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Ethics Column - Digital Health Systems – Let's Talk About Sex (and Gender)

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Digital Health Systems – Let's Talk About Sex (and Gender)

Abstract

Historically, within digital health information systems, sex and gender have been conflated as a single concept and often have been limited to a binary answer. This has led to inappropriate care, erosion of client trust and avoidance of the healthcare system. Healthcare leaders can improve care for all clients with technical and clinical information practice initiatives. While procurement processes could require digital health systems that utilize modern gender, sex and sexual orientation (GSSO) terminology, for most health leaders, technical initiatives will focus on modernizing existing systems to the maximum extent possible. Terminology updates may not be immediately visible to clients, but providing the correct information to clinicians will support respectful client encounters. Simultaneously, clinical information practice initiatives can directly affect clinical encounters. Change management strategies need to include all levels of employees and redesign tools and workflows to support modernized information handling practices.

Introduction

While there's greater recognition publicly that sex and gender are two different concepts, quite often our modern digital health information systems such as the electronic health record, are built on the legacy of conflating the two concepts as a single information field.[1] Furthermore, in many digital health information systems, the only accepted value for the field is binary (male or female).[2]

Sex information is routinely collected for administrative as well as clinical purposes. Administratively, sex information is used to match a client with non-healthcare identification for billing purposes. Clinically, sex information has been a shorthand method for understanding a client's anatomy such as organs and hormones and used for preventive care (screening or radiological shielding), interpretation of diagnostic tests, and treatment planning. In our existing systems, the single sex data field is inadequate for this purpose. It incorrectly assumes that sex, and corresponding anatomy and hormones, are unchanging over the human life span. For example, expected values for prostate specific antigen differ for clients post prostatectomy. Without connecting the current anatomic information to the laboratory results, incorrect and potentially fatal clinical assumptions will be made. Yet, our existing information systems may not connect that information in a way that is useful for clinicians.

There is ongoing work to separate sex information into different fields for administrative and clinical purposes. Although the long-term goal may be the inclusion of organ and hormone inventories within the electronic health record to more accurately guide clinical decision making, in the interim, a separate field "Sex for Clinical Use" (SFCU) has been proposed. The SFCU field will allow clinicians to specify the crucial information that needs to be included with an order or a result. In our example above, the clinician would be able to specify "male, post prostatectomy" and thereby link the laboratory order and results with the relevant clinical information.

Gender is felt as part of one's identity and may or may not reflect their sex or be expressed. Gender information in healthcare is collected to provide respectful care to clients.[3] It is often collected with pronoun and preferred name to use information. Collecting gender information from all clients helps to avoid mis-gendering. Gender information is also important for assessing health services program and policy outcomes.[4]

Modernizing gender, sex and sexual orientation (GSSO) information practices affects all clients. Use of a solitary binary field has led to issues of inappropriate care and client harm as well as client distrust and avoidance of the healthcare system. Healthcare staff may lack the skills and confidence to interact with clients regarding their sex and gender information. Gender diverse clients experience health inequities such as higher rates of mortality, chronic disease, depression, suicide and lower rates of preventive care.[5-7]

Ethical Leadership

While the clinical rationale for modernizing GSSO information practices may be obvious, there are also ethical reasons for doing so. At a basic level, some have argued that individuals and organizations have a fiduciary responsibility to their clients, such that organizations and their leaders are accountable for the outcomes of healthcare processes.[8] The Canadian College of Health Leaders updated Code of Ethics includes standards relevant to modernizing GSSO information practices (Table 1).[9]

