Collecting Sexual Orientation and Gender Identity (SO/GI) Data In Electronic Health Records

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The National LGBT Health Education Center
The Fenway Institute

Fenway Health
- Independent 501(c)(3) FQHC
- Founded 1971
- Mission: To enhance the wellbeing of the LGBT community as well as people in our neighborhoods and beyond through access to the highest quality health care, education, research and advocacy
- Integrated primary care model, including HIV services and transgender health

The Fenway Institute
- Research, Education, Policy
LGBTQ Education and Training

The National LGBT Health Education Center offers educational programs, resources, and consultation to health care organizations with the goal of providing affirmative, high quality, cost-effective health care for lesbian, gay, bisexual, transgender and queer (LGBTQ) people.

- Training and Technical Assistance
- Grand Rounds
- ECHO Programs
- On Line Learning
  - Webinars and Learning Modules
  - CE, and HEI Credit
- Resources and Publications

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Where We Work in the U.S.
Learning Objectives

This presentation will enable participants to:

1. Summarize how to incorporate SO/GI data collection into your EHR to improve communication, quality care, and data and quality management activities.

2. Describe the impact SO/GI data collection and development of related decision support will have on key stakeholders (patients, staff, and management).

3. Identify at least one method to actively engage and educate staff on the importance of collecting SO/GI data, how to do so, the data’s impact on health disparities, and how SO/GI can be used to direct education and clinical practice.
Why Programs for LGBTQ People
L,G,B,T,Q Concepts
Gender Identity and Sexual Orientation: The Basics

Gender Identity
Bisexual
Queer
Sexual Orientation
Genderqueer

Ally
Desire

Behavior
Gender Expression

Trans-Woman
Asexual

Trans-Masculine
Non-Binary

Trans-Feminine

MTF
Straight

Trans-Man
Lesbian

FTM
Gay

MSM
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
Gender Identity and Gender Expression

- Gender identity
  - A person's inner sense of being a boy/man/male, girl/woman/female, another gender, or no gender
  - 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

A complete glossary of terms is available at [www.lgbthealtheducation.org/publication/lgbt-glossary/](http://www.lgbthealtheducation.org/publication/lgbt-glossary/)
In a 2013 community-based survey of 452 transgender adults, 40.9% of respondents described themselves as having a “non-binary gender identity.”\(^1\)
The T in LGBTQ: 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)
- Non-binary, genderqueer
  - Genderqueer person
- Transmasculine, Transfeminine
- Gender identity is increasingly described as being on a spectrum
Sexual Orientation

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

Dimensions of Sexual Orientation:

- **Identity**
  - Do you consider yourself gay, lesbian, bisexual, straight, queer, something else?
- **Behavior**
  - What gender(s) are your sexual partner(s)?
- **Attraction**
  - What gender(s) are you attracted to physically and emotionally?
What Does ‘Q’ Stand For?

- ‘Q’ may reflect someone who is ‘questioning’ their sexual orientation, attraction to men, women, both, or neither.
- ‘Q’ may stand for ‘queer,’ a way some people identify to state they are not straight but also don’t identify with gay, lesbian or bisexual identities. The term queer is particularly commonly used among younger people, and also used by people of all ages.
Intersectionality
A Black Gay Man

“A gay man has to deal with homophobia. A black man has to deal with racism. But a black gay man will have to deal with homophobia and racism (often at the same time). It is often the case that he will face racism inside the LGBTQ community and homophobia in the [straight] black community”.
Gender Minority Stress Framework

![Diagram showing Gender Minority Stress Framework]

Fig. 1: Adapted from *Introduction to the special issue on structural stigma and health*[^1]
Interpersonal Stigma
Structural Stigma

- Structural, or institutional discrimination includes the policies of private and governmental institutions that intentionally restrict the opportunities of certain people, as well as policies that unintentionally restrict these opportunities.
Intrapersonal Stigma:

“...And to the degree that the individual maintains a show before others that they themselves does not believe, they can come to experience a special kind of alienation from self and a special kind of wariness of others.”⁴
Health Issues Throughout the Life Course

Childhood & Adolescence

Early & Middle Adulthood

Later Adulthood
LGBTQ Disparities:

- **Youth**
  - 2 to 3 times more likely to attempt suicide
  - More likely to be homeless (20-40% are LGBTQ)
  - Risk of HIV and other STIs

- Despite an overall decrease in HIV incidence from 2008-2014 reported for the first time in 2017, incidence remains high and stable among black MSM, and is now increasing among gay and bisexual Latino men (20%) and those aged 25-34 (35%).

