

# 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



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

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**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

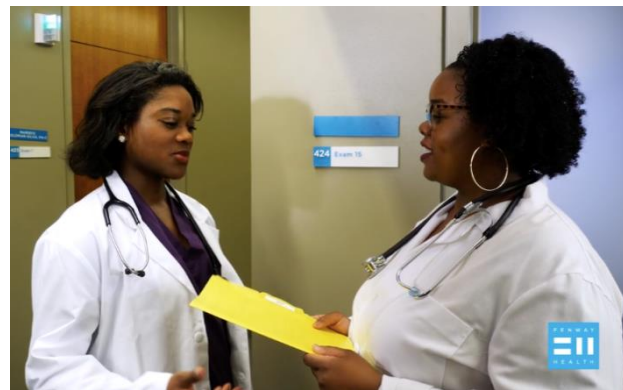
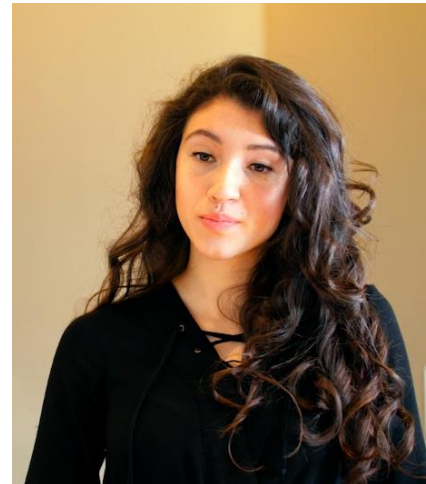
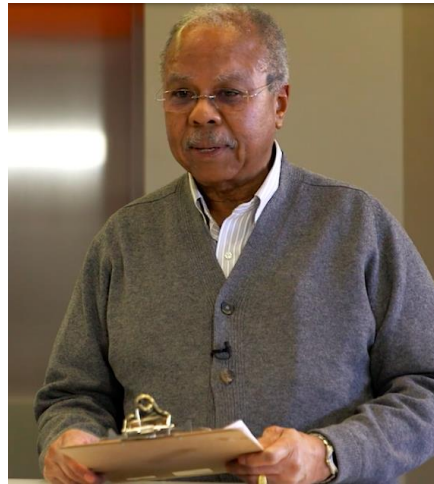
- Has a clinician ever asked you about your history of sexual health, your sexual orientation or your gender identity?
- How often do you talk with your patients about their sexual history, sexual orientation, or gender identity?



