COLLECTING SEXUAL ORIENTATION AND GENDER IDENTITY DATA IN ELECTRONIC HEALTH RECORDS

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OUTLINE

I. Why collect SO/GI data in clinical settings?

II. Federal regulatory developments re: promoting SO/GI data collection in EHRs
   - Meaningful Use Stage 3 (CMS, ONC HIT)
   - HRSA UDS 2016
   - CMS Equity Plan, VHA

III. How to collect and use SO/GI data: www.doaskdotell.org
OUR ROOTS

• Fenway Health
• Independent 501(c)3 FQHC
• Founded 1971
• Half of our 30,000 patients are LGBT
• Integrated primary care model, including HIV services
• The Fenway Institute
• Research, education, policy
I. WHY LGBT HEALTH?

Adapted from IOM 2011: The Health of Lesbian, Gay, Bisexual and Transgender People
**LGBT People Experience Disparities**

- In access to preventive care (lesbians, trans—e.g. cancer screenings)
- In access to culturally competent care
- In insurance coverage
- In health risk behaviors (e.g. smoking 1.5-2.5x)
- In health outcomes, disease burden (e.g. obesity among lesbians; CVD for all; HIV/STIs among gay & bisexual men, transgender women; treatment outcomes for cervical, breast, ovarian cancer)
SEXUAL ORIENTATION AND GENDER IDENTITY ARE NOT THE SAME

All people have a sexual orientation and gender identity

- How people identify can change
- Terminology varies

Gender Identity ≠ Sexual Orientation
SEXUAL ORIENTATION

A person’s physical and emotional attraction to others

Desire:
- Same-sex attraction

Behavior:
- MSM, WSW, WSWM

Identity:
- Straight, gay, lesbian, bisexual, queer, other

Dimensions of Sexual Orientation:

Identity
Do you consider yourself gay, lesbian, bisexual, straight, queer?

Attraction/Desire
What gender(s) are you attracted to physically and emotionally?

Behavior
Do you have sex with:
- men?
- women?
- both?

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SEXUAL ORIENTATION

Sexual orientation: a person’s physical, emotional attraction to others

- Heterosexual (straight) – describes someone who is attracted to people of a different sex
- Gay – someone who is attracted to people of the same sex; usually used to describe men attracted to other men
- Lesbian – a woman who is attracted to other women
- Bisexual – individuals who are attracted to both men and women
- Queer – some may describe their sexual orientation in other ways, such as “queer” instead of LGB
Gender identity
- A person's internal sense of their gender (do I consider myself male, female, both, neither?)
- All people have a gender identity

Gender expression
- How one presents themselves through their behavior, mannerisms, speech patterns, dress, and hairstyles
- May be on a spectrum
THE T IN LG BT: TRANSGENDER

- Gender identity not congruent with the assigned sex at birth
- Alternate terminology
  - Transgender woman, trans woman, male to female (MTF)
  - Transgender man, trans man, female to male (FTM)
  - Trans feminine, Trans masculine
- Non-binary, genderqueer
  - Gender identity is increasingly described as being on a spectrum
**Sex**
- Refers to the presence of specific anatomy. Also may be referred to as ‘Assigned Sex at Birth’

**Gender Identity**
- What your internal sense tells you your gender is

**Sexual Orientation**
- Whom you are physically and emotionally attracted to
- Whom you have sex with
- How you identify your sexuality

**Gender Expression**
- How you present your gender to society through clothing, mannerisms, etc.
GATHERING SO/GI DATA IN EHRS

POLICY FOCUS:

WHY GATHER DATA ON SEXUAL ORIENTATION AND GENDER IDENTITY IN CLINICAL SETTINGS

POLICY FOCUS:

HOW TO GATHER DATA ON SEXUAL ORIENTATION AND GENDER IDENTITY IN CLINICAL SETTINGS
WHY COLLECT SO/GI DATA?

