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Culturally responsive and accessible approaches to research: LGBTQ2S+ populations

Final report

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EXECUTIVE SUMMARY

WHAT IS THIS REPORT ABOUT?

Data increasingly show that LGBTQ2S+ (including lesbian, gay, bisexual, transgender, queer, and Two-Spirit) populations in Canada experience social, economic, and health disparities rooted in systemic stigma and discrimination. Longstanding gaps in data and evidence on health and its determinants among LGBTQ2S+ people and communities inhibit our ability to address those inequities. In turn, there have been increasing calls for data collection with LGBTQ2S+ populations that is more culturally responsive and accessible, so as not to perpetuate any further harms or systemic discrimination. The concern is not just about collecting more data, but ensuring data are of a sufficiently high quality to accurately reflect the needs and perspectives of affected communities. Processes of data collection, analysis, reporting, and action on health inequities also need to be inclusive, equity-promoting, and responsive to communities.

This project sought to identify key issues and opportunities relating to 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. The project was funded by the Public Health Agency of Canada (PHAC) and carried out by the Social Research and Demonstration Corporation (SRDC).

WHO WILL FIND IT USEFUL?

This report is aimed at public servants, researchers, and other individuals or groups working in policy and research involving data collection with, for, and about LGBTQ2S+ people and communities. It is intended for those engaged in data collection in the context of community-specific research *as well as* those involved in general research that may also include sexual orientation and gender identity (SOGI) identifiers. The goal is to provide a practical introduction to culturally responsive and accessible approaches, highlighting key issues and opportunities at each stage of research. This process should not be seen as a linear sequence; rather, activities in all stages of the research cycle should inform each other.

HOW WAS THIS REPORT DEVELOPED?

The findings of this report draw on a rapid review of peer-reviewed and grey literature summarizing relevant key issues, opportunities, and recent advances in data collection with the

LGBTQ2S+ population. We also conducted in-depth interviews with diverse key informants from
across Canada involved in research with LGBTQ2S+ populations.

WHAT ARE THE KEY FINDINGS?

Defining cultural responsiveness and accessibility

There are several key takeaways to keep in mind when thinking about cultural responsiveness
and accessibility. **Applying cultural responsiveness and accessibility is:**

- **An approach**. It is grounded in several core principles, some of which may be shared with
  other different, albeit related, concepts.

- **A process**. It is not as simple as implementing individual practices. It takes time and
  commitment.

- **Contextual**. Processes and practices are not prescriptive, but are shaped by the types of data
  collected, why they are collected, and by whom.

- **Fluid and evolving**. The literature is extensive in some areas, and scant in others.

The following are core principles underlying culturally responsive and accessible approaches:

- **Community-centered:** grows out of community needs; supports capacity-building;
  meaningfully involves community members throughout all phases; attends to diversity
  within the community.

- **Results-driven; action- and solution-oriented**: improves health and well-being of
  communities; responds to population needs; and 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 related 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.

There is a wide range of actors currently involved in the collection of different types of data with and about LGBTQ2S+ people and communities in Canada. What types of data are being collected, why are they being collected, and by whom, will shape the specific processes and practices involved in the development and implementation of culturally responsive and accessible approaches. Those engaged in research efforts involving LGBTQ2S+ people and communities are encouraged to consider the core principles underlying cultural responsiveness and accessibility to inform and build a set of practices to support such approaches in their unique contexts.

Engaging participants and communities

Engagement refers to the ways in which those involved in research interact, cooperate, or collaborate with community-based and other actors throughout these efforts. Decisions about how, when, with and by whom engagement occurs can be informed by several factors, including the nature, methodology, and purpose of a project as well as the capacity and orientation of those involved. Issues we identify at this phase of the research cycle include community mistrust fostered by a history of harmful research, the absence of conducive structures supporting good engagement practices, and the inherent complexities of engagement. The main opportunities include early and frequent engagement, a commitment to engaging the appropriate individuals and groups, valuing expertise and pursuing reciprocity through engagement, and ensuring engagement activities are substantive in nature.

Defining research objectives and questions

Defining research questions involves agenda-setting: it is in this phase of research that goals or objectives are established, and decisions are made about what research is conducted and what data are or are not collected. Key issues include what questions are (or are not) being asked and who is (or is not) asking them. These decisions carry direct implications for LGBTQ2S+ communities, including whether the questions themselves are meaningful and valid. The main opportunities for supporting culturally responsive and accessible approaches in this phase of research included equipping and engaging communities to define agendas and questions, as well as attending to diversity within the community, and adopting a strength-based orientation.

Designing methods and measuring concepts

Existing research on the design of methods and measuring concepts focuses predominantly on SOGI data. The multiplicity and complexity of measures and concepts related to gender and sexual orientation along with ongoing data gaps in Canada inhibit the collection of reliable, valid data on LGBTQ2S+ communities. Furthermore, the choice of method has implications for whether the data collected are culturally responsive and accessible.

Our research identified several opportunities in this phase of the research cycle. They include drawing on the growing body of research on SOGI measures to guide practice, moving beyond SOGI measures to capture LGBTQ2S+ peoples' lived experiences and their determinants, involving the community to identify and measure relevant, valid concepts, as well as the use of mixed methods for more comprehensive and nuanced exploration of issues and experiences.

Collecting data

Because of the history of pathologizing and unethical data collection with LGBTQ2S+ communities along with ongoing discriminatory attitudes, this phase of research requires attention to issues of safety and the risk of harm. Our findings focus particularly on the collection of SOGI data in healthcare contexts. Several key issues emerged, beginning with the fact that the relevance of SOGI data collection is still being contested, and there are concerns over privacy and mistrust of data collection. Further, a lack of infrastructure for SOGI data collection across jurisdictions and settings is compounded by gaps in cultural competence in data collection. Indeed, building infrastructure and modernizing SOGI data collection, building trust with communities, patients, and research participants, creating safe environments when collecting data, and growing cultural competencies of teams, emerged as key opportunities to support culturally responsive and accessible data collection. Other opportunities centred around choosing optimal data collection modes.

Analyzing and interpreting data

There is a dearth of literature on analytical approaches specific to sexual and gender minorities when it comes to analyzing and interpreting data in culturally responsive and accessible ways. Our findings centre on intersectionality and focus on approaches to analysis rather than specific practices. Key issues identified in our research include balancing accessibility and rigour, along with data-related limitations to conducting disaggregated analyses. There are also limited analytical frameworks and strategies that appropriately link LGBTQ2S+ experiences and contexts. The main opportunities identified for supporting culturally responsive and accessible approaches in this phase of research include equity-oriented approaches to meaningful co-analysis and building capacity to conduct intersectional analyses.

Reporting and knowledge sharing

A commitment to thoughtful and impactful reporting and knowledge sharing is key to cultural responsiveness and accessibility in research or data initiatives involving LGBTQ2S+ populations. Effective knowledge translation can ensure that findings are readily available to those most affected and can support policy change, inform programming and service provision, and equip

communities with the knowledge they need. In terms of key issues identified, we found that there are capacity gaps preventing reporting and knowledge sharing; useful and relevant data to share may not exist; and deciding how and with whom to share knowledge is complex. The main opportunities related to knowledge sharing include considering the needs and priorities of knowledge users, and prioritizing utility and accessibility in knowledge translation.

WHAT ARE THE REPORT'S CONCLUSIONS?

This report summarized findings with respect to key issues and opportunities related to culturally responsive and accessible research involving LGBTQ2S+ populations. Drawing on a rapid review of literature and interviews with key informants from across Canada, it sought to identify principles and practices to support culturally responsive practice in the process of producing research.

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 the different actors involved in research, data collection and analysis, and civil society

- Addressing data and knowledge gaps that currently 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.

Culturally responsive and accessible approaches to research are informed by several core principles. What types of data are being collected, why are they being collected, and by whom must be explicitly taken into account. Ultimately, applying cultural responsiveness and accessibility in LGBTQ2S+ contexts is a process – not a destination. While we hope this report is useful for those seeking to advance cultural responsiveness and accessibility in their own research endeavours, it should only serve as a starting point. We encourage readers to leverage its guidance to inform and build practices applicable to the unique contexts in which they live and work.

INTRODUCTION

CONTEXT AND PURPOSE

Data increasingly show that LGBTQ2S+[a] (including lesbian, gay, bisexual, transgender, queer, and Two-Spirit) populations in Canada experience social, economic, and health disparities rooted in systemic stigma and discrimination.[1–6] Furthermore, the COVID-19 pandemic has compounded existing inequities, with recent survey data showing disproportionate impacts on employment, household finances, and physical and mental health among LGBTQ2S+ populations, and particularly, racialized members of those populations.[7–9]

Longstanding gaps in data and evidence on health and its determinants among LGBTQ2S+ people and communities continue to pose a challenge to reducing health and social inequities in Canada.[10] However, government entities responsible for data collection, reporting, and action have historically perpetuated harms towards LGBTQ2S+ communities.[160] Given this historical, social, and political context, there have been increasing calls for data collection with LGBTQ2S+ populations that is more culturally responsive and accessible, so as not to perpetuate any further harms or systemic discrimination.[10] The concern is not just about collecting more data, but ensuring data are of a sufficiently high quality to accurately reflect the needs and perspectives of affected communities. Processes of data collection, analysis, reporting, and action on health inequities need also to be inclusive, equity-promoting, and responsive.

Funded by the Public Health Agency of Canada (PHAC) and carried out by the Social Research and Demonstration Corporation (SRDC), this research initiative sought to identify key issues and opportunities related to culturally responsive and accessible data collection, analysis, and reporting with LGBTQ2S+ populations, alongside existing best or promising practices in health equity data collection and data governance. The specific objectives of the project were to:

1. Summarize key issues and opportunities for the development and implementation of culturally responsive and accessible approaches along the research cycle.

2. Identify case examples and promising practices in culturally responsive and accessible approaches, highlighting key ingredients and mechanisms that support these practices.

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a   While this report uses LGBTQ2S+ to refer to gender and sexual minority individuals as a community, terminology is constantly evolving, and others may prefer different acronyms. The "+" in LGBTQ2S+ intends to convey the inclusion of individuals whose identities may not be explicitly represented in this acronym. We recognize the challenges of using one term to convey a rich diversity of gender and sexual identities, and associated experiences and outcomes.

ABOUT THIS REPORT

This report is aimed at public servants, researchers, and other individuals or groups working in policy and research involving data collection with, for, and about LGBTQ2S+ people and communities. It is intended for those engaged in research in the context of community-specific research *as well as* those involved in general research, which may include sexual orientation and gender identity (SOGI) identifiers. The goal is to provide a practical introduction to culturally responsive and accessible approaches, highlighting key issues and opportunities at each stage of research including planning, data collection, and analysis. This process should not be seen as a linear sequence; rather, activities in all stages of the research cycle should inform each other.

Cultural responsiveness and accessibility are relatively new concepts, and their broader use and understanding relatively limited. The intent here is to explore more deeply the meaning and use of these and similar concepts within the literature and through dialogue with the informants. Here are several key takeaways from our findings that are important for those seeking to promote cultural responsiveness and accessibility in their research efforts to keep in mind. **Applying cultural responsiveness and accessibility is:**

- **An approach**. It is grounded in key underlying principles, some of which may be shared with other different albeit related concepts (e.g., ethical research, cultural competence).

- **A process**. Collecting data with, about, and for LGBTQ2S+ people and communities is not as simple as implementing individual practices. While we illustrate specific practices in this report that support this type of approach, this work requires time, commitment on the part of multiple actors, and even cultural shifts.

- **Contextual**. Context is critical to collecting culturally responsive and accessible data with and about LGBTQ2S+ people, in particular – what type of data is being collected, why it is being collected, and by whom. As such, the practices highlighted are not intended to be prescriptive; they do not represent a checklist to be followed. Rather, they provide examples of practices that may – and often should – differ according to context.

- **Fluid and evolving.** Because the body of literature is extensive in some areas and scant in others, the examples and practices described may be more or less robust, such as those aimed at a particular context (e.g., collecting SOGI data in clinical settings), or specific methodological approaches such as community-based, participatory research). As such, the examples and practices described are not exhaustive.

We encourage readers to consider the core principles underlying cultural responsiveness and accessibility to inform and build a set of practices to support such approaches in their unique contexts. Appendix A offers additional resources to this end.

METHODOLOGY

RAPID REVIEW

We conducted a rapid review[11] of select peer-reviewed and grey literature related to key issues, challenges, opportunities, and recent advances in the development of datasets in LGBTQ2S+ contexts.[11,12] The review sought to identify considerations across the research cycle, with a particular focus on health outcomes and determinants among LGBTQ2S+ individuals and communities. To ensure the review was purposeful and practical and to draw out key research insights, we proceeded iteratively, adapting searches by adding or refining search terms as necessary. Searches covered a variety of peer-reviewed and grey literature databases and were complemented by hand-searches of specific grey literature sources (e.g., in French Canadian contexts). The full list of search terms and sources informing this review are included in Appendices B and C, respectively.

The following inclusion and exclusion criteria guided the rapid review:

- Language: English, French

- Years: 2010 – present (some resources published outside of that time frame were included if identified as particularly relevant to the topic area, on an exceptional basis)

- Dealt directly with research or data involving LGBTQ2S+ individuals and communities, focused on middle and high-income country contexts

- Focused on approaches to research and data involving LGBTQ2S+ individuals and communities, either in its entirety or through a detailed methods section.

Ultimately, this process led us to review a total of 227 sources. We grouped sources according to the phase of the research cycle to which they were most relevant. Sources from each phase were assigned to individual researchers for review. This process included classifying the source's relevance and extracting key information with respect to study methodology, findings along the research cycle, and recommendations. Team members grouped findings at each phase thematically and presented them to the broader research team for validation, discussion, and refinement.

KEY INFORMANT INTERVIEWS

Given the relatively short record of published research in this area, we conducted interviews with key informants involved in research and data with and about LGBTQ2S+ populations across Canada. We sought to speak with individuals who collectively brought a diversity of expertise in terms of subject matter (e.g., HIV/AIDS, social inclusion, substance use), populations of focus (e.g., bisexual women, gender minority youth, Black sexual minority men), stages of the research cycle (e.g., defining methods and measuring concepts, reporting and knowledge sharing), and contexts (e.g., clinical settings, community-based research).

We drew on our team's prior knowledge to generate an initial list of potential participants, a process that was further informed by suggestions from PHAC and other key informants. We contacted participants in waves, informed by preceding interviews as well as identified gaps and discoveries in the rapid review (e.g., that an organization or researcher was particularly relevant). A list of key informants is provided in Appendix D. Ultimately, we conducted 20 in-depth interviews with key informants with experience in at least one (and more often several) of the following four categories:

A. Experts in health equity data, data governance, and research involving LGBTQ2S+ populations;

B. Organizational and community leaders serving LGBTQ2S+ populations;

C. Government actors working to improve culturally relevant data and research practices;

D. Community advocates calling for improvements to data infrastructure.

The interviews were intended to be exploratory and practice-based, rather than exhaustive, at the cost of some limitations in coverage (e.g., limited clinical experience among key informants). Interviews explored how cultural responsiveness and accessibility were conceptualized and applied in participants' work; promising practices and challenges; and the structures and processes needed to support cultural responsiveness and accessibility on a larger scale. Conversations lasted up to 90 minutes and were conducted by teams of two researchers.

With participants' consent, interviews were recorded. The recordings supplemented detailed interview notes as needed. These notes were annotated by team member to signal emerging themes and identify key quotes, which were presented to the broader team for validation, discussion, and refinement. Participants consented separately to participate in the interview and to have quotes attributed to them. Quotes, along with the proposed attribution and organizational affiliation, were sent to participants for feedback prior to inclusion here.