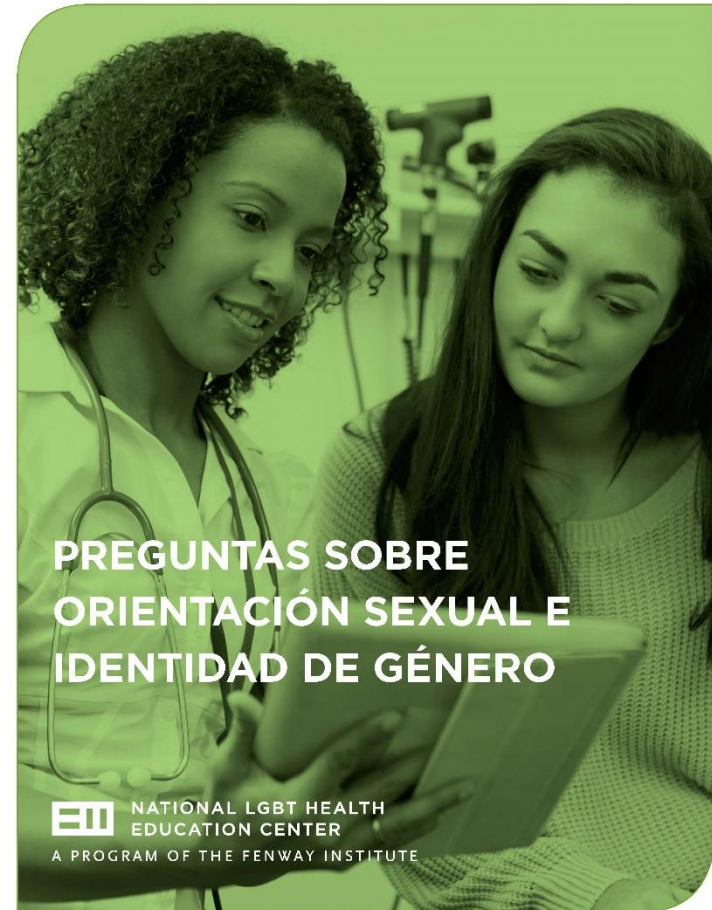
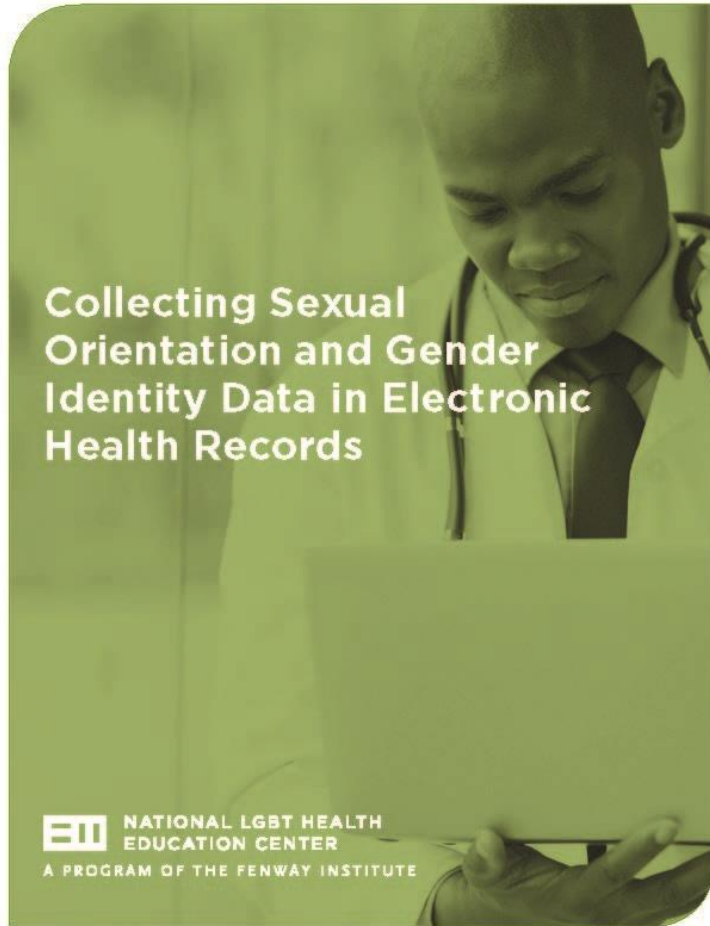
# Guidelines for Collecting SO/GI Data



# SO/GI Data Collection Demonstration Videos



# Collecting SO/GI Information



[www.lgbthealtheducation.org/topic/sogi/](http://www.lgbthealtheducation.org/topic/sogi/)



# SOGI Patient Pamphlet Translations

## 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 frequent & asked questions about why we are asking those questions and how the information will be used.

English

## أسئلة حول التوجه الجنسي الجديدة والهوية الجندرية:

معلومات حول المرضى



### قمنا بإضافة أسئلة جديدة حول التوجه الجنسي والهوية الجندرية إلى نماذج التسجيل.

يعتقد المركز الصحي لدينا أنه من المهم معرفة هذه المعلومات من مرضائنا لتوجد في الداخل بعض الأسئلة الأكثر شيوعًا حول غايتنا من طرح هذه الأسئلة وكيف سيتم استخدام هذه المعلومات.

Arabic

## Novas perguntas sobre orientação sexual e identidade de gênero:

Informação aos pacientes



Recentemente, adicionamos novas perguntas sobre orientação sexual e identidade de gênero aos nossos formulários de inscrição.

Nosso centro de saúde acredita que é importante aprender estas informações de nossos pacientes. Dentro deste folheto estão perguntas frequentes sobre porque estamos fazendo essas perguntas e como essa informação será usada.

