

## Cancer and LGBTQ Communities

Relative to the general population, LGBTQ populations' experiences of cancer<sup>1</sup> are often poor. Research shows that 1) certain cancers are more prevalent in LGBTQ populations than in the general population, 2) LGBTQ populations disproportionately experience certain cancer risk factors, 3) LGBTQ individuals' experiences of cancer care often differ from those of non-LGBTQ persons and 4) that these differences can be attributed to negative attitudes and discrimination towards LGBTQ people. This evidence brief aims to provide an overview of the existing research on LGBTQ populations and cancer and recommend actions that service providers can take to better serve their LGBTQ patients with regards to cancer prevention and treatment.

### Cancer and LGBTQ People

LGBTQ populations experience cancer differently from the non-LGBTQ population in terms of prevalence, risk, care, and outcomes.

#### Are certain cancers more prevalent in LGBTQ populations?

Research shows that some cancers are more prevalent in LGBTQ populations than in non-LGBTQ populations.

- Cancers caused by infectious agents, such as viruses, are more prevalent among individuals with compromised immune systems than among the general population. Within the LGBTQ community, these cancers predominantly affect gay, bisexual, and/or men who have sex with men living with HIV/AIDS<sup>2,3</sup>.
- The prevalence of anal intraepithelial cancer, which is associated with certain strains of human papilloma virus, is highest among men living with HIV or AIDS. Gay, bisexual, or MSM without HIV/AIDS are also significantly more likely to develop anal intraepithelial cancer than heterosexual men<sup>2,4,5</sup>.
- A systematic review found that those who engage in receptive anal intercourse are at increased risk for anal dysplasia<sup>2,6</sup>.<sup>2</sup>
- Cigarette smoking and an individual's lifetime number of sexual partners are also associated with anal cancer<sup>6</sup>.
- While infection with oncogenic (cancer-causing) strains of HPV is associated with cancers of the head and neck, existing research does not suggest that these cancers are more prevalent among MSM than in the general population<sup>2</sup>.

<sup>1</sup> Cancer refers to a collection of illnesses that occur when abnormal cells divide uncontrollably. Cancerous cells are malignant and can spread through the body. This uncontrolled growth may result in the development of tumours, which are tissue masses. Other cancers affect bodily fluids, such as leukemia. Cancers vary in the speed at which they develop and carry different prognoses depending on a wide range of factors, including the type of cancer, the condition of the patient, and access to treatment<sup>1</sup>.

<sup>2</sup> Abnormal anal tissue cells that are pre-cursors to anal cancer.

- There is a well-established link between immunodeficiency and Kaposi's sarcoma. Development of this cancerous tumour is seen among gay, bisexual, and MSM living with HIV or AIDS<sup>3</sup>.
- Research shows greater incidence of non-Hodgkin's lymphomas among gay and bisexual men than among the general population<sup>2</sup>.
- While the introduction of highly-active antiretroviral therapy (HAART) has reduced the incidence of Kaposi's sarcoma and non-Hodgkin's lymphoma in persons living with HIV or AIDs, this has not been true of anal cancer<sup>3</sup>. Incidence of anal cancer has risen since the advent of HAART, likely as a result of increased longevity<sup>7</sup>.
- Existing research paints a less clear picture of differences in lifestyle-related cancers between LGBTQ populations and the general public. This is due in part to a lack of data about cancer incidence in LGBTQ populations<sup>2</sup>.
- One Danish study, after accounting for Kaposi's sarcoma, non-Hodgkin's lymphoma, and anal squamous carcinoma, found that men and women who were in registered homosexual partnerships had no excess risk of developing cancer<sup>8</sup>.

### **What puts LGBTQ people at higher risk for getting cancer?**

Despite the lack of population level data about cancer in LGBTQ populations, research shows that LGBTQ individuals are more likely to engage in behaviours that are associated with increased cancer risk. These behaviours often stem from experiences of discrimination in their day-to-day lives.

