

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

Canadian Institutes of Health Research (CIHR) Planning Project – Version 6.0, January 07, 2021

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Or visit: <https://infocentral.infoway-inforoute.ca/en/collaboration/wg/sex-gender>

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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.

# LIST OF PROPOSED ACTIONS

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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.

## TERMS AND DEFINITIONS

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*Electronic Health Record (EHR) systems*, or digital health records, as used in this document, refer to information systems that contain collections of an individual's lifetime health history and care records in the health ecosystem. These records may reside in different places such as hospitals, nursing homes and doctors' offices (in Canada, patient records in doctors' offices are called electronic medical records, or EMRs). They also include such input sources as laboratory and pharmacy systems that collect these records, and administrative/clinical databases that house the extracted records for health system use reporting and research. Examples are the provincial client, laboratory, pharmacy and immunization repositories and pan-Canadian data holdings (e.g. Discharge Abstract Database) at the Canadian Institute for Health Information.

*Cultural Competency* is when behaviours, attitudes and policies come together across an organization, system, community and professionals that enable them to work, communicate and interact across cultural situations.<sup>1</sup>

*EQUIP-PHC* is the short name for Equipping Primary Health Care for Equity. It 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.<sup>2</sup>

*Gender, Sex and Sexual Orientation (GSSO)* data or information is a broad term that covers such concepts as sex assigned at birth, gender identity, sexual orientation, chosen/affirmed/social names and pronouns.

*GSSO definitions* refer to GSSO data standards with data names, descriptions, coding schemes and value options.

*GSSO information practices* refer to the principles, approaches, policies and processes of defining, collecting, organizing, sharing and using GSSO data.<sup>3</sup> The term GSSO documentation is also used to describe the process of recording GSSO data in the patient's EHR, as part of the health care encounter.

*LGBTQIA2S+* is the abbreviation for lesbian, gay, bisexual, trans, queer, intersex, asexual and Two-Spirit people, plus other sexual and gender minorities (SGM)<sup>4</sup>

*Secondary use* is the use of a person's health information for purposes other than the one for which it was originally collected. Examples of secondary use include clinical quality improvement, population health, health system performance and health research. The first three types of uses are also referred to as health system use.<sup>5</sup>

*Sexual and gender minorities (SGM)* is used to describe people whose gender identity or sexual orientation is not the same as the majority of people.<sup>2, p10</sup> This term includes LGBTQIA2S+.

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<sup>1</sup> Cross TL, Bazron BJ, Dennis KW, Isaacs MR. Towards a Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed. Washington, DC: CASSP Technical Assistance Center, Georgetown University Child Development Center [Internet]. 1989. Available from: <https://archive.org/details/towardsculturally00un/page/4/mode/2up>

<sup>2</sup> Browne AJ, Varcoe C, Ford-Gilboe M, Wathen CD, Smye V, Jackson BE, et al. Disruption as opportunity: Impacts of an organizational health equity intervention in primary care clinics. *International Journal for Equity in Health* 2018;17:154. From <https://equityhealth.biomedcentral.com/articles/10.1186/s12939-018-0820-2>

<sup>3</sup> Government of Canada. *Modernizing the Government of Canada's Sex and Gender Information Practices: Summary Report*. 2019-04-08. From <https://www.canada.ca/en/treasury-board-secretariat/corporate/reports/summary-modernizing-info-sex-gender.html#h-6>

<sup>4</sup> Standing Committee on Health. *The Health of LGBTQIA2 Communities in Canada – Report of the Standing Committee on Health*. House of Common, Canada. Jun 2019. Retrieved from <https://www.ourcommons.ca/DocumentViewer/en/42-1/HESA/report-28/>

<sup>5</sup> Canada Health Infoway and Canadian Institute for Health Information. *Better Information for Improved Health: A Vision for Health System Use of Data in Canada (executive summary)*. June 2013. Available at <https://www.infoway-inforoute.ca/en/component/edocman/resources/technical-documents/health-analytics/1689-a-vision-for-health-system-use-of-data-in-canada-executive-summary?Itemid=101>

## PURPOSE AND SCOPE

This action plan is the output of a 1-year planning project funded by the CIHR Institute of Gender and Health.<sup>6</sup> The purpose of the planning project was to establish a coalition of communities and organizations across Canada to co-create an action plan to modernize gender, sex and sexual orientation (GSSO) information practices in electronic health record (EHR) systems in Canada.

The project scope covers GSSO information practices, which include the principles, approaches, policies and processes of defining, collecting, organizing, sharing and using GSSO data in EHR systems.

This project responds to the Canadian government's call to modernize GSSO information practices. In the recent House of Commons Report on the health of sexual and gender minorities (SGM), Canada has recognized "... *the LGBTQIA2+ communities in Canada experience numerous health inequities ... data collection [should] be improved in order to obtain a more complete picture of the health of gender and sexual minorities in Canada.*"<sup>7</sup>

## PLANNING PROCESS

In 2020, a team of advocates, researchers, practitioners and partner organizations undertook a planning project to examine this issue and explore ways to improve the definition, collection and use of GSSO data in the Canadian EHR systems. See [Appendix A](#) for list of participants.<sup>8</sup> The team undertook the following:

- (a) Conducted an environmental scan of publicly available information sources to determine how GSSO are defined in existing EHR systems and specified in health data standards
- (b) Reviewed academic and grey literature published in the last five years on current and emerging GSSO documentation approaches and issues
- (c) Invited presentations from leaders in this area to share their work and experience
- (d) Conducted broad engagement via monthly consultation sessions to invite expert input and guidance on ways to modernize GSSO documentation within a Canadian context
- (e) Explored alignment opportunities with related policy, practice and research initiatives that are recently completed, being planned or underway across Canada as the path forward
- (f) Explored the GSSO concepts and their relationships through a mind mapping exercise.

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<sup>6</sup> CIHR. Planning and Dissemination Grants: Sponsor Description: CIHR – Institute of Gender and Health. Summary/Relevance. Aug 7, 2019. From <https://www.researchnet-recherchenet.ca/rnr16/vwOpprtntyDtls.do?prog=3138&view=currentOpps&type=EXACT&resultCount=25&sort=program&next=1&all=1&masterList=true#partnerdescription>

<sup>7</sup> Standing Committee on Health. *The Health of LGBTQIA2 Communities in Canada – Report of the Standing Committee on Health*. House of Common, Canada. Jun 2019. Retrieved from <https://www.ourcommons.ca/DocumentViewer/en/42-1/HESA/report-28/>

<sup>8</sup> Canada Health Infoway, *Sex and Gender Working Group*. n.d. From <https://infocentral.infoway-inforoute.ca/en/collaboration/wg/sex-gender>



## ACKNOWLEDGMENTS

The project team acknowledges the deeply entrenched discrimination in the health system of SGM people in Canada, especially those who also identify as Indigenous.

There is historical and ongoing stigma, discrimination, and bigotry that is based on gender, sex, and sexual orientation. The dominant Western, settler/colonial framework that enforces a binary understanding of sex and gender that erases diverse identities such as transgender, nonbinary, intersex and Two-Spirit identities. Homophobic and transphobic attitudes, beliefs, and actions still persist today within the health system and act as a barrier to achieving equity for Canadians who are not heterosexual or cisgender.

The team also acknowledges the colonial implications of GSSO information practices, and seek to address them by creating space within health information systems for Indigenous SGM identities. This work honours the Truth and Reconciliation Commission Calls to Action 18-24, and Missing and Murdered Indigenous Women and Girls Calls for Justice 1.1, 7.4, and 17.8.

It is within this context that this work takes place. While attempting to right these wrongs against SGM, team members recognize they are still actors in this larger context and as a result, might hold biased attitudes and beliefs within us consciously or subconsciously. This work is part of a larger movement in Canada to address the myriad of marginalizing conditions experienced by SGM, and serves as a step on a long journey towards health equity for all people in Canada.

In recognizing the commitment by everyone during a time when many of the resources are stretched due to COVID-19, the project team is deeply grateful to the members of the Infoway Sex and Gender Working Group and organizations and groups who have generously contributed their time and effort toward the development of this action plan. In particular, the team recognizes the contributions of Kinsey Beck, Annette Browne, Mary Byrnes, Annalijn Conklin, Amédé Gogovor, Lorraine Grieves, Geoff Hynes, Janine Kaye, Karen Luyendyk, Lindsay MacNeil, Shannon O'Connor, Sanya Palli, Erin Pichora, Mel Thompson and Colleen Varcoe who have provided written feedback on earlier versions of the draft action plan.

The current landscape on SGM needs and GSSO documentation approaches is summarized below. Further detail can be found in [Appendix B](#).

A major issue in existing EHR systems is the conflated use of sex and gender as a single binary concept to define sex and gender identity. This can create confusion when a person's biology of being a female or male along a spectrum is different from their gender identity as a woman/girl, man/boy, neither, both or something else. Other challenges with GSSO data in existing EHR systems include:<sup>9</sup>

- Inconsistency in the data names and value options used to represent sex and gender concepts in EHR systems. For instance, sex, administrative sex and patient's sex are all data names that refer to a person's biology, but different options are used including indeterminate, intersex and undifferentiated when one's sex is not female or male.
- Limited value options available for selection which perpetuate inequities faced by SGM by making them invisible in health data sets. At the same time, expanded definitions from leading organizations and international standards communities such as transgender and nonbinary gender have raised implementation challenges in how one should migrate these definitions into existing EHR systems.

Based on rapid reviews of published literature and the consultation sessions, key themes were identified on ways to modernize GSSO information practices in EHR systems.<sup>10 11</sup> These themes are summarized as follows:

- Create an inclusive, culturally competent environment with precise GSSO terminology, and standardized data collection policies with clear rationale for why the data are needed, who should collect them, when and how they should be collected, and safeguards in place for collecting, accessing and using the data
- Refine guidelines for identifying and matching SGM patients with their care needs, such as proper use of one's name and pronouns at registration, and SGM-based rules for clinical tests and lab reference ranges (e.g. pregnancy tests, testosterone levels).
- Use anatomical inventories as an objective catalogue of anatomic parts to remove sex and gender assumptions for all patients
- Improve patient-provider relationships by addressing patient rights and provider competencies. SGM patients welcome being asked to disclose their identities when provided with safe and inclusive care. Health care staff want guidance on how to communicate with SGM patients and document their GSSO data in EHRs
- Address invisibility of SGM in health data by standardizing GSSO data to guide care, support secondary use, and expand the evidence base on SGM health
- Recognize techno-socio-organizational aspects when implementing GSSO in EHRs, through flexible EHR designs to enable affirmation at data entry/output levels, and addressing socio-organizational aspects to ensure an inclusive environment with explicit policies and culturally competent staff

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<sup>9</sup> Lau F, Antonio M, Davison K, Queen R, Bryski K. *An environmental Scan of sex and gender in electronic health records: Analysis of public information sources*. *Journal of Medical Internet Research* 2020; 22(11): November. From <https://www.jmir.org/2020/11/e20050/>

<sup>10</sup> Lau F, Antonio M, Davison K, Queen R, Devor A. A rapid review of gender, sex and sexual orientation documentation in electronic health records. *Journal of American Medical Information Association* Sep 16, 2020; <https://academic.oup.com/jamia/advance-article/doi/10.1093/jamia/ocaa158/5906099>

<sup>11</sup> Davison K, Queen R, Lau F, Antonio M. *A Rapid Review of Grey Literature About Gender, Sex and Sexual Orientation Information Practices in Electronic Health Records*. Manuscript in preparation, unpublished

# EQUITY AND SGM-ORIENTED HEALTH CARE

This action plan has incorporated an equity-oriented health care intervention as an overarching approach to guide modernizing GSSO information practices in Canadian EHR systems for SGM. The equity-oriented health care intervention was developed as part of the EQUIP research program and has been designed to be used across different healthcare settings (<https://equiphealthcare.ca>).

EQUIP-PHC is the short name for *Equipping Primary Health Care for Equity*.<sup>12</sup> It is an organizational-level, multicomponent health equity intervention designed to enhance the capacity of health organizations to provide care that is explicitly equity oriented. The EQUIP intervention has 3 key dimensions that can be tailored to context and 10 strategies to guide organizations in enhancing capacity for equity-oriented health services. The 3 dimensions are trauma- and violence-informed care, culturally safe care, and harm reduction. The 10 EQUIP strategies are listed in [Figure 1](#). The EQUIP intervention involves 2 main approaches of staff education and integration discussions, and a process of organizational integration and tailoring.

<ul style="list-style-type: none"> <li>• Explicitly commit to equity</li> <li>• Develop supportive organizational structures, policies, and processes</li> <li>• Re-vision the use of time</li> <li>• Attend to power differentials</li> <li>• Tailor care, programs and services to local contexts</li> </ul>	<ul style="list-style-type: none"> <li>• Actively counter racism and discrimination</li> <li>• Promote meaningful community and patient engagement</li> <li>• Tailor care to address interrelated forms of violence</li> <li>• Enhance access to the social determinants of health</li> <li>• Optimize use of place and space</li> </ul>
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Figure 1. 10 EQUIP Strategies to Enhance Organizational Capacity for Equity-Oriented Services

This action plan has adapted and extended the EQUIP-PHC intervention to embrace SGM explicitly as the focus, applying staff education, organizational integration and enabling EHR systems as the 3 approaches to tailor the proposed actions to specific contexts. This adaptation of EQUIP-PHC, called *Equity- and SGM-Oriented Health Care Intervention*, is shown in [Figure 2](#). The 7 transformative actions are described in the next section. Note that the experiences and outcomes listed in the figure are only examples to show the different categories of quality measures that may be included to evaluate the impact of this intervention.

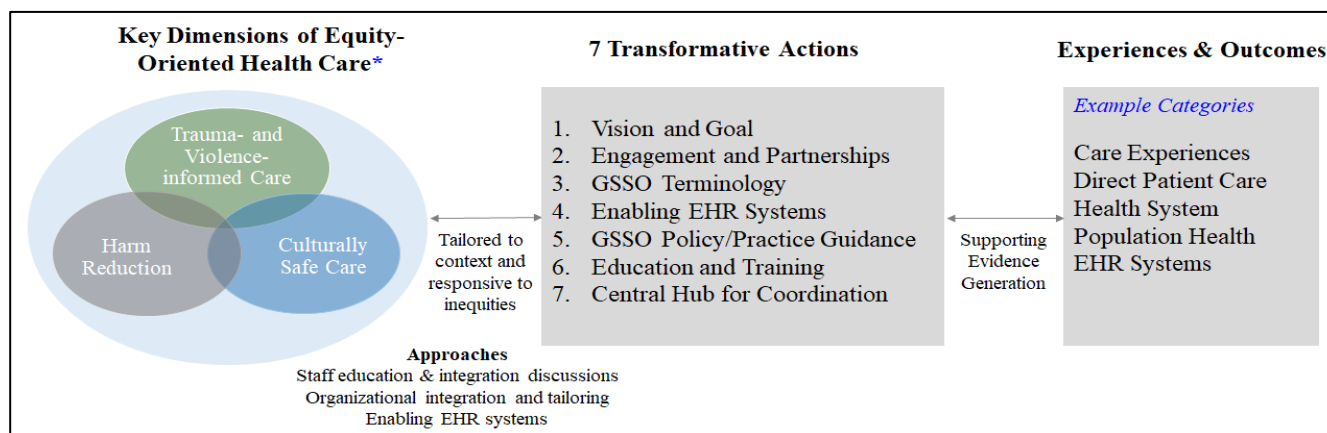


Figure 2. Equity- and SGM-Oriented Health Care Intervention

<sup>12</sup> Browne AJ, Varcoe C, Ford-Gilboe M, Wathen CD, Smye V, Jackson BE, et al. Disruption as opportunity: Impacts of an organizational health equity intervention in primary care clinics. *International Journal for Equity in Health* 2018;17:154. From <https://equityhealthj.biomedcentral.com/articles/10.1186/s12939-018-0820-2>

# MODERNIZING GSSO IN EHRs

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This section describes the 7 transformative and independent actions to modernize GSSO information practices in Canada's EHR systems. These actions are based on guidance from representatives of Indigenous organizations, diverse communities of SGM advocates, government agencies, and health organizations,

In terms of priority, Action 1 provides the overall vision and goal for this plan. Actions 2-3 are 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 steps to move this action plan forward.

Note that this plan focuses on *what* actions are needed, with *consensus* on these actions and details about *who*, *how*, *when* and *where* are yet to be discussed and established as part of the next steps.

## ACTION 1 – VISION AND GOAL

To provide focus, the action plan needs an overarching vision of health equity where SGM “*have a fair chance to reach their full potential and are not disadvantaged by social, economic and environmental conditions.*”<sup>13</sup> Achieving health equity for SGM requires changing the marginalizing conditions that create systematic barriers to accessing quality care and improving health care outcomes within the health system. One such change is to increase the visibility of SGM within the health system by incorporating GSSO data into EHR systems in order to better understand their health conditions, service use, care needs and overall experiences. This vision may be:

To envisage an equity- and SGM-oriented health system that embraces diversity with inclusive organizational policies, culturally competent staff and enabling electronic health record systems to reduce barriers, and improve access, care and outcomes for sexual and gender minorities

Where feasible, this vision should be aligned with and build on relevant initiatives that are aimed at reducing structural inequities and improving the overall health of a community or a region. Examples include:

- **House of Commons Standing Committee on Health's Report on the Health of LGBQTQIA2 Communities in Canada.**<sup>14</sup> Of particular relevance are recommendations (#2) on developing information tools in both official languages and other languages as requested; (#5) on establishing a working group to identify ways to promote education and training of health professionals on health needs of SGM; (#6) on establishing best practices for collecting gender information and identifying nonbinary people; (#7) on developing and including questions on sexual behaviour and sexual attraction in national surveys; and (#9) on including questions on sex at birth, gender identity and sexual orientation in all national surveys.
- **Truth and Reconciliation Commission of Canada's Calls to Action.**<sup>15</sup> In the area of health, two actions are notable: (a) to acknowledge that the current state of Aboriginal (i.e., Indigenous) health in Canada is a direct result of previous Canadian government policies, including residential schools, and to recognize and implement the health care rights of Aboriginal people as identified in international and Constitutional laws, and under the Treaties, and (b) to call for all medical and nursing schools to require

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<sup>13</sup> National Collaboration Centre for Determinants of Health. *Glossary – Health Equity*. From <https://nccdh.ca/index.php?/resources/glossary/>

<sup>14</sup> Standing Committee on Health. *The Health of LGBQTQIA2 Communities in Canada – Report of the Standing Committee on Health*. House of Common, Canada. Jun 2019. Retrieved from <https://www.ourcommons.ca/DocumentViewer/en/42-1/HESA/report-28/>

<sup>15</sup> Truth and Reconciliation Commission of Canada: *Calls to Action*, 2015. From [http://trc.ca/assets/pdf/Calls\\_to\\_Action\\_English2.pdf](http://trc.ca/assets/pdf/Calls_to_Action_English2.pdf)

their students to take a course on Aboriginal health issues and to provide skills-based training as a basis for practice that supports intercultural competency, conflict resolutions, human rights and anti-racism.