- Important for patient/provider communication
- To better understand LGBT health disparities and inform interventions to reduce and eliminate them
- Lesbians, transgender people have lower rates of preventive screenings (e.g. mammograms)
- Transgender men should be offered a Pap test, screened for breast cancer
- Transgender women should be offered prostate screening as appropriate
- Tobacco screenings offered to LGBT patients; weight management issues among young gay, bi men, obesity among lesbians

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INVISIBILITY OF LGBT PATIENTS

- Limited data indicate providers do not routinely ask SO/GI questions
- Lack of comfort in discussing sexual behavior and sexual risk assessment
BARRIERS IN ACCESS TO CARE

Many LGBT individuals may not be disclosing their sexual orientation to health care providers. LGBT patients report real and/or perceived stigma and discrimination in the health care setting, or know of someone who has:
- Many approach health care with the expectation of a negative encounter
- Can lead to delayed or limited access to care

Asking SOGI questions as a standard demographic variable will help insure the collection of SOGI data in health care.
DISCRIMINATION AND HEALTH IN MASSACHUSETTS: A STATEWIDE SURVEY OF TRANSGENDER AND GENDER NONCONFORMING ADULTS

Reisner SL, White JM, Dunham ED, Hefflin K, Begeny J, Cahill S, and the Project Voice Team
PUBLIC ACCOMMODATIONS DISCRIMINATION AND PUBLIC HEALTH

• n=455, March-Dec 2013 survey
• 65% reported public accommodations disc. in past year
  ▪ Transportation 36%, retail 28%, restaurants 26%, public gatherings 25%, and healthcare 24%.
• Public accommodations discrimination associated with two-fold increased risk of adverse physical (RR=1.84), emotional (RR=1.99) symptoms in past 30 days.
• Those reporting discrimination in health care 19% less likely to seek emergent care, 25% less likely to seek routine or preventive care
The Health of Lesbian, Gay, Bisexual, and Transgender People
Building a Foundation for Better Understanding
BUSINESS RATIONALE

• Collecting SOGI data will become industry standard
• In order to best know, serve your patients, you should collect data, train staff in LGBT cultural competence
  ▪ Becoming known for providing culturally competent and affirming care may draw in more LGBT patients
• More and more health facilities will begin to collect SOGI data as LGBT nondiscrimination becomes the norm
  ▪ 17 states, DC, 200+ municipalities ban SOGI discrimination in healthcare
  ▪ OCR SO/GI nondiscrimination regulation
II. FEDERAL REGULATORY DEVELOPMENTS

- Meaningful Use Stage 3
- Office of National Coordinator of Health IT
  - Certified EHR Technology requirements
- HRSA, Veterans Health Administration, CMS OMH, other federal agencies moving forward with SO/GI data collection in their systems
Meaningful Use Trajectory

STAGE 1
2011 + Data Capture & Sharing

STAGE 2
2014 + Advanced Clinical Processes

STAGE 3
2016-2017 + Improved Outcomes
• Meaningful Use priorities:
  ▪ Reduce health disparities
  ▪ Engage patients and families
  ▪ Improve population health and public health
MEANINGFUL USE GUIDELINES, STAGE 2

- Office of National Coordinator of Health IT, CMS accepted public comment on Stage 2 Meaningful Use (2012), whether to include SO/GI
- Fenway, CAP strongly urged inclusion of SO/GI
- Others raised objections or identified potential barriers
  - extremely sensitive
  - collecting of data by administrative staff could be considered offensive
  - did not see clinical significance
  - physician burden
- Bottom line: SO/GI not included in Stage 2 Meaningful Use Guidelines

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“WE DON’T KNOW HOW TO MEASURE SO/GI”

- ONC HIT response Stage 2: “Considering the lack of consensus for the definition of the concept of gender identity and/or sexual orientation as well as for a standard measure of the concept and where it would be most appropriate to store the data within the EHR, we will await further development of a consensus for the goal and standard of measurement for gender identity and/or sexual orientation.”

- During Stage 3 Standards Committee expressed sense that “we don’t know how to measure SO/GI.”
Do Ask, Do Tell: High Levels of Acceptability by Patients of Routine Collection of Sexual Orientation and Gender Identity Data in Four Diverse American Community Health Centers

Sean Cahill¹, Robbie Singal², Chris Grasso², Dana King², Kenneth Mayer³, Kellan Baker⁴, Harvey Makadon⁵

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Abstract

Background: The Institute of Medicine and The Joint Commission have recommended asking sexual orientation and gender identity (SOGI) questions in clinical settings and including such data in Electronic Health Records (EHRs). This is increasingly viewed as a critical step toward systematically documenting and addressing health disparities affecting lesbian, gay, bisexual, and transgender (LGBT) people. The U.S. government is currently considering whether to include SOGI data collection in the Stage 3 guidelines for the Incentive Program promoting meaningful use of EHR. However, some have questioned whether acceptable standard measures to collect SOGI data in clinical settings exist.

