SEEING US AS WE ARE: Gender, Sex, & Sexual Orientation Identification in Electronic Health Records

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Issue

Understanding diversity in gender, sex, and sexuality is important in medicine, but you wouldn't know it based on our record systems

Every patient is asked to fill out forms, often as a first step to receiving healthcare. Yet electronic health records (EHRs) in Canada are not set up to accurately capture gender, sex, and sexual orientation (GSSO) information. This means the lived realities of many 2S/LGBTQIA+ people are misrepresented or not captured in the healthcare system, preventing them from accessing safe, appropriate, and affirming care.

Creating data collection and storage systems that properly recognize 2S/LGBTQIA+ people is a crucial action needed to affirm patients' identities, improve access to appropriate care, and foster cultural competency among healthcare workers.

Recommendations

- **Create electronic health record systems that include 2S/LGBTQIA+ identities.** Health Canada should encourage the adoption of precise, inclusive, appropriate, and evolving terminology to more accurately capture gender, sex, and sexual orientation information. This must include collaborations with provincial and territorial governments to ensure that standardized definitions, coding schemes, and value sets are adopted across the country.

- **Engage the community.** Federal, provincial, and territorial governments should engage and partner with communities and community-based organizations in the design and rollout of modern-ized systems to more accurately capture gender, sex, and sexual orientation information.

- **Protect our information.** When health system data about our identities are collected, studied or used in research, ensure necessary safeguards are in place to protect this information.

- **Don't stop with record keeping.** Also educate healthcare workers. Provincial and territorial governments should train and raise awareness among healthcare workers to provide cultural-ly-competent and safe care so that people can comfortably and safely share their gender, sex, and sexual orientation information.

Background

Decades-old data collection systems need to catch up

Canada has used EHR systems since the mid-1960s,[1] but to date there are no regulations on how health-care institutions should collect GSSO information. This means patient forms and health records can vary from situation to situation, with most EHR systems not set up to accurately capture GSSO data. This obscures the lived realities of 2S/LGBTQIA+ people, especially those who are transgender or gender-diverse.[2]

For instance, our understandings of sex and gender have grown to see them as distinct concepts, with sex referring to someone's physical characteristics (such as male, female, or intersex) and gender referring to how that person identifies and lives their life in relation to socially constructed norms and behaviours. However, these terms are still used interchangeably in most EHRs. This conflated and poorly understood use of sex

and gender has contributed to structural barriers for 2S/LGBTQIA+ patients when they try to access safe, appropriate, and affirming care. This can lead to a wide range of health consequences.

When it comes to sexuality, many EHRs don't include any questions about sexual orientation, leaving patients unclear of how or when to bring up what may be crucial information in relation to their care. In other cases, fields related to sexual orientation are binary, asking patients to choose between lesbian/gay or straight. However, there's a host of other sexual identities (like bisexual, asexual, pansexual and many more) that could impact the care a patient may need or want to receive—especially in relation to sexual health.
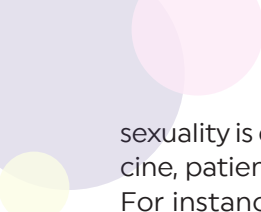
As Canada's healthcare system faces mounting pressures, we should respond not just with increased investments, but also by changing the way we offer care—and we wouldn't be starting from scratch. Canada Health Infoway, a federally-funded not-for-profit organization seeking a more collaborative and interconnected national digital health system, has identified the issue of inadequate GSSO data collection and has been leading efforts to modernize these practices since 2019.[3] The World Professional Association for Transgender Health has also published a set of recommendations on improving EHRs[4] and a significant body of research continues to highlight opportunities to better the experience of 2S/LGBTQIA+ patients through EHRs.[5]

The Consequences

Poor health records translate to poorer health outcomes

Many 2S/LGBTQIA+ people experience discrimination, stigma, ostracization, and violence. In turn, 2S/LGBTQIA+ patients have higher rates of mortality, depression, suicide, and chronic diseases, while facing barriers to health screening and preventive care.[6] In seeking help, 2S/LGBTQIA+ people turn to the healthcare system. But when the system itself is not designed to recognize 2S/LGBTQIA+ identities this makes it more difficult for people to receive the care they need and deserve.

For example, trans and non-binary patients may be deadnamed or misgendered when accessing care from a new or different healthcare worker if their EHRs are not accurate—the risk of which has been shown to drive transgender and gender-diverse people away from seeking care.[7] Poor categorization of sex and gender in EHRs can also impact the type of care received.

Trans women and some gender-diverse people, for instance, are often less up-to-date with breast and cervical cancer screenings than cisgender women.[8] This, in part, is due to the fact that many clinics in Canada use letters and telephone calls to notify patients of recommended or overdue screenings for breast, cervical, and colorectal cancers—initiatives that largely rely on gender/sex recorded in health records. When gender and sex are conflated in EHRs, or there are limited options, 2S/LGBTQIA+ people can be missed in this outreach.

