Recommendations for gathering

2S/LGBTQQIA+

Health and wellness data

Insights from available literature









Executive summary

Synthesizing available literature advances evidence-based data and wise practices to support decision making and planning for the health and wellness of Two-Spirit, lesbian, gay, bisexual, transgender, queer, questioning, intersex, asexual, and all other sexual orientations and genders (2S/LGBTQQIA+) (FNHA, 2022). The purpose of this literature review was to examine available evidence to better understand Indigenous perspectives on 2SLGBTQQIA+ health data representation, systems and best practices for data collection in Canada, the United States, Australia and Aotearoa (New Zealand). This literature review was carried out in alignment with the First Nations Health Authority's 7 Directives.

First Nations Health Authority's 7 Directives

Community-Driven, Nation-Based Increase First Nations Decision-Making and Control **Improves Services** Foster Meaningful Collaboration and Partnership **Develop Human and Economic Capacity** Be Without Prejudice to First Nations Interests Function at a High Operational Standard

Research studies, government and organizational reports and other foundational documents gathered for this summary have highlighted the ongoing systemic barriers experienced by 2S/LGBTQQIA+ people and communities due to inconsistent, non-representational and irrelevant data gathering on health and wellness (Women of the Métis Nation, 2019; The House of Commons Standing Committee on Health, 2019; Pinto et al., 2019; National Action Plan, 2021). The insufficient collection, and often complete absence of 2S/LGBTQQIA+ health and wellness data inhibits First Nations health leaders, decision makers and communities from addressing known health inequities (Bobadilla et al., 2022). In addition to this, a history of harmful and pathologizing data collection on 2S/LGBTQQIA+ people has further perpetuated the imposition of colonial gender and sexuality norms and the exclusion of 2S/LGBTQQIA+ perspectives from being included in research, policies and programming (National Inquiry into Missing and Murdered Indigenous Women and Girls, 2019; Bobadilla et al., 2022; Hunt, 2016; Two Spirits in Motion Society, 2020).

This report presents wise practices to amplify the extensive work that has been done by 2S/LGBTQQIA+ people, communities and organizations to outline the path forward in creating transformative change and addressing experiences of health inequity, harm and oppression. These wise practices focus on the role that relational, standardized, culturally relevant, distinctions-based and representative data gathering approaches have in ending violence against 2S/LGBTQQIA+ people, and supporting the wholistic health and wellness of our 2S/LGBTQQIA+ relatives.

Grounded in these five wise practices, we recommend the development of a strengths-based, culturally-grounded, standardized data collection tool that is distinctions-based to better represent the intersectional identities of First Nations 2S/LGBTQQIA+ people in BC. This tool would be funded and resourced by the FNHA, developed in partnership with 2S/LGBTQQIA+ people and communities, and used by the FNHA, BC First Nations communities across the province and provincial health partners. The overarching goal of developing this tool is to strengthen First Nations health leadership and Indigenous 2S/LGBTQQIA+ peoples' self-determination in the gathering of sex and gender information and support the development and delivery of culturally safe health programming for all BC First Nations community members.

Terminology

Indigenous

The term "Indigenous" is used throughout this work and refers to the populations included within this literature review from Canada, the United States, Australia and Aotearoa (New Zealand). "Indigenous" is used as a collective term and is intended to reflect the diverse populations of original peoples within these contexts. We acknowledge that use of this amalgamated term risks perpetuating the imposed invisibility or "lumping in" of unique and distinct cultural identities (Carriere & Richardson, 2017, p.5). However, as the focus of this summary is on the diverse population of Indigenous peoples across the globe, our intention is to use this term respectfully and inclusively, allowing space for those who choose to identify in a multitude of ways, including but not limited to, First Nations, Métis, Inuit, Native American, Aboriginal, Torres Strait Islander or Māori.

Two-Spirit (2S)

A contemporary term that incorporates Indigenous views of gender and sexual diversity, honouring both the male and female spirit as well as other gendered or non-gendered spirits and spiritual and cultural expressions of identity. It may be used by some Indigenous people, and sometimes in addition to identifying as LGBTQQIA+ (Lezard et al., 2021; Native Women's Association of Canada, 2019).

