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Case Report

Toward an inclusive digital health system for sexual and gender minorities in Canada

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ABSTRACT

Most digital health systems (DHS) are unable to capture gender, sex, and sexual orientation (GSSO) data beyond a single binary attribute with female and male options. This binary system discourages access to preventative screening and gender-affirming care for sexual and gender minority (SGM) people. We conducted this 1-year multi-method project and cocreated an action plan to modernize GSSO information practices in Canadian DHS. The proposed actions are to: (1) Envisage an equity- and SGM-oriented health system; (2) Engage communities and organizations to modernize GSSO information practices in DHS; (3) Establish an inclusive GSSO terminology; (4) Enable DHS to collect, use, exchange, and reuse standardized GSSO data; (5) Integrate GSSO data collection and use within organizations; (6) Educate staff to provide culturally competent care and inform patients on the need for GSSO data; and (7) Establish a central hub to coordinate efforts.

Key words: Gender and sexual minorities, gender, sex, and sexual orientation, health information systems, health equity, cultural competency

INTRODUCTION

Most existing digital health systems (DHS) are unable to capture gender, sex, and sexual orientation (GSSO) data beyond a single sex or gender data field with only male and female options.[1] As a result, it is often necessary for healthcare staff to record GSSO data in an ad-hoc fashion across an array of disconnected electronic and paper systems.[1–3]

This perpetuates existing inequities for sexual and gender minority (SGM) people.[4,5] Little is known about how health needs, care settings, and preventive screenings are being accessed across diverse SGM populations.[5,6] Based largely on primary research, and not digital health record data, we know that SGM populations experience health disparities, including higher rates of premature mortality, chronic diseases, depression, and suicide, and inequitable access

to preventive health screening.[1,5,7–10] Many SGM individuals are stigmatized and experience discrimination and even violence in healthcare systems.[11] SGM individuals often avoid seeking care because they do not find healthcare encounters to be sufficiently safe, accepting, or affirming.[9–11] Current initiatives, such as the Health Level Seven (HL7) Gender Harmony Project[12] and Kronk's GSSO ontology[13] have sought to address these inequities through the development of more inclusive GSSO standards.

BACKGROUND

In the context of our project, we consider SGM as an umbrella term that encompasses a diverse array of gender and sexual identities and placeholders, including lesbian, gay, bisexual, transgender, queer/

questioning, intersex, asexual, Two-Spirit, plus others (LGBTQIA/2S+). Recent calls to advance human rights and justice for Indigenous and LGBTQIA+ people have drawn attention to the systemic inequities experienced by SGM populations within Canada.[5,14–16] GSSO data fields have been built using Western ideas of gender identity and sexual orientation. In Canada, this has particular relevance for First Nations Peoples, for whom Two-Spirit embodies diverse sexualities, gender identities, roles, and/or expressions.[17]

Similar to what has been found in other countries, Canada continues to lack information practices within DHS that can fully support equitable access for SGM populations. The situation is further complicated by the historical foundations of the Canadian healthcare system. Although funding for hospitals and physicians was originally federally provided, responsibility has increasingly been transferred to provinces and territories.[18] Some groups remain within federal jurisdiction, including some First Nations Peoples living on reserves, some refugees, veterans, and inmates in federal penitentiaries.[18] Provinces differ greatly in how healthcare is structured. Alberta, for example, has a single central health authority,[19] while Ontario has 14 local health-integration networks. British Columbia has 7 health authorities, including the first and only First Nations Health Authority.[20]

The result is that Canada has a multitude of healthcare jurisdictions each with individualized DHS. The DHS within Canadian hospitals are dominated by Meditech, Epic, Cerner, Allscripts and Telus.[21] Canada Health Infoway is a pan-Canadian organization which was established in 2001 to support the integration of DHS across the diverse Canadian healthcare context.[22] It is a federally funded not-for-profit organization that works with partners involved in standards, policy, research, and practice for digital healthcare development.[22]

PROJECT OVERVIEW

The purpose of the planning project was to establish a coalition of organizations and communities to cocreate an action plan to modernize GSSO information practices in DHS across Canada. This paper describes the activities and outputs of the project (See Figure 1 for a summary of our different activities). Through a 1-year planning project grant from the Canadian Institutes of Health Research Institute (CIHR) of Gender and Health we explored ways to improve the definition, collection, sharing, and use of GSSO data in Canadian DHS.[23]

We defined information practices as the principles, approaches, policies, and process of defining, gathering, organizing, sharing, and using personal health information, such as GSSO data.[24] DHS included clinical and administrative applications and databases that collect, store, exchange, and use people's health histories and care records for primary (ie, direct patient care) and secondary uses (eg, population level) within the health ecosystem.[25] The study had institutional ethics review board approval (protocol #20-0001).

