Using Population Health, Inclusive HIM Practices to Better Treat LGBTQ Patients

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By Kerryn Butler-Henderson, CHIA, FAHIMA; Julie Dooling, MSHI, RHIA, CHDA, FAHIMA; Dustin Ginn, MA, MHA, RHIA; Lesley Kadlec, MA, RHIA, CHDA; Megan Pruente, RHIA; Donna Retallack, RHIT; Maria Ward, MEd, RHIA, CCS, CCS-P; Jami Woebkenberg, MHIM, RHIA, CPHI; and John Young III, RHIA, CHPS, CPHIMS, HCISPP

The lesbian, gay, bisexual, transgender, and queer or questioning (LGBTQ) population faces a variety of health disparities, such as barriers to appropriate healthcare access and other issues that include (but are not limited to) social stigma, discrimination, and sometimes violations of patient rights, as noted in a 2017 AHIMA Practice Brief.[1] In addition, the Practice Brief authors stated that according to the National Alliance on Mental Illness, the LGBTQ population experiences a higher incidence of a variety of mental and physical disorders that require special attention.[2] These healthcare concerns include anxiety, depression, substance abuse, and sexually transmitted infections.

Hoping to better address these specific LGBTQ healthcare concerns, as well public health concerns for the public at large, the Department of Health and Human Services (HHS) in 2010 launched its Healthy People 2020 initiative—a 10-year campaign that outlines the department's goals and objectives for health promotion and disease prevention.[3] The Healthy People 2020 campaign was the result of a multiyear process that reflects input from a diverse group of individuals and organizations. From this extensive work, Healthy People committee members made recommendations to HHS. The Mission of the Healthy People 2020 campaign is to:[4]

- Identify nationwide health improvement priorities
- Increase public awareness and understanding of the determinants of health, disease, and disabilities as well as the opportunities for progress
- Provide measurable objectives and goals that are applicable at the national, state, and local levels
- Engage multiple sectors to take action to strengthen policies and improve practices that are driven by the best available evidence and knowledge
- Identify critical research, evaluation, and data collection needs

While the Healthy People initiative has been around for decades, the Healthy People 2020 campaign for the first time specifically sought to address LGBTQ health. Because the federal government has sought to address LGBTQ health, it is imperative that health information management (HIM) professionals also take a closer look at their organizational policies and practices and ensure that they are in alignment with what is being expected and implemented at the national level.

As healthcare moves forward, it is becoming increasingly important for HIM professionals to not only ask and collect valid information from patients, but to also train staff on how these issues should be addressed. HIM professionals need to be able to do research—though no one can do research and pull stats together when organizations aren't collecting the right data. When data is collected and not obtainable, it is very challenging for researchers to identify correct populations for studies.

This article contains a variety of strategies for HIM and other healthcare professionals to assist in implementing best practices and appropriate solutions to collect and disseminate information for improving the health of the LGBTQ patient population.

How to Be an Inclusive Healthcare Organization

The Williams Institute, UCLA School of Law, indicates that in 2016, 3.8 percent of the US adult population identified as LGBTQ.[5] They further stated that 1.4 million adults, or 0.6 percent of the US adult population, identify as transgender.[6]

Healthcare professionals need to ensure they are building culturally safe work environments and organizations that are inclusive for patients and staff. This includes communities that use language that is respectful, systems and workflows that are inclusive, and staff that have received education and training to provide respectful and safe services. While many individuals want to use inclusive language and organizations want to be inclusive, there still exists an unconscious bias in how some deliver healthcare services. This section has been developed with guidance from the National LGBTI Health Alliance and provides suggestions on how organizations can create more inclusive services and workplaces, and how individuals can incorporate language that is inclusive in their everyday vocabulary.[7] Additional best practices for healthcare professionals can be found in the Fenway Institute's "Affirmative Care for Transgender and Gender Non-Conforming People: Best Practices Guide for Front-line Health Care Staff."[8]

Inclusive language is an important part of respecting people of diverse gender, sex, or sexuality. Language that is inclusive demonstrates respect for how the individual describes their own body, gender, or relationship, according to the National LGBTI Health Alliance. As identity has an impact on health and wellbeing, it is important to use inclusive language to create culturally safe environments. "Misgendering" is using language to describe someone that does not match how they identify their own gender, body, or relationship.[9] Sometimes an individual may not look or sound how others expect them to look or sound, but it is important to not assume preference and instead allow the person to inform how they wish to be identified.