Table 1: Canadian College of Health Leaders Code of Ethics Standards

Contexts	Code of Ethics Standards
Individual	• Practice in a manner that exemplifies and promotes equity, diversity, inclusivity and intersectionality • Respect confidentiality of information
Organizational	• Strive to provide quality and safe health services • Promote public understanding of health and health services • Conduct activities in cooperative ways to improve linkages, continuity of care and the health of the community • Promote a healthy work environment that is respectful, safe, resilient and makes the best use of employee skills, knowledge and experience
Professional	• Practice cultural humility in a manner that respectfully honors diversity and difference
Community	• Participate in public dialogue and recommend actions to improve health services and enhance the health of the population in all its diversity • Strive to identify and meet the health needs of the community • Assess the impact of leadership, policy, governance, and government decisions on the health of the community and society • Advocate for changes in policies and practices that adversely impact the health of the intersectional, diverse populations of the community and society

Katherine Duthie outlined the ethical considerations for healthcare leaders regarding the care of transgender clients.[10] Duthie describes ethical issues of autonomy; non-malfeasance; trust; and privacy and confidentiality at the micro, meso and macro levels in healthcare. The issues raised by Duthie would affect all clients when modernizing GSSO information practices.

When looking at ethics specific to health information practices, the International Medical Informatics Association (IMIA) Code of Ethics is useful for identifying additional ethical concerns.[11] In addition to the principles of autonomy and non-malfeasance, not modernizing GSSO practices generates ethical issues regarding beneficence and integrity. Modernizing GSSO information practices could support the principle of beneficence by improving the quality of care with more accurate client information. The principle of integrity, or the responsibility to fulfill one's obligations to the best of one's ability, is affected by outdated GSSO terminology and information displays. Modernization would support clinicians and staff in providing respectful care.

The IMIA Code of Ethics[11] is more specific regarding privacy and confidentiality. Four of the information principles would be affected by modernizing GSSO information practices (Table 2). The first three principles, Information-Privacy and Disposition; Openness; and Access call attention to how information is used and controlled throughout healthcare. By using these more specific principles, both technical and clinical initiatives would address the "life-course" of information in the organization: collection, storage, access, use, communication, manipulation, linkage, re-use and disposition. All four of these principles put the rights of the client as central.

Table 2: IMIA Code of Ethics - Information-Related Principles

Principle	Definition
Information-Privacy and Disposition	All persons and group of persons have a fundamental right to privacy, and hence to control over the collection, storage, access, use, communication, manipulation, linkage and disposition of data about themselves
Openness	The collection, storage, access, use, communication, manipulation, linkage and disposition of personal data must be disclosed in an appropriate and timely fashion to the subject or subjects of those data
Security	Data that have been legitimately collected about persons or groups of persons should be protected by all reasonable and appropriate measures against loss degradation, unauthorized destruction, access, use, manipulation, linkage, modification or communication
Access	The subjects of electronic health records have the right of access to those records and the right to correct them with respect to its accurateness, completeness and relevance.

The Role of Healthcare Leaders

Healthcare leaders can improve the care for all clients with technical and clinical information practice initiatives.

A Canadian Action Plan was co-created in 2020 with the Canada Health Infoway Sex and Gender Working Group.[12] The full Action Plan may be found on the Infoway Sex and Gender Working Group (SGWG) site.[13] Of the seven transformative actions listed in the Action Plan, four are particularly relevant for health care leaders (Table 3).

Table 3: Relevant Action Plan Items for Healthcare Leaders

Action Plan Items	Description
Action 3:	Establish GSSO terminology for patient care, health system use of data, and research.
Action 4:	Enable digital health systems to collect, use, exchange, and reuse standardized GSSO data
Action 5:	Integrate and tailor GSSO data collection with organizational structures, policies, use cases, and workflow processes.
Action 6:	Educate and train staff to provide culturally competent and safe care, and educate patients to understand the need for GSSO data.

Healthcare organizations are encouraged to participate in the monthly meetings of the Infoway SGWG as best practices for GSSO modernization are developed and discussed. SGWG members are collaborating with international organizations on GSSO terminology updates, including updates to the Canadian version of SNOMED-CT[14] and the HL-7 Gender Harmony project[15].

