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Almost invisible: A review of inclusion of LGBTQI people with cancer in online patient information resources

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ABSTRACT

Objective: This review assessed the inclusion of lesbian, gay, bisexual, trans, queer and/or intersex (LGBTQI) people in online cancer information.

Methods: The websites of Australian cancer organizations were reviewed to identify if they included LGBTQI people and the extent and nature of this inclusion. Websites that did not include LGBTQI people were then reviewed to identify if information was implicitly LGBTQI inclusive. International LGBTQI cancer information resources were reviewed to identify key content.

Results: Of sixty-one Australian cancer organization websites reviewed, eight (13%) mentioned LGBTQI people, including 13 information resources targeted to LGBTQI people and 19 general cancer information resources that mentioned LGBTQI people. For Australian cancer websites that did not mention LGBTQI people, 88% used gender neutral language to refer to partners, 69% included a range of sexual behaviours, 13% used gender neutral language when referring to hormones or reproductive anatomy but none acknowledged diverse relationship types. Internationally, 38 LGBTQI-specific cancer information resources were identified.

Conclusions: Cancer patient information resources need to be LGBTQI inclusive. LGBTQI-targeted resources are required to address this population's unique needs and improve cultural safety and cancer outcomes.

 ${\it Practice implications:} \ {\it Recommendations are provided for LGBTQI inclusive cancer patient information resources.}$

1. Introduction

There is growing awareness of the need for cancer information and care to be culturally safe and inclusive for people who are lesbian, gay, bisexual, trans (binary and non-binary), queer and/or intersex (LGBTQI) [1–3]. Described as a "growing and medically underserved population" [4], LGBTQI people with cancer report greater dissatisfaction with cancer care [5], lower quality of life [6,7], and higher levels of distress [6,8] than the non-LGBTQI cancer population. Fear of anti-LGBTQI prejudice and discrimination, driven by historical and present-day minority stressors [9], and invisibility in cis-heteronormative cancer care [2], gives rise to difficulties in patient-provider relationships. This includes anxieties about disclosure of sexual orientation and/or gender identity (SOGI) status [2,10] and feelings of exclusion [2,11], resulting in distress and dissatisfaction with cancer care [12].

Cultural safety focuses on creating an environment within the health-

care system that is emotionally, socially and physically safe, with no actions taken to challenge or diminish the identities of an individual [13, 14]. To date, research recommendations to improve LGBTQI cultural safety in cancer care have focused on the need for education and training of healthcare professionals (HCPs) [12,15-17]. Inclusive practice requires HCPs to be aware, knowledgeable and skilled in working with LGBTQI patients [16] to create environments that are experienced as emotionally, socially, culturally and physically safe by LGBTQI people, with patients receiving healthcare that is free from discrimination [18]. Inclusive practices include asking about a patient's preferred name and pronouns, including same-gender partners and other chosen family support people in consultations, displaying visible indicators of LGBTQI inclusivity and having referral pathways to LGBTQI-friendly services [1, 2,9]. Inclusive cancer care also includes recognition of the unique experiences and concerns of LGBTQI people [1,3], including anxiety about SOGI disclosure [10], sexual concerns [19], the impact of cancer on

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embodiment and LGBTQI identity [20–22], and diverse relationship and informal supports [23,24].

Cultural safety extends beyond the materiality of the clinical setting to include patient support information [2]. In the US, the American Society of Clinical Oncology recommended the development and dissemination of patient education as part of their recommendations to reduce LGBTQI cancer health disparities [4]. The Australian cancer plan advocates for improved availability of co-designed tailored information for LGBTQI patients and their carers [25]. Many people diagnosed with cancer independently seek information about their condition, treatment and prognosis to confirm or supplement the information provided by HCPs [26,27]. Patients increasingly use the internet as a tool for this self-education [28], and most printed information booklets for cancer patients are now available online. Emerging findings suggest that same-gender attracted (lesbian, gay, bisexual and queer) people are more likely than opposite-gender attracted patients to seek health information using the internet, circumventing distrust of HCPs and fear of negative responses to SOGI disclosure [28]. People with cancer who receive access to quality, accurate information have better quality of life [29], greater ability to cope [30] and report higher satisfaction in cancer care [31]. Therefore, online cancer information must LGBTOI-inclusive language and provide content that includes LGBTOI people. The invisibility of LGBTQI people in cancer information has been found to be associated with feelings of exclusion, distress and unmet needs on the part of LGBTQI patients and informal carers [2,3].

A previous audit of inclusiveness of Australian cancer information for gay and bisexual men with prostate cancer identified cisheteronormative assumptions: use of the term wife rather than partner, focus on monogamous penis-vagina sex, and little mention of gay and bisexual men or trans people [32]. The inclusiveness of cancer information for LGBTQI patients and carers across other cancer streams and LGBTQI sub-groups is unknown. There is also little knowledge of the nature and extent of international resources for LGBTQI people with cancer, with no previous review conducted. The present study aimed to investigate LGBTQI inclusiveness in online cancer information in Australia across tumour types, gender and sexualities. Our research questions were:

- 1) Are LGBTQI people explicitly included in Australian cancer organization websites, and online patient and carer resources within these websites? If so, what is the nature and extent of LGBTQI inclusion?
- 2) In Australian cancer organization websites and online resources that do not explicitly include LGBTQI people, is the information implicitly LGBTQI inclusive when referring to patients' bodies, relationships and sexual behaviours?
- 3) What is the nature and extent of online LGBTQI cancer patient and carer information resources available internationally?

2. Methods

This review is part of the Out with Cancer study, a mixed methods project exploring LGBTQI experiences of cancer and cancer care from the perspectives of LGBTQI people with cancer, their informal carers and healthcare professionals [2,6,9,15,22]. Following principles of integrated knowledge translation (iKT) [33], a stakeholder committee comprising LGBTQI people with cancer, cancer healthcare professionals, and representatives from LGBTQI health and cancer support organizations were actively involved in all stages of the study. This included co-design of the website review criteria, data collection and analysis.

2.1. Australian cancer organizations

We reviewed the websites of Australian cancer organizations, government and non-government, whose primary audience is cancer patients, either adults or adolescents and young adults. These organizations are reputable sources for cancer information, likely to be

recommended by HCPs and appear prominently in cancer information related searches. Information resources, including webpages, booklets, factsheets, brochures, information packs and videos within the websites were included in the audit. Organizations and websites were excluded from the review if their primary audience was HCPs or researchers, fundraising, if the websites belonged to private practices of clinicians, or were personal blogs. This review was conducted between May 2020 and June 2021.

A preliminary list of cancer organizations and their websites was populated by searching the list of "cancer support organizations" provided by Cancer Australia, the lead national government cancer control body. This was followed by a search of Australian national and state Cancer Council websites, the lead national non-government cancer control organizations, and other government and non-government cancer organization websites for the names of affiliated or recommended cancer organizations. Incognito Google searches were also conducted to identify Australian organizations for the most common cancers for adults and young people: breast, prostate, melanoma, colorectal, lung, non-Hodgkin lymphoma, kidney, pancreatic, thyroid, uterine, bladder, liver, stomach, ovarian, gonadal germ cell cancer, acute lymphoid leukaemia, acute myeloid leukaemia, other specialised soft tissue sarcoma, and Ewing tumour. In cases where the same information was presented in multiple formats on a single website, such as a webpage and booklet, one information resource was counted. The national website of Cancer Council Australia and the websites of the eight State and Territory Cancer Councils hosted centrally produced patient information resources. In the results, these shared patient resources are counted as representing one national organization. The nine websites were reviewed individually to identify additional content differences, which have been included in the audit tables.

2.1.1. Review criteria

Following discussion with the stakeholder group, each website was reviewed according to eight criteria adapted from Duncan et al. [32] that were broadened to include all cancer types and sexuality diverse trans and intersex communities. Table 1 outlines the review criteria used in the audit.

Explicit LGBTQI inclusivity. Each website was searched for information that specifically mentioned LGBTQI populations, using the search terms: lesbian, gay, bisexual, trans, transgender, non-binary, queer, intersex, sexual/gender minority, sexuality/gender diverse, LGBTQI or a variation of this acronym. We reviewed the coded information within the website to identify if it was tailored specifically for LGBTQI patients or was targeted to general audiences but mentioned LGBTQI people. We identified whether specific LGBTQI sub-populations were addressed (i. e., same-gender attracted people, bisexual, trans or intersex people), or if the information was provided under the broader LGBTQI umbrella (see Table 1). We also identified the nature of this information, including if it addressed aspects of cancer and survivorship unique to LGBTQI people, detailed in Table 1.