When conversing with or about individuals of diverse gender or sex, a healthcare professional should respect the person's wishes regarding the use of pronouns. Assuming what pronouns a patient might use may result in making the patient feel uncomfortable and not want to continue care with an organization. Therefore, it may be more appropriate to privately ask a person directly how they wish to be described. Avoiding use of the pronoun the person wishes you to use can make the person feel further excluded or isolated. For example, for an intersex or trans woman, instead of using "the person," "he," "it" or avoiding pronouns, instead use "she" or "the woman." When a person does not identify as a binary gender, they prefer non-binary pronouns such as "they," "zie" (pronounced zee, used instead of she or he), or "hir" (pronounced "here," used instead of "her" or "his"), or using the person's first name. Modeling inclusive language will encourage others to use language that is culturally inclusive. If a healthcare professional does misgender someone, they should apologize but not have an extended discussion about it—and then use the respectful language.

When discussing a person's relationship, it is important to use non-gendered words, to listen for how a person describes the person they are in a relationship with, or to privately ask how a person identifies. Do not assume, such as asking if someone has a boyfriend or girlfriend, or if they are a mother or father. How a person chooses (and if they choose) to label their relationship should be respected and will differ from relationship to relationship. For example, a trans woman and her girlfriend may prefer to be described as a same-gender couple and not a straight couple. People in a relationship who have non-binary genders may prefer to be described using gender-neutral language, such as a partner instead of a boyfriend or girlfriend, or a parent instead of a mother or father. Another important consideration—if a person is in a heterosexual marriage, do not assume their sexuality is heterosexual; ask appropriate questions regardless of marital or relationship status.

Healthcare professionals should not assume a person's gender, sex, or sexuality. While many healthcare organizations require sex to be documented, a culturally inclusive system will refer to a person's gender and the name they wish to be called. Education needs to be provided to staff on how to capture a person's sex and gender, and preferred name and title during the patient registration process. When conversing with patients, the clinical nomenclature can be disrespectful, so clinicians should use inclusive language and not make assumptions about sexuality. When it is necessary to discuss historical events or information, clinicians should still use pronouns to match how a person now identifies. It is disrespectful to refer to a person as a female-to-male pre-op transsexual, as the person's identified gender has not changed during that time. An online survey showed 55 percent of respondents were uncomfortable about disclosing their sexuality to a healthcare provider, according to a 2015 study by the Australian Human Rights Commission.[10] A clinician can use non-gendered language that does not include unconscious bias or assumptions. Where it is necessary to ask questions that refer to anatomy or biology, clinicians need to be aware that how they ask these questions can potentially create a barrier between the clinician and the patient, and that could lead to poor healthcare provision and poor health outcomes. For example, the following quote comes from a participant of the Australian Human Rights Commission study: "She [the doctor] asked me if I was sexually active. I said, 'Yes.' She asked me if I used contraception. I said, 'No, there is no need.' She raised her eyebrows and asked me if I was infertile. I said, 'No…,' and was about to say 'but my partners are not men,' but she interrupted and said pointedly, 'Then there's a need!' I just shut up then."

More broadly, organizations can use inclusive language to create culturally safe organizations. For example, referring to people using the obstetric services as "pregnant people" instead of "expectant mothers," or "breast services" instead of "women's services," or "urogenital services" instead of "men's health clinic." Correspondence can be formatted to use the person's preferred name and title, and not assume “Mr.” or “Mrs.,” which could be disrespectful. The use of templates or forms that a patient completes is the best way to capture this information.

Culturally safe training should be undertaken by all staff in a healthcare organization. Organizational policies and practices should be regularly reviewed to ensure they are inclusive and have engaged both healthcare providers as well as consumers in their development. There are several national and international programs that an organization can participate in to promote culturally safe environments.

