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

Chris Grasso, MPH and Danielle Funk, MA
The National LGBT Health Education Center
Learning Objectives

This presentation will enable you to:

1) Summarize how to incorporate SOGI data collection into your workflow using your EHR, and quality improvement techniques to improve communication, quality care, and data and quality management activities.

2) Identify at least one method to actively engage and educate staff on the importance of collecting and using SOGI data, how to do so, the data’s impact on health disparities, and how SOGI can be used to direct education and clinical practice.

3) Identify at least one training, tool, or other resource to assist your health center in collecting and using SOGI data.
Data Collection Toolkit

READY, SET, GO!

GUIDELINES AND TIPS FOR COLLECTING PATIENT DATA ON SEXUAL ORIENTATION AND GENDER IDENTITY

January 2018

NATIONAL LGBT HEALTH EDUCATION CENTER
A PROGRAM OF THE FENWAY INSTITUTE
Collecting GI Information in EHRs

www.lgbthealtheducation.org/topic/sogi/
Are Patients Likely to be Offended by SO/GI Questions?

- A study of 301 randomly selected patients from four racially and geographically diverse U.S. health centers found high acceptability by patients of routine SO/GI data collection: most expressed believing the questions are important and reported they would answer these again in the future (Cahill, et al., 2014).

- 78% of clinicians nationally believe patients would refuse to provide sexual orientation, however only 10% of patients say they would refuse to provide sexual orientation (Haider et al., 2017).

- No difference in patient attitudes toward registration forms that include SOGI questions vs. forms that do not; only 3% of patients reported being distressed, upset or offended by SOGI questions (Rullo et al., 2018).
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
  - Senior Management Support/Executive Champion

- Training
  - Clinical Staff (e.g. MD, Medical Assistants, Nurses, Optometrists, Dentists) and Non-Clinical staff (e.g. Front desk/Patient Services, Billing)

- Privacy and Confidentiality
  - HIPAA/Legal Protections
  - Assure patients that it will be used appropriately

- EHR Customization
Gathering Gender Identity Data During the Process of Care

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

13
Legal Name
Name
Pronouns
Insurance/Legal Sex
Gender Identity
Assigned Sex at Birth
Sexual Orientation
Parent/Guardian
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

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Managing Challenges and Opportunities

- 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?
Managing Challenges and Problems

- What other problems should you anticipate and how do you deal with them? For example:
  - Patient’s name doesn’t match their insurance card
  - Provider changes name/gender in EHR and it no longer matches the insurance information?
Privacy and Confidentiality

- How do you keep SO/GI information private and confidential?
  - In the EHR?
    - Auditing
    - Patients have a right to know who has viewed their record
    - EHR’s allow for restrictions on who can view patient records
  - In conversations?
    - HIPAA
  - In small communities?
### Interdepartmental Communication and Workflow

<table>
<thead>
<tr>
<th>Medical Dept</th>
<th>Lab</th>
<th>Pharmacy</th>
<th>Patient Services</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Add preferred name to printed materials</em></td>
<td><em>Add preferred name to the label to order</em></td>
<td><em>Send preferred Name in &quot;Note To Pharmacy&quot; field within script. Would need to do this for scripts sent to Fenway only</em></td>
<td><em>Increase font size and prominence of preferred name on the Patient Profile</em></td>
</tr>
<tr>
<td><em>Add preferred name to scripts sent to outside pharmacy</em></td>
<td></td>
<td><em>Need to add preferred name on label or electronic submission for referral services</em></td>
<td></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>
</table>
| **Medical Dept** | *Only able to search by first and last name. Cannot search by preferred name*  
   ▲ ○ Add preferred name to the search mechanism | *Nurse Call center*  
   *search feature – which is the correct name to use when contacting the patient* | *First and Last Name*  
   ▲ ○ Add preferred name to the schedule | *Has Patient’s first, last and preferred name*  
   ▲ Increase size of preferred name in the Banner | *Only Patient’s first and last name*  
   ▲ Add preferred name to the label | *Use Chart name*  
   ▲ Would need to have a mechanism to indicate the correct name on correspondence; drop salutation (Mr/Miss) | *Patient profile has first, preferred and last name*  
   ▲ Increase the font size for preferred name on Patient profile |
| **BH Dept**     | *Only able to search by first and last name. Cannot search by preferred name*  
   ▲ ○ Add preferred name to the search mechanism | *Acupuncture – patient’s sign in and introduce themselves*  
   *Only able to see Patient’s first and last name*  
   ▲ ○ Add preferred name to the schedule | *Has Patient’s first, last and preferred name*  
   ▲ Increase size of preferred name in the Banner | *Has Patient’s first, last and preferred name*  
   ▲ Increase size of preferred name in the Banner | *no mechanism to indicate which name should be used in correspondence* | *Can include preferred name on HDAP forms*** |
Pronoun Color Code

