Queering Cancer: Pride in Inclusive Cancer Care

An impact evaluation of a community partnership

Queering Cancer
Inclusive Cancer Care

May 2024

Table of Contents

Executive Summary

Queering Cancer is a Canadian volunteer-run community partnership dedicated to improving the experiences of sexual and gender diverse people affected by cancer. Three years after our launch we have assessed our activities and impact through a collaborative evaluation project. This project informs our organizational aims and ensures our work remains grounded in the needs of the community.

Queering Cancer's activities include social media engagement, website resources, provision of healthcare professional education, and collaborative initiatives like research projects and community events. These activities have facilitated steady audience growth and established us as a reliable, trustworthy and accessible resource. Community feedback shows patient stories and education are our most popular and impactful areas. Stakeholder interviews underline the importance of what we do in addressing the continuing and prevalent gaps in care for the sexual and gender diverse cancer community.

Several recommendations for Queering Cancer have emerged including:
1. Collaborating with healthcare providers to make healthcare spaces more inclusive
2. Developing a community of practice
3. Improving peer support options
4. Continuing to elevate queer and trans voices from the cancer community.
5. Build operational capacity and diversity

This work is a fundamental step in Queering Cancer's future, both strategically, and holistically. The insights from this work inform the scale-up and formalization of our organization to better serve the needs of the sexual and gender diverse community affected by cancer.

Introduction

The Queering Cancer multidisciplinary team is composed of sexual and gender diverse (SGD) clinicians, patients and researchers. Together we are improving resources, research and support for patients, families, caregivers and healthcare professionals (HCPs).

Since launching in 2020, Queering Cancer (QC) has developed a supportive network for SGD people affected by cancer, collaborated with diverse cancer advocacy groups, engaged in research partnerships, and received numerous requests to provide healthcare professional education.

As a small organization, the volume of requests we receive currently exceeds our capacity. Examining where QC has the most impact and identifying areas of community need will allow us to take a strategic and mindful approach to how we focus our resources.

We undertook a three-phased evaluation project to examine QC's activity and impact and investigate community requirements. This project informs our organizational aims and ensures our work remains grounded in the needs of the community.

Methods

This three-phase evaluation examined QC's reach, effectiveness, and benefit with;

1. An analysis of web and social media engagement to understand audience growth, popular topics, and geographic impact.
2. An online stakeholder survey of QC engagement.
3. Interviews with select highly engaged stakeholders and community partners to explore experiences with QC and generate ideas for potential future services.

Community involvement

Community engagement was integral to this project. QC has two community (patient) partners who were involved in the design and delivery of this evaluation. We also have a network of SGD cancer community members, advocacy organizations, academics and researchers who assisted with this evaluation.

Ethical considerations

Protecting the wellbeing and privacy of our participants is extremely important to us. This evaluation project involved gathering opinion and experiences from a range of stakeholders, including people with cancer from a traditionally underserved or underrepresented population. The proposal underwent an ethics review using the Alberta Innovates (2017) ARECCI Screening Tool (1). This was followed by a Second Opinion Review (SOR). The SOR concluded that the project showed strong commitment to ensuring participants are protected and respected. Minor suggestions were made by the reviewer and incorporated into the project design.

(1) https://arecci.albertainnovates.ca/

Findings

Part 1: Web and social media analytics

Website engagement

The QC website comprises four primary pillars; patient stories, healthcare provider education, a database of resources, and a blog. Since the website launched in 2020 there have been minimal changes. The main update in 2021 was the replacement of the patient forums with a new education page (2). Our current website activity is the addition of new content such as patient stories and education resources.

Analytics using Twipla Inc. (3), showed website visitors are predominantly from Canada (60%), the US (33%) and the UK (3%), see figure 1. Breakdown of respondents by province showed 38% in Ontario, 22.4% in Alberta and 18.9% in British Columbia, see figure 2.

