AGE 42, MEDICAL INTERVENTION DUE TO CANCER RISK

LGBTIQ+ people who do not wish to become parents may face pressure from healthcare professionals to undergo fertility preservation to avoid potential future 'regret', which can be distressing. This is particularly significant in LGBTIQ+ communities that may have unique family structures that provide alternative parenting and caregiving opportunities, such as blended families and stepchildren.

Equally, many people, regardless of sexuality and gender identity, do not want children.

> Before I had my bone marrow transplant, they said it would have a significant chance of making me infertile. I said "I don't really want fertility preservation". And the oncologist was understandably pressing the issue, in terms of it being something that you might regret. And I said, "This is not something that I want in my life". And then he said "Does your sexuality have to do with that?". They shouldn't really ask that. And then he sort of rested that issue for a while, but it was brought up a few times after that. it made me feel like I wasn't being listened to, and that I wasn't mature enough to make my own decisions, surrounding my fertility. Not only that, but my reasoning didn't satisfy them, and they were looking for a reason other than the fact that I didn't want children. "Maybe, maybe it's because he's gay".

CIS GAY MAN, AGE 21, LEUKAEMIA.

> We talked about that for a while, that we might have kids and ... it might have been [partner's] eggs and I have the kids so that legally in any state they couldn't say who was the mum... That was before marriage was legalised. We had a whole plan and things. And so time goes on, we don't have money yet, so it's like not time yet and then that, you know cancer hit and I got everything taken out. And we realized that really having kids wasn't for us, that kind of was when I was sitting in the car. The decision kind of came all at once... I look in the rearview mirror as though I was looking in the back seat and there's a car seat there or a kid there but they're not there.

CIS WOMAN, LESBIAN, 34, DIAGNOSED WITH UTERINE CANCER

PARTICIPANT PHOTOGRAPH

SOCIAL SUPPORT

Low social support can be a significant challenge for LGBTIQ+ individuals with cancer. This is because LGBTIQ+ patients are less likely to have a long-term partner and more likely to experience family rejection than the general cancer population. At a time when social support is even more critical, this lack of social support adds to the stress of the cancer diagnosis and treatment itself. People with low social support reported higher levels of distress (11).

> “That is where my partner’s grave is, so I’ll lie right next to him. When I wake up in the morning and my first thoughts are, well this is my future, a graveyard, what kind of future have I got? It’s a feeling of anxiety and tension and worry because I’m all on my own. I have family but I’m not close to them and it’s sort of, worry and tension and apprehension. I feel like I’m going to die on my own, it’s all morbid anxiety, depressive thoughts.”

CIS MAN, GAY, AGE 68, PROSTATE CANCER

PARTICIPANT PHOTOGRAPH

> Who do you call for help if you need it? Who do you call? Who do we call night or day just to check in with things?

CIS MAN, GAY, AGE 59, PROSTATE CANCER

PARTICIPANT PHOTOGRAPH

> This is my husband. He, of course, was my main support. As the most important person in my life by way of- well, lots things, but way of support through this. He looked after me in that period no questions asked, no ifs or buts. He took on that role of caring for me.

CIS MAN, GAY, AGE 57, SKIN CANCER

PARTICIPANT PHOTOGRAPH

The majority of LGBTIQ+ people with cancer and carers in the Out with Cancer Study had good social support from friends and family (78% people with cancer, 71% carers) and multiple people who understand and support them (80% people with cancer, 81% carers) (17).

For many, intimate partners were the primary source of emotional and practical support.

Partners also supported LGBTIQ+ people with cancer to advocate for their needs, facilitated LGBTIQ+ disclosures to healthcare professionals, and helped to navigate discrimination in healthcare systems.

> I think quite a common experience with dealing with the health system is that you kind of get lost within your own illness and the medical process sort of swirls around you. And you kind of sometimes just bob under the surface and kind of get a bit lost. And so she kept pulling me back out. And that was really. Yeah, I think probably the main thread that sort of pulled me through the whole process.

CIS WOMAN, LESBIAN, AGE 47, ENDOMETRIAL CANCER

PARTICIPANT PHOTOGRAPH

In many situations, chosen family and others in the LGBTIQ+community provide support.

Chosen family were important for those who felt disconnected, or estranged from family of origin. Chosen family in some case "replaced my biological family" as the primary caregivers.

> When you think about the queer community compared to the straight community, it just seems to be there's a sense of all-hands on deck and everybody bringing what they can to a situation, and I think that really comes from needing chosen family to navigate your way, through being othered so much. The sense of community and chosen family is very, very strong.

CIS WOMAN, LESBIAN, AGE 48, CARING FOR EX-PARTNER WITH BREAST CANCER

> When you're going through treatment, and - you've had your diagnosis and everything, that it's really important to choose who to let in...
>
> Most of the people I spent quality time with... were also people, I guess, who I'd chosen to let into my life, cause they were my lesbian friends. So they weren't only family - I mean, they weren't blood relations. And it got me thinking about, you know, how you can... choose a lot of things about friendships and relationships, and... But it's really important to make sure that when you're unwell and you're sick, that it's the right ones that you let in. And get the right sort of support that you need.

CIS WOMAN, LESBIAN, AGE 54, BREAST CANCER

PARTICIPANT PHOTOGRAPH

Chosen family helped to foster a sense of belonging, protect against isolation, and affirm LGBTIQ+ identities and community for LGBTIQ+ people with cancer and caregivers. However, some participants noted that it could be difficult to explain chosen family relationships to healthcare professionals, and to have them recognised as part of care.

> When we go to the hospital, who am I? I can't say the partner because he's walking in next. He's the partner. I don't want to diminish it, but I don't have words to describe it without this enormous long dialogue of well, who is he and who am I? And the grief that comes with that is enormous. You carry all the responsibility and don't get recognized, and you're trying not to hurt the other people who were important and doing good things too. So it becomes even harder to answer medical people's questions about who you are because you can't say the wrong thing or you hurt someone else.
>
> TRANS MAN, GAY AND ASEXUAL, 55, DIAGNOSED WITH MULTIPLE CANCERS AND CARER TO PARTNER (THEN FRIEND) WITH MULTIPLE CANCERS

Some participants described finding support from coworkers, neighbours, rural communities and pets.

> She has been the most incredible companion for me. She never fails, never ever fails. She always waits patiently for me and she was a really good focal point for me to take my eyes off myself and all the side effects I had to deal with after the operation. Just having something to look after, like her, It's a responsibility. That helps you to get through a lot of things as well. She's always happy, never sad, always, always happy. That's why I included that photo. She's been there right the way through for me too.
>
> CIS MAN, GAY, AGE 60, HEAD/NECK CANCER

PARTICIPANT PHOTOGRAPH

CHOSEN FAMILY PHOTOGRAPHS

I was incredibly well supported through my workplace and my colleagues and I often thought if you were going through the experience by yourself or without a strong network of people or support, it would be really, really challenging.

CIS MAN, GAY, AGE 57, HEAD AND NECK CANCER

PARTICIPANT PHOTOGRAPH

My best buds. All queers. So my queer family. They helped me out a lot.

CIS WOMAN, QUEER, AGE 50, BREAST CANCER

PARTICIPANT PHOTOGRAPH

SPOTLIGHT

LGBTIQ+ CARERS

LGBTIQ+ carers participating in the Out with Cancer Study were largely positive about their experiences of caregiving; the majority considered caregiving important to them (98.3%) and really wanted to care for the patient (90.4%)(12). In surveys and interviews, carers described how the caregiving experience strengthened relationships between carer and patient, and amongst carers – particularly in LGBTIQ+ communities where there was a culture of mutual caregiving.

> “I likened it to a pyramid. There was the sick person at the top and then me and then these people holding me and then people holding them and then it just fanned out like that. They were my absolute two stalwart amazing support people and they were just there.”

CIS WOMAN, QUEER, AGE 59,
PARTNER OF WOMAN WITH
OVARIAN CANCER, DECEASED

PARTICIPANT PHOTOGRAPH

> “Cancer is life-changing and in our case, an affirming experience. We have proven our strength of commitment to each other by the way we have responded to this dreadful challenge. It has made us love each other and rely on each other even more than before.”