Brazilian Portuguese

## 有关性取向和性别认同的新问题:

向患者提供的信息



我们近期在我们的登记表中增加了一些有关性取向和性别认同的新问题。

我们的健康中心认为，向我们的患者了解此类信息很重要。我们在手册中列出了一些常见问题，以说明我们为什么要了解这些信息以及我们将如何使用这些信息。

Simplified Chinese

## Nouvo kesyon sou preferans seksyèl epi sou idantite seksyèl :

Enfòmasyon pou pasyan



Tou dènyejan la, nou ajoute, nan fòmilèl enskripsyon nou yo, nouvo kesyon sou oryantasyon seksyèl epi sou idantite jann.

Dispansé nou an panse li enpòtan pou n konn enfòmasyon sa yo sou pasyan nou yo. Gen andedan kesyon moun poze souvan sou pouki nou poze kesyon sa yo ak kijan enfòmasyon yo ap itize.

Haitian Creole

## Nuevas preguntas sobre la orientación sexual y la identidad de género:

Información para pacientes



Recentemente 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 conozcamos 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.

Spanish



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# 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  $\neq$  Sexual Orientation



# Gender Identity



## Gender Identity

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




## Sex Assigned At Birth

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



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WHAT ARE WE “TREATING”  
WHEN WE USE MEDICAL  
GENDER AFFIRMATION TOOLS?

# 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)



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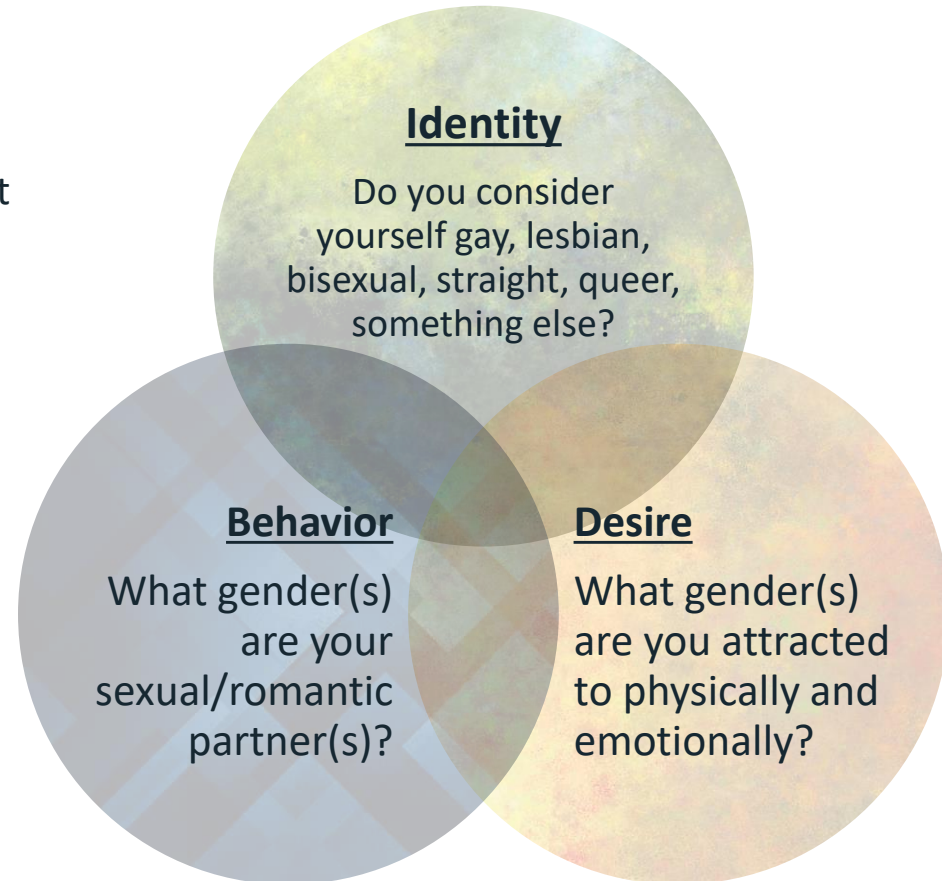
# Terminology: Understanding “Transition” or “Affirmation”