Implicit LGBTQI inclusivity versus exclusion. Each website that did not directly mention LGBTQI people was reviewed against four criteria to see if LGBTQI people might reasonably feel included or was language and imagery exclusionary (see Table 1). Information about intimate partners was assessed to identify if language was gender inclusive, such as 'partner' or 'spouse'. As same-sex marriage only became legal in Australia in December 2017 [34], references to 'husbands' and 'wives' in resources produced prior to this date could only reference or assume heterosexuality. These terms are also cis-normative and exclusionary of non-binary people. Information about intimate relationships was assessed to identify if it included relationship types such as multiple partners, non-monogamous relationship agreements and casual sexual partners. Same-gender attracted and bisexual people are reported to have experience of more varied relationship types than heterosexual people [8,35]. Information about sexual activity was assessed to identify if it included sexual practices relevant to LGBTQI relationships [36,37]

1 (2%)

7-19

10.8 (grade 6 reading level)

and did not only position "sex" solely as penile-vaginal penetration.

Information about reproductive anatomy or hormones was assessed to

identify if they were conflated with gender exclusionary to trans and

intersex people [38]. For example, sections on cervical cancer referring

to women, rather than "people with a cervix" or "women and other

Table 1 Review criteria.

Explicit LGBTQI inclusivity

LGBTQI populations are mentioned in websites

Criterion

Description

people with a cervix". People who are same-gender attracted or Same-gender attracted (lesbian, gay, bisexual (i.e., lesbian, gay, bisexual, queer) are Each website was searched independently by two researchers to bisexual, aueer) mentioned. identify if it contained information pertaining to the four review criteria. People who are trans (binary and non-binary) The information or resources were then coded against the respective Trans (binary and non-binary) are mentioned. criteria. Websites that did not contain information pertaining to the four People who have intersex variations are Intersex review criteria were excluded. Response options were: "yes", met mentioned. Information addressed same-gender attracted. criteria on at least one page or resource, including websites that partly or bisexual, trans and/or intersex people inconsistently met criteria, i.e., in some resources but not others, or collectively. inconsistency throughout a single resource; "no", did not meet criteria Topics covered that are relevant to LGBTQI (Table 1). Validity and reliability were established by checking whether LGBTQI populations such as finding LGBTQI-friendly What is the nature of the health services; SOGI disclosure; social support there was agreement between the two researchers in coding of the information? and chosen family; LGBTQI identity and body websites, with any disagreements resolved through discussion with the image; same-gender relationships; LGBTQI senior author. sexuality and intimacy; LGBTQI fertility; legal rights of LGBTQI patients; LGBTQI carers; LGBTOI support services 2.2. International LGBTQI cancer patient and carer information Implicit LGBTQI versus resources exclusion LGBTQI populations are not International LGBTQI cancer patient and carer information written mentioned in websites in English was reviewed, including websites, online booklets, factsheets YES: References to partner were genderinclusive (e.g. your partner, spouse); Quotes/ and brochures, using the search terms: lesbian, gay, bisexual, trans, examples were gender-neutral. transgender, non-binary, queer, intersex, sexual/gender minority, NO: References to partners were not gender sexuality/gender diverse, LGBTQI or a variation of this acronym. The 1. References to partners are genderinclusive (e.g. resource only represented information resources were coded to identify which LGBTQI subinclusive heterosexual relationships); no reference to partners although it was within the scope of populations were addressed, and the nature of information provided. resource (i.e. resource includes information This review of international websites was conducted between April 2021 about support, relationships, sex, fertility but and February 2022. does not mention partners). YES: A range of intimate relationship contexts were acknowledged (e.g. multiple partners, 3. Results non-monogamous relationship agreements. casual relationships). 3.1. Australian website characteristics NO: Assumption that patients have one 2. Range of intimate relationship partner only; will not have sex outside of the contexts acknowledged relationship; no reference to relationships Table 2 presents the characteristics of the 61 Australian websites although within scope of resource (i.e. included in the review. Most websites were produced by national nonresource includes information about support, government organizations (n = 45, 73%), last updated between 2016 sex, fertility, returning home but does not and 2021. Some websites provided information about many cancer mention relationships). types (n = 19, 31%). The remainder focused on specific tumours, most YES: Discussion of sex is inclusive of a range of behaviours (e.g. oral sex, anal sex, mutual masturbation; safe sex is not just about using Table 2 condoms to avoid pregnancy); partial Characteristics of Australian cancer organization websites. acknowledgement of/relevance to those engaged in diverse sexual practices; broad or Characteristic n (%) 3. Information about sex inclusive of vague language. a range of sexual behaviours Type of organization NO: Discussion of sex assumed heterosexual 2 (3%) Government website penile-vaginal intercourse; no reference National NGO 45 (73%) although within scope of resource (e.g. State NGO 3 (5%) resource includes information treatment side Clinical organization 10 (16%) effects, intimate relationships, but does not Peak body 1 (2%) discuss sex). Website scope YES: Gender was differentiated from anatomy 19 (31%) Multiple cancer types and hormones all of the time or most of the General health issues relating to cancer 9 (15%) time. The material avoided assumptions about Specific cancer type a person's gender based on anatomy/ 7 (11%) Prostate hormones, or vice versa; i.e. sections on Breast 7 (11%) 4. Gender differentiated from cervical cancer refer to "people with a cervix" Gynaecological 4 (7%) anatomy and hormones or "women and other people with a cervix". 4 (7%) Brain NO: Conflated gender and sex, or otherwise Bladder 2 (3%) makes cis-normative assumptions (e.g. 2 (3%) Bowel describes anatomy as men's/women; sections Pancreatic 2 (3%) "for men" assume all men have penises, 2 (3%) Melanoma excluding trans men. Testicular 1 (2%) Leukaemia 1 (2%)

Average Range

Approximate grade-level of language

commonly prostate (n=7, 11%), breast (n=7, 11%), gynaecological (n=4, 7%), and brain cancer (n=4, 7%). Others focused on cancer-related health issues, such as thyroid-related illness, men's health and appearance management (n=9, 14%). The number of webpages reviewed within a website ranged from 7 to 2,8982, with an average of 346 pages on each website reviewed. This included 148 online booklets, 66 fact-sheets and 16 information packs across websites. In the presentation of results below, we use the term "resources" to refer to these modalities collectively. In reporting the target audience for resources, we use the terminology used by the website.

3.2. RQ1: Australian cancer organizations that explicitly mentioned LGBTQI people on their websites

Fig. 1 contains a summary of the Australian audit methods and results. Eight (13%) websites explicitly mentioned LGBTQI populations. This included 13 resources tailored specifically for LGBTQI people and 19 that mentioned LGBTQI people as part of information targeted at a general cancer audience. Table 3 summarizes the target audience (samegender attracted, trans and/or intersex people), modality and topics covered in the 32 resources within these eight websites that mentioned LGBTQI people. Tables 4 and 5 provides details of each resource, target audience, topics covered and website URLs. Most information was online versions of print booklets (n=24,75%).

3.2.1. Information resources tailored for LGBTQI audiences

Thirteen information resources were tailored for LGBTQI people, with the most common topics being LGBTQI support services (n = 8), sexuality and intimacy (n = 3), and LGBTQI identity/body image (n = 3) (Table 3).

Same-gender attracted, trans, or intersex specific resources. Six of these information resources targeted same-gender attracted populations (Table 4). This included a series of four booklets for gay and bisexual men with prostate cancer covering diagnosis [39], treatment [40], side effects [41] and wellbeing [42]. A webpage included information for same-sex partners and caring for someone with breast cancer, covering the topics "getting the right medical team", "taking care of yourself', and information about additional cancer and LGBTQI support services [43]. A webpage for people in same-sex relationships included three dot points on disclosure of sexuality in cancer care, inclusion of same-sex partners in appointments, and information about a cancer helpline [44]. Only one resource targeted trans and gender diverse people: a two-page online brochure that provided information about breast/chest cancer screening [45]. There were no resources targeted to intersex people.

