



Editorial

Queering Cancer: Developing a resource to support sexual and gender diverse people affected by cancer

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Introduction

Cancer affects everyone; there are about 80,000 cancer deaths every year in Canada. However, depending on our backgrounds, identities, and circumstances, how we experience cancer will vary. According to the 2018 census, Canada is home to approximately one million sexual and gender diverse (SGD) people (including, but not limited to, those who identify as lesbian, gay, bisexual, trans, queer, and two-spirit). These SGD people account for 4% of the total population [1]. SGD people may encounter discrimination when accessing healthcare and often engage with healthcare professionals lacking education about their needs [2]. Some SGD patients may even delay seeking care due to fear of discrimination [3].

SGD people have a unique cluster of risk factors that lead to both greater cancer incidence and later stage diagnosis [4]. A literature review by Quinn et al. [5] highlighted seven cancer sites that may disproportionately affect the SGD population including anal, breast, and lung cancers. SGD people generally have lower rates of cancer screening and therefore may present at a later stage for treatment [6]. Cancer services are often highly gendered, which can be difficult for those SGD people who experience gender in a non-normative way [7,8]. In general, SGD patients are less satisfied with their treatment, experiencing higher levels of isolation [9,10]. Furthermore, the layering of a new cancer identity for SGD people can compound psychological distress in the survivorship phase [11].

Access to high quality, accurate patient information is essential when dealing with a cancer diagnosis and treatment; it not only facilitates better satisfaction, a sense of control and an increased ability to cope [12] but is also linked to better out-

comes [13]. There is evidence, however, that SGD people affected by cancer have less access to appropriate information and services [6,14–16]. Additionally, information and support are usually developed by and for cisgender heterosexual people [6]. A recent review of online patient information resources revealed that most cancer information sites do not specifically mention SGD people and information provision is sparse, rendering this population “almost invisible” [17].

Inclusive and equitable practice requires all patients to feel safe and be seen. Thus, there is a pressing need for information and support tailored for SGD people. This gap in cancer-specific resources and information for patients and their loved ones led to the development of Queering Cancer (QC).

The path to creating Queering Cancer

Step 1. Securing funding and forming a team

The QC initiative was founded by three graduate students from cancer-related backgrounds, Meghan McInnis (psychosocial oncology), Evan Taylor (social work), and Amanda Bolderston (radiation therapy). We were later joined by Kim Meeking (radiation therapy). Between us we identify as lesbian, bisexual, queer, gay, cis, and transgender. Our research interests encompass experiences of sexual and gender diverse patients, carers, and staff in relation to oncology healthcare. We met at the launch of a 2017 Canadian Institutes of Health Research (CIHR) grant competition “Hacking the knowledge gap”, a knowledge translation award to support innovative thinking in SGD health and wellness. The “gap” we joined together to explore was the lack of tailored resources, information, and support for SGD people affected by cancer.

Competing Interests: There is no conflict of interest to declare.

Healthcare communications company BirdComm were contracted to support the design and implementation of QC's website and social media platforms. Mary Morgan, a lesbian living with multiple myeloma in British Columbia became the founding patient partner with QC and prominent guiding voice in its aims and ethos.

Step 2. Identifying the needs of the community

A survey was developed and distributed using a snowball method to SGD patients, researchers, and community organizations. The survey received 64 responses. Sixty percent of the respondents identified as an SGD person living with cancer. There were many suggestions for resources including peer-to-peer support via the website.

The top six themes (amalgamated from 12 response categories) were:

1. Sex and intimacy
2. Dealing with side effects
3. Caregiver and partner support
4. Dealing with body image changes
5. Support group information
6. Survivorship and life after treatment

Format suggestions were downloadable information, videos/digital stories, narratives, and links to other sites. We also asked survey participants to tell us about their experiences with cancer treatment:

“MANY feel miserable and unsupported because of staff behaviour e.g., assuming a partner is a friend” [anonymous survey participant #1]

“There's nothing I've found useful to me as a trans masculine person with a reproductive cancer” [anonymous survey participant #2]

Informed by the survey and other online and in-person feedback, we held a design workshop with Mary and BirdComm to identify the name of the initiative, types of content, design elements and functionality. Our foundational ideas for the site were that it would be *intersectional*, *patients-first*, and *trans-inclusive*.

During the workshop we decided on the initiative's name 'Queering Cancer'. The idea of “queering” builds on the concept of queer theory, a perspective that questions cisgender and heterosexual identities being viewed as the norm [18]. To “queer” something is to view it with a queer lens. In healthcare, this means critiquing and challenging the heteronormative and cisnormative foundations of how we design and deliver care. In oncology, this results in a way to “articulate cancer differently” [8], p. 198. Whilst we initially had some concern around using the term queer because of its pejorative past, it's a reclaimed term and has a boldness, political stance, and inclusivity that avoids lengthy and frequently updated acronyms. As Mary Morgan said during the workshop, “I want the web-

site to be filled with the politics of cancer: class, race, environment...radical, fierce, and bold”.

