Do Ask, Do Tell! Collecting Data on Sexual Orientation and Gender Identity in Health Centers

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April 5, 2016
Continuing Medical Education Disclosure

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- **Disclosure**: No relevant financial relationships. Presentation does not include discussion of off-label products.

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Learning Objectives

1. Describe LGBT health disparities, concepts, and terms
2. Identify ways to provide a welcoming and inclusive health care environment to collect SO/GI data
3. Explain why collecting sexual orientation and gender identity (SO/GI) data is important for health centers and patient care
4. Access recommendations for collecting sexual orientation and gender identity data and entering it into electronic health records (EHR)
Questions for the Audience

- Does your health care organization collect patient data on sexual orientation?
  a) Yes
  b) Yes, but it is not collected consistently or across all sites and departments
  c) No / Not yet
  d) Not Sure

- Does your health care organization collect patient data on gender identity?
  a) Yes
  b) Yes, but it is not collected consistently or across all sites and departments
  c) No / Not yet
  d) Not Sure

Answer these questions on the right side of your screen and then hit “submit”
PROGRAM ASSISTANCE LETTER

DATE: March 22, 2016

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

DOCUMENT NUMBER: PAL 2016-02

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

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.
### Attachment 1: 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><strong>Total Patients</strong> (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><strong>Total Patients</strong> (Sum Lines 20 to 25)</td>
<td></td>
</tr>
</tbody>
</table>
Introduction

- Lesbian, gay, bisexual, and transgender (LGBT) patients have unique health needs and experience numerous health disparities.
- They are an underserved population that is largely invisible in the health care system.
- Routine and standardized collection of sexual orientation and gender identity (SOGI) information in electronic health records (EHRs) will help assess access, satisfaction with, quality of care, inform the delivery of appropriate health services, and begin to address health disparities.
Stigma, Discrimination and Health

Stigma

Interpersonal  Structural

Intrapersonal Stigma

Stress/Anxiety/Depression

Health Disparities/Inequities

Hatzenbuehler, ML, Link, BG. 2014

www.lgbthealtheducation.org
Effects of Stigma on Health

- Internalized homophobia, experiencing discrimination, and expectations of rejection, were associated with HIV risk behavior (Hatzenbuehler, Nolen-Hoeksema, & Erickson, 2008)

- Enacted and anticipated stigma resulted in approximately a 40% increase in delaying needed urgent and preventive care in a sample of 2,578 FTM trans masculine people. (Reisner et. al. 2015)
Health Issues Throughout the Life Course

Childhood & Adolescence

Early & Middle Adulthood

Later Adulthood
LGBT Disparities: Healthy People 2020

- LGBT youth
  - 2 to 3 times more likely to attempt suicide
  - More likely to be homeless (20-40% are LGBT)
  - Risk of HIV, STIs

- MSM are at higher risk of HIV/STIs, especially among communities of color

- LGBT populations have the highest rates of tobacco, alcohol, and other drug use

- Lesbians and bisexual women are less likely to get preventive screenings for cancer

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Transgender individuals experience a high prevalence of HIV/STIs, hate crimes, behavioral health issues, and suicide

- They are also less likely to have health insurance than heterosexual or LGB individuals

Elderly LGBT individuals face additional barriers to health because of isolation, fewer family supports, and a lack of social and support services
Who are LGBT People?
Understanding LGBT People

- It is important for health care providers to understand who are LGBT people and to have a common understanding of terms and definitions.
- This allows for effective and respectful communication and the delivery of culturally competent care.
- Health care providers will be better equipped to serve their patients and LGBT communities.
- L,G,B,T people are a very diverse group with many unique issues, and many common bonds.
What’s in a Word?
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

- Sexual orientation: how a person identifies their physical and emotional attraction to others
- Desire
  - Same sex attraction
- Behavior:
  - Men who have sex with men- MSM (MSMW)
  - Women who have sex with women- WSW (WSWM)
- Identity:
  - Straight, gay, lesbian, bisexual, queer--other
Gender Identity and Gender Expression

- 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
WHAT PEOPLE ASSUME GENDER IS

WHAT GENDER ACTUALLY IS
The T in LGBT: Transgender

- 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
Reviewing Terminology

**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.

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Creating a Welcoming and Inclusive Environment for Caring, Working and Learning
Creating a Caring and Inclusive Environment

- Does your center have a non-discrimination policy that includes sexual orientation, gender identity and gender expression?
- Are clinicians and staff taught about the health needs of LGBT people?
- Do LGBT employees feel respected and safe at work?
- Do forms reflect the full range of sexual and gender identity and expression?

