

DISCERNING Identities



**Capturing the LGBT Status in
the EMPI/EHR:
Today and Tomorrow**

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Our Patient Populations

“Now more than ever, it’s important that healthcare and health information management (HIM) professionals work to create a healthcare environment that is non-judgmental and welcoming to patients of all backgrounds. Providers everywhere are seeking ways to ensure that all patients have appropriate resources and documentation.”



Source: ICD10 Monitor Podcast: Improving Patient Engagement for LGBT
<https://www.icd10monitor.com/talk-ten-tuesdays/podcasts>

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LGBTQ Defined

- **Lesbian**
- **Gay**
- **Bisexual**
- **Transgender**
- **Queer or Questioning**

***Many others in the classification of LGBTQIA+**

Future of Personalized Data Collection

To care for all patient subpopulations regardless of SO/GI, race, or ethnicity, healthcare organizations need to emphasize more personalized and proactive healthcare for patients.



Source: <http://journal.ahima.org/2017/03/16/the-future-of-sexual-orientationgender-identity-sogi-healthcare-data>

SO/GI Defined

Sexual orientation tells you about a person's sexual and romantic attractions. Common words to describe sexual orientation are:

- **Heterosexual** (straight) describes someone who is attracted to people of a different sex. For example: a man who is attracted to women; or a woman attracted to men.
- **Gay** describes someone who is attracted to people of the same sex. Usually used for men who are attracted to men.
 - MSM may be used in the health record
- **Lesbian** describes a woman who is attracted to other women.
 - WSW may be used in the health record
- **Bisexual** describes someone who is attracted to both men and women
- **Queer** describes someone who identifies as something else.

Source: <http://doaskdotell.org/ehr/lgbtpeople/>

SO/GI Defined

Gender Identity describes the deep, innate understanding that each person has of their individual identity as a man, a woman, or in some cases, another gender.

- For example, most individuals identify with their gender that was assigned at birth such as “male” identifying as a man.
- Some individuals know that their gender is not the same as was assigned at birth. In these cases, the patient is referred to as “transgender”.
 - An individual who was assigned as:
 - ♦ “Male” but know their identity as “Female” and as a woman (MTF).
 - ♦ “Female” but know their identity as “Male” and as a man (FTM).
 - ♦ Others may reject Male or Female and identify as something else such as “Genderqueer”.

Source: <http://doaskdotell.org/ehr/lgbtpeople/>

Case Examples

Non-inclusive Practices

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.’”

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): extended online version.

Case Examples

Non-Inclusive Practices

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 the 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.

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Case Examples

Non-Inclusive Practices

As a result of the previous scenario:

At the follow-up visit the patient uses their preferred name and pronoun. The registrar assumes gender and because the patient used a new name to make the appointment, (which was not found when searching the system) a new record is created.

Then.. if the patient received a scan or test, it would only be documented on their new gender identity within the duplicate health record, which is not the birth gender.. and it could lead to false results or inadequate care.

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Transgender Population

AMERICA

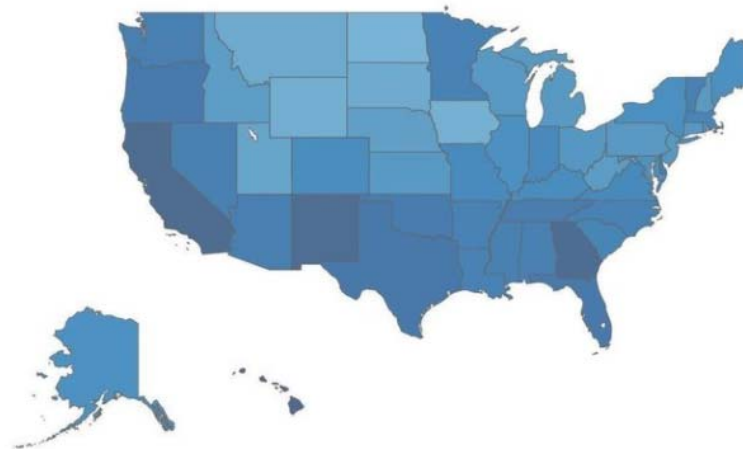
1.4 Million Adults Identify As Transgender In America, Study Says

June 30, 2016 - 8:22 PM ET

BILL CHAPPELL



Percent of adults identifying
as transgender in the U.S.
0.00% 0.78%



A map of the U.S. shows the number of adults who identify as transgender by state. Darker colors indicate a higher percentage.

