

An Action Plan to Modernize Gender, Sex, and Sexual Orientation Information Practices in Canadian Electronic Health Record Systems

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ABSTRACT

This brief report contains a summary version of the proposed action plan to modernize gender, sex, and sexual orientation (GSSO) information practices in Canadian electronic health record (EHR) systems. The plan was co-created by a research team with guidance from the Infoway Sex and Gender Working Group, organizations and communities involved with sexual and gender minorities (SGM), and those with lived and living experiences as SGM. The plan describes seven high level actions needed to improve the principles, approaches, policies, and processes of defining, collecting, organizing, sharing, and using GSSO information in EHRs.

Keywords: sex and gender, sexual orientation, information practices, electronic health records

RÉSUMÉ

Ce rapport sommaire contient un résumé du plan d'action proposé pour moderniser les pratiques de traitement des informations sur le genre, le sexe et l'orientation sexuelle (GSOS) dans les systèmes de dossiers médicaux électroniques (DME) canadiens. Le plan a été élaboré par une équipe de recherche, en collaboration avec le Groupe de travail sur le sexe et le genre d'Inforoute, des organismes et des communautés intervenant auprès des minorités sexuelles et de genre (MSG) et des personnes ayant vécu ou

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vivant une expérience de MSG. Le plan décrit sept mesures de haut niveau nécessaires pour améliorer les principes, les approches, les politiques et les processus de définition, de collecte, d'organisation, de partage et d'utilisation des informations sur le GSOS contenues dans les DME.

Mots clés : sexe et genre, orientation sexuelle, pratiques de traitement des informations, dossiers médicaux électroniques

Sexual and gender minorities (SGM) are among the most marginalized and underserved populations in Canada (Standing Committee on Health, 2019). There are major challenges SGM face in their access to health services that include historical stigmatization, structural/financial barriers, and the lack of health provider competence in caring for this population (Davison et al., 2021). Even if an individual is willing to reveal their gender, sex, and sexual orientation (GSSO) with a health provider, current electronic health records (EHRs) in most health organizations are unable to adequately collect, share, and track this information (Lau et al., 2020a). The lack of accurate and standardized GSSO information has made it difficult to understand the health needs and long-term health outcomes of the SGM populations (Lau et al., 2020b). This poses a structural challenge to population health and health services research aiming to advance equity for SGM as well as quality improvement and assessment efforts to advance their health and well-being.

For these reasons, a team of researchers, practitioners, advocates, and health organizations undertook a planning project in 2020 to create an action plan to improve the definition, collection, and use of GSSO data in Canadian EHR systems including their secondary uses. The team analyzed how GSSO concepts are defined in existing EHR systems and health data standard specifications, reviewed literature from the last five years on current and emerging GSSO documentation approaches and issues, hosted presentations from leaders in this area, conducted consultation sessions for guidance, and explored opportunities to align with other initiatives to arrive at an action plan to address these inequities.

In the action plan, the team reviews the work done to date, and proposes seven transformative actions to modernize the definition, collection, and use of GSSO data in Canadian EHR systems. The overall aim is to promote and strive towards health equity for SGM by supporting health professionals, policy leaders, and decisionmakers with the data and tools they need to provide inclusive, affirming, and equitable healthcare. The actions draw on the Equity-Oriented Health Care Intervention as the scientific base (Brown et al., 2018), and align closely with recommendations from recent SGM-related national and regional initiatives for context and guidance. They include the *Study of LGBTQIA2 Health* by the House of Commons Standing Committee on Health (Standing Committee on Health, 2019), *Calls to Action* by the Truth and Reconciliation Commission of Canada (Truth and Reconciliation Commission of Canada, 2015), and shift in *Sex- and Gender-Based Analysis* policies in health research advanced by the Canadian Institutes of Health Research (CIHR, 2019).