- 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”

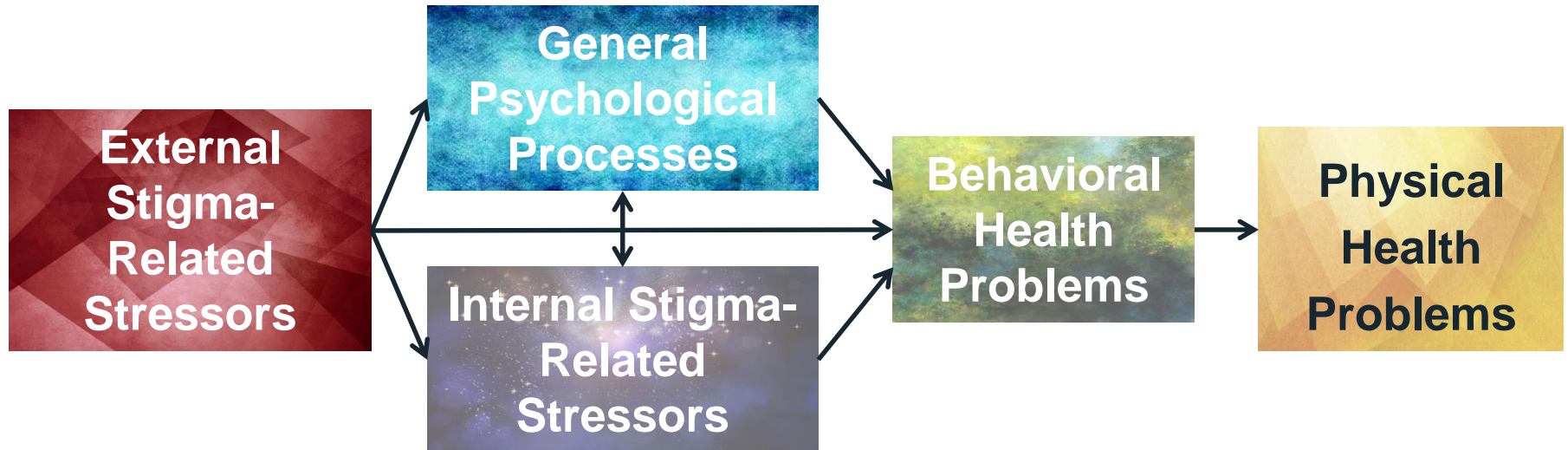
# Sexual Orientation

- **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:



# Minority Stress Framework



Adapted from *Introduction to the special issue on structural stigma and health*<sup>3</sup>

