Improved Patient Engagement for LGBT Populations: Addressing Factors Related to Sexual Orientation/Gender Identity for Effective Health Information Management

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One of the Healthy People 2020 objectives from the Office of Disease Prevention and Health Promotion is to improve the health, safety, and well-being of individuals in the lesbian, gay, bisexual, and transgender (LGBT) population.[1] This population faces health disparities with barriers to healthcare and other issues that include (but are not limited to) discrimination, social stigma, and violations of their rights. In addition, according to the National Alliance on Mental Illness, the LGBT population experiences a higher incidence of a variety of mental and physical disorders that require special attention.[2] These healthcare concerns include depression, substance abuse, and sexually transmitted infections.

In order to overcome some of the identified obstacles as well as to begin to address obstacles that have not yet been identified —such as barriers to accessing healthcare services—it is necessary to create a healthcare environment that is non-judgmental and welcoming to healthcare consumers with diverse backgrounds. Healthcare professionals must develop cultural competence and sensitivity, not only for the purpose of communicating with diverse patient populations, but also to enhance their capabilities in creating policies and determining the provision of best services.

This Practice Brief provides guidance for enhanced health information management (HIM) practices not only specifically for the LGBT population but also for any of the many varieties of sexual orientation or gender identity groups. For additional information on the patient population that is being discussed, the Human Rights Campaign website provides some basic definitions around sexual orientation and gender identity.[3] This Practice Brief will address considerations for improved practices for providing care for this patient population throughout the healthcare continuum.

One obstacle to treatment is hindered access to healthcare services for preventive health screenings and follow up for existing healthcare problems. Patients in the LGBT population, especially those in the aging population, may be hesitant to fully disclose their social history, which may lead to a missed opportunity for prevention or education related to pertinent healthcare services. There may also be instances when healthcare professionals have not received the proper training and education regarding discrimination laws or special needs of healthcare management for the LGBT population. Improved training and education may assist providers toward better service to all individuals, including LGBT individuals.

Enhancing the healthcare environment for this group of patients will contribute to improved patient care and safety. Patients will be more willing to share their personal information in a welcoming, respectful, and confidential environment. As patients become more willing to share their information, healthcare providers will have more information to make better-informed clinical decisions.

Patients sharing their preferred gender, name, and pronoun allows the healthcare team to address the patient accurately and identify the correct health record. Having a discussion with their healthcare providers about their sexual orientation, birth sex, gender identity, and, if applicable, transitional status and organ inventory are important elements of information for healthcare providers. For a sample list of gender pronouns, refer to the list available from the University of Wisconsin Milwaukee LGBT Resource Center at https://uwm.edu/lgbtrc/support/gender-pronouns/.

Changes in how health information for the LGBT population is managed need to occur not only in the patient care side of healthcare, but also in the HIM and insurance industries as well. Claim denials and payment delays can cause frustration for patients. Updating healthcare and insurance systems to include key data points to be inclusive of our LGBT patient population will aid in better processing of claims for this patient population. Much of this ultimately comes down to the definition of sexual orientation/gender identity (SO/GI). As defined by the National LGBT Health Education Center:

> **Sexual Orientation:** How a person characterizes their emotional and sexual attraction to others.
>
> **Gender Identity:** A person's internal sense of being a man/male, woman/female, both, neither, or another gender.[4]

Case Examples of Non-inclusive Healthcare Practices

The LGBT population has begun addressing healthcare practices that are not inclusive of their needs with their healthcare providers. Following are two case examples of situations that illustrate this point.

Case One: A lesbian patient gave her provider's organization the following feedback: "I just went to my women's wellness exam. I was handed an After Visit Summary with Patient Instructions on avoiding sexually transmitted diseases (STDs) that were addressed specifically to heterosexual patients. All I could think of was, 'Nothing on this page pertains to me.'"

Case Two: A transgender individual seeks medical care from a new physician in his office. They have not officially changed their name, but would like to be addressed by their chosen name and preferred pronouns. The nurse documents this in their chart. The physician enters and uses the wrong name. The patient asks him to please use this name and pronouns. Throughout the visit the physician disregards the patient's request, making the patient feel uncomfortable and disrespected. In this case, it is clear that there is potential for patient misidentification. For example, for the follow up visit the patient may use their preferred name and pronoun. At that time, the registrar could have assumed the gender and because the patient used a new name to make a follow up appointment, which was not found when searching the system, a new record could easily be created. Then, if the patient received a scan or test it would only be performed on their new gender identity within the duplicate health record, which is not the birth gender and could lead to false results or inadequate care.