LGBTQI resources. Six resources addressed same-gender attracted, trans and/or intersex people collectively using the LGBTQI acronym or its variations (Table 4). However, content within these resources primarily addressed same-gender attracted people. One was a webpage providing information about a gay/bi-sexual/trans cancer support group [46]. A webpage about breast screening for "LGBTI+" people provided information about "lgbti+ inclusive practice", "LGBTI+ community screening sessions" and answers to four "FAQ" (frequently asked questions), including a question about breast screening for intersex people [47]. Two webpages provided links to LGBTQI cancer information resources, webinars and support services under three subheadings: lesbian, bisexual, queer and/or questioning; gay, bisexual, queer and/or questioning; and, LGBTQI people and communities [48,49]. A booklet for young people who identify as LGBTIQ+ with cancer provided information on identity, support, treatment and lived experience [50]. A video promoted bladder cancer awareness for LGBT people [51] (see Table 4).

3.2.2. General cancer information resources that mentioned LGBTQI people
Nineteen information resources mentioned same-gender attracted,
trans and/or intersex people as part of information targeted to general

cancer audiences, including 18 booklets and one webpage (Tables 3 and 4). Disclosure (n=3), sexuality and intimacy (n=3) were the most common topics in general cancer resources that mentioned LGBTQI people (Table 3). Most of these resources provided brief acknowledgement that their information also applied to LGBTQI people [42,52–62] and noted that LGBTQI people may have additional needs. Fewer than half of the resources provided information that addressed LGBTQI-specific experiences (Table 4). This information included the legal rights of same-sex partners during cancer [63]; the importance of discussing sexual needs with HCPs [42,54]; a paragraph [64,65] and a page [66] about disclosure of sexual identity to HCPs for lesbian women; a paragraph on finding support for LGBTI carers [67]; and half a page for LGBT partners [68] and same-sex couples [69].

3.3. RQ2: LGBTQI inclusivity in Australian cancer information that does not mention LGBTQI people

Fig. 1 presents the findings of the review of websites that did not mention LGBTQI people, in relation to four criteria of LGBTQI inclusivity.

Gender neutral language to refer to partners. Twenty-six websites contained resources that referred to intimate partners of a person with cancer. Of these, 23 (88%) used the gender-neutral term partners, with the remainder using only husbands or wives.

Reference to a range of intimate relationships. Twenty-six websites discussed intimate relationships. Of these, none (0%) referred to multiple partners or non-monogamous relationship agreements.

Inclusive of a range of sexual behaviours. Sixteen websites discussed sexual intimacy and cancer. Of these, 11 (69%) provided information on a range of sexual behaviours, including exploring erogenous zones, mutual masturbation, oral sex, and the use of lubricants and sex toys. The remainder referred only to penile-vagina coitus.

Differentiation of gender from anatomy and hormones. Twenty-four organizations provided information or resources on their websites that discussed anatomy. Three (13%) used gender neutral and trans-inclusive language such as "people with prostates" rather than "men with prostates" and avoided gendered terms such as he and she by referring instead to the reader as "you" when discussing reproductive anatomy and hormones. The remaining 32 (80%) conflated gender with anatomy, including referring to prostate cancer as a men's disease and testosterone as a male hormone, or breast and cervical cancer as a women's cancer.

3.4. RQ3: International LGBTQI information resources

Thirty-eight international online resources were tailored for LGBTQI people, located in the UK, Canada and the USA.

Same-gender attracted resources. Six international resources were targeted at same-gender attracted populations. For example, three webpages for lesbian, bisexual and queer women, provided information about breast [70,71] and cervical screening [72]. Another webpage had content for gay and bisexual men on prostate cancer testing, treatment, side effects, sexuality, HIV, support and partners [73]. Two factsheets contained information for lesbian, bisexual and queer women on breast, lung, colorectal, gynae and skin cancer risks, screening, testing, prevention, and finding a trustworthy HCP [74,75].

Trans-specific resources. Eleven of the international resources were designed for trans people. These included two webpages for trans women and non-binary people on prostate cancer, focusing on screening, talking to HCPs [76], treatment, side effects, genital reconstructive surgery, wellbeing and support [77]; a webpage on other prostate problems for trans women [78]; and a question checklist on cancer risk and testing for prostate cancer with general practitioners [79]. Six webpages provided information about screening for breast/chest [80–82], cervical [83–85] and bowel [82] cancer for trans men, trans women and non-binary people, including what happens

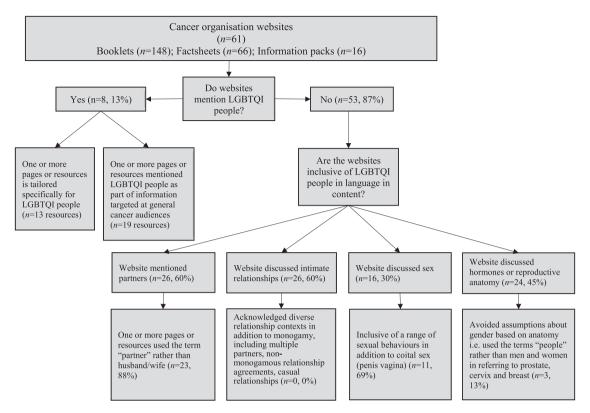


Fig. 1. Details of the LGBTQI Inclusivity Review of Australian Cancer Websites and Patient or Carer Information Resources.

during screening, additional barriers to screening, and disclosure. One booklet contained general information for trans people on cancer risks, late diagnosis and treatment, and trans-specific screening recommendations [86].

LGBTQI resources. Four websites and 16 resources addressed samegender attracted, trans and/or intersex people collectively using the LGBTQI acronym or its variations. Three webpages provided screening information on cervical [87,88], womb, ovarian and vaginal cancer [88] for LGBTQ, transgender, non-binary and intersex people, and an article about LGBT screening participation [89]. Four webpages [90-93], a booklet [94] and a factsheet [95] included content on disclosure for lesbian, gay, bisexual and transgender people. Three webpages [94,96, 97] and a factsheet [95] provided information on finding "safe" and "friendly" HCPs for LGBTQ+, LGB and trans people. A booklet [98] and two webpages [92,99] contained content on sexuality and intimacy for LGBTQ, gay, bisexual, trans and non-binary people. Two booklets [98, 100] and three webpages [73,77,96] provided information on cancer treatment for gay, bisexual, lesbian and LGBTQ+ people, and one webpage discussed healthcare needs of trans cancer survivors [97]. Four webpages included links to support organizations for LGBTQIA2S+2 people [96,101-103] and one website provided a database of LGBTQ2 + cancer resources [104]. Other topics included information on survivorship and end of life for LGBT people [100]; physical and emotional concerns for cancer survivors [105]; and food recipes for LGBTQI+ people in cancer treatment [106].

4. Discussion and conclusion

4.1. Discussion

This review revealed that LGBTQI people are almost invisible in

online Australian cancer information resources. The few Australian resources that mentioned LGBTQI people addressed breast or prostate cancer primarily, were directed to same-gender attracted people, and often provided only brief information. There was a dearth of resources produced by Australian cancer organizations for people who are trans, intersex, LGBTQI young people, carers, and for those with cancers other than in the breast and prostate. International resources predominantly focused on screening for same-gender attracted and trans people. Only a minority of Australian and international resources addressed aspects of cancer treatment and survivorship unique to LGBTQI people, often focusing on one topic, such as finding a LGBTQI friendly clinician, disclosure in cancer care or sexuality and intimacy.

Most of the Australian and international cancer information resources that mentioned LGBTQI people did so by addressing LGBTQI people as a collective population, rather than identifying the differing needs of same-gender attracted, trans and intersex populations, or by providing information specific to LGBTQI young people and carers. Each population has specific needs and concerns during cancer treatment and survivorship [21,107]. For example, same-gender attracted men with prostate cancer report unique concerns with sexual changes [8,108], and cancer treatment may increase or decrease gender dysphoria for trans people [22]. There is a need for cancer information to recognise the diversity of LGBTQI populations, as well as the potential intersection of sexuality and gendered identities [22], to address these different experiences and concerns.