CIS MAN, GAY, 56, CARING FOR
PARTNER DIAGNOSED WITH LUNG
CANCER

PARTICIPANT PHOTOGRAPH

> “Being part of a quite large lesbian community who rallied and supported us whenever we needed it was extremely beneficial in terms of our emotional wellbeing and added to my feeling of not doing this alone in a mutually supportive way.”

CIS WOMAN, LESBIAN, 76, CARING
FOR PARTNER WITH OVARIAN
CANCER

Many LGBTIQ+ caregivers had inadequate support while caregiving, because of:

- Misrecognition, exclusion and rejection by families of origin and cancer care teams
- Few support services being available to LGBTIQ+ carers, and reluctance to access mainstream support services due to feeling different from other carers, or fears of hostility
- LGBTIQ+ friends being “stretched so very thin” by cumulative stressors and caregiving demands
- Isolation from LGBTIQ+ communities due to caregiving burden and accessibility issues

This reportedly exacerbated the physical and psychosocial impacts of caregiving.

DOMAINS IMPACTED BY CANCER CAREGIVING:

INTIMATE/SEXUAL RELATIONSHIPS (64.0%)

HEALTH (62.6%)

WORK/CAREER (58.0%)

FINANCES (56.0%)

EDUCATION (16.0%)

Many LGBTIQ+ carers reported that caregiving had impacted different aspects of their life, including their relationship with the person they cared for (79.5%), their health (62.6%), their work or career (58.0%), and their finances (56.0%). Carers who reported that their health or finances were affected tended to report greater distress - for example, if they had prioritised caregiving over their own healthcare needs, or experienced financial stress while caregiving.

Some LGBTIQ+ carers reported that their ability to care for the patient was threatened by the prospect of rejection and exclusion by the patient's family of origin, or by healthcare professionals because of anti-LGBTIQ+ hostility or lack of legal protections. Some carers described having to conceal their relationships to provide care, having healthcare professionals assume they were their partner's sibling or friend, to avoid being treated disrespectfully by the cancer care team. Others reported being completely shut out of providing care by the healthcare team or family.

> "For most of our relationship my partner was in the closet with her family because they were very anti-gay. When she was diagnosed with cancer they swooped in and basically said to me, 'Off you go. We've got this now, piss off', which was pretty tough. I was just like the best friend and the flat mate. And then she did die and – it all came out about our relationship, of course, you can't really hide that stuff. They organized a full Catholic funeral for her where I wasn't acknowledged or mentioned. I had to fight to be put on the gravestone. It was very traumatic. I'd been part of her family for 11 years and then basically I got wiped."

CIS WOMAN, QUEER, AGE 59,
CARED FOR PARTNER DIAGNOSED
WITH OVARIAN CANCER

> "This is my photo of how we felt together and there was always intimacy and touching. And there's a lot of – there's trust in this picture. I feel like I'm holding us, both of us in this picture. It's like I'm strong and I'm a bit like, "don't mess with us". And I really like that about it, I'm like, "I am the guardian of our relationship and our closeness" and, you know, I still feel the same. I feel the same now even though she's died that I felt in that photograph."

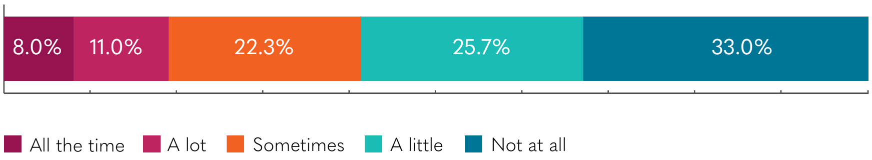
CIS WOMAN, QUEER, AGE 59,
PARTNER OF WOMAN WITH
OVARIAN CANCER, DECEASED

PARTICIPANT PHOTOGRAPH

FEAR OF CANCER RECURRENCE

Fear of cancer recurrence is defined as worry or concerns about the possibility of a cancer coming back or progressing (29), and is characterised by preoccupation, high levels of worry, persistent concerns, and hypervigilence to potential symptoms of cancer. Two thirds of participants with cancer (67%) in this study reported being afraid that their cancer would come back, and people with greater fear of cancer recurrence reported higher levels of distress. Other studies have similarly shown fear of cancer recurrence to be associated with greater anxiety and depression, and poorer quality of life and wellbeing (30).

FIGURE 13. Fear of cancer recurrence

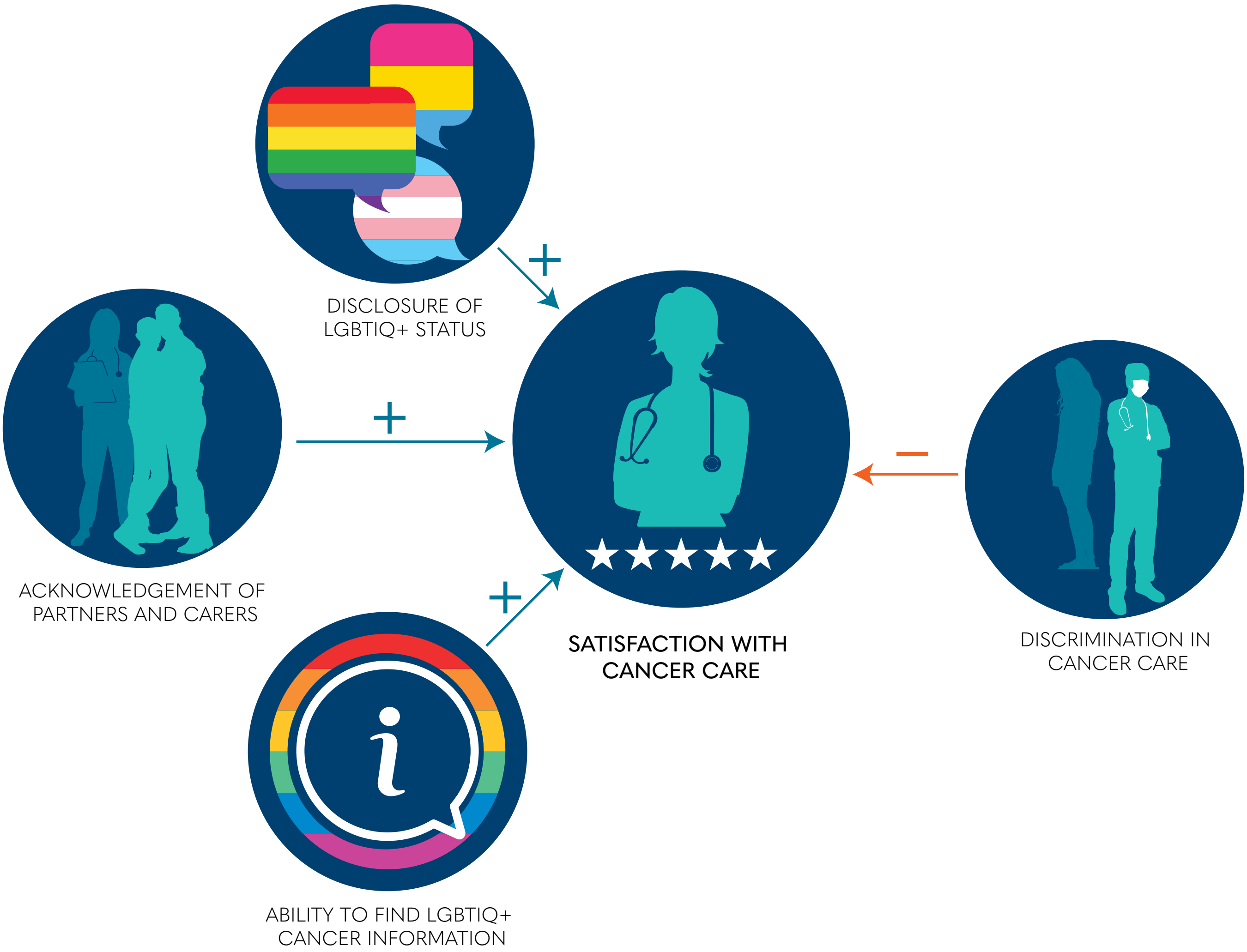


SATISFACTION WITH CANCER CARE

People who reported higher distress were also less satisfied with their cancer care (19).