CONTEXTUALIZING CULTURAL RESPONSIVENESS AND ACCESSIBILITY

DEFINING CULTURALLY RESPONSIVE AND ACCESSIBLE APPROACHES

A central goal of this project was to develop a more nuanced understanding of culturally responsive and accessible approaches to research, data, and evidence with, for, and about LGBTQ2S+ individuals and communities. **Cultural responsiveness and accessibility approaches** to define, measure, collect, analyze, and report on health outcomes and determinants among LGBTQ2S+ populations are described by PHAC as follows:

> *"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"* (p. 9).[10]

SRDC's research found limited use of the term *culturally responsive and accessible approaches* by others.[13] Although the term itself was all but absent from published literature, SRDC identified similar concepts such as community-based participatory research (CBPR), ethical research, and cultural competency within research. While terms such as cultural competence,[14] cultural sensitivity,[15] cultural safety, and cultural humility tended to appear in health care contexts, cultural responsiveness was primarily used in education and pedagogical fields.[16]

While most key informants we spoke with were not familiar with the term, they understood its intention and meaning. Many spoke of cultural responsiveness and accessibility as closely tied to community-based, ethical, and other principle-based approaches to research (e.g., OCAP®, trauma-informed). They described such approaches as grounded in several guiding principles to be integrated throughout the research cycle:

> *"Is it culturally safe to participate? Are we asking the right questions in the right way? Do we have to answer all the questions? Are we making assumptions about those answers to those questions? What are we going to do with the data? Are we truly being honest about the data we're trying to collect? What decisions are we going to make from it? Should we be asking other questions instead? So that's part of being culturally safe: it's about building trust with the participants who are providing that data to know that it'll be used in a way that is helpful…, that it'll have an impact on the decisions of the services that are going to be provided to me in my community."* ~ Marni Panas

Drawing on our findings, the following section identifies principles of culturally responsive and accessible approaches to research involving LGBTQ2S+ populations.

CORE PRINCIPLES OF CULTURALLY RESPONSIVE AND ACCESSIBLE APPROACHES

- **Community-centred:** grows out of community's needs; supports capacity-building; meaningfully involves members throughout all phases; attends to diversity within LGBTQ2S+ communities.[b]

  "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

  For several informants, this principle was inextricably linked with CBPR approaches, whereby LGBTQ2S+ community members' knowledge is seen as vital to the success of the research and the focus is on solving problems that are meaningful and empowering for LGBTQ2S+ communities.[21,22] Importantly, most informants stressed that community-centered does not mean needing to include everyone and emphasized the need to attend its diversity:

  "I think it's important to recognize that there are people who do really good, culturally relevant work with one aspect of the community, and not necessarily universally…it is not a monolith. The growing number of identities included in the acronym are diverse within each of those letters, much less across the letters." ~ Elizabeth Saewyc

- **Results-driven; action- and solution-oriented:** improves health and well-being of communities; responds to population needs; and is actionable.

  "Accessible research to me means research that we can use, that is mobilized, that is leveraged, but also research that is understandable." ~ Fae Johnstone

  Key informants made an explicit link between culturally responsive and accessible approaches and the collection of both high-quality and valid data. In turn, ensuring that optimal data are collected from LGBTQ2S+ communities is an important step toward producing high-quality research that can both improve understanding of LGBTQ2S+ people's life experiences and help to redress persisting inequities.[23]

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[b] By "community" we mean a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings.[17] In this report, we use the term "community" to refer to the diverse LGBTQ2S+ communities living across Canada.[18–20]

- **Flexible and tailored:** non-static and nuanced; recognizes change; allows for piloting, testing, and validation with communities.

  "Qualitatively, any culturally responsive data to inform surveys or policy development has to include voices of the populations, with room to express themselves in their preferred language, with colloquialisms. It needs to allow for topics to be defined by the person, not just by the institution." ~ Lance McCready

  Given rapidly evolving issues and terminology, informants stressed the importance of allowing participants to self-describe their identities and experiences, as well as piloting and validating methods, measures, and findings with the relevant communities. Flexible and contextualized approaches also require being frank in acknowledging that methods or measures may not be perfect. Finally, this principle of ensuring research is flexible and tailored was seen as key to addressing mistrust within 2sLGBTQ+ communities, as well as to supporting data validity and reliability.

- **Intentional, equity-driven, and theoretically grounded:** attends to power; considers whose voices are captured and amplified; employs a trauma-informed lens; addresses history of inequity and mistrust.

  "As somebody who's out to create change for queer, trans, and 2S folks, I need data that can tell a story. I need data that can be broken down so we can understand what is going on for diverse parts of LGBT2SQ populations, I need data that allows me to say – here are the inequalities." ~ Devon MacFarlane

  Data collection that takes an intentionally equity-driven lens was identified as paramount to cultural responsiveness and accessibility in LGBTQ2S+ contexts. Initiatives grounded in critical approaches and methodologies and explicitly social justice-informed were seen as especially to important to seeking out populations and their subgroups that have been either traditionally excluded and/or not typically engaged because of historical over-research or stigma, among other reasons. This principle brings attention to power, and the need for capacity-building in the removal of long-standing barriers to participation in research.

- **Data justice-oriented:**[c] attends to fairness and transparency in the collection and reporting of data; engages with justice concerns in the analysis of information;[25] supports data infrastructure and democratization.

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[c]   Data justice means fairness in the way people are made visible, represented, and treated in the production of data.[24]

> *"There's a desire at many community organizations to reflect the work of people's lives within public policy decisions. But there is no framework or mechanism to allow community organizations to do that in a way that's manageable. In the absence of that [framework or mechanism], I don't think [cultural responsiveness] is achievable."* ~ Maura Lawless

The principle of data justice was interpreted differently in the literature and by key informants (e.g., data democratization and data transparency vs. data surveillance). At its core, cultural responsiveness and accessibility involve careful thinking about why data are being collected, who data are for, and what is going to happen with them, especially with communities that face multiple barriers or may be highly stigmatized. While this principle was seen as key to building trust and gathering high-quality data, key informants stressed that attending to this principle requires a robust data infrastructure and capacity-building at multiple levels.

> **The principle of data justice invites us to consider who is the beneficiary of how data about LGBTQ2S+ people are used**
>
> *"Most LGBTQ people already know that homophobia, biphobia, and transphobia exist and permeate structures of everyday life… For LGBTQ people with first-hand experiences, data is not necessary to prove the existence of these problems"* (Guyan, 2022, p. 11-12).[30]

> ## Other principles for LGBTQ2S+ research
>
> In developing actionable research priorities for LGBTI* inclusion, Badgett and Crehan (*authors' acronym) proposed other principles for research, some of which are reflected in the principles we described:[48]
>
> - The importance of LGBTI community leadership and participation
> - The responsibility of governments to develop knowledge and data about LGBTI people and their inclusion and rights, including to inform laws, policies, programs, and budgetary priorities to advance these objectives
> - The use of ethical, safe, and respectful methodologies that are most appropriate for and effective in different contexts
> - The importance of research partnerships between governments, civil society, academia, and multilateral institutions
> - The understanding that research should be relevant and useful in improving the lives of LGBTI people.

Culturally responsive and accessible approaches can be implemented by a variety of actors and organizations involved in different types of research and data collection initiatives. However, the practices and approaches will differ by the types of data and the setting in which they are collected. As such, we warn that the specific practices presented may not be translatable nor appropriate in all research contexts. Later sections of this report highlight key issues and opportunities related to cultural responsiveness and accessibility across various stages of the research cycle. Prior to this, we explore three key questions intended to guide cultural responsiveness and accessibility at an overarching level: 'Who is collecting the data', 'What data are being collected?', and 'Why are data being collected?' Below, we highlight the key considerations in these areas.

WHO IS COLLECTING THE DATA?

There is a wide range of groups, individuals, and institutions in Canada currently engaged in research and data collection involving LGBTQ2S+ people and communities, including:

- LGBTQ2S+ people and communities (e.g., participation in CBPR initiatives);

- Civil society actors and community organizations (e.g., as part of service delivery, market researchers, drug companies, financial institutions, media);

- Academics and researchers (e.g., research studies);

- Clinicians and service providers (e.g., as part of routine health data collection); and

- Bureaucrats, policymakers, and government agencies (e.g., population data and surveillance).

Community involvement in research can vary widely, on a spectrum from efforts that are entirely investigator-driven, through those that are community-informed, to those that strive for community ownership. Culturally responsive and accessible approaches can be implemented by any actor across this entire spectrum. The level of community involvement and the question of who makes up the community will vary depending on the goals of the research, the type of data collected, the methods employed, and other contextual factors.

However, we heard there are key issues of power, resources, and capacity that systematically prevent or privilege certain individuals' and groups' involvement in research. In particular, structural barriers such as a lack of infrastructure, capacity, and training can result in the limited capacity of LGBTQ2S+ individuals and organizations to both lead and be involved in research initiatives. We heard from key informants about the lack of diversity on research teams, which in turn reduced

> **Culturally responsive and accessible approaches can be implemented by any actor across the entire spectrum of research**
>
> The level of community involvement and the question of who makes up the community will vary depending on the goals of the research, the type and method of data collected, and other contextual factors.

opportunities for meaningful and non-tokenistic participation of certain community members, particularly Black, Indigenous, and other racialized LGBTQ2S+ individuals.

The literature pointed to additional considerations regarding who is involved in research, particularly whether those individuals are or are not LGBTQ2S+ themselves, raising questions of power and ethics.[26,27] The literature highlighted the need for researcher disclosure and self-identification in addressing power differentials,[28] amplified risks of emotional distress and secondary trauma for LGBTQ2S+ researchers engaged in this work,[29] and noted concerns about ostracization as a result of becoming associated with LGBTQ2S+ research work.[26]

WHAT DATA ARE BEING COLLECTED?

When addressing culturally responsive and accessible approaches, both the literature and key
informants discussed a wide range of data collected about LGBTQ2S+ people and the types of
settings in which they are collected. Examples included clinical data collected in both research
and clinical settings, population-level data, and qualitative and quantitative research data
(observational, program/service, and systems), among others.

Two main distinguishing features emerged in the types of data collected as part of LGBTQ2S+
health research and data endeavours:

▪ **Sexual orientation and gender identity (SOGI) data with all patients and participants
in clinical or research settings**

The collection of SOGI data enables disaggregation of findings (e.g., patient experiences,
hospitalizations, prevalence rates, efficacy of interventions, etc.) by population subgroups to
better understand health inequities and their determinants. Because everyone has a sexual
orientation and gender identity – not only LGBTQ2S+ individuals – these are data that can
be collected universally. A more fulsome
discussion of SOGI data is included in
subsequent sections of this report.

▪ **Data on health outcomes and
determinants in general and
community-specific research and
clinical contexts**

This can include the collection of data as
part of community-specific research
(e.g., experiences of discrimination, access to gender affirming health care), but also general
research (e.g., population health surveys).

> **Culturally responsive and accessible
> approaches can be implemented in the
> collection of:**
>
> ▪ SOGI data with all patients and participants in
> clinical or research settings, and
>
> ▪ Data on health outcomes and determinants in
> general and community-specific research and
> clinical contexts.

WHY ARE DATA BEING COLLECTED?

The goals and motivations guiding research and the collection of data with, for, and about
LGBTS2S+ people and communities vary widely.[30] Most often, the reasons are guided by who is
collecting the data (e.g., personal or professional motivations) as well as organizational- or
funder-level mandates and objectives. The key informants we spoke with shared diverse
motivations, drivers, and purposes for the LGBTQ2S+ research work in which they had been
involved, including:

- To respond to urgent health issues or crises

- To pursue better or more ethical
  research and data collection

- As part of routine clinical practice
  and in-patient settings

- To solve policy problems, generate
  solutions, and facilitate change

- To support community engagement
  and/or consultation processes

- To inform or develop policy and
  programming

- To support evidence-informed
  activism

- To meet funder requirements.

> ## Motivations for LGBTQ2S+ research
>
> *"A lot of the dominant research work being conducted at the time was largely pathologizing…Responding to the historical situation, CBRC [Community-Based Research Centre] formed to generate research that answered questions by and for our communities, to generate solutions to these types of challenges."* (Ben Klassen)
>
> *"I'm out to queer the health care system in Canada."* (Devon MacFarlane)
>
> *"Previously I had been a queer activist…It seemed like a natural development to sort of academize what I had already been doing…Research was kind of a tool to do that activist work with…, it was a lot of answering questions so that I could do better activism."* (Margaret Robinson)

Our findings underscore the value of collecting data about LGBTQ2S+ communities in helping identify and address health inequities as well as community-specific needs. At the same time, informants stressed the importance of first asking if and how the data are relevant, whether they should be collected at all, and if so, how. These central questions are posed in a recent book on gender, sex, and sexuality data for action (featured in the highlight box below), whose author asks: 'Why do we collect data this way?', 'Whose interests does data serve?', and 'Why do we collect data at all?'[30]

To this end, in the following sections of this report we outline key considerations across the research cycle when defining, measuring, analyzing, and reporting data about LGBTQ2S+ populations. Alongside the overarching principles of cultural responsiveness and accessibility described previously, these considerations aim to serve as a guide for those engaged in research involving LGBTQ2S+ individuals, communities, and issues.

Queer data: Using gender, sex, and sexuality data for action

"Queer data is a tension. On one hand, it freezes in time and space particular ideas about what it means to identify as lesbian, gay, bisexual, trans and/or queer. It establishes these meanings as categories, which are fed into counting machines and used as the basis for decision-making. This construction and deployment of categories are at odds with the queering of data, which critically questions the foundations upon which these categories stand, the value granted to some identities above others and who actually benefits from the collection, analysis, and use of data about LGBTQ people.

Queer data is more than a study of individuals that sit outside the categories of heterosexual and cisgender. It is equally a brash, confrontational, and in-your-face challenge to conventional understanding of how data and identities intersect – how people respond to queer data and identities is either their problem or their wake-up call. As an approach to data and identities, queer data disrupts the binaries of male/female, heterosexual/homosexual and cis/trans and asks us to reconsider the notion that 'numbers speak for themselves.' When data captures the lives and experiences of LGBTQ people, numbers do not speak for themselves – they always speak for someone… decisions made about who to count, what to count and how to count are not value-neutral but bring to life a particular vision of the social world.

Queer data exposes the decisions made about data, from collection to its use for action, to ensure that data about LGBTQ people is used to construct a social world that values and improves the lives of LGBTQ people" (Guyan, 2022, p. 1).[30]

ISSUES AND OPPORTUNITIES ACROSS THE RESEARCH CYCLE

ENGAGING PARTICIPANTS AND COMMUNITIES

Context

Engagement here refers to the ways in which those involved in research interact, cooperate, or collaborate with community-based and other actors throughout such efforts. There is not one uniform approach to engagement; our findings depict a complex picture as to what constitutes appropriate, meaningful, and responsive engagement with LGBTQ2S+ participants and communities. Decisions about how, when, with whom, and by whom engagement occurs can be informed by several factors, including the nature, methodology, and purpose of a project, as well as the capacity and orientation of those involved (and/or need to be involved). Engagement may embrace recruiting LGBTQ2S+ community members to a project team, leveraging a steering or advisory committee to guide a project, or engaging in community consultations, among other approaches. Rather than prescribe specific types or forms of engagement, we focus instead on highlighting the considerations, principles, and practices that may be applicable across a range of research and data collection initiatives.

This section summarizes the key issues and opportunities related to culturally responsive and accessible approaches at the stage of participant and community engagement. Key issues include a history of harmful research in LGBTQ2S+ contexts which has fostered community mistrust, the absence of structures conducive to practices supporting strong and effective engagement, and the complex decisions required in engagement. Key opportunities include early and frequent engagement, a commitment to engaging appropriate individuals and groups, valuing expertise and pursuing reciprocity through engagement, and ensuring engagement activities are substantive in nature.

Key issues

The history of research in LGBTQ2S+ contexts has fostered community mistrust

The historical context of research with and about LGBTQ2S+ people poses a major barrier to engagement. Combined with ongoing systemic oppression, the history of pathologizing and stigmatizing people who identify as LGBTQ2S+, and unethical research practice[31] has fostered

deep mistrust within these communities.[26,31–34] As a result, LGBTQ2S+ individuals may feel hesitant, unsafe, or unwilling to engage with data collection, either in a participant or advisory capacity. As one of our key informants explained:

> *"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

Research that fails to promise tangible benefits for LGBTQ2S+ communities or that focuses exclusively on documenting problems can hinder engagement efforts.[35,36] Key informants also identified the issue of research fatigue, as well as the burden of emotional labour among LGBTQ2S+ individuals and organizations who are regularly called on to advise such work. In these instances, past involvement in research efforts, if they were explicitly harmful and even if they were not, may dissuade LGBTQ2S+ community members from engaging in the future.