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Health Disparities

- LGBTQ populations have high rates of tobacco, alcohol, and other drug use.
- Lesbian women and bisexual women are less likely to get preventive services for cancer.
- The 2011 National Transgender Discrimination Survey found that:
  - 26% used drugs/alcohol to cope with discrimination
  - 30% smoked cigarettes daily or occasionally (compared to 20% of US adults)
Health Disparities

- The 2015 U.S. Transgender Survey found that:\textsuperscript{12}
  - 39% of respondents experienced serious psychological distress in the month prior, compared with only 5% of the U.S. population
  - 40% had lifetime suicide attempt (compared to 4.6% of US population)
  - 55% of those who sought coverage for gender-affirming surgery in the past year were denied, and 25% of those who sought coverage for hormones in the past year were denied
Health Disparities

The 2015 U.S. Transgender Survey found that:

- 33% had at least one negative experience with a health care provider such as being verbally harassed or refused treatment because of gender identity
- 23% of transgender people report not seeking needed health care in the past year due to fear of gender-related mistreatment
- 33% did not go to a health care provider when needed because they could not afford it
LGBTQ Disparities: Healthy People 2020

- Older LGBTQ individuals face additional barriers to health because of isolation, fewer family supports, and a lack of social and support services.
Overcoming Barriers
Patients, Staff, Students

Ending Invisibility

Environment

Communications

Clinical Education

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Population Health: Ending LGBTQ Invisibility in Health Care

- Has a clinician ever asked you about your history of sexual health, your sexual orientation or your gender identity?
- How often do you talk with your patients about their sexual history, sexual orientation, or gender identity?
Appropriate Screening: Jake’s Story

- Jake 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.
- Even though he had a breast reduction, he developed cancer in his remaining breast tissue.
- No one told Jake that he needed routine breast cancer screening, even though his mother and sister also had breast cancer.
Quality Care for Transgender People: Louise’s Story

- Louise 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.
Collecting SO/GI Data in EHRs
Preparation for Collecting Data in Clinical Settings

- **Clinicians**: Need to learn about LGBTQ health and the range of experiences related to sexual orientation and gender identity.

- **Non-clinical staff**: Front desk and patient registration staff must also receive training on LGBTQ health, communicating with LGBTQ 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 Information

www.lgbthealtheducation.org/topic/sogi/
Providing Information to Patients

New Sexual Orientation and Gender Identity Questions:
Information for Patients

We recently added new questions about sexual orientation and gender identity to our registration forms.

Our health center thinks it is important to learn this information from our patients. Inside are some frequently asked questions about why we are asking these questions and how the information will be used.

Nuevas preguntas sobre la orientación sexual y la identidad de género:
Información para pacientes

Recientemente hemos añadido nuevas preguntas sobre la orientación sexual y la identidad de género a nuestros formularios de registro.

Nuestro centro de salud cree que es importante que conocemos esta información sobre nuestros pacientes. A continuación, se encuentran algunas preguntas frecuentes sobre por qué estamos haciendo estas preguntas y cómo se usará esta información.
Gathering LGBTQ Data During the Process of Care

Fig. 2. Diagram from “Fenway Guide to Lesbian, Gay, Bisexual, and Transgender Health.”

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### 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>
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<tr>
<td>□ $10,000–14,999</td>
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<tr>
<td>□ $15,000–19,999</td>
</tr>
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<td>□ $20,000–29,999</td>
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<tr>
<td>□ $30,000–49,999</td>
</tr>
<tr>
<td>□ $50,000–79,999</td>
</tr>
<tr>
<td>□ Over $80,000</td>
</tr>
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<tr>
<th>2. Employment Status:</th>
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<tbody>
<tr>
<td>□ Employed full time</td>
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<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>
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</table>

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<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>

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

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

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

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

<table>
<thead>
<tr>
<th>What is your current gender identity?</th>
<th>What name do you use?</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Male</td>
<td>□ What name do you use?</td>
</tr>
<tr>
<td>□ Female</td>
<td>□ What are your pronouns (e.g. he/him, she/her, they/them)?</td>
</tr>
<tr>
<td>□ Transgender Male/Trans Man/FTM</td>
<td>□ Additional Category (please specify)</td>
</tr>
<tr>
<td>□ Transgender Female/Trans Woman/MTF</td>
<td>□ Additional Category (please specify)</td>
</tr>
<tr>
<td>□ Gender Queer</td>
<td>□ Additional Category (please specify)</td>
</tr>
<tr>
<td>□ Additional Category (please specify)</td>
<td>□ Additional Category (please specify)</td>
</tr>
</tbody>
</table>

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

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Responding to Concerns about SO/GI Questions

- **Patient:** I don’t understand why you are asking these questions? Why do you need to know my assigned sex at birth?