Our findings confirmed that most Australian cancer information on webpages did not mention LGBTQI people. Some information implicitly exhibited LGBTQI inclusivity by adopting gender-neutral language to refer to partners and providing information on various sexual behaviours in addition to penile-vaginal intercourse. However, in not directly mentioning LGBTQI people, these resources rendered LGBTQI people invisible and failed to signal cultural awareness, inclusivity and safety [2,38]. These resources assumed cis-heteronormativity when discussing patients' bodies and intimate relationships. For example, gendered assumptions often described reproductive cancers as men's or women's

 $^{^{2}\,}$ Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, Intersex, Asexual, Two spirit

Table 3Australian cancer information that mentioned LGBTQI populations.

| | | By LGBTQI subgroup | | | | | |
|--|--------------|--|----------------------------|--------------------------------|---|--|--|
| | Total (n) | Same- gender attracted ⁱ (n) | Trans ⁱⁱ (n) | Intersex ⁱⁱⁱ (n) | Resource targeting multiple LGBTQI groups ^{iv} | | |
| Focus and | 32 | 12 | 2 | 0 | 18 | | |
| Modality of Resources 1. Resources tailored for | 32 | 12 | 2 | U | 16 | | |
| same-gender attracted, trans and/or intersex | 13 | 6 | 1 | 0 | 6 | | |
| people Modality | | | | | | | |
| Webpage | 6 | 2 | 0 | 0 | 4 | | |
| Booklet/ brochure | 6 | 4 | 1 | 0 | 1 | | |
| Video | 1 | 0 | 0 | 0 | 1 | | |
| Type of cancer General cancer | 4 | 1 | 0 | 0 | 3 | | |
| information Prostate | 5 | 4 | 0 | 0 | 1 | | |
| Breast | 3 | 1 | 1 | 0 | 1 | | |
| Reproductive | 0 | 0 | 0 | 0 | 0 | | |
| Bladder | 1 | 0 | 0 | 0 | 1 | | |
| Topics covered relevant to LGBTQI communities | | | | | | | |
| Finding LGBTQI- | 3 | 2 | 1 | 0 | 0 | | |
| friendly services | 3 | 2 | 1 | U | U | | |
| SOGI disclosure | 2 | 2 | 0 | 0 | 0 | | |
| Social support and chosen family | 2 | 1 | 0 | 0 | 1 | | |
| LGBTQI identity/ body image | 3 | 2 | 0 | 0 | 1 | | |
| Same-gender Relationships | 2 | 2 | 0 | 0 | 0 | | |
| LGBTQI sexuality and intimacy | 3 | 3 | 0 | 0 | 0 | | |
| LGBTQI Fertility | 2 | 2 | 0 | 0 | 0 | | |
| Legal rights of | 1 | 0 | 0 | 0 | 1 | | |
| LGBTQI patients | | | | | | | |
| LGBTQI carers | 1 | 1 | 0 | 0 | 0 | | |
| LGBTQI support services | 8 | 6 | 0 | 0 | 2 | | |
| Adolescents and young adults | 1 | 0 | 0 | 0 | 1 | | |
| 2. General cancer | | | | | | | |
| resources that mention LGBTQI people | 19 | 6 | 1 | 0 | 12 | | |
| Modality | | | | | | | |
| Webpage | 1 | 0 | 0 | 0 | 1 | | |
| Booklet/ brochure Type of cancer | 18 | 6 | 1 | 0 | 11 | | |
| General cancer information | 5 | 1 | 0 | 0 | 4 | | |
| Prostate | 2 | 1 | 0 | 0 | 1 | | |
| Breast | 4 | 2 | 1 | 0 | 1 | | |
| Reproductive | 7 | 2 | 0 | 0 | 5 | | |
| Testicular Topics covered relevant to LGBTQI communities | 1 | 0 | 0 | 0 | 1 | | |
| Finding LGBTQI- | 2 | 1 | 0 | 0 | 1 | | |
| friendly services SOGI disclosure | 3 | 2 | 0 | 0 | 1 | | |
| | | | | | | | |

Table 3 (continued)

| | | By LGBTQI | subgroup | | |
|------------------------------------|--------------|--|----------------------------|-----------------------------|--|
| | Total (n) | Same- gender attracted ⁱ (n) | Trans ⁱⁱ (n) | Intersex ⁱⁱⁱ (n) | Resources targeting multiple LGBTQI groups ^{iv} (n) |
| LGBTQI sexuality and intimacy | 3 | 1 | 0 | 0 | 2 |
| LGBTQI fertility | 2 | 0 | 0 | 0 | 2 |
| Legal rights of LGBTQI patients | 1 | 1 | 0 | 0 | 0 |
| LGBTQI carers | 1 | 0 | 0 | 0 | 1 |
| LGBTQI support services | 2 | 1 | 0 | 0 | 1 |
| LGBTQI AYAs | 1 | 0 | 0 | 0 | 1 |

- i. Resources only provided information for one or multiple same-gender attracted group including lesbian, gay, bisexual and queer communities.
- ii. Resources only provided information for trans people.
- iii. Resources only provided information for intersex people.
- iv. Resources provided the same information for same-gender attracted, trans and/or intersex people collectively, using the LGBTQI acronym or its variations. Individual information was not provided for any group.

cancers [38]. Resources also assumed monogamy and failed to acknowledge other relationship types, for example, that LGBTQI people may have multiple partnerships and non-monogamous relationship agreements and have casual sexual partners [8,35].

These exclusions are a human rights issue with material consequences. Invisibility of LGBTQI people and their specific needs in cancer information leads to experiences of marginalisation and fear of discrimination in cancer care, leading to non-disclosure of sexuality and gender identity to health care professionals [2]. This fear contributes to distress and reduced quality of life in LGBTQI cancer patients [6], compounding minority stress experienced by LGBTQI people [9], and negatively impacts upon satisfaction with healthcare [5], willingness to engage in cancer screening and physical health outcomes [109]. Lack of appropriate patient information increases the exposure of LGBTQI populations to misinformation, potentially compromising the capacity of LGBTQI people to make informed health decisions [110]. An absence of appropriate tailored resources also means that even aware HCPs may struggle to direct LGBTQI patients to inclusive information, thereby compromising their care [2,15,38].

This is the first study to review the LGBTQI inclusiveness of Australian cancer information across cancer streams and LGBTQI populations and to review international LGBTQI cancer online resources. One limitation was that the identification of resources mentioning LGBTQI people was dependent on the sensitivity of the search functions of websites. Our search was also limited to English language websites and public organizations. It is possible that some websites that hosted materials mentioning LGBTQI people were not identified. We also acknowledge that patient information resources may be produced and distributed by oncology services that are not available online. Our search terms did not include individual intersex diagnostic terms and may, therefore, underrepresent resources for intersex populations. Childhood cancer organizations were outside our scope; these need to be reviewed for LGBTQI inclusiveness regarding family structure descriptions. There is also a need for qualitative research to examine why organisations who do not have LGBTQI inclusive materials on their websites are non-inclusive, and how perceived barriers can be addressed.

4.2. Conclusion

As part of the iKT framework operating in this study, we have held several consultations with Australian cancer organizations, including those organizations who are partners in this project, and have engaged

 Table 4

 Australian cancer organization webpages and resources that contain LGBTQI content.