The website has had over 36,000 web page views, nearly 9,000 website visitors and 3,400 returning visitors. Top pages (after the homepage) are *Information* followed by S*tories* then *Education*. The site's "bounce rate" (the % of unengaged sessions that start and end on the same page) is 72.4%. The health sector industry average is 60% (4).
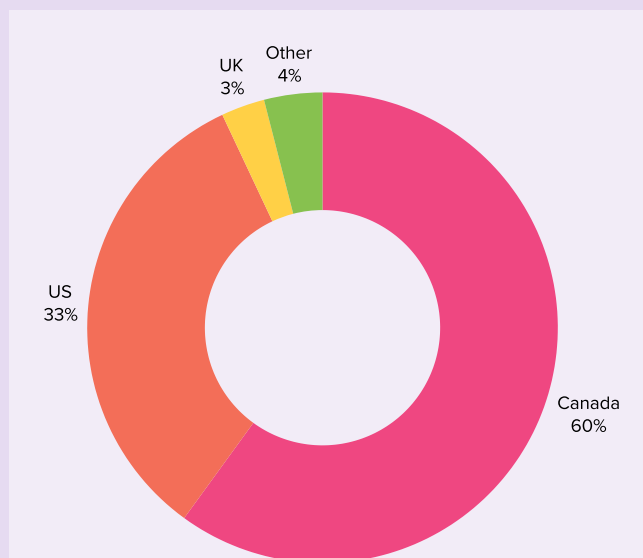

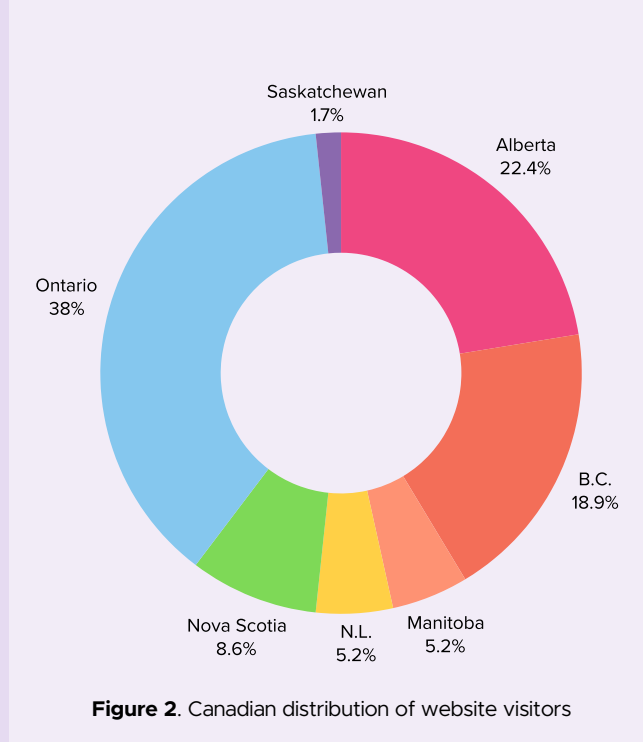**Figure 1**. Global distribution of website visitors

Figure 2. Canadian distribution of website visitors

(2) Bolderston A, Meeking K, McInnis M, Taylor E, Imayoshi L, Bilash T. Queering Cancer: Developing a resource to support sexual and gender diverse people affected by cancer. J Med Imaging Radiat Sci. 2023 Dec;54(4S):S3-S7
**(3)** https://www.twipla.com/en
(4) https://databox.com/website-traffic-benchmarks-by-industry

Social media engagement

Social media is the primary way we engage with our community. We launched on Twitter (X) in 2018 and Instagram in 2020, more recently adding accounts on Threads and LinkedIn in 2023 (see figure 3 for our follower counts across platforms). Our primary platform is Instagram where we have found the fastest growing audience and have the most interactions.