Methods: In order to better understand how a diverse group of patients would respond if SOGI questions were asked in primary care settings, 301 randomly selected patients receiving primary care at four health centers across the U.S. were asked SOGI questions and then asked follow-up questions. This sample was mainly heterosexual, racially diverse, and...
SEXUAL ORIENTATION QUESTION

Do you think of yourself as:

- Lesbian, gay, or homosexual
- Straight or heterosexual
- Bisexual
- Something else
- Don’t know
2-STEP GENDER IDENTITY QUESTION

1. What sex were you assigned at birth? (Check one)
   - Male
   - Female
   - Decline to answer

2. What is your current gender identity? (Check and/or circle ALL that apply)
   - Male
   - Female
   - Transgender Male/Transman/FTM
   - Transgender Female/Transwoman/MTF
   - Genderqueer
   - Additional category (please specify): ________________________________
   - Decline to answer

3. What pronouns do you prefer (e.g., he/him, she/her)? ___________

Adapted from: Primary Care Protocol for Transgender Patient Care, April 2011. Center of Excellence for Transgender Health. University of California, San Francisco, Department of Family and Community Medicine
GATHERING SO/GI DATA DURING THE PROCESS OF CARE

DATA INPUT AT HOME

ARRIVAL

REGISTER ONSITE

SELF REPORT OF INFORMATION ON SEXUAL ORIENTATION (SO) AND GENDER IDENTITY (GI)

SO/GI DATA REPORTED

INFORMATION ENTERED INTO EHR

SO/GI DATA NOT REPORTED

PROVIDER VISIT INPUT FROM HISTORY

YES

INFORMATION ENTERED INTO EHR

NO
Final rule published October 6, 2015

Will require EHR systems certified under Stage 3 of the Meaningful Use incentive program to allow users to record, change, and access structured data on sexual orientation and gender identity.

This requirement is part of the 2015 Edition “demographics” certification criterion and adds SO/GI data to the 2015 Edition Base EHR definition, which is a part of the definition of Certified EHR Technology (CEHRT).
“CMS and ONC believe including SO/GI in the ‘demographics’ criterion represents a crucial step forward to improving care for LGBT communities.”
ONC RULE SPECIFIED MINIMAL STANDARD FOR SO QUESTION

(i) Lesbian, gay or homosexual.
(ii) Straight or heterosexual.
(iii) Bisexual.
(iv) Something else, please describe.
(v) Don’t know.
(vi) Choose not to disclose.

(p. 496)
ONC RULE SPECIFIED MINIMAL STANDARD FOR G1 QUESTION

(i) Male.
(ii) Female.
(iii) Female-to-Male (FTM)/Transgender Male/Trans Man.
(iv) Male-to-Female (MTF)/Transgender Female/Trans Woman.
(v) Genderqueer, neither exclusively male nor female.
(vi) Additional gender category or other, please specify.
(vii) Choose not to disclose.

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IMPORTANT TO KNOW BOTH SEXUAL IDENTITY AND BEHAVIOR

• Male same-sex behavior w/o protection can expose one to STIs like HIV, syphilis; important to discuss same-sex behavior

• Social prejudice, isolation can cause LGBT people to experience social anxiety, depression, substance use; to not seek routine health care

• These are not caused by s-s behavior but by anti-LGBT stigma; important to discuss identity
TWO OTHER FEDERAL POLICY DEVELOPMENTS

• **Health Resources and Services Administration (HRSA):** will include SO/GI in Uniform Data System in 2016

• **CMS Office of Minority Health:** Released “CMS Equity Plan for Improving Quality in Medicare”
  - Calls for expanding collection, reporting and analysis of standardized SO/GI data
  - Calls for evaluating disparity effects, integrating equity solutions
I. BACKGROUND

This Program Assistance Letter (PAL) provides an overview of approved changes to the Health Resources and Services Administration’s (HRSA) calendar year (CY) 2016 Uniform Data System (UDS) to be reported by Health Center Program grantees and look-alikes in February 2017. Additional details regarding these changes will be provided in the forthcoming 2016 UDS Manual.
II. Approved Changes for CY 2016 UDS Reporting

A. Sexual Orientation and Gender Identity (SO/GI) – Tables 3A, 3B

Sexual orientation and gender identity are reported on Table 3A, 3B.