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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.”
Do Ask, Do Tell: Talking to your provider about being LGBT
Collecting SOGI Data in EHRs
IOM Reports


- *Collecting SOGI Data in Electronic Health Records* (2013): “...data collection should start now to better understand the health care issues experienced by LGBT people.”
Collecting SOGI Information

Collecting Sexual Orientation and Gender Identity Data in Electronic Health Records
Taking the Next Steps

www.lgbthealtheducation.org/topic/sogi/
Questions for the Audience

- How does your health care organization collect sexual orientation and/or gender identity data?
  a) Registration form
  b) Provider asks the patient
  c) Non-provider staff ask the patient
  d) Patient portal
  e) Electronic survey on a tablet
  f) Other
  g) Not applicable (we don’t collect this data yet)

- Which EHR does your health care organization use?
  a) athenahealth
  b) eClinical Works
  c) Epic
  d) GE Centricity
  e) Greenway
  f) NextGen
  g) Other
  h) Not sure

Answer these questions on the right side of your screen and then hit “submit”
Federal Regulatory 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

- HRSA: 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 determining health outcomes
  - Sexual Orientation and Gender Identity are reported on UDS Tables 3A, 3B
Federal Regulatory Developments

- CMS Equity Plan
  - “Collection of standardized...data...is an important first step towards improving population health.”
  - “Comprehensive patient data, including...sexual orientation, gender identity...are required to plan for quality improvements, and to address changes among the target populations over time.”
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.

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How to Ask SOGI questions

- There are various ways SOGI information can be incorporated into the EHR and there is no single system to achieve this
  - SOGI questions can be asked on registration forms in the demographics section
  - Providers ask SOGI questions during patient visit
  - Answers can be entered into an EHR directly by a patient or member of the clinical staff, or transcribed at registration
Gathering LGBT Data During the Process of Care

Concept: Harvey Makadon, M.D. Created by: Komal Basra

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Collecting SOGI Information Prior to Arrival

Concept: Harvey Makadon, M.D. Created by: Komal Basra
Self-Administered Computer-Based Questionnaires

- SOGI information can be entered into the EHR directly by the patient through an online portal/mobile device
  - This can occur at home prior to office visit
  - There is the added benefit of additional privacy in answering SOGI questions at home

- Self-administered Computer-based questionnaires can be used to gather patient reported data
  - Have the potential to elicit more accurate responses to sensitive questions
Asking SOGI information on patient registration (intake) forms

Concept: Harvey Makadon, M.D. Created by: Komal Basra
Collecting SOGI Data During Onsite Registration

- Patients should be asked standardized SOGI questions as part of the demographic section on registration.
- Questions can be included alongside other demographic questions (i.e. race, ethnicity, language).
- Patients should be informed that information will help healthcare 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.
- Patients must be assured information will be kept confidential.
## Collecting Demographic Data on Sexual Orientation (Example)

