

**Improving LGBTIQ+  
cancer care  
across NEMICS:  
A summary report**

**2023**

# Acknowledgements

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NEMICS is a cancer services improvement network. NEMICS builds relationships between healthcare providers and other cancer care stakeholders to develop, implement and evaluate initiatives that improve the way our member health services provide care and support people affected by cancer. For more information, [www.vics.org.au/nemics](http://www.vics.org.au/nemics).

There are three documents that inform this summary report:

- LGBTIQ+ cancer care research, experience, barriers, facilitators and recommendations: scoping review 2023.
- LGBTIQ+ acknowledgement, inclusion, and targeted action in Australian cancer care policy resources: environmental scan 2023.
- Sexual orientation and gender identity (SOGI) data identifiers in Victorian cancer datasets: evaluation report 2023.

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# Glossary

Term	Definition
Cancer care policy resources	Used as a collective term within this report to include policy, cancer plans, cancer strategies, position statements, service plans, and best practice guidance. Referred to in brief as policy resources.
Gender identity	<p>Refers to the way that a person experiences their gender, independent of the sex they were assigned at birth. Gender identity is a social construct, and can include:</p> <ul style="list-style-type: none"> <li>• Cisgender (identifying with the biological sex assigned at birth)</li> <li>• Transgender (identifies with a gender different to the biological sex assigned at birth)</li> <li>• Nonbinary (does not identify with a gender that conforms to binary descriptions of gender)</li> <li>• Gender fluid (someone who has a fluid experience of gender that may change at different times or in different situations)</li> <li>• Genderqueer (an umbrella term that generally refers to anyone who does not experience their gender to be aligned solely with the biological sex they were assigned at birth)</li> <li>• Sistergirl (a term for Aboriginal and/or Torres Strait Islander gender diverse people with a female spirit who take on feminine roles within their community)</li> <li>• Brotherboy (a term for Aboriginal and/or Torres Strait Islander gender diverse people with a male spirit who take on masculine roles within their community)</li> </ul> <p>Other terms may also be used to describe a person's gender identity.</p>
LGBTIQA+	One of several commonly used acronyms that refers to people with a non-heterosexual sexual or romantic orientation and/or a gender identity that does not align with the sex they were assigned at birth. The letters represent lesbian, gay, bisexual/pansexual, transgender, intersex, queer/questioning, and asexual/aromantic people, and the plus sign represents all other individuals that identify as something other than heterosexual and/or cisgender.
Romantic orientation	Refers to the gender a person is willing to enter a relationship with, independent of the gender a person may be sexually attracted to. Romantic orientation is generally seen as driven by personal choice and may change throughout a person's life. A person's romantic orientation may or may not align with their sexual orientation.

	For example, an asexual person may be willing to enter a romantic relationship with another person, even though they do not experience sexual attraction to others.
Sexual orientation	<p>Refers to the gender a person feels sexual attraction for. Some sexual orientations include:</p> <ul style="list-style-type: none"> <li>• Heterosexual (a person attracted to people of the opposite gender)</li> <li>• Lesbian (typically a woman attracted to other female-identifying people)</li> <li>• Gay (typically a man attracted to other male-identifying people)</li> <li>• Bisexual (a person attracted to both female-identifying and male-identifying people)</li> <li>• Pansexual (a person attracted to others regardless of their gender identity)</li> <li>• Asexual (a person who is not sexually attracted to other)</li> </ul> <p>Other terms may also be used to describe a person's sexual orientation. A person's sexual orientation does not always align with their romantic orientation.</p>
SOGI	Term used in research and data collection referring to a person's sexual orientation and gender identity.

# Introduction

There is a global need for improvement in the care and support of people diagnosed with cancer who identify as lesbian, gay, bisexual, trans, intersex, queer/questioning, asexual and other sexual and gender minority communities (LGBTIQ+). In recognition of this need, the Victorian Cancer Plan 2020-24 outlines a commitment by the Victorian Government to improving cancer outcomes for all Victorians, including those who identify as LGBTIQ+. The Victorian Cancer Plan defines care that is appropriate for members of the LGBTIQ+ community as avoiding heterosexual assumptions, using inclusive language, providing tailored information, and involving partners in care. The plan demonstrates two Victorian cancer service improvement initiatives for the LGBTIQ+ community, including in Breast Screen Victoria and in Adolescent and Young Adult services.

The LGBTIQ+ acronym is evolving and describes a diverse range of people and communities with different gender identities and/or sexual orientations. Gender identity refers to how a person experiences their gender, independent of the sex they were assigned at birth e.g., how masculine and/or feminine a person understands themselves to be. Sexual orientation refers to the gender(s) a person feels sexual attraction for.