- **Front Desk Staff:** These are new questions, and we have this informational pamphlet for you explaining why we are asking all patients these questions. If you would like to discuss this more, your provider will welcome your questions.

- **Patient:** Thanks, I’ll discuss with my nurse practitioner.
Directly Asking SO/GI Questions

- If patients leave SO/GI 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.
Directly Asking SO/GI Questions

- As part of your history, generally as part of social history or filling in blanks left at registration, you might simply say, “We have begun asking patients about their sexual orientation and gender identity so we can provide affirmative care.”

- Another example might be, “I see you left these questions blank at registration, and I was wondering if you had questions, and whether we might talk about how you think about yourself in this regard?”
Beyond Data Collection
Systems that Facilitate Getting it Right: Clinical Decision Support
Decision Support

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

- Guidelines for the Primary and Gender-Affirming Care of Transgender and Gender Non-binary People, June 17, 2016, Second Edition\(^1\)

- US Preventive Services Task Force\(^2\)
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
<table>
<thead>
<tr>
<th>Gender Identity</th>
<th>Sex Assigned at Birth</th>
<th>Sexual Orientation</th>
<th>Age</th>
<th>Surgery</th>
<th>Medication/Drug Use</th>
<th>Alerts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>Female</td>
<td>Bisexual</td>
<td>56</td>
<td>Bilateral Reduction Mammoplasty.</td>
<td>Testosterone</td>
<td>Sexual Hx</td>
</tr>
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<td></td>
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<td></td>
<td>Voice Surgery</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## USPSTF A: 56 Year Old Woman

<table>
<thead>
<tr>
<th>Grade</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Cervical Cancer: Screening -- Women 21 to 65 (Pap Smear) or 30-65 (in combo with HPV testing)</td>
</tr>
<tr>
<td>A</td>
<td>Colorectal Cancer: Screening -- Adults aged 50 to 75 years</td>
</tr>
<tr>
<td>A</td>
<td>HIV: Screening - Adolescents and Adults</td>
</tr>
<tr>
<td>A</td>
<td>High Blood Pressure: Screening -- Adults 18 and Over</td>
</tr>
<tr>
<td>A</td>
<td>High Blood Pressure: Screening and Home Monitoring -- Adults</td>
</tr>
<tr>
<td>A</td>
<td>Syphilis: Screening -- Asymptomatic, nonpregnant adults and adolescents who are at increased risk for syphilis infection</td>
</tr>
<tr>
<td>A</td>
<td>Tobacco Smoking Cessation: Behavioral and Pharmacotherapy Interventions -- Adults who are not pregnant</td>
</tr>
<tr>
<td>A</td>
<td>Tobacco Smoking Cessation: Behavioral Interventions -- Pregnant Women</td>
</tr>
</tbody>
</table>
## USPSTF B: 56 Year Old Woman

