COLLECTING AND REPORTING SEXUAL ORIENTATION/GENDER IDENTITY DATA OF AGRICULTURAL WORKER PATIENTS

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Agenda

- Introductions

- Overview – Collecting SOGI Data in EHRs

- Collecting SOGI Data – An Affirming Approach

- Consent Board Game

- FJ & LGBT Health Education Center Learning Collaborative

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

Alex S. Keuroghlian, MD MPH and Cei Lambert, MFA
The National LGBT Health Education Center
Why Collect Sexual/Romantic Orientation and Gender Identity Data?

1. To better understand your patients and their needs
2. To help LGBTQI+ people become visible through informatics
3. Because it is a UDS requirement for all Federally Qualified Health Centers
Population Health: Ending LGBTQI+ 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?
Guidelines for Collecting SO/GI Data

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

www.lgbthealtheducation.org
SO/GI Data Collection Demonstration Videos

www.lgbthealtheducation.org
Collecting SO/GI Information

www.lgbthealtheducation.org/topic/sogi/
**New Sexual Orientation and Gender Identity Questions:**

Information for Patients

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**Arabic**

**Brazilian Portuguese**

**Simplified Chinese**

**Haitian Creole**

**Spanish**

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**English**

**SOGI Patient Pamphlet Translations**

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**French**

Novas perguntas sobre orientação sexual e identidade de gênero:

Informação aos pacientes

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**Chinese**

**Spanglish**

**Portuguese**

**Haitian Creole**

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Frequenterly asked questions about sexual orientation and gender identity in our organization.

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New health sector referrals are important to ensure the health of all. 

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Accepted all genders and sexual orientations.

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Recentemente, adicionamos novas perguntas sobre orientação sexual e identidade de gênero.

Nosso centro de saúde enfatiza a importância de apresentar estas perguntas para os nossos pacientes. 

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Recentemente, avons adicionado novas perguntas sobre orienación sexual y la identidad de género.

Nuestro entorno de salud enfatiza la importancia de presentar estas preguntas para nuestros pacientes. 

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Nuestro entorno de salud enfatiza la importancia de presentar estas preguntas para nuestros pacientes.
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
Sex Assigned At Birth

Is the designation of female, male, or intersex based on observed biological characteristics at birth.

Gender Identity

A person’s inner sense of being a girl/woman, boy/man, something else, or having no gender.
Gender Dysphoria

“Discomfort or distress that is caused by a discrepancy between a person’s gender identity and that person’s sex assigned at birth (and the associated gender role and/or primary and secondary sex characteristics)” (Coleman et al., 2012)
The process of changing from living and being perceived as the gender assigned at birth according to the anatomical sex (M or F) to living and being perceived as the individual sees and understands themselves

- Social affirmation
- Legal/document changes
- Hormone therapy
- Surgical affirmation

Many prefer the term “gender affirmation” or “gender confirmation” over “transition”
Sexual Orientation

- **Sexual orientation**: how a person identifies their physical, romantic, and emotional attachments to others

- **Desire**
  - Need not be sexual
  - Can be about a person’s physical body, but not always

- **Behavior**
  - Men who have sex with men- MSM (MSMW)
  - Women who have sex with women- WSW (WSWM)
  - People who have sex with people who identify as men and as women
  - People who do not have sex by choice
  - And much more...

- **Identity**
  - Straight, gay, lesbian, bisexual, queer, pansexual, demisexual, asexual...

**Dimensions of Sexual Orientation:**

- **Identity**
  - Do you consider yourself gay, lesbian, bisexual, straight, queer, something else?

- **Desire**
  - What gender(s) are you attracted to physically and emotionally?

- **Behavior**
  - What gender(s) are your sexual/romantic partner(s)?
Minority Stress Framework

Adapted from Introduction to the special issue on structural stigma and health

External Stigma-Related Stressors

General Psychological Processes

Internal Stigma-Related Stressors

Behavioral Health Problems

Physical Health Problems

www.lgbthealtheducation.org
The Why: Rodrigo’s Story

- 40-year-old trans man who came in with pelvic pain and spotting
- A biopsy determined that Rodrigo had cervical cancer
- No one had told Rodrigo that he needed routine cervical pap tests

>> If Rodrigo’s chart reflected his identity, he may have been offered appropriate screening and his cancer may have been caught earlier.
Preparation for Collecting Data in Clinical Settings

- **Clinicians**: Need to learn about LGBTQI+ 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 LGBTQI+ health, communicating with LGBTQI+ 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.
Are Patients Likely to be Offended by SO/GI Questions?

- 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).
Responding to Staff Concerns

- Some staff may need extra coaching and reassurance
- Supervisors should explain that the health center is trying to provide the best care for all patients, and staff do not need to change their own values to collect SO/GI data
- Regular check-ins with staff members will help identify and address their concerns
Gathering SO/GI Data During the Process of Care

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

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

- What name do you use?
- What name is on your insurance records?
- What are your pronouns (e.g. he/him, she/her, they/them)?

www.lgbthealtheducation.org
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).
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?”
SO/GI Reporting For 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
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 father’s names?”
  - *Say:* “What is your guardian’s name?”
Putting What You Learn into Practice

- If you are unsure about a patient’s name or pronouns:
  - “I would like to 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.”
# Inclusive Registration and Medical History Forms