Questions to guide culturally responsive and accessible engagement

Written with trans communities in mind, the Canadian Professional Association for Transgender Health's *Ethical Guidelines for Research Involving Transgender People & Communities* offers the following guiding questions as a valuable starting point for thinking about engagement with LGBTQ2S+ communities more broadly (p. 5-6).[35]

- Have you engaged trans communities to determine if your proposed research addresses an appropriate priority?
- Who represents trans communities or trans issues?
- Have you engaged a diversity of trans people with respect to race, class, and other identities or social positions?
- Have you developed a terms of reference articulating decision-making within the project?
- Is there trust between community members and researchers?
- Is there community engagement in all aspects of the project, including interpretation and knowledge translation?
- Will trans community members be fairly compensated for their labour and expertise? Can these costs be incorporated in the budget in the planning phase?
- Are there measures to ensure that trans research team members do not bear a disproportionate burden for any possible negative community reactions to aspects of the project?
- Will support be provided to ensure the safety of trans people being engaged, as well as avoid (re)traumatization?
- If community organizations are involved, will the research avoid detracting from their primary missions?
- Is your research designed to provide learning, experience, or employment opportunities for trans community members?
- Are there opportunities for trans students to do project, practicum, or thesis work on the project?
- Are there ways to prioritize hiring trans research staff, particularly those who are multiply-marginalized?
- Will trans community members being engaged have opportunities to speak on behalf of the project, to present at conferences, or do other knowledge translation work?

Research, data, and funding environments are not conducive to good engagement practices

Good engagement practices can be complex, time-intensive, and expensive; however, data systems, institutions, and structures are not always well-equipped or willing to support such practices. For example, the expectations and requirements of research funding applications, including short deadlines, complicated letters of support, and an emphasis on formal qualifications, can present challenges for applicants seeking to engage community-based partners.[22] As a result, projects are often designed and funded before community partnerships can be fully established.

Capacity challenges further compound this issue. While key informants highlighted the importance and value of research activities that are informed by LGBTQ2S+ civil society, we heard that these organizations are often overstretched and under resourced. In many cases, engagement relies on specialized skills, knowledge, or expertise that is not always available or accessible: *"How do you engage with the community in a field with very technically precise language and specifications?"* (Marcy Antonio). Because these competencies are neither universal nor equitably distributed, this can further entrench inequities between researchers and community partners.[22,37] Finally, several key informants remarked that the financial resources to build this knowledge and capacity among community partners are rarely available.

(Re)building trust: Practices for consideration

Culturally responsive and accessible engagement relies on establishing and cultivating trust between LGBTQ2S+ communities and the individuals, institutions, and systems involved in research. Building trust is integral to research that is not only ethical, but also rigorous and reliable.[44] The (re)building of trust is a structural and long-term issue. Our findings highlight some practices for consideration by those involved in research with LGBTQ2S+ communities:

- **Acknowledge and be explicit about the history of harm and violence associated with research in LGBTQ2S+ contexts**. Members of project teams should have a clear understanding of the context in which they are operating and be prepared to justify their interest in working with this population.[21]

- **Embrace transparency and open communication**. Share information about a project's rationale, process, and findings regularly and accessibly to build trust and support engagement in the longer-term: *"Trust will be built over time. We may not find all the trust in this particular survey, but if we show results, that it had meaningful impact, that I didn't just share my stories for your entertainment…then more are likely to participate further"* (Marni Panas).

- **Be accountable to LGBTQ2S+ communities and be prepared to navigate tensions**. *"If we've got a particular project that is focused on a particular thing that we've been funded to do, [if] someone else says, 'well, why can't you also do x, y, and z with this other group as part of this project?' we can't always say, 'oh yeah, we're going to do that.' But we also need to really be accountable for why we haven't"* (Elizabeth Saewyc).

- **Focus on building relationships with LGBTQ2S+ communities and organizations**. Researchers' active presence and visibility in the community allows them to make themselves available to community members and for potential participants to evaluate a researcher's trustworthiness for themselves.[44] Valuable practices include connecting with population-specific groups and organizations (e.g., those working with Two-Spirit individuals, LGBTQ2S+ youth, etc.), developing ongoing relationships that span multiple projects, and collaborating with service providers, particularly when engaging with groups experiencing multiple forms of oppression.[122]

- **Allocate time**. A commitment to building, rebuilding, and maintaining trust and relationships is worthwhile, yet often time intensive. Ensure that this is accounted for, and as far as is feasible, avoid rushing this process.[37]

Disciplinary or methodological tradition also plays a role; for instance, quantitative practitioners may see participant and community engagement as less of a priority.[38] A lack of established, population-specific practices poses a barrier even where engagement is prioritized. In the context of research with bisexual participants, one study noted the resources and time investment associated with developing rigorous and inclusive recruitment practices for bisexual individuals in particular.[39] Without knowledge of or access to promising practices for culturally responsive and accessible engagement, those leading this work are often charged with creating new approaches.

Engagement is a complex, political, and power-laden process

Navigating decisions about who and how to engage constitutes another major challenge. Those pursuing engagement grapple with resource constraints, rich diversity within the LGBTQ2S+ community, and unlimited potential partners to involve. As such, decisions about who to include or exclude from engagement activities are both complex and political. Several key informants critiqued engagement efforts that consistently fail to reach certain actors (e.g., LGBTQ2S+ individuals who are low-income, precariously employed, or not 'out,' or organizations serving racialized LGBTQ2S+ communities), raising concerns about representation. Some questioned the practice of engaging service providers as a substitute for LGBTQ2S+ community members.

Being exposed to new perspectives through increased engagement means that those involved in research efforts are frequently confronted with different or competing objectives and priorities, both within and between research teams and external partners.[37] Speaking to federal government engagement processes, Tanya Lary noted that *"some people will feel that they were*

Why engage?

When done well, engagement can support research efforts that are more ethical, accessible, responsive, and rigorous. Many key informants saw meaningful participant and community engagement in research with LGBTQ2S+ individuals as central to advancing social justice and inclusion. The literature also stressed the need for gender and sexually diverse people to be directly involved in the planning, design, development, and implementation of research, programs and services, and health care and social service delivery.[38]

Because of the rich knowledge and expertise held by LGBTQ2S+ individuals and communities, better engagement can contribute to the rigour, quality, and validity of findings.[14,21] Literature included examples of the ways in which blending lived experiences with sound science can help develop deeper understandings of phenomena and, in turn, interventions that are more likely to be culturally congruent and effective, thereby reducing health disparities.[123] As one of our interviewees, Tyler Boyce, noted, *"there are no folks that are more well-positioned to tell the stories around them than those with lived experience."*

Strong engagement practices were associated with several other benefits. These include improvements or enhancements in responsiveness to community needs, cultural relevance and appropriateness, community research capacity, sample diversity and representativeness, community trust and ownership, participant benefits (e.g., sense of contribution, opportunity for self-expression), and knowledge dissemination and use.[14,21,37,42,108]

meaningfully engaged, and some people won't." We heard that while consensus may not always be a realistic outcome, frustration, disenfranchisement, or conflict can emerge from engagement that uncovers but fails to appropriately attend to these tensions.

A final issue is that engagement can seem tokenistic or superficial in nature. For example, while several interviewees framed community advisories as a valuable engagement mechanism, others were cautious of those that rarely met or did not meaningfully inform a project. In some cases, projects may seek to address this by devolving decision-making authority to community researchers or partners. However, this can present additional bureaucratical or logistical challenges, particularly when those formally leading the project are ultimately accountable for its activities and outcomes.[22]

The implications of insufficient engagement

Engagement is a process; while there is not one single "right" way to do engagement, going about it poorly or not at all can pose consequences. When communities do not see what they perceive to be appropriate engagement practices in place, it can lead to mistrust of research and researchers, the reproduction of harm and exclusion, and an extractive approach to research and data collection. In an interview, Margaret Robinson reflected on how her experiences as a community member have shaped her research praxis:

"A project got released into the queer community in Toronto, and my community – bisexual women particularly – felt like they had been ignored by the project, which was just focusing on lesbians but was presenting itself as a project focused on experiences of homophobia among women. It kind of felt to community members as if this project had just shown up out of nowhere, because they never heard of it until it got released. And as if it was implying that [bisexual women] didn't experience homophobia or that their experiences of oppression didn't count at all…When I think about doing a project myself, I think, 'how can I avoid having that happen to me, where a group that should have been included is going to be angry and upset that they weren't?'"

Opportunities

Engaging early, engaging often

The timing of engagement can have implications for cultural responsiveness and accessibility. Key informants stressed the importance of early engagement as a means of building support and buy-in, particularly among populations facing ongoing marginalization and oppression. When communities are engaged prior to project objectives being defined or funding applications being submitted, they can be given opportunities to shape the initiative: *"Meaningful engagement means that from the very first moment you're undertaking a project, communities are part of that conversation"* (Fae Johnstone).

Instead of occurring exclusively towards the beginning of the project, engaging LGBTQ2S+
participants and communities across the entirety of the research or data cycle can enhance the
meaningfulness of this process, and support more genuine partnership and collaboration.[26,37,38]
More frequent engagement can also better capture input from those participating, particularly
where "one-off" approaches risk being superficial or performative in nature.

The value of engagement throughout the project life cycle

Our findings suggest that a commitment to engagement is beneficial and can be feasible throughout the research or
data lifecycle.[46,48] Engagement can take various forms at different stages. For example, in one study exploring domestic
violence among ethnic and sexual minority women, bringing community advocates into a research team to offer
guidance has been found helpful to advancing cultural safety and responsiveness during data collection.[25] In that study,
the community advocate developed an augmented protocol that included questions to screen people into services that
helped differentiate batterers from victims. This was done because of the risk that a survivor and her batterer
theoretically could be in the same focus group. This insight was an invaluable contribution made by the LBT advocate
on an issue that was not immediately obvious to the researchers.[36]

The figure below offers examples of various roles and responsibilities that might be assumed by those being engaged
at different project stages.

Design & development	Methods & measures	Data collection	Data analysis	Knowledge translation
• Identifying research priorities or questions	• Informing methodological decisions; supporting tool development; offering feedback on language/terms	• Advising on recruitment; engaging in data collection	• Identifying key themes; engaging in co-analysis; validating findings/themes	• Providing guidance on accessible language/ messaging; advising on formats/platforms

Ensuring the right people are at the table

We heard from interviewees about the need for those involved in research to continually reflect
on whether the appropriate individuals, groups, and communities are being engaged. While the
specific actors will vary across projects, the following broad recommendations emerged related
to who is leading and taking part in engagement:

▪ ***Project team composition.*** Where feasible, a project team that includes those with lived
experience can foster safety and trust, mitigate power imbalances, promote cultural
responsiveness, and support research legitimacy.[40,41] Team composition can also have
implications for rigour and validity through contributions to the quality of data gathering
and analysis.[42] Reflecting on participating in consultations for the LGBTQ2 Action Plan that
were led by a Black LGBTQ2S+ facilitator, one key informant explained:

*"Being able to provide those suggestions, having a facilitator that speaks our language is nice
because we don't have to code switch…When people are in that environment that's warm and
reflects their cultural ways, that's when you can get the most beautiful information."*
~ Debbie Owusu-Akyeeah

- ***Community embeddedness, knowledge, and connections.*** LGBTQ2S+ and non-LGBTQ2S+
  individuals supporting engagement efforts should first familiarize themselves with the
  relevant context, language, and issues.[26] In addition to building cultural awareness, there is
  also value in establishing deeper community connections and relationships as a foundation
  for engagement; as Elizabeth Saewyc noted, *"it is important for groups doing this work to
  actually be involved in or engaged with the communities."* Meaningful community
  connections among those leading engagement can enhance knowledge of key players,
  credibility among community members, and cultural relevance and responsiveness.[43] Several
  practices were identified to build visibility and connection within communities, including
  sharing one's positionality in introductions to community stakeholders, volunteering with
  LGBTQ2S+ organizations, and participating in community events.[44]

- ***Engaging diversely, strategically, and inclusively.*** Engagement may include a diversity of
  actors and groups, such as community members, service providers, advocates and advocacy
  organizations, and policymakers. Engagement with different individuals can serve different
  purposes; engaging with decision-makers might encourage the uptake of findings in policy,
  while engaging with non-LGBTQ2S+ individuals could help build broader support or
  understanding.[21] Among LGBTQ2S+ individuals and communities, key informants stressed
  the importance of inclusive engagement to foster cultural responsiveness and accessibility. It
  is important to avoid expecting one or a few individuals to speak for all gender and sexual
  minorities, and to consider which voices are often excluded from engagement processes,
  such as LGBTQ2S+ individuals who are sex workers, and those who are older, racialized,
  living outside of urban centres, or income insecure. As one of our interviewees noted:

*"Seek input from people who don't typically engage in research and consultation, particularly
because of reasons of historical over-research, racism, inaccessible processes, language
barriers, and who face multiple barriers."* ~ Maura Lawless

Finally, ensuring that the language, terminology, tools, and platforms used are accessible and
appropriate to those being engaged also emerged as critical to supporting culturally
responsive and accessible research involving LGBTQ2S+ people and communities.

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Connecting with Two-Spirit individuals and communities

When seeking to engage specific populations or communities, there may be a need to further tailor or adapt engagement approaches to promote cultural responsiveness and accessibility. Interviewees spoke to the value of a close partnership with a Two-Spirit Elder throughout a project seeking to engage Two-Spirit people. Recommended practices when engaging Two-Spirit individuals in research or data initiatives include:[124]

- **Avoid conflating or equating Two-Spirit with Western identities**. Carefully consider which acronyms are used and whether they accurately reflect the communities represented (e.g., LGBTQ/2S, 2SLGBTQ+, LGBTQ+). Avoid homogenizing the experiences of Two-Spirit and other LGBTQ+ individuals.
- **Ensure Two-Spirit people are represented on a research team, including in decision-making roles**. Incorporate the feedback and perspectives of Two-Spirit team members. Do not rely on or expect one Two-Spirit or Indigenous person on the team to speak for entire communities.
- **Invite Two-Spirit and Indigenous individuals to inform and contribute to projects**. This input and involvement can support the recruitment of Indigenous participants and the development of culturally responsive data collection tools, among other benefits.

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Valuing lived expertise and pursuing reciprocity

Culturally responsive and accessible approaches to engagement seek to recognize LGBTQ2S+ community members "as experts in their own right"[21] throughout this process. In practice, this means ensuring that the time, labour, and expertise of those being engaged is both acknowledged and valued: *"When we ask people to provide input, are we honouring the valuable expertise that goes into that?"* (Marni Panas). Adopting this type of approach can help challenge extractive engagement practices, ensure that LGBTQ2S+ individuals and communities see material benefit from these initiatives, and redress the historic injustices associated with research in LGBTQ2S+ contexts.[45] As this process can be costly, it is important that engagement activities are adequately resourced.[36,38] Financial compensation is integral to equitable and inclusive engagement.[35,46]

Building community capacity is an especially valuable practice when it comes to promoting cultural

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Building capacity through engagement: CBRC's Investigaytors program

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.[124] Guided by community-based participatory research principles, participants gain hands-on experience throughout the research process. They are equipped with practical research skills while responding to knowledge gaps identified by the community.[125] A qualitative evaluation with eight investigaytors found that the program supported capacity-building among participants in myriad ways, for example, to gain quantitative and qualitative research skills; connect with other GBT2Q men; engage in networking opportunities; and inform their future career or education plans.[127] investigaytors

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responsiveness and accessibility.[21,38,43] Engagement that integrates capacity-building elements has the potential to support the development of future LGBTQ2S+ researchers, grow community research and advocacy capacity, offer tangible benefits to LGBTQ2S+ individuals and organizations, and foster more reciprocal relationships as a foundation for longer-term engagement.[21,43] One interviewee shared his experience with this type of approach when conducting focus groups as part of a project on substance use among LGBTQ2S+ individuals:

> *"We had people from the community and trained them up to facilitate the groups. I was a note taker at all the groups to ensure consistency and ask supportive prompts for questions, and be a support just in case."* ~ Devon MacFarlane

A study of sexual healthcare experiences among sexually and gender diverse persons in Arctic Canada described a similar approach, involving peer researchers who were trained to conduct the interviews and actively participated in co-analysis.[40] This type of engagement can offer distinct benefits to community-based actors, especially those facing time and resource constraints, by facilitating development of new knowledge and skills:

> *"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

While the scope, feasibility, and relevance of such an approach will likely differ across projects, exploring ways to build knowledge, skills, and expertise through engagement represents a key opportunity for those involved in research activities.