We post content on social media once a week on average and this has remained consistent since our launch in 2020.
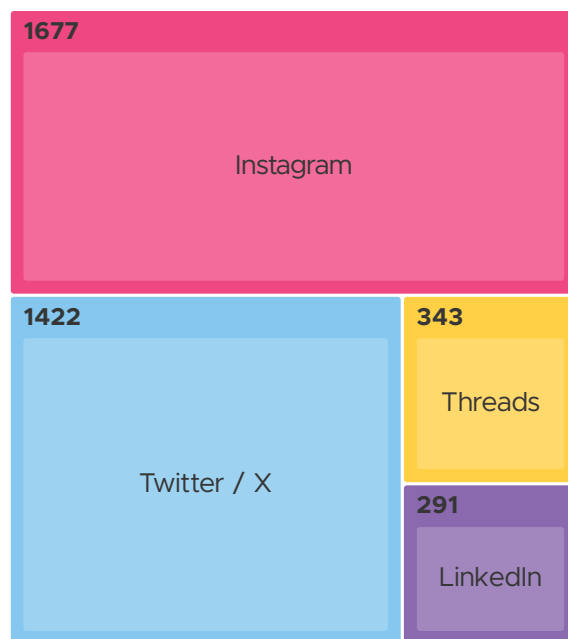
Figure 3. Follower distribution across platforms Apr 2024

An analysis of the number of posts and likes on Instagram (2021-2023) revealed our most recurrent and most liked social media content, see table 1.
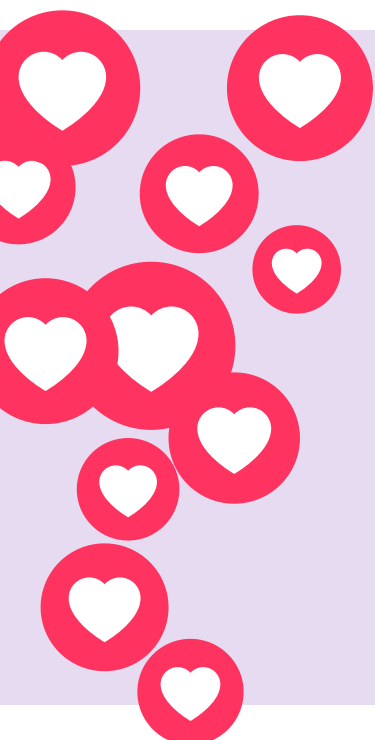
Category of content	Number of Instagram posts (2021-2023)	Average likes per post
Patient Stories	20 (14%)	70
Education e.g. inclusive care tips	21 (15%)	51
New patient support resources	5 (4%)	50
QC and collaborations info	38 (27%)	46
Dates in the 2SLGBTQ+ calendar	12 (17%)	44
Information about events	14 (10%)	42
New published research	18 (13%)	40

Table 1. Categories of Queering Cancer's Instagram posts by proportion and popularity

Findings

Part 2: Stakeholder survey

A 14 question online survey was circulated (11.11.23 to 24.12.23) via social media, the QC mailing list, and email. Anyone who had heard of or engaged with QC was invited to complete the survey.

Who completed the survey?

110 responses were received. 56% from Canada, 31% from the United States, 10% from Europe, and 3% from Asia Pacific.

71.3% of respondents were part of the sexual and gender diverse community, see figure 4. The category labeled as 'other' included asexual, omnisexual, androsexual and abrosexual orientations. A quarter of respondents selected more than one option to describe their sexual orientation.

Respondents reflected a wide range of gender identities, see figure 5. The category labeled as 'other' included agender, trans woman and two-spirit identities. Over 20% of respondents selected more than one gender identity option.