While the majority (76.3%) of LGBTIQ+ patients surveyed expressed satisfaction with their cancer care, a notable proportion (23.7%) were not satisfied. Bisexual and queer participants, adolescents and young adults (under 40 years), and intersex participants all reported lower satisfaction with care.

Participants who disclosed that they were LGBTIQ+, whose healthcare professionals acknowledged their partners and carers, who could find helpful LGBTIQ+ cancer information, and who experienced *less* discrimination tended to report greater satisfaction with their cancer care:

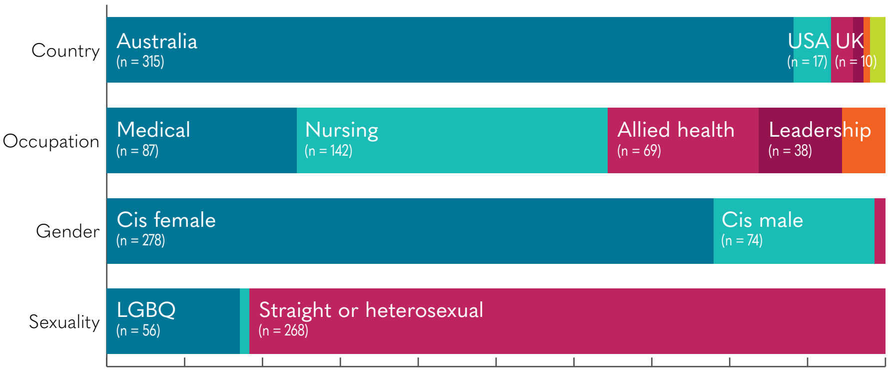


HEALTHCARE PROFESSIONALS' APPROACHES TO LGBTIQ+ CANCER CARE

HEALTHCARE PROFESSIONAL DEMOGRAPHICS

357 healthcare professionals completed the online survey, including medical (24.4%), nursing (39.9%) and allied health professionals (19.4%); 48 also completed interviews. Participants were between 22 and 82 years old (M=47.3yrs) and had worked in cancer care for 14.3yrs on average (range 4 months - 45yrs). Most participants were women (77.9%), lived in Australia (85.4%) and were white (85.4%); 18.3% described themselves as LGBTQI+. Interviews were conducted with 48 healthcare professionals.

FIGURE 14. Demographics of healthcare professional survey participants



HEALTHCARE PROFESSIONAL ATTITUDES AND KNOWLEDGE ABOUT LGBTIQ+ PEOPLE AND CANCER

Most healthcare professionals were comfortable treating LGBTIQ+ patients, with the majority reporting openness and willingness to provide culturally safe LGBTIQ+ cancer care, as well as a desire for education. However, they were less confident in their knowledge of LGBTIQ+ health needs, particularly those of trans, non-binary, and intersex patients (13).

When asked to complete an LGBTIQ+ cancer knowledge test, only 2.9% of HCPs answered all questions correctly and 45.5% answered less than half correctly (13).

FIGURE 15. Healthcare professional comfort and confidence in working with LGBTIQ+ patients

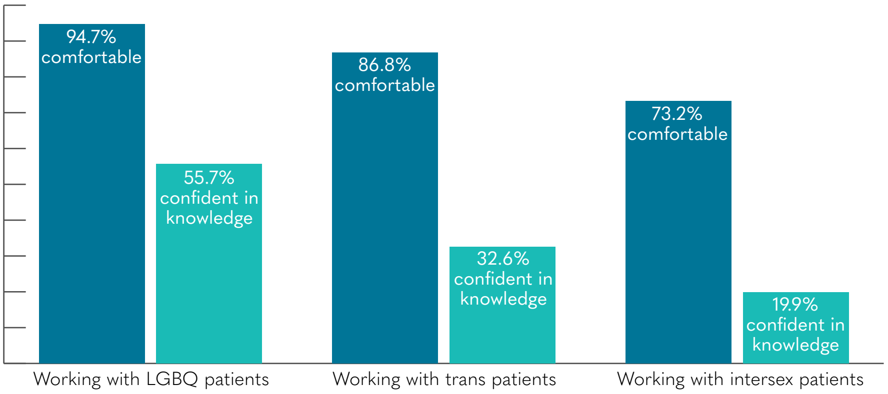


FIGURE 16. Health care professional knowledge about LGBTIQ+ cancer

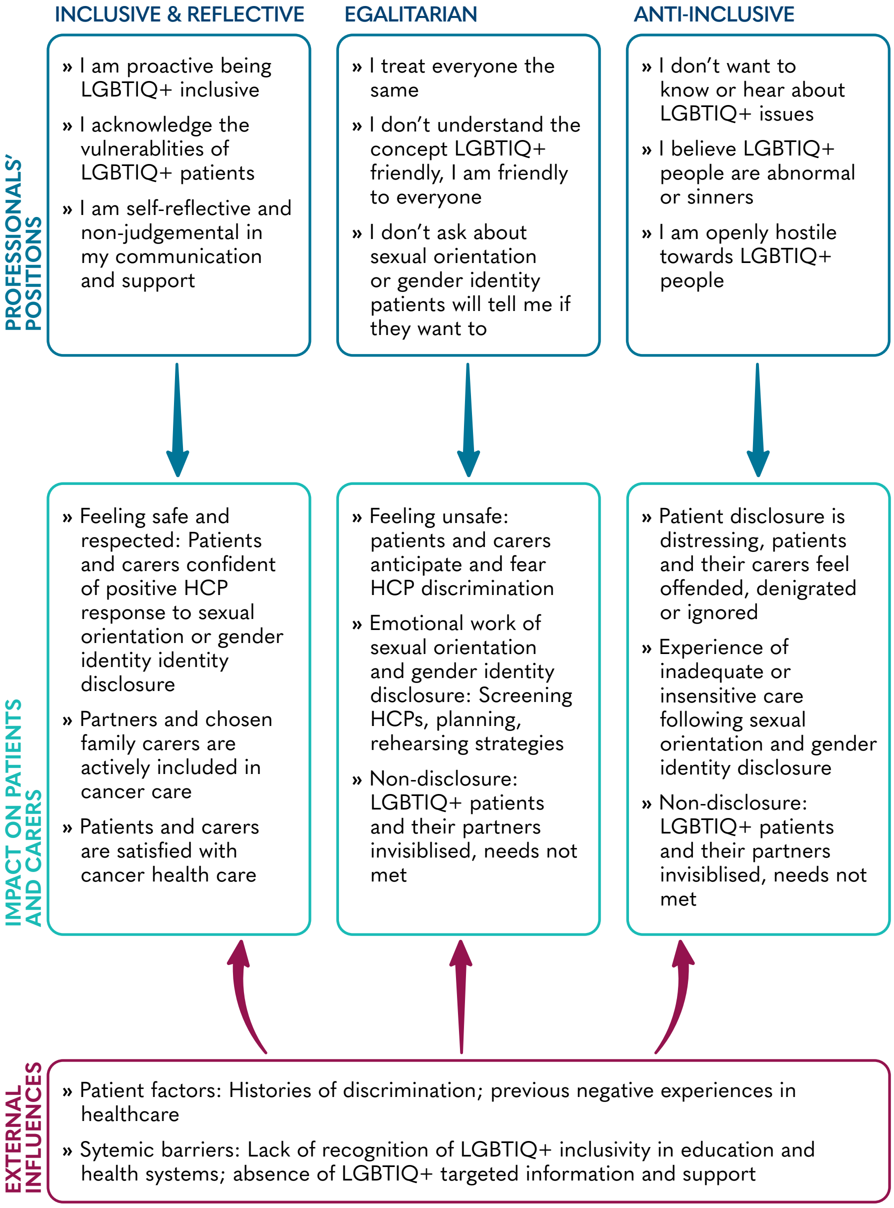
Only 3%
answered all ten true/false questions correctly

Less than half (46%)
answered five or more questions correctly

Many indicated they **did not know the answers**
(13-55% per question)

HEALTHCARE PROFESSIONAL APPROACHES TO LGBTIQ+ PATIENTS

The Out with Cancer Study identified three approaches that healthcare professionals took to LGBTIQ+ patients' cancer care: inclusive and reflective; egalitarian; and anti-inclusive (18). These approaches shaped how LGBTIQ+ patients and carers experienced their cancer care, as follows.