These are just two known examples of existing care gaps for LGBT patients. It is critical that modern healthcare finds a culturally sensitive and clinically accurate way to address all patient populations. In the first case, the provider's organization could produce patient instructions about STDs that are gender-neutral and more inclusive of a diverse audience. The result is a more respectful and inclusive discharge document.

Another critical gap to address is gender identity for transgender individuals. Just as the patient above needed her patient instructions to actually be pertinent to her, transgender patients need to be addressed properly by their providers and given appropriate care. There needs to be use of gender-neutral pronouns when a person's gender is unknown or undisclosed, and choices other than he/she/other when a person is not comfortable being addressed with traditional masculine or feminine pronouns. There also needs to be workflows that allow a transgender individual who uses a masculine name and pronoun to present at the obstetrics and gynecology (OB/GYN) department for a women's wellness exam and be assured that they will be addressed or cared for in an appropriate manner. Another example could be a transgender individual with a feminine name and pronoun presenting at the urology department.

Some healthcare providers are beginning to use their electronic health record (EHR) to capture preferred name and pronouns. For example, designing the patient header so preferred name and pronouns will display prominently so anyone—from staff taking a phone call or scheduling an appointment to clinicians performing a physical exam—can see the patient preferences immediately upon consulting the chart.

Examples of several pronouns include he/him, she/her, they/them, and ze/zim. Another pronoun option is ne/nir, which is considered gender balanced. "Ne" is n+(he or she), "nem" is n+her+him, "nir" is n+him+her. Or, ve/ver/vis is another option.

EHR tools can include discrete fields for "Gender Identity," "Sexual Orientation," "Sexual Partners," "Sex Assigned at Birth" (male/female/intersex/unsure/decline to answer), "Preferred Pronoun," and "Organ Inventory" (penis/testes/prostate/breasts/vagina/cervix/uterus/ovaries). The exact nature of the tool will vary depending on the EHR, but most have some way to gather this kind of discrete data. Gathering this data will enable healthcare providers to treat transgender patients with appropriate care across the continuum, from being addressed appropriately on a phone call to getting the appropriate wellness reminders based on their organ inventory, not just their gender.

Through research, some healthcare organizations have questioned the use of the term "transsexual" to refer to a transgender individual who has undergone sex reassignment surgery, and the use of "gender-affirming surgery" as opposed to "sex reassignment surgery." Note that the following does not apply for all parts of the United States nor universally across the globe, but there are areas where these terms are being adopted as defined by gender specialists.

In the term "gender affirming or confirmation surgery," the words "affirm" or "confirm" are being adopted to describe people who have transitioned from one gender to another gender, such as "affirmed female" and "affirmed male" in place of "transgender female" and "transgender male." Other terms used to refer to a person's gender prior to gender transition are "assigned female at birth" and "assigned male at birth" in place of biological male or biological female. This newer language may be seen in some documentation. For example, "Catherine is 25 years old, single, Caucasian, assigned male at birth, and

has made a gender transition to affirmed female." However, it is acceptable and maybe clearer to less experienced audiences to state, "Catherine is 25 years old, single, Caucasian, assigned male at birth, and has made a gender transition from male to female."

The term transsexual is complicated. There are some transgender individuals who have made a permanent gender transition from one binary gender to the other binary gender, who have undergone hormonal therapy and gender-affirming genital surgery, and who want to distinguish themselves from the term transgender. They may choose to use the term transsexual over transgender because transgender is considered a general term inclusive of gender non-conforming and non-binary gender expressions. However, the term transsexual might not be one that healthcare providers are familiar with using regularly. One possible source for selecting gender-neutral pronouns can be found at https://genderneutralpronoun.wordpress.com/tag/xe/. However, each organization may prefer to adopt terminology from a different resource, as local variations of pronoun use may be more relevant depending on location and other factors.

The term transgender is the term most often used with clarifying language about what—if any—gender-affirming medical care was sought by someone. Transsexual is a term that should be included in any discussions of sexual orientation but noted as one that has been used less often more recently.