Approximately 11% of Australians identify as lesbian, gay, bisexual, transgender or intersex (LGBTI). According to the Victorian Population Health Survey 2017, at least 8.5% of Victorians identify as non-heterosexual and/or gender diverse. Australian state and territory cancer registries do not collect sexual orientation or gender identity (SOGI) information, so it is unclear what proportion of people diagnosed with cancer in Australia or Victoria identify as LGBTIQ+. Without factoring in the greater vulnerability to some cancers for this community, it can be estimated that approximately 17,820 of the projected 162,000 Australians with a new cancer diagnosis in 2022 may be someone who identifies as LGBTIQ+. For Victoria, of the 36,974 individuals with a new cancer diagnosis in 2021,<sup>[8]</sup> it is estimated a minimum of 4,067 may identify as LGBTIQ+. In comparison, there were 4,953 Victorians with breast cancer reported during the same period and they were only identified as female or male.

The number of LGBTIQ+ people with cancer may be significant in size and there are known barriers to identifying them and their quality of their cancer care. The absence of SOGI data for people diagnosed with cancer throughout Australia may contribute to the “invisibility” of these individuals within the cancer care system. There is no reference to LGBTIQ+ people or SOGI other than male and female in the Cancer in Victoria 2021 report. There is a greater vulnerability for LGBTIQ+ people to some cancers including breast cancer, lung cancer, and HPV-related cancers. There also evidence that the LGBTIQ+ community is more likely to experience barriers to equitable cancer care. The known lack of identifying LGBTIQ+ people with cancer, understanding of their needs, and limited availability of resources allocated to addressing inequalities may contribute to the poorer outcomes in cancer care.

Cancer policies should set ambitious agendas for improving cancer outcomes and addressing identified inequities and areas for improvement for LGBTIQ+ people with cancer. Published research should inform our knowledge and understanding of the LGBTIQ+ community’s experience of cancer care. SOGI data should be collected and inform our understanding of cancer incidence, cancer treatment activity, and outcomes.

## Aim

A series of examinations were undertaken to understand the status of LGBTIQ+ cancer care in Victoria and the NEMICS region. Objectives included to:

- understand how the needs, barriers, inequalities, and outcomes of the LGBTIQ+ community are acknowledged and prioritised in cancer care policy resources throughout Australia and Victoria,
- identify the key LGBTIQ+ priority actions within cancer care policy resources,
- summarise the experience of cancer care and survivorship as described by LGBTIQ+ people with cancer,
- highlight known barriers and facilitators related to cancer care for members of the LGBTIQ+ community,
- summarise key published recommendations and calls to action for addressing inequities in cancer care for LGBTIQ+ communities.
- identify the use of SOGI data items within Victorian cancer related datasets and priority areas for improved SOGI data capture

## Methods

During 2022 and 2023, the following methods were implemented:

- a systematic review of publicly available Australian cancer care policy resources relating to LGBTIQ+ cancer care, obtained via an advanced Google search.
- a scoping review examining the published systematic reviews, meta-analyses, qualitative meta-syntheses, and integrated reviews specific to the LGBTIQ+ people with cancer.
- an examination of all Victorian cancer related datasets and their data dictionaries relating to SOGI data items.

To understand the methods implemented, see the full reports mentioned on page 1.

## Summary of findings

### Cancer care policy

There are limited cancer care policy resources that include LGBTIQ+ acknowledgement, inclusion, and targeted actions. Not all cancer care policy resources included definitions relating to LGBTIQ+ terminology. Most policy resources referred to the LGBTIQ+ community as a whole, rather than as a collection of unique subgroups with different needs. Policy resources that did acknowledge differences in care and/or service needs within the LGBTIQ+ community most often focused on trans and gender-diverse people with cancer.

There is limited consistent cancer care guidance and priority actions for cancer services and health workers to support improvement in cancer care and outcomes for those that identify as LGBTIQ+. Where guidance and priorities actions were identified within cancer care policy resources for the LGBTIQ+ community this included:

- ensuring data related to SOGI are collected and available to support research, planning and decision-making (NSW Cancer Plan, ACON).