	INCLUSIVE & REFLECTIVE	EGALITARIAN	ANTI-INCLUSIVE
PROFESSIONALS' POSITIONS	» I am proactive being LGBTIQ+ inclusive » I acknowledge the vulnerablities of LGBTIQ+ patients » I am self-reflective and non-judgemental in my communication and support	» I treat everyone the same » I don't understand the concept LGBTIQ+ friendly, I am friendly to everyone » I don't ask about sexual orientation or gender identity patients will tell me if they want to	» I don't want to know or hear about LGBTIQ+ issues » I believe LGBTIQ+ people are abnormal or sinners » I am openly hostile towards LGBTIQ+ people
IMPACT ON PATIENTS AND CARERS	» Feeling safe and respected: Patients and carers confident of positive HCP response to sexual orientation or gender identity identity disclosure » Partners and chosen family carers are actively included in cancer care » Patients and carers are satisfied with cancer health care	» Feeling unsafe: patients and carers anticipate and fear HCP discrimination » Emotional work of sexual orientation and gender identity disclosure: Screening HCPs, planning, rehearsing strategies » Non-disclosure: LGBTIQ+ patients and their partners invisiblised, needs not met	» Patient disclosure is distressing, patients and their carers feel offended, denigrated or ignored » Experience of inadequate or insensitive care following sexual orientation and gender identity disclosure » Non-disclosure: LGBTIQ+ patients and their partners invisiblised, needs not met

EXTERNAL INFLUENCES

» Patient factors: Histories of discrimination; previous negative experiences in healthcare

» Sytemic barriers: Lack of recognition of LGBTIQ+ inclusivity in education and health systems; absence of LGBTIQ+ targeted information and support

INCLUSIVE AND REFLECTIVE PRACTITIONERS

INCLUSIVE PRACTITIONERS

- Proactively inclusive
- Acknowledge potential vulnerabilities of LGBTIQ+ patients and carers
- Respect and acknowledge LGBTIQ+ identities, relationships and unique support needs

IMPACT ON LGBTIQ+ PATIENTS

- More reassured and satisfied with care
- Feel safer and more able to disclose that they are LBGTIQ+
- Partners and chosen family carers are included

> It's quite daunting, for every patient but particularly for LGBTIQ+ patients. Those kinds of things, like a poster or sticker or whatever it is, I think they make a big difference for the communities.
>
> MEDICAL PROFESSIONAL, AGE 44

> I did give a LGBTIQ+ cancer resource to a patient one day and he cried because he said, 'I've never had anybody give me something that's specific to my sexuality.
>
> NURSING PROFESSIONAL, AGE 58

Inclusive and reflective practitioners acknowledged the potential vulnerability of LGBTIQ+ patients associated with a legacy of discrimination and mistreatment, including in the healthcare system, and recognised how this may discourage disclosure (18). They worked to convey understanding, acceptance, and respect through their own actions, including by asking about gender and sexuality, preferred pronouns, and welcoming partners and chosen family. They aimed to create culturally safe clinical environments using visual indicators of inclusivity, such as rainbow flags and posters. Inclusive and reflective practitioners also proactively educated themselves about LGBTIQ+ cancer-related needs and experiences to provide tailored care to patients.

> There was no sign of discomfort or not knowing how to handle it. I felt at ease being there as his same-sex partner. And they respected our relationship and didn't have any issues whatsoever.
>
> CIS MAN, GAY, 50, CARER OF PARTNER WITH HEAD/NECK CANCER

> As far as the medical people have been with us, we had zero issues. They have always been respectful, and I would always go to an appointment with her. Everyone in the hospital, doctor's surgery was brilliant. Surprisingly brilliant. There was never a problem.
>
> TRANS, INTERSEX, BISEXUAL, AGE 59, PARTNER OF WOMAN WITH BREAST CANCER

This approach made LGBTIQ+ patients feel safer, more reassured, and more confident in disclosing that they are LGBTIQ+. It also facilitated the inclusion and support of partners and chosen family.

> “My medical team knew that I was transgender and that I feared discrimination. They were very supportive and went an extra step to reassure me. My status as a trans female remained as knowledge with only those that it impacted in my treatment.”
>
> TRANS WOMEN, STRAIGHT, AGE 68, HEAD/NECK CANCER

Interactions with healthcare professionals who openly identified as part of the LGBTIQ+ community were highly valued concerning feelings of safety: “out medical staff made me feel safe”; “My GP is a lesbian. I feel very safe”.

> “I saw that it had this little phrase, “All our programs are LGBTQ friendly”. And I positively shrieked. I mean (laughs), I just was so startled, so delighted, so amazed. I’ve been a lesbian since 1970, so many years- I’ve been in healthcare organisations for years. I have read about some healthcare organisations having a statement that says that they’re supportive, or that sexual orientation variety is recognised, but I have never seen something like this. And I was just absolutely thrilled.”
>
> CIS WOMAN, LESBIAN, AGE 76, NEUROENDOCRINE CANCER

PARTICIPANT PHOTOGRAPH

EGALITARIAN PRACTITIONERS

EGALITARIAN PRACTITIONERS

- Don't think that cancer or cancer care is different for LGBTIQ+ people
- Treat all patients the same
- Don't facilitate disclosure
- Out of comfort zone and worried about causing offence

IMPACT ON LGBTIQ+ PATIENTS

- Emotion work - deciding if and when to disclose
- Feeling unsafe and fearing discrimination
- Non-disclosure means safety and privacy, but also invisibility and unmet needs

> I don't tailor the care, because I don't want to be like, oh, you're a lesbian couple, come here and I'll do all this fancy stuff with you. I guess I try to treat everyone the same.
>
> ALLIED HEALTH PROFESSIONAL, AGE 28

> I don't tend to ask people. I don't proactively ask people "do you identify as LGBTIQ". I sort of pick up on it if it's there. But, that probably means that even I am missing people. Sometimes, I've been in a situation where I've had a trans patient, for example, and they just really pass. I've only realized that they are trans when I do a physical exam.
>
> MEDICAL PROFESSIONAL, AGE 40

Egalitarian practitioners believed that "cancer is the same for everyone", and therefore they "try to treat everyone the same" (18). These healthcare professionals described themselves as accepting of LGBTIQ+ patients, but did not signal their inclusivity or facilitate disclosure. Few had sought out any training or information about LGBTIQ+ patient needs. Several egalitarian practitioners described encounters with LGBTIQ+ patients as leaving them feeling uncomfortable, inadequate, and afraid of offending, because of lack of training.

The lack of inquiry about sexuality, gender, and innate variations in sex characteristics placed the onus on patients and carers to assess if healthcare professionals will be accepting and decide whether to disclose their identities. It left patients and carers fearing discrimination.

> You're constantly having to decide whether it's worth disclosing to this person, and whether that cost-benefit ratio of how much privacy you have to give up for your care is actually going to pay off.
>
> NON-BINARY, GAY, AGE 32, LEUKEMIA

It also means that healthcare professionals may use incorrect pronouns with LGBTIQ+ people, which causes distress.

> What I would have liked them to do was to ask me what pronouns I would like. Would I like to be called 'he' or 'him' or 'she' and 'her' or 'they' and 'them'. They didn't ask.
>
> TRANS, QUEER, AGE 63, PROSTATE

LGBTIQ+ people felt that their identities were invisible in cancer care and their needs were not being met (18).

> This one photo represents the ritualistic cancer pathway. So being a cancer patient is kind of like going through this – almost like a cult because you have to shave your hair off. I guess that in order to sort of make it through the tunnel and get out of the tunnel, it's important to be visible and feel accepted.