PROJECT OUTPUTS AND ACTIVITIES

Environmental scan
The environmental scan[26,27] involved an examination of public information sources on sex and gender definitions in existing Canadian DHS and international standards communities. The environmental scan included 52 databases and 55 data standards from 12

Figure 1. Activities involved in developing an action plan to modernize gender, sex and sexual orientation (GSSO) information practices in Canadian digital health systems

Canadian entities and 10 health information standard communities.[28]

Two rapid reviews on peer-reviewed literature
Two rapid reviews[29–32] were conducted that included 35 journal papers and 26 reports published between 2015 and 2020. Our rapid review of peer-reviewed literature involved a MEDLINE search with terms for gender, sex, sexual orientation, and electronic health/medical records and included all types of systematic reviews, primary studies, and commentaries.[33] Our rapid review of non-peer-reviewed publications included conference proceedings, government/research reports, education materials, and implementation guides.[34]

Mind mapping
Mind maps[35–37] were cocreated by collating GSSO concepts and descriptions located through our environmental scan and rapid reviews. We worked with a provincial health authority and subject matter experts in GSSO terminology and health information standards to cocreate 3 mind maps with 143 GSSO concepts and a glossary of 74 GSSO terms which we have incorporated in our action plan.[38]

Consultation sessions
We held 7 monthly virtual 1-hour consultation sessions[39–41] on different topics focused on modernizing GSSO information practices in DHS and gathering feedback on multiple iterations of our action plan. Consultants, communities, and organizations who were responsible for, involved with, interested in, or affected by how GSSO data were defined, collected and used in DHS were invited to take part in the sessions. Participants included SGM communities, advocacy groups, non-profit groups, health organizations, healthcare providers, government ministries, professional associations and colleges, information technology and management (IT/IM) professionals, standards organizations, researchers, educators, and consultants.

The majority of the participants (n = 30–45) were from across Canada, with a few from United States and Europe.

We also cofacilitated a virtual Sex and Gender Working Group through Canada Health Infoway where we had 8 guest presentations on current GSSO best practices and research.[42] The working group represented Indigenous and LGBTQIA+ communities, government organizations, professional associations, standards organizations, and healthcare organizations involved in the collection, sharing and use of GSSO information. Other Infoway pan-Canadian communities of practice (interoperability, benefits evaluation, change management, clinician peer network and clinician engagement network) were also invited to participate in the planning project. Research team members also participated in the HL7 Gender Harmony Project[12] in working toward international sex and gender standards.

Knowledge translation

Knowledge translation[43,44] activities to share cocreated research outputs are ongoing and have included creating products for different organizations (eg, briefing note, infographics and webinars).[38] Our current knowledge translation grant is supporting further dissemination of the action plan.

FINAL OUTPUT: AN ACTION PLAN

The above project outputs were used to cocreate an action plan that provided a high-level implementation strategy to modernize GSSO information practices in DHS within different Canadian contexts.[38] This plan focuses on what actions are needed, with details on who, how, when, and where still to be determined. As detailed results of our outputs are published elsewhere,[28,33,34] we have provided a brief summary of the action plan: the current landscape, proposed actions, and applications. The full action plan[38] can be found on the Infoway working group site.[42]

Current landscape

A major issue in existing DHS is the conflated use of sex and gender to represent a single binary concept.[1] A person's current gender may not be the same as what is typically associated with their biology. The conflation has created the following challenges with GSSO data in existing systems:[28]

- Inconsistencies in data names and value options used to represent sex and gender. For instance, sex, administrative sex, and patient's sex are data names that refer to a person's biology, and

indeterminate, intersex, undifferentiated, and others are used when one's sex is not stereotypically female or male.[2]
- Limited value options make SGM individuals largely invisible in health data sets. At the same time, newer value options such as sexual orientation, transgender, and nonbinary gender have raised implementation challenges in how one should migrate these definitions into existing systems.[8]

Seven transformative actions

We proposed 7 transformative actions to modernize GSSO information practices in Canadian DHS.[38] Table 1 provides a summary of these actions. Foundational activities focused on developing precise GSSO terminology and working with organizations, clinicians, staff, and vendors to determine the required DHS functions and processes to support GSSO information practices. Examples include: a) use of anatomical inventories as an objective catalogue of anatomic parts instead of making sex- and gender-based assumptions for all patients; and b) establishing DHS documentation that at a minimum have fields for current gender, name used, and pronouns. Other organizations may require additional fields for sex assigned at birth when this data is clinically relevant, and this may also extend to including data elements focused on sexual orientation.

