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Collecting and using sexual orientation, gender identity data in EHRs

Sean Cahill, PhD

Leandro Mena, MD, MPH

Kellan Baker, MPH, MA

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8-9am



AMERICA'S
ESSENTIAL
HOSPITALS



OUTLINE

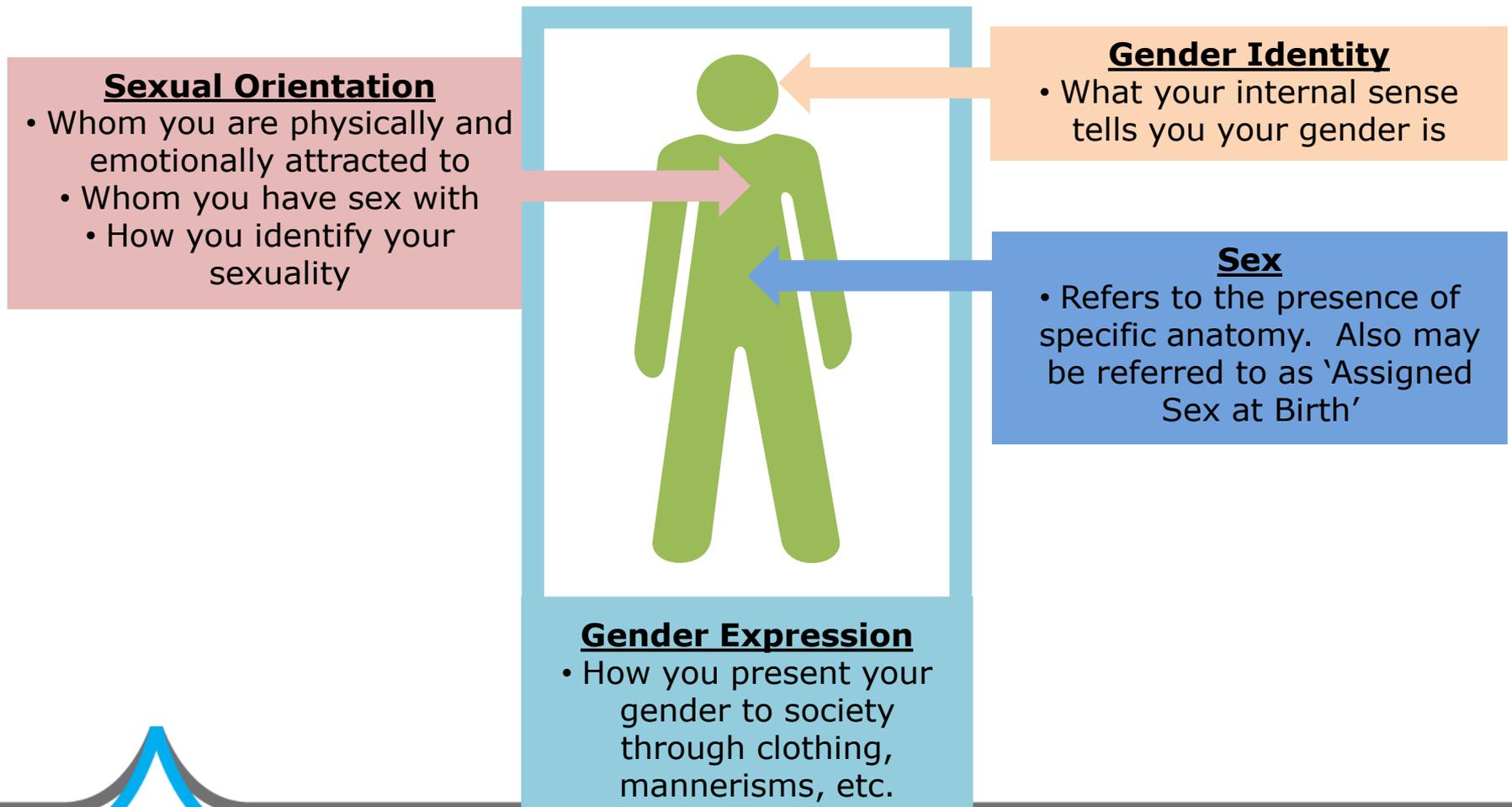
I. Why collect sexual orientation and gender identity (SO/GI) data in clinical settings?