| Organization | Resource title and reference number | Information resource URL | Resource Type | Cancer type | LGBTQI terms used | LGBTQI content |
|--|---|---|------------------|----------------------------------|--|---|
| INFORMATION RESOUR | CES TAILORED SPECIFICALLY | FOR LGBTQI AUDIENCES | | | | |
| | Diagnosis: Diagnosing prostate cancer in gay and bisexual men (2014)[39] | https://www.prostate.org. au/media/246077/1_diag nosis.pdf | Booklet | Prostate | Gay and bisexual men | Part of a series of 4 information booklets for "gay and bisexual men" with prostate cancer including information about diagnosis such as tests, diagnosis, questions to ask, feelings and finding support. Part of a series of 4 information |
| | Treatment: Treating prostate cancer in gay and bisexual men (2014)[40] | https://www.prostate.org. au/media/246104/2_treat ment.pdf | Booklet | Prostate | Gay and bisexual men | booklets for "gay and bisexual men" with prostate cancer including information about treatment such as treatment options, managing treatment, complementary and alternative therapies and support. |
| Prostate Cancer Foundation of Australia | Side effects: Managing prostate cancer treatment side effects in gay and bisexual men (2014)[41] | https://www.prostate.org. au/media/246182/3_side -effects.pdf | Booklet | Prostate | Gay and bisexual men | Part of a series of 4 information booklets for "gay and bisexual men" with prostate cancer including information about treatment such as side effects from different treatment financial cost, managing side effects and finding support. |
| - Breast Cancer Network | Wellbeing: Maintaining wellbeing in gay and bisexual men with prostate cancer (2014)[42] | https://www.prostate.org. au/media/246179/4_well being.pdf | Booklet | Prostate | Gay and bisexual men | Part of a series of 4 information booklets for "gay and bisexual men" with prostate cancer including information about wellbeing such as managing feelings, self-care, relationships, sexuality and intimacy and finding support. |
| | Shine a light – gay/ bisexual/ trans cancer support group (2020)[46] | https://www.prostate.org. au/support/find-a-support- group/shine-a-light-gay-bi- sexual-trans-cancer- support-group/ | Webpage | Prostate | Gay and bisexual men, transgender people | Information about a support group f "gay and bisexual men", and "transgender people". |
| | Information for same-sex partners (2021)[43] | https://www.bcna.org.au/ understanding-breast-ca ncer/talking-to-family-and- friends/information-for-sa me-sex-partners/ https://clara.breastscreen. org.au/intranet/docume nts/21/1164/BSV_Trans_a nd_Gender_Diverse_People. | Webpage | Breast | Same-sex partners, LGBTQI+ , lesbian | Information for "same-sex" partners caring for someone with breast cancincluding getting the right medical team, self-care and links to informatiand support. |
| Australia | Breast/ chest screening for trans and gender diverse people (2019)[45] | | Booklet | Breast | Trans and gender diverse | Two-page brochure including Information about breast/ chest can screening for "trans and gender diverse" people. |
| | Information for LGBTQI+ people diagnosed with breast cancer (2022)[113]* | https://www.bcna.org. au/understanding-breas t-cancer/information-for-l gbtiqplus-people-diagnos ed-with-breast-cancer/ | Webpage | Breast | LGBTQI+ | Thirteen information pages for LGBT people with breast cancer and their carers, developed in collaboration withe Out With Cancer Study. Includin body image and gender; disclosure is cancer care; coping as a LGBTQI+ person; fertility; discrimination and legal rights; finding LGBTQI+ friend breast cancer services; sexuality and intimacy after cancer; social support trans and gender diverse people with breast; coping with DCIS; cancer; breast cancer and people with inters variations; palliative care |
| Breast Screen Victoria | LGBTI+ people (2021)[47] | https://www.breastscreen. org.au/community-support /lgbti-people/ | Webpage | Breast | LGBTI+ , lesbian, gay, bisexual, transgender and intersex | A statement of commitment to ensurinclusive and safe services for "LGBTI+" people, information about breast screening, acknowledgment of limited guidance available on breast screening for intersex people. |
| Cancer Australia | People in a same-sex relationship (2021)[44] | https://www.canceraustral ia.gov.au/impacted -by-cancer/family-and -relationships/people-in -a-same-sex-relationship | Webpage | General cancer information | Same-sex | Three brief dot points about disclosu including "same-sex" partners in appointments and support. |

(continued on next page)

Table 4 (continued)

| Organization | Resource title and reference number | Information resource URL | Resource Type | Cancer type | LGBTQI terms used | LGBTQI content |
|----------------------------------|--|---|---|------------------------------------|---|--|
| INFORMATION RESOUR | CES TAILORED SPECIFICALI | Y FOR LGBTQI AUDIENCES | | | | |
| Cancer Council | Lesbian, Gay, Bisexual, Transgender, Queer or Questioning, and Intersex Communities (LGBTQI) Cancer Support Services (2021)[48] | https://www.cancercounci l.com.au/get-support/lgbti -support/ | Webpage on Cancer Council NSW | General cancer / information | LGBTQI, lesbian, gay, bisexual, trans, queer or questioning, intersex | Links to information resources, webinars, and support services for "LGBTQI" people with cancer and the carers. |
| | LGBTIQ+ communities (2021)[49] | https://www.cancervic.org .au/get-support/lgbtiq-co mmunities | Webpage on Cancer Council Victoria | General cancer information | LGBTIQ+ | Links to information resources, webinars, and support services for "LGBTIQ+" people with cancer and their carers. |
| | LGBTQI+ People and Cancer A guide for people with cancer, their families and friends (2023)[112]* | https://www.cancerco uncil.com.au/cancer-info rmation/lgbtqi/ | Webpage and booklet | General cancer information | LGBQTQI+ LGBTIQ+ , lesbian, | Challenges in being a LGBTQI+ person with cancer; LGBTQI+ disclosure in cancer care; coping with cancer; finding LGBTQI+ friendly cancer services; dealing with discrimination and legal rights; body image, gender identity and cancer; sexuality and intimacy after cancer; fertility; trans and gender diverse people; intersex people and cancer; advanced cancer; life after treatment; caring for someous with cancer; support and information questions for your doctor. Information for young "LGBTIQ+" |
| Peter MacCallum Cancer Centre | Being OK Being You (2019)[50] | https://www.petermac. org/beingokbeingyou | Booklet | General cancer information | gay, bisexual, trans, intersex, queer or questioning | people with cancer including specific content for same-gender attracted, TGD and intersex young people. |
| Bladder Cancer Australia | Bladder cancer awareness for the LGBT community (2021) [51] | | Video | Bladder | LGBT | Video promoting bladder cancer awareness for LGBT people. |
| INFORMATION RESOUR | CES TARGETED TO BROADE | R AUDIENCES THAT MENTIO | NED LGBTQ | I PEOPLE | | |
| | Cancer care and your rights: A guide for people with cancer, their families and friends (2019)[63] | https://www.cancercouncil. com.au/wp-content/uploads/ 2020/04/CANCER1.pdf | BOOKIET | General cancer information | Same-sex partner | Brief section about the legal rights o "same-sex partners" during cancer. |
| | Sexuality, intimacy and cancer: A guide for people with cancer and their partners (2019)[54] | https://www.cancercouncil. com.au/wp-content/uploads/ 2014/05/UCPUBS1.pdf | Booklet | General cancer information | LGBTI | Information about sexuality and intimacy with a brief section stating that the information is also relevant "LGBTI" people. |
| | Caring for someone with cancer: A guide for family and friends who provide care and support (2017) [67] | https://www.cancercouncil. com.au/wp-content/uploa ds/2014/05/UC-pub-Caring- for-Someone-with-Cancer-C AN925_web-lo-res_Oct-2017.pd | Booklet | General cancer information | LGBTI | Brief paragraph with information about support for "LGBTI" carers including a referral to an LGBTI- specific organization. |
| | Understanding prostate cancer: A guide for people with cancer, their families and friends (2020)[59] | https://www.cancer.org.au/assets/pdf/understanding-protate-cancer-booklet | | Prostate | Trans, intersex, same-sex | Information about prostate cancer with a brief acknowledgement that "trans" and "intersex" people can ge prostate cancer and a brief section titled "what if I am in a "same-sex" relationship?" |
| Cancer Council | Understanding cervical cancer: A guide for people with cancer, their families and friends (2019)[57] | https://www.cancer.org.au /assets/pdf/understanding-cervical-cancer-booklet | v Booklet | Cervical | Lesbian, gay, bisexual, trans, intersex | Information about cervical cancer wi brief acknowledgement that "lesbian gay, bisexual, trans and intersex" people are also at risk of cervical cancer. |
| | Understanding cancer of the uterus: A guide for people with cancer, their families and friends (2019) [56] | https://www.cancer.org.au/ assets/pdf/understanding-ute rus-cancer-booklet | Booklet | Uterine | Transgender men, intersex | Information about uterine cancer with brief acknowledgement that "transgender men" and "intersex people" can get uterine cancer. |
| | Understanding vulvar and vaginal cancers: A guide for people with cancer, their families and friends (2020)[61] | https://www.cancercouncil.co m.au/wp-content/uploads/ 2014/05/Understanding-Vulva -and-Vaginal-Cancers-2020.pdf | r | Vaginal and vulvar | Transgender men, intersex | Information about vaginal and vulva cancer with brief acknowledgment that "transgender men" and "interse people" can get these cancers. |
| | Understanding breast cancer: A guide for people with cancer, their families and friends (2018)[55] | https://www.cancer.org.au/ assets/pdf/understanding-brea- -cancer-booklet | st Booklet | Breast | Transgender, non- binary, gender diverse | Brief section acknowledging that "transgender, non-binary and gende diverse" people can get breast cance |
| | | | | | | (continued on next pag |