The strategic activities outlined in the plan recognize the techno-sociopolitical-organizational aspects required for DHS designs that enable affirmation at data entry/output levels and inclusive care environments. Examples include: a) Developing patient identification policies to recognize that patient's used name and gender may be different from legal name/sex; and b) Delivering culturally competent education for engaging and caring for SGM patients across all levels of organizations.

Applying the action plan

The suggested approach for the action plan begins with a readiness/needs/sustainability assessment as a form of strengths-weaknesses-opportunities-threats (SWOT) analysis. Based on the findings of the SWOT analysis, an organization can determine its priorities, scope, and current stages of focus (eg, planning, assessment, and implementation). Migration strategies are also necessary to ensure the effort can stay focused, remain visible, and demonstrate value for the organization as it migrates through the stages over time. The action plan offers examples of current best practices which could be used by other organizations in modernizing GSSO information practices. In Table 2 we provide a summary of current Canadian "best practice" examples in applying these actions and the stages where these resources may align with an organization's current focus.

Table 1. Seven transformative actions to modernize gender, sex, and sexual orientation (GSSO) information practices in digital health systems[a]

Overarching Goal	Action-1: Envisage an equity- and sex and gender minority-oriented health system.
Foundational Activities	Action-2: Engage and partner with communities and organizations to modernize GSSO information practices to meet sexual and gender minorities' needs.
	Action-3: Establish GSSO terminology for patient care, health system use of data, and research.
	Action-4: Enable digital health systems to collect, use, exchange, and reuse standardized GSSO data.
Strategic Activities	Action-5: Integrate and tailor GSSO data collection with organizational structures, policies, use cases, and workflow processes.
	Action-6: Educate and train staff to provide culturally competent and safe care, and educate patients to understand the need for GSSO data.
Next Step	Action-7: Establish a central hub to liaise, guide, assist, and monitor the progress of this action plan over time.

[a]A strength-weakness-opportunity-threat (SWOT) analysis is recommended in determining the priority areas. Further examples of how these actions have been applied can be found within our action plan.

Table 2. Canadian examples of transformative actions to modernize gender, sex and sexual orientation (GSSO) information practices for digital health systems

Source	Transformative Action	Summary of GSSO Information "Best Practice" Resource
The EQUIP[a] frontline ownership approach[45]	Actions 1 and 6	Our action plan provides an example of how EQUIP could be used to guide equitable GSSO information practices. Organizational strategies include SWOT analysis, self-led healthcare staff working groups, and identifying and prioritizing areas of improvement with the assistance of a content coach.
Trans Care BC online training on gender diversity, support tools for creating welcoming environments[46]	Actions 1, 5, and 6	Provides examples of gender-affirming care that shifts away from binary language of gender and focuses on anatomy, conditions, and symptoms. Online educational support for staff, contractors, care teams, volunteers, and students include: "*Gender inclusive language for clinical setting*," "*Organizational assessment tool*," "*Service provider reflection tool*" and "*Gender-affirming care in a hospital setting*."
Wisdom 2 Action (W2A)[47]	Actions 1, 5, and 6	Offers tips sheet on trans inclusion: "*Avoiding harmful phrasing*," "*Building organizational capacity*," "*Communication commitment*," "*Gender neutral language*," "*Guide to pronouns*," "*Intake forms*," "*Key terms*," "*Privacy and confidentiality*," "*Social media & communication*," "*Trans inclusion for COVID*," and "*Welcoming environments*."
Sex, Identity, Gender, Expression (SIGE) intake form for diagnostic imaging departments[48]	Actions 2 and 6	The SIGE form provides questions radiation technologists need to ask *all* patients to ensure correct shielding of gonadal tissue from ionizing radiation and affirming care for SGM patients.
Rainbow Health Ontario, Sherbourne Health[49,50]	Action 3	Provides a 1-page brief on how organizations can make their DHS inclusive and 7 training modules on LGBTQIA+/2S health for healthcare and social service providers.
Sociodemographic data collection in primary care[51]	Action 3	Offers a proposed national standard for sociodemographic data collection in primary care, which was developed with communities. GSSO is part of the data set.
What and who is Two-Spirit?[17]	Actions 3 and 5	Provides terminology and culturally safe information practices for Two-Spirit people. Based on community feedback, it is recommended that the acronym LGBTQ/2S be used, as it signifies that Two-Spirit is different from Western perceptions of LGBTQ+ identities.
Alberta Health Services Diversity and Inclusion Centre of Expertise web site[52,53]	Actions 3, 4, and 6	Provides tools and information to help SGM patients navigate their journey and care providers increase their ability to provide culturally safe and sensitive care. Provides an example of a province-wide initiative in reviewing and addressing how GSSO information is collected on forms and in clinical information systems.
The Center for Gender & Sexual Diversity[54]	Action 6	Offers training and educational resources, and recommendations on creating inclusive language and settings for SGM communities. Examples include inclusive nomenclature for intersex, tick boxes for all sex markers, and a resource guide for changing gender markers on identification documents.