Williams Institute

Source: <http://www.npr.org/sections/thetwo-way/2016/06/30/484253324/1-4-million-adults-identify-as-transgender-in-america-study-says>

Transgender Pronoun Usage

It's important to address a transgender person with the appropriate gender pronoun such as “he/him” and “she/her” and in some cases, “they/them”.

- There are workflows being developed to address this customer service challenge.
 - ◆ What is your organization doing?
 - ◆ Do you have a plan to capture pronouns in your EHR?

Registration

MPI/EMPI

EHR

Pt. Portal
Pre Reg
Forms

Transgender Awareness

Transitioning steps and procedures vary widely. Each person's journey may contain any combination and one can be “fully transitioned” if they themselves are affirmed in their body.

Many (not all) trans individuals begin with hormone therapy and then progress to surgery.

Don't assume that someone who identifies as “trans” wants surgery or hormone therapy.

Source: CAN Sensitivity Training

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National Support

- Institute of Medicine
- Healthy People 2020
- Joint Commission
- Fenway Institute



National Institutes
of Health



Federal Language

March 2016 - HRSA Program Assistance Letter



Aligns with:

- 2015 Edition HIT Certification Criteria
- 2015 Edition Base EHR Definition
- ONC Health IT Program Modifications

Includes guidance on recording, changing, and accessing structured SO/GI data.

****Important:**

- While this guidance enables users to collect SO/GI data points..

It is not a documentation requirement and the new data fields are not currently stored in most Master Patient Index (MPI) and Enterprise Master Patient Indexes (EMPIs).

Current Sexual Orientation Data Collection HRSA

Line	Patients by Sexual Orientation	Number (a)
13.	Lesbian or gay	
14.	Straight (not lesbian or gay)	
15.	Bisexual	
16.	Something else	
17.	Don't know	
18.	Choose not to disclose	
19.	Total Patients (Sum Lines 13 to 18)	

Source: HRSA Program Assistance Letter PAL 2016-02, March 22, 2016

Current Gender Identity Data Collection HRSA

Line	Patients by Gender Identity	Number (a)
20.	Male	
21.	Female	
22.	Transgender Male/ Female-to-Male	
23.	Transgender Female/ Male-to-Female	
24.	Other	
25.	Choose not to disclose	
26.	Total Patients (Sum Lines 20 to 25)	

Source: HRSA Program Assistance Letter PAL 2016-02, March 22, 2016

The Need for Data Collection

LGBT Field Guide – Joint Commission 2011

“Gathering patient-level data about sexual orientation and gender identity has been the subject of considerable interest and debate, and work is rapidly evolving on these issues. The growing concern about health care disparities and barriers to equitable care has demonstrated the need to collect such data, but the best ways to do so have not yet been established. Therefore, comprehensive recommendations on data collection methods are beyond the scope of this document”



Protection – Data Collection



Data Collection

Sex

Gender

- Are Both Used in Your MPI/EMPI?
- Have We Defined the Differences?
- Should We Use Both?
- What Needs to Change to Utilize Both - According to SO/GI Definitions?

Current (Mainstream) Data Collection

Most MPI/EMPI platforms use HL7 Version 3:

Sex
Male
Female
Indeterminate
Unknown
Other



Sex or
Gender?

Proposed Data Collection

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

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Proposed Data Collection

I-G: Gender Identity, Sex, and Sexual Orientation

HL7 Comments

We note that selecting "SNOMED-CT" is insufficient and requires identification of the specific branch(es) that are applicable to this use case. HL7 strives to provide that level of clarity in its implantation guides, but believes that in general references such as this it remains important to be more specific.