Advisories in action: Example from the Canadian Transgender Youth Health Survey

"We also funded our collaborators and senior investigators across Canada to work with local youth advisories. Those advisories may have from 3 to 8 to 10 young people who are on them, and they had maybe 5 to 6 meetings over the course of this one-year project. It was around getting their insights into the questions, looking at the survey and saying, 'are we missing stuff, are there things that are more important, is this not going to make sense today?' Getting advice on where…to recruit folks, where are the social media spaces that youth are on…and then meeting again when we have preliminary data. Why are we seeing what we see, what do you think is happening, what other analyses should we be doing?…Who needs to know this information, what recommendations should come from it, who should we be speaking to? How should we get the message about this work out to people in ways that don't further stigmatize or stereotype or really worsen the inequities…And how are we making sure that we also portray the strengths and fabulousness of the population, not just the places where society has failed them?" (Elizabeth Saewyc)

Making engagement substantive

Culturally responsive and accessible approaches to engagement should be substantive; to put it succinctly, *"make sure that community has a chance to dive in, shape it, and tear it all apart"* (Fae Johnstone). When engaging with LGBTQ2S+ participants or communities, consider how to ensure these individuals have agency, control, and decision-making capacity in their roles.[26]

While there is not one single or best way to achieve this aim, there is a need to examine how engagement is structured:

> *"I like to think about how power flows through a project. I don't think it's necessary for everybody on a team to have the same power, but I don't believe in creating positions where there's no power."* ~ Greta Bauer

Several strategies were identified in support of this aim, including convening project teams with major community representation, ensuring that team members accurately reflect their roles and contributions, establishing more democratic decision-making processes among teams, and establishing partnership agreements or terms of reference that clearly articulate roles and responsibilities.[21,35]

As a practical example, Greta Bauer described Trans PULSE Canada's approach to establishing "priority population teams" of various groups (e.g., sex workers, newcomers and immigrants, Indigenous Peoples) with whom the project explicitly sought to engage. These teams had specific tasks and responsibilities associated with them, including defining the group they represented for the purposes of the project and adding a set of population-questions to the survey. Such a process aimed to support each team to contribute in a way that honoured each group's autonomy while leveraging the lived expertise of team members. It also helped guarantee the utility of this input for the broader project; substantive engagement meant that feedback was not only solicited, but meaningfully incorporated.

Engagement practices and lessons in Trans PULSE Ontario

Trans PULSE Ontario is regarded as an exemplar in the realm of participant and community engagement. Several of the practices implemented and challenges encountered by the project[22] related to engagement, as summarized below:

Effective or promising practices:

- Trans community members were responsible for interviewing and selecting academic and non-profit team members for the project. Selection criteria included demonstrated allyship, resources brought to the project, experience with progressive LGBTQ2S+ research, research capacity and expertise, and willingness to centre trans voices and expertise.

- Trans community members played a core role in defining the project's objectives, theoretical framework, and methods.

- The Investigators' Committee was composed primarily of trans individuals, was driven by non-academic voices, and sought to ensure equal voice among all members.

- Terms of reference were developed early on in the project, articulating guiding principles, decision-making processes, roles and responsibilities or team members, and policies for data access.

- A Community Engagement Team of 16 well-connected trans members guided the development of data protocols, supported recruitment efforts, and advised on the project's knowledge translation strategy.

- "Community soundings" were conducted to seek broader community input throughout the project.

- Capacity-building was prioritized through mentorship and training in survey development, analysis, and writing for community members involved.

Challenges or lessons learned:

- In practice, navigating power differentials between stakeholders was complex: "*Even if a project defines its power structure differently, on paper and in processes, academics must often be the formal project leaders*" (p. 412).[22] The project grappled with trade-offs between the responsibilities and compensation of those engaged. Imbalances in power were exacerbated during activities that relied on specialized knowledge (e.g., quantitative data analysis).

- Resource constraints limited meaningful community engagement and control. Members of the Community Engagement Team were mostly volunteers receiving a small monthly honorarium, which had implications for how often they could meet. As a result, this group had fewer opportunities to substantively guide the project.

- The project team identified a need to anticipate and plan for potential conflict among those being engaged. The deeply-shared sense of the project's importance, combined with experiences of trauma and oppression, resulted in occasional conflict amongst team members. In response, the project's terms of reference were revised to include strategies to address inter-team conflict. Instead of ignoring it, the team sought to reconceptualize conflict as being "about ensuring the survival of the project, rather than threatening it."[22]

- The project team struggled with the reproduction of systemic inequities through engagement. Upon receiving feedback that racialized trans people were not adequately represented in the project, the team offered anti-racism training to investigators, added anti-racism as a standing item on meeting agendas, created co-investigator positions allocated to racialized trans individuals, and crafted a statement on anti-oppression and anti-racism. While framed as valuable, the team saw these actions as steps that ideally would have occurred proactively.

DEFINING RESEARCH OBJECTIVES AND QUESTIONS

Context

This phase of the research cycle involves agenda-setting, where a project's goals and objectives are established and decisions are made about what research is or is not conducted and what data are or are not collected. While specific questions for inclusion on data collection tools are explored subsequently, here we consider the overarching questions research or data initiatives may seek to address.

This section describes the key issues and opportunities in culturally responsive and accessible approaches in this phase of the research cycle. Key issues include what questions are being asked, and who is asking the questions. The main opportunities include equipping and engaging communities to define agendas and questions, as well as attending to diversity within the community, and adopting a strength-based orientation.

Incorporating sex and gender within research questions

Drawing upon suggestions specific to health-related implementation research,[128] here are examples of research questions that aim to consider sex, gender, and other social locations or identities:

- How does consideration of sex, gender, and other social locations or identities affect the assessment of barriers and support to practice, program, or policy uptake?
- How do gender norms, roles, or stereotypes serve as barriers or enablers to practice, program, or policy uptake?
- When and how should interventions be tailored or targeted on the basis of gender or sexual identity?
- How does an intervention affect gender- or sexuality-based inequities, including in varying cultural, geographic, or social contexts?
- Does an intervention affect individuals with different genders or sexual orientations differently?
- Are there unintended impacts of an intervention that exacerbated or diminish inequities on the basis of gender, sexuality, or other social locations or identities?

Key issues

What questions are (or are not) being asked

Defining research objectives and questions is complex and value-laden process. Decisions at this stage of the research cycle have implications for every subsequent stage, affecting the choice of

theoretical framework, methodology, data collection and analysis, and knowledge translation. If appropriate objectives and questions are not established at the beginning of a project, challenges or constraints are likely to emerge later on. Furthermore, the process of asking questions and the construction of policy problems is inherently political, shaping the range of approaches and responses available to address them.[47]

There are several barriers that can inhibit development of questions and objectives that are meaningful and relevant to LGBTQ2S+ communities. Research teams may lack the knowledge and understanding of LGBTQ2S+ communities, contexts, and issues to be able to develop appropriate and responsive research priorities. Developing culturally responsive and accessible research objectives and questions relies on community input and insights, which calls for additional time, energy, and resources.[48] As one of our key informants explained:

> *"To have good questions, you need to have good insight and good relationships. 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

In the absence of deep contextual and community understanding, there is amplified risk of research questions and objectives being shaped by problematic, inaccurate, or offensive assumptions or values. This not only reduces the relevance of an initiative to LGBTQ2S+ individuals or communities, but can actively cause harm.[27,31,49] Cisheteronormativity[d] in research can shape research questions and institutionalize bias from the outset, systematically limiting what we know.

Identifying research priorities

Community engagement represents an important opportunity for developing culturally responsive and accessible research agendas. However, there may be cases where this is not feasible, or where this work has already been done elsewhere. A thorough review of existing research, community reports, and consultation results can support the identification of research priorities that reflect and address community needs. The most pressing and actionable LGBTQ2S+ research priorities identified in the literature include health (e.g., mental health disparities); economic wellbeing (e.g., experiences of poverty); personal safety and security (e.g., transphobic violence); education (e.g., prevalence and effects of identity-based bullying); political and civic participation (e.g., policy and legal contexts); population estimates of LGBTQ2S+ individuals; and societal attitudes and beliefs.[14] Other sources point to the urgent need for health research with objectives and questions focusing on specific groups within the LGBTQ2S+ community, such as bisexual individuals or racialized LGBTQ2S+ people.[51,123,129]

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[d]   Cisheteronormativity refers the deeply entrenched belief that gender is binary, that everyone's gender aligns with their sex assigned at birth, and that heterosexuality is the norm.

> *"Heterosexist bias can affect any point in the research process, beginning with the development
> of a research question. For example, the consistent development of research questions that focus
> on marriage, childbearing, and monogamous romantic relationships assumes that all
> individuals have the same values, the same relational norms, and the same access to social and
> religious institutions such as marriage"* (p. 502).[50]

Similarly, studies exploring "gaydar" (i.e., the intuitive ability to detect sexual minority
identities) present another example of a research objective that risks promoting stigma,
stereotyping, and discrimination.[27]

Who is (or is not) asking the questions

Another key issue is who is (or is not) asking the questions, having the ability to set research
agendas. In interviews, several key informants highlighted the inequitable distribution of power
and resources, which fundamentally shapes who has the access and ability to define research
agendas. Addressing this inequity requires a commitment to changing structures and building
capacity, which can take significant time and effort.

When agenda-setting is primarily funder-driven, the questions or objectives guiding an initiative
may lack contextual understanding or community responsiveness. In the federal government
context, Tanya Lary contended that *"government is never going to be the expert – you can read
about it, but you have to leave it to the groups that are bringing the expertise and their
meaningful engagement."* Funding opportunities may have pre-determined goals or outputs that
cannot be meaningfully shaped or informed by affected communities later on due to a lack of
time, budget, or flexibility. These challenges are exacerbated when objectives and questions are
defined without community engagement, or where those leading these processes lack the
relevant lived expertise:

> *"When you go back to who makes up decision-making, there are no Black people. The
> [organizations] that don't have capacity are led by Black, LGBTQ people. If Black LGBTQ
> organizations were consulted, they would have said [the research] wasn't appropriate or the
> questions would not be appropriate."* ~ Debbie Owusu-Akyeeah

Finally, those involved in defining objectives and research questions, including governments,
academic institutions, researchers, community organizations, community members, and so
forth, may have differing priorities. There is often a need to navigate tensions and trade-offs
between community needs, funder priorities, research gaps, and researcher career interests,
goals, and pressures, among others. However, this is rarely a neutral process; power dynamics
and differentials shape whose voices are present during decision-making, as well as who has the
resources and influence to substantively inform these decisions.[48]

Opportunities

Equipping and engaging communities to define agendas and questions

Supporting the involvement of LGBTQ2S+ communities in defining agendas and research questions can reduce the potential for harm, and actively promote cultural responsiveness and accessibility.[31,48] Meaningful engagement with LGBTQ2S+ individuals, groups, and organizations at this early stage of the research cycle can yield questions that are more action-oriented, solutions-focused, and reflective of community needs.[45,48] Engaging relevant communities can also help ensure that the perspectives and priorities of those who are traditionally excluded from agenda-setting processes are considered and incorporated. In the context of Black, Indigenous, and racialized LGBTQ2S+ individuals and communities, collaboration with LGBTQ2S+ communities of color as a means of generating research questions can help expand the depth and breadth of research topics in ways that are useful to these communities.[51]

Our findings pointed to several specific strategies to foster community engagement when defining research objectives and questions:

▪ **Building trust, relationships, and capacity.** For many key informants, engagement for the purpose of defining research objectives and questions relied on building long-term relationships grounded in respect, reciprocity, patience, and a willingness to value diverse forms of knowledge and expertise. Doing so often requires knowledge of and connections with the communities affected, as well as trust and dedicated time and resources. In the context of agenda-setting, projects may seek to cede control to LGBTQ2S+ individuals and communities being engaged, allowing them to autonomously identify their priorities, challenges, interests, and needs. In some cases, this may warrant capacity-building to equip those being engaged with the necessary knowledge and skills to contribute to this process.

▪ **Creating project-based opportunities.** At the individual level, research initiatives should consider mechanisms to engage LGBTQ2S+ individuals and communities in defining research priorities. Approaches such as leveraging advisory committees, hiring peer researchers, or conducting community consultations all warrant consideration at this stage.

> ### Collaborative and community-driven research agendas
>
> Reflecting on building and leveraging community partnerships to support culturally responsive and accessible agenda-setting, Margaret Robinson shared this thought: *"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."*

Supporting the sustainability of these approaches within research efforts is needed to build

longer-term, ongoing opportunities for communities to raise issues, identify priorities, and inform future endeavours.

- **Adapting funding priorities and parameters**. Support meaningful engagement of LGBTQ2S+ communities in validating, informing, or identifying research objectives and questions requires funding bodies to have flexibility and resourcing in place. Specifically, funding opportunities that encourage community-informed, -driven, and -grounded research priorities have the potential to advance cultural responsiveness and accessibility. Finally, institutional support for community engagement in agenda-setting has been highlighted in the literature, suggesting the need for investment in formal consultations that provide community advocates with a voice to communicate research priorities.[48]

Attending to diversity within the community, and adopting a strength-based orientation

Attending to the diversity within the community and adopting a strength-based orientation when defining research questions emerged as another opportunity. At a minimum, culturally responsive and accessible approaches should seek to avoid and minimize harm in this process:

> *"Researchers need to consider how their research questions will impact the quality of life experienced by LGBTQ individuals and whether or not the research is of enough importance to justify any potential harm that might befall the participants or the community they represent"* (p. 378).[31]

Other opportunities in this area included avoiding research questions with inherent cisheterosexist or other assumptions about the community and its subgroups, as well as seeking opportunities to develop questions that do not assume inherent or essential differences based on identity alone.[50]

In fact, attending to the diversity within LGBTQ2S+ communities emerged as a central tenet of culturally responsive and accessible approaches at this phase of the research cycle. This prompted questions about who is defining questions about whom (e.g., is it appropriate an all-white project team conduct research about Black LGBTQ2S+ communities?) as well as who is engaged in doing so (e.g., disabled, low-income, or older LGBTQ2S+ individuals who are typically excluded from these processes). Research questions developed with explicit attention to intersectionality have the potential to avoid homogenizing LGBTQ2S+ populations. They also allow for consideration of social locations and systems of power beyond gender and sexuality, and the ways in which these interact to shape distinct experiences and outcomes.[52,53]

Finally, while documenting barriers and inequities experiences by LGBTQ2S+ people and communities is important to building the evidence-based required to address them, multiple key informants stressed the critical need to also explore positive experiences among LGBTQ2S+ individuals and communities:

*"Even [LGBTQ2S+] youth who experience some of the most challenging and adverse
environments and a lot of health inequities, that's not the only story. What are the positive
things? What are their strengths and what makes them fabulous, despite all the other things
that are stacked against them?"* ~ Elizabeth Saewyc

The value of applying a strength-based lens to research questions was echoed by several other
informants who spoke to the need for research endeavours that build resilience and reduce
stigma, and for funding bodies to support such initiatives.

Intersectional approaches to research design

Christoffersen's brief on intersectional approaches to equality research offers several considerations for adopting an
intersectional perspective in the creation of culturally responsive and accessible research questions. While written
with a focus on women, the following excerpt highlights potential practices and implications for developing research
questions that are also relevant in LGBTQ2S+ contexts (2017, p. 4):

*"A research question for your institution or college may be: Do female academic staff experience barriers to career
progression, compared with men? If so, what are they? From an intersectional perspective, this question would
become: Do groups of female academic staff experience barriers to career progression, compared with groups of
men and with other women?*

*An intersectional approach to such research questions would consider what barriers are experienced by different
groups of women (white women, Black and minority ethnic women, disabled women, non-disabled women, lesbian,
bisexual, transgender and genderqueer women, women of faith, younger and older women, women with caring
responsibilities, pregnant women, women on maternity leave).*

*From an intersectional perspective, it would not be assumed that these diverse women academics would experience
the same barriers to career progression. For example, disabled women may experience barriers due to the specific
combination of aspects of their identity and social position, namely their gender and disability status.*

*Without specifically opening research design and research questions up to distinct experiences, in this case for
different groups of women, you risk your research primarily uncovering only those barriers experienced by women
who do not experience inequality due to the interaction of other aspects of their identity with their gender. Any
strategies developed on the basis of this research would therefore not necessarily be effective at mitigating barriers
to career progression for all women."*[130]

DESIGNING METHODS AND MEASURING CONCEPTS

Context

We interpret methods to mean the tools used to answer research questions and achieve research objectives, while concepts are the ideas being studied. Methods can encompass a wide variety of tools and activities (e.g., interviews, surveys) that fall within broader categories of quantitative, qualitative, descriptive, applied, or other approaches to research. Many key informants and sources described methods and measures in the context of population-level survey data; however, some also considered community-based, mixed-methods, and other forms of research. While the literature focuses predominantly on SOGI measures, we also give consideration in this section to other measures relevant to LGBTQ2S+ people and communities.