#### **Substance use**

- Substance use, particularly tobacco and alcohol, is higher among some segments of the LGBTQ population than among the general population<sup>9-14</sup>.
- Tobacco use is elevated in Canada's LGBTQ populations relative to the general population<sup>15-18</sup>. However, tobacco use in the LGBTQ community is not uniform. A survey of sexual and gender minority individuals living in Toronto found elevated prevalence of smoking among bisexual, genderqueer, and youth respondents<sup>16</sup>. Similarly, research in Atlantic Canada also found gendered differences among sexual minority youth: sexual minority women were significantly more likely than sexual minority men to report daily cigarette use in the last year<sup>17</sup>. Bisexual participants were significantly more likely to report daily cigarette use in the last year than a) other sexual minority youth and b) heterosexual youth<sup>16</sup>. Research done in other countries has generally affirmed these findings<sup>11,19,20</sup>.
- Few studies explicitly examine tobacco use in trans populations, although those that do suggest that the prevalence of tobacco use among trans people is higher than among cisgender individuals<sup>11,19</sup>.
- The HONOR project, which addressed the experiences of Indigenous LGBT and Two Spirit individuals, found widespread non-ceremonial tobacco among study participants, especially among those who identified as women, trans, and/or intersex<sup>21</sup>. The study re-emphasized the relevance of trauma to the health of this population; specifically, it cited childhood, historical, and colonial trauma, in addition to trauma due to microaggressions as factors driving tobacco-use in this population<sup>21</sup>.

## Breast and ovarian cancer

- The research examining breast cancer risk between lesbian, bisexual, or queer women and heterosexual women shows mixed results. While one study finds that 1) lesbian and bisexual women have greater breast cancer risk than heterosexual women and 2) lesbian and bisexual women are less likely to get screened for breast cancer<sup>22</sup>, other research finds no difference between the self-reported histories of breast cancer for lesbian or bisexual women and the general United States female population<sup>23</sup>.
- Research has shown that risk factors for ovarian cancer are more prevalent among lesbians and bisexual women than among heterosexual women; however, there is insufficient evidence to suggest that rates of ovarian cancer are higher in this population<sup>24,25</sup>.

## Cancer and hormone use

- While case reports of cancer have suggested a link to the long-term use of hormones by transgender individuals<sup>26,27</sup>, there is insufficient substantiating evidence. Numerous studies have established that cancer rates among transgender individuals do not differ significantly from the general population<sup>28</sup>, and that the long-term use of hormones does not present a significant cancer risk<sup>29</sup>.

## Are cancer outcomes different for LGBTQ populations than for the general population?

- LGBTQ people sometimes experience poorer cancer outcomes than the general population.
  - While there is a lack of surveillance data linking sexual orientation and cancer outcomes, researchers in the United States have drawn on surveillance data showing cancer outcomes for a given area with census data about the number of same-sex partnerships in a given area.
  - This research shows that colorectal cancer mortality is positively associated with the density of MSM in a geographic area<sup>30</sup>; that is, the research established that an area with a higher-than-average number of MSM had higher levels of colorectal cancer incidence and mortality.
  - Similarly, research conducted in the same manner finds a significant positive association between the density of sexual minority women in a geographic area and breast cancer mortality<sup>31</sup>, as well as a significant positive association between the density of sexual minority men and lung cancer mortality<sup>32</sup>.

## Cancer care: What barriers do LGBTQ individuals experience?

- Scholars have proposed that systemic discrimination and marginalization may contribute to stress in LGBTQ individuals, who may then engage in coping behaviours that place them at risk of developing cancer<sup>33,34</sup>. This explanation is referred to as the minority stress theory.
- Systemic discrimination can explain the particularities of how LGBTQ people experience cancer. Forms of systemic oppression specific to LGBTQ populations include homophobia, heterosexism, biphobia, transphobia, and cissexism<sup>3</sup>. Other forms of discrimination,

<sup>3</sup> Cissexism refers to the privileging of those who identify with the gender that they were assigned at birth over those whose gender identity differs from the one they were assigned at birth.

including racism, sexism, ableism, and classism, also mediate LGBTQ people's experiences of cancer.