<table>
<thead>
<tr>
<th>1. Which of the categories best describes your current annual income? Please check the correct category:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ &lt;$10,000</td>
</tr>
<tr>
<td>□ $10,000–14,999</td>
</tr>
<tr>
<td>□ $15,000–19,999</td>
</tr>
<tr>
<td>□ $20,000–29,999</td>
</tr>
<tr>
<td>□ $30,000–49,999</td>
</tr>
<tr>
<td>□ $50,000–79,999</td>
</tr>
<tr>
<td>□ Over $80,000</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. Employment Status:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Employed full time</td>
</tr>
<tr>
<td>□ Employed part time</td>
</tr>
<tr>
<td>□ Student full time</td>
</tr>
<tr>
<td>□ Student part time</td>
</tr>
<tr>
<td>□ Retired</td>
</tr>
<tr>
<td>□ Other ____________</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3. Racial Group(s):</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ African American/Black</td>
</tr>
<tr>
<td>□ Asian</td>
</tr>
<tr>
<td>□ Caucasian</td>
</tr>
<tr>
<td>□ Multi racial</td>
</tr>
<tr>
<td>□ Native American/Alaskan Native/Inuit</td>
</tr>
<tr>
<td>□ Pacific Islander</td>
</tr>
<tr>
<td>□ Other ____________</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4. Ethnicity:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Hispanic/Latino/Latina</td>
</tr>
<tr>
<td>□ Not Hispanic/Latino/Latina</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5. Country of Birth:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ USA</td>
</tr>
<tr>
<td>□ Other ____________</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6. Language(s):</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ English</td>
</tr>
<tr>
<td>□ Español</td>
</tr>
<tr>
<td>□ Français</td>
</tr>
<tr>
<td>□ Portugês</td>
</tr>
<tr>
<td>□ Русский</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>7. Do you think of yourself as:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Lesbian, gay, or homosexual</td>
</tr>
<tr>
<td>□ Straight or heterosexual</td>
</tr>
<tr>
<td>□ Bisexual</td>
</tr>
<tr>
<td>□ Something Else</td>
</tr>
<tr>
<td>□ Don’t know</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>8. Marital Status:</th>
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</thead>
<tbody>
<tr>
<td>□ Married</td>
</tr>
<tr>
<td>□ Partnered</td>
</tr>
<tr>
<td>□ Single</td>
</tr>
<tr>
<td>□ Divorced</td>
</tr>
<tr>
<td>□ Other ____________</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>8. Veteran Status:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Veteran</td>
</tr>
<tr>
<td>□ Not a veteran</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>1. Referral Source:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Self</td>
</tr>
<tr>
<td>□ Friend or Family Member</td>
</tr>
<tr>
<td>□ Health Provider</td>
</tr>
<tr>
<td>□ Emergency Room</td>
</tr>
<tr>
<td>□ Ad/Internet/Media/Outreach Worker/School</td>
</tr>
<tr>
<td>□ Other ____________</td>
</tr>
</tbody>
</table>
Collecting Data on Gender Identity

- 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 is your preferred name, and what pronouns do you use (e.g. he/him, she/her, they/them)?
  __________________________

- What sex were you assigned at birth?
  - Male
  - Female
  - Decline to Answer
Preferred Name and Pronouns

- What is your preferred name
- What are your pronouns (e.g. he/him, she/her, they/them)?

- It is important to ask patients to include their preferred name and their 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
Asking SOGI Questions During the Clinical Encounter

Concept: Harvey Makadon, M.D. Created by: Komal Basra
Directly Asking SOGI Questions

- 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, name and pronouns questions should be asked during the first clinical visit and on an ongoing basis as indicated.

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How Providers Can Ask SOGI 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 SOGI 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
Beyond Data Collection: Systems that Facilitate Getting it Right

- Decision Support
- Coding
- Reimbursement
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.
Transgender Patients: Organs for Inventory

- It is important for clinicians to maintain an up-to-date anatomical inventory, which will direct any indicated preventive screenings

- Penis
- Testes
- Prostate
- Breasts
- Vagina
- Cervix
- Uterus
- Ovaries
Coding and Reimbursement
Transgender Health and Coding

- A transgender man may be registered in the EHR system under a male name and gender
  - If the patient has a cervix, uterus, and ovaries, providers 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 providers from entering a gynecological history and physical exam findings
- This ultimately may create billing difficulties and a failure to be reimbursed for the provision of indicated health services

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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
### Challenges in Coding: Transgender Health