Gender and sexual orientation are complex: Introductory resources

While this report does not cover in depth the different dimensions contained within the concepts of sexual orientation (e.g., identity, behaviour, attraction) and gender (e.g., gender identity, lived gender, gender expression), it does outline some key considerations in this area. For brevity, we have assumed readers understand the core concepts underlying research with LGBTQ2S+ people and communities. For a more detailed introduction to those topics, readers can consult the following resources:

- Egale's Glossary of Terms[131]

- Queering research and evaluation: An LGBTQ2S+ primer[132]

- "What and Who is Two-Spirit" in health research[124]

It is also important to note that the concepts and definitions used may be different among different groups and geographic locations. They also change over time, as do terms people use to define themselves.

This section describes the key issues and opportunities in culturally responsive and accessible approaches for this phase of the research cycle: ongoing data gaps related to gender and sexual orientation that inhibit the collection of reliable, valid data on LGBTQ2S+ communities, and the ways in which the choice of method carries different implications for collecting data in culturally responsive and accessible ways. The main opportunities include drawing on the growing body of research on SOGI measures to guide practice, moving beyond SOGI measures to capture LGBTQ2S+ people's lived experiences and their determinants, involving the community to identify and measure relevant, valid concepts, as well as the use of mixed methods for more comprehensive and complex exploration.

Key issues

Complexity of concepts along with ongoing data gaps inhibit the collection of reliable, valid data about LGBTQ2S+ people and communities

It is first important to acknowledge the complexity of measuring concepts related to gender and sexual identity. The acronym LGBTQ2S+ itself encompasses a wide variety of identities and experiences, which is necessarily complicated by incorporating an intersectional approach to understanding social location and experience. Within the different identities comprising the LGBTQ2S+ acronym, there are also varying and evolving definitions. As one informant shared in an interview, *"everyone has different definitions of every single one of those letters"* (Tanya Lary). The definitional and measurement challenges related to complex identities, each with their own methodological considerations, can shape the types and quality of data collected.

Ongoing data gaps inhibit the collection of reliable, valid data on LGBTQ2S+ people and communities, making it difficult to carry out culturally responsive and accessible research with these populations. Key factors underlying these gaps include the ongoing conflation of terms and use of limited measures, inconsistent data across jurisdictions, and competing data goals and needs across organizations.

The fundamental premise underlying the collection of SOGI data across research is that SOGI measures must be included. For many data collection tools, this is not as yet standard or even well understood.[54] As one of our key informants explained:

> *"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

Both the literature and key informants identified challenges related to data availability and consistency. Beyond the lack of SOGI measures – including in major population health surveys and databases – other challenges identified include the use of different measures across different organizations and jurisdictions, and changes to measures and vocabulary over time.[55–59] As one key informant shared:

> *"It's very challenging, and it's always evolving. What you did on your survey two years ago might not work anymore. What worked in one context might not work in the next context."*
> ~ Olivier Ferlatte

The conflation of sex and gender also continues to be a challenge in health research. While sex-disaggregated data can be pivotal to understanding health outcomes (e.g., adverse reactions to medications), gender plays a greater role as a social determinant of health.[55] The research literature identified common pitfalls to using sex categories to populate gender question options; the use of sex variables in analysis and gender terminology in reporting; a limited understanding, particularly among cisgender individuals without specialized training in gender, of the difference between the two concepts; and the interchangeable use of sex and gender in Canadian digital health systems.[56,60–62]

The literature notes a lack of clarity in many SOGI measures, including which specific dimension was being measured (e.g., for sexual orientation, whether a question captured identity, behaviour, or attraction).[63] The Statistics Canada measure on sexual orientation, for example, is a single question that asks about sexual orientation identity, but defines identity on the basis of behaviour.[54,64] Additional research highlights the importance of clear measurement. In the context of sexual orientation, for example, response rates and the reported prevalence of different sexual minority identities may vary based on what is measured (e.g., self-identification, the sex of sexual partners in the past year or over the respondent's lifetime, reported sexual attraction), whether response options are fixed or open-ended, and contextual factors (e.g., private or public settings).[65,66] Even in the case of a single dimension such as behaviour there is complexity in measurement, since participants of different sexual orientations may not share a consistent definition of what constitutes sex.[67]

> ### Why collect SOGI data and the importance of validated measures?
>
> *"Sex, gender identity, and sexual orientation are core to an individual's understanding of who they are, and these characteristics shape each person's experiences, relationships, and opportunities throughout their lives. Together, these important demographic characteristics are the axes through which personal and societal beliefs about sex (gender) differences play out within people's lives, structuring behaviors and creating gender-based inequality that can manifest itself in many ways, including as segregation, discrimination, violence, sexism, homophobia, and transphobia. Understanding the wide-ranging effects of sex, gender identity, and sexual orientation, their causes and their consequences, is crucial but doing so requires the development and use of validated measures that can represent the underlying complexity of constructs that are often assumed to be simple and uncomplicated"* (National Academies of Sciences, Engineering, and Medicine p. vii).[70]

Choice of method has different implications for collecting data in culturally responsive and accessible ways

The construction of the measure itself, and its place within larger data collection tools (e.g., surveys), has implications for the data being collected and for participants. This is because sexual orientation and gender questions, and the ways in which they are included in research

instruments, can carry implicit assumptions and value judgments that require thoughtful consideration to ensure research is culturally responsive and accessible:

> *"It is important to be really thoughtful and reflexive about how we collect and use data with these communities, including the questions that we ask, and some of the unintended consequences to the ways in which questions are framed and results are presented."*
> ~ Daniel Grace

The literature references implications of different methods and their construction for collecting data with LGBTQ2S+ communities. For example, the way in which response options are ordered can carry implicit assumptions around which response is considered the default (e.g., in a sexual orientation question, listing straight/heterosexual first, and other sexual orientation options afterwards).[68] Similarly, the location of SOGI measures on surveys can create associations between questions (e.g., grouping sexual orientation measure(s) with questions about risky sexual behaviour, suggesting that sex among sexual minority individuals is inherently risky).[69] Overall, while research specific to methods used in design is limited, key informants emphasized the importance of considering the potential implications of different methods for collecting culturally responsive and accessible data with LGBTQ2S+ populations.

Opportunities

A growing body of research on SOGI measures offers guidelines for practice

Despite the ongoing challenges related to SOGI measures, the growing body of research in this area offers guidelines for practice that support culturally responsive and accessible concept development and measurement. The recent Consensus Report by the National Academies of Sciences, Engineering and Medicine provides the most up-to-date evidence base with regards to the measurement of sex, gender identity, and sexual orientation, and their complexities. The report serves as a starting point not only for those looking to expand their SOGI data collection efforts, but also for those who wish to focus on further improvement and refinement of these

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Existing inventories of measures and guidelines for practice

- Measuring Sex, Gender Identity, and Sexual Orientation (National Academics of Science, Engineering, and Medicine, 2022)[70]

- Sex at birth and gender: Technical report on changes for the 2021 Census (Statistics Canada, 2020)[59]

- Best Practices for Asking Questions about Sexual Orientation on Surveys (SMART) (Williams Institute, 2009)[69]

- Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys (GenIUSS) (Williams Institute, 2014)[133]

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measures.[70] We invite the reader to consult other existing inventories of measures and best practice guides, including those identified in the accompanying text box.

Acknowledging the complexity involved in designing methods and measures, we also highlight several broad suggestions for those engaged in research involving LGBTQ2S+ populations. A general best practice is to collect only what the research questions, theoretical framework, and analytical plan specifically need. While decisions about appropriate SOGI measurements for any given research project should be tailored to the context and goals of the research itself, current guidelines suggest several specific considerations:

- Collect gender as the default variable. Collect data about sex as secondary to gender, and only if relevant to the specific medical and/or research context. In health contexts, consider exploring alternative approaches to collecting sex-based data when deemed necessary, such as by asking about reproductive organs.[59,61,70,71]

- Move beyond a binary construction of sexual orientation and gender (e.g., use plurisexual options beyond bisexual; include non-binary and trans*[e] options; eliminate use of 'other' and similar language).[63]

- Allow self-declaration in addition to set categories to reflect the complexity of identities.[68]

- Capture the fluidity of SOGI identities and individuals' ability to change over time (e.g., including "currently" in questions, allowing multiple response options).[68]

- Use the language the population uses.[72]

- Include definitions of terms and an explanation for why they are asked and how they will be used.[73]

- Randomize the order of response options to avoid a perceived hierarchy of identities.[68]

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[e]   The use of the asterisk in trans* is to denote an umbrella term referring to different identities within the gender spectrum.

Age-specific measurement considerations

Research suggests additional factors for the selection of SOGI measures focused on populations of a specific age, particularly young people, or older adults. A study with younger participants may, for example, benefit from using a sexual orientation measure related to attraction, rather than identity and behaviour, given the developmental stage of participants. However, such measures may not be relevant for those who have not yet, or will not ever, experience sexual attraction.[54,134]

There is an identified gap in research about older LGBTQ2S+ individuals and their unique needs and outcomes.[135,136] The National Resource Centre on LGBT Aging attributed this gap to misconceptions about a lack of LGBTQ2S+ people in studies of older adults, the assumption that researchers can identify those individuals without explicitly asking, concerns over the legality of asking, and the assumption that older participants will be unwilling to identify, among others. The Centre has recommended questions for sexual orientation, gender, and sex for older adults, including providing clear information about how the information will be used, policies around confidentiality, collecting data in private, allowing participants to skip questions, and defining terms that participants don't understand.[136] Furthermore, studies with older participants may need to pay particular attention to identity categories offered, as identity terms change over time, and older participants may identify with terms, which have fallen out of common usage with younger participants.[57]

Moving beyond SOGI measures to capture LGBTQ2S+ people's lived experiences and their determinants

Much of the current research on LGBTQ2S+ individuals and their outcomes in comparison to their cisgender, heterosexual peers uses sexual orientation and/or gender identity measures as the primary explanatory variable(s). However, the theorized mechanisms driving differences are tied to factors such as experiences of discrimination, prejudice, violence, homo/trans/biphobia, gender expression, concealment, and many more.[74] Consequently, it is critical that those wishing to incorporate culturally responsive and accessible approaches to data collection initiatives move beyond SOGI measures to collect more fulsome data on LGBTQ2S+ peoples' lived experiences. Inclusion of these measures should be based on the context of the research being conducted, such as the theorized mechanisms driving differential outcomes among people of different sexual orientations and/or gender identities.

Examples of outcome measures that were highlighted in this project include:

- Stigma and discrimination in different settings, and on the basis of different identities, as well as the fear of stigma/discrimination (e.g., in health care)[75-78]

- Feelings of safety or lack of safety[79]

- How individuals utilize health care systems, and their perspective on the care they received[79]

- Internalized homo/bi/transphobia[80,81]

- Identity affirmation measures[82]

- Gender expression[71]

- Intersecting identities, social positions, processes, and policies or other structural factors.[76,83,84]

Culturally responsive and accessible approaches involve consideration of LGBTQ2S+ peoples' lived experiences and their determinants. Several key informants also highlighted the importance of an intersectional approach in this phase:

> *"If we're not attentive to intersectionality, we run into validity issues in our research. If we're asking a survey question and we're measuring something, we assume we're measuring the same thing across all intersections. That's an assumption that's not often tested. For people who are at intersections where they experience multiple marginalizations, discrimination can play out in ways that are not going to be captured without being attentive to intersectionality."*
> ~ Greta Bauer

Involving the community is key to identifying and measuring relevant, valid concepts

When it comes to the identification of measures and concepts relevant to the research being undertaken and the populations involved, our findings point to the critical role of involving the community to capture appropriate, valid concepts. We already mentioned the growing number of guidelines and resources for the identification and selection of measures. Key informants stressed the value of using community members to help draft and test methods and tools to ensure the appropriateness of the language used and the questions asked in situations where the appropriate measure remains unclear, or in order to validate the measure selected. The use of community members in this way should be specific and targeted – the LGBTQ2S+ community as a whole is diverse and the specific group with which the research is concerned will be best placed to provide input. It is also important to note here that in engaging with community members, consensus is not necessarily possible nor the goal of the exercise. As mentioned earlier, these concepts are fundamentally fluid, and any group of individuals is likely to contain multiple perspectives, which may then be different from the perspectives of the research participants themselves. Instead, informants stressed the importance of focusing on the

Testing SOGI measures with communities

During the development of the Canadian Transgender Youth Health Survey by SARAVYC, the survey was pilot tested with youth, a process that included asking respondents follow-up questions such as "How did you like that question?" and "How well did the response options fit you?" This allowed the researchers to make adjustments and understand how other participants were likely to respond to the survey.

key principles of underlying culturally responsive and accessible approaches, particularly with
respect to building and strengthening relationships of trust with LGBTQ2S+ communities.

Mixed methods offer a tool for more comprehensive and complex exploration

Our discussion thus far has centred around quantitative methods and measures, reflecting the
dominant focus of the existing literature in this area. However, key informants noted the value of
qualitative and mixed methods as tools for more comprehensive exploration of the complex
experiences of LGBTQ2S+ individuals. Qualitative methods can help generate hypotheses, which
quantitative methods can then help test. Moreover, qualitative methods may help address gaps
or inadequacies in quantitative measures. The two methods in conjunction can contribute to
stronger overall research. Indeed, the combination of qualitative evidence and statistical data has
been found to be more persuasive than either type of evidence on its own."[85]

> *"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

A research methods series published by Rainbow Health Ontario argued that the personal stories
obtained in qualitative research can be powerful tools with which to address health disparities
among LGBTQ2S+ people, and that personal narratives enable policy makers to relate to
LGBTQ2S+ health issues.[86] Other qualitative methods highlighted in the literature that may be
particularly pertinent in research with LGBTQ2S+ communities include counterstorytelling, go-
along interviews, and participatory mapping.[f] These methods were identified as "enabling", in
that they create powerful personal stories that can both help address disparities and give voice to
stories and experiences that may have been silenced previously through systemic oppression.[86–89]

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[f]　　Counterstorytelling is a qualitative research methodology grounded in principles of critical race theory
and intended as a process for telling the lived experiences of people who are silenced and made
invisible by existing dominant narratives.[87] Go-along interviews are interviews conducted while being
and moving within participant selected spaces.[88] Participatory mapping is a data collection method
involving a range of mapping activities in which people and communities whose territories and places
are being mapped exert some control over agendas, approaches, processes, and techniques used.[89]

COLLECTING DATA

Context

Because of persistent discriminatory attitudes and practices towards LGBTQ2S+ individuals and communities, data collection efforts that address gender identity, sexual orientation, and related concepts are often viewed as 'sensitive.'[90] While concerns about sensitivity are often grounded in societal attitudes and bias, there are genuine risks of harm associated with collecting these data. Culturally responsive and accessible approaches urge researchers to pay particular attention when collecting such data because of the possibility of harm for gender and sexual minority individuals. In the context of data collection, culturally responsive and accessible approaches should be informed by the identified research question(s), the affected individuals or groups, the recruitment strategy, and the sensitivity of questions being asked.[91]

As previously outlined, it is important to carefully consider context when it comes to cultural responsiveness and accessibility to ensure trust, safety, and security. Safety and security concerns in collecting data underlie all types of research, from community-based research to large-scale government-led national health surveys. Who is collecting data (e.g., frontline staff, researcher), where data is being collected (e.g., registration desk, focus group setting), and what data are being collected (e.g., demographic information, health concerns) are all critical considerations at this stage of the research cycle. While the choice of data to collect should be consistent with and directly relevant to the purpose of data collection, and motivations for collecting the data should be transparent, the different techniques for collecting data (e.g., interviews, questionnaires, focus groups, photographs, videos, observation) require different approaches to community engagement.