CIS WOMAN, LESBIAN, AGE 36, UTERINE CANCER

PARTICIPANT PHOTOGRAPH

ANTI-INCLUSIVE PRACTITIONERS

ANTI-INCLUSIVE PRACTITIONERS

- Righteous in hostility towards LBGBTIQ+ people
- Anti-inclusive practices, mistreatment and discrimination
- Believe LGBTIQ+ people are abnormal or sinners

IMPACT ON LGBTIQ+ PATIENTS

- Damaging impact of interactions with hostile and offensive clinicians
- Active exclusion of partners and chosen family carers
- Fear of inadequate and insensitive cancer care

> I don’t see why everyone has to force their sexual orientation on others. Heterosexual people don’t go around talking about their sexual orientation. I am now forced into hearing about and watching abnormal behaviour on TV and more advertisement of non-heterosexuals.
>
> NURSING PROFESSIONAL, AGE 61

> I was in the outpatients area, one of the doctors came in and said, “there’s this patient and they’re Trans”. Then a few of the doctors and some nurses started to talk about the person, intentionally using the wrong pronouns and saying derogatory things about them. It just goes to show the lack of understanding and the lack of respect. Even if the patient didn’t hear, it’s still encouraging that sort of culture in the workplace.
>
> NURSING PROFESSIONAL, AGE 35

Anti-inclusive practitioners held negative, prejudiced and at times hostile beliefs about LGBTIQ+ patients (18), which were expressed through:

- Disrespectful and dismissive behaviours, including voicing opinions that being LGBTIQ+ is wrong and invoking hurtful stereotypes about LGBTIQ+ people
- Disregard for identities, including deliberately misgendering trans patients and continually referring to same-gender partners as friends
- Excluding LGBTIQ+ partners and carers, including prioritisation of family of origin over chosen family, and refusal to allow same-gender partners to see dying patients
- Withholding care, including withholding fertility preservation advice from gay and lesbian patients, denying pain relief after operations to trans patients

> The discrimination I have experienced from health professionals during my cancer care has reduced my ability to be proud of who I am. This discrimination prevents me from help seeking for my current maintenance care. There is so much transphobic/cisnormative talk between health workers and staff, I overhear it between them and it feels horrible.
>
> NON-BINARY, LESBIAN, AGE 38, MULTIPLE CANCERS

> It’s that kind of discrimination that is just so constant and covert and daily that it gradually chips away at your confidence and sense of self-worth, and particularly in health like you are just naked all the time. I have had surgical gynecologically, I’ve had bowel surgery, I’ve had my breasts removed, like every single body part that defines my gender – and my anus – has been penetrated by clinicians numerous times across my life, or cut with scalpels and all sorts of things, and you just think everything that is intimate and important to me has been clinically invaded by people who don’t respect me for who I am. So those people are everywhere, the health is so huge. It’s a main employer of Australians and in that systemic discrimination sort of way, it makes me distrust people in the system who do do really good work and do really care.
>
> NON-BINARY, QUEER, AGE 37, MULTIPLE CANCERS

PARTICIPANT PHOTOGRAPH

LGBTIQ+ people described being constantly afraid of hostility from healthcare professionals and feeling vulnerable because they had put up with whatever medical practitioners did or said [17]. This caused distress, distrust, and feelings of invalidation and not feeling safe, compounding the stresses associated with cancer, treatment, and caregiving. Numerous LGBTIQ+ patients reported instances wherein they perceived their medical care to be inadequate, or feared being denied health care services because they were LGBTIQ+ (18).

> A third of the time we go into an appointment, we might be looking at someone who actually wants us dead. That’s how hard it is to get medical care. You’ve got to randomly work out a way to protect yourself against someone who hates your guts.
>
> TRANS MAN, AGE 55, MULTIPLE CANCERS

Participants also reported distress following encounters with healthcare professionals who deliberately enforced heteronormative ideals through their clinical decision-making. For example, one doctor “focused entirely” on maintaining a lesbian patient’s vagina with dilators post-surgery “so that a man could put his penis in it” if she decided to be in “a proper relationship one day”. This was despite the patient telling him “that was not an issue, but he would just ignore me, just talk over the top of me” (Bisexual woman, age 61, vulval cancer).

BARRIERS TO CULTURALLY SAFE LGBTIQ+ CARE

Our study identified several key barriers to providing culturally safe and competent cancer care:

- An overstretched healthcare system that prioritises medical outcomes (e.g. survival) over holistic care (e.g. recognising patients' identities)
- A lack of training on LGBTIQ+ topics: few healthcare professionals had received formal education about the healthcare needs of LGBQ+ (27.0%), trans (20.8%) and intersex patients (14.6%)
- A lack of LGBTIQ+ specific resources, combined with LGBTIQ+ invisibility in general cancer resources.

Many healthcare professionals did not recognize the importance of knowing if a patient is LGBTIQ+. A significant proportion assumed patients were:

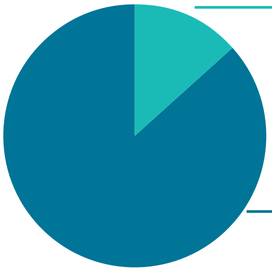
- Heterosexual: 23.7%
- Cisgender: 56.5%

There was an absence of active efforts to become more LGBTIQ+ inclusive. Specific inclusivity actions not widely implemented:

- Not displaying visual indicators of inclusivity: 30.0%.
- Not allowing patients to indicate non-binary gender on forms: 38.4%.
- Not developing LGBTIQ+ friendly referral pathways: 31.7%.

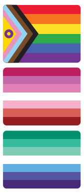
ABSENCE OF LGBTIQ+ APPROPRIATE CANCER INFORMATION

Our audit of 61 Australian cancer organisation websites found that only a minority (13%) had any content that mentioned LGBTIQ+ people (14). This included 13 resources that were tailored for LGBTIQ+ people, and 19 general cancer resources which mentioned LGBTIQ+ people. Most of this related to sexuality diverse patients; only one resource tailored for trans people, and none included intersex people.



Of 61 cancer websites, **only 8 (13%) mentioned LGBTIQ+ people**

- 13 LBGTIQ+ specific resources identified
- Primarily for LGBQ+ patients
- Most dealt with support (8), sexuality and intimacy (3) and LGBTIQ+ identity and body image (3)



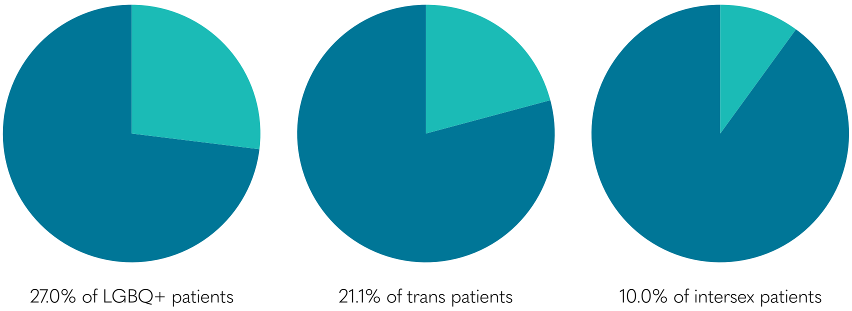
Non-LBGTIQ+ specific information was:

- Largely inclusive of same-gender partners (88%) and different sexual behaviours (68%)
- Often conflated gender with anatomy and hormones which is not inclusive of trans people and people with innate variations in sex characteristics

