Culturally responsive and accessible approaches to research involving LGBTQ2S+ populations

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Context and purpose

Objectives

This project identified key issues and opportunities related to culturally responsive and accessible data collection involving LGBTQ2S+ populations, as well as existing best or promising practices in health equity data collection and data governance. Specific objectives included:

- Summarizing **key issues and opportunities** for the development and implementation of culturally responsive and accessible approaches to defining, measuring, collecting, analyzing, and reporting on health outcomes and determinants of health among LGBTQ2S+ populations
- Identifying **case examples and promising practices** in culturally responsive and accessible methods across the research cycle, highlighting the key ingredients and mechanisms that support culturally responsive and accessible practices

Intended audience and purpose

- Public servants, researchers, and other stakeholders working in policy and research involving data collection with, for, and about LGBTQ2S+ people and communities.
    - Those engaged in community-specific research or data collection
    - Those involved in general research that may also include sexual orientation and gender identity (SOGI) identifiers
- The goal is to provide an introduction to culturally responsive and accessible approaches, highlighting key issues and opportunities along the research and data cycle.

Methods

Methods

Rapid review

- Review of 227 peer-reviewed and grey literature sources on relevant key issues, challenges, opportunities, and recent data advances in data collection with LGBTQ2S+ populations

Key informant interviews

- In-depth interviews with 20 key informants from across Canada involved in research with LGBTQ2S+ populations, and with a diversity of experience and expertise

Defining culturally responsive and accessible approaches

Culturally responsive and accessible approaches

“It is not just a matter of collecting more data, but collecting high-quality data that reflects the needs and perspectives of affected communities, and ensuring the processes of data collection, analysis, reporting, and action on health inequities are in themselves inclusive, equity-promoting, and responsive to communities.” (PHAC, 2021)

What is cultural responsiveness and accessibility?

Cultural responsiveness and accessibility are relatively new concepts. Applying cultural responsiveness and accessibility is:

- An **approach**. It is grounded in several underlying core principles.
- A **process**. It is not as simple as implementing individual practices. It takes time and commitment.
- **Contextual**. What type of data is being collected, why it is being collected, and by whom, will shape the specific processes and practices. They are not prescriptive.
- **Fluid and evolving**. The literature is extensive in some areas, and scant in others.

> *"It's not culture that links us together, it's the shared experiences of systems of oppression – homophobia, transphobia, especially as they interact with anti-Black racism, ableism." ~ Tyler Boyce*

Core principles

- **Community-centred:** grows out of community needs; supports capacity building; meaningfully involves community members; attends to diversity within LGBTQ2S+ communities.
- **Results-driven; action- and solution- oriented**: improves health and well-being of communities; responds to population needs; is actionable.
- **Flexible and tailored**: non-static and nuanced; recognizes change; allows for piloting, testing, and validation with communities.
- **Intentional, equity-driven, theoretically-grounded:** attends to power; considers whose voices are captured and amplified; employs a trauma-informed lens; addresses history of inequity and mistrust.
- **Data justice-oriented**: attends to fairness and transparency in data collection and reporting; engages with justice concerns in the analysis of information; supports data infrastructure and democratization.

Applying cultural responsiveness and accessibility

- Culturally responsive and accessible approaches can be **implemented by a variety of actors and organizations** involved in data collection initiatives across the entire spectrum of research. However, the level of community involvement and the specific practices will differ by the type of data, why it is being collected, and by whom.

- Ultimately, applying cultural responsiveness and accessibility in LGBTQ2S+ contexts is a **process – not a destination.** Those engaged in this work are encouraged to consider the core principles underlying these approaches to inform and build a set of practices to support cultural responsiveness and accessibility in their own unique contexts.

Engaging participants and communities

Key issues

- The history of research in LGBTQ2S+ contexts has fostered community mistrust
  - Oppression, and history of pathologizing, stigmatizing, and unethical research
- Research, data, and funding environments are not conductive to good engagement practices
  - Barriers to research funding applications; community capacity for engagement
- Engagement is a complex, political, and power-laden process
  - Who should be engaged? How can power and decision-making authority be yielded?