68.9% of respondents had personal experience of cancer either themselves (48%) or as a carer of a loved one (22.7%). A quarter worked with people with cancer in a patient facing role, 30% worked with people with cancer in non-patient facing roles.
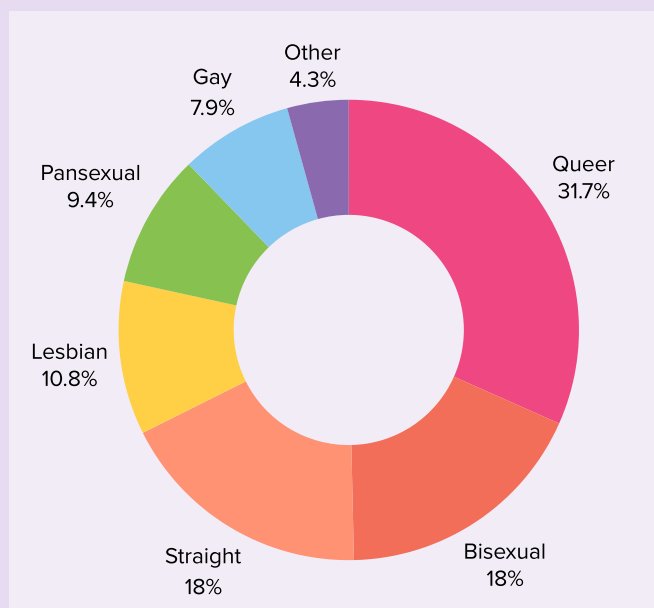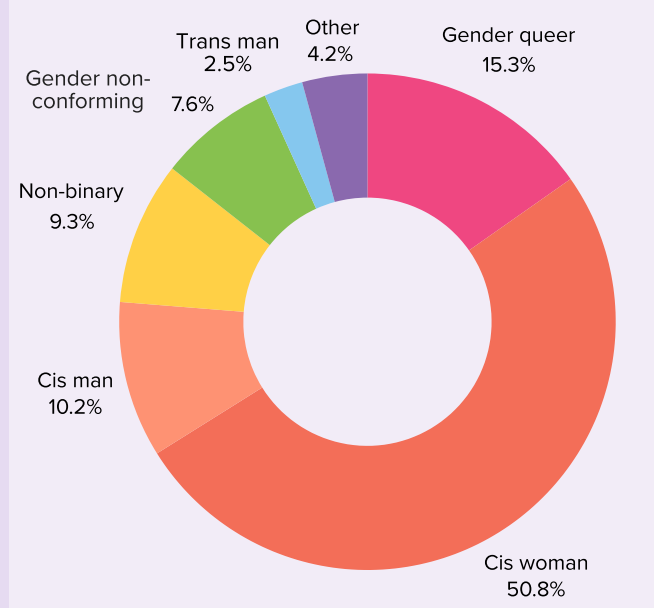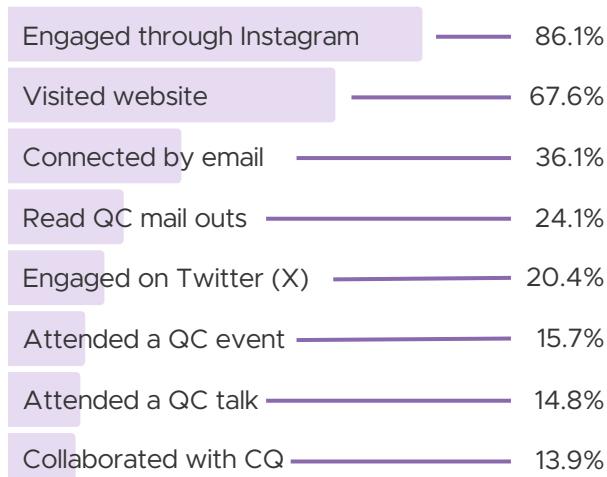
Figure 4. Sexual orientations of respondents

Figure 5. Gender identities of respondents

How respondents interact with Queering Cancer

86.1% of respondents had interacted with Queering Cancer on Instagram and 67.6% had visited our website. The majority of respondents (75%), selected multiple options.