<table>
<thead>
<tr>
<th>Avoid these terms...</th>
<th>Replace with...</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother/Father</td>
<td>Parent/Guardian</td>
</tr>
<tr>
<td>Husband/Wife</td>
<td>Spouse/Partner(s)</td>
</tr>
<tr>
<td>Marital Status</td>
<td>Relationship Status</td>
</tr>
<tr>
<td>Family History</td>
<td>Blood Relatives</td>
</tr>
<tr>
<td>Nursing Mother</td>
<td>Currently Nursing</td>
</tr>
<tr>
<td>Female Only/Male Only</td>
<td>Allow patients to choose <em>not applicable</em>.</td>
</tr>
</tbody>
</table>
Gender-inclusive Diagrams

- Images that have a specific gender may limit identification of certain medical issues
- Use gender-inclusive images to document areas of concern

Image by: Katja Tezlaff
(https://ktetzlaff.com/tag/transgender/#jp-carousel-456)
Training All Staff in Basic LGBTQ Competence

- LGBTQ concepts and common terms
- LGBTQ health disparities
- Implicit Bias
- Communicating with cultural humility
- SO/GI data collection
- Confidentiality and privacy
The National LGBT Health Education Center provides educational programs, resources, and consultation to health care organizations with the goal of optimizing quality, cost-effective health care for lesbian, gay, bisexual, and transgender (LGBT) people.

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

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🔗 www.acponline.org/fenway
Objectives

• Improved comfort in asking sexual health and gender identity questions

Photo credit: The Gender Spectrum Collection, Zackary Drucker (2019)
Disclosures

• No relevant financial disclosures
Denver Health

- FQHC within a Level 1 Trauma Center
- Cares for thirty-three percent of Denver's population annually
- 18 School-based health centers
- 11 community-based health centers (more to come)
- EIS Clinic, PLWH expanded to EISN 7/2017:
  - 50% increase in patients seeking PrEP and Gender Affirming Care
Panel demonstration of geography
Disadvantaged communities

https://www.udsmapper.org/HealthLandscape.cfm
The Rural and Suburban Migration from Denver
Population per Square Mile (Logarithmic Scale)

https://demography.dola.colorado.gov/Population-Bubbles/ 2019
EIS clinic growth

YEAR TOTALS, ACTIVE CENSUS

EIS clinic growth

ACTIVE PATIENTS

- non-PLWH
- total

2019
200
201

2019
Overall **PrEP Awareness** was **85%** | Overall **PrEP Use** was **25%**

*Pre-exposure prophylaxis* (or PrEP) is a pill that, taken daily, can protect someone from getting HIV.

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>PrEP Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black/African-American MSM</td>
<td>19%</td>
</tr>
<tr>
<td>Hispanic/Latino MSM</td>
<td>21%</td>
</tr>
<tr>
<td>White MSM</td>
<td>31%</td>
</tr>
</tbody>
</table>

By race/ethnicity, past 12-month PrEP use was less common among **Black/African-American** and **Hispanic/Latino MSM**.
<table>
<thead>
<tr>
<th>Indicator</th>
<th>2020 Target</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
<th>2014</th>
<th>2015</th>
<th>2016</th>
<th>Recent year progress</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Colorado</strong></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>New HIV infections</td>
<td>125%</td>
<td>390</td>
<td>380</td>
<td>410</td>
<td>360</td>
<td>380</td>
<td>380</td>
<td>490</td>
<td></td>
</tr>
<tr>
<td>Knowledge of HIV+ status</td>
<td>90%</td>
<td>80.6</td>
<td>81.4</td>
<td>81.7</td>
<td>81.8</td>
<td>82.7</td>
<td>84.2</td>
<td>87.2</td>
<td></td>
</tr>
<tr>
<td>New HIV diagnoses</td>
<td>125%</td>
<td>425</td>
<td>377</td>
<td>388</td>
<td>319</td>
<td>377</td>
<td>379</td>
<td>424</td>
<td></td>
</tr>
<tr>
<td>Linkage to HIV medical care</td>
<td>85%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>85.2</td>
<td>82.8</td>
</tr>
<tr>
<td>Retention in care</td>
<td>90%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>45.7</td>
<td>45.0</td>
<td></td>
</tr>
<tr>
<td>Viral suppression</td>
<td>80%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>48.7</td>
<td>51.0</td>
<td></td>
</tr>
</tbody>
</table>

- **Met 2020 Target** in most recent data year
- **Progress**: Moved toward 2020 target in most recent data year
- **No Progress**: No change or moved away from 2020 target in most recent data year
- **Cannot Assess**: Lab data not available or single year only
- **Unstable Estimate**

Photo credit: The Gender Spectrum Collection, Zackary Drucker (2019)
• PrEP interest
• New HIV cases up 12% * year (Latino)
• National surveillance data
  • Knowledge 85%
  • Use 21%
• Latinos+
• 21% Colorado’s population
• 26% of new HIV dx
• Increase of 12% 2012-2016

Source: CDC, HIV in the United States and Dependent Areas, Jan. 2019

Figure 1
New HIV Diagnoses & U.S. Population, by Race/Ethnicity, 2017

CONSENT GAME
FJ/LGBT Health Education Center SOGI Learning Collaborative

• July 1, 2017 – June 30, 2020

• Series of webinars from July 1, 2017 to June 30, 2019

• 7 health center participants

• Goal: Share tools and strategies to support health centers’ collection of SOGI data from agricultural worker patients
Next Steps

• FJ & LGBT Health Education Center will be creating an addendum to the “Ready, Set, Go” Guide focused on SOGI data collection in agricultural worker communities

• Addendum will include strategies shared by learning collaborative participants
Thank you!

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