- **National Inquiry into Missing and Murdered Indigenous Women and Girls.**<sup>16</sup> Final Report on Reclaiming Power and Place -Calls for Justice.
- **Canadian Human Rights Act:**<sup>17</sup> the Act protects people in Canada from discrimination or harassment based on race, age, gender identity, gender expression or sexual orientation.
- **Statistics Canada’s consultation work on sex and gender for the 2021 census.**<sup>18</sup> This led to (a) suggested collection of sex at birth and gender data in census questionnaire, (b) release of new standards on sex and gender, and (c) expanded gender identity concepts for the national statistical system<sup>19</sup>
- **CIHI Reference Data Model (CRDM) Toolkit.**<sup>20</sup> This Canadian Institute for Health Information (CIHI) sex at birth and gender data standards was informed by the CIHI Defining Equity Stratifiers report.<sup>21</sup> CIHI continues to monitor evolving evidence and research initiatives (including this CIHR planning project) and may update these standards as needed to align with best practices. To implement new data standards, such as the sex and gender data standards described in the CRDM, CIHI works in collaboration with the jurisdictions to make changes to existing and new CIHI data holdings.<sup>22</sup>
- **Canadian Institutes of Health Research’s action plan on sex- and gender-based analysis (SGBA).**<sup>23</sup> This is to integrate SGBA policies systematically into CIHR-funded research to ensure the research is relevant and impactful for Canada’s diverse population.
- **Health Quality Ontario’s Health Equity Plan.** Specifically the strategic priorities (#2) to increase availability of information to enable better decisions to achieve health equity locally and provincially, (#3) to evaluate and support the uptake of promising innovations and practices to improve health equity in Ontario, and (#4) to engage patients, caregivers and the public in the efforts to address health equity.<sup>24</sup>

Tangible activities from Action 1 may include reaching out to specific initiatives to seek their endorsement of this action plan. Tangible deliverables may be the inclusion of specific action plan outputs such as the GSSO terminology within ongoing work and public reports by these initiatives.

## ACTION 2 – ENGAGEMENT AND PARTNERSHIPS

Health organizations wishing to adopt equity- and SGM-oriented health care will need to engage and collaborate with different groups to co-create an inclusive environment with culturally competent staff and enabling EHR systems for SGM. Examples of these groups are 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. Typical approaches may involve forming a SGM task force or advisory group as an initial step, and creating a vision that reflects community and

<sup>16</sup> National Inquiry into Missing and Murdered Indigenous Women and Girls. Reclaiming Power and Place, Final Report -Calls for Justice. From [https://www.mmiwg-ffada.ca/wp-content/uploads/2019/06/Calls\\_for\\_Justice.pdf](https://www.mmiwg-ffada.ca/wp-content/uploads/2019/06/Calls_for_Justice.pdf)

<sup>17</sup> Canadian Human Rights Commission. *Human Rights in Canada*. From <https://www.chrc-ccdp.gc.ca/eng/content/human-rights-in-canada#:~:text=People%20can%20turn%20to%20the,is%20part%20of%20Canada's%20Constitution>

<sup>18</sup> Statistics Canada. *Sex and Gender*. From <https://www12.statcan.gc.ca/census-recensement/2021/road2021-chemin2021/fs-fi/sex-and-gender.cfm>

<sup>19</sup> Statistics Canada. *Preparing Gender Identity for the National Statistical System*, May 2018. From [http://www.asi-jea.ca/en/files/2018/09/Placemat\\_gender\\_ID\\_May12.pdf](http://www.asi-jea.ca/en/files/2018/09/Placemat_gender_ID_May12.pdf)

<sup>20</sup> Canadian Institute for Health Information. *CIHI Reference Data Model Toolkit*. 2019. From <https://www.cihi.ca/sites/default/files/document/cihi-reference-data-model-toolkit-en.pdf>

<sup>21</sup> Canadian Institute for Health Information. *In Pursuit of Health Equity: Defining Stratifiers for Measuring Health Inequality*, April 2018. From <https://www.cihi.ca/sites/default/files/document/defining-stratifiers-measuring-health-inequalities-2018-en-web.pdf>

<sup>22</sup> Also see sex, gender and other demographic data captured in CIHI and Statistics Canada data holdings, in Canadian Institute for Health Information Equity Stratifier Inventory. From <https://www.cihi.ca/sites/default/files/document/cphi-toolkit-equity-stratifier-inventory-en-web.xlsx>

<sup>23</sup> Canadian Institutes of Health Research. *Sex, Gender and Health Research*, 2019. From <https://cihr-irsc.gc.ca/e/50833.html>

<sup>24</sup> Health Quality Ontario. *Health Equity Plan*. From [http://www.hqontario.ca/Portals/0/documents/health-quality/Health\\_Equity\\_Plan\\_Report\\_En.pdf](http://www.hqontario.ca/Portals/0/documents/health-quality/Health_Equity_Plan_Report_En.pdf)

organizational priorities, developing an evidence-informed plan to guide the work and collaborate with those who are involved or affected to carry out the plan.

This work will involve consulting with SGM communities across Canada to determine the best way to ensure their voices are heard throughout all processes. There are reports of successful planning and implementation of GSSO in EHRs where organizations work closely with communities and organizations to co-create the vision and turn it into concrete actions. One example is the planning work underway on sex and gender data collection in EHRs by the Ministry of Health and Trans Care BC in British Columbia. They have done extensive consultations with SGM communities, advocacy groups, health authorities, professional associations, legal experts, care providers, researchers and other government agencies to seek guidance, reach consensus on GSSO definitions and data collection policies, and ensure alignment with related initiatives such as the recent introduction of X gender designation on BC identity documents for individuals who do not identify as male or female.<sup>25 26</sup>

Another example is Alberta Health Services (AHS), which has committed to partner with the SGM community to create an inclusive environment where everyone feels safe, welcome and included. Engagement efforts include the creation of a provincial advisory council to advise AHS health services for SGM, a provincial diversity and inclusion plan for AHS staff, patients and families, a website dedicated to promoting sexual and gender diversity, and a Diversity and Inclusion Centre of Expertise focused on creating educational resources and materials that promote a safer and more inclusive environment for everyone who interacts with AHS.<sup>27 28</sup>

Other examples include pending investments into Two-Spirit LGBTQ2 communities, leveraging groups such as 2 Spirits in Motion Foundation and Enchante<sup>29</sup> and keeping an eye on new national initiatives to amplify effort. During the consultation sessions, the need to extend this work to include federal health systems such as the Canadian Forces and Correctional Services, and government agencies responsible for client registries and identities such as birth certificates, passports and driver's licenses was also expressed. There is motivation to partner with these entities and those in non-health sectors to harmonize GSSO information practices in their information systems, since the same people and their data can move between these systems over time.

Possible partnership activities may involve inviting these entities to be part of the Infoway Sex and Gender Working Group to: (a) present their current information systems and GSSO documentation approaches at the monthly working group meetings, (b) provide further input to refine the action plan, (c) co-develop the GSSO terminology and best practices in GSSO documentation, (d) co-create and share SGM education resources and tools, and (e) sharing of GSSO implementation experiences and lessons.

Tangible activities from Action 2 include ongoing efforts to engage communities and organizations in specific activities and exploring partnership opportunities with other entities that are involved with, affected by or interested in GSSO data collection and use in EHRs. Tangible deliverables may include the creation of multidisciplinary task forces, alliances and networks to jointly take on the GSSO modernization work.

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<sup>25</sup> BC Government News. 'X' gender identity now recognized on government ID, Nov 2018. From <https://news.gov.bc.ca/releases/2018HLTH0079-002116>

<sup>26</sup> Clark B, MacNeil L. Collection of Sex and Gender Data in EHRs: A Clinical Use Case Approach, May 12, 2020. From <https://infocentral.infoway.inforoute.ca/en/resources/docs/sex-gender/sex-gender-presentations/3310-sex-and-gender-may-12-presentation-trans-care-bc-beth-clark-and-lindsay-macneil>

<sup>27</sup> Priestley M. What AHS is doing to create safe and inclusive environments. CARE – Summer 2019. College of Licensed Practical Nurses of Alberta. From [https://issuu.com/clpna/docs/care\\_magazine\\_summer\\_2019/s/124524](https://issuu.com/clpna/docs/care_magazine_summer_2019/s/124524)

<sup>28</sup> Alberta Health Services. LGBTQ2S+ / Sexual and Gender Diversity. From <https://www.albertahealthservices.ca/info/Page15590.aspx>

<sup>29</sup> Women and Gender Equity Canada. Government of Canada Invests in LGBTQ2 communities in Western Canada. From <https://www.canada.ca/en/status-women/news/2019/08/government-of-canada-invests-in-lgbtq2-communities-in-western-canada.html>



## ACTION 3 – GSSO TERMINOLOGY

SGM-competent GSSO information practices are rooted in the language and terminology used by health care staff to communicate with, for and about SGM across the health system continuum. A common understanding and appropriate use of precisely defined GSSO concepts is required to deliver SGM-competent and safe care. This action is to establish a precise, appropriate, inclusive, evolving, and multi-level GSSO terminology with standardized data definitions, coding schemes and value options that will support affirming patient care, health system use of data and health research. The GSSO terminology should be precise and appropriate to ensure the consistent and correct use of the language.<sup>30</sup> The terminology needs to be inclusive of all SGM identities and adaptable as the GSSO language evolves over time. In particular, the terminology needs to support a full range of self-reported SGM identities to facilitate communication with health professionals during direct patient care encounters. At the same time, the terminology should allow for the aggregation of these self-reported identities into a smaller standardized set of GSSO value options that can support health system and research use.

A modernized GSSO terminology also requires an openness to explore alternative ways of defining GSSO concepts and their relationships to allow the full expression of related terms that have the same or similar meaning without ambiguity. Many existing EHRs in Canada have a single sex or gender data field as part of the patient's demographic data with restricted sets of coded values for female, male and unknown/other based on some local or regional (e.g., Health Level Seven (HL7)) coding schemes.<sup>31</sup> Recent health data standard specifications<sup>32</sup> have introduced separate sex and gender fields with expanded value options through the terminology standards LOINC<sup>33</sup> and SNOMED CT.<sup>34</sup> Some hold the view that expanded GSSO data should only be collected when needed by those who provide care, and documentation of sexual orientation should be part of the clinical observations in the EHR. These are all outstanding issues that require further dialogue to reach consensus, since the intended use of the GSSO terminology can affect how this data standard is defined. A proposed GSSO terminology to support direct patient care, health system and secondary use is in [Appendix C](#).

Tangible activities from Action 3 include reaching consensus on what GSSO data to collect and how they should be defined, and establishing a GSSO terminology standard with specific data elements, coding schemes and value sets that can be implemented in EHR systems. Tangible deliverables may include a GSSO terminology standard specification that has gone through a formal consensus process and is ready for adoption.

## ACTION 4 – ENABLING EHR SYSTEMS

The practice of culturally competent and safe care requires a flexible EHR system that can be tailored to address local GSSO documentation and reporting needs. The system can be an in-house or commercial application, designed for federal agencies (e.g., correctional facilities) or different care settings (e.g. primary and residential care). Enabling EHR systems are expected to share a number of common characteristics. Typically, these are in the areas of data fields, terminology, interfaces, security and privacy, data quality, decision support rules, outputs and information technology (IT) support. These features are briefly described as follows:

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<sup>30</sup> Madsen TE, Bourjeily G, Hasnain M, Jenkins M, Morrison MF, et al. Sex and gender-based medicine: the need for precise terminology. *Gender and the Genome* 2017; 1(3):122-8. From <https://journals.sagepub.com/doi/pdf/10.1089/gg.2017.0005>

<sup>31</sup> Lau F, Antonio M, Davison K, Queen R, Bryski K. *An Environmental Scan of Sex and Gender in Electronic Health Records*. *Journal of Medical Internet Research* 2020; 22(11): November. From <https://www.jmir.org/2020/11/e20050/>

<sup>32</sup> Office of the National Coordinator for Health Information Technology. 2020 Interoperability Standard Advisory. Section I: Vocabulary/Code Set/Terminology Standards and Implementation Specification – Sex at Birth, Sexual Orientation and Gender Identity. From <https://www.healthit.gov/isa/section-i-vocabularycode-set-terminology-standards-and-implementation-specifications>

<sup>33</sup> LOINC - Logical Observations Identifiers, Names and Codes. Regenstrief Institute. From <https://loinc.org/>

<sup>34</sup> SNOMED International. From <http://www.snomed.org/>

- **Data fields** – There is no mandate in Canada on what GSSO data should be collected beyond the current single sex or gender data field. Discussions from the Infoway Sex-Gender Working Group and consultation sessions suggested the need for gender identity, sex assigned at birth, anatomical inventory and sexual orientation, but only when the information is relevant to the care being sought.<sup>35</sup> In addition, name used and pronouns should be prominently displayed, and we should move away from the language of *preferred* as this may suggest that these are optional<sup>36</sup>. Another need is in health system performance and population level reporting with a smaller standardized value set options to identify health inequities for SGM (e.g. man, woman, transgender, nonbinary). There was also discussion to include an anatomic inventory to document the status of reproductive organs for all patients, rather than making assumptions of one’s sex based on sex assigned at birth. Anatomic inventory can also be useful for non-SGM patients who have undergone procedures like mastectomy of not having to repeatedly mention these procedures when seeking care which could be traumatic for them. Further discussion is needed.
- **Terminology** – Existing value sets for the sex or gender data field are limited to male, female, unknown and indeterminate options. There are emerging standards from HL7, LOINC and SNOMED CT with additional value options for gender identity,<sup>37</sup> sex assigned at birth<sup>38</sup> and sexual orientation.<sup>39</sup> However, their value options are incomplete and somewhat outdated due to the rapidly changing GSSO language and terms used to describe SGM. In addition, there are few examples of anatomic inventory and how organ variations should be tracked. See [Appendix C](#) for the proposed GSSO terminology in this plan.
- **Interfaces** – There is no user interface standard in place to guide the design of data entry and display screens containing GSSO data. The experiences from AHS<sup>40</sup> and the Fenway Institute<sup>41</sup> are to have prominent displays of names and pronouns used for proper identification (e.g. big fonts, bright color codes). Response options should allow for multiple coded values, including ‘chose not to disclose,’ ‘unknown’ and free-text write-in options for such fields as gender identity.
- **Security and privacy** – GSSO data are highly sensitive and personal. Therefore, strict safeguards must be in place to ensure one’s privacy is respected when GSSO data are being collected, and once collected the data are secure and protected from unauthorized access. This is especially important for free-text fields which could contain sensitive, identifying information such as names and identifiers. Safeguards can build on existing policies that most organizations already have to ensure the security, privacy and confidentiality of highly sensitive personal and aggregated data in the EHRs and clinical/administrative data repositories and for the person who provided the data.
- **Data quality** – There should be a data quality assurance process as part of governance to ensure the integrity of GSSO data in the EHR. Given the evolving nature of the GSSO language, it is important to track the consistency, usage and trends of GSSO terms over time (e.g., through mapping to show the evolution of terms). There should be periodic extraction and analysis of all free-text write-in entries for such fields as gender identity to ensure the GSSO terminology is current and updated as needed to reflect the evolving GSSO language used.

<sup>35</sup> Infoway Sex-Gender Working Group. Consultation Session 2 May 26, 2020. From <https://infocentral.infoway-inforoute.ca/en/resources/docs/sex-gender/sgwg-planning-project/3318-consultation-session-2-may-26-2020>

<sup>36</sup> Ibid.

<sup>37</sup> Office of National Coordinator for HIT. Interoperability Standards Advisory, 2020. Representing Patient Gender Identity. From <https://www.healthit.gov/isa/representing-patient-gender-identity>

<sup>38</sup> Office of National Coordinator for HIT. Interoperability Standards Advisory, 2020. Representing Patient Sex (At Birth). From <https://www.healthit.gov/isa/representing-patient-sex-birth>

<sup>39</sup> Office of National Coordinator for HIT. Interoperability Standards Advisory, 2020. Representing Patient-Identified Sexual Orientation. From <https://www.healthit.gov/isa/representing-patient-identified-sexual-orientation>

<sup>40</sup> Panas M. *Inclusive EHRs in Action: AHS, SOGIE Tools and Full Patient Experience in Connect Care*, Jul 14, 2020. Unpublished presentation.