In healthcare, many interventions are also unique or nuanced according to sexual orientation. When hetero-

> *"From looking at me, it's hard to tell I was born male and the doctors don't know that. So they'll ask me questions like, when was your last menstruation? I would like them to just know that off the bat, so that I don't have to have the awkward conversation. It's kind of disconcerting when doctors are, like, surprised."*

> *"I don't actually like blood [testing] places, they misgender me all the time and they don't care. They see the 'F' on the thing and then they don't know how to relate it to the blood test work."*

> *"I remember going even for an eye exam and being really hesitant about writing down my birth name. I was like, I don't even want you to write that down. I am a new patient here, this is what my name is. Like, you don't need to write down my old name."*

Anonymous testimonials from 2S/LGBTQIA+ people in Canada

sexuality is considered the default orientation in medicine, patients may miss crucial opportunities for care. For instance, men who have sex with men may miss out on interventions such as PrEP (a highly-effective HIV prevention medication), or information relevant to epidemiological trends, such as the emergence of Mpox (formerly known as "Monkeypox") in the summer of 2022. Meanwhile, in 2021, one quarter of gay, bisexual, trans, or queer men in Canada were not out to their family doctor or nurse practitioner.[9] Normalizing discussions related to sexual orientation and sexuality in clinical settings would allow many more Canadians to access appropriate care. Accurately recording sexuality in EHRs would also reduce burdens on patients to repeatedly have to come out when they go to a new clinic or interact with a new healthcare worker.

Overall, knowing patients' sex, gender identity, and sexual orientation is an important part of patient-centred care, allowing healthcare workers to learn about their patients' lives and to provide care with a better understanding of their lived experiences. Anything less is a disservice to 2S/LGBTQIA+ patients.

Data Gap

We can't solve a problem if we can't measure it

When we collect data using only binary categories, and few variables related to GSSO, we miss out on crucial information. This renders many 2S/LGBTQIA+ people less visible in health data, and by extension, in the healthcare system.

We know less than we should about 2S/LGBTQIA+ people's health needs, which settings they access care in, whether they receive appropriate care, and their health outcomes. Health research about 2S/LGBTQIA+ patients is largely conducted through primary research studies, rather than using health system data, because of this data collection gap. This means we have fewer insights into the specifics and realities of 2S/LGBTQIA+ patients. This lack of data results in a lack of action. For example, 2S/LGBTQIA+ people experience disproportionate harm from substance use, including overdose; yet, primary research on this topic is sparse and limited in scope.[10] GSSO information in EHRs could shed light on this issue and spark change—for instance, prompting relevant clinical resources to be shared in jurisdictions with large 2S/LGBTQIA+ populations.

According to the Canadian Institute for Health Information (CIHI), collecting race-based and Indigenous identity data is essential for measuring health disparities and inequalities that stem from racism, bias, and discrimination.[11] CIHI released an interim data collection standard in 2020 with an aim to do safer and more appropriate data collection for these communities. CIHI also affirms that health systems across Canada need to be able to identify inequities experienced by racialized and Indigenous groups and implement systemic changes to advance equity in healthcare. The same can and should be accomplished for 2S/LGBTQIA+ communities, many of whom are also Black, Indigenous, and other People of Colour.

Taking steps to improve GSSO data also aligns with other recommendations from health system research. Take, for instance, the "learning health system" framework; one founded on the principle that a health system should be responsive to itself—able to combine internal data with external evidence and put that knowledge into practice.[12] As a result, patients in a learning health system get higher quality, safer, more efficient care, and care delivery organizations become better places to work. By replicating that approach—better collecting information through EHRs, more comprehensively reflecting on that collected data, and sufficiently integrating it into healthcare solutions—everyone seeking care would benefit.

Getting to the Source

No more ad-hoc solutions. We need EHRs to evolve

While it's true that many 2S/LGBTQIA+ patients are receiving the care they need by communicating their full selves to healthcare workers, 2S/LGBTQIA+ patients shouldn't have to go through the emotional labour to clarify their identities a within a system that is not build with them in mind. This can be exhausting, and may be another reason why 2S/LGBTQIA+ patients access care at lower rates, or don't disclose their identities. Such omissions can also put patients at risk because healthcare workers will not have a full picture of patients and what care they might need.

Similarly, healthcare workers may try to "fix" the system themselves by recording a patient's full gender, sex, and sexual orientation information outside of the EHR system, such as in paper-based notes or patient charts.[13] But, such records are sensitive and highly personal, and when healthcare workers resort to ad hoc data capture styles, patients' privacy may be at risk. Everyone has a right to protection of their personal information, which is why EHRs in Canada are regulated for privacy.[14] 2S/LGBTQIA+ patients are not afforded the same privacy standards as their cisgender counterparts when their GSSO information is not stored with appropriate protections.

Building on Better

Updating EHRs won't be enough. Practitioners also need to learn.