Step 3. Website development and testing

Development of the website took 18 months of iterative design and testing. Pre-launch, the draft website was reviewed by six SGD people affected by cancer. Several changes were made to improve the look and feel of the website, including a review of the resource inventory, recategorizing content (e.g., flagging “medicalized” terms like transsexual and avoiding gendered categories like “men's” and “women's” cancers). The first iteration of the website had three pillars:

- Information: A searchable database of approximately 200 cancer resources related to and tailored for SGD populations.
- Forums: Several peer support forums organised by disease trajectory such as treatment, survivorship, and palliative care.
- Stories: A collection of SGD patient stories including narratives in various formats such as zines, news articles, peer reviewed journal papers, and videos.

Step 4. Social media strategy

Ahead of the launch, a social media strategy was developed. It included an environmental scan of organizations/accounts with a similar focus and helped us select our primary platforms: Instagram and X (formerly Twitter). A content inventory was created for the launch and initial phase of operation to introduce QC and the team, and to drive traffic to the website's functional areas by highlighting the three pillars.

Step 5. Launching Queering Cancer and responding to community needs

The Queering Cancer website (www.queeringcancer.ca) and social media profiles (“@queeringcancer” on Instagram and X) launched on 27 October 2020. BirdComm developed a press release which generated considerable media interest, including several national television and radio interviews [19,20].

Monitoring website and social media engagement showed steady increase of our follower base on social media (Figure 1) and growing traffic to our website, particularly the Information and Stories pages (Figure 2). Our community forums, however, were seeing limited uptake. It was clear that establishing and moderating peer support forums would be too resource intensive for a small group of volunteers. We had also connected with a growing number of other organizations that were better placed and resourced to provide online support for SGD people. After a year we removed the community forums and reconfigured the website to add an Education pillar. The section has information and links to many free and low-cost courses that can fill the known knowledge gap experienced by many healthcare professionals (HCPs) [21].

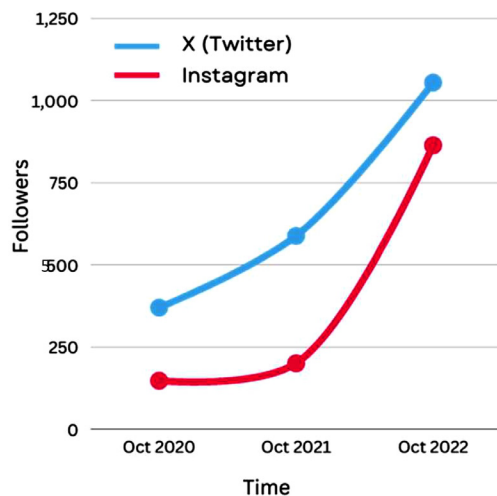


Figure 1. Social media followers over first two years.

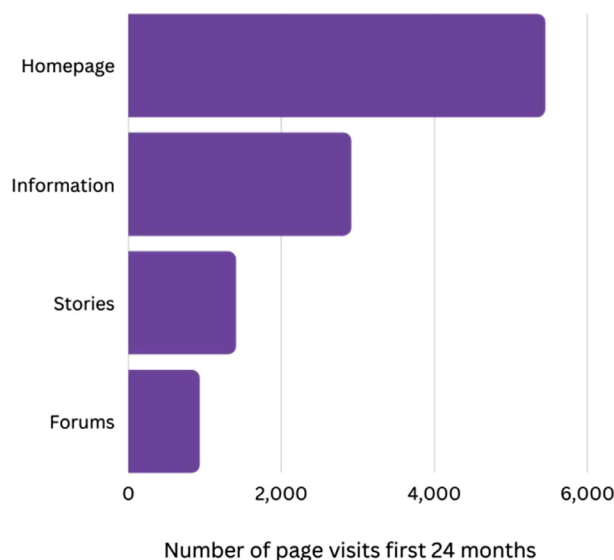


Figure 2. Webpage visits over first two years.

Community engagement and collaboration

As a queer organization we are sustained and supported by the community that we serve, by fostering and maintaining connections with those affected by cancer and similarly minded individuals and organizations. Figure 3 demonstrates the intersecting communities QC has developed links with since its launch, from patients and caregivers, healthcare people and spaces, and charities and community organizations.

In 2022 we welcomed community partners Laura Imayoshi and Tristan Bilash. Both are members of the SGD community

and have personal experience with cancer. Laura was inspired to help “for other people who received a cancer diagnosis and find it troubles their relationship to gender, I want them to know that they are not alone” [22]. Tristan commented that he wanted to see trans-specific representation because “I know first-hand how transformative it can be to see someone else who can relate to what I’ve been through” [22].