- **She**
  - Use this pronoun color block when patient pronouns are always She series

- **He**
  - Use this pronoun color block when patient pronouns are always He series

- **They**
  - Use this pronoun color block when patient pronouns are always They series

- **Ask**
  - Use this pronoun color block when patient pronouns are fluid or not He/She/They series

- **none**
  - Use this pronoun color block when patient does not want any pronouns used

- **He or She**
  - Use this pronoun color block when patient pronouns are either He or She based on gender presentation at the time of the visit

- **He or They**
  - Use this pronoun color block when patient pronouns are fluid and He or They are okay

- **She or They**
  - Use this pronoun color block when patient pronouns are fluid and She or They are okay
Current Practice: CPS Registration Screen
Current Practice: Modified Chart View

1. She

2. Chrissy

3. THP
Forms: Transgender Intake

TRANSGENDER MEDICAL INTAKE FORM

SECTION V: LABS AND DOSING RECOMMENDATIONS

1. General dosing recommendations:

Click to print consent forms:

- **FTM (Masculinizing 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)
    - Testosterone (If history or exam suggests PCOS)

- **MTF (Feminizing Treatment) Consent**
  - MTF (Feminizing Treatment) labs to order:
    - BMP
    - Lipids
    - Serum prolactin (If patient has been on self-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 hepatic illness)
    - ALT (If patient has history of hepatic illness)

5d. How long have/did you take these?

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# EHR Form: Organ Inventory

## Breast
- Congenital Absence
- Chest Reconstruction
- Bilateral Mastectomy
- Unilateral Mastectomy, R
- Unilateral Mastectomy, L
- Breast Augment/Implant(s)

## Cervix
- Congenital Absence

## Ovary
- Bilateral Salpingo-Oophorectomy
- Unilateral Salpingo-Oophorectomy, R
- Unilateral Salpingo-Oophorectomy, L

## Penis
- Phalloplasty/Metoidioplasty/Penile Transplant
- Erectile Device

## Prostate
- Prostatectomy

## Testis
- Testicular Implant(s)

## Urethra
- Urethral Lengthening

## Uterus
- Hysterectomy - Cervix Removed
- Hysterectomy - Cervix Remains

## Vagina
- Colpopoiesis - Closure of the Vagina
- Vaginoplasty
Custom Forms: PrEP
Clinical Decision Support (CDS)/Health Maintenance

Current Variables:
- Sex
- Age
- Problems/Disease Conditions
  - e.g. Diabetes
- Medications
  - e.g. Coumadin
- Observations
  - e.g. Blood Pressure > 220

Recommended Additional Variables:
- Sexual Orientation
- Gender Identity
- Sex Assigned at Birth
- Anatomical Inventory
Decision Support/Health Maintenance

- Patient Due For:
  - LDL
  - HDL
  - TRIGLYCERIDE
  - CHOLESTEROL
  - HGBA1C
  - STD
  - HEP C
  - ???????

Sex=Male
Age = 52 yo
Sex assigned at birth=Female
Sex = Male
Age = 52 yo
Sex assigned at birth = Female

Patient Due For:
- Cervical Pap Smear
- Mammogram
- ??????????