The Equity-Oriented Health Care Intervention, known as EQUIP, is designed to enhance the capacity of health organizations to be responsive to the diverse needs of populations affected by intersecting forms of social and health inequities (Brown et al., 2018). EQUIP uses staff education and practice facilitation to support practice and policy changes at the organizational level; it can be tailored to specific care contexts depending on local needs. In this action plan, the EQUIP intervention has been adapted and extended to

include EHR systems that are equity-oriented in design and use modernized GSSO information practices for SGM in different care contexts. The plan allows for different scope coverage, implementation options, and staged migration by health organizations depending on the overall fit of the plan with regional priorities, community and organizational readiness, and resource availability.

Proposed Actions

The list of proposed actions was guided by groups who are responsible for, involved with, or affected by modernized GSSO information practices in EHR systems. They represent diverse communities of Indigenous and SGM advocates, government agencies, health organizations, professional associations, healthcare providers, non-profit entities, researchers, and private industries. Seven transformative and interdependent actions are proposed as a high-level implementation strategy to improve the definition, collection, and use of GSSO data in Canadian EHR systems including their secondary uses.

In terms of priority, Action 1 provides the overall vision and goal for this plan. Actions 2–3 are the foundational activities that provide the bases for all other activities. Actions 4–6 are strategic activities that are dependent on local and regional priorities and readiness. Action 7 is the immediate step to move this action plan forward.

Vision and goal. Envisage an equity- and SGM-oriented health system that embraces diversity and aligns with other SGM-related initiatives. The ultimate goal is to have inclusive organizational policies, culturally competent staff, and enabling EHR systems with modernized GSSO information practices to help achieve equitable healthcare access, experiences, and outcomes for SGM.

Engagement and partnerships. Engage organizations and communities across Canada to modernize GSSO information practices in EHRs that support equity-oriented healthcare and meet SGM needs. Explore opportunities to partner with other agencies outside of the health system that also collect and use GSSO data to ensure consistency, leverage resources, optimize efforts, and maximize impact.

GSSO terminology. Establish a precise, inclusive, appropriate, evolving, and multi-level GSSO terminology with standardized data definitions, coding schemes, and value sets to support affirming patient care, provide complete and accurate health system use of data, and inform health research.

Enabling EHR systems. Adopt a common set of EHR functions that support the collection and use of standardized GSSO data, SGM-oriented clinical care guidelines (e.g., radiation shielding in imaging exams, lab reference ranges, reminders, and reports), clinical quality improvement, health system performance tracking, and health evidence generation.

GSSO policy/practice guidance. Integrate and tailor GSSO data collection and use including secondary uses within all organizational structures, policies, practices, governance, use cases, and workflow processes in order to be responsive to specific care needs of SGM.

Education and training. Educate and train healthcare staff to enhance their capacity to provide culturally competent and safe care, and ensure implementers, policymakers, and researchers have the required safeguards in place to protect these data. Inform patients about the need for GSSO data collection and protections for safe access and use.

Central hub for coordination. Establish a central hub to liaise, guide, assist, and monitor the progress of this action plan over time. To do so, the hub needs a pan-Canadian mandate, member commitment, consensus process, and proper resourcing.

This action plan can be adapted for different scope coverage, implementation options, and migration stages depending on its overall fit with an organization's regional priorities, organizational and community readiness, and resource availability. To determine overall fit, the suggested approach is to conduct an organizational readiness and needs assessment, which can identify the enablers and barriers present, some of which are at the structural and system level. Based on the findings, an organization can determine their scope coverage, implementation options, and migration stages as the path forward.

Concluding Remarks

This action plan is the beginning of a multi-year, dynamic, complex, and ongoing journey toward an SGM-inclusive health ecosystem. There is still a lot of work ahead, but this is a unique opportunity for health professionals, especially those in community mental health settings to help lead the way towards a more equitable future for all Canadians. Readers interested in this work can find more information on the Infoway Sex and Gender Working Group website (Infoway [a], n.d.). The summary and full reports and an infographic can be found under the Action Plan folder of the Infoway Sex and Gender Working Group website (Infoway [b], n.d.).

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