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

LGBT TERMINOLOGY



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 behavior (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)

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

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



TAKING ROUTINE HISTORIES OF SEXUAL HEALTH:

A System-Wide Approach for Health Centers

New Edition: November 2015

Sexual Risk Assessment^{2,3}

The Centers for Disease Control and Prevention (CDC) has developed a simple categorization of sexual history questions that may help providers, or other members of the clinical care team, remember which topics to cover. These are called the Five P's:



The following risk assessment questions are organized according to these categories.

PARTNERS

These questions may already have been covered during the first three screening questions (see page 6) of the sexual history. They are listed again here but do not need to be repeated.

- Are you having sex with women only, men only, or both? (if both, ask the next question twice—once for male partners, and once for female partners)
- How many sexual partners have you had in the past year?

Additional questions about partners:

- Have you ever had sex with someone you didn't know or just met?
- Have you ever traveled internationally, to places such as Thailand or Africa, to have casual sex?
- Have you ever experienced physical, sexual, or emotional violence from someone you were involved with?

PRACTICES AND PROTECTION FROM STDs

Some patients respond better to open-ended questions about their sexual practices, and some prefer

² This risk assessment has been adapted from: Centers for Disease Control and Prevention. A guide to taking a sexual history. Available at: <http://www.cdc.gov/ghl/health/>

³ STD/HIV Risk Assessment & Risk Reduction: A Quick Reference Guide. March 2008. Mountain Plains AIDS and Education Training Center; Seattle STD/HIV Prevention Training Center.

BARRIERS IN ACCESS TO CARE

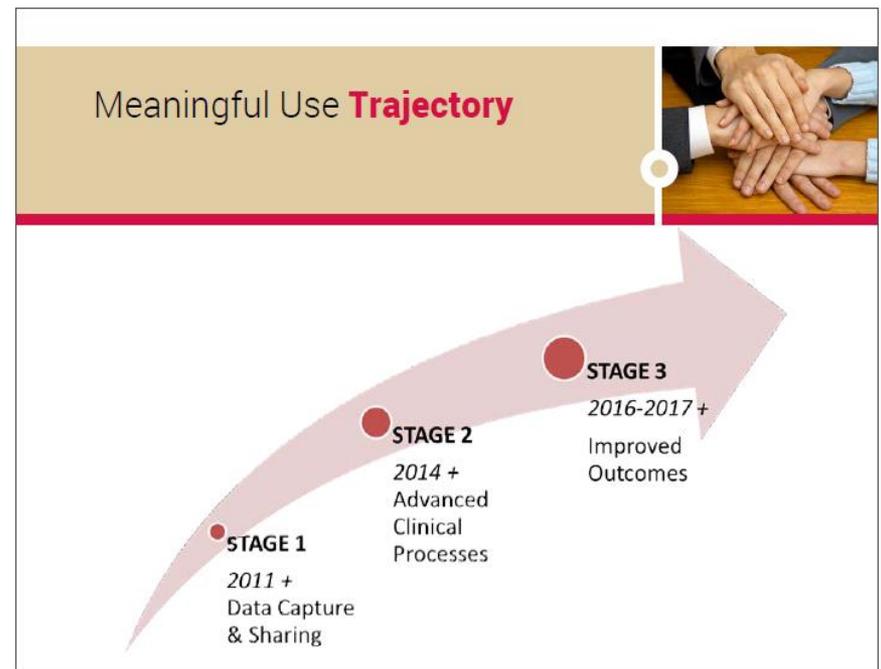
- Many LGBT individuals may not disclose their SO/GI to health care providers
- LGBT patients report real and/or perceived stigma and discrimination in the health care setting, or know of someone who has
 - » Many approach health care with the expectation of a negative encounter
 - » Can lead to delayed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