<sup>41</sup> Keroghlian A, Grasso C. *Collecting Sexual Orientation and Gender Identity Data in EHRs*. Jun 9, 2020. From <https://infocentral.infoway-inforoute.ca/en/resources/docs/sex-gender/sex-gender-presentations/3339-sex-and-gender-june-9-presentation-fenway-health-alex-keroghlian-and-chris-grasso>



- **Decision support rules** – Some clinical and administrative guidelines are based on biological sex that default to sex assigned at birth recorded in the EHR. This can be an issue when patients update their sex/gender data field to indicate their current gender.<sup>42</sup> Current examples are prostate cancer screening for male, protective shielding in imaging exams based on sex, lab tests reference ranges based on sex, and pregnancy test billing for female.<sup>43</sup> These guidelines should be reviewed and updated to reflect one’s current sex status, preferably based on an up-to-date anatomical inventory that shows what sex organs the person has such as testes, penis, ovaries and breasts, rather than using terms of male and female.<sup>44</sup> Some literature has reported the use of decision rules to derive one’s gender identity for the purpose of statistical analysis based on their sex assigned at birth and current gender. For example, gender identity may be derived as follows: IF sex=female AND gender=male, THEN gender identity= transgender, ELSE gender identity=cisgender.<sup>45</sup> Organizations wishing to adopt such practice needs to ensure this rule-based labeling is done only with de-identified data in order to protect individual’s privacy.
- **Outputs** – There is no standard in place to guide the design of outputs containing GSSO data such as patient lists, specimen labels, wristbands, correspondences and clinical reports. As with screen displays involving GSSO data, there should be prominent printed texts showing patient’s name used and pronouns, and gender identity if appropriate. Where legal names are required to identify patients as in billing and blood transfusion, they should be printed alongside in clearly marked but smaller fonts.<sup>46 47</sup>
- **IT Support** - Well-managed IT support is needed to ensure the initiation, development, deployment and ongoing maintenance of modernized GSSO information practices adhere to industry standards. Small-scale pilots and spin-off projects should be encouraged to gain experience, share lessons and build capacities on innovative approaches and best practices. Successful examples of SGM-oriented enabling EHR implementations that can guide future efforts include the Alberta Health Services,<sup>48</sup> Rainbow Health Ontario,<sup>49</sup> Fenway Institute,<sup>50</sup> and the University of California Davis Health System.<sup>51</sup>

An enabling EHR system can also help advance SGM research through integration with existing national health database holdings, EHR/data-driven analytics and quality improvement approaches, SGM-oriented quality metrics, and sex- and gender-based analysis, and SGM-oriented informatics capacity building. The rationale for these suggested areas are as follows:

<sup>42</sup> Goldstein Z, Corneil TA, Greene DN. When gender identity doesn’t equal sex recorded at birth: the role of the laboratory in providing effective healthcare to the transgender community. *Clinical Chemistry* 2017;63(3):1342-57. From <https://academic.oup.com/clinchem/article/63/8/1342/5612643>

<sup>43</sup> Imborek KL, Nisly NL, Hesseltine MJ, Grienke J, Zikmund TA, et al. Preferred names, preferred pronouns, and gender identity in the electronic medical record and laboratory information system: is pathology ready? *Journal of Pathology Informatics* 2017; 8(42):1-14. From <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5653959/>

<sup>44</sup> Deutsch MB, Buchholz D. Electronic health records and transgender patients – practical recommendations for the collection of gender identity data. *Journal of General Internal Medicine* 2014; 30(6):843-7. From <https://link.springer.com/content/pdf/10.1007/s11606-014-3148-7.pdf>

<sup>45</sup> Ibid.

<sup>46</sup> Ibid.

<sup>47</sup> Keroghlian A, Grasso C. *Collecting Sexual Orientation and Gender Identity Data in EHRs*. Jun 9, 2020. From <https://infocentral.inforoute.ca/en/resources/docs/sex-gender/sex-gender-presentations/3339-sex-and-gender-june-9-presentation-fenway-health-alex-keroghlian-and-chris-grasso>.

<sup>48</sup> Panas M. *Inclusive EHRs in Action: AHS, SOGIE Tools and Full Patient Experience in Connect Care*, Jul 14, 2020. Unpublished presentation.

<sup>49</sup> Nambia D. *Electronic Health Records: Inclusive Intake Forms and Inclusive Language*, Nov 10, 2020. From <https://infocentral.inforoute.ca/en/resources/docs/sex-gender/sex-gender-presentations>

<sup>50</sup> Keroghlian A, Grasso C. *Collecting Sexual Orientation and Gender Identity Data in EHRs*. Jun 9, 2020. From <https://infocentral.inforoute.ca/en/resources/docs/sex-gender/sex-gender-presentations/3339-sex-and-gender-june-9-presentation-fenway-health-alex-keroghlian-and-chris-grasso>.

<sup>51</sup> Callahan EJ, Sitkin N, Ton H, Eidson-Ton WS, Weckstein J, Latimore D. Introducing sexual orientation and gender identity into the electronic health record: one academic health center’s experience. *Academic Medicine* 2015; 90: 154-60. From [https://journals.lww.com/academicmedicine/fulltext/2015/02000/Introducing\\_Sexual\\_Orientation\\_and\\_Gender\\_Identity.15.aspx](https://journals.lww.com/academicmedicine/fulltext/2015/02000/Introducing_Sexual_Orientation_and_Gender_Identity.15.aspx)

- Integration of GSSO data with the national database holdings maintained by CIHI to help reduce disparities, address determinants of health inequities in opportunity, and improve experiences in care<sup>52</sup>
- EHR data-driven analytics and quality improvement approaches that draw on GSSO data as part of the health equity stratifiers, evidence-based implementation science principles<sup>53</sup> and data-driven Quality Improvement Plans (QIP)<sup>54</sup> will enable organizations to “*profile who is being served, stratify health service utilization and outcome data and inform clinical care*” to ensure that all populations receive timely and high quality care<sup>55</sup>
- Having a common set of quality metrics that draws on CIHI’s health indicators framework can “*provide comparable and actionable information [on SGM populations] across different geographic, organizational or administrative boundaries and/or can track progress over time.*”<sup>56</sup> Efforts should also be undertaken to identify, collate, and consolidate a set of evidence-informed, SGM-oriented quality metrics that can be tailored for different Canadian contexts and compared over time.
- The prospect for SGM-oriented health informatics capacity building is excellent and timely – the field of SGM health is maturing, there is an increasing demand for inclusive EHR systems, and advances in digital and personalized health can empower SGM in managing their own health. Organizations should seize on this opportunity to train the next generation of informatics specialists and knowledge users with the cultural humility, knowledge, expertise and compassion in equity- and SGM-oriented digital health.

Tangible activities from Action 4 include working with organizations, clinicians, staff and vendors to specify a common set of EHR functions and processes to support GSSO data collection and use. Tangible deliverables may include the deployment and adoption of these EHR functions and processes in specific health organizations.

## ACTION 5 – GSSO POLICY/PRACTICE GUIDANCE

Emerging approaches to GSSO documentation include the adoption of a 2-step method and standardized process to collect one’s gender identity and sex assigned at birth. The 2-step method involves asking patients the question “*what is your gender identity?*” followed by “*what sex were you assigned at birth?*” with predefined responses that include options for choosing not to disclose and write-in.<sup>57 58 59</sup> The standardized process involves asking all patients the same two questions so SGM do not feel singled out in having to disclose the information. It also avoids staff in making assumptions about one’s sex and gender based on appearance that can impact the delivery of culturally competent care which includes receiving appropriate screening and treatments. The 2-step method is the recommended practice in Rainbow Health Ontario,<sup>60</sup> StatCan’s 2021 Census,<sup>61</sup> Fenway Health,<sup>62</sup>

<sup>52</sup> Rainbow Health Ontario. *LGBTQ2 Health in Canada: Study Brief for the Standing Committee on Health*, Jun 2019. From <https://www.ourcommons.ca/Content/Committee/421/HESA/Brief/BR10445304/br-external/RainbowHealthOntario-revised-e.pdf>

<sup>53</sup> Bauer MS, Damschroder L, Hagedorn H, Smith J, Kilbourne AM. An introduction to implementation science for the non-specialist. *BMC Psychology* 2015; 3(32). From [https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4573926/pdf/40359\\_2015\\_Article\\_89.pdf](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4573926/pdf/40359_2015_Article_89.pdf)

<sup>54</sup> Health Quality Ontario. *Health Equity Plan*. From [http://www.hqontario.ca/Portals/0/documents/health-quality/Health\\_Equity\\_Plan\\_Report\\_En.pdf](http://www.hqontario.ca/Portals/0/documents/health-quality/Health_Equity_Plan_Report_En.pdf)

<sup>55</sup> Toronto Central Local Health Integration Network and Sinai Health System. *Measuring Health Equity. Demographic Data Collection and Use in Toronto Central LHIN Hospitals and Community Health Centres*, Jul 2017. From <http://torontohealthequity.ca/>

<sup>56</sup> Canadian Institute for Health Information. *Health Indicators*, n.d. From <https://www.cihi.ca/en/health-indicators>

<sup>57</sup> Panas M. *Inclusive EMRs in Action: AHS, SOGIE Tools and Full Patient Experience in Connect Care*, Alberta Health Services, July 14, 2020.

<sup>58</sup> Canadian Institute for Health Information. *In Pursuit of Health Equity: Defining Stratifiers for Measuring Health Inequality*, April 2018. From <https://www.cihi.ca/sites/default/files/document/defining-stratifiers-measuring-health-inequalities-2018-en-web.pdf>

<sup>59</sup> Pinto AD, Aratangy T, Abramovich A, Devotta K, et al. Routine collection of sexual orientation and gender identity data: a mixed methods study. *Canadian Medical Association Journal* 2019; 191(3):E63-8. From <https://www.cmaj.ca/content/cmaj/191/3/E63.full.pdf>

<sup>60</sup> Rainbow Health Ontario. *How to Make Your EHR Inclusive -2020*.

<sup>61</sup> Statistics Canada. Sex at birth and gender: Technical report on changes for the 2021 census. Available at <https://www12.statcan.gc.ca/census-recensement/2021/ref/98-20-0002/982000022020002-eng.cfm>

<sup>62</sup> Fenway Health. *Ready-Set-Go: A Guide for Collecting Data on Sexual Orientation and Gender Identity, Updated 2020*. Fenway Institute. Available at [https://www.lgbtqihealtheducation.org/wp-content/uploads/2018/03/TFIE-47\\_Updates-2020-to-Ready-Set-Go-publication\\_6.29.20.pdf](https://www.lgbtqihealtheducation.org/wp-content/uploads/2018/03/TFIE-47_Updates-2020-to-Ready-Set-Go-publication_6.29.20.pdf)

and New Zealand.<sup>63</sup> Studies have found that asking both sex at birth and gender questions contributes to a lower non-response rate and SGM participants have less difficulty answering the two questions than one alone.<sup>64</sup>

There are variations to these approaches. For instance, some organizations have included the question “*what is your sexual orientation?*”<sup>65</sup> Others have added “*what name would you like us to use?*” and “*what are your pronouns?*”<sup>66</sup> with write-in options to allow more respectful ways for staff to address the patient as a person and reduce the risks of deadnaming<sup>67</sup> and misgendering<sup>68</sup> the individual. When these questions are asked, one should include the definitions of the terms used, since they may not be familiar to people with different cultural backgrounds. While the 2-step method is currently the recommended practice, during the consultation sessions some participants suggested that sex-assigned at birth should only be collected if it is relevant to the care being sought. This has been identified in the action plan as one issue that requires further discussion.

The collection and use of GSSO data including secondary uses should be guided by explicit organizational policies, and the process should be integrated with the organization’s workflows. In particular, the policies should describe (a) what data should be collected and who should collect them, (b) when, where and how the data should be collected, (c) why should the data be collected, (d) who should have access to the data, and (e) what safeguards are in place to protect the confidentiality of the data being collected and privacy of the individual who is being asked to disclose the information.<sup>69</sup> Increasingly, organizations have adopted different methods of collecting GSSO data that include having (a) patients complete paper intake forms then have registration staff enter the data in the EHR, (b) patients complete the questions on their own through an online patient portal, (c) providers enter the data directly into the EHR after talking with the patient.<sup>70 71</sup> At this time, there is no clear evidence on the preferred method. Regardless of the methods used, it is suggested that the GSSO questions be asked annually, since this information may change over time.<sup>72</sup>

While GSSO data collection efforts should be standardized, the process should also be integrated to fit with the organization’s workflows in different clinical/administrative departments, and be tailored to specific use cases based on patients’ specific needs. For instance, the need for GSSO data may differ for patient registration, scheduling, correspondence, tests, treatments, billing, clinical decision support, and population level analysis.<sup>73</sup> A common requirement is the proper use of one’s name and pronouns when identifying and addressing the patient. Clinical departments may have specific GSSO data requirements to ensure patient safety for transgender

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<sup>63</sup> Stats NZ (2020). Sex and gender identity statistical standards: Consultation. From [www.stats.govt.nz](http://www.stats.govt.nz).

<sup>64</sup> Slade T, Gross DP, Niwa L, McKillip AB, Guptill C. Sex and gender demographic questions: improving methodological quality, inclusivity, and ethical administration. *International Journal of Social Research Methodology* 2020; DOI: [10.1080/13645579.2020.1819518](https://doi.org/10.1080/13645579.2020.1819518)

<sup>65</sup> St. Michael’s Hospital. *We Ask Because We Care. The Tri-Hospital + TPH Health Equity Data Collection Research Project Report*, Sep 2013. From <http://www.stmichaelshospital.com/quality/equity-data-collection-report.pdf>

<sup>66</sup> National LGBT Health Education Center. Ready, Set, Go! Guidelines and Tips for Collecting Patient Data on Sexual Orientation and Gender Identity, January 2018. Fenway Institute. From [https://www.lgbtqiahealtheducation.org/wp-content/uploads/2018/03/TFIE-47\\_Updates-2020-to-Ready-Set-Go-publication\\_6.29.20.pdf](https://www.lgbtqiahealtheducation.org/wp-content/uploads/2018/03/TFIE-47_Updates-2020-to-Ready-Set-Go-publication_6.29.20.pdf)

<sup>67</sup> Deadnaming occurs when a transgender person is addressed by the name that was given at birth but no longer used by the person

<sup>68</sup> Misgendering is when the wrong pronouns or other gender-specific words are used when referring to or speaking to a transgender person

<sup>69</sup> Rainbow Health Ontario. *How to Make Your EHR Inclusive -2020*.

<sup>70</sup> Callahan EJ, Sitkin N, Ton J, Eidson-Ton WS, Weckstein J, Latimore D. Introducing sexual orientation and gender identity into the electronic health record: One academic health center’s experience. *Academic Medicine* 2015; 90:154-60. From [https://journals.lww.com/academicmedicine/fulltext/2015/02000/Introducing\\_Sexual\\_Orientation\\_and\\_Gender\\_Identity.15.aspx](https://journals.lww.com/academicmedicine/fulltext/2015/02000/Introducing_Sexual_Orientation_and_Gender_Identity.15.aspx)

<sup>71</sup> Grasso C, McDowell MJ, Goldhammer H, Keuroghlian AS. Planning and implementing sexual orientation and gender identity data collection in electronic health records. *Journal of American Medical Informatics Association* 2019; 26(1): 66-70. From <https://pubmed.ncbi.nlm.nih.gov/30445621/>

<sup>72</sup> *ibid*.

<sup>73</sup> Clark BA, MacNeil L. *Collection of Sex and Gender Data in Electronic Health Records: A Clinical Use Case Approach*. Provincial Health Services Authority. May 12, 2020. From <https://infocentral.infoway-inforoute.ca/en/resources/docs/sex-gender/sex-gender-presentations/3310-sex-and-gender-may-12-presentation-trans-care-bc-beth-clark-and-lindsay-macneil>

patients, such as expected lab reference ranges,<sup>74</sup> shielding of gonads in imaging<sup>75</sup> and medication dosing before, during and after the transition process.<sup>76</sup> More descriptions on data collection can be found in [Appendix D](#). There should be the requirement where patients can select more than one value option. For example, under gender identity, one should be able to identify as a man and a trans man. This approach needs further discussion.

There should be strong governance mechanisms to ensure appropriate, seamless and incremental introduction of new/enhanced EHR functions over time. Since the introduction of GSSO data can have profound implications at many levels, strong governance should be in place to ensure the voices of those responsible for, involved with and affected by this modernization effort are heard. An exemplar is the Alberta Health Services (AHS) Provincial Advisory Council on Sexual Orientation, Gender Identity and Expression made up of patients, families and caregivers with SGM experience. Its mandate is to provide recommendations to AHS on safer and more inclusive care for all Albertans, which include respectful provider interactions, correct GSSO terminology and data collection for health care services and key performance indicators.<sup>77</sup> Another example is the BC First Nation's Data Governance Framework that is based on the purpose of cultivating equity through the elimination of systemic racism and oppression, the process of respectful relationship grounded in community governance, and the tool of disaggregated demographic data.<sup>78</sup>

Tangible activities from Action 5 include developing organizational policy and practice guidance on GSSO documentation for health care staff and patients in different care contexts and accountable governance at the community level. Tangible deliverables include having the guidance and governance as published documents that are easily accessible through public websites.