Data Collection Issues and Workarounds

So, what does the future of electronic health record (EHR) platforms look like at healthcare organizations in terms of being inclusive? It depends. To answer that question, one needs to know what system the organization has implemented, the current version update, the business process workflow for registration and clinical staff, and the data collected around sexual orientation/gender identification (SO/GI) status. Additionally, each organizations’ data requirements for SO/GI status may vary depending on healthcare services rendered by the organization. System limitations, customized workflows, and end user training can vary widely across the healthcare arena and play a critical role in how the nation provides consistent quality care to the LGBTQ community.

For many organizations that are on older versions of their EHR platform, generic information around the patient’s SO/GI status is collected at the point of registration or in the clinical application by nurses and physicians. In these older versions, it is rare to see the SO/GI status information entered at the time of registration carry over to the clinical application for clinical staff to make medical decisions. Many master patient indices (MPIs) only capture patients’ gender or sex and the terms are used interchangeably. Furthermore, the values in these fields are typically consistent with interface transaction standards, which currently have limited ability to transfer more than male, female, or unknown values. In many cases, the patient’s gender or sex status is being collected twice, once during registration and second in the clinical setting.

From a HIM perspective looking at quality patient data and patient safety concerns, having two points of entry for similar information can cause data integrity issues. These data discrepancies can have an impact throughout the continuum of care. For example, many downstream systems are only able to ingest data collected in the MPI, which flows into best of breed support systems. If SO/GI status was collected in the clinical encounter in the main EHR—which is where most of this information is currently being populated—caregivers working in the downstream systems may not get the full patient history prior to their consultation or treatment. Imagine if each provider or caregiver encountered during a hospital visit addressed you with the incorrect pronoun, and you had to explain yourself to each person. This does not create a welcoming visit for the patient.

Looking forward, EHR platforms have begun to include several system enhancements to address data collection and integration issues for the LGBTQ population. It is important for HIM professionals to continue to work with their specific EHR vendor for future development and align business workflows based on new EHR functionality for more accurate, up-to-date data fields that allow better care of the entire patient population.

Coding and Billing Considerations

The need for accurate code assignment is, as always, an important factor in improved data accuracy. For researchers looking to improve healthcare for the LGBTQ community, the data is rather limited. With the implementation of ICD-10, the specificity of data has increased, but with only three full years of claims data the ability to analyze in-depth is just beginning. In February 2018, researchers at Johns Hopkins published findings in *JAMA Surgery* regarding gender affirming interventions ranging from hormone therapy to gender reassignment.[11] Utilizing the National Inpatient Sample (NIS) on Healthcare Cost and Utilization Project (HCUP) website, the researchers examined the increasing trend in gender-affirming procedures and coverage of these procedures by Medicare, Medicaid, and private insurance.[12] While this research provides great information related to future trends, the downside is that the data was based on ICD-9-CM.

Coding professionals need to be confident in their understanding of how to accurately assign diagnostic and procedure codes for those patients receiving gender affirming procedures in order for additional research be to accurate and reliable. The Medicare Claims Processing Manual, Chapter 32 – Billing Requirements for Special Services should be referenced for guidance.[13] For hospital-based coding professionals, this includes understanding what procedures are inherent to the creation of a root operation as it pertains to gender reassignment and knowing what additional procedure codes should be assigned. For example, in female-to-male reassignment, codes should be assigned for the harvesting of any graft material used for the phalloplasty in addition to the creation procedure. Additionally, the hospital billing department needs to be aware of the need for condition code 45 to be placed on any inpatient or outpatient claim when there is a sex/diagnosis or sex/procedure edit in order to alert the payer that the edit is not a conflict and should be bypassed.

Accurate code assignment is also important when coding for the physician providing these services. When assigning CPT codes, the individual billing provider is required to append modifier KX on any line item procedure that is gender-specific—again, allowing the claim to be processed normally.