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

FEDERAL POLICY DEVELOPMENTS

- Stage 3 Meaningful Use Guidelines
 - » According to CMS and ONC, SOGI data fields must be incorporated in EHR software certified under the Meaningful Use Incentive Program
- “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

ONC RULE SPECIFIED MINIMAL STANDARD FOR GI 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

FEDERAL POLICY DEVELOPMENTS

- HRSA: Proposed Changes for CY 2016 UDS Reporting
 - » Improving the health of the nation's underserved...is a priority of the Health Center Program
 - » Sexual orientation and gender identity can play a significant role in health outcomes
 - » Sexual Orientation and Gender Identity are reported on UDS Tables 3A, 3B



PROGRAM ASSISTANCE LETTER

DOCUMENT NUMBER: PAL 2016-02

DATE: March 22, 2016

DOCUMENT TITLE: Approved Uniform Data System Changes for Calendar Year 2016

TO: Health Centers
Primary Care Associations
Primary Care Offices
National Cooperative Agreements

I. BACKGROUND

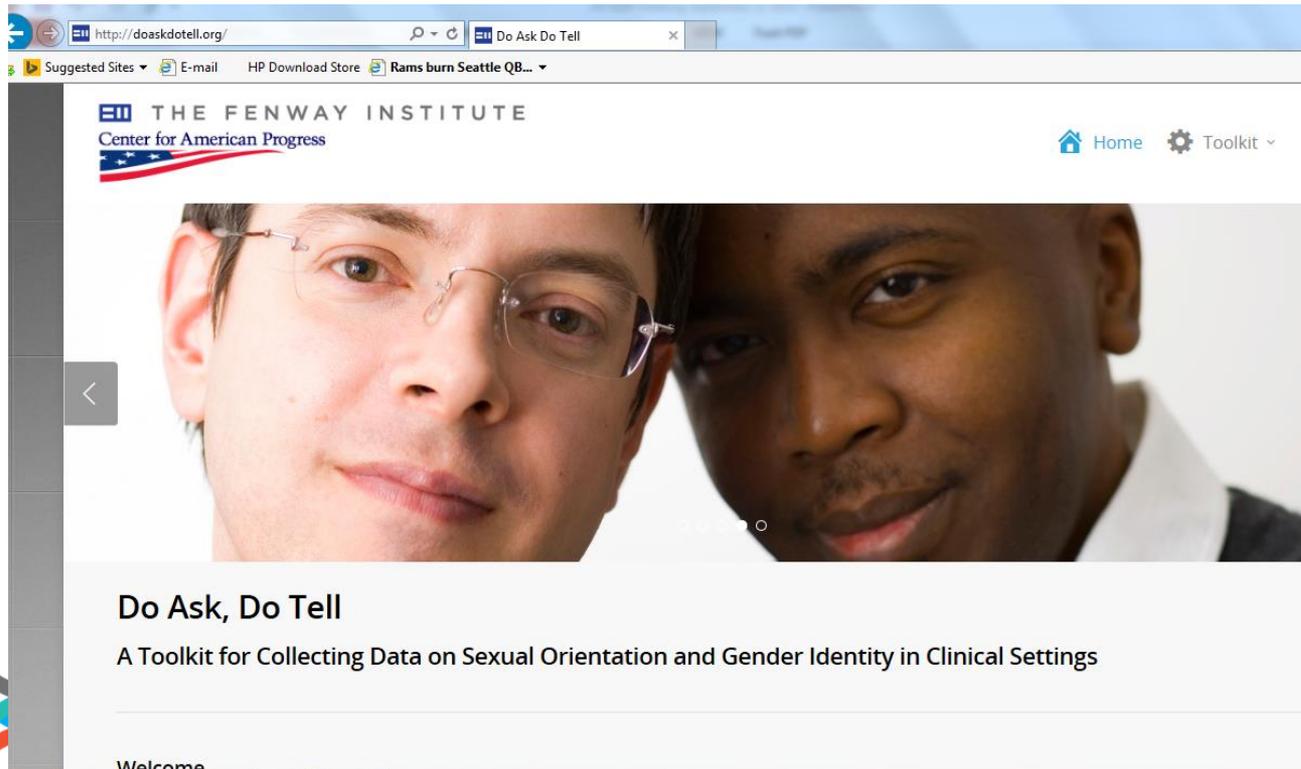
This Program Assistance Letter (PAL) provides an overview of approved changes to the Health Resources and Services Administration's (HRSA) calendar year (CY) 2016 Uniform Data System (UDS) to be reported by Health Center Program grantees and look-alikes in February 2017. Additional details regarding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