Our community engagement work involves providing individual information and support to many patients, either from email contacts through the website or through social media in-

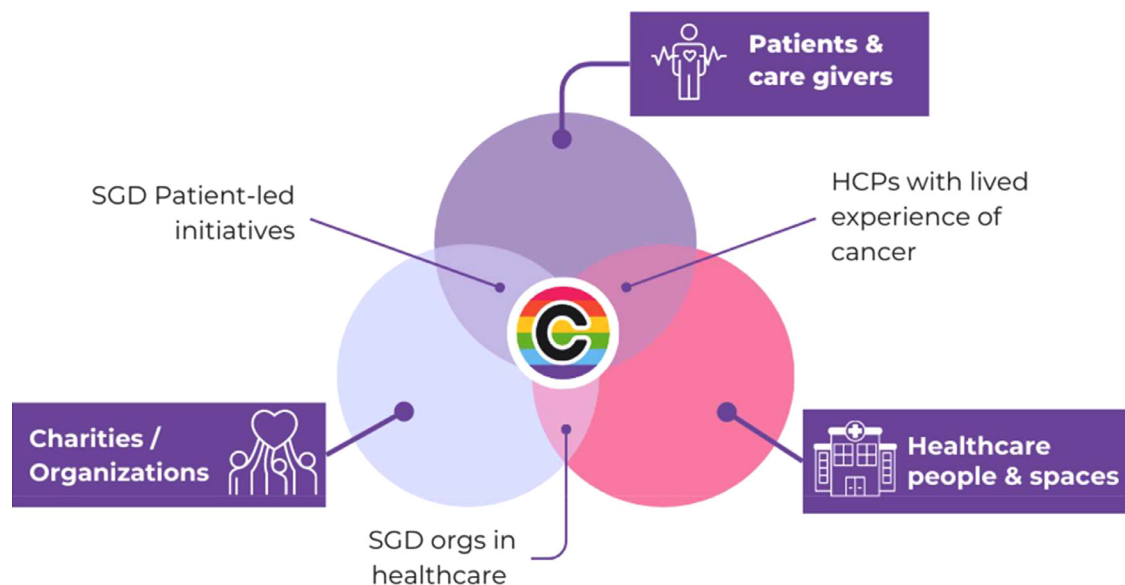


Figure 3. Queering Cancer's intersecting communities.

teractions. Recent examples include sharing a new journal article about gender affirming hormone use and cancer, amplifying a story from a cancer caregiver, and exchanging messages of support, understanding and affirmation with community members. Feedback from people who have interacted with QC include:

“The research and stories that QC shares have been really important to me following my diagnosis with breast cancer. It’s hard to express just how alienating the pink-washed world of breast cancer can be for a soft butch queer woman.”

And:

“I’m so happy I was directed to you guys. When I was going through cancer treatment, I really could have used resources like yourself. So, thank you for creating a space for our community.”

Queering Cancer's ongoing work

Our ongoing work for the QC initiative includes:

- **Social media engagement:** Content for X and Instagram includes QC updates, patient story features, knowledge translation posts summarising relevant research reports and articles, and collated tips for patients and HCPs.
- **Education:** We have developed bespoke online education for organizations that include webinars and live events. In addition, we developed a webinar for Pride 2022, and hosted a film screening for Pride 2023.

- **Fundraising:** We hold fundraising events and have partnered with other organizations to develop and sell merchandise to cover expenses including website hosting and maintenance.
- **Research:** We regularly provide support and advice for other researchers and policy makers as well as unique QC research projects.
- **Outreach:** We continue to provide interviews and collaborations for various media and other outlets (for example, podcasts, newsletters, panel discussions, and online articles). We have presented at several conferences and events to publicize QC and the need for SGD affirming healthcare.

What's next for Queering Cancer?

The work of QC is carried out by volunteers and is time consuming. Additionally, the initiative has no external source of operational funding. To affect change at a larger scale, Queering Cancer's next steps must include acquiring funding for sustainability and formalizing the organization.

We recently obtained a second grant from CIHR to evaluate the impact of the QC website and social media platforms. Our focus for the next six months is to carry out a series of interviews with people and organizations that interact with QC, to conduct a survey via our social media channels and to gather web and social media analytics. The information will be used to inform the future direction of the organization.

Conclusion

We successfully launched a grass-roots initiative that has evolved from a research project to a source of support, advocacy and information for SGD people affected by cancer. QC has proven to be agile in evolving both website and content to meet the needs of the community and those that care for them. QC has become a go-to resource for patient and community organizations and a trusted provider of affirming HCP education. We have seen ripples of positive change through our collaborations and have been successful in curating and developing useful resources and information for patients and their loved ones.

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