Demographic Data Capture for LGBT Population

Demographic data capture for the LGBT population has many challenges in the current EHR landscape. The average master patient index (MPI) typically only allows assignment of gender/sex (terms that are used interchangeably across EHR platforms) and is collected in a standardized data format allowing for one of the three Health Level Seven (HL7) Version 3 options: male, female, or unknown. The discrete data captured within the MPI differs from the documentation captured within a patient's health records that may indicate a patient's preferred pronouns, name, etc. In order for the care team to see how the patient prefers to be addressed, the correct chart must be identified first and foremost.

Clearly, not all individuals may fit into one of the male, female, or unknown designations, creating issues in accurate patient identification, duplicate record creation and/or inaccurate data exchange. For example: A patient transitioning from male to female comes in for treatment. The registrar collects their name, date of birth (DOB), and gender and performs a search using what they think to be the "assumed" gender. They could easily misidentify the patient by selecting the wrong chart or could end up creating a new one. These are scenarios that could pose a significant risk to the patient and their safety as well as place liability on the organization.

When reviewing duplicate record detection algorithms most commonly used in healthcare, it is also important to note that with the creation of additional demographic identifiers that can be used to more accurately search and find the correct patient, these same criteria should be applied to duplicate record detection algorithms. For example, if gender and sex are collected as separate fields with an expanded list of terminology to select from, these should be used in the logic to assess records as being a possible duplicate. It might also be helpful to assess preferred name vs. legal name vs. alias names for commonalities and record linking.

Standardized Collection of SO/GI Demographic Data

Standardized collection of accurately reported SO/GI demographic data is an important component of EMPI integrity. It is critical that all stakeholders in the data collection process communicate appropriately with LGBT patients and are educated in the concepts of SO/GI, the importance of SO/GI data, and its appropriate use. A careful review of existing data collection tools will help ensure the full range of sexual and gender identity and expression is represented. Preparation for data collection in clinical settings includes providing education for clinicians and non-clinical staff on LGBT health and the multifaceted concepts related to sexual orientation and gender identity. It is important to provide patient education on the importance of SO/GI information as it relates to culturally competent care and reassurance that their information is safeguarded and will be used appropriately. SO/GI should be updated as needed on an ongoing basis for both new and returning patients.

There are various methods of incorporating SO/GI data into the EHR, including:

- Responding to SO/GI questions in the demographics section of the registration form
- Providers ask SO/GI questions during a patient's visit and directly enter data in EHR
- Direct entry of SO/GI information by patient during a visit
- Self-reporting of SO/GI information by patient prior to arrival via a patient portal

Collection of accurate SO/GI data depends upon the availability of comprehensive choices from which the patient can select their response. For example, answer options for the question “What is your current gender identity?” could include:

- Male
- Female
- Transgender Male/Trans Man/FTM (female-to-male)
- Transgender Female/Trans Woman/MTF (male-to-female)
- Genderqueer
- Additional Category (please specify)
- Decline to Answer

EHR Customization for Consistency

Creation of structured and discrete data fields with limited free text ability promotes consistent data entry and EMPI consistency. Examples of discreet data fields follow. Drop down menu choices would follow each question. For example:

- Do you think of yourself as [insert sexual orientation]?
- What is your gender?
- What was your sex at birth?
- Do you identify as transgender or transsexual?

Measuring Data Integrity

Periodic, focused reviews of SO/GI data entered into patients’ charts compared to completed registration forms is a good method of measuring data integrity.

Addressing Needs for Transgender Patients

In the overall LGBT community, the transgender segment of the population is more likely to require a change in name and/or gender marker. Policies should be developed to govern these demographic changes in a consistent manner, recognizing that the adult and pediatric populations may have different requirements. Determine which documents will need to be presented as proof. Adopt best practices from the insurance industry, the healthcare community, or the public sector. How will any demographic changes be communicated to data-sharing partners and to health information exchanges (HIEs)?

A duplicate record for a transgender patient could easily be created if the patient’s transgender status is not recognized. Upon registering the patient, it could be determined incorrectly that Roni’s record and Ronald’s record belong to two different individuals. By the same token, an overlay could be identified erroneously if the reader does not recognize the transgender status of the patient. In both situations, more in-depth reading of the record will disclose the patient’s transgender status and explain why the patient has been referenced as both Roni and Ronald.