Wholistic

The term "wholistic" is intentionally used throughout this summary as opposed to "holistic" when referring to the wellness of Indigenous people and communities. As Mi'kmaw Elder Murdena Marshall suggests, the word is spelled in this way to remind us of "whole" rather than "hole" (Marshall et al., 2015), reflecting the understanding that when we refer to health we are describing the interconnected well-being of the whole person (physical, spiritual, mental and emotional), the whole family, and the whole community (First Nations Health Authority, 2022).

Background

Data collection structures and practices within healthcare, justice and education systems not only fail to accurately capture and report on Indigenous 2S/LGBTQQIA+ information, but actively contribute to the underreporting and misreporting of data (Hunt, 2016; Lehavot et al., 2009; Adams & Phillips, 2006). Historical and contemporary colonial policies and practices continue to have significant negative impacts on the health, wellness and safety of 2S/LGBTQQIA+ people, contributing to distrust of colonial systems and wariness in sharing personal and community health information (Goodman et al., 2018; Bobadilla et al., 2022; National Inquiry into Missing and Murdered Indigenous Women and Girls, 2019). While this issue spans across several social determinants of health, the lack of accurate and representative data collected on violence committed against 2S/LGBTQQIA+ people is of particular concern (National Action Plan Data Strategy, 2021). Significant evidence exists that confirms the disproportionate rates of violence experienced by Indigenous women and girls, and yet data surrounding violence against members of Indigenous 2S/LGBTQQIA+ communities remains scarce. Of additional concern are findings that highlight the increased risk of human rights violations experienced by 2S/LGBTQQIA+ people when their personal data -- such as name and sex -- in government documents do not align with their gender identity or expression (United Nations Office of the High Commissioner on Human Rights, 2023).

Following the lead of Indigenous scholars who are trailblazers in this work, our report focuses on the barriers and challenges created by information systems that do not currently uphold the rights or meet the needs of 2S/LGBTQQIA+ people (Representative for Children and Youth, Charlesworth, 2023). This report and resulting recommended path forward align with recommendations put forward by both the National Action Plan (2021), and the National Action Plan Data Strategy (2021) to address violence against Indigenous women, girls and 2S/LGBTQQIA+ people in Canada through the co-creation of data accountability mechanisms that are rooted in Indigenous and 2S/LGBTQQIA+ ways of knowing and being. Drawing on the strengths, resiliencies and expertise of Indigenous 2S/LGBTQQIA+ people and communities, we summarize available literature on Indigenous-led solutions from both indexed and non-indexed sources, acknowledging that this is not a complete representation of Indigenous 2S/LGBTQQIA+ health data representation, systems and wise practices for data collection. Rather, this review offers a snapshot of current challenges within the context of 2S/LGBTQQIA+ data, and the many wise practices that Indigenous 2S/LGBTQQIA+ communities have put forward that demonstrate leadership and innovation in intersectional, culturally-relevant approaches to gathering sex and gender specific health data. These wise practices have informed our recommended path forward to support the FNHA, First Nations communities in BC and other health partners in upholding our collective responsibility to end violence against, and support the wholistic health and wellness of First Nations 2S/LGBTQQIA+ people in BC.

Scope and approach

As considerations for the collection of 2S/LGBTQQIA+ health and wellness data are dynamic and multi-faceted, the scope of this review was broad in nature to reflect the many ways 2S/LGBTQQIA+ people, communities and organizations are creating systems change and addressing experiences of health inequity, harm and oppression. Indexed or published literature that met our search criteria was systematically gathered from Google Scholar and the SFU Library Catalog and included any resources that met the search criteria. Our search criteria included literature that offered both Indigenous and Two-eyed Seeing perspectives on 2S/LGBTQQIA+ health data representation, systems and best practices for data collection within the context of Canada, the United States, Australia and Aotearoa (New Zealand). In addition, non-indexed or gray literature was systematically gathered using Google to target resources that were relevant to these criteria. These searches resulted in 13 indexed and 23 non-indexed resources being included in this review.

