



Analysis of Inclusive Gender, Sexuality and Sexual Orientation Data Elements in Academic Electronic Health Records

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Findings from an analysis of three vended academic electronic health records used in health science education are presented in this article. The quality assurance project examined the lexical and semantic fit and content coverage of gender, sexuality, and sexual orientation data elements within the academic electronic health records. A semantic comparative content analysis using a cognitive walkthrough was conducted as a means of comparing the ideal set of gender, sexuality, and sexual orientation data elements with those found in the three vended academic electronic health records. The results indicated a need for alignment to the research literature, expert consensus, and technical standards similar to what is expected for electronic health records used in clinical practice because of a lack of ideal state data elements. The findings align with ongoing issues with bias and disparities seen in the care of the lesbian, gay, bisexual, and transgender population and a lack of diverse, inclusive media and teaching technologies in health science education. The quality project and findings can inform academic electronic health record vendors on how they can create more inclusive systems and bring awareness to healthcare educators about the potential for implicit and explicit bias in their teaching technologies.

KEY WORDS: Academic electronic health records, Gender identity, Inclusive educational practices, Sexual behavior, Simulation

Students in health professional programs must be prepared to work with a wide range of patient populations, including those outside their culture, ethnicity, sexual orientation, gender identity, or socioeconomic status. Societal and professional imperatives for inclusive and culturally competent care^{1,2} combined with the widening healthcare inequalities^{3,4} require professional introspection and action from practicing clinicians and educators. Unfortunately, antibias and

antidiscrimination academic programming, particularly for lesbian, gay, bisexual, transgender, and queer/questioning (LGBTQ+) populations, is not widespread despite findings that educational interventions can be effective.⁵⁻⁷ A survey of 140 schools of nursing found that most students received less than 5 hours of content devoted to LGBTQ+ topics, with barriers identified as faculty knowledge and difficulty integrating the content.⁸ Similarly, only a third of graduate medical education program directors reported any didactic training specific to LGBTQ+ health needs.⁹ In another study of medical students, 69% reported not receiving any LGBTQ+ content at all.¹⁰

The lack of preparation to work with the LGBTQ+ population in health science programs is paralleled by reports that health professionals lack the skills and knowledge to confidently provide care.¹¹⁻¹³ LGBTQ+ patients face emotional, psychological, and physical harm from the healthcare system due to outdated and biased information and practices.¹⁴⁻¹⁹ Coupled with societal stigma, discrimination, and violence, it is unsurprising that this population experiences disproportionately higher rates of health disparities and negative health outcomes such as higher rates of smoking, mental health issues, infectious diseases, and low utilization of preventive services.^{18,20,21}

Understanding and reducing healthcare disparities and adverse outcomes for the LGBTQ+ population were initially challenging due to a lack of options to digitally represent the established standards for gender, sexuality, and sexual orientation (GSSO).²²⁻³⁰ Gender, sexuality, and sexual orientation data collection is vital for measuring, monitoring, and improving the LGBTQ+ population's health, satisfaction, and quality of care. Its absence hampers communication and continuity of care, perpetuates digital invisibility, creates research challenges, codifies bias in algorithms, and can pathologize a patient's expression of self.^{22-24,28,31-34} Global efforts to improve GSSO data standardization and mandates for documentation and quality monitoring have made improvements in options for clinical documentation, interoperability, and research. For example, work by the Canada Health Infoway group^{24,26} has resulted in action toward modernizing and standardizing the expression of GSSO concepts in Canada and globally through collaboration with Health Level 7. In the United Kingdom, the

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National Health Service drove changes to GSSO concept data collection that influenced changes to vendor systems and clinical data sets.³⁵ Similarly, changes to interoperability standards³⁶ and Meaningful Use of EHR criteria in the United States³⁷ have all shown how research, advocacy organizations, and health systems can collaboratively drive change to EHR vendor systems and clinical practice documentation.

