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Standards Developments for Improving Care for Transgender People

Kelly Davison

Abstract

Outdated GSSO information practices contribute to institutional and interpersonal stigma for transgender people in healthcare. Poorly defined data elements, conflated sex and gender concepts, constrained representation of gender variation, and lack of cultural understanding on the part of health information professionals and clinicians are contributing to healthcare environments and interactions that stigmatize transgender people and that drive health inequities. In this chapter, I will review recent developments in standards oriented toward addressing gender bias in the technical structures that support healthcare institutions. I will focus on the international work of Canada Health Infoway's Sex and Gender Working Group and the Health Level Seven International Gender Harmony Project. The intent is to provide an overview of these efforts and garner further interest, participation and adoption standards that support safe and gender-affirming healthcare for all people.

Keywords: GSSO information practices, Canada Health Infoway, Sex and Gender Working Group, HL7 International, Gender Harmony Model, health equity

1. Introduction

An estimated 1–3% of people in Canada are transgender, and just over 7% of Canadians identify as lesbian, gay or bisexual [1]. Approximately 32% of them report having unmet healthcare needs [2]. In the United States, there are over 1,000,000 transgender people, a third of which report avoiding healthcare for fear of discrimination [3]. Transgender people and sex and gender minorities (SGM) experience unnecessary and preventable health inequities including higher rates of mortality, depression, anxiety, substance use, chronic disease and suicidality which are, in part, the summary result of atrocious experiences of discrimination and stigmatization on the part of healthcare staff and institutions [1, 4–6]. Institutionalized cisheteronormativity, a term which refers to the culturally-driven normalization of cisgender, heterosexual status and the invisibilization of non-cis, non-heterosexual people [7, 8], is a primary social bias encoded into digital health structures and care cultures that prevents meaningful knowledge development about the health status

and needs of this population [1, 6, 7]. Poorly defined data elements, conflated sex and gender concepts, constrained representation of gender variation, and lack of cultural understanding on the part of health information professionals and clinicians are all conditions contributing to healthcare systems, environments and interactions that stigmatize transgender people, and that drive health inequities [1, 6–10]. Since 2019, technical, data and messaging standards development organizations (SDOs) have been working to modernize gender, sex and sexual orientation (GSSO) information practices in electronic health records (EHRs) to enable inclusive and affirming care for transgender people and SGM [1, 8, 11]. In this chapter, I will provide an overview of these recent innovations, including work of Canada Health Infoway's Sex and Gender Working Group and the HL7 Gender Harmony Model.

1.1 Health is a human right

The global population of transgender people and SGM live with higher burdens of disease and lower health than many other populations, especially cisgender people [12, 13]. Despite of the fact that the human rights of transgender people are protected by national and internal law [14], transgender people continue to face severe discrimination. The experiences of transgender people in healthcare, at the hands of healthcare staff, are atrocious [1], and ought to be a central concern to healthcare decision makers, policy makers and legal supports, and to society at large [15, 16]. Healthcare, as an organizational, regional, national and global social system with a specific ethical orientation that ought to adhere to, uphold, and advocate for the Universal Human Rights of transgender people, and *Health for All* [17]. Health is a human right [18]. Modernization of outdated gender, sex and sexual orientation information practices is a foundational step to creating healthcare institutions that are gender-affirming [9, 10, 12, 13].

2. Outdated GSSO information practices

Modernization of outdated GSSO information practices is an equity-oriented endeavor [19] intended to address the technical conditions that enable structural and institutional bias and that contribute to health inequities for transgender people and SGM [16]. Information practices include the definition, collection, organization, sharing and use of health information [17]. The term “Gender, Sex and Sexual Orientation” or “GSSO” was coined by C. Kronk, PhD of Yale University, who has created and published a Queer Ontology to facilitate increased awareness and improved understanding and consistency of use of GSSO terms [14, 20]. Outdated GSSO information practices include:

- Poor definition of GSSO information
- Conflation of the meaning of distinct gender and sex concepts.
- Problems related to collection of GSSO information
- Confusion as to who should be collecting what GSSO information, when, and for what purpose(s) in healthcare workflows.
- Problems related to the organization of GSSO information

- Use of sex and gender codes as though they are interchangeable and synonymous in administrative and clinical domains.
- Problems related to information sharing and exchange
- Problematic mapping of sex and gender codes between code systems in exchange standards.
- Inadequate representation of sex and gender diversity in exchange standards.
- Problems of use
- Unconscious bias and assumptions related to sex and gender concepts.
- Inadequate emphasis on quality clinical care and the therapeutic relationship for SGM.
- Overemphasis on business requirements and efficiency at the expense of clinical care quality.