<table>
<thead>
<tr>
<th>Grade</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>B</td>
<td><em>Alcohol Misuse: Screening and Behavioral Counseling Interventions in Primary Care -- Adults</em></td>
</tr>
<tr>
<td>B</td>
<td><em>Aspirin Use to Prevent CVD and CRC: Preventive Medication -- Adults aged 50 to 59 years with a ≥10% 10-year CVD risk</em></td>
</tr>
<tr>
<td>B</td>
<td><em>BRCA-Related Cancer: Risk Assessment, Genetic Counseling, &amp; Genetic Testing -- Women at Increased Risk</em></td>
</tr>
<tr>
<td>B</td>
<td><em>Breast Cancer: Preventive Medications -- Women At Increased Risk</em></td>
</tr>
<tr>
<td>B</td>
<td><em>Breast Cancer: Screening with Mammography -- Women aged 50 to 74 years</em></td>
</tr>
<tr>
<td>B</td>
<td><em>Chlamydia: Screening -- Sexually Active Women</em></td>
</tr>
<tr>
<td>B</td>
<td><em>Depression: Screening -- General adult population, including pregnant and postpartum women</em></td>
</tr>
<tr>
<td>B</td>
<td><em>Diabetes Mellitus (Type 2) and Abnormal Blood Glucose: Screening -- Adults aged 40 to 70 years who are overweight or obese</em></td>
</tr>
<tr>
<td>B</td>
<td><em>Gonorrhoea: Screening -- Sexually Active Women</em></td>
</tr>
<tr>
<td>B</td>
<td><em>Healthy Diet and Physical Activity for CVD Disease Prevention: Counseling -- Adults with CVD Risk Factors</em></td>
</tr>
<tr>
<td>B</td>
<td><em>Hepatitis B: Screening -- Nonpregnant Adolescents and Adults At High Risk</em></td>
</tr>
<tr>
<td>B</td>
<td><em>Hepatitis C Virus Infection: Screening -- Adults at High Risk and Adults born between 1945 and 1965</em></td>
</tr>
<tr>
<td>B</td>
<td><em>Latent Tuberculosis Infection: Screening -- Asymptomatic adults at increased risk for infection</em></td>
</tr>
<tr>
<td>B</td>
<td><em>Lung Cancer: Screening -- Adults Ages 55-80 who have a 30 pack-year smoking history and currently smoke or have quit within the past 15 years</em></td>
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<tr>
<td>B</td>
<td><em>Obesity: Screening for and Management of -- All Adults</em></td>
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<tr>
<td>B</td>
<td><em>Osteoporosis: Screening -- Women 65+ and Younger Women at Increased Risk</em></td>
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<tr>
<td>Gender Identity</td>
<td>Sex Assigned at Birth</td>
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Sexual Hx
HIV/STI
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<th>Gender Identity</th>
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<tr>
<td>Male</td>
<td>Female</td>
<td>Bisexual</td>
<td>56</td>
<td>Bilateral Reduction Mammoplasty. Voice Surgery</td>
<td>Testosterone</td>
<td>Sexual Hx</td>
</tr>
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<td>Gender Identity</td>
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<td>HIV/STI</td>
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<td>HPV</td>
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<td>Testosterone Levels (Ref Std)</td>
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<tr>
<td>Gender Identity</td>
<td>Sex Assigned at Birth</td>
<td>Sexual Orientation</td>
<td>Age</td>
<td>Surgery</td>
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<td>HIV/STI</td>
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<td>Testosterone Levels (Ref Std)</td>
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<td>Pregnancy Plans</td>
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<tr>
<td>Gender Identity</td>
<td>Sex Assigned at Birth</td>
<td>Sexual Orientation</td>
<td>Age</td>
<td>Surgery</td>
<td>Medication/Drug Use</td>
<td>Alerts</td>
</tr>
<tr>
<td>-----------------</td>
<td>-----------------------</td>
<td>--------------------</td>
<td>-----</td>
<td>---------</td>
<td>---------------------</td>
<td>--------</td>
</tr>
<tr>
<td>Male</td>
<td>Male</td>
<td>Bisexual</td>
<td>56</td>
<td>Bilateral Reduction Mammoplasty. Voice Surgery</td>
<td>Testosterone</td>
<td>Sexual Hx</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>HIV/STI</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>HPV</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Testosterone Levels (Ref Std)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Pregnancy Plans</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Breast Screening</td>
<td></td>
</tr>
</tbody>
</table>
Communications: The Whole Team

Affirmative Care for Transgender and Gender Non-Conforming People:

Best Practices for Front-line Health Care Staff

Updated Fall 2016
Anticipating and Managing Expectations

- LGBT people have a history of experiencing stigma and discrimination in diverse settings
- Don’t be surprised if a mistake results in a patient becoming upset
- Don’t personalize the reaction
- Apologizing when patients become upset, even if what was said was well-intentioned, can help defuse a difficult situation and re-establish a constructive dialogue

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Avoiding Assumptions

- You cannot assume someone’s gender identity or sexual orientation based on how they look or sound.

- To avoid assuming gender identity 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’s and fathers’ names?”
  - *Say:* “What is your guardian’s name?”
Pronouns

People may use a range of pronouns, including she/her/hers and he/him/his, as well as less-common pronouns such as they/them/theirs and ze/hir/hirs (pronounced zee/hear/hears).