Anatomical Inventory
- Cervix
- Vagina
- Uterus
- Ovaries
- Breasts
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
- Add 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
Opportunities to Monitor, Use and Report Data on LGBTQ Patients

- Develop Summary Reports
- Develop Dashboards
- Incorporate into existing reports or workgroups
  - UDS
  - Diabetes/Hypertension
  - Intimate Partner Violence
  - Social Determinants of Health
- Presentations to Senior Management or All Staff Meetings
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

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>What is your current gender identity?</td>
</tr>
<tr>
<td></td>
<td><img src="X" alt="Male" /> Male</td>
</tr>
<tr>
<td></td>
<td><img src="%E2%96%A1" alt="Female" /> Female</td>
</tr>
<tr>
<td></td>
<td><img src="X" alt="Transgender Male/Trans Man/FTM" /> Transgender Male/Trans Man/FTM</td>
</tr>
<tr>
<td></td>
<td><img src="%E2%96%A1" alt="Transgender Female/Trans Woman/MTF" /> Transgender Female/Trans Woman/MTF</td>
</tr>
<tr>
<td></td>
<td><img src="%E2%96%A1" alt="GenderQueer" /> GenderQueer</td>
</tr>
<tr>
<td></td>
<td><img src="%E2%96%A1" alt="Additional Category (please specify) (please specify)" /> Additional Category (please specify) _________</td>
</tr>
</tbody>
</table>

| 2. | What sex were you assigned at birth? |
| ![Male](□) Male |
| ![Female](X) Female |
| ![Decline to Answer](□) Decline to Answer |
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**
Quality and Integrity Checking

Examples of Stratification by other Socio-Demographic Data

- Gender Identity by:
  - Country of birth
  - Age group
  - New medical patients
  - Social determinants of health

<table>
<thead>
<tr>
<th>Country of Birth</th>
<th>Transgender Male/Trans Man/FTM</th>
<th>Transgender Female/Trans Woman/MTF</th>
<th>Female</th>
<th>Male</th>
<th>Gender-queer/Gender Expansive</th>
<th>Missing</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>US Born</td>
<td>300 (54%)</td>
<td>65 (12%)</td>
<td>85 (15%)</td>
<td>50 (9%)</td>
<td>20 (4%)</td>
<td>40 (7%)</td>
<td>560</td>
</tr>
<tr>
<td>Born outside of US</td>
<td>35 (35%)</td>
<td>10 (10%)</td>
<td>4 (4%)</td>
<td>1 (1%)</td>
<td>5 (5%)</td>
<td>45 (43%)</td>
<td>100</td>
</tr>
<tr>
<td>Missing</td>
<td>32 (64%)</td>
<td>5 (10%)</td>
<td>5 (10%)</td>
<td>1 (2%)</td>
<td>5 (10%)</td>
<td>2 (4%)</td>
<td>50</td>
</tr>
<tr>
<td>Total</td>
<td>367 (52%)</td>
<td>80 (11%)</td>
<td>94 (13%)</td>
<td>52 (7%)</td>
<td>30 (4%)</td>
<td>87 (12%)</td>
<td>710</td>
</tr>
</tbody>
</table>

Compare data proportionally and within categories to identify problem areas.
### Quality Report Example: Cancer Screening

<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>Gender Identity)</th>
<th>Screening Needed</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></td>
<td>Non-Compliant</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>N/A</td>
<td>N/A</td>
<td>Non-Compliant</td>
</tr>
<tr>
<td>4444</td>
<td>Kathy</td>
<td>Test</td>
<td>Smith MD, Jane</td>
<td>Female</td>
<td>55</td>
<td>Non-Compliant</td>
<td>Non-Compliant</td>
<td>N/A</td>
<td>Non-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></td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>8888</td>
<td>Maddie</td>
<td>Test</td>
<td>Smith MD, Joseph</td>
<td>Male</td>
<td>56</td>
<td>Homosexual</td>
<td>N/A</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>Female</td>
<td>49</td>
<td>Straight or</td>
<td>Compliant</td>
<td>Compliant</td>
<td>Compliant</td>
</tr>
<tr>
<td>9999</td>
<td>Sammy</td>
<td>Test</td>
<td>Smith MD, Jane</td>
<td>F</td>
<td>49</td>
<td></td>
<td>Compliant</td>
<td>Compliant</td>
<td>Compliant</td>
</tr>
</tbody>
</table>
# Quality Reports: Rates of Cervical Cancer Screening Among Patients By Sexual Orientation

<table>
<thead>
<tr>
<th>Sexual Orientation</th>
<th>Yes (%)</th>
<th>No (%)</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lesbian/Gay</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bisexual</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Straight/Heterosexual</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Something Else</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don't Know</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td></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/Latinx # (%)</th>
<th>Non-Hispanic/Non-Latino/Non-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>
## Stratifying UDS Measures by SOGI