<table>
<thead>
<tr>
<th></th>
<th>ICD-10</th>
<th>ICD-11</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender Dysphoria-Adults/Adolescents</td>
<td>F64.1</td>
<td></td>
</tr>
<tr>
<td>Gender Dysphoria-Children</td>
<td>F64.2</td>
<td></td>
</tr>
<tr>
<td>Hormone Disturbance NOS</td>
<td>E34.9</td>
<td></td>
</tr>
<tr>
<td>Preventive Health: PAP, Prostate, Breast, Etc.</td>
<td>With or without change in legal gender?</td>
<td></td>
</tr>
<tr>
<td>Gender/Body Divergence Vs. Gender Incongruence</td>
<td>Consideration but must be removed from mental health chapter</td>
<td>?</td>
</tr>
</tbody>
</table>
Where the rubber meets the road: Our experiences
Starting the Process

- Create your Team
  - Include key staff who can be champions and provide feedback
    - Management/Department Directors, Clinical Staff, Non-Clinical Staff, HIT Staff
  - Senior Management Support
- Training
  - Clinical Staff (e.g. MD, Medical Assistants, Nurses, Optometrists, Dentists)
  - Non-Clinical staff (e.g. Front desk/Patient Services, Billing)
    - Don’t neglect non-clinical staff
  - Privacy and Confidentiality
- Pilot the process
  - Start with one location or floor
  - Start with one department
  - Choose front desk/patient services staff who are champions
  - Frequent check-ins with staff piloting the process
  - PDSA
    - Consider using this process to implement and monitor data collection
Starting the Process (cont’d)

- **EHR Customization**
  - Create structured and discrete data fields
  - Limit ability to free text responses into the field
  - Differentiate between default values and missing/unknown values
  - Placement of data fields and how data will be stored/entered
  - Incorporate necessary elements of a data collection (i.e. response categories, data fields, decision support)
  - Access to SOGI information
    - Does staff have EHR permission to enter, modify or view data?
  - Creating or editing new templates/intake forms
Providing Information to Patients

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 like all of your other health information.

Thank you for taking the time to complete the registration form.
Sample Registration Intake Form

- Legal Name
- Preferred Name
- Pronouns Used
- Legal Sex
- Sexual Orientation
- Gender Identity
- Assigned Sex at Birth
# Interdepartmental Communication

<table>
<thead>
<tr>
<th>Medical Dept</th>
<th>Lab</th>
<th>Pharmacy</th>
<th>Patient Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Add preferred name to printed materials</td>
<td>Add preferred name to the label to order</td>
<td>Send preferred Name in &quot;Note To Pharmacy&quot; field within script. Would need to do this for scripts sent to Fenway only</td>
<td>Increase font size and prominence of preferred name on the Patient Profile</td>
</tr>
<tr>
<td>Add preferred name to scripts sent to outside pharmacy</td>
<td></td>
<td>Need to add preferred name on label or electronic submission for referral services</td>
<td>Add preferred name on label or electronic submission for referral services</td>
</tr>
</tbody>
</table>
### Task and Workflow Issues

<table>
<thead>
<tr>
<th></th>
<th>Patient Search</th>
<th>Phone Calls</th>
<th>Schedule</th>
<th>Chart Summary</th>
<th>Patient Banner</th>
<th>Labels</th>
<th>Letters/Bills/Emails</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medical Dept</strong></td>
<td>*Only able to search by first and last name. Cannot search by preferred Name</td>
<td>*Nurse Call center</td>
<td>*Only able to see Patient's first and last name</td>
<td>*First and Last Name</td>
<td>*Has Patient's first, last and preferred name</td>
<td>*Only Patient's first and last name</td>
<td>*Use Chart name</td>
<td>*Patient profile has first, preferred and last name</td>
</tr>
<tr>
<td></td>
<td>▲ Add preferred name to the search mechanism</td>
<td>▲ Search feature – which is the correct name to use when contacting the patient</td>
<td>▲ Add preferred name to the schedule</td>
<td>▲ Add preferred name</td>
<td>▲ Increase size of preferred name in the Banner</td>
<td>▲ Add preferred name to the label</td>
<td></td>
<td>▲ Increase the font size for preferred name on Patient profile</td>
</tr>
<tr>
<td><strong>BH Dept</strong></td>
<td>*Only able to search by first and last name. Cannot search by preferred Name</td>
<td>*Acupuncture</td>
<td>*Only able to see Patient's first and last name</td>
<td>*Has Patient's first, last and preferred name</td>
<td>▲ Increase size of preferred name in the Banner</td>
<td>*no mechanism to indicate which name should be used in correspondence</td>
<td></td>
<td>*Can include preferred name on HDAP forms</td>
</tr>
<tr>
<td></td>
<td>▲ Add preferred name to the search mechanism</td>
<td>▲ patient's sign in and introduce themselves</td>
<td>▲ Add preferred name to the schedule</td>
<td>▲ Add preferred name</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Pronoun Color Code