Interoperability Need: Representing patient gender identity

Type	Standard/Implementation Specification	Standards Process Maturity	Implementation Maturity	Adoption Level	Regulated	Cost	Test Tool Availability
Standard	SNOMED-CT	Final	Unknown	Unknown	No	Free	N/A

Limitations, Dependencies, and Preconditions for Consideration:

- The HIT Standards Committee recommended collecting discrete structured data on patient gender identity, sex, and sexual orientation following recommendations issued in a [report](#) by The Fenway Institute and the Institute of Medicine.

Applicable Security Patterns for Consideration:

- Feedback requested

Source: 2016 Interoperability Standards Advisory, ONC for Health IT

Proposed Data Collection

Continued...

Interoperability Need: Representing patient sex (at birth)

Type	Standard/Implementation Specification	Standards Process Maturity	Implementation Maturity	Adoption Level	Regulated	Cost	Test Tool Availability
Standard	For Male and Female, HL7 Version 3 Value Set for Administrative Gender	Final	Production	● ● ● ● ○	No	Free	N/A
Standard	For Unknown, HL7 Version 3 Null Flavor	Final	Production	● ● ● ● ○	No	Free	N/A

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Limitations, Dependencies, and Preconditions for Consideration:	Applicable Security Patterns for Consideration:
<ul style="list-style-type: none"> The HIT Standards Committee recommended collecting discrete structured data on patient gender identity, sex, and sexual orientation following recommendations issued in a report by The Fenway Institute and the Institute of Medicine. 	<ul style="list-style-type: none"> Feedback requested

Interoperability Need: Representing patient sexual orientation

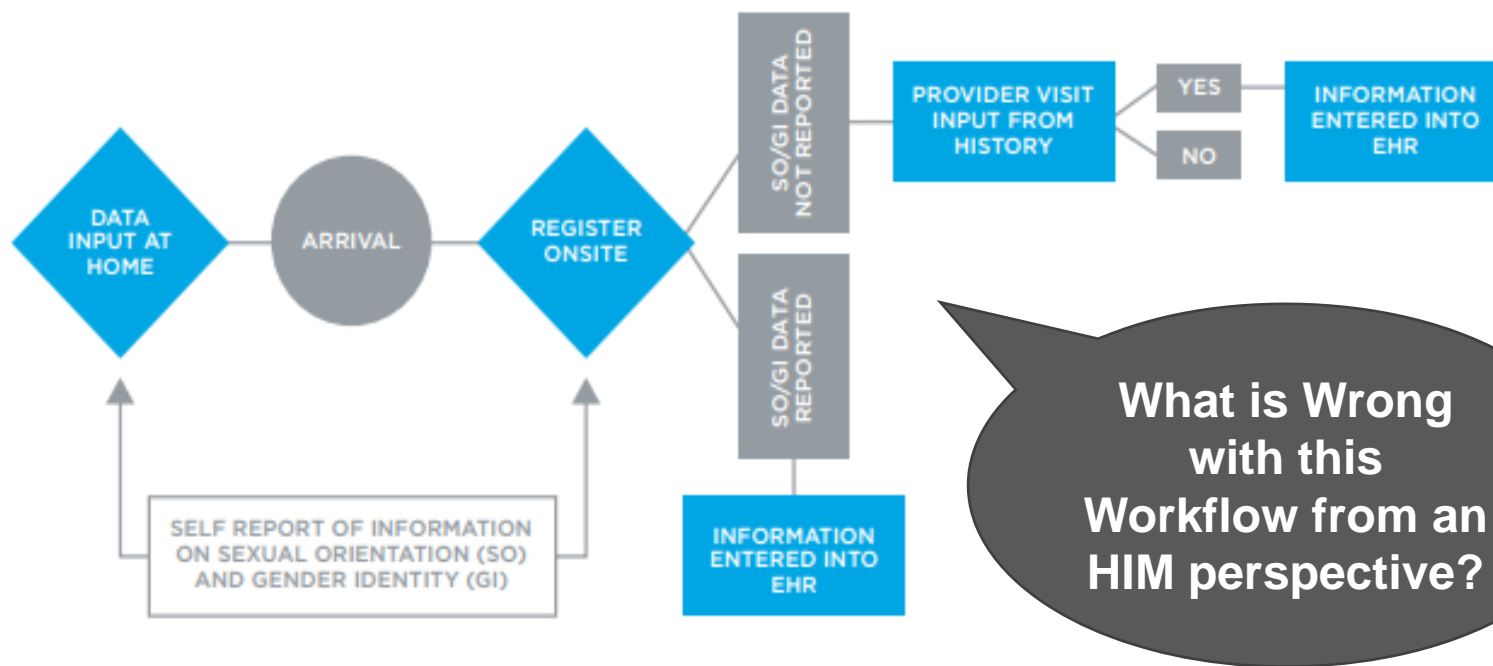
Type	Standard/Implementation Specification	Standards Process Maturity	Implementation Maturity	Adoption Level	Regulated	Cost	Test Tool Availability
Standard	SNOMED-CT	Final	Unknown	Unknown	No	Free	N/A