3. Modernizing GSSO information practices

Building on the momentum of the work of such expert agencies as the Fenway Institute, Trans Care BC and Rainbow Health Ontario, there has been a recent increase in activity related to raising the critical awareness about the importance of diversity, equity, and the role of healthcare in creating the conditions for the well health of transgender people and SGM in North America and beyond [11, 12]. A diverse international community of people and organizations, including expert agencies, SDOs, researchers, EHR and solutions vendors, healthcare professionals and health information professionals, have dedicated their time and expertise to making healthcare more inclusive. In this section, I will discuss key developments within this community and key activities in relation to the healthcare of transgender people and SGM beginning with my own country, Canada.

3.1 Canada Health Infoway

Heading up the co-development, maintenance and support of technical and interoperability standards that support healthcare in the country, Canada Health Infoway (Infoway) has been a key organization enabling digital health in Canada since 2001. As Canada's National Release Center for such technical standards as the HL7 International information exchange standards, the Systematized Nomenclature of Medicine—Clinical Terms (SNOMED CT) and Logical Observation Identifiers, Names and Codes (LOINC), Infoway's mandate includes bringing a Canadian perspective to international standards development with SDOs such as HL7 International, SNOMED International, and the Regenstrief Institute. At the national level, Infoway collaborates with a network of pan-Canadian Healthcare Organizations, provinces, jurisdictions, vendors and governance bodies to support the implementation of technical standards in the Canadian digital health ecosystem and develops, maintains and publishes pan-Canadian and jurisdictional subsets via

the Terminology Gateway service. Infoway convenes stakeholders by establishing communities for collaboration and working groups on a central information sharing and engagement platform, InfoCentral. One such working group is Infoway's Sex and Gender Working Group (SGWG).

3.2 Canada Health Infoway's sex and gender working group

Infoway's SGWG was established in 2019 with the primary aim of modernizing outdated GSSO information practices in Canadian electronic health records [17] to support the health of all Canadians. Since then, this international community of researchers, pan-Canadian Health Organizations, healthcare agency representatives, subject matter experts, and people with lived experience have been convening monthly to share recent and relevant research, discuss the process of modernization [17] and lead modernization by taking evidence-informed action.

3.3 A proposed action plan to modernize GSSO information practices

After 2 years of convening, Infoway's Sex-Gender Working Group produced *A Proposed Action Plan to Modernize GSSO Information Practices in Canadian Electronic Health Records* (the Action Plan) in early 2021 [17]. This visionary work, led by Dr. Francis Lau of the University of Victoria and supported by a network of people and agencies participating in the SGWG including Health Canada, the Canadian Institutes of Health Research Institute of Gender and Health, Canada Health Infoway, the Canadian Institute for Health Information, the Canadian Health Information Management Association, the University of Victoria GSSO research team and more, provides a comprehensive summary of existing research and proposes a plan to modernize the outdated GSSO information practices that stigmatize transgender people and SGM [21]. Although grounded in the grassroots of Canadian healthcare, the vision, recommendations and research knowledge outlined the Action Plan could be applied internationally. There are seven primary aims of the GSSO Action Plan produced by the Infoway SGWG:

1. Envisage an equity- and SGM-oriented health system that embraces diversity and aligns with other SGM-related initiatives.
2. Engage organizations and communities across Canada to modernize GSSO information practices in EHRs that support equity-oriented healthcare and meet SGM needs.
3. 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. 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. 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. Educate and train healthcare 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. Establish a central hub to liaise, guide, assist and monitor the progress of this action plan over time [21].

Although there remains much work to do, members of Infoway's SGWG are using the Action Plan and its aims as a guide to specify and cultivate adoption of modern, consensus-based data, technical and exchange standards that address structural cishetermnormativity in Canadian healthcare. The community continues to meet on a monthly basis and drive new research, insights, and the development of modern approaches and practices to realize the aims outlined in the Action Plan.