## **ACTION 6 – EDUCATION AND TRAINING**

Education is needed to address underlying implicit assumptions that can impact the delivery of care. Staff education and training is key to the provision of culturally competent and safe care. Health care staff need to learn about the challenges experienced by SGM and their health needs, how to provide affirmative care and services and ways to communicate effectively and respectfully when interacting with SGM patients. Staff need to learn cultural competence, address patients consistently with their correct names and pronouns, and feel comfortable acknowledging mistakes when made to “*maintain a culture of accountability.*”<sup>79</sup> Vendors, implementers, policy-makers, and researchers need education on required safeguards to protect GSSO data. Education is also needed to address the stigmatizing experiences in clinic waiting rooms, or during practitioner visits that may discourage patients from sharing GSSO data. Patients should be informed as to why GSSO data are needed, who has access to the data, and how the data will be used and protected. The public also need education about SGM, the GSSO language used, and how improved GSSO data collection and use can reduce barriers and improve the health of SGM in their communities. Equally important is for educational institutions to

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<sup>74</sup> Institute for Quality Management in Healthcare. *Care Considerations for Inclusion of Gender Diversity within Medical Laboratory Services*, version 2.0, 2019-07-08. From <https://iqmh.org/Portals/0/Docs/Resources/Education/White%20Paper%20-%20Care%20Considerations%20for%20Inclusion%20of%20Gender%20Diversity%20Within%20Medical%20Laboratory%20Services.pdf>

<sup>75</sup> Pedersen S, Sanders V. A new and inclusive intake form for diagnostic imaging departments. *Journal of Medical Imaging and Radiation Sciences* 2018; 49:371-5. From [https://www.jmirs.org/article/S1939-8654\(18\)30223-6/fulltext](https://www.jmirs.org/article/S1939-8654(18)30223-6/fulltext)

<sup>76</sup> Webb AJ, McManus D, Rouse GE, Vonderheyde R, Topal JE. Implications for medication dosing for transgender patients. A review of the literature and recommendations for pharmacists. *American Journal of Health-System Pharmacists* 2020; 77(6):427-32. From <https://pubmed.ncbi.nlm.nih.gov/32012216/>

<sup>77</sup> Alberta Health Services. Bylaw for the Provincial Advisory Council on Sexual Orientation, Gender Identity and Expression, 2019. From <https://www.albertahealthservices.ca/assets/about/ac/ahs-pac-sogie-bylaws.pdf>

<sup>78</sup> BC Office of the Human Rights Commissioner. Disaggregated demographic data collection in British Columbia: The grandmother perspective Sep 2020. From <https://bchumanrights.ca/publications/datacollection/>

<sup>79</sup> Grasso C, McDowell MJ, Goldhammer H, Keuroghlian AS. Planning and implementing sexual orientation and gender identity data collection in electronic health records. *Journal of American Medical Informatics Association* 2019; 26(1): 66-70. From <https://pubmed.ncbi.nlm.nih.gov/30445621/>

incorporate this training as part of the formal curricula in health-related pre-licensed education and professional development programs.<sup>80</sup>

Staff education is a key part of the EQUIP Health Care Intervention Approach, which is the foundation for equity- and SGM-oriented health care in this action plan. Its aim is to enhance staff knowledge, attitudes and practices of trauma- and violence-informed and culturally safe care and harm reduction for SGM patients. To be effective, organizational integration and tailoring are needed to embed this learning in the context of practice, and create locally relevant structures and processes to facilitate and sustain this practice change.<sup>81</sup>

There are numerous SGM-oriented learning resources and tools that are publicly available, and the volume of materials is increasing steadily over time. These include online learning modules, information brochures, coaching courses, practice guides and intervention toolkits. Some examples are listed below:

- AHS. *Sexual Orientation, Gender Identity & Gender Expression (SOGIE) – Safer Places Toolkit*, Nov 2018<sup>82</sup>
- BC Centre for Disease Control (BCCDC) *COVID-19 Language Guide - Guidelines for inclusive language for written and digital content*, Jul 2020<sup>83</sup>
- The Centre for Addiction and Mental Health (CAMH). *Asking the Right Questions 2. Talking with Clients about Sexual Orientation and Gender Identity in Mental Health, Counselling and Addiction Settings*, 2007.<sup>84</sup>
- EQUIP Health Care. *Equipping for Equity Online Modules, Health Equity Toolkit*,<sup>85</sup>
- Rainbow Health Ontario. *Education & Training –Online Learning Platform*.<sup>86</sup>
- Trans Care BC. Provincial Health Services Authority. *Gender-Affirming Care for Trans, Two-Spirit, and Gender Diverse Patients in BC – A Primary Care Toolkit*, Oct 2019<sup>87</sup>
- Trans Care BC. *Trans Intro Resources: Online Training Modules, Support Tools, Trans Rights BC*<sup>88</sup>
- The Canadian Centre for Gender and Sexual Diversity *Support Resources*<sup>89</sup>

Tangible activities from Action 6 include compiling a common set of best practice and learning resources, and creating a directory of these resources that can be shared through a common website, and embedding the content into organization's training programs and/or learning platforms. Tangible deliverables can include an up-to-date and well-maintained online directory of where one can find these resources, and embedded content within organizations as training and/or online resources.

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<sup>80</sup> Gogovor A, Mollayeva T, Etherington N, Colantonio A, Légaré F, on behalf of the GIKT Group. (2020). Sex and Gender Analysis in knowledge translation interventions: challenges and solutions. *Health Research Policy and Systems* 2020; 18;108. From <https://health-policy-systems.biomedcentral.com/articles/10.1186/s12961-020-00625-6>

<sup>81</sup> Browne AJ, Varcoe C, Ford-Gilboe M, Wathen CN, et al. EQUIP healthcare: an overview of a multi-component intervention to enhance equity-oriented care in primary health care settings. *International Journal for Equity in Health* 2015; 14:152. From <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4688920/>

<sup>82</sup> Alberta Health Services. From <https://www.albertahealthservices.ca/assets/info/pf/div/if-pf-div-sogie-safer-places-toolkit.pdf>

<sup>83</sup> BCCDC. From <http://www.bccdc.ca/Health-Info-Site/Documents/Language-guide.pdf>

<sup>84</sup> CAMH. From [https://lgbtqpn.ca/wp-content/uploads/woocommerce\\_uploads/2014/08/arq2.pdf](https://lgbtqpn.ca/wp-content/uploads/woocommerce_uploads/2014/08/arq2.pdf)

<sup>85</sup> EQUIP Healthcare. From <https://equiphealthcare.ca/resources/>

<sup>86</sup> Rainbow Health Ontario. From <https://www.rainbowhealthontario.ca/education-training/>

<sup>87</sup> Trans Care BC. From <http://www.phsa.ca/transcarebc/Documents/HealthProf/Primary-Care-Toolkit.pdf>

<sup>88</sup> Trans Care BC. *Trans Intro resources* [website]. From <http://www.phsa.ca/transcarebc/health-professionals/education/trans-intro>

<sup>89</sup> Canadian Centre for Gender+Sexual Diversity. *Resources*. From <https://ccgsd-ccdgs.org/resources/>



## ACTION 7 – CENTRAL HUB FOR COORDINATION

The effort to modernize GSSO information practices in Canadian EHR systems is timely, as there is growing attention across Canada to reduce structural inequities within the health system. There are organizations, communities and jurisdictions across the country that are in different stages of planning or embarking on the work to expand the definition, collection and use of GSSO data in EHR systems. To reduce duplication and build on work already done, there is strong motivation to coordinate efforts across the country through a central hub to maximize the impact. There are many aspects where centralized coordination seems prudent. Examples include the sharing of common GSSO terminology, SGM-oriented educational materials, inclusive EHR design features, affirmative policy and practice guidance, best practices in GSSO documentation, use case and workflow scenarios, performance and evaluation metrics, and EHR implementation experiences. A comparable initiative is the FHIR Implementations Working Group hosted by Infoway involving multiple organizations working collaboratively to advance Fast Healthcare Interoperable Resources (FHIR) implementations across Canada.<sup>90</sup>

A central hub can act as a coordinating body to liaise, guide, assist and monitor the progress of this action plan and ongoing GSSO modernization efforts across the country. It can also facilitate the formal process needed to reach national consensus on the action plan items. Efforts should also be made to collaborate with existing advisory committees and working groups that are focused on GSSO. Since community engagement is key to the success of moving this plan forward, the consensus process should have broad representation and meaningful participation from communities across Canada. This requires much work to ensure community voices are front and centre to drive the process as much as possible, including ongoing governance for decision-making.

Other hub activities may include (a) hosting of regular seminars to share best practices and lessons, (b) refining GSSO terminology to reflect current thinking, (c) discussing GSSO documentation approaches and implications, (d) sharing of relevant tools and resources, and (e) co-creating an annual report card on progress made with the action plan and implementation efforts.

To be credible, the hub ought to be an impartial body with broad representations from groups across the country who are responsible for, involved with, or affected by modernized GSSO information practices in EHR systems. At the operating level, the hub may play the role of a pan-Canadian task force, secretariat or servant-leader, and be accountable to the hub members. To be effective, the hub needs a mandate, proper resourcing, a consensus process and open memberships.

This proposed action plan is the beginning of a multi-year, dynamic, complex and ongoing journey toward an equity-oriented health system that is enabled by EHR systems and GSSO information practices to embrace diversity and inclusion for all people in Canada. Having a national conversation about this action plan and reaching consensus on the action items are the logical next steps to move forward. An initial (and growing) list of pending work items is included in [Appendix E](#).

Tangible activities from Action 7 include creating the central hub and continuing the conversation on next steps. Tangible deliverables may include an operational central hub with a mandate, consensus process, work plan and resource support.

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<sup>90</sup> Infoway. FHIR Implementations Working Group. From <https://infocentral.infoway-inforoute.ca/en/collaboration/wg/fhir-implementations>

## ENABLERS AND CONSTRAINTS

This action plan is adaptable to local/regional priorities and community/organizational resources and readiness. It allows for different scope coverage, implementation options and staged migration by health organizations. 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. Examples of readiness/needs/sustainability assessments include the following:

- **Rainbow Health Ontario** has created a 1-page brief guide on “how to make your EHR inclusive” in response to requests from organizations on guidance to incorporate GSSO on intake forms and EHRs. This is an excellent way to focus discussion on GSSO data collection and implications.<sup>91</sup>
- **The Fenway Institute LGBT Health Readiness Assessment**<sup>92</sup> involves the use of two tools for staff and leadership assessment. The staff assessment tool asks all staff members in the organization about LGBT health needs, the care environment, staff awareness of policies, and LGBT health training needs. The leadership assessment tool for executives and department heads has two parts. The first part has the same staff assessment questions, the second part has questions on how the organization collects GSSO data, and leaders’ preparedness to provide leadership to staff on addressing SGM needs.
- **The EQUIP frontline ownership approach**<sup>93</sup> uses self-led health care staff working groups assisted by a change coach and a content coach to identify and prioritize areas of improvement to foster equity for specific populations through a SWOT analysis. The groups are provided with online learning EQUIP modules, a context profile of the communities served including demographics, history and marginalized groups, and data snapshots from patient and staff surveys on their perceptions and needs.<sup>94</sup>
- Deutsch et al.<sup>95 96</sup> has published **recommendations on the collection of gender identity data in EHRs** that can serve as a roadmap and checklist for the changes needed. The recommendations include: (a) the collection of patient-reported gender identity, name used and pronouns; (b) an inventory of a patient’s medical transition history and current anatomy; (c) the ability to change from one name, anatomical inventory and/or sex to another; (d) a means of notifying providers and staff of patient’s name used and pronouns if different from legal name/sex; and (e) a data collection logic flow for gender identity, birth sex and name used.
- Other assessment tools that may be considered include the **Practical Implementation Science Heuristic**<sup>97</sup> and the **Ready-Set-Change Online Readiness for Change**.<sup>98 99</sup>

<sup>91</sup> Rainbow Health Ontario, Sherbourne Health. *How to Make Your EHR Inclusive* – 2020. From <https://infocentral.infoway-inforoute.ca/en/resources/docs/sex-gender/sex-gender-publications/3396-how-to-make-your-ehr-inclusive-by-rainbow-health-ontario>

<sup>92</sup> National LGBT Health Education Center. Fenway Institute. *LGBT Health Readiness Assessments in Health Centers: Key Findings*, 2017. From <https://www.lgbtqihealtheducation.org/wp-content/uploads/2017/11/LGBT-Health-Readiness-Assessment-Key-Findings.pdf>

<sup>93</sup> Varcoe C, Bungay V, Browne AJ, Wilson E, Wathen N, Kolar K, et al. EQUIP Emergency: study protocol for an organizational intervention to promote equity in health care. *BMC Health Services Research* 2019; 19:687. From <https://link.springer.com/article/10.1186/s12913-019-4494-2>

<sup>94</sup> EQUIP Health Care. Welcome to the Equipping for Equity Modules. From <https://equiphealthcare.ca/equipping-for-equity-online-modules/>

<sup>95</sup> Deutsch MB, Green J, Keatley J, Mayer G, Hastings J, Hall AM. EMR and the transgender patient: recommendations from the World Professional Association for Transgender Health EMR Working Group. *JAMIA* 2013; 20: 700-3. From <https://academic.oup.com/jamia/article/20/4/700/2909343>

<sup>96</sup> Deutsch MB, Buchholz D. Electronic health records and transgender patients – practical recommendations for the collection of gender identity data. *Journal of General Internal Medicine* 2015; 30(6):843-7. From <https://link.springer.com/content/pdf/10.1007/s11606-014-3148-7.pdf>

<sup>97</sup> Scaccia JP, Cook BS, Lamont A, Wandersman A, et al. A practical implementation science heuristic for organizational readiness: R=MC2. *J Community Psychol* 2015; 43(4):484-501. From <https://pubmed.ncbi.nlm.nih.gov/26668443/>

<sup>98</sup> Timmings C, Khan S, Moore JE, et al. Ready, Set, Change! Development and usability testing of an online readiness for change decision support tool for health care organizations. *BMC Medical Informatics and Decision Making* 2016; 16:24. From <https://bmcmmedinformdecismak.biomedcentral.com/articles/10.1186/s12911-016-0262-y>

<sup>99</sup> Ready, Set, Change, n.d. From <http://readiness.knowledgetranslation.ca/>

A readiness/needs/sustainability assessment can help the organization identify enablers and constraints present, including those at the systems level and are structural in nature. Based on the findings, an organization can determine the path forward. Examples of possible paths include the following:

- For **scope coverage**, an organization may focus initially on only an aspect of GSSO modernization. The focus could be on: (a) documentation of sex at birth, gender identity, name used and pronouns in EHRs, leaving sexual orientation for later; (b) patient identification policies where patient's name used and gender identities may be different from legal name/sex; (c) GSSO data collection and workflows in clinical departments such as imaging and labs; and (d) staff education to increase their cultural competencies when interacting with SGM patients.
- For **implementation options**, an organization may choose different strategies, such as: (a) starting with a small-scale pilot project in one department applying a rapid quality improvement approach to test out the process then expanding it to other departments based on feedback and adjustments; (b) leveraging other initiatives underway (e.g., LGBTQIA2S+ awareness campaigns or planned EHR upgrades to optimize resources and amplify effects); or (c) making a major commitment to take on this work as a high priority item for the community.
- For **staged migration**, an organization may choose to carry out some of the actions in stages with incremental milestones, tangible outputs and formative evaluations in iterations. This is to ensure the effort can stay focused, remain visible and demonstrate value for the organization and everyone involved as it migrates through the stages over time.

Below are examples of successful planning and implementation of GSSO data collection in EHR systems:

- **Departmental level** – Pedersen et al. has created a Sex, Identity, Gender, Expression (SIGE) intake form for diagnostic imaging departments that accommodate all patients regardless of sex and gender. The SIGE form asks questions that radiation technologists need to know to interact with patients, shield gonadal tissue from ionizing radiation, and make SGM patients feel safe and respected.<sup>100</sup>
- **Organizational level** – Fenway Institute has published a guide with a sample 14-month timeline starting with planning implementation, training staff, customizing EHR, piloting in single department, analyzing outcomes, scaling up, and ending with the completion of a first data summary report, followed by ongoing data quality monitoring<sup>101</sup>
- **Multi-Site SPARK study** – This is an ongoing multi-province research study (2018-2022) funded by CIHR to create a national standard for socio-demographic data collection in primary care, with a focus on addressing poverty at point-of-care. GSSO is part of the data set being collected in different EHRs.<sup>102</sup>
- **Province-wide approach** – AHS has made a major commitment as one of the largest health authorities in Canada to create safe and inclusive environments for staff and patients. Notable efforts include the creation of a provincial diversity and inclusion plan, a Diversity and Inclusion Centre of Expertise, a website to provide tools and information to help patients navigate their journey and care providers increase their ability to provide culturally safe and sensitive care to SGM, and task forces to review and address how GSSO information is collected on forms and in clinical information systems<sup>103</sup>

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<sup>100</sup> Pedersen S, Sanders V. A new and inclusive intake form for diagnostic imaging departments. *Journal of Medical Imaging and Radiation Sciences* 2018; 49: 371-5. From [https://www.jmirs.org/article/S1939-8654\(18\)30223-6/fulltext](https://www.jmirs.org/article/S1939-8654(18)30223-6/fulltext)

<sup>101</sup> Cahill S. Do Ask, Do Tell: A Toolkit for Collecting Data on SOGI in Clinical Settings, 2020. From <https://doaskdotell.org/>

<sup>102</sup> The Upstream Lab. SPARK - Screening for Poverty And Related social determinants and interventions to improve Knowledge and links to resources. From <https://upstreamlab.org/spark-study/>

<sup>103</sup> Priestley M. What AHS is doing to create safe and inclusive environments. *CARE* – Summer 2019. College of Licensed Practical Nurses of Alberta. From [https://issuu.com/clpna/docs/care\\_magazine\\_summer\\_2019/s/124524](https://issuu.com/clpna/docs/care_magazine_summer_2019/s/124524)



This action plan is intended to modernize GSSO information practices in Canadian EHR systems. In the report, the team described the current landscape of GSSO documentation in EHRs, and proposed 7 transformative actions to improve the definition, collection and use of GSSO data in Canadian EHR systems. Also included in the plan is the Equity- and SGM-Oriented Intervention called EQUIP as an overarching approach to guide health organizations in their planning and implementation of the proposed actions.

The action plan is adaptable to different scope coverage, implementation options and staged migration by health organizations depending on the overall fit of the plan with regional priorities, organizational and community readiness, and resource availability. Examples of readiness/needs/sustainability assessment processes and planning and implementation efforts to collect GSSO data in EHR systems have been provided to illustrate possible paths forward.

Lastly, the importance of this work takes on even greater significance by the current pandemic, illuminating the inequities experienced by marginalized populations, including SGM.<sup>104</sup> In conclusion, the team wishes to make clear that this proposed action plan is only the beginning of a multi-year, dynamic, complex and ongoing journey toward an affirming health system with enabling EHRs and modernized GSSO information practices that embrace diversity and inclusion for all people. Establishing a central hub to continue a national conversation and reach consensus on the action items is the logical, necessary and important next step.