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Source: 2016 Interoperability Standards Advisory, ONC for Health IT

Data Collection Model

FIGURE 3: SAMPLE PROCESS FOR COLLECTING DATA FROM PATIENTS IN CLINICAL SETTINGS



Source: <http://lgbthealtheducation.org/wp-content/uploads/Collecting-SOGI-Data-in-EHRs-COM2111.pdf>

Data Collection

CHC Patient Registration - Test, Apple Pie (573629)

☒ Patient ☐ Guarantor

☒ Patient Same as Guarantor

Prefix First Middle Last Suffix
Apple Pie Test

Address 1340 boylston Street

City/State Boston MA 02215

Country

Homeless ☐ Effective Date 12/13/2012

Status Not Homeless

Phone 1 (617) 927-6000 Work

Phone 2

Birthdate 12/31/1988 25 Yrs SSN

Marital Status (None)

Gender Female Occup.

Employer

Status (None) Date / /

Last Modified syue 11/03/2014

Mini Registration Additional Contact Info Notes Other Pt Info

Do you think of yourself as (sexual orientation): Lesbian, Gay, or H

What is your gender? Female

What was your sex at birth? Male

Do you identify as Transgender or Transsexual? Yes

OK Cancel

Source: Collecting SOGI Data Webinar, April 5, 2016

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Data Collection

Fenway Health Patient Registration Information

Why is my demographic information needed?

Fenway Health realizes that every patient has a unique set of health needs. We feel that it is most important to respect an individual's choice about how to identify. These questions are asked of all our patients and most are completely voluntary.

How do I choose the correct information?

There are no right or wrong answers. If you don't find an answer that exactly fits, choose one that comes closest. This information will help us give you the best care possible.

Who will see this information?

Your provider will see this information, and it will become part of your medical record. In addition to your provider, limited Fenway staff have access to this information. Your information is confidential and protected by law just like all of your other health information.

Thank you for taking the time to complete the registration form.

Source: Collecting SOGI Data Webinar, April 5, 2016

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Australia

How do we Compare to other Countries?

Sex and Gender Classification in Australian Government Records

19. Where sex and/or gender information is collected and recorded in a personal record, individuals should be given the option to select M (male), F (female) or X (Indeterminate/Intersex/Unspecified).

- If the X descriptor set out at paragraph 19 is too lengthy for collection forms or data systems, the Australian Government's preference is to use either 'unspecified' or 'indeterminate'. This classification system is consistent with the Australian Government passports policy for applicants who are sex and gender diverse and Australian Standard *AS4590 – Interchange of client information*.⁷

Source:

