Gender Identity and Sexual Orientation in Healthcare Delivery and Data Collection

> Middlesex College February 6, 2019



Background

- This all began with Julie Dooling's of Just Associates presentation titled "Capturing the LGBT Status in the EMPI/EHR: Today and Tomorrow" back at the CtHIMA Annual Meeting in Mystic in 2017
- Continues to launch much discussion with still many unanswered questions!
- Many issues still needing discussion from a variety of healthcare professionals:
 - Patients' Rights and Advocacy
 - Patients' Safety and Quality
 - Patient Access/Registration
 - Coding and Billing/Revenue Cycle
 - Compliance/Legal
 - Data Integrity/Data Governance



Sources

- Office of Disease Prevention and Health Promotion's: "Healthy People 2020" – almost there!!!
- 45 C.F.R. Part 92 of the *Federal Register* September 8, 2015
 - Nondiscrimination in Health Programs and Activities
- AHIMA's Engage
- AHIMA Work Group: "Improved Patient Engagement for LGBT Populations: Addressing Factors Related to Sexual Orientation/Gender Identity for Effective Health Information Management"
 - Journal of AHIMA 88, no. 3 (March 2017)



Today's Objectives

- Evaluate where we now stand in our healthcare communities
- Gather more information from both the patient perspective and the provider perspective
- Write a White Paper for submission to AHIMA
- Make providers aware of patients' objectives
- Make patients aware of potential risks from the providers' perspective
- Identify best practices for a solution



"After almost 3 years of rulemaking activity, the Department of Health and Human Services' (HHS) Office for Civil Rights (OCR) issued its final rule implementing Section 1557 of the Affordable Care Act (ACA) (the Final Rule) which [was] codified in 45 C.F.R. Part 92."



- Every health program or activity, any part of which receives Federal financial assistance or made available by HHS is subject to the Final Rule.
 - All tax credits and subsidies made available by HHS to individuals purchasing insurance through the exchanges are included in the definition of "Federal financial assistance"
- Entities principally engaged in providing health services or health insurance, all of those entities' activities are defined with "health program or activity"



- With that, the Final Rule's provisions apply to *all* activities of *every* issuer of plans sold on a state or federally-facilitated exchange, and to *all* activities of *all* providers, provider groups, and hospitals that accept Medicare or Medicaid patients!
- So that pretty much covers everyone!



- Discrimination on the basis of gender identity, including exclusions or limitations on care for gender transition or the treatment of gender dysphoria or gender identity disorder, is prohibited.
- Additional cost-sharing or other limitations or restrictions on gender identity-related care are prohibited if they result in discrimination against a transgender person.
- Individuals must be treated consistently with their gender identity.
 - Including access to such facilities as restrooms
 - Treatments ordinarily or exclusively available to persons of one gender may not be denied



- The Final Rule does not explicitly prohibit discrimination on the basis of sexual orientation, but OCR evaluates complaints of sexual orientation discrimination to determine if they involve sex stereotyping
- "However, a recent EEOC decision concluded that Title VII's prohibition of discrimination "on the basis of sex" precludes sexual orientation discrimination because discrimination on the basis of sexual orientation necessarily involves sex-based considerations."



AHIMA's Engage

- Facilities face challenges but are making progress
- Most address patient preferences using the EHR
- Previously hl7 could not accommodate all necessary data elements
- In the FHIR R4 Draft currently open for comments, the necessary options are available



AHIMA's Engage

This value set includes codes from the following code systems:

Include these codes as defined in http://hl7.org/fhir/gender-identity

Code	Display	
male	male	the patient identifies as male
female	female	the patient identifies as female
non-binary	non-binary	the patient identifies with neither/both female and male
transgender-male	transgender male	the patient identifies as transgender female-to-male
transgender-female	transgender female	the patient identifies as transgender male-to-female
other	other	other gender identitiy
non-disclose	does not whish to disclose	the patient does not whish to disclose his gender identity



AHIMA's Engage

- Federal Register:
 - "... a covered entity is permitted to ask transgender enrollees to provide such additional information, as long as the covered entity does not unduly burden enrollees or make unreasonable inquiries that serve to delay their receipt of coverage."
- One facility's legal team advised changing a patient's gender on request and only change it back to their birth gender to override billing edits
- Templates in the EHR create issues as well





AHIMA Work Group

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

Journal of AHIMA 88, no. 3 (March 2017)

AHIMA's Goals and Objectives

- To create a healthcare environment that is non-judgmental and welcoming to patients with diverse backgrounds
- To help healthcare develop cultural competence and sensitivity for all healthcare professionals
- To improve communication in healthcare with diverse patient populations
- To help healthcare to create effective policies and procedures
- To help healthcare determine best practices for the provision of best care and services



AHIMA's Findings

- Patients would be more willing to share their personal information in a welcoming, respectful, and confidential environment
- This will give healthcare providers improved information to make better-informed clinical decisions
- The aging population in particular is far less likely to divulge such information -- leading to missed opportunity for prevention or education related to pertinent healthcare services