- **Female Pronouns**, e.g. She/Her/Hers
- **Male Pronouns**, e.g. He/Him/His
- **Non-binary Pronouns**, e.g. They/Them/Their
Current Practice: CPS Registration Screen
Current Practice Registration Screen

[Image of CHC Patient Registration - Test, Apple Pie (573629) window]

- 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

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Current Practice: Modified Chart View

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Custom Forms

SECTION V: LABS AND DOSING RECOMMENDATIONS

1. General dosing recommendations:

Click to print consent forms:

- FTM (Masculinizing Treatment) Consent
- MTF (Feminizing Treatment) Consent

FTM (Masculinizing Treatment) labs to order:
- CBC
- Lipids
- Urine HCG (if pregnancy is a possibility)
- Glucose (if history or exam suggests PCOS)
- LFTs (if history or exam suggests PCOS)

MTF (Feminizing Treatment) labs to order:
- BM/F
- Lipids
- Serum prolactin (if patient has been or is prescribed hormones for a year or more, or if taking antipsychotic medications)
- Serum testosterone (if history or exam suggests that the patient may be hypogonadal)
- AST (if patient has history of hepatitis illness)
- ALT (if patient has history of hepatic illness)
Additional Customizations

- All letter templates updated to exclude salutations (e.g. Mr., Miss, Ms.)
  - Changed to ‘Dear Fenway Patient’
  - Clinicians can still edit the letters as needed
  - Note: changes were made as legally permitted
- Added preferred name to other documents such as:
  - Patient Instructions
  - Internal labels
  - Chart Summary
- Bulk mailings are reviewed to determine the correct name
  - Consideration given to name patient uses outside of organization

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You’ve Built it Now What?
Data Reporting and Quality Checks
Understanding Your Data: Data (DSI)

- Does it look like what you assumed?
- Has something changed?
- What are the sources of the data?
  - Manual data entry
  - Collected electronically
- Data Interpretation - the data is useless if we don’t know all of the rules behind the data
- Data Usability - Can you get the answer from the available data
  - Relevant data is missing
Data Integrity and Quality Checks

- **Validate** – assessing the correctness and reasonableness of the data
  - Compare completed registration form against data entered in patient’s chart
    - Start with 100% QC
    - Taper off process as errors decrease but continue random checks
  - Missing values and defaults should be distinguishable
  - Check to make sure values are not truncated

- **Completeness** – no data or very little data
  - Compare and investigate missing values
  - How does completeness compare to other demographic data?
  - Errors of omission - Check if data are missing randomly or are localized in some way
    - Look for patterns of incorrect/incomplete/missing data by staff
Data Integrity and Quality Checks (cont’d)

- **Accuracy** – check for abnormal values
  - Does the data make sense?
  - Outliers
    - Are the outliers legitimate or expected?
  - Are there response categories that don’t belong in that field?
    - For example: Sexual Orientation field has a response recorded as ‘Male to Female Transgender’

- **Adjudicating Data** – confirming data based on other data
  - Frequently used for clinical data but methodology can be used for SOGI
    - For example: Compare GI questions against other data in your system
## Quality Reports: Transgender Dashboard