This section describes key issues and opportunities with respect to the data collection stage of the research cycle in both research and clinical contexts, and focuses particularly on the collection of SOGI data in healthcare settings. Issues identified at this phase of the research cycle include both the relevance and lack of infrastructure for SOGI data collection across jurisdictions and settings. These issues are compounded by concerns over privacy and mistrust of data collection among LGBTQ2S+ populations along with gaps in researchers' cultural competencies during data collection. The main opportunities include building infrastructure and modernizing SOGI data collection; creating safe environments when collecting data; developing cultural competencies across research, clinical, and non-clinical teams and staff; building trust with communities, patients, and research participants; and choosing optimally appropriate data collection modes.

Key issues

The relevance of SOGI data collection is still contested

The relevance and necessity of collecting SOGI data continues to be contested. While there are
cases where collecting data about LGBTQ2S+ individuals and issues may be perceived as
legitimate (e.g., to support subsequent analysis through a GBA+ lens), others point to concerns
over individual privacy rights and the purported sensitivity of this information.[90] However,
concerns about the appropriateness of collecting these data are not borne out in the literature.
For example, a US-based study on collecting SOGI data in emergency departments found that
while clinicians did not perceive routine SOGI data collection to be medically relevant in most
circumstances, patients perceived benefits that included recognition of individual identity and
improved therapeutic relationships.[92] In healthcare settings, patients may be more willing to
disclose information about gender and sexuality than providers anticipate, and even see value in
doing so.[92]

As a result of these tensions and an ongoing reluctance to capture this information systematically
in healthcare settings, key informants highlighted challenges related to compromised patient
safety and quality of care, especially for sexual and gender minority individuals. Overall, we
found that guidance on safe practices to collect SOGI data continues to develop, and more
understanding is still needed with respect to why, when, and how information should be
collected across different contexts and settings.

Infrastructure for SOGI data collection across jurisdictions and settings is lacking

In part due to a lack of inclusive, standardized terminology and measures across methods of data
collection (e.g., surveys, health administrative data, statistics), SOGI data collection practices
remain inconsistent and are not supported structurally.[90] Across clinical settings, protocols for
systematic SOGI data collection are largely absent.[93] In the Canadian context, the introduction of
Electronic Health Records (EHRs), which lack dedicated fields for or appropriate terminology
surrounding gender, presents another barrier to the systematic collection of SOGI data.[94–97] A
lack of inter-jurisdictional alignment across federal, provincial, and territorial approaches to
SOGI data collection in health contexts further exacerbates this challenge.[90]

*There are concerns over safety and mistrust of data collection among LGBTQ2S+
populations*

A legacy of harmful and stigmatizing research and healthcare policies and practices have
negatively affected LGBTQ2S+ individuals' perceived safety and trust in these settings, including
when asked to share identity-based information.[98,99] As one of our key informants explained:

*"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? 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

Because of historical and current contexts certain groups — for instance, trans individuals,[73]
Two-Spirit people[90] and older gay men[99] — may be more distrustful of researchers and health
care providers, and less likely to disclose their identity as a result. Data collection occurring in
person (versus online) may also make LGBTQ2S+ individuals more wary of disclosure.[91,100]

Cultural competency skills during data collection are still lacking

Gaps in cultural competency during data collection represent another barrier to culturally
responsive and accessible research with LGBTQ2S+ communities. Key informants described that
those working in research and clinical settings may feel uncomfortable or lack the skills and
language required to ask questions related to gender and sexuality during data collection, intake,
or clinical encounters. The literature suggests that increased awareness is needed among
researchers and health care providers to be mindful of heteronormative assumptions and
knowledgeable about LGBTQ2S+ health both during data collection and at each point in the
patient journey.[101,102] Because of limited awareness that gender and sexual orientation may
change over time, protocols for the frequency of data collection and routine updating of patient
information need to be established in a way that is sensitive to continually emerging identities.[66]

Opportunities

Building infrastructure and modernizing SOGI data collection

Culturally responsive and accessible approaches to LGBTQ2S+ research are grounded in an
action orientation and a desire to identify and address inequities for LGBTQ2S+ individuals and
communities. Because action relies on data collected in a safe, affirming, and accurate way,
development of infrastructure and systems that support systematic collection of these data
represents a key opportunity at this stage. This is true across health care, government, and civil
society contexts:

*"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

Within healthcare settings, another opportunity involves adapting EHRs to ensure data about gender, sexuality, and other relevant information is both sought and collected.[94,95–98,103] Indeed, most existing digital health systems are unable to capture SOGI data beyond a single sex or gender data field with only male and female options.[73] Notably, some commercial EHR vendors in the United States have begun to address these gaps by adding LGBTQ2S+-inclusive fields for gender identity, sex assigned at birth, sexual orientation, relationship status, pronouns, and chosen name.[98] However, there is a need to engage with Canadian vendors to pursue similar changes:

> *"We need to engage vendors directly… unless they're engaged to participate, you can only go so far. We rely on vendors to update with proper codes…In Canada, there is an opportunity and challenge to engage vendors."* ~ Francis Lau

  In clinical settings, consistent implementation of inclusive, patient-centred approaches to routine SOGI data collection is critical to patient safety and privacy.[92] There is value in offering training on culturally responsive and accessible SOGI data collection and documentation to clinicians and researchers alike.[93] One key strategy to support consistent SOGI data collection across clinical sites and health teams is to develop information collection workflows (e.g., ordering and reviewing diagnostic tests, blood bank ordering, managing medications, billing, and quality reporting).[98,104] Once established, routine SOGI data collection has the potential to ensure clinical sites have reliable patient data, can better track outcomes among LGBTQ2S+ populations, and improve overall quality of care.[104]

Developing data collection workflows in clinical settings

A recent guide for collecting data on sexual orientation and gender identity published by The National LGBTQIA+ Health Education Center of the Fenway Institute proposed the following workflow for collecting SOGI data that allows for multiple data collection points across a clinical encounter.[104]
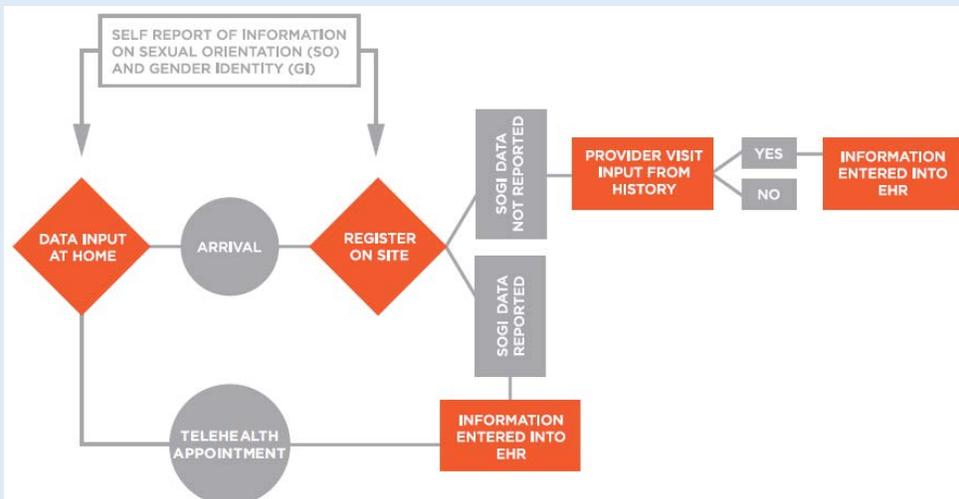
Creating safe environments when collecting data

A key opportunity to support cultural responsiveness and accessibility throughout this process is to create safe environments for collecting data, including through the use of trauma-informed approaches. Given ongoing challenges related to safety, privacy, and discrimination in health care settings for LGBTQ2S+ people in Canada, there is a need to foster emotional and physical safety in these settings. The process begins by recognizing the role of past or anticipated trauma and violence in shaping LGBTQ2S+ individuals' health care experiences:

> *"We have to acknowledge that transphobia, homophobia, and racism are public health issues, and the impact of stigma and discrimination has a profound impact on health and well-being, whether it's accessing vaccines, going to a physician, calling 911, or participating in preventative health."* ~ Marni Panas

Transparency surrounding data collection – including the rationale for collecting data,[90] what the information will be used for, and who it will be shared with – are all key to building trust and safety.[105] Ensuring the privacy and confidentiality of LGBTQ2S+ individuals' information is crucial, including that they are aware of these rights. Other inclusive and affirming practices that can foster safer environments include collecting only necessary data as well as using language, measures, and data collection tools that respect identity and autonomy.[70] Cultural responsiveness and accessibility at this phase can be further promoted by creating space for individuals to report gender and sexual identity in ways that support self-identification, are integrated into existing practices (e.g., patient registration forms), and maximize privacy throughout the process (e.g., electronically at home, tablet at check-in, a quiet and private physical space).[92,104]

Growing cultural competencies across research, clinical, and non-clinical teams

Another opportunity to support culturally responsive research is addressing the need to develop cultural competencies across research, clinical, and non-clinical teams and staff. Several informants stressed that this process starts with growing competencies in culturally responsive care. As Francis Lau remarked, *"Cultural humility, responsivity, and accessibility are central because if they can't get care, everything is secondary."*

Priorities identified to support efforts to modernize SOGI data practices in Canada were education and training, designed to enhance the ability of healthcare staff to provide culturally competent and safe care and to ensure that policymakers and researchers have the required safeguards in place to protect data.[94] Comprehensive cultural competency education and training can also be an important mechanism for improving communication and building a culture of awareness among research and healthcare teams to break down barriers of misunderstanding

and mistrust.[98] Effective training programs address terminology, health disparities, inclusion, and provide opportunities to practice using inclusive language and affirming information (e.g., explaining what information will be collected, why, how it will be used and kept private).[98,106]

Building trust with communities, patients, and research participants

Throughout all stages of research, building trust emerged as a key priority. While the research question, nature of the data collected, and who is collecting it should guide the extent to which community is involved, how, and when, working in partnership with LGBTQ2S+ individuals and communities as much as possible is critical to building trust. Building relationships and trust with communities when there is direct involvement between researchers and participants is particularly important. For those collecting data with trans and gender diverse individuals, engaging with and establishing trust with community members is not only about building collaborative equity and ensuring research is empowering to the community, but fundamental to ethical and valid research.[44] One of our key informants highlighted the importance of trust building when collecting data:

> *"I'm really excited about research and any data collection that has come from context where there are partnerships with organizations that are embedded in community and have a relationship of trust. You mentioned the historical context of framing the possibility for building trust in our communities, but I think in some ways that's not only historical. It's also ongoing because it lives in people's bodies, and some of it is still being felt on a daily basis."*
> ~ Tanya Neumeyer

Choosing optimal data collection modes

Choosing optimal data collection modes can support culturally responsive and accessible approaches to research with LGBTQ2S+ populations. While there is limited research about mode differences in studies specific to sexual minorities, the literature on methods to elicit sensitive

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Collecting data with LGBTQ2S+ cultural competence[14]

Providing a safe and welcoming environment is critical when engaging the LGBTQ2S+ community. The following strategies can help establish a welcoming and safe space:

- Ensure that symbols of LGBTQ2S+ inclusion are visible
- Provide privacy when collecting data
- Ensure responses are kept confidential and inform respondents about your confidentiality policy and practice
- Utilize openly LGBTQ2S+ staff or volunteers when implementing evaluation data collection
- Ensure that staff and volunteers who engage evaluation participants regularly receive LGBTQ2S+ cultural competency training and supervision, including on how to meet the needs of community members who experience multiple forms of marginalization
- Include LGBTQ2S+ representation on Boards and in management; ensure they represent the entire community racially, geographically, ethnically, across the SOGI spectrum, etc.

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information such as sexual orientation suggests that self-administered questionnaires are more likely to give participants a sense of anonymity as compared to face-to-face methods.[91] Within clinical settings, sexual or gender minority patients reported greater comfort and improved communication when SOGI data was collected via nonverbal self-report. In a study on patient-centered approaches to SOGI data collection in emergency departments, collection via registration form was found to be the optimal method.[92]

Qualitative methods may be particularly suitable when seeking to offer participants an opportunity to describe their experiences in their own words, making it possible to capture nuances, complexities, and attitudes related to lived experiences. Strategies to help evoke experiences include organizing conversations about relevant situations or resonant symbols and allowing participants to unpack their own meanings.[107] Importantly, when participants feel safe and motivated to participate in research, they are more likely to share their authentic insights, feedback, and lived experience, which serves to enhance the validity of findings.

As some of our interviewees noted, data collection itself can be considered an intervention. Resources must be made available to participants should they experience any form of distress associated with their participation, and it is important that these resources are LGBTQ2S+ affirming.[28,31] At the same time, the choice of data collection mode — centred on the goals and needs of the participants — can help shift the inherent power imbalance underlying research studies. Explicit efforts to engage and build meaning for participants can also motivate their participation and help them feel like they are making a difference. Research suggests that young LGBTQ adults are motivated by the sense that their participation serves a purpose, such as raising awareness and supporting social change, supporting knowledge production where gaps exist, or opportunity to engage in self-reflection and expression.[108]

Select resources for data collection practices in clinical settings

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. The toolkit includes assessment tools to help guide people through the process of building safer and more inclusive environments, an overview of relevant terms, including terms and phrases to avoid, and tips for inclusive communication and building safer physical spaces.

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 modernise 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).

Recruitment and sampling considerations for data collection with LGBTQ2S+ people

Challenges recruiting a diverse, inclusive, and representative sample in research involving LGBTQ2S+ individuals are well-documented.[26,123,137] Our findings highlight several promising practices in approaches to recruitment and sampling in research or data initiatives involving LGBTQ2S+ people. These include:

- **Trust** between researchers and participants and communities is a key prerequisite to effective and inclusive recruitment in LGBTQ2S+ contexts.[44,51,119]

- **Community engagement** throughout the recruitment process is key to building trust and ensuring recruitment is responsive and accessible to prospective participants.[44] For example, survey promotion for Trans PULSE involved public information sessions, meetings with community leaders, a Facebook group, a promotional video, and a phone line for prospective participants. The success of this survey recruitment strategy, especially given the length of the survey, was attributed to continued contact with community members.[22]

- A **multi-pronged approach to recruitment and outreach** can help maximize sample diversity and recruit "hard-to-reach" LGBTQ2S+ individuals, including those who are not 'out.' Effective strategies include promotion via social media, researchers' networks, community and LGBTQ2S+ organizations' contacts, in-person events or community spaces, and referrals from other participants (i.e., respondent-driven or snowball sampling).[15,39,44,119,122,137,138] Strategies to reach specific excluded or marginalized groups can include in-person recruitment at events for racialized LGBTQ2S+ individuals or promotion through organizations serving Black, Indigenous, and people of colour, etc.[44,51]

- Inclusive **inclusion and exclusion criteria** can help participants feel validated and affirmed in their identities, experience, and participation in a study. For example, one key informant described past work on HIV/AIDS in gay men's communities, where trans people of any gender who self-identified as having a current or historical connection to that community were invited to participate. The *Who I Am* survey focusing on bisexual people welcomed bisexual, pansexual, or other individuals attracted to multiple genders to participate.[39] Where identifying as LGBTQ2S+ is part of the eligibility criteria, broad definitions based on identity, attraction, or behaviour – as applicable or appropriate – could also be considered.[137]

- Consider the role of **recruitment and outreach materials** in promoting a diverse sample, including through the use of inclusive and culturally appropriate language and the representation of diverse genders, races, and abilities in any images or graphics.[44]

- **Address and remove barriers to participation** in the recruitment process.[15,35,44] Is participation safe for those who have experienced trauma, do not have access to Internet or transportation, or are living in poverty?