Engaged through Instagram — 86.1%

Visited website — 67.6%

Connected by email — 36.1%

Read QC mail outs — 24.1%

Engaged on Twitter (X) — 20.4%

Attended a QC event — 15.7%

Attended a QC talk — 14.8%

Collaborated with CQ — 13.9%

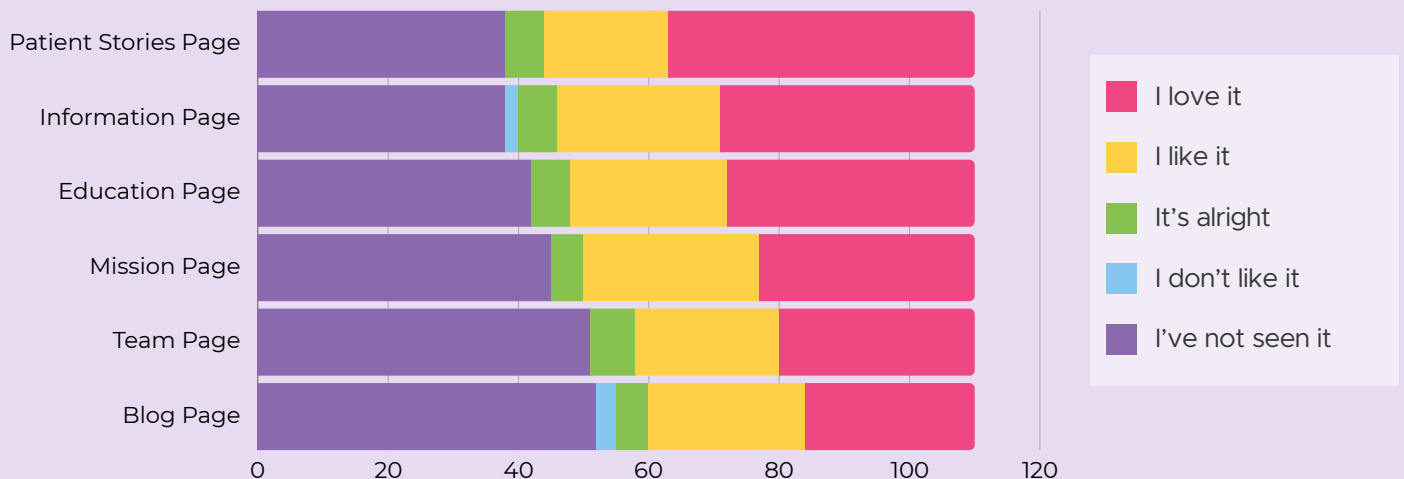**Figure 6**. How respondents engage with Queering Cancer

Feedback for website improvements included:
- Better user interface and responsiveness
- Make it easier to search and share website content
- Better tagging and filtering for the resources

Most liked webpages

Legend:
- I love it
- I like it
- It's alright
- I don't like it
- I've not seen it

Figure 7. How respondents rated QC's webpages

Most liked social media content
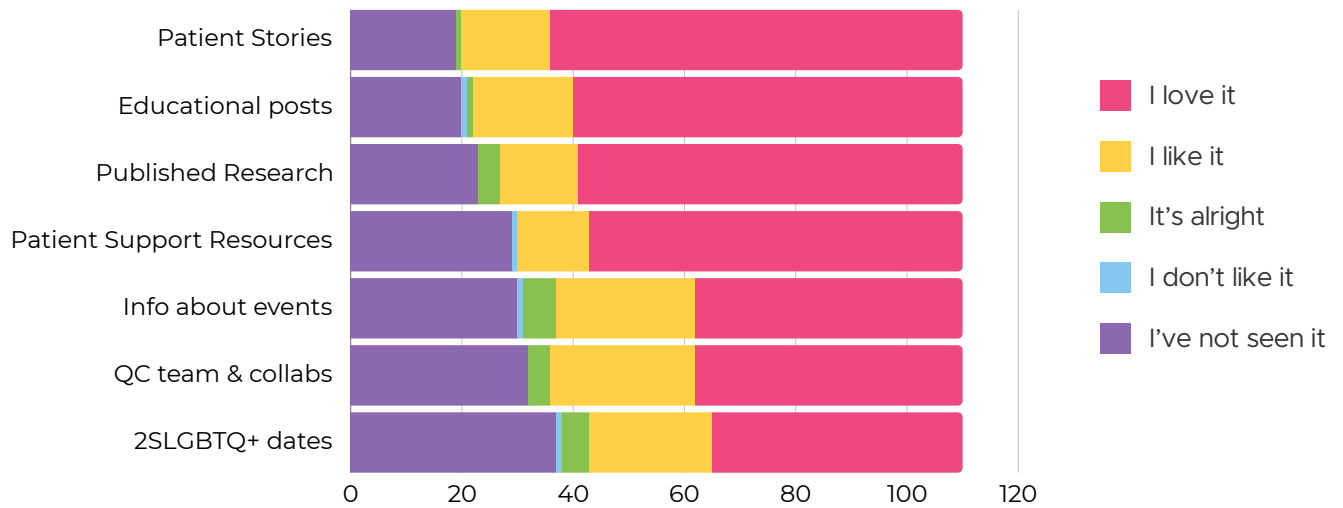
Figure 8. How respondents rated QC's social media posts