> *"Often there is already a mistrust within certain institutions, because of historical trauma, because parts of that community haven't been treated particularly well in those institutions…There's a lot of reasons why people don't trust the system [engaging in research and data work], and they're quite valid." ~ Marni Panas*

Opportunities

- Engaging early, engaging often
- Ensuring the right people are at the table
  - Project team composition and lived expertise
  - Community embeddedness, knowledge, and connections
  - Strategic, inclusive, and diverse engagement
- Valuing lived expertise and pursuing reciprocity
  - Acknowledging time, labour, and expertise through honoraria and capacity-building
- Making engagement substantive
  - Ensuring those engaged have autonomy; resisting tokenism

"What we're particularly interested in is creating opportunities for staff to develop the experience and expertise to look at research and see where that information can inform programs and at the same time develop staff competencies through the process." ~ Maura Lawless

In practice: Trans PULSE Canada

Trans PULSE Canada is regarded as an exemplar in the realm of participant and community engagement. Its team consists of community and academic researchers most of whom are themselves trans, in addition to family members and allies. Engagement practices included a central role for community members in interviewing and selecting the research team and “community soundings” conducted throughout the course of the project.

IN THIS CENSUS, TRANS & NON-BINARY PEOPLE COUNT!

Trans PULSE Canada is a community-based research survey for all trans and non-binary people aged 14+ in Canada.

Indigenous and trans, non-binary, gender diverse or Two-Spirit? *Trans PULSE Canada includes questions designed by and for Indigenous community members to better understand our health, wellness, and strengths.*

About Trans PULSE Canada

Trans PULSE Canada is a national community-based survey of the health and well-being of trans and non-binary people in Canada

INDIGENOUS LEADERSHIP GROUP

Comprised of Indigenous co-investigators who are academic or community researchers (including with the Canadian Aboriginal AIDS Network) as well as a larger group of research team members, Indigenous gender-diverse persons, and elders.

Defining research questions and objectives

Key issues

- What questions are (or are not) being asked
    - Defining questions and objectives is a complex and value-laden process
    - Without knowledge of and connections to LGBTQ2S+ communities, agendas risk being shaped by problematic or inaccurate assumptions
- Who is (or is not) asking the questions
    - Inequitable access to power and resources restricts agenda-setting ability
    - Agendas and questions may be pre-determined and inflexible
    - Differing priorities between governments, academic institutions, researchers, community organizations and community members

> *"To have good questions, you need to have good insight, and good relationships. And to build good relationships takes a lot of time…You can't just go to community partners when you need a letter of support." ~ Olivier Ferlatte*

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Opportunities

- Equipping and engaging communities to define agendas and questions
  - Building trust, relationships, and capacity
  - Creating project-based opportunities (e.g., advisory committees, peer researchers)
  - Adapting funding priorities and parameters (e.g., institutionalizing support for community-informed agenda-setting)
- Attending to diversity within the community, and adopting a strength-based orientation

> *"Sometimes it's developed really slowly, sometimes it happens really fast. But it's that interplay, that creative back and forth between people who are outside of academia, telling you what's happening for them and what they're noticing, and people in academia who are reading things and seeing patterns and trying to figure out what the connections are. It's a creative dynamic." ~ Margaret Robinson*

In practice: Investigaytors

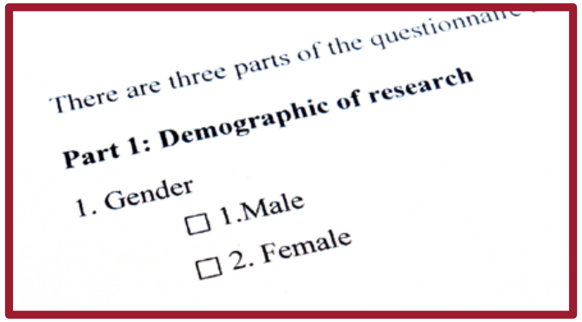
Established in 2011, CBRC's *Investigaytors* program aims to provide meaningful opportunities for young gay, bisexual, trans, Two-Spirit, and queer (GBT2Q) men to contribute to community-based health research.