Integrating LGBTQ+ content and concepts into the health science curriculum and teaching technologies can potentially reverse these trends. Simulation and experiential learning have been identified as teaching strategies for disrupting student bias as well as expanding student comfort with LGBTQ+ patients.³⁸⁻⁴¹ Simulation has been an important and effective health science teaching strategy and was a critical means of bridging the lack of on-site clinical experiences for many health science programs during the COVID-19 pandemic. Academic EHRs (aEHRs) are often used in simulation to promote the use of clinical data systems as a part of clinical reasoning, treatment planning, and readiness to use actual EHRs when students enter practice.^{12,42-48} Student exposure to inclusive GSSO concepts in an aEHR context may influence classroom conversations, particularly the importance of accurate clinical documentation, digital visibility for marginalized communities, and the impacts of bias on healthcare outcomes. Little is known, though, about how well aEHRs represent GSSO data elements and the documentation options needed to learn about caring for LGBTQ+ patients. Examining aEHRs can offer insights into what language and concepts students may or may not be exposed to, particularly given known issues with bias and a lack of inclusion and diversity in teaching media and textbooks.^{12,49} Academic EHRs can then ideally be improved to meet the recommendations identified in the research literature, expert consensus, and technical standards development organizations.

MATERIALS

Three aEHRs created and maintained by independent vendors were utilized for the analysis. As described in their marketing materials, all three systems were intended to build a student's clinical judgment through exposure to case studies and simulations that allow for data presentation and documentation similar to what they would experience using an actual EHR. Systems 1 and 2 were created and maintained by large vendors of digital and print educational materials and were marketed primarily for use in educating RNs. System 3 was marketed as an interprofessional educational technology and was the vendor's primary product. All three systems had documentation and functional module sets that included medication administration, physical assessment documentation, notes, and various flowsheets that mirrored the functional modules found in most EHRs.

The data collection instrument was created to reflect GSSO variables identified as ideal documentation and data elements by GSSO researchers, health systems, expert consensus work, and technical standards development organizations.^{23-26,31,35}

The data collection instrument was designed to allow for the examination of conceptual coverage for inclusive digital representation of GSSO clinical variables, planning, and interventions. Given the progressive evolution of scientific and social perspectives on some of the GSSO terms, definitions, and clinical impacts, more contemporary initiatives and publications (prior to 2018) were reviewed. The publications informed the creation of an ideal set of GSSO data elements, categories, and documentation functional options (eg, free text comments) to be inventoried via the data collection instrument (Table 1).

METHODS

An application was submitted to the Saint Catherine University (St Paul, MN) institutional review board. They deemed the project to be a quality improvement study that did not require a full review (October 12, 2021). A semantic comparative content analysis using a cognitive walkthrough was conducted to allow for the quality analysis and comparison of GSSO data elements between the ideal state data elements and those found in the three aEHRs. Determining the level of lexical and semantic fit and getting an inventory of actual data elements allowed for drawing inferences about the representation of GSSO concepts in the three systems. A match rating was assigned for a subset of the GSSO data elements, similar to what has been used in other lexical and semantic content analysis studies.^{50,51} These data element categories included name used, pronouns, sex, gender, and sexual orientation. They were selected because of their consistent prominence in the publications and resources consulted for background research and their potential for discrete, structured responses for matching to data elements within the aEHRs. The Canadian Institutes of Health Research GSSO Action Plan²⁶ was selected as the best source for creating a response selection match list because of their inclusion of concept definitions and exhaustive lists that also reflected concepts and terms from other consulted publications, resources, and standards.

An exact match was defined as two terms being lexically identical. A partial match was defined as related terms or a partial set of terms, including specific reference to a data element as a documentation element. No match was defined as a lack of exact or partial lexical match or the complete lack of a documentation field in which to capture the data elements for that concept. If there appeared to be a semantic fit, these matches were noted in the data collection instrument. The remaining ideal state data elements (Table 2) were considered exploratory and were not given a match rating. Two additional data element categories (avatar/photo and nursing care plan documentation) were added, given

Table 1. Ideal State GSSO Variables

Sources	GSSO Data Element Category Recommendations	Reference
2018	Name to use; gender pronouns; risk screening; gender; sex; family/relationships; gender-affirming therapeutic and holistic treatments; sex-based organs; medical/surgical history; preventive care screenings	Bosse et al ³¹
2021	Sex assigned at birth; gender identity; anatomical inventory; sexual orientation (including subcategories); name used; pronouns	Lau, ²⁴ Canada Health Infoway ²⁶ CIHR
2021	Preferred name ^a ; gender pronouns; sexual orientation; sexual behavior; gender identity; anatomical inventory; preventive screening	Davison et al ²³
2021	Gender identity; sex for clinical use; name to use; pronouns	McClure et al ²⁵ HL7 Gender Harmony Project
2022	Sex, gender identity, and sexual orientation, including information about: sex traits; intersex/difference of sex development status; sex assigned at birth; gender identity and pronouns; transgender experience and identity; and sexual orientation identity, attraction, and behavior.	National Academies of Sciences, Engineering, and Medicine ³⁵

Abbreviation: CIHR, Canadian Institutes of Health Research.