Rationale: Improving the health of the Nation’s underserved communities and vulnerable populations by assuring access to comprehensive, culturally competent, quality primary health care services is a priority of the Health Center Program. Sexual orientation and gender identity can play a significant role in determining health outcomes. Gaining a better understanding of populations served by health centers, including sexual orientation and gender identity, promotes culturally competent care delivery and contributes to reducing health disparities overall. In addition, adopting sexual orientation and gender identity (SO/GI) data collection in the UDS aligns with the 2015 Edition Health Information Technology (Health IT) Certification Criteria, 2015 Edition Base Electronic Health Record (EHR) Definition, and the Office of the National Coordinator for Health Information Technology (ONC) Health IT Certification Program. Alignment of UDS SOGI data elements with ONC certification criteria also reduces overall health center reporting burden.
### Table 3B: Demographic Characteristics

**Reporting Period:** January 1, 2016 through December 31, 2016

<table>
<thead>
<tr>
<th>Line</th>
<th>Patients by Sexual Orientation</th>
<th>Number (a)</th>
</tr>
</thead>
<tbody>
<tr>
<td>13.</td>
<td>Lesbian or gay</td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>Straight (not lesbian or gay)</td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>Bisexual</td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>Something else</td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>Don’t know</td>
<td></td>
</tr>
<tr>
<td>18.</td>
<td>Choose not to disclose</td>
<td></td>
</tr>
<tr>
<td>19.</td>
<td>Total Patients (Sum Lines 13 to 18)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Line</th>
<th>Patients by Gender Identity</th>
<th>Number (a)</th>
</tr>
</thead>
<tbody>
<tr>
<td>20.</td>
<td>Male</td>
<td></td>
</tr>
<tr>
<td>21.</td>
<td>Female</td>
<td></td>
</tr>
<tr>
<td>22.</td>
<td>Transgender Male/ Female-to-Male</td>
<td></td>
</tr>
<tr>
<td>23.</td>
<td>Transgender Female/ Male-to-Female</td>
<td></td>
</tr>
<tr>
<td>24.</td>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>25.</td>
<td>Choose not to disclose</td>
<td></td>
</tr>
<tr>
<td>26.</td>
<td>Total Patients (Sum Lines 20 to 25)</td>
<td></td>
</tr>
</tbody>
</table>
SECTION 1557 OF THE AFFORDABLE CARE ACT

- Prohibits discrimination in health programs funded, even in part, by federal money or provided by a federal agency on the basis of race, color, national origin, sex, age, or disability (federal civil rights laws—Civil Rts Act 1964 Title VII, Education Amendmts 1972 Title IX)

- HHS Office of Civil Rights regulation April 2016: Sex discrimination interpreted to encompass sexual orientation and gender identity discrimination

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III. HOW TO USE SO/GI DATA TO IMPROVE QUALITY CARE AND REDUCE DISPARITIES

- www.doaskdotell.org
- Modeled after HRET Racial and Economic Disparities online toolkit
ONLINE TOOLKIT FOR COLLECTING SO/GI DATA IN EHIRS
WWW.DOASKDOTELL.ORG

Do Ask, Do Tell
A Toolkit for Collecting Data on Sexual Orientation and Gender Identity in Clinical Settings
Health Data Systems: Decision Support and Coding

SO/GI data are relevant to numerous aspects of patient health. To support a wide range of actors in clinical settings in successfully collecting and using these data to promote patient health, developers of EHR software for hospitals, health centers, and other health systems should incorporate structured SO/GI data into decision support and coding.
LEARNING BY EXAMPLE

Eliminating Disparities: Why It’s Essential and How to Get It Done

Hospitals Must Take the Lead in Eliminating Disparities in Care
By Rich Umbdenstock, AHA President and CEO and Kevin E. Lofin, CEO of Catholic Health Initiatives, Past Chair, AHA Board of Trustees and Chairman of the AHA’s Special Advisory Group on Improving Hospital Care for Minorities

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• “Measures of outcomes have become increasingly important for demonstrating effectiveness of care…”
• “Disparities in health care can be addressed through a quality of care framework if data on race, ethnicity, and primary language are available”
• “According to the report ‘The Right to Equal Treatment’ issued by Physicians for Human Rights, data collection has long been central to the quality assurance process.”
• “It also helps ensure nondiscrimination in access to care.”
PREPARATION FOR COLLECTING DATA IN CLINICAL SETTINGS

• Clinicians: Need to learn about LGBT health and the range of expression related to identity, behavior, and desire. Staff needs to understand concepts

• Non-clinical staff: Front desk and patient registration staff must also receive training on LGBT health, communicating with LGBT patients, and achieving quality care with diverse patient populations

• Patients: Need to learn about why it is important to communicate this information, and feel comfortable that it will be used appropriately
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.
SEXUAL ORIENTATION QUESTION

Do you think of yourself as:
- Lesbian, gay, or homosexual
- Straight or heterosexual
- Bisexual
- Something else
- Don’t know
GENDER IDENTITY QUESTIONS