Enhanced Data Integrity

- As meaningful and important as any past medical history in the record are patient discussions about –
 - Sexual orientation
 - Birth sex
 - Gender identity
 - Transitional status
 - Organ inventory
 - Partners/Relationships
- Periodic, focused reviews of SO/GI data entered into patients' charts compared to completed registration forms is a good method of measuring data integrity



Definitions: SO/GI

- Sexual Orientation (SO):
 - How a person characterizes their emotional and sexual attraction to others
 - Heterosexual/Straight someone who is attracted to people of a different sex
 - Homosexual/Gay someone attracted to people of the same sex and usually men attracted to men
 - MSM may be used in the health record
 - Homosexual/Lesbian describes a woman attracted to other women
 - WSW may be used in the health record
 - Bisexual someone attracted to both sexes
 - Queer someone who identifies as still something else



Definitions: SO/GI

- Gender Identity (GI):
 - A person's internal sense of being a man/male, woman/female, both, neither, or another gender
 - Some individuals identify with their gender assigned at birth
 - Some individuals know their gender is not the same as what was assigned at birth
 - May have been born "male" but know their identity as "female"
 - MTF
 - May have been born "female" but know their identity as "male"
 - FTM
 - Some may reject both "male" and "female" and identify as something else
 - "Genderqueer"
 - Remembering that "queer" means "something else"



Clarifications

- "Transgender" is considered a general term inclusive of gender nonconforming and non-binary gender expressions
- The term "transsexual" is complicated!
- Some transgender individuals wish to distinguish themselves having made a permanent gender transition from one binary gender to the other undergoing hormonal therapy and gender-affirming surgery
- The term "transsexual" seems less likely to be used in the healthcare setting for whatever reason



More Vocabulary

- "Assigned male at birth"
- "Assigned female at birth"
- "Gender affirming or confirmation surgery"
 - As opposed to "sex reassignment surgery"
- "Affirmed female"
 - As opposed to "transgender female"
- "Affirmed male"
 - As opposed to "transgender male"



AHIMA's Case One

A lesbian patient goes for her annual women's wellness exam and is given an After Visit Summary with Patient Instructions with all of the information on avoiding STDs directed specifically to the heterosexual patient population.

The feedback she gave to the facility was, "Nothing on this page pertains to me."

Not uncommon!



AHIMA's Case Two

A transgender who has not yet legally changed their name presents as a new patient at a physician's office stating their preferred name and pronouns to be used. The nurse enters this is the newly created record.

The physician enters and uses the wrong name.

The patient corrects the physician and tells the physician their preferred name and pronouns.

The physician seemingly disregards the patient's request making the patient feel uncomfortable and disrespected.



AHIMA's Case Two

- Opens the door to patient misidentification
- Chance for creating a duplicate medical record
 - At a follow-up visit the registrar could just assume the patient's gender and when the name does not appear create a new record
 - The original registrar could have made assumptions and entered misinformation
 - Further tests and diagnostics could easily have been ordered as well and stand the potential for never matching up!
- Is this patient really going to want to open up!
- There goes data integrity!



Gender Neutral/Gender Inclusive Pronouns

- University of Wisconsin Milwaukee LGBT Resource Center
- <u>http://uwm.edu/lgbtrc/support/gender-pronouns/</u>
- A pronoun which does not associate a gender with the individual who is being discussed
- English of course lacks
- Attempts made to create in the interest of greater equality
- Tough to adapt and adopt such change uniformly



Gender Neutral/Gender Inclusive Pronouns

HE/SHE	HIM/HER	HIS/HER	HIS/HERS	HIMSELF/HERSELF
zie	zim	zir	zis	zieself
sie	sie	hir	hirs	hirself
ey	em	eir	eirs	eirself
ve	ver	vis	vers	verself
tey	ter	tem	ters	terself
е	em	eir	eirs	emself



Options for Data Collection

- Most EHRs have the capacity to capture preferred name and pronouns
- EHRs can include discrete fields for
 - Gender identity
 - Sexual orientation
 - Sexual partners
 - Sex assigned at birth
 - Preferred pronouns
 - Organ inventory
 - Gender-affirming surgery



Challenges

- Current standardized demographic data capture for gender/sex for the Master Patient Index (MPI) offers only three options using hI7 Version 3:
 - Male
 - Female
 - Unknown
- Additionally sex and gender are considered interchangeable
- Therefore the *discrete* data captured in the MPI can differ from the documentation captured in the patient's health record



Challenges

- Meeting patient expectations
- Maintaining a clean MPI
 - Always remember to include any newly created demographic identifiers for gender in any algorithms used to detect duplicate medical records
- Any risks associated with a duplicate medical record or overlay
 - Allergies
 - Medication errors
 - Release of information issues
 - Other legal issues



Challenges

- Scheduling/Registration
 - Use of different names
 - Use of different GIs
 - Staff assumptions
 - Confirmed duplicate health records with gender discrepancies
 - 2007 3%
 - 2014 6%
- Medical Necessity
- Billing and payment
 - Condition Code 45
 - Modifier -KX