<table>
<thead>
<tr>
<th>Subjective</th>
<th>Objective</th>
<th>Possessive</th>
<th>Examples</th>
</tr>
</thead>
</table>
| He         | Him       | His        | He is in the waiting room.  
The doctor is ready to see him.  
That chart is his. |
| She        | Her       | Hers       | She is in the waiting room.  
The doctor is ready to see her.  
That chart is hers. |
| They       | Them      | Theirs     | They are in the waiting room.  
The doctor is ready to see them.  
That chart is theirs. |
| Ze         | Hir       | Hirs       | Ze is in the waiting room.  
The doctor is ready to see hir.  
That chart is hirs. |
Keeping Up with Terminology

- Obvious “don’ts” include
  - Use of any disrespectful language
  - Gossiping about a patient’s appearance or behavior
  - Saying things about someone not necessary for their care:
    - “You look great, you look like a real woman/real man!”
    - “You are so pretty I cannot believe you are a lesbian!”

<table>
<thead>
<tr>
<th>Avoid these Outdated Terms (in English)</th>
<th>Consider these Terms Instead</th>
</tr>
</thead>
<tbody>
<tr>
<td>Homosexual</td>
<td>Gay, lesbian, bisexual, or LGBT</td>
</tr>
<tr>
<td>Transvestite; Transgendered</td>
<td>Transgender</td>
</tr>
<tr>
<td>Sexual preference; Lifestyle choice</td>
<td>Sexual orientation</td>
</tr>
</tbody>
</table>
Putting What You Learn into Practice....

- If you are unsure about a patient’s name or pronouns:
  - “I would like be respectful—what are your name and pronouns?”

- If a patient’s name doesn’t match insurance or medical records:
  - “Could your chart/insurance be under a different name?”
  - “What is the name on your insurance?”

- If you accidentally use the wrong term or pronoun:
  - “I’m sorry. I didn’t mean to be disrespectful.”
Creating a Welcoming and Inclusive Environment for Caring, Working and Learning
The Physical Environment Welcomes and Includes LGBTQ People

- What message does your health care organization give to LGBTQ people when they enter? Are there images or brochures specific to LGBTQ people anywhere? Areas to consider include:
  - Do educational and marketing materials include images of LGBTQ people?
  - Are there relevant educational and reading materials in the waiting areas?
  - Are there all-gender restrooms, or a policy stating you should use the restroom that reflects your gender identity?
Adding Affirmative Imagery and Content to Education and Marketing Materials
Do Ask, Do Tell: Talking to Your Provider about Being LGBTQ
Our Challenge:
Quality Care for All, Including LGBTQ People

Data Collection
Clinical Education

Consumer Education
Patient Centered Care

www.lgbthealtheducation.org
Where the rubber meets the road: Our experiences
Getting Started....

You don’t have to be LGBTQ to do this well, and don’t assume LGBTQ people don’t need training too!
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**
  - HIPAA/Legal Protections
  - Assure patients that it will be used appropriately
Starting the Process (cont’d)

- **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

- **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
    - Staff have EHR permission to enter, modify or view data?
  - Creating or editing new templates/intake forms
Sample Registration Form

- Legal Name
- Name Used
- Pronouns
- Legal Sex
- Parent/Guardian
- Sexual Orientation
- Gender Identity
- Assigned Sex at Birth
SOGI Reporting For Pediatric Patients

- How to deal with Pediatric patients?
- At what age do you start asking these questions?
  - Recommend asking GI early
  - Recommend asking SO from 13+ years old
- At what age do you start reporting these data?
  - Are parents answering these questions?
  - Potential bias
Managing Challenges and Problems

- How do you respond to patients who do not want to disclose SO, GI, or sex assigned at birth?
  - Patients who have a primary language other than English or different cultural backgrounds?
- What kinds of communication problems occur (e.g., misgendering/pronouns, etc.), and how do you deal with mistakes?
- How else do you handle patient complaints?
  - e.g., working with transgender patient navigator, clinical staff
# Interdepartmental Communication and Workflow

<table>
<thead>
<tr>
<th></th>
<th>Medical Dept</th>
<th>Lab</th>
<th>Pharmacy</th>
<th>Patient Services</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medical Dept</strong></td>
<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></td>
<td></td>
<td></td>
<td>• Need to add preferred name to scripts sent to outside pharmacy</td>
<td>• Add preferred name on label or electronic submission for referral services</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
Custom Forms: Transgender Intake

5. Recommendation for Hormone Therapy
Select all that apply and include whether there are other things the client is recommended or required to do prior to or concurrent with starting hormones, such as therapy for 3 months for support, substance abuse treatment, etc.