Many transgender patients may have identification documents and insurance forms that do not reflect their current name and gender identify. Duplicate records for transgender patients could be unnecessarily created if the patient’s transgender status is not recognized. For each encounter, it is vital to recognize the transgender status of the patient in order to map the patient to the correct record and avoid duplicates.

Creation of Duplicates Examples

Consider the following example of a duplicate record being created. A patient that has been to a facility before returns for care. This patient is undergoing transition and some days appears to be female while other days appears male. This particular day there is a new registrar who is not familiar with this patient. The patient already has a record with gender documented as male and name documented as “Christopher,” but today the patient presents as female and goes by the name “Kris.” The patient’s new driver’s license contains a new name and gender. The registrar registers the patient as new and creates a duplicate. One record is under Christopher with gender listed as male and one is under Kris with gender listed as female.

In another example, a patient who identifies as lesbian goes into the lab for a blood work-up. The lab registrar didn’t collect the gender value because they were uncertain. Therefore, only the name and date of birth were captured. This information flowed into the main EHR system and created a new health record with limited demographic information. The information

was so limited, in fact, that it would never meet the threshold to populate on the hospital's potential duplicate record list. This duplicate with associated blood work results gets posted to a duplicate health record in the EHR with no link or access to the other record that may contain much of the patient's clinical history.

Partner/Spouse and Parent Rights

LGBT patients also face healthcare challenges related to partner/spouse rights, as well as parent rights, including receiving healthcare from a provider, completion of a birth certificate after the birth of a child, and ability to request and obtain access to a partner or same-sex spouse's medical information.

Members of the LGBT community have concerns when participating in their healthcare, specifically when it comes to childbirth and the birth certificate. An informal survey of LGBT patient concerns conducted by one of this Practice Brief's authors included questions about:

- How the birth certificate is handled when there are two mothers or two fathers
- How they handle giving access to their partner or spouse concerning their medical information
- The challenges faced when obtaining healthcare
- Handling consent treatment of a minor child
- Feelings regarding policies and procedures surrounding healthcare and how they affect or relate to LBGT patients
- Requesting and obtaining health information access for their spouse/partner or for their children

Participants in the survey were asked how they identify (i.e., lesbian, gay, bi-sexual, or transgender). A majority identified themselves as lesbian, and one participant identified as bi-sexual. The responses received showed that when a member of this community has a child, the question is always whose name or names will be listed on the birth certificate under "Mother."

It is recommended that every healthcare organization check with local and state laws or review any bills passed or pending approval about revisions to the birth certificate. For example, a long-term acute care (LTAC) facility does not register births. Additionally, California has revised their birth certificates effective January 2016 with the legislation AB 1951 to be more inclusive of options for LGBT parents (i.e., parents can now be listed as two mothers, two fathers, or a mother and a father, etc.). A data element of the gender-neutral term "Parent" is available along with the option to check "Mother," "Father," or "Parent." Birth certificates may be changed regardless of birthplace or birth date if this situation applies to a previously issued birth certificate in which one parent was not listed or was listed in error.[5]

Best practice to address the issue of previously standard birth certificates not having same-sex options for parents has been to have a worksheet that can be filled out by the parents. In a same-sex relationship, this may be a concern. Some people may scratch out the "father" section and write in the mother's name and information in that section. Despite the fact that same-sex marriages are now nationally legally recognized, birth certificates have not yet all been updated to reflect this. Adoption is another way that a same-sex marriage can have the birth certificate reflect two mothers or two fathers. If the child is adopted by the non-biological parent, all members of this family will have the same name—which makes it easier to obtain medical treatment and access to patient information. Additional consideration may be forthcoming related to completion of death certificates for transgender individuals, so guidance should be sought in the absence of state-level guidelines.

When it comes to accessing a partner's medical information, common practice is to make sure both partners sign their provider's HIPAA-approved form, thus giving access to each other's medical information. For example, on a release of information form, each should add the other partner/spouse as their emergency contact or obtain a health proxy. The exchanging of access information for a spouse or partner's patient portal is another way in which same-sex couples can access their spouse or partner's medical information.

Some of the challenges that the LGBT community faces concerning access to healthcare were reported by the Fenway Institute, one of which is the perception of provider judgment of the patient when they disclose their sexual orientation or transgender status. In the past, this has been a barrier for LGBT patients' participation in their own healthcare. Members were perhaps more likely to share information among themselves and then make the decision to seek medical care despite the possibility of provider judgment. Members of this community have had to correct medical providers when they mention the patient's "husband" or "wife," assuming a heterosexual relationship. In this instance, the provider would be corrected and informed that they have a wife or husband (or same sex partner) depending on the sexual orientation of the patient.