The continued support of standards organizations such as Canada Health Infoway will play a foundational role in the ongoing process of modernization of healthcare. More information about Canada Health Infoway and Infoway Communities can be found on InfoCentral.

4. HL7 International

The beliefs, attitudes and organizational practices required to create culturally and psychologically safe, quality healthcare for transgender people will be adopted by individual health organizations. However, meaningful change will not happen unless the standards that we use to communicate health information from one service to another—the standards we use to connect a continuum of care services—are also modernized such that they are inclusive of transgender people and SGM and are designed to address the problems related to outdated information practices. Health information exchange standards (sometimes referred to as messaging standards) are powerful drivers of systemic change. As a world-leading exchange standard development organization, HL7 International plays an important role in the specification and implementation of health information exchange standards that support *Health for All*.

4.1 The HL7 International gender harmony project

In 2019, HL7 International created the Gender Harmony Project as an open, international collaboration of volunteers and experts from international agencies and SDOs dedicated to creating gender-inclusive standards in healthcare, and to addressing harms associated with biased exchange standards [11]. Members of this group have been meeting regularly to define, specify, model and explicate the Gender Harmony Logical Model since its establishment.

4.2 The HL7 International gender harmony logical model

In early 2021, the Gender Harmony Project produced the informative-ballot-for-comment that outlines the Gender Harmony Logical Model. Input on the document was collected from international stakeholders, and the first release of the informative document was published by the HL7 International Vocabulary Working Group in August of 2021: *Gender Harmony—Modeling Sex and Gender Representation, Release 1* [22]. The Gender Harmony Logical Model is a model that can be applied in the design of inclusive digital health systems and messaging standards such as HL7 version 2 (HL7v2), Version 3 (V3), Clinical Document Architecture (CDA®) and Fast Health Interoperability Resources (FHIR®) used to exchange health information between digital health systems [11]. The Gender Harmony Logical Model supports modernized design of interoperable EHRs and related standards, and is designed to enable:

4.2.1 Improved definition of gender and sex information

1. Unambiguous, evidence and consensus-based definitions of key sex and gender concepts that support model elements.
2. Avoidance of stigmatization in value sets by enabling nonbinary options without the use of such labels as “other” or “complex” in model elements.

4.2.2 Improved guidance on collection of gender and sex information

- Explicit description of model concept and element attributes means that organization of administrative and clinical GSSO information is clearly defined, streamlining GSSO data collection use cases.

4.2.3 Clear organization of gender and sex information

1. Clear definition of administrative and clinical sex and gender data.
2. Clear division between administrative and clinical sex and gender data in model elements.
3. Clear articulation of essential elements that support affirmative care interactions.

4.2.4 Semantic sharing and exchange

1. Unambiguously defined concepts and clear organization of model element concepts and attributes reduces risk for transformation of sex and gender concepts during sharing and exchange.
2. Representation of gender diversity in messaging standards.

4.2.5 Reduced risk of use of outdated information practices

1. Reduces unconscious bias and unchecked assumptions related to sex and gender.

2. Emphasizes care quality by supporting gender-affirming patient-provider interactions.
3. Supports business requirements by separating administrative data from clinical data.

The consistent application of the Gender Harmony Model in the design of joined-up health information systems is a shift in paradigms—from outdated GSSO information practices to modern ones, and a shift that enables quality healthcare for transgender people and SGM.

4.3 The gender harmony paradigm

The Gender Harmony Paradigm in healthcare is implementing systems design that addresses conditions resulting in health inequities for SGM. It involves meaningful integration of the HL7 Gender Harmony Logical Model, modern GSSO information practices and associated standards enabling culturally safer institutional policies and practices that support inclusive healthcare for transgender and SGM people. The Gender Harmony Model reduces real and latent harms associated with current gender constructs in health by: (1) decoupling administrative and clinical concepts in digital health systems; (2) addressing the conditions that lead to negative clinical interactions that deter transgender people from seeking care (e.g. being misgendered, misnamed or outed); and finally (3) by addressing conditions that make transgender people and people with nonbinary gender identities invisible to clinicians, policy makers, analysts and researchers who use health information for system improvement. At the patient level, the Gender Harmony Model enables clinicians' use of person-centred language in clinical interactions and provides them with the information necessary for objective and appropriate preventive screening, treatment and referral options based on unambiguous sex and gender health information. At the organizational level, implementation of the Gender Harmony Model involves the adoption and use of logical, technical and data standards necessary to support gender affirming care cultures and practices. At the health system level, implementation of the model orients clinical and institutional healthcare toward gender equity by addressing problems associated with the omission of data elements required to generate knowledge for health system improvement.