- **Sampling approaches**, such as purposive sampling or the intentional oversampling of specific groups, may yield a more inclusive sample that better reflects the diversity of LGBTQ2S+ communities.[35,44,137,139] Fae Johnstone described adopting this type of approach in the context of racialized LGBTQ2S+ participants: *"We will pause at a project milestone, look at our survey responses, and say, 'this is a lot of white people, who else do we need to be reaching out to?'"* Consider the appropriateness and potential implications of the sampling strategy. While approaches such as respondent-driven sampling have proven valuable in some contexts, challenges or limitations have been identified in others (e.g., inability to reach those who are not out to friends, reproduction of exclusion among those who are not invited).[22,123,140]

- In longitudinal data collection, **strategies shown to support retention** in other research contexts (e.g., with marginalized groups) such as providing financial incentives or collecting detailed contact information may also be useful in LGBTQ2S+ research.[23,141]

ANALYZING AND INTERPRETING DATA

Context

When it comes to analyzing and interpreting data in culturally responsive and accessible ways, there is a dearth of literature on analytical approaches specific to sexual and gender minorities. Technical and scientific methods for incorporating sexuality- and gender-related variables into analysis have been unclear; they also continue to evolve to capture different measures, which themselves face issues of definition.[109] While the research question(s) should generally guide all stages of the research design (including the selection of methods and related variables, and appropriate qualitative and quantitative analyses), the epistemic positions of the analyst also shape findings, gaps, and areas of interrogation.[110] In the context of limited research, our key informants tended to focus their discussions of this phase of research on intersectionality, and spoke to considerations for general approaches to analysis rather than specific practices. The findings presented in this section reflect this.

Key issues in this phase of the research cycle include balancing accessibility and rigour, data-related limitations to conducting disaggregated analyses, and limited analytical frameworks and strategies to appropriately link to LGBTQ2S+ experiences and contexts. The main opportunities identified centre around equity-oriented approaches to meaningful co-analysis and building capacity to conduct intersectional analyses.

Key issues

Balancing accessibility and rigour

The actors who are engaged in the analytical process can shape findings, insights, and identified gaps. Interviewees pointed to the ways in which including individuals with lived experience in analysis contributes substantially to both culturally responsive and accessible approaches and analytical rigour. Individuals with lived experience bring expert knowledge to identify and understand specific nuances within their particular identities and/or local contexts. However, research teams can struggle to achieve this accessibility because of limited time for engaging communities and – importantly – building capacity for the community to be meaningfully engaged. Key informants stressed the need to dedicate time and resources to engage community members at the outset and to draw out insights in support of rigorous analysis. Finally, the limited research identified pointed to the need for developing analytical methods grounded in the

realities of people who experience health inequities while also examining the larger contextual issues, structures, and processes within systems of power that shape their experiences.[110]

Data-related limitations to conducting disaggregated analyses

There are several data-related limitations specific to disaggregated analyses, such as analyses disaggregated by SOGI categories. Ethical issues and privacy concerns derive from small sample sizes and the potential for identifying information to be disclosed in the analysis process.[31,45,111] Sample sizes can also present a barrier to conducting relevant and appropriate disaggregated analyses in the first place. Specifically, without sufficient sample sizes to differentiate between groups, multiple identities are often combined within single categories, obscuring important differences within diverse communities.[31,65,69,112] Some interviewees noted that the experiences of intersectional identities along with different plurisexual identities (e.g., pansexual and bisexual) are particularly challenging to identify, describe, and address.

There may be a need to build an explicit intersectional framework a priori to help address issues of disaggregation and facilitate meaningful analyses. Those involved in research involving LGBTQ2S+ people and communities should consider whether disaggregation is an appropriate analytical method when dealing with embodied human experiences that cannot be stratified into parts representing their multiple dimensions.[83,113] Measures that capture the intersectional position or identity, including methods that go beyond statistical interactions, are currently limited.[83]

Limited analytical frameworks and strategies that appropriately link to LGBTQ2S+ experiences and contexts

Analytical frameworks and strategies that appropriately link to LGBTQ2S+ experiences and contexts are currently limited. While most key informants highlighted the need for intersectional approaches to research with LGBTQ2S+ populations, they also spoke to how intersectionality is frequently misunderstood as an analytical framework, obscuring its focus on social positions or processes that create inequalities between groups.

> *"When there's a lack of a real 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

The literature reinforced the idea that more attention may need to be paid to social processes (versus social positions or identities) across both quantitative and qualitative methods in order to identify and distinguish how social processes generate, amplify and temper inequalities between groups to produce potential privilege or oppression among groups.[83]

In particular, a recent systematic review by Bauer et al. outlined gaps in current quantitative methodological approaches resulting from misunderstandings of intersectional theory, suggesting that decomposition analyses and decision trees hold promise for the assessment of potential drivers of intersectional inequalities.[114] Interviewees highlighted addressing gaps in the precision of analytical approaches to intersectionality as key to producing reliable evidence to inform policy, practice, and ultimately the health outcomes of LGTBTQ2S+ communities.

> *"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

A key opportunity identified both in our interviews and the literature to support culturally responsive and accessible approaches at this stage of the research cycle is adoption of equity-oriented approaches to meaningful co-analysis.[28,86,111] Giving power to and building capacity among community members to analyze and interpret findings, identify gaps, and guide future research directions, were seen as crucial to producing findings that are appropriate, relevant, and useable by communities and groups experiencing health inequities.

Substantive engagement of community members (e.g., through transcript review, inviting feedback on themes) offers an opportunity to strengthen theoretical approaches through better understanding the complexities and nuances of lived experiences,[28,111] but also to ensure the validity of findings. Capitalizing on the principle of LGBTQ2S+ people and communities being "experts in their own right"[21] can help to advance technical approaches by ensuring analyses are appropriate and grounded by lived experience. This effort requires building the technical capacity of communities to be engaged in and lead analyses and interpretation of findings to support their own advocacy. In speaking to scientific rigour as an advocacy tool, one informant explained:

> *"I would call scientific rigour an advocacy tool, in some ways, because it's harder for government to ignore well-done research evidence. That said, it is also important to ensure that research is not just technical but is actually put in the hands of people who can do the advocacy. We are not advocates in search of evidence to support us. We are researchers who are in search of evidence that then can guide directions of what should happen.*" ~ Elizabeth Saewyc

Building capacity to conduct intersectional analyses

Building capacity to conduct intersectional analyses was highlighted as another key opportunity. Increased attention to intersectional issues can be particularly important to reducing measurement bias and improving construct validity by better identifying relevant social positions, processes, or policy variables, rather than using proxy variables such as social identity.[83] Both qualitative and quantitative data can benefit from intersectional analyses, while mixed methods can build on the complementary strengths of each type of data to better answer the research questions posed.[115] Integrating intersectionality into quantitative research can bring increased attention to issues of social power, although further work is needed to develop or adapt quantitative methodology to increase clarity around definitions so it moves beyond simplistic analysis of intersectional position components.[114]

The literature also noted the need for more consideration of gender as a main, interaction, or mediating effect.[109,116] Promising approaches to intersectional analyses identified in the literature included descriptive analyses (cross-classification), analytical analyses (causal processes or structural contexts), mediation analysis, multi-level methods, variable-centred approach, person-centred statistics, documenting and reporting within-intersection heterogeneity, and the Intersectionality-Based Policy Analysis Framework.[116,117]

Foundational resources for intersectional methods and analyses

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.[115]

Questions to guide quantitative intersectional analyses

In this Meet the Methods issue by Greta Bauer (2021) outlines guiding questions to develop quantitative analyses using intersectional approaches in health research.[142]

REPORTING AND KNOWLEDGE SHARING

Context

A commitment to thoughtful and impactful reporting and knowledge sharing is key to cultural responsiveness and accessibility in research or data initiatives involving LGBTQ2S+ populations. At its core, this stage of the research cycle ensures that findings are readily available to those most affected – in this case, LGBTQ2S+ individuals and communities. Effective knowledge translation can also drive policy change, inform programming and service provision, and equip communities with the knowledge they need for advocacy, grant-writing, or other purposes:

> *"I use data in my advocacy all the time…I cite that 84% of trans people avoid at least one public space out of fears of harassment every single time I give a public talk. 50% of trans people make under $15,000 a year."* ~ Fae Johnstone

Dissemination of findings can take several forms, from peer-reviewed publications through to social media content, to community-based presentations. While specific examples of activities are highlighted throughout this section, we focus primarily on considerations, principles, and practices that apply to this stage more generally. We describe the key issues and opportunities that emerged for culturally responsive and accessible approaches at this stage of the research cycle. The key issues identified were priority and capacity gaps prevent reporting and knowledge sharing; useful and relevant data to share may not exist; and deciding how and with whom to share knowledge is complex. The main opportunities that emerged included 1) considering the needs and priorities of knowledge users, and 2) prioritizing utility and accessibility in knowledge translation.

Disseminating findings, convening community

Reporting and knowledge sharing activities designed with community in mind may offer additional benefits beyond the dissemination of findings. For instance, when describing a summit hosted by the Risk & Resilience project team to share results from their study, Margaret Robinson suggested that the opportunity for community members to connect with one another was among the event's most positive outcomes. Along similar lines, CBRC described their annual summit as a "community-centred space for researchers, healthcare professionals, policy makers, and community members alike to pool their knowledge and learn from each other,"[143] with attendees reporting high levels of satisfaction, relevance, and learning.[144] Co-sponsored by Trans PULSE and Rainbow Health Ontario, the stated objectives of the Trans Health Advocacy Summit included sharing results from the Trans PULSE study, supporting trans attendees in their advocacy, and strengthening trans community networks. To this end, programming included presentations of findings, networking and social events, self-care and mental health workshops, and capacity-building opportunities related to social media, advocacy, and leveraging art for social change.[145]

Key issues

Priority and capacity gaps prevent reporting and knowledge sharing

A major issue at this stage of the research is often the absence of reporting and knowledge sharing altogether, including with the individuals or communities most affected.[35] Project teams may not prioritize these activities or be required by funders to pursue them. Furthermore, low demand for research or data related to LGBTQ2S+ health may render knowledge translation less of an imperative. As Marcy Antonio noted, *"there's not a central hub that can serve as an overarching body pushing this work forward in Canada."* Within health care systems, key informants pointed to a lack of infrastructure or processes to support communication and best practice sharing across provinces.

Capacity constraints can further inhibit the type of meaningful and effective knowledge translation that lends itself to cultural responsiveness and accessibility. Those with the appropriate networks, trust, and influence to effectively share findings within LGBTQ2S+ communities often lack the resources to do so. As one of our key informants noted:

> *"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

Those involved in research or data initiatives may also encounter resource barriers in terms of time or funding, in addition to gaps in the knowledge or skills relevant to dissemination (e.g., communications and digital media, advocacy, graphic design, etc.).

Leveraging outside expertise for creative dissemination

Collaboration represents a valuable opportunity to blend academic, community, artistic, and other forms of expertise at the reporting and knowledge sharing stage. Jake Pyne described partnering with transgender director Rémy Huberdeau to share findings from a research project on the experiences of trans parents through a documentary. Together, they applied for funding to support the initiative, connected with former participants to discuss considerations around ethics and consent, and worked with these same individuals to identify key messages and audiences for the film. To-date, *Transforming FAMILY* has been shown at film festivals in Canada, the United States, Australia, Brazil, and Germany.[146,147] By working with an artist and leveraging a unique skillset, the final product was characterized as more innovative, compelling, and impactful than it would have been otherwise.

Transforming FAMILY
☐ WATCH ON DEMAND

Rémy Huberdeau
Canada / 11:01 / 2012 / sound / colour / English

"Transforming FAMILY" jumps directly into an ongoing conversation among trans people about parenting. It's a beautiful snapshot of current issues, struggles and strengths of transsexual, transgender and gender fluid parents (and parents-to-be) in North American society today.

Useful and relevant data to share may not exist

In many cases, the data that may be most relevant for knowledge translation purposes have not been collected, and therefore cannot be disseminated. For example, Fae Johnstone described the simultaneous need for and absence of evaluation data on specific interventions for LGBTQ2S+ youth, which could serve both programming and advocacy purposes:

> *"We really need assessments of the efficacy of different kinds of interventions. How good are all of the peer-led youth groups that are the primary interventions for...2SLGBTQ young folks?...I think they're making miracles happen [and] I want the data that says that...If I could take a program, put it in a box, and go knock on government's door and say, 'you give me this much money and I will bring this program to 12 different cities,' there's a chance that can happen. But I need that box with that program and the statistic that says, 'this reduces the rate of trans kids showing up in emergency rooms by 67 per cent'....I can't say that right now."*
> ~ Fae Johnstone

The above example highlights the potential consequences of decisions made early in a project for its later stages. When project objectives or research questions do not meaningfully reflect the issues that LGBTQ2S+ individuals and communities identify as relevant, the likelihood that findings shared will be taken up in these contexts may be significantly reduced. Similarly, the failure to collect data about – and share findings that are disaggregated by – gender, sexuality, and other sociodemographic characteristics, can further constrain its utility in LGBTQ2S+ contexts. For instance, the lack of systematic collection and reporting of SOGI data in the American public health system throughout COVID-19 resulted in major gaps in knowledge that might have otherwise informed policy, programming, or advocacy endeavours.[118]

Deciding how and with whom to share knowledge is complex

Crafting an accessible, impactful, and ethical narrative for reporting and knowledge sharing can be a complex task. For initiatives that are longer-term or more technical in nature, creating understandable and usable knowledge translation products can be especially difficult. There are also distinct risks in LGBTQ2S+ contexts for identifying participants, requiring researchers to take extra precautions when presenting information to ensure participants' anonymity. From an ethical perspective, tensions can also arise in how findings are framed:

> *"What are the costs of these inequalities; how can information about these costs impact where and how we spend money? But from a social justice perspective, how we frame issues regarding differences in costs of care for any marginalized population is critical; we need to be careful to avoid creating a victim-blaming situation."* ~ Devon MacFarlane

Finally, reporting and knowledge sharing activities can entail political and power-laden decisions about what information is and is not mobilized, with whom, in what ways, and with what resources. In many cases, these decisions are informed by who funds research or owns data, rather than participants or community partners.[119]

Avoiding harm and challenging stigma in the presentation of findings

Culturally responsive and accessible approaches require accountability to LGBTQ2S+ participants and communities throughout the presentation of findings. Results shared in knowledge translation outputs should seek to amplify participants rather than speak for them.[120] Those conducting this work should anticipate, avoid, and address any potential stigma or harm that may result from how findings are interpreted.[26,35,48,119,148] Consider the following questions:[35,120]

- Do knowledge translation products clearly explain what results do and do not mean?
- Can findings that risk reinforcing stigma or stereotypes be contextualized?
- Can any positive findings or outcomes be highlighted?
- Could results be misused, misinterpreted, or otherwise leveraged for harmful purposes?

Opportunities

Considering the needs and priorities of knowledge users

Because culturally responsive and accessible approaches call on research initiatives to respond meaningfully to community needs, a strategic approach to reporting and knowledge sharing is crucial. Our findings highlight the importance of determining who is best placed to leverage research or data outputs early on in a project, such as advocates, policymakers, and service or health care providers, and consulting with these actors to inform knowledge translation activities.[35] While potentially more labour-intensive, leveraging engagement to support knowledge translation can enhance its effectiveness. Some sources contend that stakeholder involvement can significantly increase the potential for acceptance of the findings and responsiveness to the resulting recommendations.[119] Key informants also spoke to the value of consulting with intended knowledge users about the information they need and how to present it, and tailoring dissemination strategies accordingly:

> *"Find the people who are willing to be champions and ask what data they need. What's the story they 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

Culturally responsive and accessible approaches to reporting and knowledge sharing place particular emphasis on the benefits and relevance of these activities to LGBTQ2S+ individuals and communities themselves.[44,120] At a minimum, it is important to consider how results will be returned to participants and communities.[35] The Trans PULSE Ontario team regarded themselves as "stewards of lived experience," with an ethical obligation to return research findings to the trans community and decision-makers who could implement change.[22] While LGBTQ2S+-led and -serving organizations may be well suited to support the dissemination and application of findings, work is required to build these relationships:

> *"We need strategies that are actually leveraging the trust of organizations we do have to get those resources out of the door."*
> ~ Fae Johnstone

Equipping LGBTQ2S+ civil society with the skills and resources to support reporting and knowledge sharing is key to incorporating the needs and priorities of knowledge users.
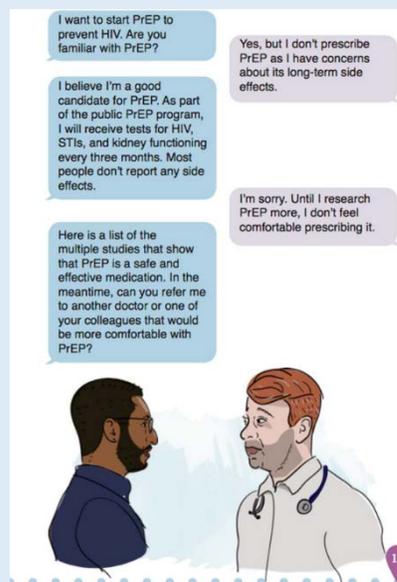
Prioritizing accessibility and utility in knowledge translation

Accessibility and utility are core features of culturally responsive and accessible approaches to reporting and knowledge sharing. Knowledge users must be able to access findings for them to be useful, prompting questions about where this information is shared and in what formats.