# 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

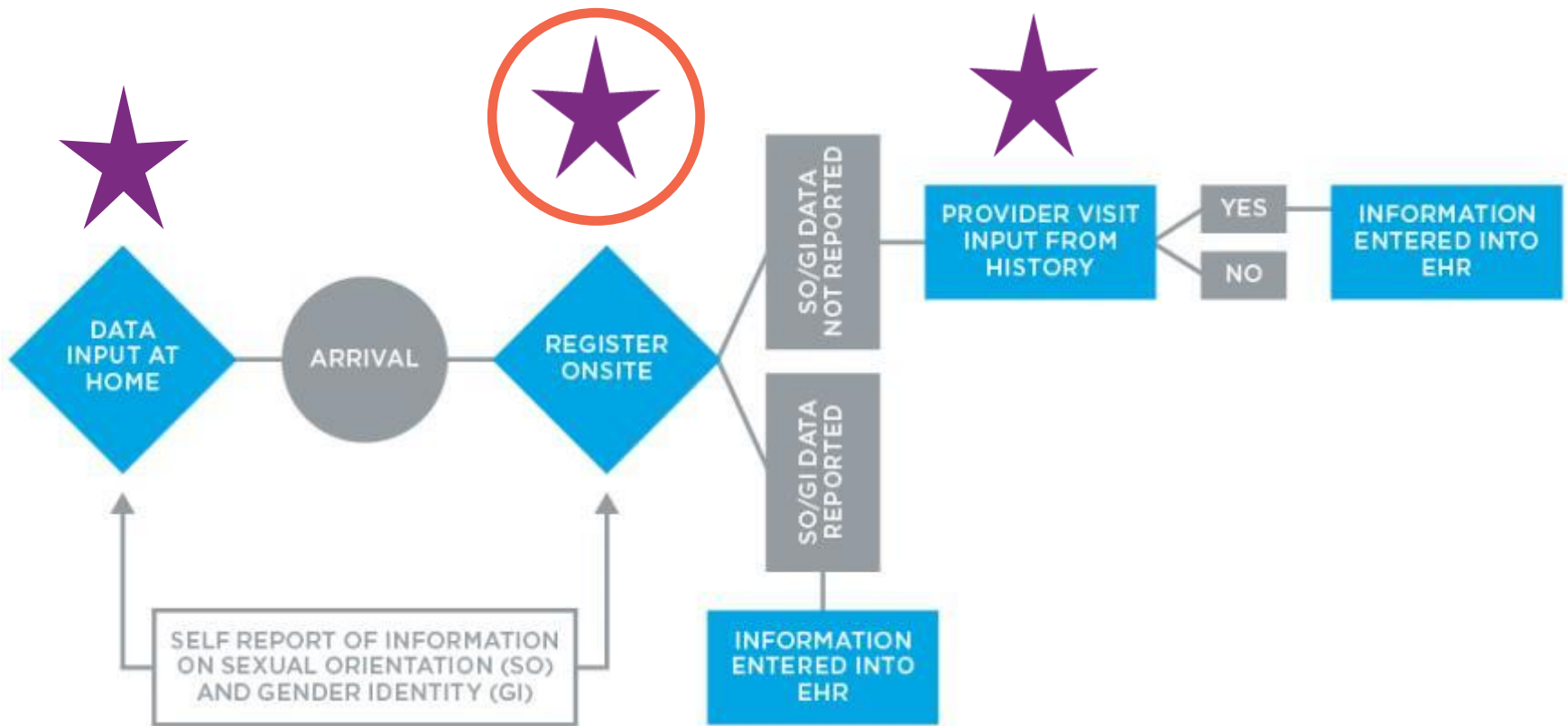


Diagram from "Fenway Guide to Lesbian, Gay, Bisexual, and Transgender Health."<sup>13</sup>

# 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)?



# 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).



Subjective	Objective	Possessive	Examples
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.

# 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 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

Avoid these terms...	Replace with...
Mother/Father	Parent/Guardian
Husband/Wife	Spouse/Partner(s)
Marital Status	Relationship Status
Family History	Blood Relatives
Nursing Mother	Currently Nursing
Female Only/Male Only	Allow patients to choose <i>not applicable</i> .



Focus on Forms and Policy:

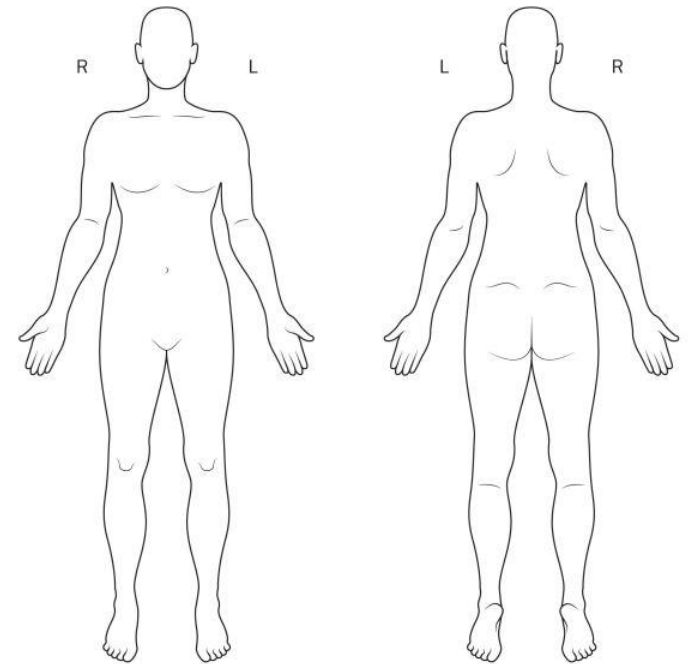
**Creating an Inclusive Environment  
for LGBT Patients**