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<sup>104</sup> Phillips II G, Felt D, Ruprecht MM, Wang X, Xu J, et al. Addressing the disproportionate impacts of the COVID-19 pandemic on sexual and gender minority populations in the United States: Actions toward equity. *LGBT Health* 2020; 7(6):279-82. Available from <https://www.liebertpub.com/doi/full/10.1089/LGBT.2020.0187>

## APPENDIX A – LIST OF PARTICIPANTS

### LGBTQIA2+ Communities / Advocacy Groups

Community-based Research Centre  
 Rainbow Health Ontario  
 Sherbourne Health  
 Human Sexuality Research Laboratory  
 Institute for Sexual Minority Health  
 Two-Spirited People of Manitoba  
 The Canadian Centre for Gender & Sexual Diversity

### Indigenous Health Organizations

MB First Nations Health & Social Secretariat  
 First Nations Health Authority

### Government Ministries / Departments

BC Health Ministry  
 Alberta Health  
 PEI Department of Health & Wellness  
 Nova Scotia Department of Health & Wellness  
 New Brunswick Department of Health  
 Saskatchewan Health Authority  
 Women and Gender Equality Canada  
 Gender Inclusive Services Treasury Board Secretariat  
 Statistics Canada

### Professional Associations / Colleges

Canadian College of Health Information Management  
 Canadian Sex Research Forum  
 Doctors of BC, Information Technology Group  
 College of Physicians & Surgeons of BC  
 Registered Nurses Association of Ontario  
 World Professional Association for Transgender Health  
 European Professional Association for Transgender Health  
 Canadian Professional Association for Transgender Health

### Private / Non-profit Organizations

Info Technology Association of Canada  
 Cambian  
 Gevity Consulting  
 Health Solutions LLC  
 Logical Outcomes  
 Transgender Strategies Consulting  
 Alberta Precision Laboratories

### Health Organizations

Alberta Health Services  
 Canadian Institute for Health Information  
 Public Health Association of Canada  
 Public Health Ontario  
 eHealth Ontario  
 Halton Healthcare  
 Hospital Diagnostic Imaging Repository  
 NL Centre for Health Information  
 Ontario Health Digital Services  
 Provincial Health Services Authority (BC)  
 Trans Care BC  
 Vancouver Coastal Health  
 Waypoint Centre for Mental Health  
 Women's College Hospital

### Standards Organizations / Groups

Infoway Sex and Gender Working Group (40+ members)  
 Integrating Healthcare Enterprise Canada  
 Canadian Standards Association CSA Group  
 HL7 International, Gender Harmony Project

### CIHR Planning Project Team Members

Francis Lau, UVic  
 Aaron Devor, UVic  
 Marcy Antonio, UVic  
 Roz Queen, UVic  
 Alaysha Ogilvie, UVic  
 Nathan Lachowsky, UVic  
 Andrew Pinto, U of T  
 Jody Jollimore, CBRC BC  
 Zander Keig, USNASW on LGBT Health  
 Finnie Flores, CIHI  
 Andrea MacLean, Canada Health Infoway  
 Jeff Nesbitt, CHIMA/CCHIM  
 Kelly Davison, Canada Health Infoway  
 Nicki Islic, CSA Group  
 Keltie Jamieson, Nova Scotia Health Authority  
 Dorrell Metcalfe, Nova Scotia Health Authority  
 Thomas Armstrong, Nova Scotia Health Authority, UVic

## APPENDIX B – CURRENT LANDSCAPE DETAIL

### (a) Environmental Scan

The team examined publicly available information sources on sex and gender definitions in existing Canadian EHR systems and international standard specifications.<sup>105</sup> The information sources consisted of website descriptions of 52 EHR/health databases and 55 data standard specifications from 12 Canadian entities and 10 standards communities. The key findings are as follows:

- A major issue is the conflated use of sex and gender as a single binary concept to define sex and gender identity. This can create confusion when a person's biology of being a female or male along a spectrum is different from one's gender identity as a woman, man, neither, both or something else.
- There is inconsistency in the data names and value options used to represent sex and gender concepts in EHR systems. For instance, sex, administrative sex and patient's sex are all data names that refer to a person's biology, but different options are used including indeterminate, intersex and undifferentiated when one's sex is not female or male.
- The appropriateness of some value options are questioned as our societal understanding of SGM and GSSO concepts continues to evolve. Examples are hermaphrodites and natal sex that are now offensive terms. Outdated value options also raise concerns about EHRs in supporting the provision of culturally competent, safe and affirmative health care.
- The limited value options available also perpetuate the inequities faced by SGM. At the same time, expanded definitions from leading Canadian organizations and international standards communities such as transgender and nonbinary gender have raised implementation challenges in how one should migrate these definitions into existing EHR systems.

### (b) Literature Review

The team conducted a rapid review of academic literature published in the last five years to examine current GSSO documentation approaches and how one should modernize GSSO information practices in EHRs.<sup>106</sup> Findings from 35 English journal articles revealed a number of challenges and five themes on reported needs and efforts to address them. They involve the following:

- Create an inclusive, culturally competent environment with precise GSSO terminology, and standardized data collection policies with clear rationale for why the data are needed, who should collect them, when/how they should be collected, and safeguards for accessing the data.
- Refine guidelines for identifying and matching SGM patients with their care needs, such as proper use of one's name and pronouns at registration, and SGM-based rules for clinical tests and lab reference ranges (e.g. pregnancy tests, testosterone levels).
- Improve patient-provider relationships by addressing patient rights and provider competencies. SGM patients want reassurance of their inclusion and safety when seeking care; they welcome being asked to disclose their identities. Health care staff want guidance on how to communicate with SGM patients and document their GSSO in EHRs.

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<sup>105</sup> Lau F, Antonio M, Davison K, Queen R, Bryski K. *An environmental Scan of sex and gender in electronic health records: Analysis of public information sources.* *Journal of Medical Internet Research* 2020; 22(11): November. From <https://www.jmir.org/2020/11/e20050/>

<sup>106</sup> Lau F, Antonio M, Davison K, Queen R, Devor A. A rapid review of gender, sex and sexual orientation documentation in electronic health records. *Journal of American Medical Association* Sep 16, 2020; <https://academic.oup.com/jamia/advance-article/doi/10.1093/jamia/ocaa158/5906099>

- Recognize techno-socio-organizational aspects when implementing GSSO in EHRs, through flexible technical EHR designs to enable affirmation in data entry and output tasks, and addressing socio-organizational aspects to create an inclusive care environment.

A companion rapid review of grey literature from the last five years was also done to supplement the academic literature.<sup>107</sup> Findings from 23 such reports overwhelmingly highlighted the importance of cultural competence when dealing with GSSO data and documentation. Health care staff need appropriate, accurate language to create a welcoming environment for SGM, care practices must be grounded in SGM-competency, and be supported by organizational policies to ensure all staff and interactions are SGM-competent. There are many specific recommendations for SGM-competency in the reports. Examples are:

- Adopting a stance of cultural humility and including Two-Spirit as a sex, gender and sexual orientation concept are important for culturally safe and SGM-competent care for Indigenous people.
- Seeking explicit consent from SGM patients to document GSSO in EHRs and assuring them that the information will be kept confidential and only shared for health care purposes.
- Using anatomical inventories as an objective catalogue of organ parts to remove sex and gender assumptions for all patients.
- Being knowledgeable about the unique care needs of SGM, especially those who are transgender, intersex and Indigenous people, older GSM adults and newcomers.
- Acknowledging the legal rights of SGM to identify and express gender in a manner that is consistent with their identity as stipulated by the 2017 amended Canadian Human Rights Act.

### (c) Consultation Sessions

A series of virtual presentations and consultation sessions were held during March and August of 2020.<sup>108</sup> The presentations were by leaders who shared their approaches and experiences in GSSO data collection and use. The consultation sessions were with groups across Canada on ways to modernize GSSO information practices in Canadian EHR systems. The key takeaways from these sessions are:

- The need for an Indigenous perspective that is *“open to reflection of pre-colonial society gender differences for Indigenous people in Canada”*
- Mindful to *“separate policy on how we capture [GSSO data] in EHRs from the therapeutic conversations that we may have with an individual”*
- Legally, *“gender trumps sex”* but sometimes *“sex might trump gender in clinical setting”* where the need to address a health issue will give reasons to *“... ask the organ [question] and what body parts need to be cared for and/or screened for”*
- Sex at birth and administrative/legal gender are *“restricted by other systems (e.g., government IDs), but gender identity is where we have the opportunity to make a much more proud system”*
- Some suggested sex at birth should not be collected because of potential harm, but sometimes that information is needed as part of care. *“I don’t want to build a system around danger ... we should build very strict protocols on need to know basis. The information should be accessible when clinically necessary, and not accessible when it is not clinically necessary”*

<sup>107</sup> Davison K, Queen R, Lau F, Antonio M. *A Rapid Review of Grey Literature About Gender, Sex and Sexual Orientation Information Practices in Electronic Health Records*. Manuscript in preparation, unpublished

<sup>108</sup> Canada Health Infoway. *Sex and Gender Working Group*. n.d. From <https://infocentral.infoway-inforoute.ca/en/collaboration/wg/sex-gender>

- Focus should be on “*what organs do I have, or not have, and what my need is at the moment*” and “... *as a practitioner it does matter what body parts people have*”
- May need to “*blow up the binary. [Knowing one’s] organ inventories and hormone levels solve a lot of the problems ... have enough room to appropriately identify themselves that can be rolled up into different identities, while allowing a lot of choices for individuals*”
- LGBT and women are still invisible in the military, and “... *veterans are a specifically vulnerable Canadian patient population that requires veteran-specific identifiers in provincial health systems to allow for research to count, address care needs and knowledge gaps after military release/retirement*”
- Need a sense of “*corner-flags and priorities,*” “*overarching constraints*” or “*small-medium-large [implementation options] regarding cost and timing implications*” and “*which are the ones we know to be most important to use to create some priorities*”
- LGBT community should be empowered to offer their guidance of best way to be inclusive of terminology, as “*nothing about us, without us.*” There needs to be “*an officially recognized LBGTQ2A+ participatory voice*” to guide government in these decisions
- SGM communities already have a lot of mistrust with the health system because of systemic discrimination, bias and stigma. “*Before we ask these GSSO questions, we need to build trust, tell patients why we are collecting the data and how it will be used*”

#### (d) Alignment Opportunities

The team examined a number of SGM-related policy, practice and research initiatives that have recently been completed, are currently being planned, or are underway in Canada and abroad. Given the myriad of health system priorities, resource limitations and competing demands that exist across the country, there is strong motivation for this work to align with and leverage existing initiatives inside and outside of Canada to build on what works, amplify the efforts, and maximize the impact. Examples are provided throughout the action plan to demonstrate the path forward through strategic collaborations, alliances and partnerships where appropriate.

#### (e) Mind Mapping GSSO Concepts

The team also explored the GSSO concepts through a mind mapping exercise, which draws on ontological principles to define the relationships of a set of related concepts. The exercise involved the creation of visual mind maps to show the GSSO concepts and their relationships, and synonyms and definitions for each concept. In addition, the GSSO concepts were mapped to existing health terminology standards used in EHR systems (i.e., SNOMED CT and LOINC), with missing and inconsistent concepts highlighted.

**Note:** After the completion of this review more studies have been published.<sup>109 110 111 112 113 114</sup>

<sup>109</sup> Abramovich A, de Oliveira C, Kiran T, Iwajomo T, Ross LE, Kurdyak P. Assessment of health conditions and health service use among transgender patients in Canada. *JAMA Network Open* 2020; 3(8): e2015036. Doi: <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2769915>

<sup>110</sup> Dichter ME, Ogden SN, Scheffey KL. Provider perspectives on application of patient sexual orientation and gender identity in clinical care: A qualitative study. *Journal of General Internal Medicine* 2018; 33(8): 1359-65. From [https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6082205/pdf/11606\\_2018\\_Article\\_4489.pdf](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6082205/pdf/11606_2018_Article_4489.pdf)

<sup>111</sup> Suen LW, Lunn MR, Katuzny K, Finn S, et al. What sexual and gender minority people want researchers to know about sexual orientation and gender identity questions: a qualitative study. *Archives of Sexual Behaviors* 2020;49:2301-18. From <https://link.springer.com/article/10.1007/s10508-020-01810-y>

<sup>112</sup> Gogovor A, Mollayeva T, Etherington N, Colantonio A, Légaré F, on behalf of the GIKT Group. (2020). Sex and Gender Analysis in knowledge translation interventions: challenges and solutions. *Health Research Policy and Systems* 2020; 18:108. From <https://health-policy-systems.biomedcentral.com/articles/10.1186/s12961-020-00625-6>

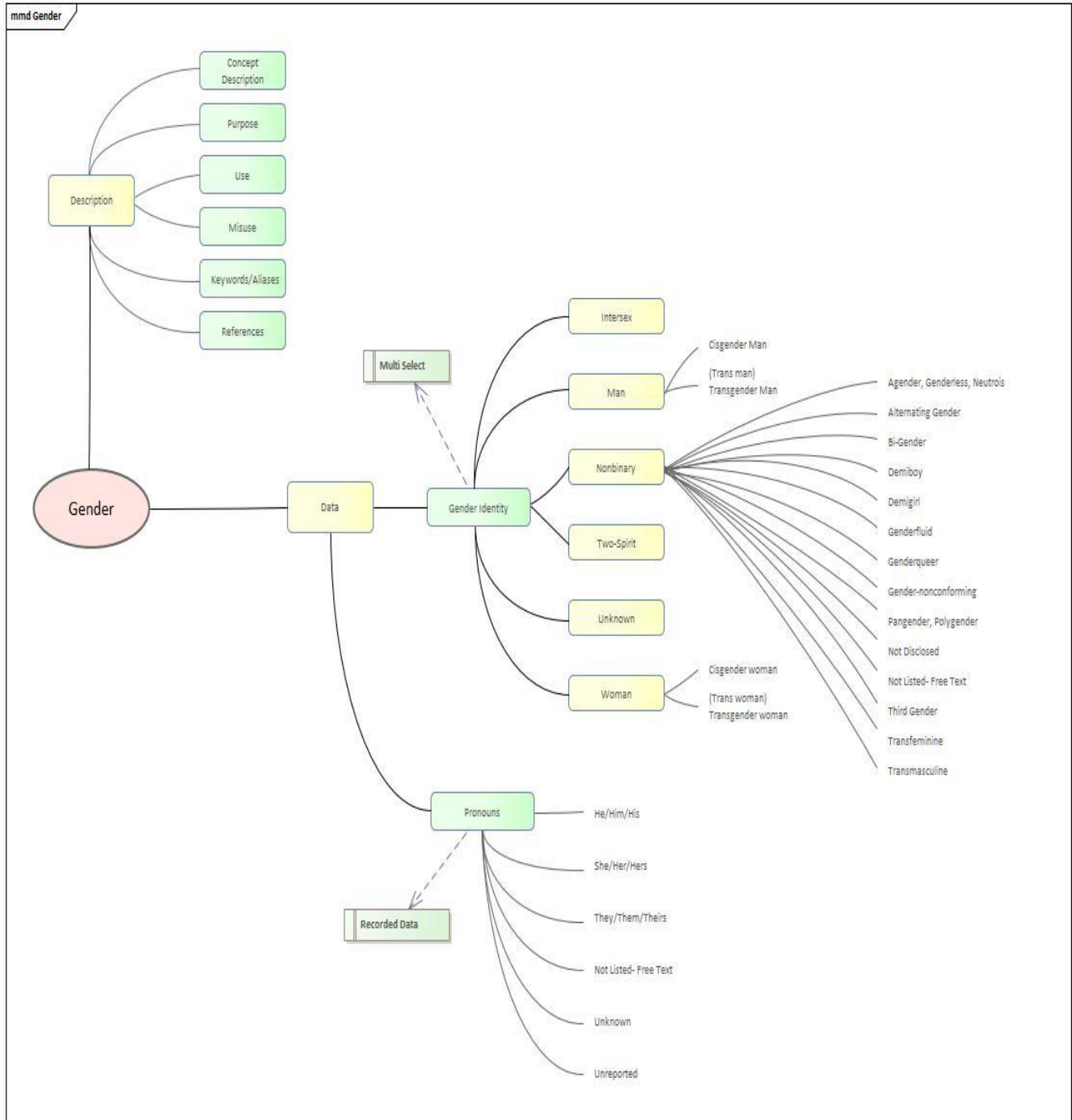
<sup>113</sup> The Intersex Roadshow. April 2011. From <https://intersexroadshow.blogspot.com/2011/04/intersex-genitalia-illustrated-and.html>

<sup>114</sup> Owen J, Hranilovic S, Nambiar D. Chapter 12. Supporting LGBTQ2S+ People. In *U of T Family Medicine Report. Caring for Our Diverse Populations* 2020. From [https://www.dfcu.utoronto.ca/sites/default/files/university\\_of\\_toronto\\_family\\_medicine\\_report\\_-\\_caring\\_for\\_our\\_diverse\\_populations.pdf](https://www.dfcu.utoronto.ca/sites/default/files/university_of_toronto_family_medicine_report_-_caring_for_our_diverse_populations.pdf)