- Capacity-building as the primary objective
- *Investigaytors* participants contribute across the research cycle, from developing project proposals to design, data collection, and analysis
- Participants also take part in knowledge translation, authoring numerous peer-reviewed publications and community reports as well as presenting at national and international conferences

Designing methods and measuring concepts

Key issues

- Complexity of concepts along with ongoing data gaps inhibit the collection of reliable, valid data about LGBTQ2S+ people and communities
  - Ongoing conflation of terms and concepts; limited measures
  - Inconsistent data collection across jurisdictions
  - Competing data goals and needs
- Choice of method has different implications for collecting data in culturally responsive and accessible ways



There are three parts of the questionnaire

Part 1: Demographic of research

1. Gender

☐ 1.Male

☐ 2. Female

> *"If we don't measure it, we don't attend to it. We can't address what we don't see. So, asking and collecting that data and measuring the priorities of the populations that are part of Canada is so critically important. Health equity will be addressed only if the people who are experiencing the inequities have some voice in the process and are made visible." ~ Elizabeth Saewyc*

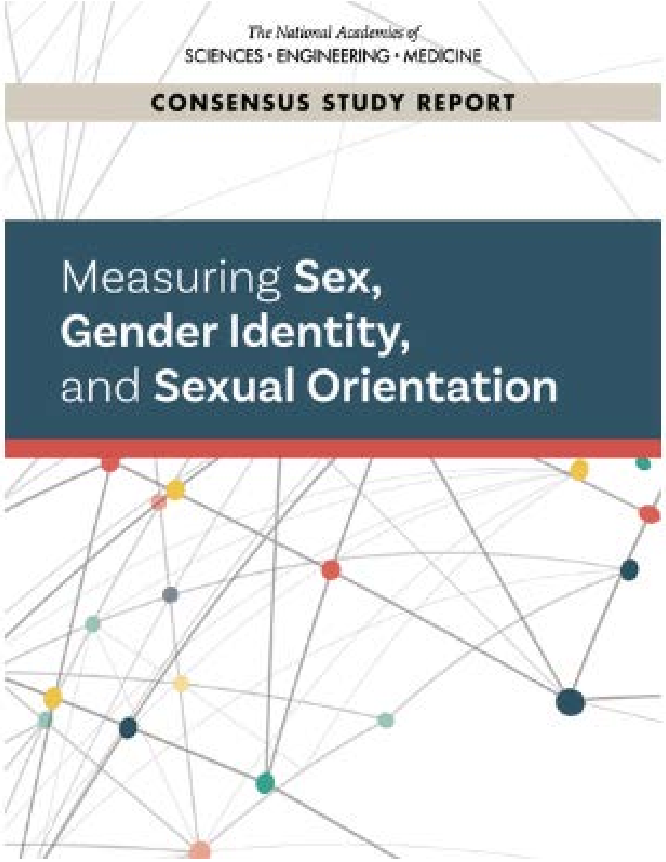
Opportunities

- A growing body of research on SOGI measures offers guidelines for practice
  - Specific considerations include collecting gender as the default variable, defining concepts and terms used, and avoiding othering language
- Moving beyond SOGI measures to capture LGBTQ2S+ people's lived experiences and their determinants
  - For instance: experiences of stigma, gender expression, identity affirmation, etc.
- Involving the community is key to identifying and measuring relevant, valid concepts
- Mixed methods offer a tool for more comprehensive and complex exploration

"It's about understanding the multifaceted experiences and health needs of diverse communities. For me, that requires a commitment to equity, mixed methods, interdisciplinary and community-based research, and the use of critical social science research approaches." ~ Daniel Grace

In practice: Existing measures guidelines

- Measuring Sex, Gender Identity, and Sexual Orientation (National Academies of Science, Engineering, and Medicine, 2022)
- Sex at birth and gender: Technical report on changes for the 2021 Census (Statistics Canada, 2020)
- Best Practices for Asking Questions about Sexual Orientation on Surveys (SMART) (Williams Institute, 2009)
- Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys (GenIUSS) (Williams Institute, 2014)


The National Academies of SCIENCES · ENGINEERING · MEDICINE

CONSENSUS STUDY REPORT

Measuring Sex, Gender Identity, and Sexual Orientation

Collecting data

Key issues

- The relevance of SOGI data collection is still contested
- Infrastructure for SOGI data collection across jurisdictions and settings is lacking
- There are concerns over safety and mistrust of data collection among LGBTQ2S+ populations
- Cultural competency skills during data collection are still lacking