<table>
<thead>
<tr>
<th>AGE</th>
<th>Previous Calendar Year</th>
<th>Calendar Year to Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;18</td>
<td>2013</td>
<td>CY'14 Q1</td>
</tr>
<tr>
<td>18-19</td>
<td>1/1/14-3/31/14</td>
<td>CY'14 Q2</td>
</tr>
<tr>
<td>20-29</td>
<td>4/1/14-6/30/14</td>
<td>CY'14 Q3</td>
</tr>
<tr>
<td>30-39</td>
<td>7/1/14-9/30/14</td>
<td>CY'14 Q4</td>
</tr>
<tr>
<td>40-49</td>
<td>10/1/14-12/31/14</td>
<td></td>
</tr>
<tr>
<td>50-59</td>
<td></td>
<td></td>
</tr>
<tr>
<td>60-69</td>
<td></td>
<td></td>
</tr>
<tr>
<td>70+</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Sexual Orientation
- Bisexual
- Heterosexual or Straight
- Lesbian, Gay, or Homosexual
- Something Else
- Don't know
- Not reported
- Missing

### Hormones
- Male on insurance
- % on hormones
- Female on insurance
- % on hormones
- Sex on insurance unknown
- % on hormones

### Department & Location
(unduplicated count of patients accessing services in the time period)
- Medical Patients: 1340
- BH Patients: 1340
- Medical Patients: South End
- BH Patients: South End
- Medical Patients: Borum
- BH Patients: Borum
- Opt Patients
- Dental Patients

### Comorbidities
- HIV+
- Diabetic
- Depression/Mood Disorders
- Anxiety disorders including PTSD
Ongoing Monitoring

- **System Glitches = Data Glitches**
  - Are staff using the correct registration forms?
  - System issues external to the process
    - Is the EHR software installed and working correctly?

- **Run Regular Reports**
  - Provide feedback to key staff
  - Create crosstabs of each question
  - Identify glitches
  - Look at trends over time
    - For example: Is there a sudden drop or spike?

- **Include in other quality reports and initiatives**
  - For example: PCMH, Meaningful Use both monitor demographics – add SOGI as an internal part of the monitoring process

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Ongoing Monitoring (cont’d)

- Create Standard Operating Procedures (SOP’s) and Training Materials
  
  Should include:
  - Clear definitions for each data element
  - Ensure the data capture provides specific instructions to the end user on how to properly populate the data field
  - Identical steps for each process
  - Document issues and resolutions

- Ongoing Training for staff
  - Staff turnover
  - Incorporate into new staff orientation
  - Include as part of annual trainings
Question for the Audience

Which issues are most important to you as you move forward in collecting SOGI data? (Select your top 3)

a) Creating fields in your electronic health record
b) Ensuring patient confidentiality
c) Training staff to collect data and communicate with patients
d) Updating registration forms
e) No additional help needed

Answer this question on the right side of your screen and then hit “submit”
Getting Started!!!

- Do you ask questions regarding SO/GI?
- Does your EHR have fields to allow necessary questions?
- EHR development takes a long time, what can you do while developing systems and work flows?
- What can you do outside an EHR that builds toward the goal?
Getting Started

- Changes in an EHR make take a long time to develop!
- Could you start on paper or with a sticker as above for the front of the chart?
- What would be advantages?
- How will you proceed to ask SO/GI?

<table>
<thead>
<tr>
<th>Preferred Name</th>
<th>Pronouns</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anthony Marks</td>
<td>They, Them, Theirs</td>
</tr>
</tbody>
</table>
Resources

SOGI Resources can be found on our website:
www.lgbthealtheducation.org/topic/sogi/

Includes:

- Archive of this webinar
- Publications:
  - Collecting Sexual Orientation and Gender Identity Data in EHRs: Taking the Next Steps
  - Glossary of LGBT terms
  - Providing Inclusive Services and Care to LGBT People: A Guide for Health Care Staff
Announcing SO/GI Office Hours

A regularly scheduled opportunity to ask questions about collecting SO/GI data.

- **Faculty**: Dr. Harvey Makadon and Chris Grasso
- **Launch**: Wednesday, May 4th 2016: 12:00-2:00pm
- **Format**: Drop-in, registration preferred

Register: [bit.ly/sogiofficehours](bit.ly/sogiofficehours)