# APPENDIX C - PROPOSED GSSO TERMINOLOGY

(a) Mind maps, as of Dec 2, 2020 <sup>115</sup>

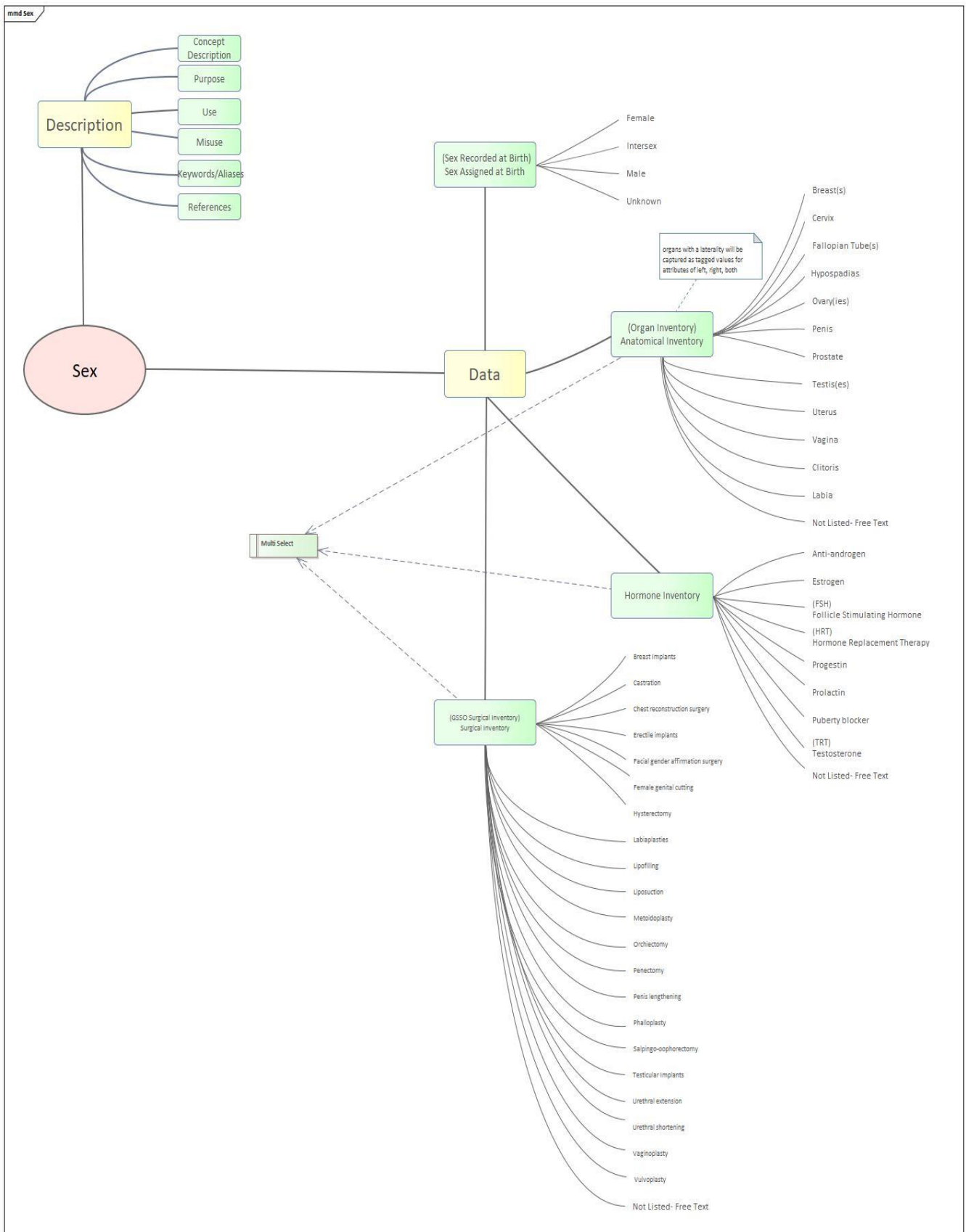
## Gender



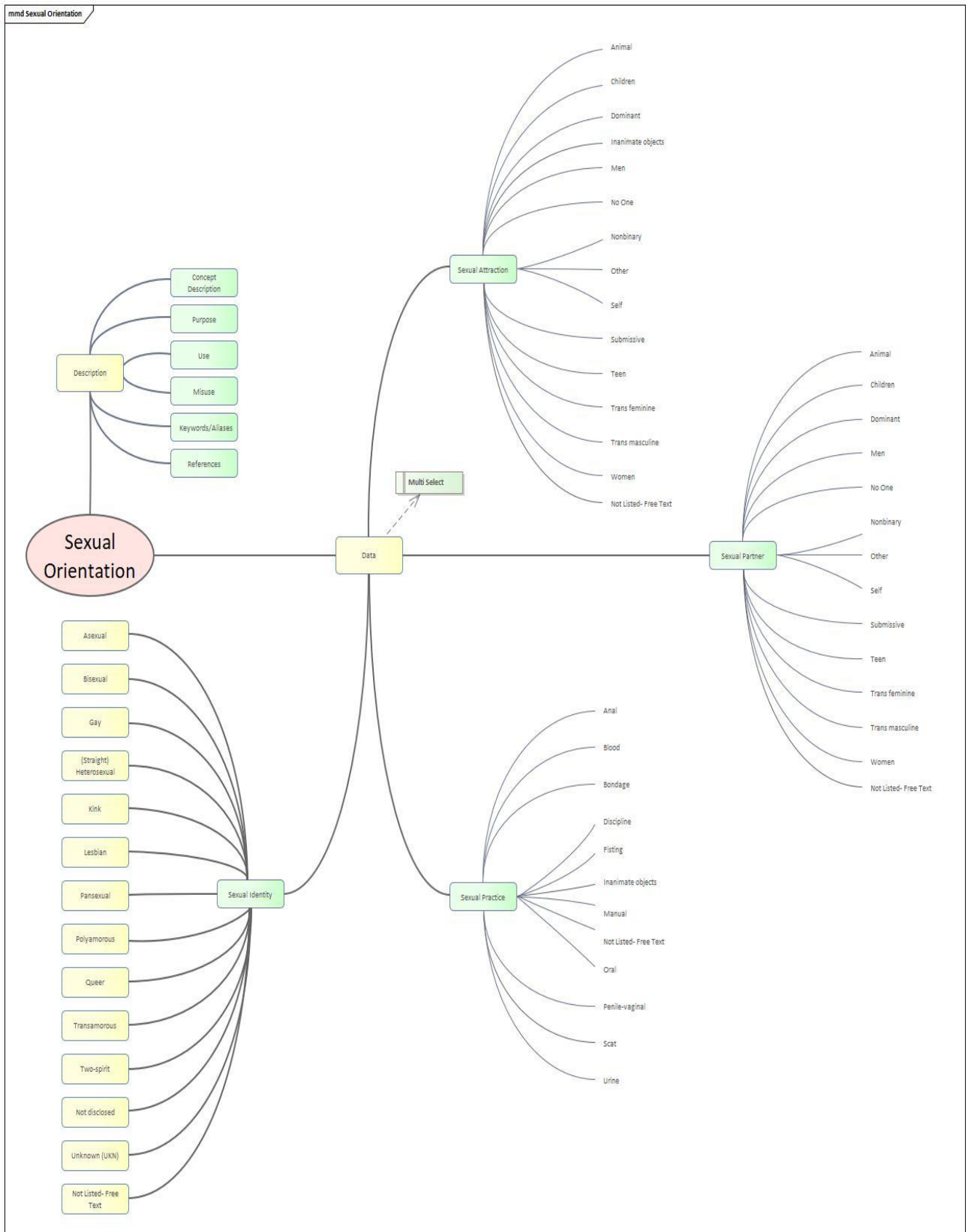
<sup>115</sup> These mind maps are created and maintained by Dorrell Metcalfe at Nova Scotia Health Authority using the software Enterprise Architect.



# Sex



# Sexual orientation





**(b) Glossary of concepts/terms – As of Dec 17, 2020**

Term	Definition
Gender-related concepts	
Administrative Gender	Gender recorded on primary official government documents such as birth certificates and passports or on other documents such as health care cards or drivers licenses A term used in most existing electronic health record systems that refers to either one’s sex or gender recorded and used for administrative purposes such as billing purposes. Also known as legal gender in some systems. Source – Burgess <a href="#">link</a>
Alternating Gender	The person’s expression alternates between two or more gender expression
Bigender	Referring to a person who identifies as having two genders. GovCanada <a href="#">link</a>
Cisgender	People whose current sex and gender identities match the ones they were assigned at birth. Source - Goldman <a href="#">link</a>
Demiboy	Also called a demiguy, demiman or demimale, refers to a person who partially, but not wholly, identifies as a man, boy, or otherwise masculine, regardless of their assigned sex at birth. They may or may not identify as another gender in addition to feeling partially a boy or man. GenderWiki <a href="#">link</a>
Demigirl	Also called demiwoman or a demifemale person, is a gender identity describing someone who partially, but not wholly, identifies as a woman, girl, or otherwise feminine, whatever their assigned sex at birth. They may or may not identify as another gender in addition to feeling partially a girl or woman. GenderWiki <a href="#">link</a>
Female Gender	This category includes persons whose current gender was reported as female. This includes cisgender and transgender persons who were reported as being female. StatCan <a href="#">link</a>
Feminine	A gender expression consistent with socially typical expectations for people assigned female at birth
Gender	Refers to the gender that a person internally feels (gender identity) and/or the gender a person expresses (gender expression) in their daily life, including at work, while shopping or accessing other services, in their housing environment, or in the broader community. A person’s current gender may differ from what is typically expected based on the sex a person was assigned at birth and may differ from what is indicated on their current legal documents. A person’s gender may change over time. StatCan <a href="#">link</a> Source – Goldman et al. <a href="#">link</a>
Gender Diverse	This category includes persons whose current gender was not reported exclusively as male or female. It includes persons who were reported as being unsure of their gender, persons who were reported as both male and female, or neither male nor female StatCan <a href="#">link</a> Umbrella term for people who are not cisgender.
Gender Identity	Each person’s internal and individual experience of gender. It is their sense of being a woman, a man, both, neither or anywhere along the gender spectrum. A person’s gender identity may be the same as or different from their birth-assigned sex. CIHI <a href="#">link</a> (p59) A person’s internal and deeply-felt sense of being man or woman, both, neither, or somewhere along the gender spectrum GovCanada <a href="#">link</a>
Gender-Nonconforming	The extent to which a person’s gender identity or gender expression differs from what is typically expected for people assigned to a particular sex or gender at birth. Source - Goldman et al. <a href="#">link</a>
Genderfluid	Referring to a person whose gender identity or expression changes or shifts along the gender spectrum. GovCanada <a href="#">link</a>
Genderqueer	An umbrella term with a similar meaning to non-binary. It can be used to describe any gender identities other than man and woman, thus outside of the gender binary. GenderWiki <a href="#">link</a>
Legal Gender	Gender recorded on primary official government documents such as birth certificates and passports. Also referred to as Administrative Gender or Sex, and as Recorded sex or gender in the proposed HL7 Gender Harmony Project
Male Gender	This category includes persons whose current gender was reported as male. This includes cisgender and transgender persons who were reported as being male. StatCan <a href="#">link</a>
Man	May be a gender identity and a gender expression. Does not require that the person was assigned male at birth.
Masculine	A gender expression consistent with socially typical expectations for people assigned male at birth
Neutrois, Agender, Genderless	Can be seen either as a non-binary gender identity, or as a statement of not having a gender identity. Agender people describe themselves as one or more of the following: genderless or lacking gender, gender neutral, neutrois, an unknown or undefinable gender that does not align with any binary or non-binary gender, not having words to fit their gender identity, not knowing nor caring about gender, deciding not to label their gender, identify more as a person than any gender at all.
Nonbinary	Referring to a person whose gender identity does not align with a binary understanding of gender such as man or woman GovCanada <a href="#">link</a> Gender identities adopted by people who reject the idea of gender binary. They may identify as partially a man and partially a woman or identify as sometimes a man and sometimes a woman or identify as some gender other than a man or woman, or as not having a gender at all. They most commonly use the pronouns they/them/their instead of he/him/his or she/her/hers. Some nonbinary people consider themselves to be trans or transgender; some do not because they consider transgender to be part of the gender binary. The shorthand NB (pronounced “enby”) is sometimes used as a descriptor for nonbinary people. Source - Goldman et al. <a href="#">link</a>
Pangender	Referring to a person who identifies as having all the genders culturally available to them. GovCanada <a href="#">link</a>
Polygender	Referring to a person who identifies as having multiple gender identities
Third Gender	Any gender identity other than man or woman.
Transfeminine	Anyone who was assigned male at birth and identifies more as a woman than as a man. Transfeminine people may identify as trans women, as nonbinary, as Two-Spirit, or as another gender identity. Source – Goldman et al. <a href="#">link</a>
Transgender	An umbrella term used to describe people whose gender identities and/or gender expressions are not what is typically expected for the sex and gender to which they were assigned at birth. Some nonbinary people identify as transgender and some do not.

Term	Definition
	Source – Goldman et al. <a href="#">link</a>
Transgender Man	Individuals who were assigned female at birth and who have gender identities as men. They may or may not have undergone any transition. Source – Goldman et al. <a href="#">link</a>
Transgender Woman	Individuals who were assigned male at birth and who have gender identities as women. They may or may not have undergone any transition. Source – Goldman et al. <a href="#">link</a>
Transmasculine	Anyone who was assigned female at birth and identifies more as a man than as a woman. Transmasculine people may identify as trans men, as nonbinary, as Two-Spirit, or another gender identity. Source – Goldman et al. <a href="#">link</a>
Two-spirit	An English-language term adopted by North American Indigenous peoples to communicate a broad range of identities used in indigenous communities. Each indigenous language has its own specific terms and nuanced cultural meanings. Two-Spirit can encompass any kind of gender identity or sexual orientation other than cisgender and heterosexual. Some people identify only as Two-Spirit. Some people identify as Two-Spirit and lesbian, or gay, or bisexual, or trans, or nonbinary. Only indigenous people should call themselves Two-Spirit. Source - Goldman et al. <a href="#">link</a>
Woman	May be a gender identity and a gender expression. Does not require that the person was assigned female at birth.
Pronouns	
Gender Pronoun	A personal pronoun chosen by a person that matches their gender identity. GovCanada <a href="#">link</a>
He/Him/His	This pronoun is traditionally masculine and used to refer to people who identify as men. Gender Wiki - <a href="#">link</a>
She/Her/Hers	This pronoun is traditionally feminine and used to refer to people who identify as women. Gender Wiki - <a href="#">link</a>
They/Them/Theirs	Commonly used as a third-person singular or plural pronoun by people who identify as nonbinary.
Sex-related concepts	
Legal sex	Sex as defined by legal documents, such as birth certificate, passport, driver’s license or health care card. Source – Goldstein et al.
Female	This category includes persons who were reported as being of female sex. Binary category of sex defined by XX chromosomal, and gonadal and anatomic characteristics typically associated with XX chromosomes. Source – Madsen <a href="#">link</a>
Intersex	A term that describes a person whose primary sex characteristics at birth do not meet the medical criteria of the male or female sex. Refers to variations in the development of sex characteristics, such as reproductive anatomy, sex chromosomes, or sex-related hormones that is not consistent with typical/medical definition of male or female. Note: Some existing systems used the terms indeterminate and/or undifferentiated but it is not clear if they have the same meaning
Male	This category includes persons who were reported as being of male sex. Binary category of sex defined by XY chromosomal, and gonadal and anatomic characteristics typically associated with XY chromosomes. Source – Madsen <a href="#">link</a>
Sex	A person’s status as male, female, or intersex based on biologic and physiologic characteristics. Sexes are usually assigned at birth based on simple visual inspection of the genitals of a newborn baby. Source – Goldman et al.
Sex assigned at birth	Sex assigned and recorded at birth, usually based on simple visual inspection of genitals of a newborn baby. Also known as birth sex. Source – Goldman et al. <a href="#">link</a> Note- The designation of male or female can reinforce sex being viewed as a binary rather than acknowledging variations in sex characteristics - <a href="#">link</a>
Sex Unknown	The person’s sex at birth was not recorded.
Inventory-related concepts	
Anatomical Inventory	Anatomical inventory allows providers to record into the chart (and/or updated as needed) the organs each patient has at any point in time; this inventory would then drive individualized auto-population of history and physical exam templates. Source Deutsch- <a href="#">link</a>
Chest reconstruction surgery	Surgical procedures to create a masculine chest for a transmasculine person. This surgery could also include breast reductions.
Facial gender affirmation surgery	A combination of surgical procedures to alter the appearance of a person’s face to make it look more congruent with their gender identity.
Hormone Inventory	An accurate record of what hormones a patient may or may not have. May include estrogen, FSH, testosterone, among others
Labiaplasty	Surgery that involves creating or modifying the labia minora (inner lips), and/or the labia majora (outer lips). Also known as vaginal rejuvenation when done for cosmetic purposes.
Metoidioplasty	Metoidioplasty, also known as meta, is a term used to describe surgical procedures for transmasculine individuals that fashion a small phallus from testosterone-enhanced clitoral tissues
Phalloplasty	Surgery that creates a penis. Can be combined with scrotoplasty, testicular implants and erectile implants.
[GSSO] Surgical Inventory	[GSSO] surgical inventory contains common treatments and procedures which may not be listed in current systems but should be included in the medical or surgical history of transgender patients. Source Deutsch- <a href="#">link</a>
Vaginoplasty	Surgery that creates a vagina. May be combined with vulvoplasty.
Vulvoplasty	A surgery that creates the vulva (including mons, labia, clitoris, and urethral opening)
X	Government-issued identification documents such as health card, birth certificate, passport, or driver’s license has an X in the sex and/or gender field. Used by people who do not identify as solely male or female or by people who do not want a specific gender marker to be visible on their identification.

Term	Definition
Sexual orientation-related concepts	
Anal	Sexual activity involving the anus
Asexual	A person who feels little to no sexual attraction
Bisexual	Refers to a person of one binary gender who is sexually or romantically attracted to those of the same binary gender and also to those of the other binary gender.
Blood	Sexual activity involving blood
Bondage	Sexual activity involving physically restraining a body, most commonly using rope, tape, or handcuffs
Discipline	Sexual activity involving controlling another's actions.
Dominant	A dominant person in bondage and discipline, sado-masochistic sexual practices. Also called a dom, femme, or top
Fisting	Sexual activity involving insertion of fists into anus or vagina
Gay	Refers to a person who identifies as one binary gender and is sexually or romantically attracted mainly to people of the same binary gender. This term is used to refer to both men and women, but is used primarily to refer to men.
Heterosexual	Refers to a person who identifies as one binary gender and is mainly attracted to people of the other binary gender.
Kink	An umbrella term for a wide range of paraphilias
Lesbian	Refers to a person who identifies as a woman and is sexually or romantically attracted mainly to women.
Polyamorous	Being sexually or romantically involved with multiple people at the same time. Often shortened to poly
Queer	As an umbrella term, queer is often used to describe any sexuality that is not heterosexual, or any gender that is not cisgender. As a sexual identity, queer refer to any sexuality that is not heterosexual.
Scat	Sexual activity involving feces
Sexual Attraction	One's sexual attraction to self or others, including people, animals, and objects.
Sexual Orientation	Patterns of sexual attractions, activities, identities.
Sexual Partner	The people, animals, and objects with which one engages in sexual activities.
Sexual Practice	The sexual practices in which a person engages with their sexual partner(s) or alone
Submissive	A submissive person in bondage and discipline, sado-masochistic sexual practices. Also called a sub, subbie or bottom
Transamorous	Being sexually or romantically attracted to trans people
Urine	Sexual activity involving urine

### (c) Supplementary Notes

- The mind maps in this report are GSSO concepts that reflect the contemporary societal view of SGM. These concepts will continue to evolve over time. Therefore, the mind maps will need to be maintained to ensure they are current.
- The gender concepts of man and woman require further discussion in finding ways to include boys and girls (i.e. ≤18yrs), and to ease the transition from male and female to man/boy and woman/girl,
- To implement the mind maps one needs to expand them into detailed data models as the next steps.
- Legal/administrative sex and legal/administrative gender are data field names defined in most existing EHR systems with limited value options (e.g. F, M, 1, 2, UNK, O). They are often used inconsistently and interchangeably in EHRs to represent sex or gender without recognizing them as two distinct concepts. As such, these concepts have been excluded from the mind maps<sup>116</sup>
- The concept of intersex requires further discussion on how to define it and the value options available

<sup>116</sup> Lau F, Antonio M, Davison K, Queen R, Bryski K. *An environmental Scan of sex and gender in electronic health records: Analysis of public information sources.* *Journal of Medical Internet Research* 2020; 22(11): November. From <https://www.jmir.org/2020/11/e20050/>

## APPENDIX D – GSSO DATA COLLECTION AND USE

This section contains references to published examples of (1) data input forms, (2) questions, (3) workflows, (4) outputs and (5) use case scenarios that involve GSSO data. Also included is the (6) reference to a complete EHR example with data input forms, outputs and decision rules from Fenway Health, (7) examples of Canadian GSSO data elements and values, (8) a use case template, (9) Canadian government documents with GSSO data, and (10) HL7 Gender Harmony Project initial ballot material on sex and gender context definitions.