> *"Queer and trans people will feel different differently about answering questions that are on the census survey versus on a community-based survey, so there's lots of complications there, but we still need to be asking the questions, even if there are limitations in terms of what people are willing to disclose to the federal government. For example, who's collecting the data? How is it going to be used what? Do you know what will happen with the data? For what purpose? It affects people's willingness to engage even within that effort." ~ Ben Klassen*

Opportunities

- Building infrastructure and modernizing SOGI data collection
    - Changes to EHRs; patient-centred approaches to collecting SOGI data
- Creating safe environments when collecting data
- Growing cultural competencies across research, clinical, and non-clinical teams
- Building trust with communities, patients and research participants
- Choosing optimal data collection modes

> *"The LGBTQ2 sector is growing and strengthening, but so much more needs to be done. The infrastructure is still growing, and still building strength – capacity building is an important part of being able to fully and optimally gather, share, and leverage data, knowledge and wisdom from communities and beyond." ~ Fernand Comeau*

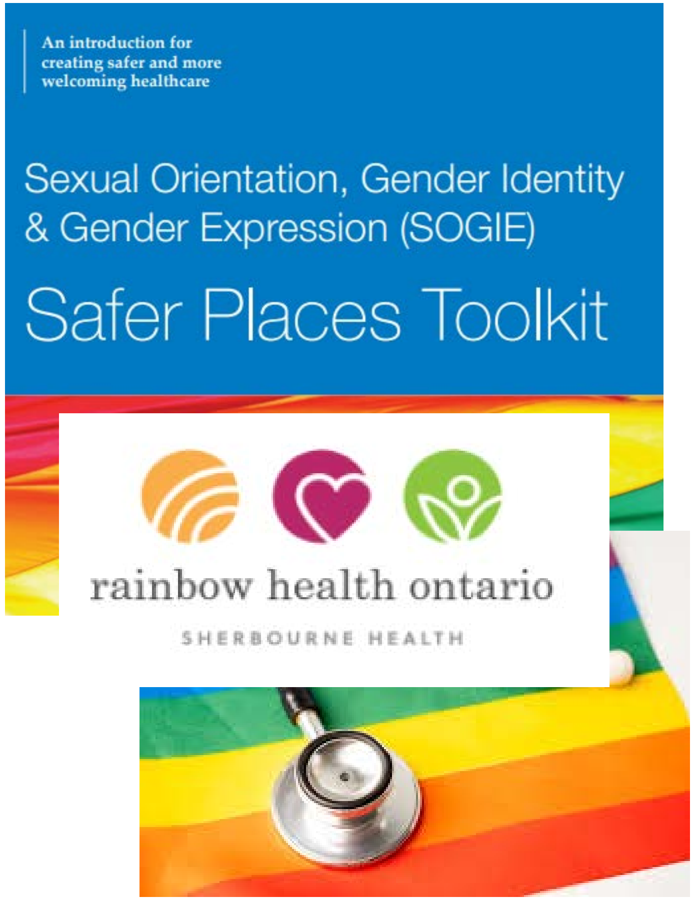
In practice: Collecting data with cultural competence

Providing a safe and welcoming environment is critical when collecting data with the LGBTQ2S+ community. Einhaus et al. (2018) describe the following strategies:

- Ensure that symbols of LGBTQ2S+ inclusion are visible
- Provide privacy when collecting data
- Ensure responses are kept confidential; inform respondents about confidentiality policies and practices
- Engage openly-LGBTQ2S+ staff or volunteers when collecting data
- Ensure that staff and volunteers who engage participants regularly receive LGBTQ2S+ cultural competency training and supervision, including how to meet the needs of community members who experience multiple forms of marginalization
- Ensure there is LGBTQ2S+ representation on the Board of Directors and among management, including those who represent the wide diversity of LGBTQ2S+ communities

In practice: Resources for clinical data collection

- **Canada Health Infoway Sex and Gender Working Group:** Established in 2019 to modernize gender, sex, and sexual orientation information practices, the work of the Group included an implementation strategy to modernize sex and gender information practices in EHR systems in Canada.
- **Rainbow Health Ontario Foundations Course:** Offered by Sherbourne Health for healthcare and social service providers seeking to build foundational knowledge for providing care to LGBTQ2S+ people. This 7-module self-directed course qualifies for Mainpro-M1 credits (Ontario).
- **Alberta Health Service's Safer Places Toolkit for Sexual Orientation, Gender Identity & Gender Expression:** A resource for health care professionals to increase awareness, encourage self-reflection, and build skills to provide welcoming and safe care for LGBTQ2S+ people and their families.