6. Are these recommendations to be...
- Concurrent with hormone treatment
- Prior to hormone treatment

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:
- BMI
- Lipids
- Serum prolactin (if patient has been on BH-prescribed hormone 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 hepatic illness)
- ALT (if patient has history of hepatic illness)
Additional Customizations

- Custom Clinical Forms
- Clinical Decision Support/Protocols
- 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
You’ve Built it Now What?
Data Reporting and Quality Checks
“If you do not know how to ask the right question, you discover nothing.”

- W. Edward Deming
Opportunities to Monitor, Use and Report Data on LGBTQ Patients

- Develop Summary Reports
- Develop Dashboards
- Incorporate into existing reports or workgroups
- Presentations to Senior Management or All Staff Meetings
Data Quality, Improvement and Integrity: Staff Roles

- **Front Desk/Patient Registration Staff**
  - Quality checks of paper registration forms against data in HER
  - Provide feedback on challenges (e.g. language barriers)

- **Data Analyst/Programming Staff**
  - Create reports
  - Analyze and interpret results
  - Identify problem areas

- **Quality Control Staff**
  - Incorporate into existing workgroups for monitoring
  - Help develop changes in workflow

- **IT Staff**
  - Create checklists and confirm all components are installed after upgrades

- **Clinical Staff**
  - Provide guidance on how they document info in the EHR
  - Provide guidance on quality measures (e.g. who should be in a denominator)
## PCMH Missing Demographic Data Report

Total Appointments in June: 2,510

<table>
<thead>
<tr>
<th>Fields with Missing Value</th>
<th>Total # missing</th>
<th>% Missing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Email</td>
<td>63</td>
<td>3%</td>
</tr>
<tr>
<td>Sex</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Language</td>
<td>16</td>
<td>1%</td>
</tr>
<tr>
<td>Race</td>
<td>4</td>
<td>0%</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>17</td>
<td>1%</td>
</tr>
<tr>
<td>Income</td>
<td>664</td>
<td>26%</td>
</tr>
<tr>
<td>Sexual Orientation</td>
<td>700</td>
<td>28%</td>
</tr>
<tr>
<td>Gender Identity</td>
<td>715</td>
<td>28%</td>
</tr>
<tr>
<td>Sex assigned at birth</td>
<td>700</td>
<td>28%</td>
</tr>
</tbody>
</table>

Total Missing ÷ Total Appts = % Missing
Differentiating Between SO and GI in Data Analysis

- Sexual Orientation ≠ Gender Identity
  - Everyone has both a Sexual Orientation and Gender Identity
- Be careful not to lump all LGBTQ people into every denominator or numerator for every question
- Important to differentiate between the two in data quality checking
- You will need to use **BOTH Sex Assigned at Birth and Current Gender Identity** to identify your Transgender/GenderQueer/Non-Binary Patients
Using Gender Identity and Sex Assigned at Birth Questions

1. What is your current gender identity?
   - [ ] Male
   - [ ] Female
   - [X] Transgender Male/Trans Man/FTM
   - [ ] Transgender Female/Trans Woman/MTF
   - [ ] GenderQueer
   - [ ] Additional Category (please specify) __________

2. What sex were you assigned at birth?
   - [ ] Male
   - [X] Female
   - [X] Decline to Answer
### Example: Identifying Transgender/GenderQueer/Gender Non-conforming Patients using a Crosstab with Gender Identity and Sex Assigned at Birth

#### Current Gender Identity

<table>
<thead>
<tr>
<th>Sex Assigned at Birth</th>
<th>Female</th>
<th>Male</th>
<th>Transgender Male/Trans Man/FTM</th>
<th>Transgender Female/Trans Woman/MTF</th>
<th>GenderQueer or not exclusively male or female</th>
<th>Not Reported</th>
<th>Default</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>2413</td>
<td>156</td>
<td>200</td>
<td>250</td>
<td>84</td>
<td>6</td>
<td>60</td>
</tr>
<tr>
<td>Male</td>
<td>140</td>
<td>5062</td>
<td>150</td>
<td>100</td>
<td>43</td>
<td>1</td>
<td>73</td>
</tr>
<tr>
<td>Not Reported</td>
<td>2</td>
<td>4</td>
<td>20</td>
<td>15</td>
<td>0</td>
<td>500</td>
<td>0</td>
</tr>
<tr>
<td>Default</td>
<td>47</td>
<td>42</td>
<td>30</td>
<td>50</td>
<td>4</td>
<td>0</td>
<td>1997</td>
</tr>
</tbody>
</table>
# Example: PCMH Cancer Screening Report