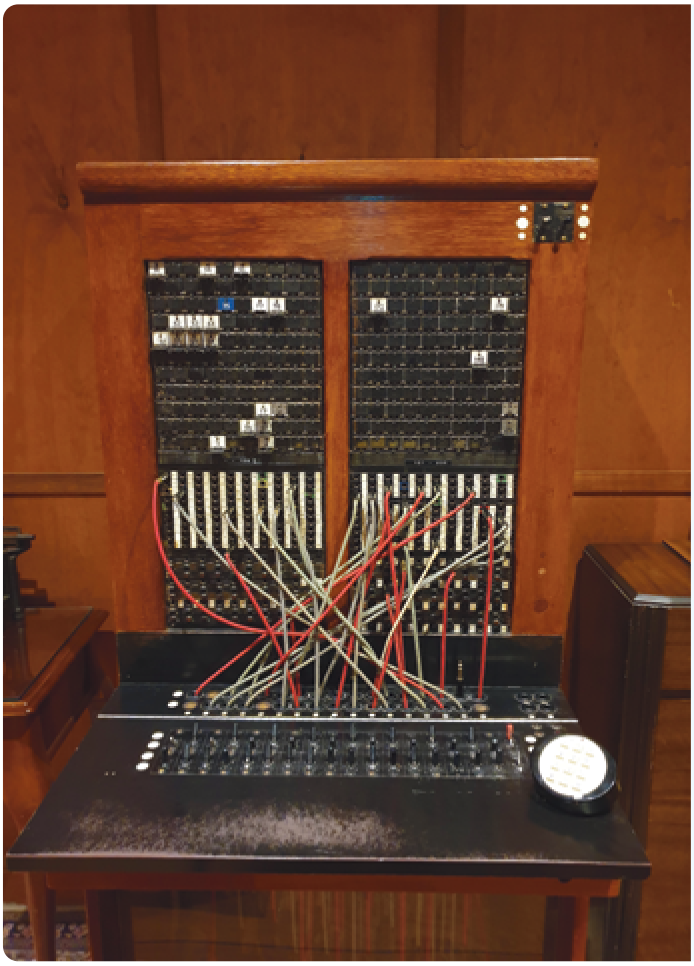
Of the websites which did not mention LGBTIQ+ people, many were implicitly inclusive of LGBQ+ people by using gender-neutral language to refer to partners, and providing information on various sexual behaviours. However, the majority assumed people were cisgender, without innate variations in sex characteristics, rendering trans and intersex people invisible.

The lack of LGBTIQ+ specific information resources contributes to an environment where LGBTIQ+ patients and carers struggle to locate relevant and appropriate information. Only a minority of LGBTIQ+ patients surveyed were able to find helpful information about being a LGBTIQ+ person with cancer, and this proportion was lower for trans and intersex participants (Figure 17).

FIGURE 17. Proportion of people with cancer who could find LGBTIQ+ cancer information



This can potentially compromise LGBTIQ+ patients' capacity to make informed health decisions.



> Often I felt quite isolated and disconnected and not part of what I called "The Big Pink". Which was all the pink breast cancer stuff. You know, it's all pink, it's all heterosexual, and I really struggled with some of that.
>
> I mean, for me, pink's always been a colour... associated with the pretty little girls at school that I could never relate to, and I was never part of, and it was quite foreign to me, and... So it was almost like the whole pink stuff associated with breast cancer reminds me of negativity with my childhood. So then of all cancers to get, I have to get the breast cancer which is all about pink.

CIS WOMAN, LESBIAN, AGE 54, BREAST CANCER

PARTICIPANT PHOTOGRAPH

LGBTIQ+ RESISTANCE AND ADVOCACY

Many participants described how their cancer experiences had driven them to become involved in activism and advocacy, with the aim of improving the standards of care and support available to other LGBTIQ+ people with cancer and their carers (17).

These efforts included:

- **Being more open and vocal** about being LGBTIQ+, with the aim of increasing visibility of LGBTIQ+ communities and challenging ideas of them being different or abnormal
- **Educating healthcare professionals** about the experiences of LGBTIQ+ people with cancer, or **becoming involved in advocacy within healthcare systems**, to improve the quality of care provided to other LGBTIQ+ people with cancer and carers
- **Educating LGBTIQ+ communities** about cancer screening and survivorship
- **Setting up support groups** for other LGBTIQ+ people with cancer

> That is the banner photo for the group that I made, LGBTQ with cancer... it was the guts that I had to say, actually no. Actually, I don't have to settle. Actually, I can do something and even if it's not much it's a fucking start. My hope is that somebody like you, not you, you, but your entity, that some organization with resources and trained people will come alongside me and take it over so that I can just kind of relax and let somebody else be in the driver's seat. But until that day, I'm just hoping to have some sort of a start because there has to be something for us, there has to be more.

NON-BINARY, QUEER, AGE 34, UTERINE CANCER

PARTICIPANT PHOTOGRAPH

COMMUNITY ACTIVIST

> I got involved with diversity, ACT and Spring Out and became the vice president of [LGBTQI organisation] and then the president. So I've been the president now for three years. ... That was really big for me because I didn't know if I would actually physically be able to do it... that picture is one of me being really happy to be part of my community again. Yeah, so that was me kind of going 'this is where it's at, this is what I want to do.

CIS WOMAN, LESBIAN, AGE 61, OVARIAN CANCER

PARTICIPANT PHOTOGRAPH

Participants described being driven by both the need to channel their own experiences into creating systemic change, as well as ensuring that LGBTIQ+ services that "weren't there for me… can be there for someone else". Becoming involved in LGBTIQ+ advocacy also reportedly affirmed participants' LGBTIQ+ identities and facilitated community connection, which one described as "like coming home".

> It felt really important to me to be involved in, my professional life is fundamentally being about activism, either HIV, sexual health, or LGBTQ+ activism. And so it felt like a very natural progression to couple that with activism around sexuality and prostate cancer, sexual orientation and prostate cancer.

CIS MAN, GAY, AGE 60, PROSTATE CANCER

PARTICIPANT PHOTOGRAPH

> The bromeliads. So even though I said I'm not into positivity, this photo was all about holding onto hope and beauty. I did have to remind myself at times that I will get through this. I'm going to come out the other side a slightly different person. You won't be returning to normal, you get the new normal, as they say, and you have to create that for yourself. The group of people I've got together, we still meet. And we call it the new normal's dinner, and we come together once a month to talk and.. just sort of chat about life now. Rather than having had cancer.

CIS WOMAN, LESBIAN, AGE 55, BREAST CANCER

PARTICIPANT PHOTOGRAPH

RECOMMENDATIONS AND DIRECTIONS FOR IMPROVEMENT

When asked about how they envisioned ideal cancer care for LGBTIQ+ communities, participants had several individual- and system-level requests and recommendations for improvement (18, 19).

Participants recommended that individual practitioners should:


be supportive, empathic and non-judgemental


avoid assuming patients are cisgender, heterosexual, and do not have innate variations in sex characteristics

ask patients their pronouns and mirror language about body parts and partners


acknowledge and involve partners and carers

Participants emphasised the importance of healthcare professionals engaging in awareness, sensitivity, diversity and inclusivity training addressing the cancer care needs of LGBTIQ+ people. They suggested that such training should cover "how to ask the right questions" about how cancer treatment may affect gender and sexuality identity, and how support structures may differ for LGBTIQ+ people. Training should also account for differences across LGBTIQ+ communities, covering the needs of trans people and people with innate variations in sex characteristics, who are often overlooked.

Participants highlighted the importance of creating a non-discriminatory and visibly supportive healthcare environment to foster safety and inclusivity.

> I think my key message would be how important it is for queer, intersex and trans people to have a safe and welcoming experience. Walking in the doors of a cancer centre and see themselves reflected in the intake forms and the materials so they know it's a safe place to come out.
>
> TRANS MAN, STRAIGHT, AGE 47, OVARIAN CANCER

In summary, this is what LGBTIQ+ people with cancer and LGBTIQ+ carers want:

WELCOMING PHYSICAL SPACES

> We need reassurances and signs that we identify as meaning, 'Oh, this is safe'. Unless you have the visual cues, you can't really be sure, you're just invisible as usual. This could be rainbow flags or stickers with rainbows. Something that indicates that they are not ashamed or embarrassed to be seen to be welcoming.

CIS WOMEN, LESBIAN, AGE 61, BREAST CANCER

- Clinics and clinic websites displaying visual signifiers of inclusivity, like pride flags, rainbow stickers, and posters which include LGBTIQ+ people
- Links to antidiscrimination policies and complaint systems on clinic websites
- Healthcare professionals wearing pronoun badges – he/him, she/her, they/them, he/they, she/they.
- Gender neutral toilets that signal a deepened understanding of gender diversity for trans or non-binary individuals.
- Avoiding labelling cancers "women's" or "men's"

> If healthcare reframed its information and if everybody lost their pronouns talking about cervical cancer rather than women's cancer it just helps people access the service.