An introduction for creating safer and more welcoming healthcare

Sexual Orientation, Gender Identity & Gender Expression (SOGIE)

Safer Places Toolkit

Analyzing and interpreting data

Key issues

- Balancing accessibility and rigour
  - Limited time, resources, capacity, and methods for communities' engagement in analysis
- Data-related limitations to conducting disaggregated analyses
- Limited analytical frameworks and strategies that appropriately link to LGBTQ2S+ experiences and contexts

"We want our research to provide guidance, and when we produce overall research for a group without being attentive to intersectionality, we run the risk of producing results that might not provide the best advice for anybody. We could just average out a lot of effects and end up with something that's so shallow that it's not going to provide good guidance for communities; neither in terms of how to preserve and promote their own health, how to advocate for themselves, nor for the people advocating on behalf of those communities, or trying to make change to support their health." ~ Greta Bauer

Opportunities

- Equity-oriented approaches to meaningful co-analysis
  - Building capacity among community members to analyze and interpret findings, identify gaps, and guide future research directions

- Building capacity to conduct intersectional analyses

"When there's a lack of intersectional framework, it forces people to compartmentalize themselves: we create an environment where people have to choose what to speak on. It changes the context and how power collides. Lived experience looks like so many different things." ~ Debbie Owusu-Akyeeah

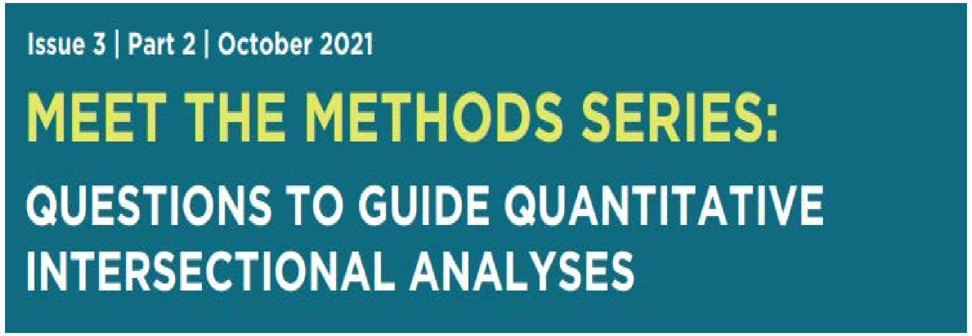
In practice: Resources on intersectional approaches

- **Intersectionality-informed Mixed Method Research:** This primer by Daniel Grace (2014) reviews existing intersectionality-informed mixed methods research using case studies focusing on gay men's health across the life course and key factors for mixed methods procedures, including timing, weighting, mixing, and theorizing.

- **Questions to Guide Quantitative Intersectional Analyses:** This Meet the Methods issue by Greta Bauer (2021) outlines guiding questions to develop analysis using intersectional approaches to quantitative data analysis in health research.

Intersectionality-informed
Mixed Methods Research: A Primer

Daniel Grace, PhD



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MEET THE METHODS SERIES:

QUESTIONS TO GUIDE QUANTITATIVE INTERSECTIONAL ANALYSES

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Reporting and knowledge sharing

Key issues

- Priority and capacity gaps prevent reporting and knowledge sharing
- Useful and relevant data to share may not exist
    - Data that is collected often lacks utility/relevance for LGBTQ2S+ communities
- Deciding how and with whom to share knowledge is complex
    - Challenges of crafting accessible, impactful, and ethical narratives
    - Risk of findings being misused or perpetuating stigma

> *“2SLGBTQ organizations are the best vehicle to reach our communities, but we cannot do that without support….A lot of research on 2SLGBTQ issues sits on shelves…because we don't have a sector that is organized and structured and able to disseminate research effectively.” ~ Fae Johnstone*

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Opportunities

- Considering the needs and priorities of knowledge users
    - Leveraging engagement to support knowledge translation
    - Tailoring messages according to audiences
    - Equipping LGBTQ2S+ civil society to support reporting and knowledge sharing
- Prioritizing utility and accessibility in knowledge translation
    - Making findings understandable, useful, and compelling