FEDERAL POLICY DEVELOPMENTS

- Nondiscrimination regulation implementing 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
 - » Sex discrimination interpreted to encompass gender identity discrimination

HOW TO COLLECT SO/GI DATA

- www.doaskdotell.org
- Modeled after HRET Racial and Economic Disparities online toolkit



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 is your current gender identity?

- Male
- Female
- Transgender Male/Transman/FTM
- Transgender Female/Transwoman/MTF
- Genderqueer
- Additional category (please specify): _____
- Decline to answer

2. What sex were you assigned at birth?

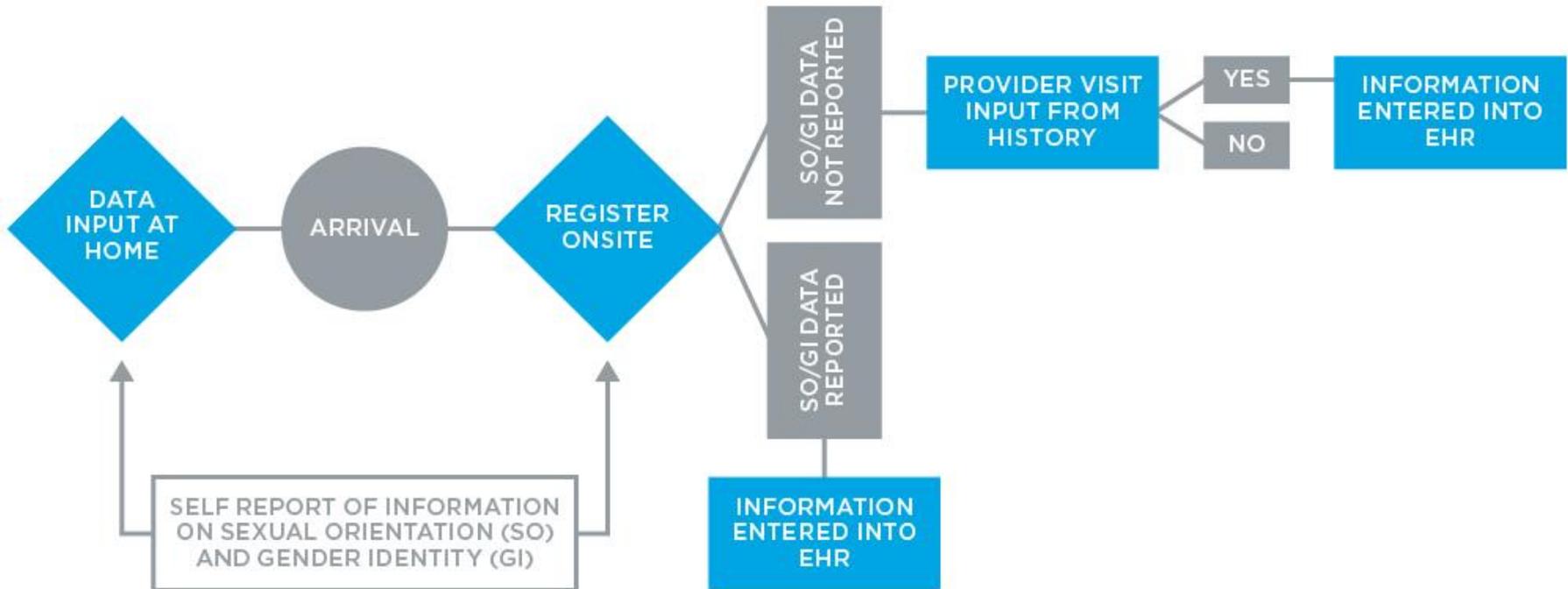
- Male
- Female
- Decline to answer

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

PREFERRED NAME AND PRONOUNS

- 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

GATHERING SO/GI DATA DURING THE PROCESS OF 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

COLLECTING SO/GI DATA PRIOR TO ARRIVAL

- SO/GI information can be entered directly by the patient through an online portal/mobile device
 - » This can occur at home, prior to the office visit
 - » Added benefit of additional privacy in answering questions at home
 - » Self-administered computer-based questionnaires have the potential to elicit more accurate responses to sensitive questions

COLLECTING SO/GI DATA DURING ONSITE REGISTRATION

- Questions can be included alongside other demographic questions (i.e. race, ethnicity, language)
- Use standardized SOGI questions as part of the demographic section on registration
- Inform patients of purpose in collecting SOGI data
 - » SOGI information will help health care providers to deliver appropriate prevention, screening, and treatment services
- SOGI information should be updated as needed on an ongoing basis for both new and returning patients

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 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

CULTURAL COMPETENCY: AVOIDING ASSUMPTIONS

- You cannot assume someone's gender or sexual orientation based on how they look or sound
- To avoid assuming gender or sexual orientation with new patients:
 - Instead of:* "How may I help you, sir?"
Say: "How may I help you?"
 - Instead of:* "He is here for his appointment."
Say: "The patient is here in the waiting room."
 - Instead of:* "Do you have a wife?"
Say: "Are you in a relationship?"