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# 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

ANATOMICAL DIAGRAMS-SKIN SURFACE ASSESSMENT



Case Number \_\_\_\_\_

Initials of Examiner \_\_\_\_\_

Image by: Katja Tezlaff  
(<https://ktetzlaff.com/tag/transgender/#jp-carousel-456>)

# Training All Staff in Basic LGBTQ Competence



Learning to Address  
Implicit Bias Towards  
LGBTQ Patients:  
Case Scenarios

September 2018

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- 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.



Advice from one health care provider to another.

JANUARY 18, 2017



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 [www.acponline.org/fenway](http://www.acponline.org/fenway)



TRANSGENDER TRAINING FOR  
HEALTHCARE PROVIDERS



# Collecting Sexual Orientation and Gender Identity Data: An Affirming Approach



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



Kim Powell, MS, FNP-C  
she/her/hers  
Denver Health  
Early Intervention Services  
Network: HIV Care and Prevention,  
trans+ inclusive primary care



# 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

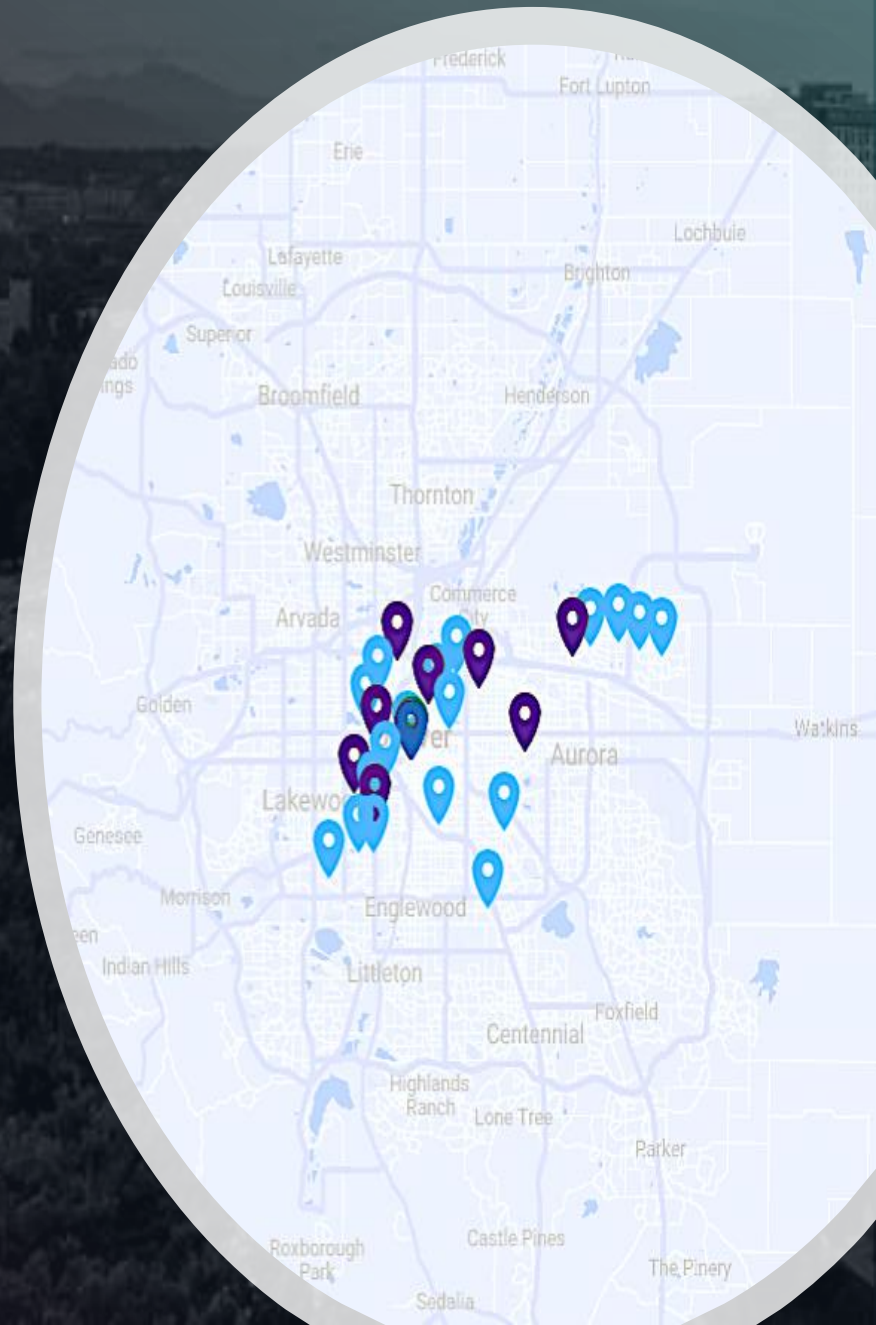


Photo credit: The Gender Spectrum Collection, Zackary Drucker (2019)

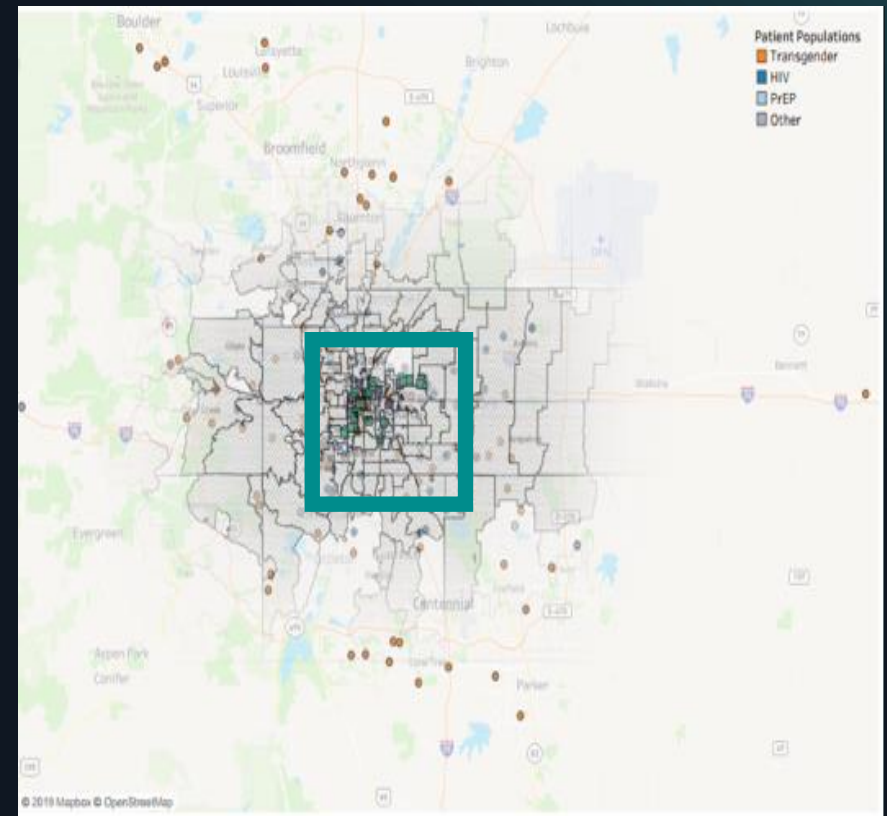
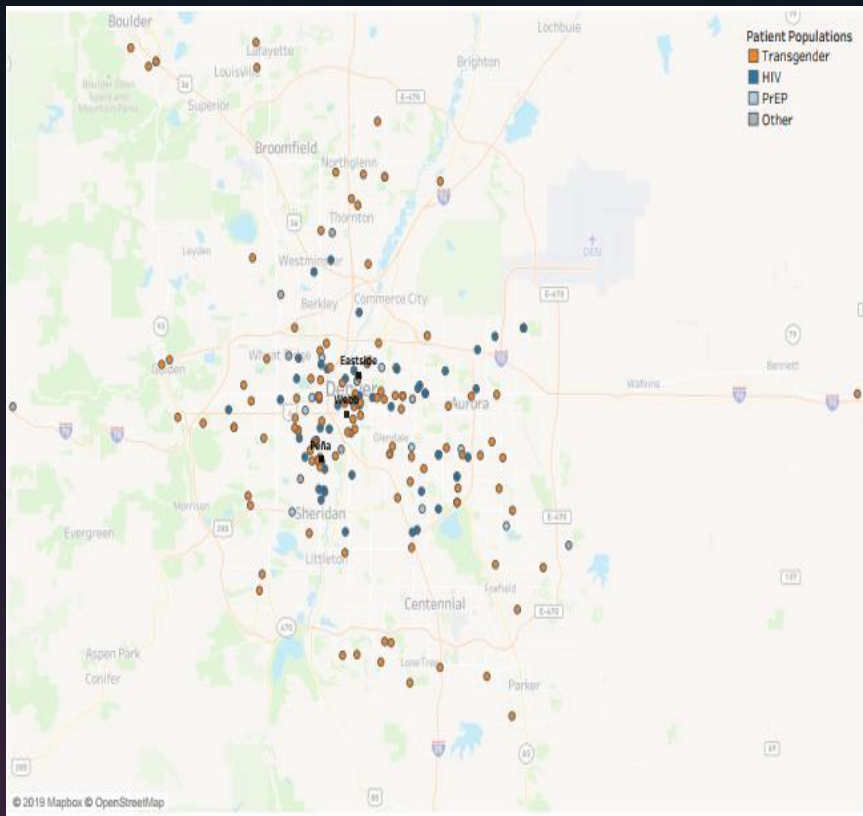