The informal survey of LBGT patients collected the following suggested best practices concerning healthcare:

1. Tell a new provider that they are lesbian, gay, bi-sexual, or transgender during the patient's first visit so that the patient can see if the provider has any issues with the patient's sexual orientation or transgender status.
2. Don't assume that all healthcare forms have spouse/partner on them. If you want to make a change to the form such as adding a second mother or father, let the healthcare provider know.
3. Providers should review the patient's paperwork prior to meeting with them. This would enable the provider to ask the patient questions that are relevant to them. For example, if the patient is a lesbian in a committed relationship, they do not need to be asked what kind of birth control they are using.
4. Provide more training for providers regarding LGBT marriages and partnerships.
5. Seek out LGBT-friendly providers. Ask friends for recommendations.
6. Have your paperwork in order and know your primary care provider.

Regulatory and Legal Considerations

Several federal laws and regulations offer protection against discrimination. Title VI of the Civil Rights Act of 1964 prohibits discrimination based on national origin, and the Americans with Disabilities Act of 1990 and Section 504 of the Rehabilitation Act of 1973 prohibit discrimination based on physical disability. State laws vary, however, and not all potential methods of discrimination are covered. Various regulatory agencies provide guidance on how to best serve LGBT patients. For more details, see Appendix A: Regulatory and Legal Considerations, available in the online version of this Practice Brief in AHIMA's HIM Body of Knowledge at http://bok.ahima.org.

The Patient Portal and LGBT Patients

The patient portal can be an important tool in how people manage their health, engage with their treatment, and connect with their care team. There are aspects of the patient portal which should be set-up to encourage use specific by LGBT patients.

First, more patient portals now allow for patients to submit data securely through the web or via a mobile app.[6] This can help alleviate concerns that a patient may have regarding the need to identify personal and private information at registration as well as avoid potentially uncomfortable situations if the LGBT patient is still not fully out with their sexual identity and is uneasy about making this identification aloud.

Additionally, the content of what an organization posts to their patient portal is important to consider. Having the portal capable of listing the patient's preferred name and gender, along with their legal name and gender—that which appears on their driver's license or insurance card—is essential in making transgendered persons feel accepted even while using a piece of software.[7] This idea also impacts how procedures and medications are listed in the portal. A listing of the hormones a patient undergoing gender reassignment surgery is taking is just as vital as the list of medications a cancer patient may be taking, and thus should be available for the patient to view in their portal.[8]

Many patient portals offer reference ranges based on lab results to help indicate to a patient if their result is expected or not. These ranges should be adapted and modified according to a patient's gender status. For example, a person undergoing female-to-male reassignment may have a different "normal" range than someone born male. Having the proper information in the portal will help these patients better manage their conditions.

The 2011 Institute of Medicine report *The Health of Lesbian, Gay, Bisexual and Transgender People: Building a Foundation for Better Understanding* explains that members of the LGBT community are at a higher risk for many health disparities, including prevalence of mental health issues as well as tobacco, alcohol, and drug use.[9] Knowing that patient portals have showed early promise in treating these conditions, promoting their use to a population who is at greater risk for these diseases is an influential aspect in getting buy-in for the portal from LGBT patients.[10,11]

Access is an important topic. Though any LGBT patient should have the same level of access as any other patient to join and use a patient portal, setting up the hierarchy of proxy access or decision making is important for organizations to outline.[12] Unlike persons who may fall into traditional relationships, members of the LGBT community may have a different support structure. Organizations need to address these concerns and work with LGBT patients to ensure the people they deem as proxy decision makers are documented, and those rights extend even to proxy access to the patient portal.

Lastly, the layout and appearance of the portal should be tailored in a way to be inclusive of the LGBT community. This includes having a notice about nondiscrimination being displayed as well as having pictures—if any are included—showing non-traditional families and patients.[13] This would expand to promoting information about LGBT health concerns through the portal via educational material or information about classes the organization may be hosting. For more information on

designing and maintaining a patient portal, refer to the AHIMA Patient Portal Toolkit available at http://bok.ahima.org/doc?oid=301419.