[a]The Equity-Oriented Health Care Intervention, known as EQUIP, is an organizational-level, multi-component health equity intervention designed to enhance the capacity of health organizations to provide care that is explicitly equity-oriented.

NEXT STEPS

Through the planning project we cocreated an action plan informed by evidence gathered through our reviews and guided by open discussions across diverse Canadian and international communities and expert organizations. Action-7 is to move the plan forward within Canada under the oversight of a central hub, an approach that is consistent with other standards development efforts by such groups as International Standards Organization (ISO) and HL7, done with working groups in an ad hoc fashion.[55] In the current knowledge-translation stage of our project, we are reaching out to different organizations to determine alternative avenues for consensus if a formal hub cannot be established.[56]

GSSO terminology requires further work. The GSSO concepts in the mind maps need further validation by subject matter experts and need to be expanded into data models, standard terminologies, code systems, and value sets for implementation. The anatomical inventory should be evaluated as a complement to surgical histories and hormonal inventories to determine its impact on care quality for all patients. The expansion of sexual orientation into 4 dimensions of sexual identity, attraction, behavior and partner(s) requires further

discussion of its feasibility and practicality. The GSSO terminology should be examined to determine if it is sufficiently robust to support all direct patient care activities and at the same time can be aggregated meaningfully to support secondary data use. Canada is bilingual and multicultural; the GSSO terminology needs to be in both English and French at a minimum. Cross maps are needed to ensure GSSO data can be shared between organizations without recoding.

There are also challenges in implementation logistics. Most existing DHS require updating to include new GSSO data fields and functions. Explicit policies on GSSO data collection, use, and protection are needed. Education is needed for staff and trainees, and patients need to be informed of the changes and rationale. As language evolves over time, a process is needed to maintain GSSO terminology to ensure it accurately reflects both the provenance and contemporary views of GSSO concepts. Sex-based clinical guidelines, such as preventive care and lab reference ranges, should be reviewed to ensure they are appropriate for SGM populations. Relevant quality metrics are needed to monitor the impacts over time and whether implementation of the proposed actions can lead to improved access, care, and outcomes for SGM individuals.

The creation of the action plan was an organic process that evolved during the project; there was no independent consensus process on the action items. Even though the action plan has gone through several iterations with participants, the overall feasibility and impact of this plan is not known at this time. The literature review and environmental scan were limited in scope and important and relevant publications and information sources could have been missed. The mind maps did not receive formal testing to ensure their accuracy and utility. While participants were recruited from across Canada and abroad, it was unclear if their views were representative of SGM individuals who are most affected. To fully gain this representation requires additional engagement strategies with SGM communities that extend beyond our public consultation sessions.

CONCLUSION

This project examined current GSSO information practices and issues, and proposed an implementation strategy as an action plan to cocreate an inclusive DHS for SGM people. The proposed actions are the beginning of a multi-year transformative journey to achieve a more equitable future for healthcare for Canadian SGM populations. Our project can inform current international efforts in creating inclusive GSSO language and data standards.

DATA STATEMENT

The data from the consultation sessions were in the form of deidentified summary notes.

The full action plan[38] and summary notes that are underlying this article can be found on the Infoway working group site.[42]

FUNDING

AUTHOR CONTRIBUTIONS

All authors gave approval of the submitted manuscript, and agreed to be accountable for ensuring the integrity of the manuscript. MA and FL drafted the manuscript, and all coauthors reviewed and revised it. MA created the tables and figure. FL, MA, AD, KD, and RQ were part of the initial CIHR planning grant that supported the development of the action plan. All authors are part of the next stage in dissemination of the action plan.

ACKNOWLEDGMENTS

CONFLICT OF INTEREST STATEMENT

None declared.

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