- These forms of discrimination manifest in both overt discrimination, such as oppressive attitudes or behaviours, and other barriers to access such as a lack of information and resources about LGBTQ people and cancer<sup>35</sup>.
- Cancer screening and prevention
  - Researchers have shown that LGBTQ people are less likely to access health services, such as routine cancer screening<sup>9</sup>, due to a fear of encountering discriminatory attitudes from service providers<sup>22,36-40</sup> or in some cases, harassment in a clinical setting<sup>40</sup>. Many respondents to a US survey of transgender and gender variant people said that they had been refused medical care on the basis of their gender identity<sup>41</sup>. Transgender and gender variant people of colour more frequently reported being refused medical care than white respondents.
  - Discriminatory attitudes and behaviours include making assumptions about the gender of a patient's partner, providing information or resources that are irrelevant to their life experiences, or misgendering<sup>4</sup> a patient. Sexual minority patients who are comfortable discussing their sexual identity with a physician are more likely to undergo cancer screening<sup>42</sup>.
  - Research shows that lesbians and bisexual women may not perceive a need for certain forms of cancer screening, such as Pap tests or breast examinations<sup>21,37</sup>. Health care professionals may pass on incorrect knowledge and contribute to this perception<sup>43</sup>.
  - While a large American study found no difference in the likelihood of gay and bisexual men to undergo prostate cancer screening<sup>44</sup>, other researchers note that individuals with more risk factors were less likely to have undergone screening<sup>40</sup>.
  - In certain cases, comprehensive screening and prevention programs are not available. Existing cancer prevention programs do not encompass certain cancers that disproportionately affect LGBTQ populations. Not all Canadian provinces offer the HPV vaccine to boys or men, despite HPV's involvement in the development of anal cancer in gay, bisexual, and men who have sex with men. As of October 2011<sup>5</sup>, there are no anal cancer-screening programs in Canada.
  - Despite the many barriers to cancer care that LGBTQ people experience, research shows that gay and bisexual men have higher screening rates for colorectal cancer than heterosexual men. There is little data about colorectal cancer screening in other sexual and gender minority populations<sup>10,45</sup>. We do know, however, that colorectal cancer screening is higher among patients who openly discussed their sexual identity with their physician<sup>42</sup>.

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<sup>4</sup> Misgendering occurs when one refers to an individual using the incorrect pronoun.

## Community responses to cancer

While marginalization may adversely affect LGBTQ people's experiences of cancer, LGBTQ identity may also be a source of resilience in the face of cancer.

- Get Screened is an initiative of the Canadian Cancer Society that aims to increase the rates of colon, breast/chest, and cervical cancer screening among LGBTQ Ontarians. Developed in partnership with community members, Get Screened features a website intended for healthcare providers as well as LGBTQ communities. Visit [www.cancer.ca/getscreened](http://www.cancer.ca/getscreened) to find out more.
- Cancer's Margins is a community-based research response to cancer based in multiple provinces. Through digital storytelling, participants explore the intersection between their LGBTQ identities and the experiences with cancer. Specifically, participants discuss the process of finding cancer care and supports. Find out more at [www.lgbtcancer.ca](http://www.lgbtcancer.ca).
- "Check It Out, Guys: The Trans Men's Pap Campaign" is a project that aims to encourage trans men to get screened for cervical cancer. Developed via a partnership with community members and health care professionals, the project appeals directly to its audience through posters depicting community members with slogans such as "Got a cervix? Get a Pap!" The associated websites provide more detailed information about the Pap test, cervical cancer, and how to get screened. For more information visit [www.checkitoutguys.ca](http://www.checkitoutguys.ca).
- Behind Closed Drawers, a social media initiative of the United States-based National LGBT Cancer Network, aimed to increase awareness of anal cancer through Facebook, Twitter, and Google+. Community members were invited to share photographs of themselves in their underwear, along with the hashtag #BehindClosedDrawers as a means of starting a conversation about anal cancer. Visit their website at [http://www.cancer-network.org/behind\\_closed\\_drawers.php](http://www.cancer-network.org/behind_closed_drawers.php) for more information.
- The National LGBT Cancer Network operates a database of LGBT-friendly cancer treatment facilities, in addition to spearheading awareness campaigns and running a support group for LGBT individuals with cancer. See more at <http://www.cancer-network.org>.

## Recommendations for future research

- Despite these findings, we still do not know a lot about how certain segments of the LGBTQ population experience cancer. The existing research predominantly focuses on the experiences of white, cisgender individuals, especially those that identify as gay or lesbian. This reality applies to research on LGBTQ health more broadly<sup>46</sup>. Less is known about individuals who have multiple marginalized identities, relevant as they may be to LGBTQ people's cancer care experiences. For instance, Black lesbian participants in one American study said that health care providers used their race to make inferences about their socioeconomic status and hence the sort of care that would be appropriate for them<sup>38</sup>. Additional research should address how multiple aspects of identity factor into how LGBTQ individuals experience cancer.
- Studies of cancer in LGBTQ populations vary in geographic context. Accordingly, their findings may not necessarily be generalizable to all geographic contexts. As these contexts vary with regards to their demographics and access to health care, additional research is needed to better understand how LGBTQ people in Canada experience cancer. This research should also explore whether urban and rural LGBTQ populations have differing cancer care needs.