### 1. Data input forms

- a. Sample client registration form, p8. *Ready-Set-Go: A Guide for Collecting Data on Sexual Orientation and Gender Identity, Updated 2020*. Fenway Institute. Available at [https://www.lgbtqihealtheducation.org/wp-content/uploads/2018/03/TFIE-47\\_Updates-2020-to-Ready-Set-Go-publication\\_6.29.20.pdf](https://www.lgbtqihealtheducation.org/wp-content/uploads/2018/03/TFIE-47_Updates-2020-to-Ready-Set-Go-publication_6.29.20.pdf)
- b. Recommendations for SO/GI data collection in EHR –table 1. Donald C, Ehrenfeld JM. The opportunity for medical systems to reduce health disparities among lesbian, gay, bisexual, transgender and intersex patients. *J Med Syst* [Internet]. 2015 Sep; 39(11): 178. At <https://link.springer.com/article/10.1007/s10916-015-0355-7>
- c. Fill-in-the-blank and checkbox methods. Little C, Cheevers C. *Best Practices: Electronic Medical Record Data Collection on Sexual Orientation and Gender Identity*. University of Colorado, Colorado. OneColorado; 2019. Available at [https://one-colorado.org/wp-content/uploads/2019/06/Best-Practices\\_-\\_Electronic-Medical-Record-Data-Collection-on-Sexual-Orientation-and-Gender-Identity-SOGI.pdf](https://one-colorado.org/wp-content/uploads/2019/06/Best-Practices_-_Electronic-Medical-Record-Data-Collection-on-Sexual-Orientation-and-Gender-Identity-SOGI.pdf)
- d. SOGI data collection form. Coffey J. *Care Considerations for Inclusion of Gender Diversity within Medical Laboratory Services*. Institute for Quality Management in Healthcare presentation. IQMH; 2019. Available at: <https://med-fom-polqm.sites.olt.ubc.ca/files/2019/11/For-website-Gender-Presentation-For-Sharing-Post-Conference.pdf>
- e. SOGI data collection form for adults and youth, p15-16. *Sinai Health System. Measuring Health Equity: Demographic Data Collection and Use in Toronto Central LHIN Hospitals and Community Health Centres*. Toronto, ON. SHS; 2017. Available at <http://torontohealthequity.ca/wp-content/uploads/2013/02/Measuring-Health-Equity-Demographic-Data-Collection-Use-in-TC-LHIN-Hospitals-and-CHCs-2017.pdf>
- f. SOGI data on lab requisition form, p17-8. Institute for Quality Management in Healthcare. Whitepaper: *Care Considerations for Inclusion of Gender Diversity within Medical Laboratory Services*. London, ON. IQMH; 2019. Available at: <https://iqmh.org/Portals/0/Docs/Resources/Education/White%20Paper%20-%20Care%20Considerations%20for%20Inclusion%20of%20Gender%20Diversity%20Within%20Medical%20Laboratory%20Services.pdf>
- g. Sample SOGI questions. National LGBT Health Education Centre. *Collecting Sexual Orientation and Gender Identity Data in Electronic Health Records*. Boston, MA. Fenway Health; 2016. Available at <https://www.lgbthealtheducation.org/wp-content/uploads/Collecting-Sexual-Orientation-and-Gender-Identity-Data-in-EHRs-2016.pdf>
- h. SOGI survey form. United States Federal Interagency Working Group on Improving Measurement of Sexual Orientation and Gender Identity in Federal Surveys. *Current Measures of Sexual Orientation and Gender Identity in Federal Surveys working paper*. United States. USSOGIIWG, 2016. Available at [https://s3.amazonaws.com/sitesusa/wp-content/uploads/sites/242/2014/04/WorkingGroupPaper1\\_CurrentMeasures\\_08-16.pdf](https://s3.amazonaws.com/sitesusa/wp-content/uploads/sites/242/2014/04/WorkingGroupPaper1_CurrentMeasures_08-16.pdf)
- i. Sexual orientation data collection form example. Bradford JB, Cahill S, Grasso C, Makadon HJ. *Policy focus: How to gather data on sexual orientation and gender identity in clinical settings*. The Fenway Institute. Available at [https://www.lgbthealtheducation.org/wp-content/uploads/policy\\_brief\\_how\\_to\\_gather.pdf](https://www.lgbthealtheducation.org/wp-content/uploads/policy_brief_how_to_gather.pdf)
- j. Two-step questionnaire on SOGI. Deutsch MB. *Guidelines for the primary and gender-affirming care of transgender and gender non-binary people*. 2nd ed. Center for Excellence for Transgender Health. University of California, San Francisco [dated 2016 June 17]. Available at <https://transcare.ucsf.edu/sites/transcare.ucsf.edu/files/Transgender-PGACG-6-17-16.pdf>
- k. Two-step questionnaire on SOGI –table 2. Bosse, JD, Leblanc RG, Jackman K, Bjarnadottir RI. Benefits of implementing and improving collection of sexual orientation and gender identity data in electronic health records. *Comput Inform Nurs* [Internet]. 2018; 36(8): 267-74. Available at [https://journals.lww.com/cinjournal/Abstract/2018/06000/Benefits\\_of\\_Implementing\\_and\\_Improving\\_Collection.3.aspx](https://journals.lww.com/cinjournal/Abstract/2018/06000/Benefits_of_Implementing_and_Improving_Collection.3.aspx)

- l. SOGI data collection form- chart 1. Callahan EJ, Sitkin N, Ton H, Eidson-Ton WS. Introducing sexual orientation and gender identity into the electronic health record: one academic health center's experience. *Acad Med* [Internet] 2015 Feb; 90(2): 154-60. Available at <https://pubmed.ncbi.nlm.nih.gov/25162618/>
- m. Two-step questionnaire. Tordoff DM, Morgan J, Dombrowski JC, Golden MR, Barbee LA. Increased ascertainment of transgender and non-binary patients using a 2-step versus 1-step gender identity intake question in an STD clinical setting. *Sex Transm Dis* [Internet]. 2019 Apr [cited 2020 May 27]; 46(4): 254-9. Available at <https://pubmed.ncbi.nlm.nih.gov/30516726/>
- n. Two-step questions. Reisner SL, Deutsch MB, Bhasin S, G, Bockting W, Brown GR, & Feldman J, et al. Advancing methods for U.S. transgender health research. *Curr Opin Endocrinol Diabetes Obes* [Internet]. 2016 Apr; 23(2): 198-207. Available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4916925/>
- o. SOGIE form for diagnostic imaging department. Pedersen VSS. Improving communication with the gender diverse community diagnostic imaging departments. *Radiography* [Internet]. 2018 Oct; 24(Suppl 1). Available at <https://pubmed.ncbi.nlm.nih.gov/30166006/>

## 2. Questions

- a. Provider questions to determine if patient is ready for hormones, p5. Trans Care BC. *Gender-affirming Care for Trans, Two-Spirit, and Gender Diverse Patients in BC: A Primary Care Toolkit*. Vancouver, BC, 2018. Available at <http://www.phsa.ca/transcarebc/Documents/HealthProf/Primary-Care-Toolkit.pdf>
- b. Interview questions for providers and staff. Zeigler E. *Exploring the delivery and implementation of primary care services for transgender individuals: An Ontario case study: Doctoral thesis*. McMaster University Institutional Repository; 2012. 206 p. 68. Available at <https://macsphere.mcmaster.ca/handle/11375/24479>
- c. Tips for culturally competent discussions – table 5. Goldman M, Butler-Foster T, Lapierre D, O'Brien SF, Devor A. Trans people and blood donation. *Transfusion* 2020; 60(May): 1084-92. Available from <https://onlineacademiccommunity.uvic.ca/ahdevor/wp-content/uploads/sites/2247/2020/05/Trans-people-and-blood-donation.pdf>

## 3. Workflows

- a. Sample process of collecting SOGI data -figure 5, p10. *Ready-Set-Go: A Guide for Collecting Data on Sexual Orientation and Gender Identity, Updated 2020*. Fenway Institute. Available from [https://www.lgbtqiahealtheducation.org/wp-content/uploads/2018/03/TFIE-47\\_Updates-2020-to-Ready-Set-Go-publication\\_6.29.20.pdf](https://www.lgbtqiahealtheducation.org/wp-content/uploads/2018/03/TFIE-47_Updates-2020-to-Ready-Set-Go-publication_6.29.20.pdf)
- b. Process of gathering LGBT data in clinical settings Bradford JB, Cahill S, Grasso C, Makadon HJ. *Policy focus: How to gather data on sexual orientation and gender identity in clinical settings*. The Fenway Institute [cited 2019 May 7]. Available at: [https://www.lgbthealtheducation.org/wp-content/uploads/policy\\_brief\\_how\\_to\\_gather.pdf](https://www.lgbthealtheducation.org/wp-content/uploads/policy_brief_how_to_gather.pdf).
- c. Workflow logic of collecting sex at birth and gender identity patient data. Deutsch MB, Buchholz D. Electronic health records and transgender patients – Practical recommendations for the collection of gender identity data. *J Gen Inter Med* [Internet]. 2015 Jun; 30(6):843-7. Available at: <https://pubmed.ncbi.nlm.nih.gov/25560316/>.
- d. Workarounds to collect SOGI data during encounters. Nadler LE, Ogden SN, Scheffery KL, Cronholm PF, & Dichter ME. Provider practices and perspectives regarding collection and documentation of gender identity. *J Homosex* [Internet]. 2019 Sep; 1-13 Available from <https://www.tandfonline.com/doi/abs/10.1080/00918369.2019.1667162?journalCode=wjhm20>

## 4. Outputs

- a. Patient ID labels. Deutsch, M. B., & Buchholz, D. (2015). Electronic health records and transgender patients--practical recommendations for the collection of gender identity data. *Journal of general internal medicine*, 30(6), 844-45. At [https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4441683/pdf/11606\\_2014\\_Article\\_3148.pdf](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4441683/pdf/11606_2014_Article_3148.pdf)

## 5. Use case scenarios



- a. Scenarios (i) transgender person providing information if person's identification has not been legally changed to reflect gender identity, (ii) transgender person providing information if person's identification has been legally changed to reflect gender identity, (iii) genderqueer person having to choose between male or female. Deutsch, M. B., & Buchholz, D. (2015). Electronic health records and transgender patients--practical recommendations for the collection of gender identity data. *Journal of general internal medicine*, 30(6), 844. Available at <https://doi.org/10.1007/s11606-014-3148-7>  
[https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4441683/pdf/11606\\_2014\\_Article\\_3148.pdf](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4441683/pdf/11606_2014_Article_3148.pdf)
  - b. Scenario (i) inadequate STI form options and lack of health info for LGBTQ people, (ii) interaction when physician is unaware of the patient's name/pronouns. Improved Patient Engagement for LGBT Populations: Addressing Factors related to Sexual Orientation/Gender Identity for Effective Health Information Management. (2017). *Journal of AHIMA*, 88(3), 34–39. Available at <https://link.springer.com/content/pdf/10.1007/s11606-014-3148-7.pdf>
  - c. Scenario of improper use of name, pronouns and gender if a person has not legally changed identity. Canadian House of Commons Standing Committee on Health. Committee Report: *The Health of LGBTQIA2 Communities in Canada*. Canada. Library of Parliament; 2019, p. 34. Available from: <https://www.ourcommons.ca/DocumentViewer/en/42-1/HESA/report-28/>
  - d. Case study on training employees on trans and LGBT interaction. Sinai Health System. *Measuring Health Equity: Demographic Data Collection and Use in Toronto Central LHIN Hospitals and Community Health Centres*. Toronto, ON. SHS; 2017, pp. 15-16. <http://torontohealthequity.ca/wp-content/uploads/2013/02/Measuring-Health-Equity-Demographic-Data-Collection-Use-in-TC-LHIN-Hospitals-and-CHCs-2017.pdf>
6. **Complete EHR example from Fenway.** Sex and gender presentation on Jun 9, 2020. Available at – <https://infocentral.infoway-inforoute.ca/en/resources/docs/sex-gender/sex-gender-presentations/3339-sex-and-gender-june-9-presentation-fenway-health-alex-keroghlian-and-chris-grasso>
- a. Pronoun colour codes
  - b. Patient chart view (screen)
  - c. Transgender intake form
  - d. Clinical decision support health maintenance variables needed
  - e. Decision support/health maintenance examples
  - f. Additional customization examples
  - g. Opportunities to monitor, use and report data on LGBTQ patients
  - h. Data quality and integrity checking
  - i. Stratifying unified diagnostic services (UDS) measures by sexual orientation and gender identity (SOGI)
  - j. Quality report examples, e.g. cancer screening, HIV testing rates, transgender dashboard

## 7. Canadian GSSO data elements and value options – Examples only

Organization	Data Element	Value Set	Source
AHS	Gender Identity	Agender, Choose not to disclose, Female, Gender Fluid, Intersex, Male, Non-binary, Not Listed, Questioning, Transgender Female, Transgender Male, Two Spirit	[a]
	Sex Assigned at Birth (only used when clinically relevant at time of encounter)	Female, Male, Unknown, Not recorded on Birth Certificate, Choose not to disclose	
	Administrative Gender (part of every patient record)	F-Female, M-Male, U-Unknown: Gender not asked or unable to collect generally used for administrative purposes, X-Does not identify their gender as male or female or has chosen not to disclose their gender	
	Sexual Orientation	Asexual, Bisexual, Choose not to disclose, Gay, Lesbian, Not Listed, Pansexual, Questioning, Straight, Two Spirit	
	Pronouns	She/Her/Hers, He/Him/His, They/Them/Theirs, Patient's Name, Decline to Answer, Unknown, Not Listed	
	Organ Inventory (ask what current organs a patient has)	Breasts, Cervix, Fallopian Tubes, Ovaries, Prostate, Testes	
CIHI	Sex at Birth	F-Female, M-Male, I-Indeterminate, UNK-Unknown	[b]
	Gender	F-Female, M-Male, D-Gender Diverse, UNK-Unknown, NA-Not Applicable	
Ontario Health Study Ontario Institutes for Cancer Research	Sexual orientation	Heterosexual or straight, Gay or lesbian, Bisexual, Prefer not to answer, Don't know	[c]
	Sex assigned at birth	Male, Female, Undetermined, Prefer not to answer	
	Felt gender	Male or primarily masculine, Female or primarily feminine, Both male and female, Neither male nor female, Don't know, Prefer not to answer	
	Lived gender	Male, Female, Sometimes male sometimes female, Third gender or something other than male or female, Prefer not to answer	[d]
	Current gender identity	Male, Female, Indigenous or other cultural gender minority (e.g. two-spirit), Other (e.g. gender fluid, non-binary), Prefer not to answer	
	Lived gender	Male, Female, Sometimes male sometimes female, Third gender or something other than male or female, Prefer not to answer	
Rainbow Health Ontario / Sherbourne Health	Sex assigned at birth	Female, Male, write-in option	[e]
	Gender	How do you identify your gender (with write-in option), Female, Male, Trans masculine, Trans feminine, Questioning, Prefer not to answer, write-in option	
	Sexual orientation	lesbian, gay, bisexual, pansexual, queer, two-spirit, questioning, heterosexual, prefer not to answer, other	
	Sexual behavior	MSM, WSW, serial monogamy, polyamory, celibacy, kink, etc.	
StatCan	Sex	M-Male, F-Female, I-Intersex	[f]
	Gender	M-Male gender, F-Female gender, D-Gender diverse	[g]
	Cisgender & transgender	C-Cisgender, T-Transgender	[h]
	Cisgender	CM-Cisgender man, CF-Cisgender woman	
	Transgender	TM-Transgender man, TF-Transgender woman, TG-Transgender person, n.e.c. (not exclusively classified)	
StatCan – Census 2021	Sex at birth	Male, Female	[i]
	Gender	Male, Female, or please specify this person's gender (space for typed or handwritten answer)	
TC LHIN	Gender	Female, Intersex, Male, Trans –Female to Male, Trans – Male to Female, Write-in option, Prefer not to answer, Do not know	[j]
	Sexual orientation	Bisexual, Gay, Heterosexual, Lesbian, Queer, Two-Spirit, Write-in option, Prefer not to answer, Do not know	
Un-named Example	Gender identity Sex at birth Sexual orientation Gender role Administrative gender Pronouns Titles (Ms, Mx, Mr)	<p>The source codelists (or value sets) for sex and gender should code each concept separately. Each concept would be associated with a codelist. Each codelist would include all possible options.</p> <p>Codelists (or value sets) should have no overlaps within a concept. For example, gender identity might include <i>non-binary</i>. A newer term like <i>enby</i> would be coded as non-binary. If the local community preferred the term <i>enby</i>, it could be added to the form, but it would be coded within the system as <i>non-binary</i>. This would provide flexibility regarding vocabulary while maintaining the ability to code for identical constructs over time and populations.</p> <p>What's important about this approach is that terms could be constructed from the various codelists as combinations. No one would ever have to fill out all the options. For example, for most social services, we would only need: gender identity, pronouns. Most social services do not need administrative gender for insurance, but if they do need more concepts they could be added. And under gender identity, a particular use case would only select a subset of possible options that are appropriate to the community served, e.g. 2-spirit, hijra, mizh manidoowag ...</p> <p>And for aggregation purposes, researchers could combine any terms as long as they described how the terms were combined and what the rationale was</p>	[k]

Legend: AHS – Alberta Health Services, CIHI-Canadian Institute for Health Information, StatCan – Statistics Canada, TC LHIN –Toronto Central Local Health Integration Network

## Source

- [a] Panas M. Personal email communication, Oct 13, 2020.
- [b] Canadian Institute for Health Information. *CIHI Reference Data Model Toolkit*, 2019. Available at <https://www.cihi.ca/sites/default/files/document/cihi-reference-data-model-toolkit-en.pdf>
- [c] OntarioHealthStudy. Baseline 1 Questionnaire, upload 2020-08. Available at <https://www.ontariohealthstudy.ca/wp-content/uploads/2020/08/OHS-Baseline-1-Qx-final-version-withToC-clean.pdf>
- [d] Kerr G. Personal email communication regarding OntarioHealthStudy COVID-19 questionnaire. Jun 24, 2020.
- [e] Nambiar D. *EHR inclusive intake and language Nov 10 presentation*. Rainbow Health Ontario / Sherbourne Health. Available at xxx
- [f] Statistics Canada. *Variant of classification of sex*, Jan 25, 2018. Available at <https://www23.statcan.gc.ca/imdb/p3VD.pl?Function=getVD&TVD=469276>
- [g] Statistics Canada. *Classification of gender*, Jan 25, 2018. Available from <https://www23.statcan.gc.ca/imdb/p3VD.pl?Function=getVD&TVD=467245>
- [h] Statistics Canada. *Classification of cisgender and transgender*, Apr 12, 2018. Available from <https://www23.statcan.gc.ca/imdb/p3VD.pl?Function=getVD&TVD=469267>
- [i] Statistics Canada. *Sex at birth and gender: Technical report on changes for the 2021 census*. July 20, 2020. Available at <https://www12.statcan.gc.ca/census-recensement/2021/ref/98-20-0002/982000022020002-eng.cfm>
- [j] Toronto Health Equity. *We Ask Because We Care*. Dec 2014. Available at [http://torontohealthequity.ca/wp-content/uploads/dlm\\_uploads/2014/12/TC-LHIN-Hospitals-Demographic-Questions-English-visible-v2.pdf](http://torontohealthequity.ca/wp-content/uploads/dlm_uploads/2014/12/TC-LHIN-Hospitals-Demographic-Questions-English-visible-v2.pdf)
- [k] Un-named example. Personal email communication with consultation session participant, Sep 2020.