Technical Initiatives

While the way information is encoded within and exchanged by digital health systems may seem esoteric, it can affect the quality of client care. Patient and family advisory groups should be a part of the process to modernize GSSO terminology.

If actively procuring new digital health systems, modern GSSO terminology inclusion may be one of the requirements requested of vendors. Similarly, vendors may be asked for how sex and gender fields may be customized to meet organizational needs. Outside of the procurement process, existing digital health systems may be able to accommodate some of the new sex and gender fields and options. There are a number of healthcare organizations in Canada that are optimizing their systems now rather than waiting for the next generation of digital health systems or the next procurement opportunity.[12,16]

First steps for some organizations may be transitioning to differentiated fields for sex and gender. For other organizations, modernizing may mean updating the options for clients for sex and gender fields. For others, modernization may be including a SFCU field or beginning work on organ and hormone inventories.

A thorough examination of how data is used and re-used throughout the system is important before embarking on these changes. For example, is sex information being used in embedded decision support systems, such as dosage calculators? Is gender or pronoun information reused in written communications with the client? Likewise, how is sex or gender information currently being used in analyzing program or policy outcomes? Modernization will likely result in greater precision for clinical services and for evaluating program or policy outcomes. Client control of information sharing will need to be considered as these changes propagate through the digital health systems.

Clients have complained that outdated sex information from non-healthcare documents have overridden their more recent and correct information in digital health systems. Healthcare leaders may want to challenge the use of sex information for client identification purposes. Are there other more accurate ways to match client identity for payment purposes for your organization?

Clinical Information Practice Initiatives

Workplace culture is an important consideration in modernizing GSSO clinical information practices.[17] Change management strategies should be fully utilized for these initiatives. Like with the technical initiatives, the involvement of patient and family advisory groups is critical for understanding how the current client experiences your organization. Assessing organizational readiness for change among clinicians, staff and leadership will be important in preparing initiatives for your organization.

How information is displayed to clinicians and staff should be part of the initial assessment. Most clinicians and staff want to "get it right" when working with clients. Are your digital health systems supporting them in following your policies or do the systems make it harder? Digital health systems should be displaying the sex and gender information (when needed) in ways that support respectful interactions. For example, when a client's record is displayed to the clinician, the preferred name of the client should be the most prominent name visible rather than a name that matches an administrative document. Similarly, it should be easy to find a client's preferred pronouns when looking at client information. When digital health system auto-populate screens and reports they should be using a client's preferred name and pronouns.

Working with patient and family advisory groups will help organizations identify the "pinch points" within the existing systems where client-facing information is displayed. With the growth of patient portals and access to their own information, it is important to consider how information is displayed to clients via these systems. Consider how clients may assist the organization in updating their information and how clients may want to control information sharing.

How sex and gender information is collected, used and shared by clinicians, staff and administrators should also be a component of modernization. Organization workflows should include private, non-intrusive collection when possible. Organizational education modules can be created for new processes and workflows. These modules should be co-developed with patient and family advisory groups. Incorporating these into standard operating policies and procedures is important for ongoing compliance. Sex and gender information should be explicitly considered in privacy and information security policies and procedures. Materials such as scripting should be provided to assist clinicians and staff in asking for sex and gender information of all clients. Additionally, supportive materials for clinicians and staff on how to handle clients who react negatively to information requests is important.

Other change management strategies such as clinician, staff and leadership champions is important to the success of these initiatives. The Infoway SGWG regularly has presentations from organizations that are successfully implementing these types of changes. Past presentation materials may be found within the documents of the SGWG.[16] The SGWG also has additional information on GSSO modernization different settings.[18]

Conclusion

Even small steps in modernizing GSSO information and practices can be impactful for clients. It is important to recognize that these initiatives will be ongoing as terminology and practices will evolve over time. Continuing involvement of patient and family advisory groups can assist in keeping the initiatives current and relevant to those served by the organization.

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