Legend:
- I love it
- I like it
- It's alright
- I don't like it
- I've not seen it

Categories (top to bottom): Patient Stories, Educational posts, Published Research, Patient Support Resources, Info about events, QC team & collabs, 2SLGBTQ+ dates

X-axis: 0, 20, 40, 60, 80, 100, 120

Suggestions for most wanted social media content:

- Education e.g. inclusive care tips (77.8%)
- New research related to cancer and the SGD community (75.0%)
- Information about support resources for patients and caregivers (72.2%)
- Posts featuring patient stories (68.5%)

What could QC do to improve SGD cancer experiences?

We offered nine actions to rank in order of priority. The highest ranked were working with and educating healthcare providers to make healthcare spaces more affirming, and providing online peer support, see figure 9.

Working with healthcare providers to make healthcare spaces more affirming

Educating healthcare professioon delivering inclusive care

Provide online peer support

Political / societal advocacy e.g. lobbying for policy change to increase SGD education

Undertake community based research on improving SGD cancer care

Producing SGD specific cancer information

Peer-to-peer matching program

Host community events

Media campaigns for SGD topics e.g. cancer screening awareness

Highest priority

Lowest priority

Figure 9. How respondents rated nine priority areas for Queering Cancer

What else should QC prioritize?

- "Partner with community groups already providing peer support resources, to help them establish queer-centered ones."

- "Make resources available to the community across Canada where patients are getting cancer screenings done; i.e., posters, pamphlets, website link…Making Queering Cancer an available resource from the start of a patient's cancer journey."

- "As a healthcare professional, I would love a Community of Practice group through Queering Cancer to work on projects like [tackling bigoted mindsets in the workplace] / and other projects identified by patients in order to create safer, more affirming healthcare experiences and spaces."

Findings

Part 3: Interviews

Six online interviews were carried out with patients (including QC community partners) and QC stakeholder organizations. The interviews were transcribed and analyzed thematically. Patient participants discussed their experiences within the healthcare system as well as their support and resource needs. All participants discussed how they had interacted with QC, what they felt the organization did well and what could be improved or built on.

Theme 1: Experiences as an SGM patient in the cancer system

There were many examples of heteronormativity (5) and cisnormativity (6) within the healthcare system. Healthcare professionals (HCPs) routinely made incorrect assumptions about pronouns, relationships and their patient's needs.

> **"I knew that I was going to have to pretty much out myself every time. Otherwise, I was going to have the same issues of - how was my husband dealing with it, and how it was affecting our relationship, very presumptuous that I was straight and married." (Patient)**

These assumptions included treatment goals and disease management:

> **"I said that I'm gay, and I've got no children. And then she made out that it was okay that I'd lost my fertility, because there's a presumption that because I'm a gay woman that I didn't want to have children."(Patient)**

The intersection of gender identity and cancer was a significant issue. The patient participants encountered highly gendered messages and assumptions from HCPs, for example that breast cancer and ovarian cancers are "women's diseases". SGD people affected by cancer may have positive experiences with some cancer surgeries that are also offered as gender affirming surgeries (e.g. hysterectomy). One participant described receiving an "nonconsensual hug" from a nurse who assumed the participant was upset about their double mastectomy:

> **"I'm not mourning the loss of my breasts so much. I actually feel good in my body for the first time in a couple of years." (Patient)**

(5) Heteronormativity is the assumption that heterosexuality is the preferred or normal sexual orientation.
(6) Cisnormativity is the assumption that gender identity aligns with sex assigned at birth i.e. cisgender.