Ensuring an Inclusive Environment and Culture

To ensure an inclusive environment, start by ensuring that the organization has a policy on diversity. If one doesn't exist, encourage development of a policy on diversity. Providing education for all workforce members who interact with this patient population is critical to providing patient safety and care. Education should be offered to everyone involved in interacting with patients, including registration staff, physicians, nurses, technicians, billing staff, and customer service center representatives. Education topics should include:

- Definition of terms
- Unique health needs/challenges
- Recommendation for respectful and sensitive verbal and written communications
- Form/systems and patient portal development inclusive of LGBT patient population

Patient education is also important. Develop patient-centered materials for patients regarding the importance of sharing their health information and how it will be used within the healthcare setting. Acknowledging to patients that systems/forms/processes may not be fully developed and inclusive of LGBT patients yet is important. Patients will likely understand and appreciate organizations sharing with them that systems may not be up-to-date, but that they are aware and are working on enhancing those processes. Assuring patients that their information will be kept confidential and only used on an as-needed basis is also important.

A vital success factor in the evolution of healthcare is the realization that the healthcare population will become increasingly more diverse. An inclusive focus on patient engagement for all patient demographics will play a critical role in ensuring quality care and reducing healthcare risks. A deeper understanding of diverse populations will enable healthcare professionals to better serve their patients. Traditional policies and practices may create barriers for diverse patients when seeking healthcare. Due to this reality, organizational policies and practices should be continuously examined and updated to ensure they do not present barriers to engagement regardless of sexual orientation, gender identity, or transgender status.

Notes

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2. National Alliance on Mental Illness. "LGBTQ."
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7. Ibid.
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The Fenway Institute. “Improving the Health Care of Lesbian, Gay, Bisexual, and Transgender People: Understanding and Eliminating Health Disparities.”

University of Wisconsin Milwaukee Lesbian, Gay, Bisexual, Transgender Resource Center. “Gender Pronouns.”

We Are Family. “LGBT A-Z (Glossary).”

Appendix A: Regulatory and Legal Considerations

Several federal laws and regulations offer protection against discrimination. Title VI of the Civil Rights Act of 1964 prohibits discrimination based on national origin, and the Americans with Disabilities Act of 1990 and Section 504 of the Rehabilitation Act of 1973 prohibit discrimination based on physical disability. However, state laws vary and not all potential methods of discrimination are covered. It is also important to begin to address privacy considerations for the LGBT patient population. As healthcare organizations start collecting more data about patient gender/sex status, this data and changes to that information should be protected similar to other types of patient information. Various regulatory agencies provide guidance on LGBT practices including those in the list below.

1. **The Joint Commission (TJC)**
   As part of the patient-centered communication standards for hospitals, The Joint Commission requires hospitals to have internal policies prohibiting discrimination based on gender identity and sexual orientation. TJC's standard, Non-Discrimination in Care (RI.01.01.01, EP 29), highlights the importance of providing unbiased care to all patients. This standard applies to all hospitals and prohibits discrimination based on age, race, ethnicity, religion, culture, language, physical or mental disability, socioeconomic status, sex, sexual orientation, and gender identity or expression. Source: http://www.jointcommission.org/assets/1/18/R3%20Report%20Issue%201%2020111.PDF
2. **Patient Protection and Affordable Care Act of 2010 (ACA)**
   Section 1557 of the Affordable Care Act prohibits discrimination in healthcare and health coverage based on gender identity, transgender status, or gender stereotypes in any hospital or health program that receives federal funds.

   Other programs and activities subject to Section 1557 include:

   - Tricare
   - Veterans Health Administration (VHA): The VHA touts a commitment to LGBT veterans and LGBT health issues. To ensure non-discrimination practices and inclusive language, the VHA performs an ongoing review of their policies and offers ongoing educational programs for staff about best practices in LGBT healthcare.
   - Employer-sponsored health plans
   - Student health plans

3. **Health Insurance Portability and Accountability Act (HIPAA)**
   Individually identifiable health information, including that related to transgender status and transition, is protected. HIPAA also affords LGBT patients the right to access, inspect, and copy protected health information held by hospitals, clinics, and health plans. This information should not be disclosed unless there is a relevant need to do so.

4. **Centers for Medicare and Medicaid Services (CMS)**
   Protects the right of patients to choose their visitors and assign medical decision-makers independent of the assignee's legal relationship to the patient. This means that LGBT patients or their families will not be discriminated against in recognizing a patient's designated decision-maker or in the facility's visitation policy.