### Key UDS Measures by SO/GI Category

<table>
<thead>
<tr>
<th>Sexual Orientation Categories</th>
<th>Gender Identity Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lesbian/Gay</td>
<td>Cis Women</td>
</tr>
<tr>
<td>Bisexual</td>
<td>Cis Men</td>
</tr>
<tr>
<td>Straight or Heterosexual</td>
<td>Trans Men</td>
</tr>
<tr>
<td>Something Else</td>
<td>Trans Women</td>
</tr>
<tr>
<td>Don’t Know</td>
<td>Other (Genderqueer)</td>
</tr>
<tr>
<td>Not Disclosed / Unknown</td>
<td>Not Disclosed / Unknown</td>
</tr>
</tbody>
</table>

- **HIV test**
- **Mammogram**
- **Screening, Brief Intervention, and Referral to Treatment (SBIRT)**
- **Cervical Cancer Screening - Patients Aged 23 through 64**
- **Tobacco Use: Screening and Cessation Intervention**
- **Screening for Clinical Depression and Follow-Up Plan - Total Patients Aged 12 and Older**
### Hormones by Type

<table>
<thead>
<tr>
<th>Total in Panel</th>
<th>Previous Year: 2017</th>
<th>YTD: 2018</th>
<th>Q1 (JAN-MAR)</th>
<th>Q2 (APR-JUN)</th>
<th>Q3 (JUL-SEP)</th>
<th>Q4 (OCT-DEC)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total in Panel</td>
<td>3454</td>
<td>2179</td>
<td>2179</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- **Masculinizing Hormones**
  - Not screened
  - On any masculinizing hormones

- **Feminizing Hormones**
  - Not screened
  - On any feminizing hormones

- **Both Hormones**
  - On both hormones

#### PAP Tests

- **# Patients 23 and older**
  - Anal or Cervical PAP within last 3 years
  - Anal PAP within last 3 years
  - Cervical PAP within last 3 years

#### Comorbidities

- **HIV+**
- **Diabetic**
- **Depression/Mood Disorders**
- **Anxiety disorders including PTSD**
- **PrEP**
  - Patients with an active PrEP prescription during the reporting period

#### Quality Reports: Transgender Dashboard

- **age**
- **Race**
- **Ethnicity**
- **Sexual Orientation**
- **Federal poverty level**
- **Insurance**
- **New/Returning**
- **Location of care**

#### Alcohol Use

- **AUDIT (Alcohol Use)**
  - Negative/Not at Risk
  - Mild/Risky Use
  - Moderate/Problematic Use
  - Severe/Disordered Use
  - Not screened

#### Drug Abuse

- **DAST 10 (Drug Abuse)**
  - Negative/Not at Risk
  - Mild/Risky Use
  - Moderate/Problematic Use
  - Severe/Disordered Use
  - Not screened

#### Depression

- **PHQ 9 (Depression)**
  - No Depression
  - Mild Depression
  - Moderate Depression
  - Severe Depression
  - Not screened

#### Anxiety

- **GAD 7 (Anxiety)**
  - Low Anxiety
  - Mild Anxiety
  - Moderate Anxiety
  - Severe Anxiety
  - Not screened

#### Intimate Partner Violence

- **Isolation**
- **Physical**
- **Sexual**
- **Refused**
  - Not screened

#### Tobacco Use

- **Age**
- **Race**
- **Ethnicity**
- **Sexual Orientation**
- **Federal poverty level**
- **Insurance**
- **New/Returning**
- **Location of care**

#### Drug Use

- **Drug Use**
  - Negative/Not at Risk
  - Mild/Risky Use
  - Moderate/Problematic Use
  - Severe/Disordered Use
  - Not screened
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
Next Steps

- Better integration of the anatomical inventory, gender and sexual orientation fields into clinical decision support
- Changes to HEDIS/NCQA Quality Measures and USPSTF to be more inclusive
- Name and pronoun fields collected in structured fields used throughout EHR
  - Available in Name search mechanisms
  - Available in schedule views for registration staff
- Transmit name, pronoun and gender information between HIT systems (ie. C-CDA/HL7)
- Insurance/Billing Forms