4.4 HL7 International gender harmony model overview

The Gender Harmony Logical Model, which I will call 'the Model' throughout the remainder of this chapter for ease of reading, does not exclusively benefit transgender and nonbinary people. All patients benefit from higher quality care and analytics enabled by the Model. Application of the Model can broadly be considered a step toward personalized medicine and more person-centred care since it enables more granular use and understanding of complex social and medical phenomena. The data elements of the Model [22] are designed to address the conditions that are currently leading to health inequities for transgender people such as problems associated with omission of data elements required for affirming care (i.e. Name to Use, Pronouns), conflation of administrative sex and gender concepts (i.e. Gender Identity, Recorded Sex or Gender) and by creating opportunities for clinicians to provide care by specifying care needs, rather than making assumptions related to outdated binary

constructs (i.e. Sex for Clinical Use) [11]. In this section, I will provide an overview of each data element and its specific attributes that support design and implementation decisions in digital health systems such as EHRs. Model data elements will be capitalized to improve readability.

4.4.1 Gender identity

In healthcare, knowing a patient's gender identity allows clinicians to provide informed and affirming, quality care, without misgendering them based on assumptions or pre-existing and out of date information in the patient record. All people have a gender identity. Gender Identity is a person or patient's personal sense of being a man, woman, boy, girl or something else [22]. Gender identity must be declared by the person or patient, rather than them being labeled with it. Gender identity is fluid and can change, and so must be collected routinely [23]. People can identify with none, one, or many genders, and can set time constraints on specific gender identities. Gender Identity should be used in conjunction with the other Model data elements to support gender-affirming, quality healthcare and should be validated privately with the patient to avoid outing them. Outing is when information about a person's gender or sexual identity is made known to specific people without permission. If this is done by a clerk or a clinician in the context of an emergency room or a waiting room, it may be directly harmful to the person being outed or lead to harm. As with all EHR data, informed consent about collection, sharing and use of Gender Identity information should be acquired before it is entered in the patient chart.

In order to ensure international applicability of the Model, the terms *male gender identity* and *female gender identity* have been used to represent gender identities associated with binary male and female sexes. The term nonbinary gender identity is proposed as a value option to represent code value options that are not accurately represented within the binary male/female construct [22].

Gender Identity is included in the Canadian Institute for Health Information CIHI Reference Data Model [24] (CRDM) and the United States Core Data for Interoperability Version 2 [25] (USCDIv2).

4.4.2 Name to use

Name to Use is the name that the person accessing healthcare services uses and wishes the care team to use. Importantly, Name to Use may not simply be a person's preferred name. Name to Use may be a name associated with the person's gender identity, and so should be used in healthcare interactions to avoid misnaming or outing people. Name to Use may or may not be consistent with a person's legal name. Mislabeled people based on legal records can be harmful, so it is best to ensure that the name the patient uses is validated privately, and that this validated information is updated in the patient record routinely and promptly upon patient arrival to prevent misnaming or outing in subsequent care interactions. Use of the Name to Use may be time-limited [22].

4.4.3 Pronouns

Pronouns (also called third person pronouns, personal pronouns and incorrectly often called preferred pronouns) and possessives are language tools used to communicate with and about people. They include such options as he/him/his, she/her/

hers, and they/them/theirs, among many options [7]. Pronouns come in sets. The most common pronouns used are gendered, and so by validating pronouns used by a patient and updating the care record before clinical interactions occur, intake staff can help ensure that patients are not misgendered by clinicians in subsequent interactions by the use of incorrect pronouns, and maintain the integrity of the therapeutic relationship. The Pronouns data element of the Model complements Gender Identity and Name to Use to ensure that communications with and about a patient are person-centred and affirming of their gender [21]. A useful rule of thumb is that until pronouns are confirmed by the patient, the gender-neutral options they/them/theirs can be used in interpersonal interactions to avoid misgendering. Like Name to Use and Gender Identity, patients may use more than one pronoun or set of pronouns, and their use of specific pronouns may be time delimited.