Examples of mistreatment and/or support gaps were experienced across other intersectional identities and persisted across the cancer trajectory. One participant had a delayed diagnosis because of her fatness. A trans survivor with ovarian cancer was unable to access a standard follow-up blood test because the test was coded as "female" in the provincial software. Another participant spoke about their identity as an adolescent or young adult (AYA) with cancer:

"I think about how no one asked about my gender identity. And then I think about all the other queer patients out there, especially AYA patients...I have friends who just graduated med school, graduating law school and buying their first house, buying their first fancy car, getting engaged, getting married. All these big things, and my life was put on hold. (Patient)

On the positive side, two participants felt that their queer identities had built resilience that had helped them to cope and advocate for themselves as a cancer patient.

Theme 2: The need for support and resources

There was a general absence of specific support for SGD people affected by cancer identified and some participants struggled to find answers to their questions related to sexual and gender diversity:

"There just seems to be a certain type that they support, and it tends to be the straight couples with a family and with a better prognosis than me." (Patient)

Online support was helpful for some participants, both as an informal online network as well as more structured moderated peer support. However, support for partners and loved ones is lacking:

"I know I didn't really have any queer support. I'm honestly very comfortable and confident in my gender identity and my sexuality. So for me, this was more about (my partner), and how she had to go through that alone." (Patient)

Theme 3: QC interactions and ideas

> **"It was almost as cathartic for me to discover QC as it was the first time I went to a queer dance. Or the first time I had my first testosterone injection where I really felt like I landed in myself. It just had been such a long time that I had been researching."** (Patient)

Areas of strength for QC identified included content curation, social media outreach (in particular Instagram) and a collaborative approach. The patient stories collection was mentioned by a number of participants:

> **The stories, especially for newly diagnosed patients, can be really helpful in terms of creating a sense of hope and they're not the only people struggling ... Sometimes hearing stories can be a lovely conversation point ... to help people to find words to express their experience. (Stakeholder & HCP)**
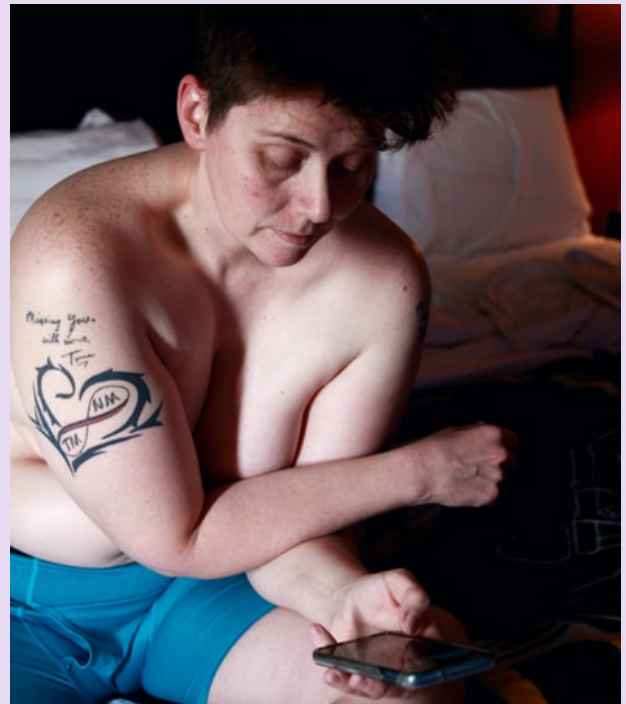
Having a specific SGD cancer space online that is "authentic and safe" was seen as important:

> **"I find it helpful, and I feel like I have been supported well by people like you, and it's a place where we can go and get information, and on inclusive care."** (Patient)

The QC focus on education was highly valued. This included sharing social media content, website resources, course development and delivery as well as online community events.