Table 4 (continued)

| INFORMATION RESOUR | CES TARGETED TO BROADI | ER AUDIENCES THAT MENTION | ED LGBT | QI PEOPLE | | | |
|---|---|--|-----------------|----------------------------|--|---|--|
| | Understanding ovarian cancer: A guide for people with cancer, their families and friends (2020)[58] | https://www.cancer.org.au/a ssets/pdf/understanding-ovaria n-cancer-booklet | Booklet | Ovarian | Transgender men, intersex | Information about ovarian cancer that acknowledges that "transgender men" and "intersex" people can get ovarian cancer. | |
| | Understanding testicular cancer: A guide for people with cancer, their families and friends (2018)[60] | https://www.cancer.org.au/a ssets/pdf/understanding-testic ular-cancer-booklet | Booklet | Testicular | Transgender women, male- assigned non-binary people, intersex | Information about testicular cancer that acknowledges that "transgender women" and "intersex people" can get testicular cancer. | |
| | Fertility and cancer: A guide for people with cancer, their families and friends (2020)[62] | https://www.cancercouncil.co m.au/wp-content/uploads/ 2016/07/Fertility-and-Cancer- 2020.pdf | Booklet | General cancer information | Transgender, non- binary, intersex | Information about fertility and cancer with a brief statement that the information is also relevant to "transgender, non-binary and intersex people". | |
| | Intimacy and sexuality for women with gynaecological cancer - starting a conversation (2012)[52] | https://www.canceraustralia.go v.au/publications-and-resourc es/cancer-australia-publicat ions/intimacy-and-sexuality-wo men-gynaecological-cancer-start ing-conversation | Booklet | Gynaecological | Homosexual | Two-page booklet including information about intimacy and sexuality for women with gynaecological cancer, stating it is also relevant for "homosexual" women. | |
| Cancer Australia | Epithelial ovarian cancer: Understanding your diagnosis and treatment (2012)[64] | https://www.canceraustralia. gov.au/sites/default/files/pu blications/occ-epithelial-ova rian-cancer_505aa93e2004f.pdf | Booklet Ovarian | | Lesbian | Brief section with information around disclosure of sexual identity to healthcare professionals and links to support for "lesbian" women with epithelial ovarian cancer. | |
| | Guide for women with secondary breast cancer (2012)[65] | https://www.canceraustralia.go v.au/sites/default/files/publica tions/sbc_guide_for_women_wi th_secondary_breast_cancer _52aa470918f7a.pdf | Booklet | Breast | Same-sex couples, lesbian | Brief paragraph about disclosure of sexual identity for "same-sex" couples and information about finding suppor services for "lesbian" women. | |
| Breast Cancer Network Australia | 'I wish I could fix it': Supporting your partner through breast cancer (2016)[66] | https://www.bcna.org.au/ media/3684/bcn1198_p artnerbooklet-2016_online.pdf | Booklet | Breast | Lesbian, homosexual women, same-sex partners | Information for "lesbian" women in a "same-sex" relationship around disclosure of sexual identity to healthcare professionals, accessing information relevant for same-sex partners, and resources and support. | |
| | When someone close to you have metastatic breast cancer (2018)[68] | https://www.bcna.org.au/me dia/6408/whensomeonecloseto youhasmetastaticbreastcancer -2018.pdf | Booklet | Breast | Lesbian, gay, bisexual, transgender, LGBT | Information about caring for someone with cancer included a brief section, "support for LGBT partners". | |
| Prostate Cancer Foundation Australia | Wellbeing: Information for partners and carers of men affected by prostate cancer (2014)[42] | https://www.prostate.org. au/media/430572/Wellbeing. pdf | Booklet | Prostate | Homosexual, same- sex, gay, bisexual | Brief paragraph acknowledging that sexuality and intimacy are equally important in "same-sex" relationships and "same-sex" partners should be included in discussions with healthcare professionals. | |
| Canteen | Maybe later baby? A guide to relationships, sex and fertility for young people with cancer (2015)[53] | https://www.canteen.org.au/ho w-we-help/books-resources/gui de-to-fertility-for-young-people -with-cancer | Booklet | General cancer information | Gay, bisexual, transgender | Information about fertility for young people with cancer included a question and answer acknowledging that fertility is also relevant for "gay, bisexual and transgender" people | |
| Ovarian Cancer Australia | Resilience kit for women living with ovarian cancer (2018)[69] | https://ocaovariancanceraus. blob.core.windows.net/assets /pages/Digital-Interactive-Res ilience-Kit.pdf | Booklet | Ovarian | Lesbian, gay, bisexual, transgender, intersex, LGBTI, same-sex couples | Brief sections about support for "same sex couples" and referrals to "LGBTT"-specific organizations. | |

^{*} These two resources [112,113] were developed as part of the Out with Cancer Study, following the review. They have been included in this table as they are discussed in the body of the paper as translational outcomes of the study.

in a process of co-design to develop LGBTQI cancer resources. Several organizations have publicly stated their commitment to LGBTQI-inclusive service provision [47,49,111] and in collaboration with the Out with Cancer study team have produced a range of patient information resources targeted to LGBTQI people with cancer. To date, these include an 80-page Cancer Council booklet "LGBTQI+ People and Cancer: A guide for people with cancer, their families and friends" [112], and a series of 13 information pages for LGBTQI people with breast cancer and their carers hosted by Breast Cancer Network Australia (BCNA) [113]. These resources address topics such as LGBTQI+ disclosure in cancer care; finding LGBTQI+ friendly cancer services; dealing with discrimination and legal rights; body image,

gender identity and cancer; sexuality and intimacy after cancer; trans and gender diverse people with cancer; intersex people with cancer; advanced cancer; and caring for someone with cancer. The Australian and New Zealand Urogenital and Prostate Cancer Trials Group (ANZUP) [114] reviewed and revised all its internal and outward-facing documentation to ensure language was LGBTQI inclusive and has implemented this as an ongoing standard process as future documentation and communication is developed. We have also collaborated with ACON, one of our study partners, to ensure that LGBTQI populations are included in the Australian Cancer Plan [25].

 Table 5

 International websites and information resources tailored for LGBTQI audiences with cancer.

| Organization | Resource title and reference number | Information resource URL | Resource Type | Cancer type | LGBTQI terms used | LGBTQI content |
|-------------------------------|---|---|-----------------------|---|---|---|
| NTERNATIONA | | DURCES TAILORED SPECIFICALLY FOR LGBTO | | S | | |
| | Lesbian, bisexual and queer women and breast screening (2022) [70] | https://cancer.ca/en/cancer-information/ find-cancer-early/screening-in-lgbtq- communities/lesbian-bisexual-and-queer- women-and-breast-cancer-screening | Webpage | Breast | Lesbian, bisexual, queer | Acknowledgment that "lesbian", "bisexual" and "queer" women may face additional barriers to breast screening. |
| | As a trans man, do I need to get screened for chest cancer? (2022)[80] | https://cancer.ca/en/cancer-information/find-cancer- early/screening-in-lgbtq-communities/as-a-trans-man-do- i-need-to-get-screened-for-chest-cancer | Webpage | Breast | Trans men, trans masculine, trans guy | Acknowledgment that "trans men" may face additional barriers in receiving chest screening. Acknowledgment that "trans |
| | As a trans woman, do I need to get screened for breast cancer? (2022)[81] | https://cancer.ca/en/cancer-information/find-cancer- early/screening-in-lgbtq-communities/as-a-trans-woman- do-i-need-to-get-screened-for-breast-cancer | Webpage | Breast | Trans women, transfeminine | women" may face additional barriers in receiving breast screening and information about the risk of breast cance in trans women. |
| Canadian Cancer Society | Lesbian, bisexual and queer women and cervical cancer screening (2022) [72] | https://cancer.ca/en/cancer-information/find-cancer- early/screening-in-lgbtq-communities/lesbian-bisexual- and-queer-women-and-cervical-cancer-screening | Webpage | Cervical | Lesbian, bisexual, queer, gay | Information for "lesbian", "bisexual", "gay" and "queer women about cervical cancer risk and screening. |
| | As a trans woman, do I need to get screened for cervical cancer? (2022)[83] | https://cancer.ca/en/cancer-information/find-cancer- early/screening-in-lgbtq-communities/as-a-trans-woman- do-i-need-to-get-screened-for-cervical-cancer | Webpage | Cervical | Trans woman | Information about cervical cancer risk and screening for "trans women". |
| | As a trans man, do I need to get screened for cervical cancer? (2022)[84] | https://cancer.ca/en/cancer-information/find-cancer- early/screening-in-lgbtq-communities/as-a-trans-man-do- i-need-to-get-screened-for-cervical-cancer | Webpage | Cervical | Trans men, transmasculine, female to male, FtM gender spectrum | Acknowledgment that "trans men" may face additional barriers to cervical screening and information about the ris of cervical cancer in trans men. |
| | Questions about cervical screening from LGBTQ community (2022) [87] Cervical screening | https://cancer.ca/en/cancer-information/find-cancer- early/screening-in-lgbtq-communities/questions-about- cervical-cancer-screening-from-lgbtq-community | Webpage | Cervical | LGBTQ | Questions and answers including, "I've had bottom surgery. Do I still need to be screened?" and "I'm on T. Do still need a Pap test?" Information for "trans men" |
| Jo's Cervical Trust | for trans men and/ or non-binary people (2020)[85] | https://www.jostrust.org.uk/information/cervical-screening/trans-non-binary | Webpage | Cervical | Trans men, non-binary people | and "non-binary people about cervical cancer screening and disclosure. |
| Γhe Eve Appeal | Info for the transgender, non- binary and intersex communities (2021) [88] | https://eveappeal.org.uk/gynaecological- cancers/tnbiinfo/ | Webpage | Cervical, womb, ovarian, vaginal | Transgender, non- binary, intersex | Information about womb, ovarian, cervical, vulval, vaginal cancers; cervical screening; tips for HCPs. |
| | Information for gay and bisexual men (2018)[73] | https://prostatecanceruk.org/prostate-information/living- with-prostate-cancer/gay-and-bisexual-men | Webpage | Prostate | Gay, bisexual | Information about prostate cancer for "gay and bisexual men" including, testing, treatment, side effects, sexuality, HIV, support and partners. |
| | Prostate cancer tests and treatment: A guide for gay and bisexual men (2018)[98] | https://shop.prostatecanceruk.org/pdf/ publication/ guide_for_gay_and_bisexual_men-ifm.pdf | Booklet | Prostate | Gay, bisexual, trans | Information about prostate cancer for "gay and bisexual men" including testing, treatment, side effects, HIV, sexuality, support and links t LGBTQI organizations. |
| Prostate Cancer UK | Checklist for talking to your GP about prostate cancer as a trans woman (2020) [79] | https://prostatecanceruk.org/media/ 2499882/gp-form-for-trans-women.pdf | Question checklist | Prostate | Trans women, non- binary | Checklist of questions for "trans women" to ask a GP regarding cancer risk and testing for prostate cancer. |
| | Trans women and prostate cancer (2020)[99] | https://prostatecanceruk.org/prostate- information/are-you-at-risk/trans-women- and-prostate-cancer | Webpage | Prostate | Trans women, non- binary, intersex | Information for "trans women" about the prostate, prostate cancer, sexuality, symptoms and risk. Information about prostate |
| | Prostate cancer diagnosis in trans women (2020)[76] | https://prostatecanceruk.org/prostate- information/prostate-tests/prostate-cancer- diagnosis-in-trans-women | Webpage | Prostate | Trans woman, non- binary | cancer for "trans women" including screening and speaking to health professionals. |