Maintaining appropriate and up-to-date GSSO information for patients is an important step in improving care for 2S/LGBTQIA+ people. These changes must be accompanied by support for healthcare workers.[15]

Healthcare workers often lack the training, resources, and confidence to provide safe, affirming, and appropriate care to 2S/LGBTQIA+ patients. For instance, healthcare workers may not have a shared understanding of GSSO terminology. The lack of shared understanding across healthcare institutions can cause confusion, inconsistent use of GSSO information, and miscommunications about patients, which can have a negative effect on the quality and type of care they receive. So, even if the EHRs are updated to reflect the more authentic lived experience of 2S/LGBTQIA+ patients, it will have little effect if healthcare workers continue to use outdated and inconsistent language. Such gaps in training can contribute to and exacerbate health inequities 2S/LGBTQIA+ people face, and have consequences for patients' comfort levels, trust, and decisions to seek care.

The Opportunity Before Us

Solutions are already within reach

Updating and standardizing EHRs isn't just a matter of replacing the old with the new. This is an exciting, promise-filled opportunity to improve the way people navigate through and experience the healthcare system. And unlike other challenges in such a system, the tools for improving EHRs are already at our disposal. In British Columbia, for example, efforts are underway to standardize and link up EHRs across different regions— and there has been a large rollout of EHR technology in several clinics and hospitals. This represents a huge milestone for Canada, the benefits of which are already being realized by all healthcare users in BC.

By creating national standards for EHRs, informed by diverse communities of 2S/LGBTQIA+ people, continuity of care can be improved for many more people.

Conclusion

Canada's EHR systems must be modernized to improve care for 2S/LGBTQIA+ people. Building EHRs that are inclusive and evolving helps ensure that personal health records are reliable, allowing healthcare workers to provide appropriate and affirming care. It will also contribute to closing the gap between 2S/LGBTQIA+ health outcomes and those of other people, and will inform how healthcare evolves into becoming more inclusive and 2S/LGBTQIA+-oriented.

This update cannot happen without consultations and partnerships with communities and organizations, as well as collaboration between researchers, policy-makers, and implementers to ensure required safeguards are in place to protect such information. Training and resources for healthcare workers should also be given so that they are able to provide culturally competent and safe care, and resources should be made available to inform patients on the need for GSSO data collection, how to use GSSO terminology, and protections for safe access and use.

References

1. Chauvette A, Paul P. (2016). History of nursing informatics in Canada. Canadian Journal of Nursing Informatics, 11(4). https://cjni.net/journal/?p=5032

2. Roberts T, Fantz C. (2014). Barriers to quality health care for the transgender population. Clin Biochem, 47 (10-11): 983–7.

3. https://infocentral.infoway-inforoute.ca/en/collaboration/wg/sex-gender

4. Deutsch MB, Green J, Keatley J, et al. (2013). Electronic medical records and the transgender patient: recommendations from the World Professional Association for Transgender Health EMR Working Group. J Am Med Inform Assoc, 20 (4): 700–3.

5. Lau F, Antonio M, Davison K, et al. (2020). A rapid review of gender, sex, and sexual orientation documentation in electronic health records, Journal of the American Medical Informatics Association, 27 (11): 1774–1783, https://doi.org/10.1093/jamia/ocaa158

6. Wallace BC, Santacruz E. Health disparities and LGBT populations. LGBT psychology and mental health: emerging research and advances. Santa Barbara, CA: Praeger. 2017 Oct 27:177-96.

7. Deutsch MB, Buchholz D. (2015) Electronic Health Records and Transgender Patients—Practical Recommendations for the Collection of Gender Identity Data. J GEN INTERN MED 30, 843–847. https://doi.org/10.1007/s11606-014-3148-7

8. Kiran T, Davie S, Singh D, et al. (2019) Cancer screening rates among transgender adults: Cross-sectional analysis of primary care data. Can Fam Physician, 65(1): 30-37. PMID: 30674526; PMCID: PMC6347308.

9. https://www.cbrc.net/ourstats_dashboard

10. Moazen-Zadeh E, Karamouzian M, Kia H, Salway T, Ferlatte O, Knight R. A call for action on overdose among LGBTQ people in North America. The Lancet Psychiatry. 2019 Sep 1;6(9):725-6.

11. https://www.cihi.ca/en/race-based-and-indigenous-identity-data

12. Institute of Medicine (US) Roundtable on Evidence-Based Medicine; Olsen LA, Aisner D, McGinnis JM, editors. (2007) The Learning Healthcare System: Workshop Summary. Washington (DC): National Academies Press (US). Available from: https://www.ncbi.nlm.nih.gov/books/NBK53494/ doi: 10.17226/11903

13. Nadler LE, Ogden SN, Scheffey KL, et al. Provider practices and perspectives regarding collection and documentation of gender identity. J Homosex 2021; 68 (6): 1–13.

14. Electronic Health Records: a Glimpse Into the Legal Framework

15. Lau F. (2021). An Action Plan to Modernize Gender, Sex, and Sexual Orientation Information Practices in Canadian Electronic Health Record Systems. Canadian Journal of Community Mental Health, 40(3): 73-76. https://doi.org/10.7870/cjcmh-2021-022

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