4.4.4 Recorded sex or gender

One of the primary problems associated with outdated GSSO information practices is that sex and gender concepts, the code values that represent them, the labels on the data fields they occupy and their distinct meanings, are conflated and used as though they are synonymous [6]. Administrative values cannot be used for clinical decision making with 100% reliability, particularly when used in the care of people whose sex at birth does not align with their gender identity and people who identify as transgender. Separating the sex or gender value that has been recorded on identification and other administrative or legal artifacts from clinical sex and gender identity helps to reduce unchecked assumptions about anatomy based on inaccurate recorded sex or gender information. The Model data element called Recorded Sex or Gender does just this: it separates administrative sex and gender information from the clinical sex and gender information, and is necessary to provide safe, quality, and gender-affirming clinical interactions.

Because there are so many different possibilities in the documentation that patients can present to support identification, it may be important to know the provenance of the Recorded Sex or Gender information. Provenance includes details about the jurisdiction that issued the record, its acquisition date, its validity period, and information about the source record including the name and definition of the field name and definition. Sex or gender information that is displayed on drivers' licenses, government IDs, birth certificates and other documents are Recorded Sex or Gender information. In many cases, this information is acquired through active interfaces between health information systems and government administrative databases via exchange standards. Inconsistencies between Recorded Sex or Gender data values and Gender Identity should not automatically be regarded as erroneous and should be validated with the patient.

Birth sex, or sex assigned at birth, as an example of recorded sex or gender that is present in most care records, is included in the CRDM [24] and the USCDIv2 [25].

4.4.5 Sex for clinical use

Sex for Clinical Use is a novel clinical data element that supports person-centred care by enabling clinicians to specify clinical sex beyond binary options based on different observations. Much like the explicit inclusion of a patient-declared Gender Identity, the key value of Sex for Clinical Use is that it enables the removal of unchecked assumptions about a person's sex that may be present in administrative

binary male/female constructs. To achieve this, a provider may refer to an anatomic inventory, a surgical history, a hormonal inventory or other artifacts that inform the context for the observation. Four such examples include:

- ordering a screening mammography for a transman who has had top surgery;
- specifying testicular protection for a transgender woman receiving an imaging procedure;
- referencing a nonbinary hormonal reference range for a nonbinary person in transition; or
- ordering a Pap smear for a man whose sex assigned at birth does not match his gender identity.

Full transition is not always required to address gender dysphoria [10], but the ability for providers to reduce unchecked assumptions based on recorded sex or gender, and provide agile, appropriate and quality care to all people is an important feature that the model supports. Value options that are proposed for the model include 'male,' 'female' and 'specified' sex for clinical use. The term 'specified' was chosen for the Model to eliminate stigma associated with a value options of 'complex' (not all patients who may benefit from the use of this element are particularly complex), to align with the use case where an option is specified by the provider, and to enable backwards compatibility with (and avoid use) of the stigmatizing term 'other,' as is so commonly used in health information systems [8].

5. Stigma, encoded

When used together, the five data elements of the Gender Harmony Logical Model facilitate the tight alignment between social concepts, code systems, health terminology standards, exchange standards, EHR design and healthcare practices required to address stigma and drive health equity through the provision of gender-affirming care. However, code systems and health terminology standards are dynamic in nature and remain prone to the inappropriate codification of stigmatizing or pathologizing terms, codes or concepts [4]. As society becomes more complex and technology become more ubiquitous, the importance of remaining vigilant for standards that exclude marginalized populations and intersectional patient identities will become increasingly important. Primary care providers, in particular, are instrumental to the implementation of changes that will close the equity gap for transgender people because they provide the bulk of preventive screening and treatment related care and serve as a primary coordination point for patients. Modernized GSSO information practices help primary care providers to ensure that patients are appropriately matched to their care needs, and that assumptions related to conflated sex and gender concepts are avoided [13]. However, regulated health information professionals that have healthcare-specific training and awareness of healthcare models, ethics and practice will play a critical role in supporting modernization efforts. Certified Terminology Standards Specialists (CTSS), Certified Classification and Coding Specialist (CCCS), Certified Healthcare Information Management (CHIM) professional credentials, signal professional adherence to a base set of demonstrated