^a“Chosen name” or “used name” may be the more common terms.

the use of these technologies for nursing students and for simulations, and could aid in high-quality learning and for creating robust GSSO case studies.

The comparative analysis used a cognitive walkthrough guided by a fictional clinical case study in which a transman sought emergency care. The case study detailed clinical documentation typically used by RNs and other healthcare providers. The case study included the primary scenario, physical assessment findings, vital signs, medications, medical history, and social history. The user persona for the cognitive walkthrough was a faculty member creating the case study shell itself in the aEHR. The students participating in a hypothetical simulation or virtual case study would be presented with the case study and the pertinent initial clinical data added into the aEHR by the faculty. The students would then be required to add additional documentation in the aEHR based on how the case unfolded, as would be typical in a simulation learning experience.

Two reviewers, both RNs and nurse educators, navigated each of the three aEHR systems as if they were the educator persona described working to create the case study shell and seeking options for students to add or review related health information and to document the patient encounter further. During the walkthrough, the reviewers logged findings using the data collection instrument built from the ideal documentation state data categories and data elements.

RESULTS

The primary variables of interest in this quality assurance analysis were data elements directly related to sex, gender, sexuality, and sexual orientation. The researchers also examined documentation categories, documentation functional options, and features that would promote the creation of robust simulation case studies. Match ratings for the following data elements are summarized in Table 3 and included name used, pronouns, sex, gender, and sexual orientation. None of the three

aEHRs allowed for the documentation of pronouns or alternate names such as a preferred or chosen/used name.

Data elements and documentation options for sex and gender were either absent or appeared to be a conflating of gender and sex rather than treating them as conceptually different data elements. For example, all three systems included the option for “male” or “female” to be selected in the “gender” fields within their systems. These data elements are typically aligned with documentation of “sex.” The inclusion of “ambiguous” in the data element list of System 1 is another indicator of the conflating of sex and gender, notably because ambiguous is an outdated term that is more commonly associated with a description of genitalia rather than gender identity. System 1 did allow for the option of adding additional free text in the gender field. System 3 had the most data element options, with some that could be matched to value set options identified in the CIHR action plan data element lists.

In terms of matches for sexual orientation, none of the three systems had specific documentation fields. The term “sexuality” was used in an admission history section that lacked a free text entry field in System 2. The structured list found indicated that the section was not likely intended as an area for sexual identity or orientation to be documented. System 3 had a urinary/reproductive health assessment section in which there was a specific question about whether the patient was transgender. This was most likely intended to reflect a physical assessment component and did not include any sexual orientation or psychosocial gender identity documentation options. System 3 had a partial match in a psychosocial nursing assessment section in which the user was prompted to add a free text note about the patient's “adult relationship history,” including specific reference to “sexual history and orientation.”

The results for the non-match-rated, exploratory GSSO data elements are shown in Table 4 and reveal similar patterns of a lack of structured options for documenting GSSO-related care and concepts. All three systems typically

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Table 2. GSSO Data Elements Selected and Values Set Based on CIHR Variables