5. **Social Security Administration (SSA)**
   The Social Security Administration (SSA) allows transgender people to change their gender marker without having undergone sex reassignment surgery. The gender marker can be changed with presentation of a government-issued documentation reflecting change of gender marker or letter from physician attesting that patient is undergoing gender transition.
   Source: http://www.glaad.org/blog/victory-social-security-administration-changes-requirements-transgender-people

6. **The Nursing Home Reform Act**
   The Nursing Home Reform Act established a set of rights for nursing home residents:

- Right to privacy, including during visits from friends or loved ones
- Right to be free from abuse, mistreatment, and neglect
- Right to choose one's physician
- Right to dignity and self-determination
- Right to file grievances without retaliation

7. **State and Local Nondiscrimination Laws**
   Twenty-two states prohibit healthcare discrimination based on a person's sexual orientation. Fourteen of those states prohibit discrimination in public accommodation policies based on gender identity.
   Source: http://www.nolo.com/legal-encyclopedia/health-care-antidiscrimination-laws-protecting-32296.html

8. **Health Insurance/Payers**
   The Office for Civil Rights has explicitly stated that the anti-discriminatory prohibitions in the ACA extend to discrimination based on gender identity or failure to conform to gender stereotypes. This means that in almost every state, insurance companies cannot:

   - Exclude any sort of transition-related care to transgender people
   - Refuse to enroll a person in a plan, cancel coverage, or impose higher rates based on a person's transgender status
   - Deny coverage for care typically associated with one gender
     Source: http://www.transequality.org/know-your-rights/healthcare

9. **State Department (Passports):**

   - In June 2010, the State Department announced a new policy to allow a transgender person to obtain a passport reflecting his or her current gender by submitting a certification from a physician confirming that the individual has had appropriate clinical treatment for gender transition. Surgery is not necessary to change gender marker for issuance of US passport. Source:
     http://www.transequality.org/sites/default/files/docs/kyr/passports_2014.pdf

Appendix B: LGBT Patient-Specific Data Integrity and Information Governance Practices

There is an upward trend in healthcare organizations planning to capture gender specifics in their health information systems and overall documentation. The need for capturing accurate and complete data are evidenced by a results from a recent research study[1] that showed three percent of confirmed duplicate health records contained gender discrepancies in 2007, compared to six percent gender discrepancies in 2014.

The US Department of Health and Human Services (HHS) has recognized the importance of collecting Sexual Orientation/Gender Identity (SO/GI) information to enable better care, as well as evaluating the quality of care for the LGBT patient population. Last year, the Office of the National Coordinator (ONC) proposed capture of the SO/GI data in their 2015 Edition Base Electronic Health Record (EHR) Definition, which is a part of the CEHRT definition under the "meaningful use" EHR Incentive Program.

The 2015 Edition final rule includes "demographics" certification criteria that allow SO/GI to be captured to meet the CEHRT definition in 2018 and onward. HHS sees this as a "critical first step forward to improving care for the LGBT communities"[2]

It is important to note the distinction that HHS/ONC regulations are not "requiring" the data (not part of the Common Clinical Data Set definition) to be collected at the current time, rather that the fields are available in the EHR to enable an end-user to capture the data if desired.

According to the 2015 Edition EHR Certification Companion Guide (45 CFR 170.315(a)(5),[3] the Demographics regulation text states, "enable a user to record, change and access patient demographic data including race, ethnicity, preferred language, sex, sexual orientation, gender identity, and date of birth."

These sexual orientation terms were submitted to SNOMED for revised terminology. The codes will remain the same.

These include 170.207(o)(1) Standard in SNOMED CT:

Lesbian, gay or homosexual	38628009
Straight or heterosexual	20430005
Bisexual	42035005
Something else-please describe	nullFlavor OTH
Don't know	nullFlavor UNK
Choose not to disclose	nullFlavor ASKU

From the Final Rule

(Birth) Sex: 170.207(n)(1); standard is HL7 version 3 which only allows for Male(M), Female(F), and Unknown(UNK). The "suggested questions" have not been scientifically validated for use in healthcare settings and thus, the final rule did not adopt them. It should be noted that the following questions are being used in the industry as a starter set in developing "best practice."