Community-engaged research for knowledge translation

A case study of CBRC's Investigaytors program described the implications of leveraging community-based participatory research approaches to inform knowledge translation[126] and to move beyond passive and unidirectional approaches to dissemination.[149-153] As part of a qualitative research project on HIV PrEP, co-researchers with the Investigaytors program participated in a capacity-building workshop on knowledge translation, collectively developed a knowledge translation strategy, and led the design and development of a printed toolkit resource on accessing PrEP.[154] In a subsequent focus group with these co-researchers, participants perceived the toolkit to practically fill an important knowledge gap, and felt that the collaborative approach to its creation lent to its strength and credibility. Participants also reported skill gains in problem solving and communication, increased capacity to synthesize and present complex information, and enhanced understanding of their own knowledge of sexual health and PrEP.

While publication in peer-reviewed journals can be a valuable way to share findings within academic or research communities, other mechanisms (e.g., in-person presentations, community

reports, social media) will be more accessible to and usable by a wider audience, including but
not limited to LGBTQ2S+ community members.[35,44] Rather than assume that findings will
organically make their way to their intended audience, cultural responsiveness and accessibility
calls on research initiatives to promote utilization and uptake more actively.

Sharing data reliably and accessibly: Trans PULSE e-bulletins

Among its several knowledge translation products, the Trans PULSE Ontario project produced "e-bulletins" sharing
snapshots of research findings on specific topics, including transphobia in public spaces, experiences of incarcerated
trans people, and suicide among trans communities.[155-156] Each e-bulletin offered a background on the subject, a
summary of key findings, and any implications for policy and practice. The e-bulletins were brief (i.e., 2-3 pages), used
plain and accessible language, and were offered in both English and French. Products like these can also support
research initiatives to disseminate findings in a quicker and more targeted manner.[35]

Decisions about knowledge sharing made early on can support more meaningful and effective
knowledge translation later. Early and ongoing engagement with communities and other
intended knowledge users can build understanding and buy-in for future findings.[35,119] In terms
of methods selection, key informants identified both mixed methods as well as arts-based
approaches as offering innovative opportunities for knowledge sharing.

Implementing useful, accessible, innovative, and ethical reporting and knowledge sharing
activities is a skill. Our findings highlight the need to improve training and capacity for those
working in research contexts related to LGBTQ2S+ issues and communities. This also requires
flexibility and adaptability, which poses implications for project budgets and workplans.[35]

More generally, the following three questions offer guidance when disseminating findings with,
about, or for LGBTQ2S+ or communities, with a view to advancing accessibility and utility:

1. How are inequities presented?

   It is essential to consider and address potential harm in the presentation of findings about
   LGBTQ2S+ individuals or communities and explore opportunities to equally highlight
   strengths or positive findings. There are several important considerations when presenting
   inequities that emerge on the basis of gender, sexuality, or other characteristics. The
   following quote from one of our informants underscores the importance of inequities being
   made clear and visible through knowledge translation efforts, both between LGBTQ2S+ and
   non-LGBTQ2S+ individuals as well as within the LGBTQ2S+ community.[35]

   *"My current role entails funding work to advance sexual and reproductive health. I want to
   know, for instance, what's going on around prostate cancer rates for Black gay and bi men.
   That's the level of detail that I would want. I would want that level of granularity because some*

*of the research is indicating already that Black men may be diagnosed later with prostate cancer
and so have poorer health outcomes. And there's some indication that gay and bi men may also
have higher rates of prostate cancer...I need that level of granularity so I could then consider
what I need to invest in to improve health outcomes. I have a limited pot of money. I need to
know which parts of populations are doing the poorest and on what fronts, and what would
make a difference for them, if my investments are to have a better chance of advancing health
equity. I also want to know which parts of marginalized populations are doing better than we
might expect, and what is contributing to that, so that we can see if there is anything that can
be applied to other populations."* ~ Devon MacFarlane

A commitment to sharing findings in this way can help shed light on strengths and
disparities within LGBTQ2S+ populations (e.g., on the basis of gender, sexuality, race,
ability, and so forth), ensure that success stories and problems are plainly understandable to
those tasked with addressing them, and inform policy and programming responses as well as
resource allocation.

Making data public: Sex Now's *Our Stats* dashboard

Developed by CBRC, the *Our Stats* dashboard was launched in 2019 to make data from the Sex Now Survey
more available and accessible to community members, advocates, and leaders.[125] The dashboard allows users to
manipulate and visualize findings longitudinally and geographically, as well as to filter observations by various
demographic, behavioural, and health-related variables.[157] Though relying on a small convenience sample, an
evaluation of the dashboard found that participants generally held a favourable view of the tool, would
recommend it to others, perceived it to be better than traditional knowledge translation outputs, and saw several
practical applications for it in their work.[157] Greater support for users navigating the dashboard (e.g., via
instructional documentation) emerged as one recommendation.[157]

2. Is the information shared clear and compelling?

    - **Is it rigorous?** Research and data that are seen to be more credible or reliable may promote uptake and use.

    - **Is it easy to understand?** Knowledge products that are succinct, incorporate visual elements, and avoid using over-technical language or jargon can help promote understanding among users, community-based or otherwise:

    "Government is often too busy or doesn't have a lot of the background knowledge to really appreciate high-jargon content, and would actually prefer the infographic and the 'at a glance' – especially if they know that there is some solid rigorous research that backs it up."
    ~ Elizabeth Saewyc

    - **Is it interesting?** Leveraging qualitative data in dissemination efforts can be a powerful way to amplify participants' voices while establishing a more compelling narrative.[119]

3. Do the findings lend themselves to action?

    The actionability of findings was seen as integral to culturally responsive and accessible approaches to reporting and knowledge sharing. Those engaged in knowledge translation should be explicit about the practical of implications of findings and identify potential opportunities for their application or use. As one interviewee elaborated:

    "Knowledge mobilization has to be blended with implementation. So not just, 'this is what the research says,' but, 'this is how you do it.' If we know that peer-based interventions are one of the most effective interventions to address 2SLGBTQ youth suicide and poor mental health, 'here is how you implement the best practices, this is what the research identified, this is your guide.' It can't just be the statistics and the data. It needs to be how you actually use that data in a program or a particular context, so organizations are able to put it into place...At the end of day, [knowledge mobilization] is about taking good things and putting them into practice. We get stuck at the practice." ~ Fae Johnstone

Practical suggestions for disseminating research findings

Based on their experience conducting campus climate studies for LGBTQ2S+ students, Brown and Gortmaker shared the following recommendations regarding dissemination:

"Multiple reports (e.g., a full report, technical report, executive summary, reports targeted for specific subgroups) are likely to have the most impact. A technical report may satisfy the social science critics but may overwhelm others. Qualitative data from interviews and open-ended questions can personalize the findings in a way that influences many. Using mixed methods that blend quantitative and qualitative findings and preparing multiple reports increases the possibility of meeting the concerns of diverse audiences. A particularly effective reporting strategy involves having a panel of LGBT students discuss the findings as they are presented to various campus groups. A PowerPoint presentation of percentages in a table and written quotes from students can be effective, but combining them with the presence of LGBT students sharing their personal stories can be many times more powerful."[119]

CONCLUSION

This report summarized findings with respect to key issues and opportunities for culturally responsive and accessible research with LGBTQ2S+ populations, with a focus on (but not exclusive to) health contexts. Drawing on a rapid review of literature and interviews with key informants from across Canada, the report sought to identify principles and practices that support culturally responsive practice along the research cycle.

Cultural responsiveness and accessibility are relatively new concepts. As such, our intent was to explore more deeply the meaning and use of such approaches to research involving LGBTQ2S+ people and communities. At their core, culturally responsive and accessible approaches to research are informed by several core principles: these approaches are community-centred, results-driven, and action- and solution-oriented; they are flexible and contextualized, intentional, equity-driven, and theoretically grounded; and they are oriented to data justice. Ultimately, applying cultural responsiveness and accessibility in LGBTQ2S+ contexts is a process, not a destination.

What type of data are being collected, why they are being collected, and by whom, must be explicitly taken into account. While we hope this report is useful for those seeking to advance cultural responsiveness and accessibility in their own research endeavours, it should only serve as a starting point. We encourage readers to leverage its guidance to inform and build practices applicable to the unique contexts in which they live and work.

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 data collection for, with, and about LGBTQ2S+ people and communities. Many of these opportunities centre around building trust and developing capacity in the system and across the different actors involved in research, data collection and analysis, and civil society. Building capacity among LGBTQ2S+ individuals and communities, particularly those experiencing multiple forms of marginalization and oppression, emerged as central to these efforts. There are also significant data and knowledge gaps that must be addressed since they continue to inhibit progress and action. Implementing culturally responsive and accessible research requires developing a comprehensive data infrastructure, with the aim of modernizing SOGI data collection in Canada.

Finally, the advancement of culturally responsive and accessible approaches requires higher-order leadership to champion and steer this work. To this end, there are further opportunities to embed and integrate these efforts within existing provincial and federal initiatives, such as within the implementation of the federal LGBTQ2 Action Plan.[121]

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APPENDIX A: ADDITIONAL RESOURCES

The following is a non-exhaustive list of resources freely available online that may be helpful for those interested in learning more about LGBTQ2S+ research and exploring more deeply some of the issues identified in this report.

Training

- Rainbow Health Ontario's **Breaking Down Barriers: A Tool to Address Inequalities in LGBT2-SQ Healthcare in Sudbury, Ontario, Health Care Provider Handbook**

- Alberta Health Service's **Sexual Orientation, Gender Identity & Gender Expression (SOGIE) Safer Places Toolkit**

- Heal All Consulting's **Neutralizing clinical language: Working with gender and sexual diversity**

Overarching research guidelines

- Canadian Professional Association for Transgender Health's **CPATH Ethical Guidelines for Research Involving Transgender People & Communities**

- Canadian Institute of Health Research's **Meet the Methods Series: "What and Who is Two-Spirit in Health Research"**

- LGBTQ TA Center's **LGBTQ Population Evaluation Guidelines**

- The New Mexico LGBTQ Health Collaborative's **Guidelines for Conducting Health Research With LGBTQ+ Individuals and Communities in New Mexico**

- LGBT Foundation's **Ethical research: Good practice guide to researching LGBT communities and issues**

- SRDC's **Queering research and evaluation: An LGBTQ2S+ primer**

Community engagement

- Rainbow Health Ontario's **Community-based Research with LGBTQ Communities**

Methods

- Rainbow Health Ontario's **Qualitative Interviewing with LGBTQ Communities**

- Daniel Grace's **Intersectionality-informed Mixed Methods Research: A Primer**

- Canadian Institute of Health Research's Meet the Methods Series: **Methods for Prospectively and Retrospectively Incorporating Gender-Related Variables in Clinical Research**

- Canadian Institute of Health Research's Meet the Methods Series: **Questions to Guide Quantitative Intersectional Analyses**

Measurement

- Statistics Canada's **Sex at birth and gender: Technical report on changes for the 2021 Census**

- The National Academies of Sciences, Engineering, and Medicine's **Measuring Sex, Gender Identity, and Sexual Orientation**

- Gloria Fraser's **Evaluating inclusive gender identity measures for use in quantitative psychological research**

- Rainbow Health Ontario's **LGBTQ Research with Secondary Data**

- GRIS Montréal's **Workshop Questionnaire**

- The Williams Institute's **Best Practices for Asking Questions about Sexual Orientation on Surveys**

- The Williams Institute's **Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys**

- Clair A. Kronk et al.'s **Transgender data collection in the electronic health record: Current concepts and issues**

- National LGBT Health Education Center's **Collecting Sexual Orientation and Gender Identity Data in Electronic Health Records**

- Canadian Institute of Health Research's **Meet the Methods Series**

APPENDIX B: RAPID REVIEW KEYWORDS

LGBTQ2S+-related terms	Data-related terms	Health-related terms
Sexual and gender minorit*	Project management	Health
Sexual minorit*	Project planning	Physical health
Bisexual*	Project team	Mental health
Homosexual*	Lived experience	Wellbeing
Transgender*	Timeline	Determinants of health
Transsexual*	Intersectional*	SDOH terms (Income, deprivation, disadvantage, welfare, social protection, child care, marital status, education, immigration, refugee, race, ethnicity, housing, homeless, transportation, mental health, employment, unemployment, youth, adult, senior, rural, urban, disability, policing, incarceration, crime, trauma, violence, drug use, addiction, health care access, primary care physician, health insurance, legislation, policy, media, social capital, social support)
Lesbian*	Research question	
Gay	Research objectives	
Non-monosexual OR nonmonosexual	Quantitative data	
Men who have sex with men	Qualitative data	
MSM*	Data collection	
Women who have sex with women	Participant confidentiality	
WSW*	Community-based research (CBR)	
Queer	Participatory research	
Two-Spirit*	Research ethics	
LGB*	Research design	
GLB*	Research methodology	
LGBT*	Sampling strategy	
Sexual orientation	Survey measures	
Sexual attraction	Data confidentiality	
Gender identity	Data privacy	
Agender	Participant recruitment	
Asexual	Data instruments	
Non-binary	Data collection	
Pansexual	Data analysis	
Intersex	Reporting	
Gender-non-conforming	Knowledge translation	
Questioning	KTE	
Gender expression	Cultural responsiveness	
	Accessibility	
	Surveillance	

APPENDIX C: RAPID REVIEW SOURCES

PEER REVIEWED DATA SOURCES

- Ovid Medline

- CINAHL

- PsycINFO

- Sociological Abstracts

- Web of Science

- Google Scholar

GREY LITERATURE DATABASES AND SOURCES

- OpenGrey

- GreyNet

- Grey Literature Report

- Google search (e.g., 5 first pages)

- Statistics Canada

- Health Canada/Public Health Agency of Canada

- Canadian Institute for Health Information

- Canadian Institute for Health Research

- Researching for LGBTQ Health

- Community-Based Research Centre

- National Collaborating Centres for Public Health

- TransPulse

- SexNow

- Egale

- Pride at Work Canada

- Canadian Centre for Gender and Sexual Diversity

- Rainbow Health

- Williams Institute

- GRIS Montréal

- Fondation Émergence

- Centre Communautaire LGBTQ+ de Montréal

- Concordia University Centre for Gender Advocacy

- The ArQuives

APPENDIX D: KEY INFORMANT LIST

Name	Position	Organization
Marcy Antonio	Postdoctoral Researcher	University of Michigan, School of Information
Greta Bauer	Professor	University of Western Ontario, CIHR Sex and Gender Science Chair
Tyler Boyce (he/him)	Executive Director	Enchanté Network
Fernand Comeau (he/him)	Executive Director	LGBTQ Secretariat
Olivier Ferlatte (he/him)	Assistant Professor	University of Montreal
Daniel Grace	Associate Professor	Dalla Lana School of Public Health, University of Toronto, Canada Research Chair in Sexual and Gender Minority Health
Fae Johnstone, MSW (she/they)	Executive Director Consultant	Wisdom2Action
Ben Klassen (he/him)	Sex Now Research Manager	Community-Based Research Centre
Tanya Lary	Manager	Women and Gender Equality
Francis Lau	Professor	University of Victoria
Maura Lawless (she/her)	Executive Director	The 519
Karine Leclerc	Senior Research Analyst	Statistics Canada
Devon MacFarlane[g]	Expert, LGBT2SQ Health Equity	
Lance T. McCready, PhD (he/they)	Associate Professor	Leadership, Higher & Adult Education
Tanya Neumeyer	Education and Training Specialist	Rainbow Health Ontario
Debbie Owusu-Akyeeah (she/her)	Executive Director	Canadian Centre for Gender and Sexual Diversity
Marni Panas[g]		
Jake Pyne[h]	Assistant Professor	York University
Margaret Robinson	Assistant Professor	Dalhousie University
Elizabeth Saewyc (she/her)	Professor & Distinguished University Scholar, Executive Director	Stigma and Resilience Among Vulnerable Youth Centre, School of Nursing, University of British Columbia

[g]   Opted to speak independently for the purpose of the interview.

[h]   Direct quotes not validated and therefore not included.

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