SUMMARY: A PROPOSED ACTION PLAN TO MODERNIZE GENDER, SEX AND SEXUAL ORIENTATION INFORMATION PRACTICES IN CANADIAN ELECTRONIC HEALTH RECORD SYSTEMS

Planning Project

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Canadian Institutes of Health Research (CIHR) Planning Project – Version 5.2, Dec 19, 2020

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On behalf of the Canada Health Infoway Sex and Gender Working Group members and groups and individuals who participated in the consultation sessions

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People who identify as sexual and gender minorities (SGM) in Canada experience numerous health inequities. Many health organizations lack inclusive policies for SGM, and health care staff often lack the knowledge and confidence to provide affirming and appropriate care. Most existing electronic health record (EHR) systems 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. There is no commonly agreed upon GSSO language or data standards, often making it necessary for health care staff to record GSSO data in an unreliable ad-hoc fashion in different parts of EHRs and paper charts. These factors have made SGM largely invisible in EHRs, and by extension, in the health system and in any data it provides. This is a major problem on many levels - little is known about people who are SGM, their health needs, which care settings they access, whether or not they receive appropriate care and their health care outcomes. What is known from the literature, largely based on primary research and not EHR data, is that SGM tend to have higher rates of mortality, chronic diseases, depression and suicide, and lower rates of health screening and preventive care. Many SGM experience discrimination and even violence. SGM are stigmatized, and avoid seeking care when they need it because they do not find the health system as safe, accepting, inclusive or affirming.

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 use. 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 consultations sessions for guidance, and explored opportunities to align with other initiatives to arrive at an action plan to address these inequities.

In this report, the team reviews the work done to date, and proposes 7 transformative actions to modernize the definition, collection and use of GSSO data in Canadian EHR systems. The overall aim of these actions is to promote and strive towards health equity for SGM by supporting health professionals, policy leaders and decision makers with the data and tools they need to provide inclusive, affirming and equitable health care. The actions draw on the Equity-Oriented Health Care Intervention as the scientific base, 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, the *Calls to Action* by the Truth and Reconciliation Commission of Canada, and the shift in *Sex- and Gender-Based Analysis* policies in health research advanced by the Canadian Institutes of Health Research (CIHR).

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. 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.

This action plan is the beginning of a multi-year, dynamic, complex and ongoing journey toward an equity- and SGM-oriented health system that is enabled by EHR systems and GSSO information practices to embrace diversity and inclusion for all people in Canada. The next step is to have a national conversation about this plan.

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, and represented diverse communities of Indigenous and SGM advocates, government agencies, health organizations, professional associations, health care providers, non-profit entities, researchers and private industries. Seven transformative and interdependent actions are proposed as the path forward to improve the definition, collection and use of GSSO data in Canadian EHR systems including their secondary use. This plan focuses on *what* actions are needed, with *consensus* on these actions and with details about *who, how, when* and *where* yet to be established as part of next steps.

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.

1. **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 health care access, experiences and outcomes for SGM. An alignment example is with the *LGBTQIA2 Health Report* from the House of Commons recommending that health inequities be reduced and health outcomes be enhanced with improved GSSO data collection and use to support decision-making.

2. **Engagement and Partnerships:** Engage organizations and communities across Canada to modernize GSSO information practices in EHRs that support equity-oriented health care and meet SGM needs. Representatives of these groups include SGM and Indigenous Two-Spirit communities, patients, advocates, executives, clinicians, staff, professional associations, government representatives, vendors, IT professionals, legal and privacy experts, researchers, educators and the public. 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.

3. **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.

4. **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, cancer screening, lab reference ranges, reminders, and reports), clinical quality improvement, data-driven analytics, health system performance tracking and health evidence generation.

5. **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.

6. **Education and Training:** Educate and train health care staff to enhance their capacity to provide culturally competent and safe care, and implementers, policy-makers and researchers to ensure required safeguards in place to protect these data. Inform patients on the need for GSSO data collection and protections for safe access and use.

7. **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. An immediate next step is to have a national conversation about this action plan and reach consensus on a path forward.

This action plan can be adapted for varying scope coverage, implementation options and staged migration by health organizations depending on the overall fit of the plan with regional priorities, and organizational and community readiness and resource availability. To determine overall fit, the suggested approach is to conduct a readiness/needs/sustainability assessment as a form of strengths-weaknesses-opportunities-threats (SWOT) analysis. The readiness/needs/sustainability assessment can help the organization 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.

For full version of the plan please visit: https://infocentral.infoway-inforoute.ca/en/collaboration/wg/sex-gender