Promoting Equality and Education of LGBTQ Issues

The Human Rights Campaign (HRC) is one of the largest groups to advocate for the equality and education of LGBTQ issues. HRC promotes creation and adoption of LGBTQ-inclusive policies and procedures by working with organizations around the world. To support its efforts, HRC has published the Healthcare Equality Index for the past 11 years. The criteria used for the Healthcare Equality Index 2018 asked participants questions related to LGBTQ-inclusive policies and procedures and divided the responses based on four criteria:

1. Non-Discrimination and Staff Training
2. Patient Services/Support (including patient self-identification)
3. Employee Benefits and Policies
4. Patient and Community Engagement

A total of 626 hospitals and healthcare facilities participated in the Healthcare Equality Index survey, and of those, 97 percent demonstrated some level of engagement to support the LGBTQ population.[15] Research was also done through more than 900 non-participating hospitals and healthcare facilities, and, unfortunately, the adoption rates and engagement were far below those of the active participants. Only 63 percent had policies that included both sexual orientation and gender identification. Also, 53 percent had LGBTQ-inclusive employment non-discrimination policies. Equal visitation policies were in place at 93 percent of the non-participating facilities, the closest to that of the participating facilities. These results clearly indicate that many hospitals and healthcare facilities still have much work to do to fully embrace and support the LBGTQ community. This was also evidenced by participants in the study through the following:

- Only 37 percent of EHR systems have an explicit means to capture sexual orientation; 54 percent responded that the information is captured in free-text fields.
- 56 percent of the participants are able to capture in an explicit means that the patient's current gender is different from that at birth; 39 percent responded that it can be captured through free-text fields.
- 49 percent use a two-method approach to capture this information (gender at birth followed by current gender).

Privacy and Security Considerations for LGBTQ

For years, the US's LGBTQ community has raised concerns about the privacy and security of sensitive personal identifying data collected throughout their healthcare visits. The following laws address privacy and security in some fashion for this patient population. The laws provide a floor for managing protected health information (PHI) and personally identifiable information. There are no laws that specifically address this population. But in practice, collection of this information is no different than when healthcare organizations started collecting HIV information. Consideration can be given to additional protections if determined operationally appropriate within the individual healthcare organization.

The HIPAA Privacy Rule states:

- SO/GI or history of transition-related procedures may constitute PHI
- Hospitals and other covered entities should provide training to physicians, employees, and contractors to ensure compliance
- A covered entity must have in place and apply appropriate sanctions against members of its workforce who violate the entity's policies and procedures and the HIPAA Privacy Rule

- Hospitals may use or disclose a patient's PHI to a family member, other relative, close friend, or any other person the patient identifies
- The law respects the patient's wishes on matters of privacy and confidentiality

The Patient Protection and Affordable Care Act of 2010 (§1557) prohibits sex discrimination in any hospital or health program that receives federal funds.[14] The Office for Civil Rights (OCR) has explicitly stated that this prohibition extends to claims of discrimination based on gender identity. This is the first federal civil rights law to prohibit discrimination on the basis of sex (and other characteristics) in all health programs and activities receiving federal financial assistance. Section 1557 builds on prior federal civil rights laws to prohibit sex discrimination in healthcare. The final rule requires that all gender identities be treated equally in the healthcare they receive. It prohibits the denial of healthcare or health coverage based on an individual's sex, including discrimination based on pregnancy, gender identity, and sex stereotyping. The final rule also requires covered health programs and activities to treat individuals consistent with their gender identity.

The Joint Commission standard RI.01.01.01, EP 29 also protects LBGTQ individuals. Related to CMS Patient Visitation Rights and Conditions of Participation (CoPs) from 2011, RI.01.01.01 requires hospitals to respect, protect, and promote patient rights. EP 29 prohibits hospital discrimination based on age, race, ethnicity, religion, culture, language, physical or mental disability, socioeconomic status, sex, sexual orientation, and gender identity or expression.[16]

In 2016, Federal Rule 45 CFR 170 under the HITECH Act provided the following as a guideline to "improve health care quality, safety, and efficiency through the promotion of health IT and electronic health information exchange."[17] It particularly refers to "reducing health disparities" by:

1. Ensuring that each patient's health information is secure and protected, in accordance with applicable law
2. Improving healthcare quality, reducing medical errors, reducing health disparities, and advancing the delivery of patient-centered medical care
3. Reducing healthcare costs resulting from inefficiency, medical errors, inappropriate care, duplicative care, and incomplete information
4. Providing appropriate information to help guide medical decisions at the time and place of care

In comparison to the US, Canada has the Ontario Human Rights Commission (OHRC), which focuses on human rights including poverty, disabilities, and people with diverse gender identities.[18] Some community AIDS health networks in the US seek guidance from this resource.