Finally, in terms of areas for improvement, several participants mentioned that the website needs updating as it can be slow, difficult to navigate and "clunky".

Recommendations

The following recommendations drawn from this evaluation will inform our strategic aims and future programming.

1 **Make healthcare spaces more inclusive and affirming**
Source, provide and promote healthcare professional education with attention to specific unmet needs (e.g., supports for cancers related to biological sex such as breast, prostate and gynecological and the screening needs of the SDG community).
Research and develop SGD cancer care inclusivity standards and/or an accreditation program

2 **Develop a community of practice**
Bring experts, advocates and allies together to better identify, understand and address unmet needs of the SGD cancer community and healthcare professionals caring for them.

3 **Improve peer support**
Evaluate gaps in SGD cancer community peer support and co-develop peer support programming to include partnering with community organizations.

4 **Elevate queer and trans voices in the cancer community**
Collaborate with the community to source, develop and share patient stories in a variety of formats focusing on the unique experiences of SGD individuals affected by cancer.

5 **Build capacity and diversity**
Grow our organization to meet our increasing operational and community needs. To include; investing in website improvements, undertaking organizational incorporation, and increasing our community partners to broaden representation of identities and experiences.

Conclusion

For Queering Cancer's successful program development and expansion, it will be essential to plan our path effectively and continue building richly diverse partnerships, ensuring we are in the best position to secure grant funding from a variety of sources and implement impactful programming.
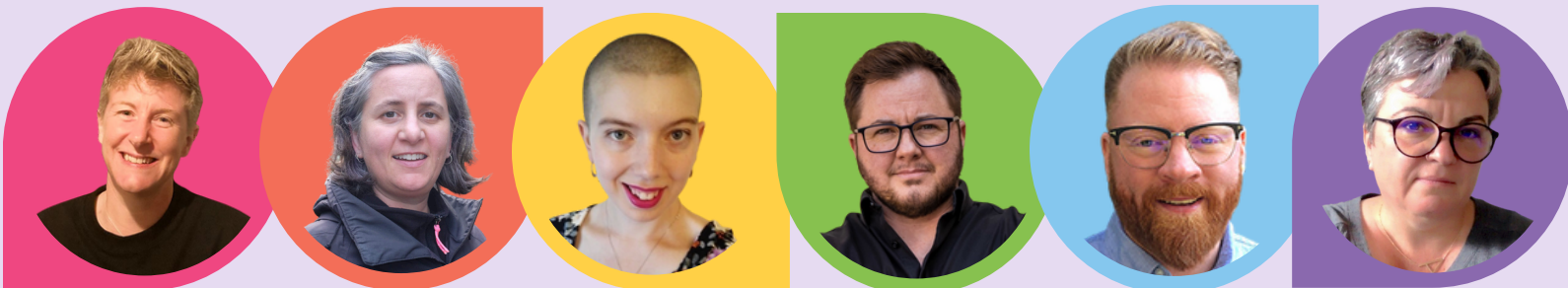
This project has underlined what the last three-plus years has shown us; Queering Cancer is more than a website and a social media presence, it is a community. Sexual and gender diversity has always needed, built, and found strength in, community. We will keep this at our core as we continue to take pride in inclusive cancer care together.

Acknowledgments

Queering Cancer would like to thank Derek Parker for their review and support with some graphical elements of this report. We would also like to extend our gratitude to the survey respondents, interview participants and everyone who continues to support us in our work. The image on page 10 is included with thanks to The Gender Spectrum Collection.

Kim, Laura, Meghan, Tristan, Evan & Amanda

CIHR IRSC
Canadian Institutes of   Instituts de recherche
Health Research   en santé du Canada

Suggested citation:
Queering Cancer (2024). Queering Cancer: Pride in Inclusive Cancer Care. queeringcancer.ca/wp-content/uploads/2024/05/report.pdf