What we have learned

Systemic Violence Against 2S/LGBTQQIA+ People

Challenges

Indigenous families, communities and organizations have long called for action to end the high rates of violence against Indigenous women, girls and 2S/LGBTQQIA+ people. The number of missing and murdered Indigenous 2/SLGBTQQIA+ people in Canada is largely unknown, with the vast majority of deaths or disappearances being unreported or misreported (National Action Plan, 2021; Betasamosake Simpson, 2014; Ristock et al., 2019). Ongoing systemic barriers and long histories of harm and distrust within both the criminal justice and health systems mean that Indigenous Peoples are unlikely to report incidents of violence (National Inquiry into Missing and Murdered Indigenous Women and Girls, 2019). When incidents are reported, the data gathered is often inaccurate or nonrepresentative of diverse genders and sexualities, it is also not shared with families, communities, organizations and other stakeholders due to privacy concerns (Women of the Metis Nation, 2019; National Inquiry into Missing and Murdered Indigenous Women and Girls, 2019). Without this necessary baseline data, it is impossible for Indigenous leaders and communities to make decisions regarding the health, wellness and safety of 2S/LGBTQQIA+ community members, as well as measure any meaningful change at federal, provincial, or community levels (National Action Plan, 2021; National Inquiry into Missing and Murdered Indigenous Women and Girls, 2019; Robinson, 2022).

Wise practices

In order to understand the wholistic health and wellness of 2S/LGBTQQIA+ people, health data collection and systems must include considerations of ongoing systemic violence and harm experienced by 2S/LGBTQQIA+ people and communities. The following wise practices highlight ways in which this data can be respectfully gathered to inform health policies and practices that address these harms:

Continued on next page

- Statistics alone are not enough to fully capture the harms perpetrated against Indigenous 2S/LGBTQQIA+ people and communities (Woman's Earth Alliance & Native Youth Sexual Health Network, n.d). The experiences, perspectives and wisdom of Indigenous gender-diverse people and communities must be central to all aspects of this work to ensure inclusive, representative and relevant information is gathered to inform decision making (Woman's Earth Alliance & Native Youth Sexual Health Network, n.d.; Lezard et al., 2021);
- 2S/LGBTQQIA+ narratives must be gathered and shared in safe ways to strengthen community understanding and foster inclusivity (Lezard et al., 2021);
- Establishment of culturally safe and relevant strategies and infrastructure for reporting and monitoring violence against 2S/LGBTQQIA+ community members (Lezard et al., 2021).

Relational approaches

Challenges

It must be acknowledged that a long history of harmful and stigmatizing research practices has resulted in Indigenous communities' distrust of colonial systems and wariness in sharing personal and community health information (Goodman et al., 2018; Bobadilla et al., 2022). Further to this, 2S/LGBTQQIA+ voices continue to be largely absent from health research, with limited data that does exist focusing primarily on health disparities (Thomas et al., 2022). This perpetuates the misrepresentation and stigmatization of 2S/LGBTQQIA+ people and calls into question both the direct and indirect benefit of health research for themselves and their communities (Thomas et al., 2022; Goodman et al., 2018). Going forward, the gathering of 2S/LGBTQQIA+ health and wellness data must be done in ways that foster safety, trust and reciprocity in order to maintain good relations.

Wise Practices

Culturally safe and relevant data gathering with 2S/LGBTQQIA+ people and communities requires relational approaches that prioritize respect, accountability and the centering of 2SL/BTQQIA+ voices and experiences to ensure collective benefit (Wilson, 2008; Sanchez-Pimienta et al., 2021; CIHI, 2022; Bobadilla et al., 2022; Hunt, 2016). The following wise practices outline relational approaches to gathering 2S/LGBTQQIA+ health and wellness data and recommendations for embedding these practices within our health systems:

- First and foremost, meaningful engagement is foundational to appropriately collecting Indigenous and 2S/LGBTQQIA+ data (CIHI, 2022; Bobadilla et al., 2022). The inclusion and acknowledgment of 2S/LGBTQQIA+ people as the experts throughout the entire research and data collection process is critical to ensure health indicators measured are relevant, valid and actionable for health system decision-makers (CIHI, N.d);
- Ensure the inclusion and leadership of 2S/LGBTQQIA+ people on research and data gathering teams (Pruden & Salway, 2020; Sanchez-Pimienta et al., 2021) while also dedicating resources to support the self-determination of 2S/LGBTQQIA+ organizations and communities to gather their own data (National Action Plan, 2021);
- Move away from academic, written knowledge products to prioritize relational ways of knowledge sharing and emphasize lived experience as a source of knowledge (Sanchez-Pimienta et al., 2021; Two Spirits in Motion Society, 2020).