- improving LGBTIQ+ community access to and participation in population cancer screening programs and research (Victorian Cancer Plan 2020-2024, NSW Cancer Plan, ACON)
- investing in tailored communications and targeted approaches to reach unscreened and under-screened groups including people from LGBTIQ+ backgrounds (CCV recommendations to Victorian Cancer Plan, NSW Cancer Plan, ACON)
- employing staff who are sensitive to the needs of LGBTIQ+ people with cancer (BSV, Victorian Cancer Plan 2020-2024, ACON, RACGP)
- ensuring LGBTIQ+ representation at the system level through training, co-design, leadership, and governance structures (YCAB, NSW Cancer Plan, ACON)
- creating cancer services that actively consider and address SOGI issues as part of their service planning, policy development and delivery (YCAB, ACON)
- ensuring the unique experiences of LGBTIQ+ community subgroups (e.g., trans and gender diverse people, or people living with HIV, etc.) are actively and independently considered in all stages of cancer care, policy development, and service provision as their needs may and experiences may be different to other members of the LGBTIQ+ community (ACON)
- partnering with community-led organisations to develop initiatives, services and other supports that are safe, inclusive, responsive, and meet community needs and preferences (NSW Cancer Plan, ACON)
- ensuring resources use inclusive language and healthcare professionals have access to training on using inclusive language e.g., using pronouns, using language that does not assume heterosexual or cisgender status (BSV, AMSA, Victorian Cancer Plan 2020-2024, ACON, RACGP).

## LGBTIQ+ published evidence

Although the unique needs of LGBTIQ+ people with cancer and their barriers to equitable cancer care has somewhat been published in the literature, substantial research is required to build on the understanding of needs, experience, barriers, facilitators, and gaps. Where evidence has been published, findings included:

- issues with limited or no access to relevant or inclusive information and services designed for their community, fear of and/or the experience of discrimination within the healthcare system, and a lack of knowledge by health practitioners about the unique needs of LGBTIQ+ people with cancer
- having previous positive experiences with routine cancer screening and access to relevant, accurate information about cancer risk increased the likelihood that people who identify as LGBTIQ+ would undertake routine cancer screening. For trans people, being provided with options for cancer screening that mitigated feelings of gender dysphoria were of particular benefit
- consumers reported that displaying rainbow flags and/or posters promoting LGBTIQ+ inclusivity in health services, developing LGBTIQ+ specific resources, using inclusive language in existing forms and resources, and implementing anti-discrimination policies would be beneficial
- health practitioners reported a lack of training and/or knowledge on the needs of LGBTIQ+ people with cancer, and not having access to LGBTIQ+ specialist resources and/or services to refer patients to
- significant data gaps exist that contribute to the cisgendered and heteronormative approach to cancer care embedded in the health care system. Some of the



highlighted issues identified included the absence of SOGI data in cancer registries and other health data, the use of unvalidated measurement tools and/or approaches in research that require further validation, inconsistencies in cancer screening guidelines, and the inherent cis-het normativity in healthcare that often applies a “one-size-fits-all” approach to tumour-nonspecific aspects of cancer care.

- recommendations included expanding health data to include the collection of SOGI information, using more inclusive language throughout the cancer system, ensuring accurate LGBTIQ+ training and information is embedded in health practitioner education and continued professional development, and increasing access to support services that are designed for and/or more inclusive of LGBTIQ+ people with cancer.

## SOGI data items

Victorian cancer datasets currently collect limited data related to gender identity and no data related to sexual orientation. Data related to patient sex is collected consistently, however definitions and coding notes for recording patient sex differ between datasets. The absence of SOGI data from all but one dataset, and inconsistencies in coding practices for people who no longer identify by their birth gender, affects our understanding of the number of Victorian LGBTIQ+ people with cancer, their cancer treatment activity, their experience of cancer care, and their outcomes.

The LGBTIQ+ population group is currently not easily identifiable, their cancer incidence, survival, and mortality are not reported in Victoria. Their cancer treatment activity cannot be identified and is not reported. Their experience of cancer care cannot be reported due to past VHES only allowing for male or female categories. Recommendations include:

- the implementation of SOGI data items within Victorian cancer related datasets is urgently required
- clear and consistent data category definitions are needed across cancer datasets that can accommodate a variety of experiences related to sex and gender, or to sexual orientation
- the Improving Cancer Outcomes (Diagnosis Reporting ) Regulations need to include SOGI data items
- Patient Administration Systems should capture SOGI data items to inform other Victorian cancer related datasets.

## Conclusion

These series of examinations and the identified priorities assist in the understanding of the status of LGBTIQ+ cancer care in Victoria and the NEMICS region. Clinical leadership and consumer advocacy for LGBTIQ+ cancer care in Victoria and the NEMICS region is yet to be identified despite efforts to find leaders. Substantial action is required to address these findings and improve the experience and outcome of cancer care for the LGBTIQ+ community with cancer.

Findings should be translated into local improvement activities for NEMICS and member health services to implement. Findings should also inform advocacy during Victorian Cancer Plan consultations and improvement of LGBTIQ+ cancer care should be a priority within Victoria.