Table 5 (continued)

| | Prostate cancer treatments for trans women (2020)[77] | https://prostatecanceruk.org/prostate- information/treatments/prostate-cancer- treatments-for-trans-women | Webpage | Prostate | Trans woman, non- binary | Information about prostate cancer for "trans women" including treatment, side effects, genital reconstructive surgery, wellbeing and support. |
|--|--|--|-----------|----------------------------------|--|--|
| | Other prostate problems in trans women (2020)[78] | https://prostatecanceruk.org/prostate- information/further-help/other-prostate- problems-in-trans-women | Webpage | Prostate | Trans women, non- binary | Information for "trans women" about prostate problems. |
| Zero: The end of prostate cancer | The LGBTQ+ community and prostate cancer (2021)[90] | https://zerocancer.org/learn/about- prostate-cancer/risks/lgbtq-community- prostate-cancer/ | Webpage | Prostate | LGBTQIA+ , gay, bisexual, transgender woman, | Information for "gay or bisexual men" and "transgender women" with prostate cancer, disclosure and support. |
| Living Beyond Breast | Breast Cancer in Focus: Getting the care you need as a lesbian, gay or bisexual person (2014)[94] | https://www.lbbc.org/sites/default/files/ LBBC%2BIn%2BFocus%2BLGB%2BWeb% 2B2014.pdf | Booklet | Breast | Lesbian, gay, bisexual, transgender, genderqueer, gender variant | Information for "lesbian", "gay" and "bisexual" women about disclosure and finding "LGB-friendly" HCPs. |
| Cancer | Coming out as transgender to your breast cancer care team (2014)[91] | https://www.lbbc.org/lgbt-breast-cancer/ lifestyle-and-practical-matters/ relationships-communication/coming-out | Webpage | Breast | Lesbian, gay, bisexual, transgender | Information for "lesbian", "gay", "bisexual" and "transgender" people about disclosure to HCPs. Information for "lesbian" and |
| LGBT Foundation | Breast Cancer [71] | https://lgbt.foundation/who-we-help/ women/general-health/breast-cancer | Webpage | Breast | Lesbian, bisexual | "bisexual" women around breast awareness, cancer risk, getting to know your breasts and screening. |
| BC Cancer | LGBTQIA2S+ Pathfinder: A guide to finding library resources and support services (2022)[101] | http://www.bccancer.bc.ca/library-site/ Documents/pathfinder_LGBT-General.pdf | Webpage | General cancer information | LGBTQIA2S+ | Links to resources and support organizations for LGBTQIA2S+ people. |
| LGBT Health | Resources for LGBTQ2S+ Cancer Patients (n.d.)[102] | http://www.bccancer.bc.ca/about-site/ Documents/ sogi_resources_cancer_patients_web.pdf | Webpage | General cancer information | LGBTQIA2S+ | Links to resources and support organizations for LGBTQIA2S+ people. Information for "lesbian", "bi" |
| Link: The Network for Health Equity | Cancer and lesbian, bisexual and queer women (n.d.)[74] | file://ad.uws.edu.au/dfshare/HomesCMB\$/90935679/ Downloads/LGBTHealthLink-queerwomen_brochure_v7% 20(1).pdf | Factsheet | General cancer information | Lesbian, bi, queer | and "queer" women about breast, lung and other cancer risks, screening and finding a HCP. |
| Trekstock: Young adult cancer support | Shining a light on LGBTQ+ sex and cancer (2022)[92] | https://www.trekstock.com/news/shining-a-light-on-lgbtq-sex-and-cancer | Webpage | General cancer information | LGBTQ+ , trans | Information for "LGBTQ+" and "trans" people about sexuality, intimacy and cancer. Information for "LGBTO+" |
| Canadian Cancer Survivor Network | LGBTQ+ information (n.d.) [96] | https://survivornet.ca/cancer-type/all-cancers/cancer-survivorship/lgbtq-information/ | Webpage | General cancer information | $\begin{array}{c} \text{LGBTQ+} \; , \\ \text{transgender, queer} \end{array}$ | people about cancer screening, treatment, disclosure, barriers, finding safe and inclusive HCPs, and LGBTQI-specific resources. Information for "LGBT" people about diagnosis, treatment, survivorship, |
| Macmillan Cancer Support | The emerging picture: LGBT people with cancer (2014)[100] | https://www.macmillan.org.uk/_images/ lgbt-people-with-cancer_tcm9-282785.pdf | Booklet | General cancer information | LGBT, lesbian, gay, bisexual, transgender | progressive illness and end of life, prostate cancer and gay and bisexual men, breast cancer and lesbian and bisexual women, cervical cancer and lesbian and bisexual women, lifestyle factors impacting cancer risk. |
| Live Through This | Cooking community: Cancer aware recipes made to share (n.d.)[106] | https://secureservercdn.net/ 160.153.137.99/04 v.b4d.myftpupload. com/wp-content/uploads/2021/05/ cook_book_web.pdf | Booklet | General cancer information | LGBTIQ+ | Recipes for people going through cancer treatment. |
| CancerCare | Coping with cancer as an LGBT person (2019)[95] | https://media.cancercare.org/publications/ original/209-fs_lgbt.pdf | Factsheet | General cancer information | LGBT, lesbian, gay, bisexual, transgender | Information for "LGBT" people around health disparities for LGBT people, difficulties accessing care, disclosure and finding LGBT friendly health care professionals (continued on next page) |