competencies and ethics, and professionals with health information credentials such as these are more likely to have knowledge about the importance of the therapeutic relationship and downstream impacts of technical design on patient care [26]. A major responsibility of certified health information professionals is to align technical design with clinical requirements such that the integrity of this most sacred and fundamental component of healthcare—the therapeutic relationship—is protected. Like credentialed and regulated clinicians, certified health information professionals are accountable for upholding the core evidence-based values and ethics that support healthcare (i.e., person-centred care, trauma-informed care, the Gender Harmony Logical Model). The Digital Health Revolution has arrived [27], and the ongoing datafication of healthcare and society means that informatics professionals must regularly visit their ethics to ensure they are aligned with healthcare values, develop critical awareness of the impact of structural bias in data and technical design and standards on social justice, cultivate ethical communities around the design and analysis of information systems and standards, and evaluate the impact of their work on the lives of the patients they serve [28].

6. Conclusion

Transgender people experience unnecessary and preventable health inequities that are, in part, the result of social bias encoded into the technical and data structures that connect systems in the digital health ecosystem. Poorly defined data elements, conflated sex and gender concepts, constrained representation of gender variation in code systems, outdated terminology standards and health information exchange standards contribute to this harm. Canada Health Infoway's Sex and Gender Working Group is an international, transdisciplinary community of people and agencies with an Action Plan to modernize gender, sex and sexual orientation information practices in healthcare. The HL7 International Gender Harmony Project has recently published the first release of the informative document for the Gender Harmony Logical Model, a consensus-based, evidence-informed logical model developed to address outdated information practices and support the modernization of healthcare for sex and gender minorities. Though there remains much work to do, this dedicated international community of professionals, researchers and people with lived experience are undertaking actions that enable inclusive and affirming care for transgender people and SGM.

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Conflict of interest

The author(s) declare no conflict of interest.

Notes/thanks/other declarations

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References

- [1] Canadian House of Commons Standing Committee on Health. Committee report: The health of LGBTQIA2 communities in Canada [Internet]. Casey B, editor. The Parliament of Canada; 2019. Available from: <https://www.ourcommons.ca/DocumentViewer/en/42-1/HESA/report-28/>
- [2] Giblon R, Bauer GR. Healthcare availability, quality, and unmet need: A comparison of transgender and cisgender residents of Ontario, Canada. *BMC Health Services Research*. 2017;**17**(1):283
- [3] Kronk CA, Everhart AR, Ashley F, Thompson HM, Schall TE, Goetz TG, et al. Transgender data collection in the electronic health record: Current concepts and issues. *Journal of the American Medical Informatics Association*. 2021:1-14
- [4] Ram A, Kronk CA, Eleazer JR, Goulet JL, Brandt CA, Wang KH. Transphobia, encoded: An examination of trans-specific terminology in SNOMED CT and ICD-10-CM. *Journal of the American Medical Informatics Association*. 2021:1-7
- [5] Baldwin A, Dodge B, Schick VR, Light B, Scharrs PW, Herbenick D, et al. Transgender and genderqueer individuals' experiences with healthcare providers: What's working, what's not, and where do we go from here? *Journal of Healthcare for the Poor and Underserved*. 2018;**29**(4):1300-1318
- [6] Kattari SK, Bakko M, Langenderfer-Magruder L, Holloway BT. Transgender and nonbinary experiences of victimization in healthcare. *Journal of Interpersonal Violence*. 2021;**36**(23-24):NP13054-NP13076. DOI: 10.1177/0886260520905091. Epub 2020 Feb 11
- [7] Carrera-Fernández MV, Lameiras-Fernández M, Blanco-Pardo N, Rodríguez-Castro Y. Preventing violence toward sexual and cultural diversity: The role of a queering sex education. *International Journal of Environmental Research and Public Health*. 2021;**18**(4): 2199
- [8] Gato J, Leal D, Moleiro C, Fernandes T, Nunes D, Marinho I, et al. "The Worst Part Was Coming Back Home and Feeling Like Crying": Experiences of lesbian, gay, bisexual and trans students in Portuguese schools. *Frontiers in Psychology*. 2020;**10**:2936
- [9] 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):e20050
- [10] Davison K, Queen R, Lau F, Antonio M. Culturally competent gender, sex, and sexual orientation information practices and electronic health records: Rapid review. *JMIR Medical Informatics*. 2021;**9**(2):e25467
- [11] McClure RC, Macumber CL, Kronk C, Grasso C, Horn RJ, Queen R, et al. Gender harmony: Improved standards to support affirmative care of gender-marginalized people through inclusive gender and sex representation. *Journal of the American Medical Informatics Association*. 2021:1-10
- [12] Antonio M, Lau F, Davison K, Devor A, Queen R, Courtney K. Toward an inclusive digital health system for sexual and gender minorities in Canada. *Journal of the American Medical Informatics Association*. 2021:1-6