Some organizations have discussed placing additional security on patient records that contain sensitive sexual orientation and gender identity—similar to "break glass" technology or protections that are currently used with behavioral health records and substance use disorder records today. There are no clear industry guidelines or standards. For example, a continuity of care release of information workflow for this population may include calling the client to confirm if an outside release or legal request should be authorized due to the sensitive nature of the information.

Another area of concern is what some are calling "special security access" for the LGBTQ population. For example, a patient has undergone reassignment surgery. Questions have arisen about going to the extent of masking or placing increased EHR security on pre-reassignment surgery or clinical records such as Male-to-Female (MTF) or Female-to-Male (FTM). This practice is not recommended as it would change the clinical picture of the patient and would not allow the caregiver to have a comprehensive, historical patient story. Many questions remain unanswered and HIM professionals, in particular, are being challenged to answer these questions as the need for privacy is balanced with the expectations for high quality care provision and data usage and reporting.

For many organizations, data collection in their EHRs and registration platforms are not conducive to collecting patients' SO/GI status. Some of the larger EHR vendors have been working on the creation of LGBTQ modules where patient identity and preferred name can be captured and displayed in the patient header. In other EHR systems, it is rare to see the ability to collect the SO/GI status and preferred name at the time of registration, and it is certainly not carried through to clinical applications for clinical decision-making. In some instances, the patient's SO/GI status is being collected multiple times throughout the patient's visit in a non-structured way—which prevents quick, discrete data retrieval. Having two or more points of entry for similar information creates data quality and data integrity issues that can lead to patient safety concerns. These data discrepancies can have a huge impact on patient care.

Also, there is an increased concern for correct SO/GI identity documentation from a revenue cycle standpoint. The gender sometimes is changed in systems long enough to allow for a bill to be dropped due to certain procedures being classified as only "female" or "male." This creates a delay in submitting the claim as well as receiving payment from an insurance company. Future EHR releases (2018 and beyond) may include information about the integration of registration/clinical data, but most organizations have yet to adopt these technologies.

HIM's Opportunity for Inclusion

Healthcare professionals have a growing urgency to focus on LGBTQ data collection to enable inclusive, quality, and patient-centric care for all populations. SO/GI data collection has been initially supported by national and federal sources and initiatives. Vendors will need to create additional tools and resources to ensure health data can be easily accessed, utilized, and maintained. EHR workflows should be carefully reengineered (in a highly collaborative and iterative manner) and technology must keep pace with new data elements to correctly identify all patient populations.

Special consideration should be given for addressing SO/GI data in the following areas: privacy/security, population health, physician engagement, and patient/consumer engagement.[19] HIM professionals have a unique opportunity to assist in the design, implementation, and execution of technology and operational processes that ensure LGBTQ patients can receive quality, inclusive, and safe healthcare. HIM can also ensure data is sound and available to foster population health, and that it is managed safely, securely, and privately—an expectation of all healthcare consumers.

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Notes

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Kerryn Butler-Henderson (Kerryn.butlerhenderson@utas.edu.au) is a senior lecturer and course coordinator of the master of health information management program at the Australian Institute of Health Service Management Division of the Tasmanian School of Business and Economics, University of Tasmania. Julie Dooling (jdooling@justassociates.com) is vice president of national sales at Just Associates, Inc. Dustin Ginn (dustin.ginn@uky.edu) is data quality lead at the University of Kentucky Healthcare. Lesley Kadlec (lesley.kadlec@ahima.org) is a director of HIM Practice Excellence at AHIMA. Megan Pruente (megan.munns33@gmail.com) is identity manager team lead at Just Associates, Inc. Donna Retallack (d.retallack@gmail.com) is HIM manager at CAN Community Health. Maria Ward (maria.ward@ahima.org) is director, data and coding standards, at AHIMA. Jami Woebkenberg (jami.woebkenberg@bannerhealth.com) is HIMS director at Banner Health. John Young III (john.young@kindred.com) is a HIM consultant at Kindred Healthcare.

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