A commentary on the action plan to modernize gender, sex and sexual orientation information practices in Canadian digital health systems

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Sexual and gender minorities (SGM) face numerous health inequities and challenges in Canada. Many are stigmatized, face discrimination and even violence when seeking care (Standing Committee on Health, 2019). Bauer et al. (2014) found in an Ontario survey that 21% of SGM avoided Emergency Department (ED) care because of perceived negative encounters with their identities, and 52% had negative ED experiences with their felt gender. One structural challenge is that most existing digital health systems are unable to capture gender, sex, and sexual orientation (GSSO) data beyond a single-sex or gender data field with male and female options (Lau, Antonio, Davison, Queen, & Bryski, 2020). In many health organizations, SGM-inclusive language, data standards and policies do not exist, making it often necessary for nurses and other healthcare staff to record GSSO data in an ad-hoc fashion in different parts of the electronic and paper charts (Lau et al., 2020). These factors have made SGM largely invisible in digital health systems. What we do know from the literature, based largely on primary research and not digital health system data, is that SGM populations have higher rates of premature mortality, chronic diseases, depression and suicide, and barriers to preventive health screening and care (Standing Committee on Health 2019; Abramovich et al., 2020).

The Infoway Sex and Gender Working Group was established in December 2019 and spent 12 months working with organizations and communities across Canada to address this challenge (Infoway, n.d. [a]). The result of this effort was the co-creation of a high-level action plan to modernize GSSO information practices in Canadian digital health systems (Infoway, n.d. [b]). The plan has seven transformative actions, as outlined below.

Action 1 - Vision and Goal: Envisage an equity- and SGM-oriented health ecosystem that embraces diversity and aligns with other SGM-related initiatives. The goal is to have inclusive organizational policies, culturally competent staff and enabling digital health systems with modernized GSSO information practices to help achieve equitable healthcare access, experiences and outcomes for SGM.

Action 2 - Engagement and Partnerships: Engage organizations and communities across Canada to modernize GSSO information practices in digital health systems that support equity-oriented healthcare and meet SGM needs. Explore opportunities to partner with agencies beyond health that collect and use GSSO data to ensure consistency, leverage resources, optimize efforts and maximize impact.

Action 3 - GSSO Terminology: Establish a precise, inclusive, appropriate and multi-level GSSO terminology with standardized data definitions, coding schemes, and value sets that support affirming patient care, provide complete and accurate health system use of data, including research. The terminology should be inclusive of all SGM identities and adaptable, as the GSSO language evolves over time.

Action 4 - Enabling Digital Health Systems: Adopt a common set of digital health functions that support the collection and use of standardized GSSO data, SGM-oriented clinical care guidelines, data-driven analytics, health system performance monitoring, and health evidence generation. There should be common

specifications on data fields, terminology, interfaces, security and privacy, data quality, decision support rules, outputs and technology support.

Action 5 - GSSO Policy/Practice Guidance: Integrate and tailor GSSO data collection and use, including secondary purposes within all organizational structures, policies, practices, governance, use cases and workflow processes in order to address specific SGM needs. Examples of policies include explicit guidance on why, what and when GSSO data should be collected, who should collect the data, and safeguards in place for the data, and privacy of the individuals asked to disclose the information.

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

Action 7 - Central Hub for Coordination: Establish a central hub to liaise, guide, assist and monitor the progress of this plan over time. Examples of hub activities include hosting seminars to share lessons and best practices, refining the GSSO terminology to reflect current trends, discussing GSSO documentation approaches and implications, and sharing relevant tools and resources.

This high-level action plan addresses what should be done, with details on who, how, when and where still to be elaborated. The plan can be adapted for different scope coverage, implementation options and migration stages depending on its overall fit with an organization's priorities, readiness, and capacity. Since ED is the main place of contact for those seeking emergency care, it is important to ensure all ED staff, especially nurses, can provide culturally competent, safe and affirmative care in ways that are supported by a welcoming environment that is inclusive and respects diversity. Readers interested in this work can contact the author for further detail.

Acknowledgement

Author notes

Dr. Francis Lau, PhD, FCAHS, CTSS, has a PhD in Applied Sciences in Medicine from the University of Alberta with specialization in medical informatics. During 2008–2013, he was the recipient of the eHealth Chair funded by CIHR/Infoway to establish an eHealth Observatory to examine the impact of health information system deployment in Canada. Dr. Lau's current research covers eHealth equity, patient-centred measurements, patient portals, evidence-based health informatics, and health terminology standards.

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