

Bringing Sexual Orientation and Gender Identity Data Collection and Education to an Academic Medical Center

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Conflict of Interests

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SOGI Data: Domains from a Literature Review

- Validated Questions
- Data collection validation
- Workforce Training
- Patient Responses
- Workforce Collection Protocol
- Privacy/Legal

SOGI Data: Domains from a Literature Review

- Validated Questions
 - Clinically validated questions exist to collect sexual orientation and gender identity information
 - One-part sexual orientation and two-part gender identity question
- Data collection validation
 - Few studies have shown that collected data is consistent with patient identification
 - This issue will have to be pursued as workforce training and protocol best-practices are implemented
- Workforce Training
 - SOGI data collection implementation must be coupled with staff cultural competency training
 - Teach utility of data, how to accurately collect, privacy considerations, department-specific concerns

SOGI Data: Domains from a Literature Review

- Patient Responses
 - Patients understand questions, are willing to answer, and perceive the importance of asking
 - Emerging consensus that emergency departments have positive response to SOGI questions
- Workforce Collection Protocol
 - SOGI data should go in demographic variables, with preferred name and/or pronoun, anatomical inventory, and means to maintain chart integrity when interfacing with insurance
 - Emerging agreement that self-report is preferred by patients, provider preference unclear
- Privacy / Legal
 - Non-discrimination policies are critical to implement SOGI data collection successfully
 - Fears of homophobia and negative consequences decrease willingness to answer questions

Implementing SOGI Data Collection

Successes

1) Identify institutional subject experts, champions, and key players/resources

LGBT Faculty Council
Champions across departments

2) Assess EHR's current SOGI capacity and IT resources for making change

EPIC LGBT SOGI Data Task Force
has centralized change efforts

3) Outline current workflow procedure, attitudes and skills, and need for training

Capability to collect in structured data exists

4) Evaluate patient safety concerns around SOGI data, discrimination, and privacy

Departments with high volume of T/GNC patients have received trainings first

Challenges

Large and growing body of staff
requires varying levels of training

There is a lag time between new standards
and update implementation

Difficulty standardizing training across
inpatient and outpatient networks

How and when patients can most safely and
accurately disclose SOGI data under discussion

SOGI Data - Collection Tools and Methods

- Potential for multiple means of collection: pre-visit by web portal or phone, at the visit electronically via iPad, visit by in-person registrar, the clinical encounter
- Lack of data-validated best practices for SOGI data collection methods
- We did not find a robust body of data that looked at accuracy of EHR information collection methods and SOGI data specifically
- Avoid stigmatizing the information by having it in clinical information, but other information domains may be handled with less sensitivity in more public areas

SOGI Data - Training and Education

- Training requires more than the EHR-related SOGI input mechanics
- Training is time and resource intensive
- Multiple training modalities likely needed to ensure data is safely and accurately collected, eg. simulation and observation
- EHR capacity and training goals impact SOGI collection roll out timeline
- Once in EHR, how is data being used in the clinic - knowing where to disclose and when

Data Collection – SO/GI in EMR

Visit Note (APC) (Initial) By (9/2014)*

New Event Time Mon, 27 Jun 16 1047 Prev Event Status (0

8 Social/Family Hx

1) Lives with:	<input type="text"/>
2) Employment/Income:	<input type="text"/>
3) Drug Use:	<input type="text"/>
4) Sexual History:	<input type="text"/>
5) Gender Identity:	<input type="text"/>
6) Assigned Sex at Birth:	<input type="text"/>
7) Family History:	<input type="text"/>
8) Psychiatry History:	<input type="text"/>
9) Other History:	<input type="text"/>

**2-Part Gender Identity
Question**



Data Collection – SO/GI in EMR

Visit Note (APC) (Initial) By (9/2014)*
New Event Time Mon, 27 Jun 16 1047 Prev Event Status
16 Social/Family Hx

3) Drug Use: _____
4) Sexual History: _____

Sexual Pattern Options

1	is active
2	is inactive
3	no prior experience
Contacts	
4	one partner
5	numerous partners
Orientation	
6	Lesbian
7	Gay
8	Straight/heterosexual
9	Bisexual
10	Queer
11	Something else
Risk factors	
12	hx anal intercourse
13	hx of cervical dysplasia
14	hx of STD's
15	contraception use
16	condom use
17	exp to known carrier
18	-
19	partner aware
20	partner unaware
Modifiers	
21	and

Multiple Options for Sexual Orientation



Sexuality

Patient's sexual orientation:

Gender Identity

Autofill with default responses for:

Patient's gender identity:

Patient's sex assigned at birth:

Patient's pronouns:

Steps patient has taken to transition, if any:

Patient's future plans to transition, if any: 

Patient's Sexual Orientation

Autofill with default option

Gender Identity and Sex Assigned at Birth

Pronouns

Steps taken to transition

Future plans to transition

Organ Inventory

Organs the patient currently has:

breasts cervix ovaries uterus vagina penis prostate testes

Organs present at birth or expected at birth to develop:

same as current organs

breasts cervix ovaries uterus vagina penis prostate testes

Organs hormonally enhanced or developed:

breasts

Organs surgically enhanced or constructed:

breasts vagina penis

Organ inventory

Organs present at birth/expected at birth – “same as current option”

Organs hormonally enhanced or developed

Organs surgically enhanced or constructed

SOGI Data - Creating Demand

- Growing literature about LGBTQ health disparities and best practices
- Quality improvement, performance improvement, and clinical outcomes measures are impossible to assess without accurate capture of SOGI data
- Demand will increase as regulatory bodies ask for this data
- Demand will increase as providers try to assess their own performance
- Creating competencies with all levels of health professional learners through higher level education on LGBTQ health and health disparities

Questions?