## 8. Example of a GSSO-related use case template – As of Sep 22, 2020

This suggested template may be used to guide discussions around the types of data elements and value set options to be collected in different clinical use case scenarios, and the rationale for such data

When should these data fields be accessed										What use cases should be considered?											
Circumstances, Data Fields and Value Sets	Registration	Scheduling	Insurance	Billing	Report/letter	Lab	Imaging	Prescribing	Sexual history	Gender-affirming care	Questions	Add use case here	Add use case here	Add use case here	Add use case here	Add use case here					
	Patient identification number												Examples								
Chosen and legal name											What data do we need?										
Birthdate											How to identify patients?										
Administrative/legal gender											How to address patients?										
Effective date											How to communicate?										
Effective until date											How to provide care?										
Pronouns											How to protect privacy?										
Gender expression																					
Gender identity																					
Sex assigned at birth																					
Legal sex																					
Anatomic inventory																					
Hormonal inventory																					
Surgical inventory																					
Sexual orientation																					
DATA FIELDS AND VALUE SETS										What additional values should be considered?											
Patient identification number	Jurisdictional health care card number, Local patient ID																				
Chosen and legal name	Chosen/preferred/affirmed/social name, First name, Last name																				
Birthdate	YYYY-MM-DD, Year, Unknown																				
Administrative/legal gender	Female, Woman, Gender diverse, Male, Man																				
Effective date	Date on which recorded data become effective, e.g. administrative gender																				
Effective until date	Date on which recorded data become deprecated, e.g. administrative gender																				
Pronouns	He/him, She/her, They/Them, Ze/zir/Zirs, Write-in																				
administrative gender	Female/Woman, Gender diverse, Male/Man																				
Gender expression/Lived gender	Gender fluid (variable), Feminine, Masculine, Nonbinary, Not listed-free text																				
Gender identity	Nonbinary, Man, Unknown, Woman, Intersex																				
Man	Cisgender man, Transgender man/Trans man, Two-Spirit																				
Woman	Cisgender woman, Transgender woman/Trans woman, Two-Spirit																				
Nonbinary	Agender/Genderless/Neutrois, Alternating gender, Bi-gender, Demiboy, Demigirl, Genderfluid, Genderqueer, Gender-nonconforming, Pangender/Polygender, Third gender, Two-Spirit, Transfeminine, Transmasculine, Not disclosed, not listed-free text																				
Pronouns	He/Him/His, She/Her/Hers, They/Them/Theirs, Not listed-free text, Unknown, Unreported																				
Sex assigned at birth	Female, Intersex, Male, Unknown																				
Legal sex	Birth certificate, Driver's license/Provincial ID, Health card, Passport, Status card																				
Legal sex -Birth certificate	Female, Male, No indicator, X																				
Legal sex -Driver's license / provincial ID	Female, Male, No indicator, X																				
Legal sex -Health card	Female, Male, No indicator, X																				
Legal sex -Passport	Female, Male, X																				
Legal sex -Status card	Female, Male, No indicator, Two-Spirit, X																				
Anatomic inventory*	Breast(s), Cervix, Fallopian Tube(s), Ovary(ies), Penis, Prostate, Testis(es), Uterus, Vagina, Clitoris, Labia																				
Hormonal inventory	Anti-androgen, Estrogen, Follide Stimulating Hormone, Hormone Replacement Therapy, Progestin, Prolactin, Puberty Blocker, Testosterone																				
Surgical inventory	breast implants, Castration, Chest reconstruction surgery, Erectile implants, Facial gender affirmation surgery, Female genital cutting, Hysterectomy and salpingo-oophorectomy, Labiaplasties, Lipofilling, Liposuction, Metaoidoplasty, Orchiectomy, Penectomy, Penis lengthening, Phalloplasty, Testicular implants, Urethral extension, urethral shortening, Vaginoplasty, Vulvoplasty																				
Sexual orientation	Sexual identity, Sexual attraction, Sexual partner, Sexual practice																				
Sexual identity	Asexual, Bisexual, Gay, Heterosexual/Straight, Kink, Lesbian, Pansexual, Polyamorous, Two-Spirit, Not disclosed, Unknown, Not listed -free text																				
Sexual attraction	Animal, Child, Dominant, Inanimate objects, Man, On one, Nonbinary, Other, Self, Submissive, Teen, Trans feminine, Trans masculine, Woman, Not listed-free text																				
Sexual partner	Animal, Child, Dominant, Man, On one, Nonbinary, Other, Self, Submissive, Teen, Trans feminine, Trans masculine, Woman, Not listed-free text																				
Sexual practice	Anal, Blood, Bondage, Discipline, Fisting, Inanimate objects, Manual, Not listed-free text, Oral, Penile-vaginal, Scat, Urine																				
Add data field here	Add values here																				
Insert more rows if needed																					

\*Organs with laterality will be captured as tagged values for attributes of left, right or both

## 9. Sex and Gender Data in Legal Documents from Federal / Provincial / Territorial Governments - As of Nov 1, 2020

Jurisdiction	Document	Data field	Value set	Change to	Change process	Source	Comment
Federal	Indian Status	Sex	Male, Female	Female from Male or Male from Female.	There are two forms. One is for adults (16 and older), and one is for children (15 and younger). Children aged 15 and younger require consent from a parental guardian. Application can be completed in person at a regional office or sent in via mail.	<a href="#">Link</a> <a href="#">Form</a>	The sex must be the same sex as on the birth certificate, updating the sex on the birth certificate is required before updating the sex on a status card. The original birth certificate must be used. A Guarantor Declaration form signed by the guarantor is required for mail-in applications. Signed and dated photocopies of both sides of id are required.
Federal	Passport	Sex	F, M, or X, none	Can change from male, female, X, or none to female, male, or x (another gender)	Update gender identifier form	<a href="#">Link</a>	Cannot confirm all countries will accept the gender identifiers
Federal	Permanent Residency Card/Canadian Citizen Card	Gender	M, F, X	Can change from male to female or X. Can change from female to male or X. Can change from X to male or female.	Fill out a request for change of sex or gender identifier form.	<a href="#">Link</a>	
Federal	Social Insurance Number	Gender	Male, Female, X	Can change from male to female, female to male, male to X, female to X. X to female, or X to male.	Can apply in-person or by mail. Submit required documents. Sign and submit application form.	<a href="#">Link</a> <a href="#">Form</a>	No fee required. The list of required documents to be submitted with the application includes an original primary proof-of-identity document, and an original supporting proof-of-identity document. Photocopies of the documents are not allowed. Parents and guardians can apply on behalf of their minor children but must submit their own information/documents including primary proof-of-identity, government-issued identification, original letter of authorization (Stating that the this is the child's guardian), and original confirmation that this is the child's guardian.
Federal	Veteran's Service Card	N/A	N/A	N/A		<a href="#">Link</a> <a href="#">Form</a>	Sex or gender information is not captured on a Veteran's Service card, therefore, there is no change process.
Federal	Work permit, study permit, visa, or eTA	Gender identifier	M, F, X	Can change from male to female or X. Can change from female to male or X. Can change from X to male or female.	Fill out an application (separate one for each document).	<a href="#">Link</a>	The gender on your passport must be changed first. There is a different form to fill out if the gender identifier on these documents is incorrect.
Provincial - Alberta	Birth certificate	Sex	F, M, X	From M to F From M to X From F to M From F to X From X to M From X to F	Must request through Alberta registry agent	<a href="#">Link</a>	Those less than 18 can have this changed with a consent for minor form filled out by guardians.
Provincial - Alberta	Driver's license	Sex	F, M, X	Can change from male to female or X. Can change from female to male or X. Can change from X to male or female.	There is an application form and different options for a person under age 18 to change their gender.	<a href="#">Link</a>	Persons under 18 can have a guardian fill out a consent form or be married.
Provincial - BC	Birth certificate	Gender	F, M, X	From female, male, X to female, male or X.	Complete the application forms	<a href="#">Link</a>	Enhanced driver's licence and enhanced identification card cannot have X
Provincial - BC	Driver's License, BC Services card, and BC Identification Card	Gender	M, F, X	Can change from M to F or X. Or, can change from F to M or X.	There are two ways to update this. You can receive and submit an updated birth certificate, or	<a href="#">Link</a>	You will receive a "Gender information card" which explains to others what "X" means, if you choose to be identified as X.

					you can submit an application form and go to ICBC.		
Provincial - Manitoba	Birth certificate/birth registration/marriage registration	Sex	M, F, X	Change from M, F, X to M, F, or X.	Complete application form, sign declaration, return previous birth certificate, pay \$60.00	<a href="#">Link</a>	\$30 for birth certificate \$30 for birth registration
Provincial - Manitoba	Driver's license	Gender identifier	M, F, X	Can change from male to female or X. Can change from female to male or X. Can change from X to male or female.	Can be changed at an MPI service centre or Autopac	<a href="#">Link</a>	No supporting documentation or fee required.
Provincial - New Brunswick	Birth certificate	Sex	F, M, X	Male to female Male to X X to male Female to male Female to X X to female	Must write statement with new gender and medical professional must write one too.	<a href="#">Link</a>	Must be born in New Brunswick or lived there 3 months before change request. Can be changed with consent for children under 15.
Provincial - New Brunswick	Driver's license/health card/vehicle registration	Sex designation	M, F, X	Can change from male to female or X. Can change from female to male or X. Can change from X to male or female.	Once the sex on the birth certificate has been changed, the driver's license etc. can be changed at a Service New Brunswick	<a href="#">Link</a>	
Provincial - Newfound Land and Labrador	Birth certificate	Sex	F, M, X	Male to female Male to X X to male Female to male Female to X X to female	Application form, written consent for children under 16, written consent from medical professional for children under 16, and one extra for children under 12.	<a href="#">Link</a>	Birth certificate change fee of \$30 (online) or \$35
Territorial - NWT	Birth certificate	Sex	M, F, X	Male to female Female to male Male to X Female to X	Must complete application form and pay \$33.00	<a href="#">Link</a>	Parents can help those under 19 fill out the form
Territorial - NWT	Driver's licence	Sex	M, F, X	Male to female Male to X X to male Female to male Female to X X to female	Fill out application and go to licence office	<a href="#">Link</a>	No fee.
Provincial - Nova Scotia	Birth certificate	Sex indicator	M, F, X	Can change from male to female or X. Can change from female to male or X. Can change from X to male or female.	An application form to change the sex indicator must be complete. The current birth certificate must be submitted, and a declaration of consent that the identifyee identifies as this new gender.	<a href="#">Link</a>	You must order a new birth certificate; you can also choose to not have your gender displayed on the birth certificate. There is no fee for the first change in birth certificate. You can complete this process if you were not born in Nova Scotia but have been a resident for more than three months.
Provincial - Nova Scotia	Driver's licence	Gender identity	M, F, X, no indicator	From M to F, X, or no indicator. From F to M, X, or no indicator. From X to M, F, or X. From no indicator to F, M, or X.	Update it at Registry of Motor Vehicles or Access Nova Scotia	<a href="#">Link</a>	No fee
Territorial - Nunavut	Birth certificate	Sex	M, F, X	Change from male to female, female to male, male to X, or female to X.	Must complete application form and pay \$33.00	<a href="#">Link</a>	Parents can help those under 19 fill out the form
Territorial - Nunavut	Driver's license	Gender marker			Must contact GNWT Department of Infrastructure	<a href="#">Link</a>	

Provincial - Ontario	Birth Certificate	Sex	F, M, X	Male to female Male to X X to male Female to male Female to X X to female	Fill out application and declaration forms	<a href="#">Link</a>	Can also get a birth certificate that does not state sex
Provincial - Ontario	Driver's licence	Sex	F, M, X	Change sex from M to F or F to M. Can change sex to an X.	Visit a service Ontario centre	<a href="#">Link</a>	Do not require surgery to change sex
Provincial - PEI	Birth Certificate	Sex	M, F	Female to male, or male to female.	Request to change form	<a href="#">Link</a>	Must get confirmation from a physician
Provincial - PEI	Driver's license	Gender	X, Blank, M, F	Can change from Male to X, F, or blank. Can change from Female to M, X, or blank.	Go to Access PEI	<a href="#">Link</a>	
Provincial - Quebec	Birth certificate	Sex designation	M, F	Can change from male to female or from female to male.	There are three forms depending on the person's age, there is a form for persons above 18. There are two forms for persons aged 14-17, one that the parent fills out and the other the person fills out. For children under 14, the parent must fill out the form.	<a href="#">Link</a>	If the person has had a sex change, they must include documentation. If the person is under 18, they must include a letter from a physician, psychologist, social worker, etc. stating that this person deems the change appropriate.
Provincial - Quebec	Health insurance card, driver's licence, passport	Gender identity	M, F	Change from male or female to male or female.	Submit an application, decision is made by Directeur de l'etat civil.	<a href="#">Link</a> <a href="#">Link 2</a>	Surgery or medication not required for changes Required to acquire these new identification documents on your own
Provincial - Saskatchewan	Birth certificate	Sex designation			There are two steps 1). A signed declaration stating that the person will identify with the new gender. 2. There must be a letter from a physician or psychologist outlining that the person is capable of making this decision (if under 18) and identifying as this gender.	<a href="#">Link</a>	Person must be born in Saskatchewan. People can request to not have their sex displayed on their birth certificate. You must return previously issued birth certificates. There is a \$20.00 fee to change the birth certificate.
Provincial - Saskatchewan	Driver's licence	Sex	F, M, X	Change from male to female, female to male, male to X, or female to X.	Visit authorized licence insurance	<a href="#">Link</a>	No fee
Territorial - Yukon	Birth certificate/birth registration	Sex	M, F	Male to female. Or, female to male.	There are two applications, one for those over 16 years of age and one for those younger.	<a href="#">Link</a>	There is a \$10.00 fee.
Territorial - Yukon	Driver's license/ gender identification card	Gender	M, F	Can change from male to female or female to male.	Complete application form. Must be completed by applicant and physician or psychologist.	<a href="#">Link</a>	

**(10) HL7 Gender Harmony Project Initial Ballot Material – Sex and gender model element descriptions <sup>117</sup>**

Data element	Definition	Proposed Value Set
Gender Identity	An individual’s personal sense of being a man, woman, boy, girl or something else	Female, Male, Unknown, Nonbinary
Recorded Sex or Gender	A multi-element attribute that describes the sex and/or gender information recorded on a document at some time	Attributes Identity Type, Acquisition Date, Validity Period, Jurisdiction, Source Field Name, Source Field Description
Sex for Clinical Use	A category based upon observations related to a biological distinction between male and female	Female, Male, Complex, Unknown
Name to Use	Text attribute that provides the name that should be used for the patient	
Third Person Pronoun	Third-person pronouns specified by the patient to be used when replacing the person’s name when referring to the patient in speech, in clinical notes, and in written instructions to caregivers.	He, Him, His, Himself She, Her, Hers, Herself They, Them, Their, Theirs, Themselves Uses Other Pronouns Unknown Pronouns

<sup>117</sup> HL7 Gender Harmony Project. Ballot material. Available at <https://confluence.hl7.org/display/VOC/Ballot+material>

## APPENDIX E – PENDING WORK ITEMS

A list of items gathered from the ongoing discussions that need to be addressed as part of the next steps is compiled here. The items are listed in no particular order and the list is expected to grow over time.

1. Formal consensus on all action items
2. Who will take on the actions, how will the actions be carried out, and when will the actions be started and completed
3. Mapping of GSSO terminology to existing code systems and coded values
4. Communication and marketing plan to promote and raise awareness of this action plan
5. Change management and maintenance process for action items in the plan
6. Migration and risk mitigation strategies for organizations wishing to implement the action plan items
7. French and English language requirements
8. An inventory of all GSSO-related EHR initiatives in Canada (and elsewhere?)
9. An inventory of SGM-oriented and GSSO data use case scenarios
10. An inventory of GSSO data collection and use related workflow processes
11. An inventory of SGM-oriented clinical care and administrative guidelines
12. Monitoring and reporting on action plan progress
13. Discussion of 2-step data collection method for sex and gender as to its appropriateness
14. Discussion of all other outstanding issues and questions identified in this action plan