GSSO Data Element Category	Match Rating?	Data Elements for Matching
Used name	Yes	Field for name other than legal name (eg, used name or preferred name)
Pronouns	Yes	<ul style="list-style-type: none"> • She/her/hers • He/him/his • They/them/theirs • Neopronouns (eg, xe/xem/xyr; ze/zir/zirs) • Unreported • Not listed
Gender	Yes	<ul style="list-style-type: none"> • Agender, genderless • Alternating gender • Bigender • Demiboy • Demigirl • Genderfluid • Gender-nonconforming • Intersex • Man <ul style="list-style-type: none"> • Cisgender man • Transgender man • Nonbinary • Not listed: free text • Pangender, polygender • Third gender • Transfeminine • Transmasculine • Two-spirit • Unknown • Woman <ul style="list-style-type: none"> • Cisgender woman • Transgender woman
Sex	Yes	<ul style="list-style-type: none"> • Female • Intersex • Male • Unknown
Sexual identity/orientation	Yes	<ul style="list-style-type: none"> • Asexual • Bisexual • Gay • Heterosexual (straight) • Kink • Lesbian • Pansexual • Polyamorous • Queer • Questioning (unknown) • Transamorous • Two-spirit • Not disclosed • Not listed: free text
Sexual organs (inventory)	No	
Sexual attraction	No	
Sexual practice	No	
Relationships/partner	No	
Hormone inventory	No	
Surgical procedure inventory	No	
Surgical inventory: implants/devices	No	
Nursing care (plans and documentation)	No	

Table 3. GSSO Data Element Matching Results by System With Match Rating and Values

Data Elements	System 1	System 2	System 3
Used Name	No match	No match	No match
Pronouns	No match	No match	No match
Sex	No match	Partial: male; female	Partial match: male; female
Gender	Partial match ^a : male; female; unknown; ambiguous; not applicable; other	Partial match: male; female	Partial match ^b : male; female; transmale/transman/FTM; transfemale/transwoman/MTF; different identity/other
Sexual identity/orientation	No match	No match	Partial match ^a : psychosocial nursing assessment with prompt for a free text note related to sexual history and orientation

Abbreviations: FTM, female-to-male; MTF, male-to-female.

^aOption to add free text notes.

^bDifferent lists in different modules/sections that had different documentation options.

had physical and behavioral assessment fields that could be utilized to document clinical information such as sexual organs or surgical history. System 3 had the most opportunities for structured section names and prompts to utilize for constructing a simulated patient with data elements related to the case study. For example, the optional “surgical implants” section could add more clinical context and specificity for teaching purposes.

DISCUSSION

The findings of this quality assurance analysis demonstrated relatively limited GSSO content and concept coverage

within three aEHRs. Unfortunately, the results reflect the early state of vended EHRs prior to multiple efforts to modernize and standardize appropriate GSSO documentation options within them.^{22–26,28–30,35–37} It has and will continue to require global, concerted efforts to make progress toward full digital visibility for communication and high-quality, equitable, continuity of care for the LGBTQ+ population.

Although efforts have been made for improving GSSO data in vended EHRs, aEHRs have not kept pace as the results of this quality assurance project showed. A lack of GSSO documentation granularity seen within the three aEHRs was particularly true for the core set of GSSO variables, which included a name

Table 4. GSSO Exploratory Data Element Results by System

Data Elements ^b	System 1	System 2	System 3
Avatar/photo	Not a feature of the system	36 Clip art images and ability to upload photo	Case study patient photo could be uploaded
Sexual organs	Structured physical assessments ^a	Structured physical assessments ^a	Structured physical assessments ^a
Sexual attraction	“Sexually active?”: drop-down list options: men, women, both men and women, refused to answer	Sexuality/reproductive health history dropdown list: sexually transmitted disease; menstrual problems; abnormal bleeding; sexual function problems; abuse; multiple partners; infertility “Sexually active?”: radio button response of yes or no	Psychosocial nursing assessment with prompt for a free text note related to sexual history and orientation
Relationship/partner(s)	See sexual attraction results	See sexual attraction results	Multiple structured options in “marital status” fields
Hormone inventory	Minimal medication history documentation other than in notes	Pharmacy orders include a structure list that includes items such as “testosterone”	Structured fields from catalog of medications
Surgical inventory	Surgical procedure field ^a	Limited pick list with no free text	Free text field for past surgeries
Surgical implants	Surgical procedure field ^a	Limited pick list with no free text	Free text field for prompt of “any implanted medical devices”
Nursing care	Care plan and patient teaching modules including a “Being Transgender” handout	Structured nursing care plan terminology options	Care plan module

^aOption to add free text notes.

^bDifferent lists in different modules/sections had different documentation options.

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other than a patient's legal name, pronouns, sex, gender, and sexual orientation. These core GSSO variables have been described consistently as critical data elements for digital and conceptual representation within EHRs and for holistic, patient-centered care. Their absence in aEHRs may not have direct clinical repercussions of their absence in EHRs, but may impact health science students' attitudes, perpetuate bias, and influence how they might care for and treat those in the LGBTQ+ community.