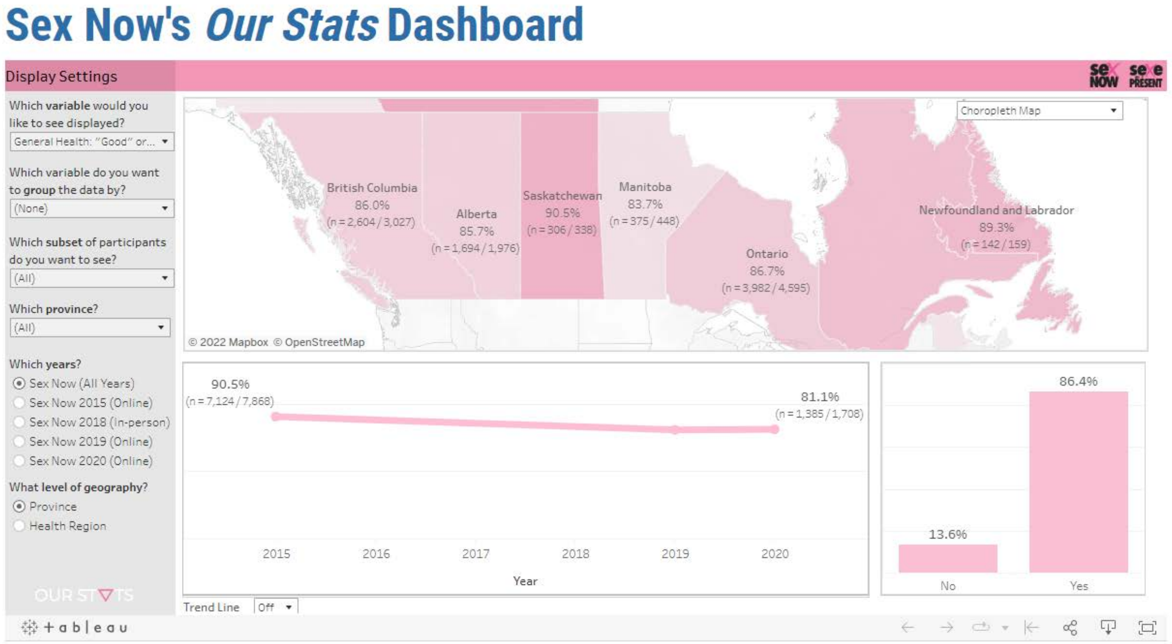
> *"Find the people who are willing to be champions and ask what data they need. What's the story they need need to be able to tell in order to make change?...A huge part of data mobilization is understanding...who are the key influencers, how they need to get information, and what's going to make a difference for them? What is it that would make them want to – have to – act on LGBT2SQ health? What is it they would need to understand?" ~ Devon MacFarlane*

In practice: Sex Now *Our Stats* dashboard

- The Community-Based Research Centre's *Our Stats* dashboard was launched in 2019 to make data from the Sex Survey Now more available and accessible to community members, advocates and leaders.

- Building on the Centre's principles of accessible data and knowledge sharing, it allows users to manipulate and visualize findings longitudinally, geographically, as well as filter observations by various demographic, behavioural, and health-related variables.

OUR ST▽TS



Sex Now's *Our Stats* Dashboard

Display Settings

Which **variable** would you like to see displayed?
General Health: "Good" or... ▾

Which variable do you want to **group** the data by?
(None) ▾

Which **subset** of participants do you want to see?
(All) ▾

Which **province**?
(All) ▾

Which **years**?
● Sex Now (All Years)
○ Sex Now 2015 (Online)
○ Sex Now 2018 (In-person)
○ Sex Now 2019 (Online)
○ Sex Now 2020 (Online)

What **level of geography**?
● Province
○ Health Region

Choropleth Map ▾

Trend Line Off ▾

Conclusion

Overarching opportunities

The opportunities presented throughout this report highlight the need for more structural supports and mechanisms to support both the application and development of culturally responsive and accessible approaches to research involving LGBTQ2S+ people and communities. These opportunities include:

- Building trust and developing capacity in the system and across different actors involved in research, data collection and analysis, and civil society
- Addressing data and knowledge gaps that inhibit progress and action
- Developing a comprehensive data infrastructure with the aim of modernizing SOGI data collection in Canada
- Embedding and integrating efforts within existing provincial and federal initiatives