Standardized data collection

Challenges

Sexual orientation and gender identity are key social determinants of health, but data are rarely collected in a routine or standardized way (Pinto et al., 2019). When this data is collected, there are vast inconsistencies in the ways in which sex and gender are asked about (Ristock et al., 2010; The House of Commons Standing Committee on Health, 2019). This patch-work approach results in limited availability of information, difficulties in understanding and utilizing the data, and barriers to understanding the health and wellness status of 2S/LGBTQQIA+ people and communities (Ristock et al., 2010). Significant gaps in knowledge exist across all health and social systems, including but not limited to the physical health of 2S/LGBTQQIA+ people, the overall health and wellness of 2S/LGBTQQIA+ youth and older adults, and the number of 2S/LGBTQQIA+ children and youth in the Canadian child welfare system (The House of Commons Standing Committee on Health, 2019; Charlesworth, 2023). Without standardized collection of this sex and gender data, key health information and perspectives are absent from the decision making process that informs policy, practice and systemic change (Charlesworth, 2023).

Wise practices

In response to the challenges around consistency, availability, and accuracy of 2S/LGBTQQIA+ health and wellness data, many Indigenous leaders, organizations and scholars have called upon the federal government to implement Nation-wide policies and standards for sex and gender data collection (Women of the Métis Nation, 2019; CIHI, 2018; National Action Plan, 2021). The following recommendations and wise practices offer a path forward for the respectful collection of representative sex and gender information:

- Development of a standard data collection tool across governments and ministries that reflects the unique and intersectional realities of all Canadians (Women of the Métis Nation, 2019; The House of Commons Standing Committee on Health, 2019; Charlesworth, 2023);
- Data collection standards must be representative and inclusive of all identities and experiences, and allow individuals to identify in one or many of the categories provided: "People carry mixed identities and should not have to 'give up' any to fit in one category." (National Action Plan, 2021; Charlesworth, 2023);
- Two-Spirit data must be collected appropriately, noting that it should be embedded within race and ethnicity questions offered only to Indigenous-identifying individuals. Two-Spirit should not be included as an option in gender or sexual orientation questions (Pruden & Salway, 2020)

Example:

Please select all that app	ıy:	
☐ Black	Prefer to self-describe (specify)	☐ White
☐ East/Southeast Asian	☐ Prefer not to say	☐ Another category (specify)
Indigenous:	Are you Two-Spirit? 🗌 Yes 🔲 No	
☐ First Nations	Latino	☐ Prefer not to say
☐ Métis	☐ Middle Eastern	
☐ Inuit	South Asian	

Cultural context

Challenges

Historical and ongoing colonial systems have had detrimental impacts on the traditional roles and identities of Two-Spirit people within our communities and families (Lezard et al., 2021). Further to this, western binary conceptualizations of gender and sexuality have excluded Indigenous experiences of sex and gender, and in turn, restricted 2S/LGBTQQIA+ voices and perspectives within research, policies and programming (Two Spirits in Motion Society, 2020; National Action Plan Data Strategy, 2021). It is important to note that just as Indigenous Peoples each have their own distinct cultures across Nations, Two-Spirit identity is meant to facilitate connection with Nation-specific expressions and roles of gender and sexual diversity (Women of the Métis Nation, 2019; Pruden & Salway, 2020). In order to ensure sex and gender data is gathered in culturally safe, relevant and representative ways, Indigenous 2S/LGBTQQIA+ people and communities must be involved in all aspects of the development of data infrastructure, policies and standards (National Action Plan, 2022).