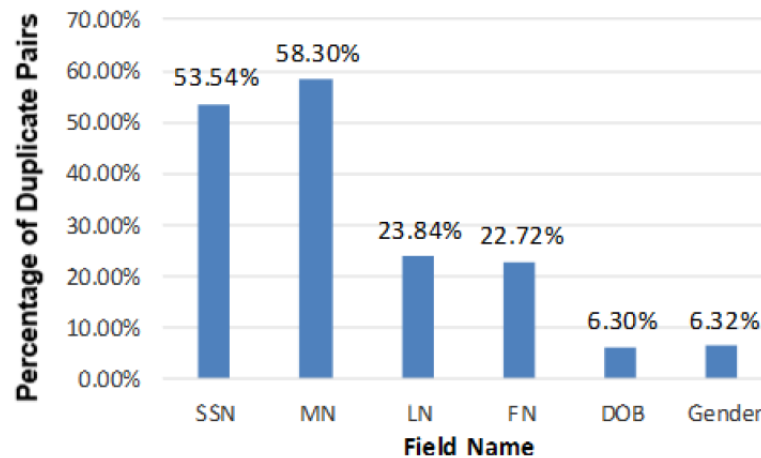
<https://www.ag.gov.au/Publications/Documents/AustralianGovernmentGuidelinesontheRecognitionofSexandGender/AustralianGovernmentGuidelinesontheRecognitionofSexandGender.pdf>

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Data Integrity

Figure 2

Percentage of Duplicate Pairs with a Mismatch in the SSN, MN, LN, FN, DOB, or Gender Field
($n = 398,939$)



Abbreviations: DOB = date of birth, FN = first name, MN = middle name, LN = last name, SSN = Social Security number.

Source: Just, Beth; Marc, David; Munns, Megan; Sandefer, Ryan. "Why Patient Matching Is a Challenge: Research on Master Patient Index (MPI) Data Discrepancies in Key Identifying Fields"

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Data Integrity – Duplicate Errors

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.



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Data Integrity – Duplicate Errors

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.

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Documentation and Workflow

New Workflows:

Workflows will need to be Reversed Engineered

- The intake of this sensitive data must be collected by a trusted clinical provider.
- The intake of patient demographics will need to be carefully evaluated.
 - ♦ Eventually, data must be structured for interoperability and it must make its way back into the MPI and EMPI alike.



Documentation and Workflow

Considerations:

- **Code Sets: Prostate is a male only procedure**
 - Will it be denied by insurance?
- **Lab reference ranges (male/female differences)**
- **Reference ranges for pulmonary function testing (predicted)**
- **Physician Orders**
 - Can a physician order a pap test on a transgender patient that is registered in the MPI as a male?
 - **EHR Decision Support**
 - Documentation templates and forms

Accurate and Useful Population Health Reporting

Documentation and Workflow

Considerations, Continued:

- **Name Change and Birth Certificates**
 - **Alias' or self described/self identified names**
- **Release of Information:**
 - **How are two moms documented to ensure proper access to their child's health information?**

Summary

Focus on data collection to enable quality of care for all our patient populations

LGBT status data collection has been initially supported by National and Federal Sources and Initiatives

MPI/EMPI/EHR workflows should be carefully reengineered and technology must keep pace with new data elements to correctly identify our patient populations.

Thank You, Questions?



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Resources

- <http://journal.ahima.org/2017/03/16/the-future-of-sexual-orientationgender-identity-sogi-healthcare-data/>
-
- <https://www.healthcare-informatics.com/article/guest-blog-optimizing-use-sexual-orientation-and-gender-identity-information-emr>
- <https://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health>
- <http://www.sageusa.org/files/Recommendations%20to%20Improve%20the%20Health%20of%20LGBT%20Communities.pdf>
- https://www.jointcommission.org/assets/1/18/LGBTFieldGuide_WEB_LINKED_VER.pdf
- <http://lgbthealtheducation.org/wp-content/uploads/Collecting-SOGI-Data-in-EHRs-COM2111.pdf>
- <https://www.lgbthealtheducation.org/webinar/sogi-collection-in-chcs/>
- <http://doaskdotell.org/ehr/lgbtpeople/> <http://doaskdotell.org/category/ehr/>
- https://www.healthit.gov/isa/Representing_Patient_Gender_Identity
- <https://bphc.hrsa.gov/datareporting/>