Table 5 (continued)

| Livestrong | Coming out with cancer: Living after cancer treatment (2014)[105] | https://d1un1nybq8gi3x.cloudfront.net/ sites/default/files/what-we-do/portfolio/ assets/LACT_Coming-Out-With-Cancer- LGBT.pdf | Booklet | General cancer information | LGBT, lesbian, bisexual, gay, transgender | Information for "LGBT" people around physical, emotional and day to day concerns for cancer survivors and checklists of concerns to discuss with HCPs. |
|--|---|--|-----------|--|--|---|
| PHE Screening- GOV.UK | Addressing inequalities in LGBT cancer screening coverage (2019) [89] | https://phescreening.blog.gov.uk/2019/ 03/15/addressing-inequalities-in-lgbt- cancer-screening-coverage/ | Webpage | General cancer information | LGBT, lesbian, gay, bisexual, transgender | Article about screening participation |
| American Cancer Society | Cancer facts for lesbian and bisexual women (2021)[75] | https://www.cancer.org/content/dam/ CRC/PDF/Public/7708.00.pdf | Factsheet | General cancer information | Lesbian, bisexual | Information for "lesbian" and "bisexual" women around barriers to healthcare; about breast, colorectal, gynae and skin cancers - risks, prevention, testing; what else you can do to help reduce your cancer risk. |
| Canadian Rainbow Health Coalition | Trans people and cancer (2006)[86] | https://www.rainbowhealthontario.ca/wp-content/uploads/2009/05/Cancer.pdf | Booklet | General cancer information | Trans | Information for "trans" people around what is cancer; cancer risks; risk of late diagnosis and treatment; trans-specific cancer screening recommendations. |
| Cancer Research UK | I'm trans or non- binary, does this affect my cancer screening? (2019) [82] | https://www.cancerresearchuk.org/about- cancer/screening/trans-and-non-binary- cancer-screening#screening60 | Webpage | General cancer information | Trans, non-binary | Information about cervical, breast and bowel cancer screening for "trans" and "non-binary" people. |
| Conquer: The patient voice | Join us in celebrating transgender cancer survivors (2018) [97] | https://conquer-magazine.com/issues/ 2018/vol-4-no-1-february-2018/636-join- us-in-celebrating-transgender-cancer- survivors | Webpage | General cancer information | Transgender, gender non-conforming, lesbian, gay, bisexual, queer, intersex | A magazine article that provides information around healthcare needs of trans and gender non confirming cancer survivors, health insurance claims, finding trans-friendly HCPs. |
| INTERNATIONA | L LGBTQI-SPECIFIC CA | INCER ORGANIZATION WEBSITES | | Cancer | | Website of a cancer support |
| Live Through This | Live through this (2022)[103] | https://livethroughthis.co.uk/ | Website | support and advocacy | LGBTIQ+ | and advocacy charity for LGBTIQ+ people affected by cancer |
| National LGBT Cancer Network | National LGBT Cancer Network (2022)[116] | https://cancer-network.org/cancer-information/ | Website | General cancer information | LGBT, lesbian, gay men, transgender/ gender nonconforming people, LGBT caregivers | Website providing a series of fact sheets with information about cancer and LGBT people. |
| National LGBT Cancer Project | National LGBT Cancer Project (2022)[93] | https://www.lgbtcancer.org/lgbt-cancer- survivorship/ | Website | General cancer information | LGBT, lesbian | Website of a cancer survivor support and advocacy non-profit organization. Information about LGBT health risks, lived experiences, LGBT cancer survivorship, coming out to Doctors, Intersectionality, caregiving. Information about cancer treatment centres, clinical trials and support groups. |
| Queering Cancer | Queering Cancer – Inclusive Cancer Care (2022)[104] | https://queeringcancer.ca/ | Website | Directory of LGBTQ cancer resources | LGBTQ2 + , trans, genderqueer, non-binary, agender, non-cis identities, asexual, demisexual, pansexual | Website containing a database of LGBTQ2 + cancer resources, information and education for healthcare professionals, first person accounts from LGBTQ2 + patients and carers, information about consultancy and education in LGBTQ2 + oncology care and research in LGBTQ2 + cancer experiences and improvement of care. |

Table 6

Recommendations for LGBTQI patient cancer information.

To be LGBTQI inclusive and safe, general cancer information needs to:

- Explicitly acknowledge LGBTQI patients, partners and other carers in all resources.
 This includes using quotes and case studies from LGBTQI people.
- Consistently use gender-inclusive language. For example, you, they, sibling, parent and partner. Alternatively, use an additive approach that acknowledges trans people, for example "your boyfriend, girlfriend or non-binary partner".
- Recognise diverse social support structures including partners, friends and other chosen family as well as those who have limited or no support.
- Provide information that encompasses a range of relationship types in addition to coupled monogamy, such as information for those in multiple or casual romantic and/or sexual relationships.
- 5. Information about the impacts of cancer and treatment on sexual activities and implications for safer sex practices need to be inclusive of a range of sexual behaviours such as oral sex, anal sex and mutual masturbation in addition to penile-vagina intercourse. This should include concerns beyond changes to sexual and reproductive organs; for example, radiation to the head/neck may affect oral sex
- Provide information about LGBTQI specific cancer information and support (e.g., in Australia: Cancer Council NSW[112], Breast Cancer Network Australia[113]) as well as other LGBTQI support services (e.g., in Australia: Qlife). Where possible, indicate if general cancer information and support is LGBTQI inclusive.
- Use images that are inclusive of LGBTQI people and that represent LGBTQI people from a range of cultural backgrounds, including LGBTQI Indigenous Australians, religious backgrounds and people with disability.

There is a need for Australian cancer patient information that addresses the impacts of cancer for LGBTQI patients and carers across a broad range of tumour types in relation to topic such as:

- 1. Finding LGBTQI friendly cancer HCPs.
- 2. LGBTQI disclosure in cancer care how to 'come out' to clinicians.
- 3. Dealing with cis-heteronormativity in cancer care.
- 4. Dealing with discrimination in cancer care and legal rights of LGBTQI patients
- Navigating inclusion of LGBTQI partners and chosen family in cancer care, as well as acknowledging that support systems may be affected by stigma and rejection of LGBTQI identities.
- 6. LGBTQI inclusive peer support.
- The potential impacts of cancer and treatment on exploration and acceptance of sexual and gender identities, coming out, and establishing relationships and LGBTQI community.
- 8. Impacts of cancer and treatment on sexual and gender identities and body image such as the potential impacts of hair loss, weight loss or gain, scarring, reduced mobility, incontinence; impacts and meanings of changes to sexuality, intimacy and fertility for LGBTQI people; impacts of mastectomy on gender identity and decisions about reconstruction or flatness.
- 9. Coping with cancer as an LGBTQI person.
- 10. Specific information for trans people such as about the impacts of cancer on trans embodiment (contributing to gender dysphoria or euphoria); impacts of cancer and cancer caring on gender affirmation; navigating cis-genderism in cancer care.
- 11. Specific information for intersex people such as about the impacts of cancer on gendered embodiment; navigating informed consent in cancer care; impacts of cancer on hormone therapies used by some intersex patients; impact of cancer prevention surgery in childhood on trust in health care professionals.
- 12. End of life planning and palliative care for LGBTQI people.
- Cancer information for LGBTQI people needs to represent LGBTQI people from a range of cultural backgrounds, including LGBTQI Indigenous Australians, religious backgrounds and people with disability.
- 14. Ensure that information specifically addresses the LGBTQI communities that are mentioned. For example, information using the LGBTQI acronym needs to include information for people who are same- and multi-gender attracted, trans, and intersex. Information for LGBT people needs to include information for people who are same-gender attracted and trans. And so on.

For recent Australian examples, see Cancer Council NSW [112] and Breast Cancer Network Australia (BCNA) [113].

4.3. Practice implications

Creating an environment where LGBTQI patients and their carers feel safe and included is central to the provision of equitable cancer care [25, 115]. There is a need for patient-centered education materials and survivorship resources reflective of the lives of LGBTQI patients and their families, in addition to a visible bill of patient rights, cultural competency training for staff, and inclusion of SOGI information on

intake forms [115]. Cancer organizations need to be LGBTQI inclusive within general cancer information, and also need to work with LGBTQI organizations and LGBTQI people who have lived experience of cancer to co-design LGBTQI tailored patient information that addresses the unique needs of individual LGBTQI populations. Table 6 contains guidelines for the development of this information.

Declarations

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Author contributions

JU and JP designed the study and prepared the application for funding, in collaboration with The Out with Cancer Study team. The audit review criteria was developed by JU, JP and RP in collaboration with The Out with Cancer Study Team. Data were collected by SR and RP. SR conducted the data analysis, in collaboration with RP and JU. JU, SR and RP wrote the paper with critical input from JP. The Out with Cancer Study Team provided critical commentary on the written paper. All authors approved the final paper.

CRediT authorship contribution statement

Power Rosalie: Formal analysis, Writing – original draft. **Perz Janette:** Conceptualization, Supervision, Validation, Writing – review & editing. **Out with Cancer Study Team The:** Conceptualization, Writing – review & editing. **Ussher Jane:** Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Supervision, Validation, Writing – original draft,

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Declaration of Competing Interest

The authors have no conflict of interest to declare.

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