Wise practices

To ensure that Indigenous sex and gender data is rooted in the unique cultural contexts of 2S/LGBTQQIA+ people, data infrastructure must reflect Indigenous knowledge systems and the lived experiences of 2S/LGBTQQIA+ people and communities (Lezard et al., 2021, Quinless, 2022; Pruden, 2021). The following wise practices offer a path forward in establishing culturally safe and relevant data policies and systems for the gathering, analyzing and sharing of 2S/LGBTQQIA+ health and wellness information:

- Culturally appropriate and relevant data infrastructure must be based on the principles of Indigenous data sovereignty and culturally-rooted, distinctions based indicators of health and wellness, regardless of where 2S/LGBTQQIA+ people or communities are (National Action Plan, 2021, Ristock et al., 2010);
- Indigenous methods for data gathering, analysis, and sharing, such as storytelling, sharing circles, narrative analysis, and land-based learning offer culturally appropriate ways to honour the lived experiences and intersectional cultural identities of 2S/LGBTQQIA+ people and communities (Lezard et al., 2021; NWAC, 2019);
- Utilize strengths-based approaches that centre the cultural strengths, knowledges and identities
 of 2S/LGBTQQIA+ people and acknowledge their traditional roles in supporting the health and
 wellness of families and communities (Lezard et al., 2021; National Action Plan Data Strategy, 2021)

Distinctions and identity-based data

Challenges

Mainstream approaches to data gathering and analysis rarely reflect the diversity of Indigenous 2S/LGBTQQIA+ perspectives or lived experiences, and often lack appropriate identifiers that are distinctions and identity based (Hunt, 2016; CIHI, 2022). Distinctions-based approaches acknowledge the distinct lived experiences of First Nations, Inuit and Métis people and communities, avoiding pan-Indigenous approaches (NWAC, 2019). In regards to sex and gender information, data sourced from health cards, census surveys, intake forms and other administrative sources typically do not distinguish between sex and gender and do not capture the diversity within 2S/LGBTQQIA+ communities (CIHI, 2022; Lezard et al., 2021). Absence of distinctions and identity-based approaches results in misrepresentation within health data and a disregard for the unique experiences of 2S/LGBTQQIA+ people and the ways in which they are differently impacted by policies and programs (Pruden, 2021; Two Spirits in Motion Society, 2020; NWAC, 2019).

Wise practices

There is a need to increase accurate and representative 2S/LGBTQQIA+ health and wellness data to ensure these diverse experiences of 2S/LGBTQQIA+ people and communities are reflected in health policies and programs (Lezard et al., 2019). In addition to calls for distinctions and identity-based approaches to address violence against Indigenous 2S/LGBTQQIA+ people and communities (AFN, 2022; National Action Plan, 2021), many recommendations have been put forward to establish culturally appropriate data infrastructure that is reflective of Indigenous 2S/LGBTQQIA+ people. The following wise practices provide guidance for gathering this data in culturally safe and inclusive ways:

- Data collection must be inclusive, with full and active participation of all Indigenous people, including both Status and non-Status First Nations, Inuit and Métis 2S/LGBTQQIA+ people and communities (regardless of where they live), and be applied as needed in distinctions-based and disaggregated ways (National Action Plan, 2021);
- Data collection standards must allow people to identify in one or many of the categories provided to honour complex identities and improve representation and accuracy (National Action Plan, 2021; Charlesworth, 2023);
- When reporting on sex and gender, a two-step approach is required to distinguish between assigned sex at birth and gender identity (CIHI, 2022);
- For data collection regarding gender identity, eliminate "either-or" gender options and include gender inclusive, gender neutral, or non-binary options (Lezard et al., 2019). A minimum of three categories should be used, for example: female, male, and another gender or "X" option (CIHI, 2022).