NON-BINARY, GAY, AGE 31, LEUKEMIA

> It's actually quite significant because it's a very generous sign. It's welcoming people in a range of different languages and messages and ways. And it also has a rainbow flag there. And that's indicates a safe space. And I think in terms of this study and in terms of being in a same sex relationship, knowing that the hospital you're going to is going to be nonjudgmental and treat you as anybody else, that that's reassuring. [...] It kind of gave me a sense of reassurance that I was going to a safe space and [my partner] was in good hands there.

CIS MAN, GAY, AGE 51, CARING FOR HUSBAND WITH SKIN CANCER

PARTICIPANT PHOTOGRAPH

LGBTIQ+ CANCER INFORMATION

> I'd want the flyer or the information to say "whether you're straight or you identify as LGBTQI". I'd like them specifically to countenance that, because otherwise you'd just think, oh, it's just the usual sort of stuff for straight people.

CIS WOMEN, LESBIAN, AGE 61, BREAST CANCER

- Mentioning LGBTIQ+ people in the general sections of cancer information booklets and websites, and having specific sections for LGBTIQ+ people.
- Acknowledging multiple relationship types and LGBTIQ+ partners and support people in cancer information; not assuming the gender of partners in cancer information.
- Displaying LGBTIQ+ information material such as the Cancer Council LGBTIQ+ cancer booklet.

> Some information about disclosure would be useful. If intersex status is relevant, how it is relevant, and when you might choose to disclose. Referrals onto intersex peer support. Avenues of complaint or recourse when facing medical mistreatment. Your right to refuse procedures or examinations you don't feel respect your bodily autonomy as an intersex person.

NON-BINARY, INTERSEX, AGE 31, MEDICAL INTERVENTION FOR CANCER RISK

> Both my deceased partner and myself would have benefitted had we had access to LGBTIQ+ inclusive literature on cancer. I would have benefitted being a both LGBTIQ+ carer and a LGBTIQ+ person with cancer. When it came to my own experiences I have at times felt isolated and lost.

CIS WOMAN, LESBIAN, AGE 65, CARER FOR PARTNER WITH RARE CANCER

SYSTEMS AND PRACTICES

> I try to make my gender and sexuality known early whenever I can and feel safe to do so; I appreciate options on forms that allow for this, since that also implies some degree of acceptance and valuing that information.

QUEER, PANSEXUAL, NON-BINARY/GENDER FLUID, AGE 33, TESTICULAR CANCER

> We have been so invisible and silent as a community and as we say, the "I" should be for Intersex inclusion, no more "I" for Invisible.

NON-BINARY, PANSEXUAL, INTERSEX, AGE 55, SKIN CANCER

- Including space to specify sexual orientation, gender identity, innate variations in sex characteristics, and pronouns on intake forms
- Facilitating access to meaningful social support, such as LGBTIQ+ specific support groups
- Healthcare professionals being open and inclusive at first meetings: asking about pronouns, sexual orientation, and innate variations in sex characteristics
- Inclusion of chosen family and LGBTIQ+ partners in care

> My experience with the medical practitioners has been positive and inclusive. They have not presumed my sexuality and have asked open questions.

CIS MAN, GAY, AGE 43, LEUKAEMIA

> It's really important to find a specialist that you feel does respect you and takes you seriously and takes your relationship seriously and will include your partner as an equal member of the group that is dealing with all of this.

CIS WOMAN, LESBIAN, AGE 68, BREAST CANCER

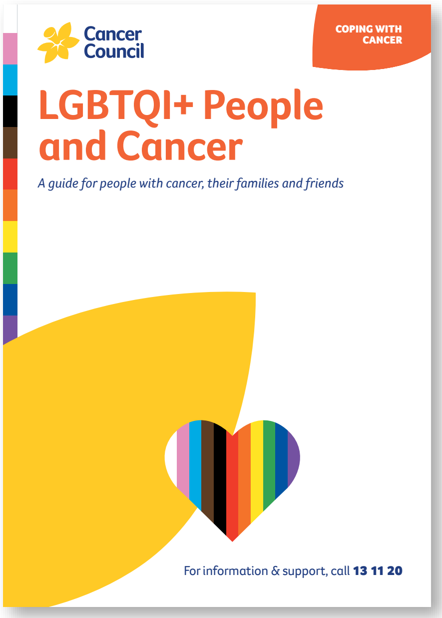
> "This photograph is when we've just arrived at Peter Mac on the day of our wedding and we had no idea what they were doing for our wedding. I'm wheeling her into the wellbeing centre and this is the first time that we're seeing the wellbeing centre set up for our wedding. And it was just striking, the decoration, the light of love and the rainbow balloons and it was just gorgeous. It was all set up with the media and the microphones and all that sort of thing. It was just, it was pretty special. They had that whole floor segregated off for us. They sort of closed off a floor and the teenage centre was basically where we were able to get dressed and prepared and, you know, it was just magical what they did."

CIS WOMAN, LESBIAN, AGE 59,
PARTNER OF WOMAN WITH BREAST
CANCER, AGE 55, DECEASED

PARTICIPANT PHOTOGRAPH

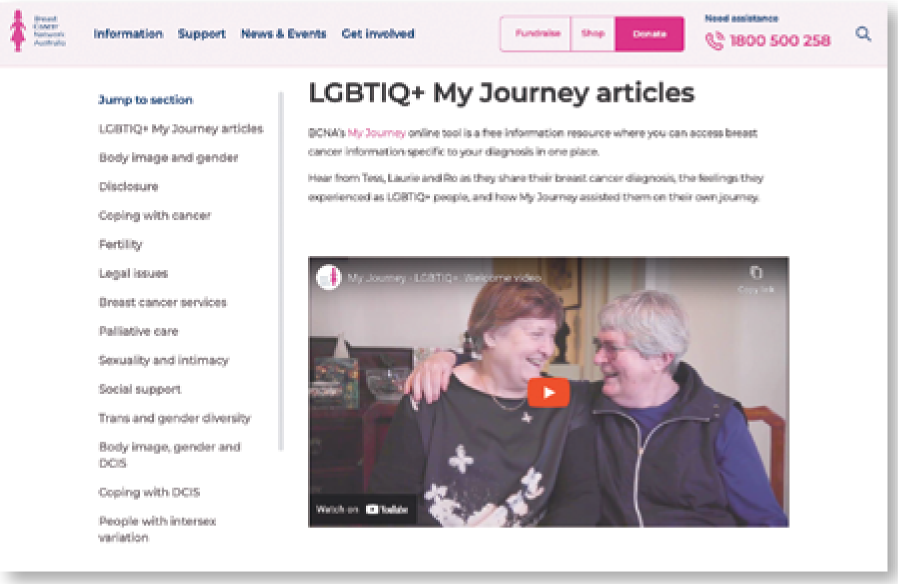
TRANSLATIONAL OUTCOMES OF THE OUT WITH CANCER STUDY

The Out with Cancer Study findings have been translated into resources for LGBTIQ+ people with cancer and their carers, and training materials for healthcare professionals, co-designed with our stakeholder advisory group of LGBTIQ+ people, LGBTIQ+ and cancer organisatons, cancer clinicians, and researchers.