- In many cases, researchers relied on convenience samples; accordingly, research findings may not reflect what is actually occurring at a population level. Data quality would be improved by collecting data about sexual orientation and/or gender minority status in surveillance and census data.
- The link between oral HPV infection and oropharyngeal cancer<sup>5</sup> is a public health issue that has been emerging across the board. As we do not currently have information about this issue in relation to LGBTQ populations, future research should establish whether there are special concerns about which LGBTQ individuals and their physicians need to be aware. For instance, given recent research establishing a link between oral HPV infection—likely acquired from performing oral sex on partners with vulvas—and oropharyngeal cancer in heterosexual men, future research should explore whether this is a concern for WSW.
- To date, researchers have not thoroughly explored cancer survivorship in LGBTQ communities. Given other cancer disparities between LGBTQ communities and the general population, this issue should be the subject of further academic study. Future work in this area should also address caretaking for LGBTQ individuals with cancer.

## Implications for health care providers

### Behavioural and attitudinal concerns

- Research suggests that patients who feel more comfortable discussing their sexual orientation with their physician are more likely to undergo cancer screening<sup>41</sup>. Health care providers can take steps to foster a clinical environment that is inclusive of sexual and gender minorities.
- Health care providers can attend to the language they use with their patients. In particular, they should take care to avoid making assumptions about the gender or sexual identity of their patients, as well the gender and sexual identities of their patients' family or partner(s).
  - For instance, health care providers can ask a patient about their 'partner,' a term that does not presume a gender identity.
  - Health care providers can promote inclusive practice through adopting intake paperwork that allows patients to self-identify outside of a gender binary. For instance, a form might include a field that reads: "None of these categories describes my gender identity. My gender identity is \_\_\_\_\_". Both providers and administrative staff can ask what name and pronouns the patient uses. When the name and gender listed on a patient's identification differs from those provided by the patient, use the latter.
  - In a similar vein, health care providers can ask patients how they name their body parts. Gender minority patients, in particular, may use different anatomical terms that are better aligned with their gender identity.
  - Furthermore, health care providers should not base assumptions about a patient's sexual practices on their sexual orientation or gender identity. We would encourage health care providers to make open-ended inquiries about the types of sexual behaviours that their patients engage in.

<sup>5</sup> Oropharyngeal cancers can affect the back of the tongue, the soft palette, and the side and back of the throat.

- Health care providers can maintain resources specific to LGBTQ people, where such resources exist. This might include a list of LGBTQ-specific support groups or web-based resources<sup>47</sup>.
- Health care providers can play an important role in advocating for the expansion of HPV vaccination programmes to include boys, as well as gay, bisexual, and MSM.

### Specific health conditions

- Given strong evidence linking HPV to anal cancer in gay, bisexual, and MSM patients, health care providers can discuss anal health with their gay, bisexual, and MSM patients, especially those living with HIV/AIDS. Anal cancer screening for these patients is advisable<sup>48</sup> as is vaccination against HPV, although the latter is not yet insured by the Ontario Health Insurance Plan.
- While trans individuals are not necessarily at greater risk for developing cancer due to gender-affirming medical treatment, they may nonetheless have specific screening needs. These needs vary according to their anatomy, their use of hormones, and any gender-affirming procedures they may have undergone but might include screening for breast/chest mammography, cervical, and/or colon cancers. Additional information regarding cancer screening recommendations for trans clients is available from Rainbow Health Ontario<sup>49</sup>, the Canadian Cancer Society, and the University of California, San Francisco Center of Excellence for Transgender Health<sup>50</sup>. Other research provides specific information regarding screening procedures with transgender clients<sup>51</sup>.

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## Acknowledgements

*This fact sheet was written by Dominic Popowich with the thoughtful assistance of Arti Mehta, formerly Screening Saves Lives Coordinator at the Canadian Cancer Society, Dr. Lara Descartes, Professor of Family Studies at Brescia University College, Dr. Margaret Robinson, Researcher in Residence-Indigenous Health at the Ontario HIV Treatment Network, Dr. Tae Hart, Professor of Psychology at Ryerson University, Susan Flynn and Julie Data of Get Screened Program at the Canadian Cancer Society, and James Murray of the AIDS Bureau, Ontario Ministry of Health and Long-Term Care.*

*Feedback on this document is welcome. Comments and questions can be addressed to Lorelee Gillis: [lgillis@RainbowHealthOntario.ca](mailto:lgillis@RainbowHealthOntario.ca).*