Health science education researchers have identified simulation and experiential learning as techniques for promoting knowledge, empathy, and comfort in working with LGBTQ+ patients.^{41–44} Unfortunately, the aEHR analysis demonstrated a lack of proper terminology and even conflating of terms that would allow for creating contemporary LGBTQ+ scenarios for educating health science students. In settings where simulation and experiential learning should be used to help students build cultural competence and humility, faculty and students may instead be forced to literally and figuratively “other” their simulated LGBTQ+ patients because of a lack of appropriate, accurate, and sensitive documentation options. These findings add to a pattern seen within academic media, such as textbook language and images reflecting a lack of diversity and inclusivity.^{12,49} A lack of diversity or even bias in educational materials can potentially perpetuate and promote negative stereotypes and attitudes already seen in the healthcare workforce. It may also hamper efforts to build comfort, knowledge, and skill for future health science students who must be properly prepared to work with all patient populations, particularly vulnerable populations and those with known healthcare disparities. The lack of well-designed teaching technologies and techniques will only further exacerbate what Kronk et al²⁸ labeled as ongoing “structural incompetency” by clinicians whose behaviors and lack of knowledge worsen health disparities and treatment inequalities. Teaching aids, whether textbooks or technologies such as aEHRs, must arguably be held to even higher standards so that the next generation of healthcare providers is better equipped to recognize their biases and disrupt them when identified in their workplaces.

Health science educators have enormous agency and accountability regarding how aEHRs are used and how they are enhanced moving forward. Educators and students are paying customers who can use their financial influence alongside the guidance from expert consensus and standards-setting groups as to how GSSO content and concepts should be properly integrated into EHRs and aEHRs. Educators can potentially use GSSO terminological deficits as teaching points and to emphasize the downstream impacts of the lack of standardized and appropriate terminology, GSSO or otherwise (eg, biased data creating biased care algorithms). Free text fields and the more generic assessment and treatment

planning fields identified in this analysis may allow for some role-modeling of inclusivity and terminological best practices sans the standardization identified as best practice. Academic EHR vendors have equal accountability in modernizing their products, particularly given their marketing messages that these technologies will prepare students for contemporary practice and that they strive for fidelity to the EHRs used in clinical practice. These action steps require that health science educators and aEHR vendors be more aware of their own biases and remain current with terminology standards and care practices for LGBTQ+ patients.

LIMITATIONS

The analysis of three aEHRs reflects only a sampling of the available technologies, although there are only a small number of them on the market. Even within the timeframe of study approval, data collection, and manuscript preparation, norms and language continued to evolve and change that could quickly result in outdated language within this study. For example, Kronk et al²⁸ noted the ongoing evolution and sometimes disagreement related to gender identity terminology. Similarly, usage of “preferred name” in research and GSSO documents was noted to have, in some cases, shifted to “chosen name” or “used name” as carrying more weight in terms of the patient's expectations of how they should be addressed. For future research and vendor efforts to continuously modernize their systems, this should not be a deterrent but rather a challenge to be nimble and sensitive to the power of language and its impact on future health science professionals.

CONCLUSION

Bias and mistreatment of those in the LGBTQ+ community persist despite some advances in incorporating simulation and content into health science curricula. Health science professionals and educators must actively work to disrupt bias and close healthcare equity gaps and disparities. Both clinical EHRs and teaching aEHRs lack the GSSO content and concept coverage to fully realize their effectiveness as research, education, and communication technologies for all patient populations. Academic EHRs must be updated to reflect contemporary GSSO documentation standards and terminology to ensure the widest range of teaching/learning options for case studies, experiential learning, and simulations to promote inclusive care and positive attitudes toward LGBTQ+ patients. Technologies such as aEHRs used in health science education must be held to the same standards as the systems they claim to emulate, perhaps to even higher standards because of their potential impact on clinician attitudes and development. Educators and aEHR vendors must work to continuously improve teaching technologies so that they incorporate inclusive terminology. These technologies

can then be used to help disrupt bias while also promoting the knowledge and comfort needed to reverse the health disparities and inequalities for at-risk and vulnerable patients, including the those in the LGBTQ+ community.

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