Cancer Council LGBTIQ+ booklet: 80 page information about cancer for LGBTIQ+ people with cancer and LGBTIQ+ carers. Disributed nationally in all Australian cancer hospitals and clinics and available online.

cancercouncil.com.au/lgbtqi



LGBTIQ+ My Journey articles

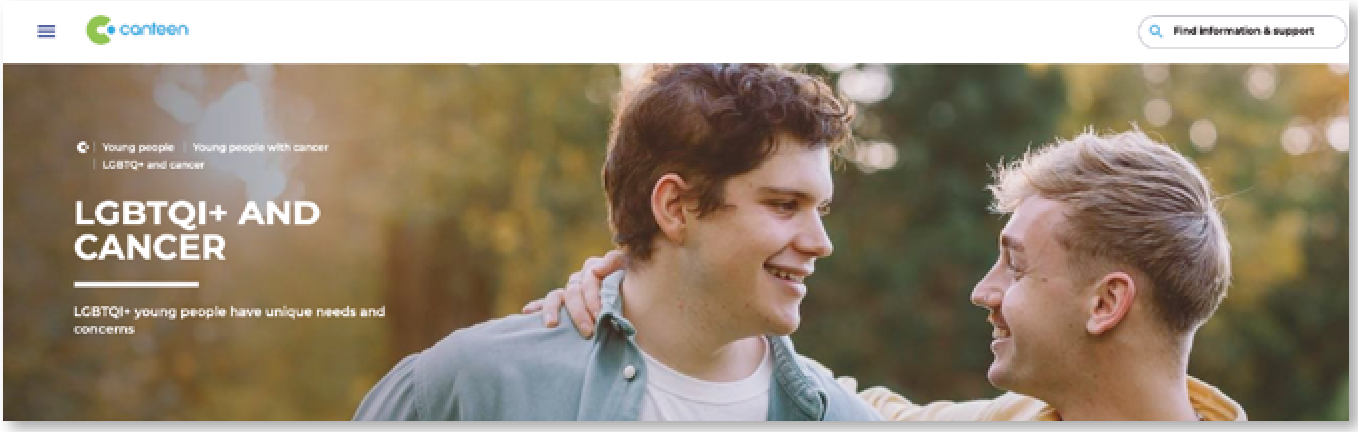
BCNA's My Journey online tool is a free information resource where you can access breast cancer information specific to your diagnosis in one place.

Hear from Tess, Laurie and Ro as they share their breast cancer diagnosis, the feelings they experienced as LGBTIQ+ people, and how My Journey assisted them on their own journey.

Information for LGBTIQ+ people diagnosed with breast cancer

BCNA My Journey 16 online information resources and 2 podcasts

https://www.bcna.org.au/understanding-breast-cancer/information-for-lgbtiqplus-people-diagnosed-with-breast-cancer/



LGBTQI+ AND CANCER

LGBTQI+ young people have unique needs and concerns

Canteen website information for adolescents and young adults
https://www.canteen.org.au/young-people/with-cancer/lgbtq-and-cancer

LGBTIQ+ CANCER TOOLKIT

Module 1:
Understanding Inequity in Cancer Care for LGBTIQ+ People

McGrath Foundation training modules for Health Care Professionals
Freely available on eviQ.

OUT WITH CANCER STUDY PUBLICATIONS

Allison, K., Power, R., Ussher, J. M., Perz, J., Hawkey, A., Parton, C., Watson, L., Hickey, M., Dowsett, G. W., Anazodo, A., Boydell, K., Bruce, J., Gilmore, T., Ryan, S., Ellis, C., & the Out with Cancer Study, T. (2024). "Queer people are excellent caregivers, but we're stretched so very thin": Psychosocial wellbeing and impacts of caregiving among LGBTQI cancer carers. *BMC Cancer, 24*(1), 36. https://doi.org/10.1186/s12885-023-11732-2

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APPENDIX

DEMOGRAPHIC CHARACTERISTIC	People with cancer (n=430)	Carers (n=129)	Healthcare professionals (n=357)
	M (SD), range	*M (SD),* range	*M (SD),* range
Age at time of study (years)	52.5 (15.7), 16-92	50.2 (17.2), 15-76	47.3 (12.5), 22-82
Time working in cancer care (years)	-	-	14.3 (10.2), 0.3-45
	n (%)	*n* (%)	*n* (%)
COUNTRY			
Australia	311 (72.3%)	91 (70.5%)	315 (88.2%)
United States of America	62 (14.4%)	14 (10.9%)	17 (4.8%)
United Kingdom	29 (6.7%)	8 (6.2%)	10 (2.8%)
New Zealand	8 (1.9%)	6 (4.7%)	5 (1.4%)
Canada	7 (1.6%)	4 (3.1%)	3 (0.8%)
Other	13 (3.0%)	6 (4.7%)	7 (2.0%)
LOCATION			
Urban	234 (54.5%)	66 (51.2%)	247 (69.2%)
Regional	145 (33.8%)	48 (37.2%)	85 (26.6%)
Rural or remote	50 (11.7%)	15 (11.6%)	13 (3.6%)
RACE/ETHNICITY			
Caucasian	362 (85.2%)	106 (82.2%)	305 (85.4%)
Asian	11 (2.6%)	5 (3.9%)	22 (6.2%)
Australian Aboriginal, Torres Strait Islander or Maori	9 (2.1%)	4 (3.1%)	1 (0.3%)
Mixed background	19 (4.5%)	6 (4.7%)	8 (2.2%)
Other/unclear background	24 (5.6%)	8 (6.2%)	16 (4.5%)
GENDER			
Cis female	216 (50.2%)	80 (62.0%)	278 (77.9%)
Cis male	145 (33.7%)	26 (20.2%)	74 (20.7%)
TGD[1]	63 (14.7%)	23 (17.8%)	5 (1.4%)
Different identity	6 (1.4%)	0	-
SEXUALITY			
Lesbian, gay or homosexual	317 (73.7%)	95 (73.0%)	-
Bisexual or pansexual	47 (10.9%)	17 (13.2%)	-
Queer	45 (10.5%)	12 (9.3%)	-
LGBQ, not further specified	-	-	56 (17.1%)
Straight or heterosexual	10 (2.3%)	2 (1.6%)	268 (81.7%)
Different or multiple identities	11 (2.6%)	3 (2.3%)	-
Prefer not to answer	-	-	4 (1.2%)
INTERSEX VARIATION			
Yes	31 (7.2%)	5 (3.9%)	1 (0.3%)
No	388 (90.2%)	124 (96.1%)	313 (98.4%)
Prefer not to answer	11 (2.6%)	0	4 (1.2%)

DEMOGRAPHIC CHARACTERISTIC	**People with cancer (n=430)**	**Carers (n=129)**	**Healthcare professionals (n=357)**
	M (SD), range	*M (SD),* range	*M (SD),* range
Age at time of study (years)	52.5 (15.7), 16-92	50.2 (17.2), 15-76	47.3 (12.5), 22-82
Time working in cancer care (years)	-	-	14.3 (10.2), 0.3-45
	n (%)	*n* (%)	*n* (%)
EDUCATION			-
Less than secondary	10 (2.4%)	7 (5.5%)	
Secondary	45 (10.7%)	17 (13.3%)	
Some post-secondary	55 (13.0%)	9 (7.0%)	
Post-secondary	312 (73.9%)	9.5 (74.2%)	
CANCER DIAGNOSIS (FIRST)			-
Brain	11 (3.0%)	9 (7.1%)	
Breast	90 (24.3%)	37 (29.4%)	
Cervical	11 (3.0%)	3 (2.4%)	
Colorectal	17 (4.6%)	8 (6.3%)	
Head/neck	14 (3.8%)	10 (7.9%)	
Leukaemia	17 (4.6%)	5 (4.0%)	
Lymphoma	24 (6.5%)	6 (4.8%)	
Ovarian	17 (4.6%)	13 (10.3%)	
Prostate	59 (15.9%)	7 (5.6%)	
Skin	25 (6.8%)	3 (2.4%)	
Uterine	23 (6.2%)	4 (3.2%)	
Other	58 (15.7%)	18 (14.3%)	
Not sure or unknown	4 (1.1%)	3 (2.4%)	
RELATIONSHIP TO PERSON WITH CANCER	-		-
Partner/ex-partner		84 (65.1%)	
Family		31 (24.0%)	
Friend		11 (8.5%)	
Different relationship		1 (0.8%)	
Multiple patients/relationships		2 (1.6%)	
PROFESSIONAL DISCIPLINE	-	-	
Medical			87 (24.4%)
Nursing			142 (39.9%)
Allied health			69 (19.4%)
Leadership			38 (10.7%)
Other			20 (5.6%)

OUT WITH CANCER