<table>
<thead>
<tr>
<th>MRN</th>
<th>Patient first</th>
<th>Patient last</th>
<th>Provider</th>
<th>Insurance/Chart Sex</th>
<th>Age</th>
<th>Cervical Pap Screening</th>
<th>Breast Cancer Screening</th>
</tr>
</thead>
<tbody>
<tr>
<td>1111</td>
<td>Donald</td>
<td>Test</td>
<td>Smith MD, Joseph</td>
<td>M</td>
<td>45</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>5555</td>
<td>Genny</td>
<td>Test</td>
<td>Smith MD, Jane</td>
<td>F</td>
<td>31</td>
<td>Non-Compliant</td>
<td>Non-Compliant</td>
</tr>
<tr>
<td>5555</td>
<td>Genny</td>
<td>Test</td>
<td>Smith MD, Jane</td>
<td>F</td>
<td>31</td>
<td>Non-Compliant</td>
<td>Non-Compliant</td>
</tr>
<tr>
<td>4444</td>
<td>Kathy</td>
<td>Test</td>
<td>Smith MD, Jane</td>
<td>F</td>
<td>35</td>
<td>Non-Compliant</td>
<td>Compliant</td>
</tr>
<tr>
<td>3333</td>
<td>Paul</td>
<td>Test</td>
<td>Smith MD, Jane</td>
<td>M</td>
<td>60</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>3333</td>
<td>Paul</td>
<td>Test</td>
<td>Smith MD, Jane</td>
<td>Male</td>
<td>56</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>9999</td>
<td>Sammy</td>
<td>Test</td>
<td>Smith MD, Jane</td>
<td>F</td>
<td>49</td>
<td>Compliant</td>
<td>Compliant</td>
</tr>
</tbody>
</table>

**Notes:**
- **Gender Identity:**
  - Female
  - Male
  - Non-Binary
- **Orientation:**
  - Heterosexual
  - Lesbian, Gay, or Bisexual
  - Transgender
  - Queer
  - Other

**Screening Status:**
- Compliant
- Non-Compliant
- N/A (Not Applicable)
# Quality Reports: Rates of Cervical Cancer Screening Among Patients By Sexual Orientation

<table>
<thead>
<tr>
<th>Sexual Orientation</th>
<th>Cervical Cancer Screen Completed?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes (%)</td>
</tr>
<tr>
<td>Lesbian/Gay</td>
<td></td>
</tr>
<tr>
<td>Bisexual</td>
<td></td>
</tr>
<tr>
<td>Straight/Heterosexual</td>
<td></td>
</tr>
<tr>
<td>Something Else</td>
<td></td>
</tr>
<tr>
<td>Don't Know</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
</tr>
</tbody>
</table>
## Quality Reports: Rates of HIV Testing Stratified by Ethnicity and Sexual Orientation

<table>
<thead>
<tr>
<th>Sexual Orientation</th>
<th>Hispanic/Latino/Latina/Latinx # (%)</th>
<th>Non Hispanic/Latino/Latina/Latinx # (%)</th>
<th>Unknown # (%)</th>
<th>Total # (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lesbian/Gay</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bisexual</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Straight/Heterosexual</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Something Else</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don't Know</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
PATIENTS (50+) BY SEXUAL ORIENTATION

61% Straight or Heterosexual
27% Lesbian, Gay, or Homosexual
5% Bisexual
5% Don't Know
2% Something Else
Ongoing Monitoring: Beginning Not an End

- **System Glitches = Data Glitches**
  - Are staff using the correct registration forms?
  - System issues external to the process

- **Run Regular Reports**
  - Identify glitches
  - Look at trends over time
    - For example: Is there a sudden drop or spike?
  - Standard Operating Procedures (SOP’s)

- **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

- **Ongoing Training for staff**
  - Staff turnover
  - Incorporate into new staff orientation
  - Include as part of annual trainings
References


7. James et al.


References


12. James et al.