- [13] 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 the American Medical Informatics Association*. 2020;**27**(11):1774-1783
- [14] Kronk C. Modeling and Operationalizing Gender, Sex and Sexual Orientation: Recommendations and Future Directions [Internet]. Canada Health Infoway Sex-Gender Working Group, University of Cincinnati; 2021 [cited: 2021 Jul 2]. Available from: <https://infocentral.infoway-inforoute.ca/en/collaboration/wg/sex-gender>
- [15] Divan V, Cortez C, Smelyanskaya M, Keatley J. Transgender social inclusion and equality: A pivotal path to development. *Journal of the International AIDS Society*. 2016;**19**:20803
- [16] Swartz TH, Palermo A-GS, Masur SK, Aberg JA. The science and value of diversity: Closing the gaps in our understanding of inclusion and diversity. *The Journal of Infectious Diseases*. 2019;**220**(Suppl. 2):S33-S41
- [17] Rifkin SB. Alma Ata after 40 years: Primary healthcare and health for all—From consensus to complexity. *BMJ Global Health*. 2018;**3**(Suppl. 3):e001188
- [18] Safer JD, Coleman E, Feldman J, Garofalo R, Hembree W, Radix A, et al. Barriers to healthcare for transgender individuals. *Current Opinion in Endocrinology, Diabetes, and Obesity*. 2016;**23**(2):168-171
- [19] Browne AJ, Varcoe C, Ford-Gilboe M, Nadine Wathen C, 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**(1):154
- [20] Kronk C, Tran GQ, Wu DTY. Creating a queer ontology: The gender, sex, and sexual orientation (GSSO) ontology. *Studies in Health Technology and Informatics*. 2019;**264**:208-212. DOI: 10.3233/SHTI190213
- [21] Infoway Sex and Gender Working Group. A Proposed Action Plan to Modernize Gender, Sex and Sexual Orientation Information Practices in Canadian Electronic Health Record Systems. Planning Project [Internet]. Canada Health Infoway; 2021. Available from: <https://infocentral.infoway-inforoute.ca/en/resources/docs/3496-gsso-action-plan-full-document/view-document>
- [22] HL7 International. HL7 Informative Document: Gender Harmony—Modeling Sex and Gender Representation, Release 1 [Internet]. HL7 International; 2021 [cited: 2021 Aug 29]. Available from: https://www.hl7.org/implement/standards/product_brief.cfm?product_id=564
- [23] National LGBT Health Education Centre FH. Collecting sexual orientation and gender identity data in electronic health records [Internet]. Fenway Health; 2018. Available from: <https://www.lgbtqiahealtheducation.org/wp-content/uploads/Collecting-Sexual-Orientation-and-Gender-Identity-Data-in-EHRs-2016.pdf>
- [24] Canadian Institute for Health Information. CIHI Reference Data Model Toolkit. p. 105
- [25] Office of the National Coordinator for Health Information Technology. United States Core Data for Interoperability Version 2 [Internet]. Office of the National Coordinator for Health Information Technology; 2021 [cited: 2021 Jul 17]. Available from:

<https://www.healthit.gov/isa/sites/isa/files/2021-07/USCDI-Version-2-July-2021-Final.pdf>

[26] Kluge E-H, Lacroix P, Ruotsalainen P. Ethics certification of health information professionals. *Yearbook of Medical Informatics*. 2018;**27**(1):037-040

[27] Duggal R, Brindle I, Bagenal J. Digital healthcare: Regulating the revolution. *BMJ*. 2018;**360**:k6

[28] Taylor L. What is data justice? The case for connecting digital rights and freedoms globally. *Big Data & Society*. 2017;**4**(2):205395171773633