What is your current gender identity?
- Male
- Female
- Transgender Male/Trans Man/FTM
- Transgender Female/Trans Woman/MTF
- Gender Queer
- Additional Category (please specify)
  __________

What sex were you assigned at birth?
- Male
- Female
- Decline to Answer

What is your preferred name and what pronouns do you use (e.g. he/him, she/EHR)?
______________________
PREFERRED NAME AND PRONOUNS

What is your preferred name and what pronouns do you use (e.g. he/him, she/EHR)?
_____________________

• Important to ask patients to include their preferred name, pronouns on registration forms
• Many transgender patients may have identification documents and insurance forms that do not reflect their current name and gender identity
• Some patients may have a non-binary gender identity and use pronouns such as “they” or “ze”, which may be unfamiliar to some providers
COLLECTING SO/GI DATA DURING CLINICAL ENCOUNTER

• If patients leave SOGI questions unanswered on registration forms, health care providers should re-ask these questions during the clinical encounter.

• Sexual orientation, sexual behavior, gender identity, and preferred pronoun questions should be asked during the first clinical visit and on an ongoing basis as indicated.
HOW PROVIDERS CAN ASK SO/GI QUESTIONS

Open-ended questions can allow patients to feel comfortable to disclose SOGI information

- “Tell me a little bit about yourself”
- “Do you have any concerns or questions about your sexual orientation, sexual desires, or gender identity?”

SOGI questions can also be asked during the social or sexual history during history taking

- Providers can normalize this process by saying “this is something I ask all of my patients”
CHALLENGES ASSOCIATED WITH ASKING SO/GI QUESTIONS

Patient concerns regarding privacy and confidentiality
- This may limit patient disclosure of SOGI information
- Critical to develop adequate standards for encoding medical information and computer infrastructure to manage threats to privacy

Provider-reported concerns regarding lack of comfort in asking SOGI questions

Time constraints during the clinic visit
- Despite concerns regarding time constraints, it is important for providers to discuss these issues to adequately care for LGBT patients
DECISION SUPPORT: PREVENTIVE HEALTH SCREENINGS

- Charles M is a 35-year-old male who presents with symptoms of burning on urination and urethral discharge.
- At first he said he is straight, but on further questioning, he said he occasionally has unprotected sex with other men.
- Given history, he will need repeat HIV testing, assessment of risk behaviors and STI screening.
APPROPRIATE SCREENING: JAKE R’S STORY

• Jake R is a 45-year-old man who came in with pain and on x-ray what appeared to be metastases from an unknown primary cancer.

• Evaluation ultimately showed that he had developed cancer in his residual breast tissue after surgery to remove his breasts.

• No one told Jake that he needed routine breast cancer screening, even though his mother and sister also had breast cancer.
LOUISE M

- Louise M is a 59-year-old woman who developed a high fever and chills after head and neck surgery
- The source of infection was her prostate gland (acute prostatitis), but no one knew that she had this anatomy
- No one asked her about her gender identity or knew she was transgender
- She had never had prostate screening
DECISION SUPPORT

Decision support in the form of alerts and reminders must be built into the EHR system in order to remind HCPs to conduct indicated preventive screenings.

Decision support systems for transgender patients should be based on **assigned sex at birth** and an up-to-date anatomical inventory.

- For example, a transgender man may retain his cervix and may need a Pap test.
LGBT PEOPLE LIVE EVERYWHERE

All health care providers, even those in rural and Southern areas, should ask about SOGI because LGBT people live in all areas across the country.

Percentage of LGBT Population, by state (Source: Gallup, 2013)

http://williamsinstitute.law.ucla.edu/research/census-lgbt-demographics
LGBT PEOPLE LIVE EVERYWHERE

- Not only in Boston and Northampton, but in every part of the Commonwealth, including rural areas.
- LGBT people come to your health center, social service center.
- It’s important to create a welcoming, affirming environment in which people are comfortable being “out”.
- Being “closeted” causes minority stress.
Same-sex couples per 1,000 households
by Census tract (adjusted)
The National LGBT Health Education Center provides educational programs, resources, and consultation to health care organizations with the goal of optimizing quality, cost-effective health care for lesbian, gay, bisexual, and transgender (LGBT) people.

The Education Center is a part of The Fenway Institute, the research, training, and health policy division of Fenway Health, a Federally Qualified Health Center, and one of the world’s largest LGBT-focused health centers.
THANK YOU. QUESTIONS?

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