Representation

Challenges

2S/LGBTQQIA+ voices and perspectives have largely been excluded from system- and program-level decision-making (Sanchez-Pimienta et. al., 2021; National Inquiry into Missing and Murdered Indigenous Women and Girls, 2019; Bobadilla et al., 2022; Hunt, 2016; Two Spirits in Motion Society, 2020). While health disparities for 2S/LGBTQQIA+ people are well-known, the lack of data on such disparities has resulted in funding mechanisms and organizations not having adequate information to prioritize tailored programming (Charlesworth, 2023; Bobadilla et al., 2022; Hunt, 2016; Rainbow Health Ontario, 2016). Dominant policy and program frameworks are often structured according to individual identity markers (e.g., Indigenous, LGBTQQIA+), and so Indigenous 2S/LGBTQQIA+ people may not be fully represented in either contexts due to their overlapping identities (Hunt, 2016). Available data largely comes from Indigenous organizations across the United States, which calls into question cultural relevance of these data to program and service design for Indigenous communities across Canada, and specifically First Nations people in British Columbia (Rainbow Health Ontario, 2016). Without fulsome data and representation on the priorities of 2S/LGBTQQIA+ communities, the health and social support needs of these communities will not be adequately addressed (Hunt, 2016; Two Spirits in Motion Society, 2020).

Wise practices

Indigenous 2S/LGBTQQIA+ people must be able to represent the needs and rights of their communities at decision-making tables. This presence, combined with having more complete and representative health data on the 2S/LGBTQQIA+ people and communities, are critical to the development of culturally safe, tailored programming and resources. The following wise practices provide exemplify where and how to increase representation of 2S/LGBTQQIA+:

- Prioritize the inclusion and representation of 2S/LGBTQQIA+ perspectives in research and policy on Social Determinants of Health, such as: housing, education, gender-based violence, healthcare and reformation of the criminal justice system (Lezard et al., 2021).
- Prioritize representation of youth and Two-Spirit people on research teams, advisory councils and health decision-making bodies (Pruden & Salway, 2021; Two Spirits in Motion Society, 2020; Bobadilla et. al., 2022).
- Develop 2S/LGBTQQIA+ dedicated spaces, tailored programming and resources within specific agencies and services (National Action Plan, 2021).

Recommended path forward

Drawing upon the many calls to action and wise practices put forward by 2S/LGBTQQIA+ people, communities and organizations summarized throughout this report, we offer a recommended path forward to support the FNHA, First Nations communities across BC, and other health partners in transforming the way 2S/LGBTQQIA+ health and wellness data is gathered. These recommendations reflect our collective responsibility to take action on known 2S/LGBTQQIA+ experiences of violence, harm and oppression within the health system. Through the creation of data infrastructure that captures accurate, representative and culturally-relevant health and wellness information, First Nations health leaders, decision makers and communities will be better equipped to address health inequities and support the wholistic health, wellness and safety. The following recommendations offer guidance in the co-development of standardized data gathering systems that are created in partnership with 2S/LGBTQQIA+ people and communities to best reflect the unique needs, priorities and experiences of First Nations 2S/LGBTQQIA+ people in BC.

FNHA funds and resources the development of a standardized data collection tool that is distinctions-based, inclusive and representative of the intersectional identities and realities First Nations 2S/LGBTQQIA+ people in BC. This tool would be used by the FNHA, First Nations communities in BC and provincial health partners (Regional health authorities, Ministry of Health).

- When reporting on sex and gender, use a two-step approach that distinguishes between assigned sex at birth and gender identity. A minimum of three categories should be used when asking about gender, for example: female, male and another gender or "X" option.
- Two-Spirit identity questions should only be offered as an option to individuals who self-identify as First Nations, Inuit and Métis.

FNHA co-develops and evaluates a standardized data collection tool in partnership with 2S/LGBTQQIA+ people and communities, acknowledging their role as the leaders and experts in this work.

- Ensure meaningful inclusion and leadership of 2S/LGBTQQIA+ voices in data collection and governance to inform health policy decision-making by and for First Nations in BC.
- Develop data infrastructure that supports self-determination of 2S/LGBTQQIA+ organizations and communities to gather and steward their own data.

Utilize strengths-based and culturally relevant approaches in the development and implementation of a standardized data collection tool.

- Use qualitative indicators that centre First Nations ways of knowing and being to reflect the lived experiences and intersectional identities of 2S/LGBTQQIA+ people.
- Prioritize relational ways of knowledge sharing, such as storytelling, sharing circles and land-based learning to honour the ways First Nations communities have engaged in data gathering and research since time immemorial.

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