Do you think of yourself as:

- Straight or heterosexual;
- Lesbian, gay, or homosexual;
- Bisexual;
- Something else, please describe.
- Don't know.

What is your current gender identity? (Check all that apply.)

- Male;
- Female;
- Transgender male/Trans man/Female-to-male;
- Transgender female/Trans woman/Male-to-female;
- Genderqueer, neither exclusively male nor female;
- Additional gender category/(or other), please specify.
- Decline to answer.

Currently, healthcare providers are using either "sex" or "gender" in their master patient index (MPI) or enterprise master patient index (EMPI) and likely capturing HL7 version 3's data values of M(male), F(female), or U(unknown). However, the presence of "indeterminate" and "other" is also found in the MPI. This shows a clear need for universal standards updated terminology underneath a larger data governance/information governance umbrella. Information governance (IG) is very broad as it applies to the digital HIM environment. These examples are a few of the common quality tools for IG that might be helpful for monitoring and ensuring data integrity related to data collection of SO/GI variations.

As the adoption of EHR technology continues along with the planning to capture gender-specific data for healthcare, it will be important that the quality improvement program of the healthcare organization includes the processes to assess and ensure data integrity. Essential quality and risk management tools can be used to support information governance of data integrity. The tools can help detect, monitor, and mitigate data integrity and potential patient safety concerns associated with data capture of the variable sexual orientation and gender identity occurrences. A few examples of some common tools are the flowchart, cause and effect diagram, and audit tools. With regard to the growing concern of increased occurrences of duplicate health records and discrepancies in gender identification, the following is a brief description on how the tools can be applied.

The development of a flowchart will facilitate the review and analysis of a process and identify opportunities to improve the process. For example, the patient registration process can be illustrated in a flowchart or the workflow of how the various gender identifications are handled in the EHR and downstream systems. Each step with the decision points that cause the workflow to change or introduction of a potential problem is identified in the flowchart. A cause and effect diagram can be applied to further illustrate the cause of a problem. For example, the problems caused by technology, people, or process can be readily identified in the registration process and data workflow. An audit tool has been useful for assessment of compliance with regulatory standards and quality measures. In the case of information governance, the audit tool will facilitate

identification of the gaps in the EHR workflow of the SO/GI data elements and registration process. The tool can also help reassess the effectiveness of corrective and preventive actions.

In general, the tools also are referred to as performance improvement tools and are an integral part in the achievement of continuous quality improvement goals. Therefore, it is important to either assume the leadership role as Quality Assurance Coordinator or collaborate with the leaders in quality and risk management at healthcare organizations. Active involvement will help support the overall IG efforts.

There should be a process identified for handling record amendments after patient transitions or legally changed name/gender. It is recommended that healthcare organizations consult legal counsel on the appropriateness of retrospectively changing this information in the health record.

It is important for each organization to address how to verify one's gender identity for change in the MPI, for a birth certificate or other identifying documents. Will it require a driver's license? Updated social security card? MPI clean-up experts, in soliciting the answer to this question from multiple sources, have suggested that HIM may be currently requiring a patient to provide legal documentation in order to update their name. However, if other care providers have access to update name/gender fields in the EHR and HIM is not monitoring demographic data changes, this could still be done outside of the HIM department's knowledge and outside of defined HIM practice policies.

For example, in an adolescent clinic with a relatively large transgender population, the organization has adopted the practices of CMS and SSA-requesting that the patient provide a letter from a treating provider or present insurance card or government-issued ID representing the new identity.

Potential changes in how and what we capture data for the LGBT patient population will require changes in our organizations. Sound data and information governance practices in addition to a thorough inventory assessment will be necessary to ensure data integrity throughout the enterprise. Considerations include:[4]

- Identifying, defining, and auditing sources of truth
- Monitoring data capture redundancies to improve overall data integrity
- Instituting quality controls to ensure the "source of truth"

Notes

1. Just, Beth Haenke et al. "Why Patient Matching is a Challenge: Research on Mast Patient Index (MPI) Data Discrepancies in Key Identifying Fields." Perspectives in Health Information Management (Spring 2016).

2. Ibid.

3. Office of the National Coordinator for Health IT. 2015 Edition Certification Companion Guide. HealthIT.gov. Updated March 24, 2016.

4. Spath, Patrice L. Introduction to healthcare quality management, Second Edition. Chicago, IL: Health Administration Press, 2013.

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