 - Instead of:* "What are your mother and fathers' names?"
Say: "What are your parents' names."

WORKING WITH EHR VENDORS

- How to structure SOGI questions
 - » EHR vendors should use standard methods to ask and document SOGI information
 - » SO and GI questions should be collected as discrete data in each of their own fields within EHRs
 - » Data should be visible in different sections of the EHR (i.e. registration and chart)
- Development of clinical decision support
 - » Placement of data has implications for how it is displayed for patient portals and billing purposes

EHR SUPPORT AND CONSULTATION

- EHR support staff (which may include personnel from other departments) can help develop, integrate, and/or modify existing EHR systems to collect SOGI data
 - » Determine placement of data fields and how they will be stored/entered
 - » Provide access to SOGI information
 - » Develop decision support protocols
 - » Integrate response categories and data fields, modify systems if needed
 - » Create or edit new templates/intake forms

USING SO/GI DATA CASE STUDY: APPROPRIATE SCREENING

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



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

TRANSGENDER HEALTH AND CODING

- A transgender man may be registered in the EHR system under a male name and gender
 - » If the patient has retained a cervix, uterus, and ovaries, HCPs will require the ability to enter gynecological history and pelvic physical exam findings
 - » May need to order a Pap test through the EHR system
- EHR templates that use pre-populated fields may prevent HCPs from entering gynecological history and physical exam findings
- This ultimately creates billing issues and HCPs may not be reimbursed for the provision of indicated health services

ADDRESSING CODING AND REIMBURSEMENT ISSUES

- Adequate EHR coding mechanisms must be in place to accurately document LGBT health information and bill for health services
- Must engage health insurance providers about LGBT standards of care
 - » Necessary so that indicated health services are routinely covered by insurance providers
- The lack of transgender specific health codes often results in inappropriate denials of services rendered

THANK YOU. QUESTIONS?

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Contact: Sean Cahill

scahill@fenwayhealth.org

617-927-6016