# Denver Health

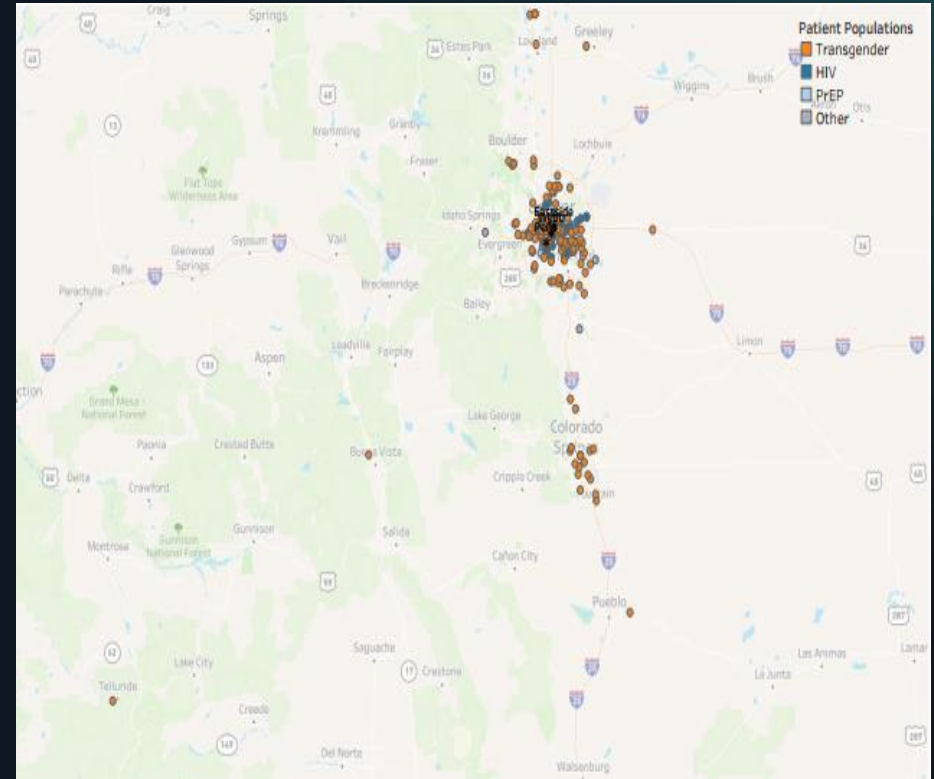
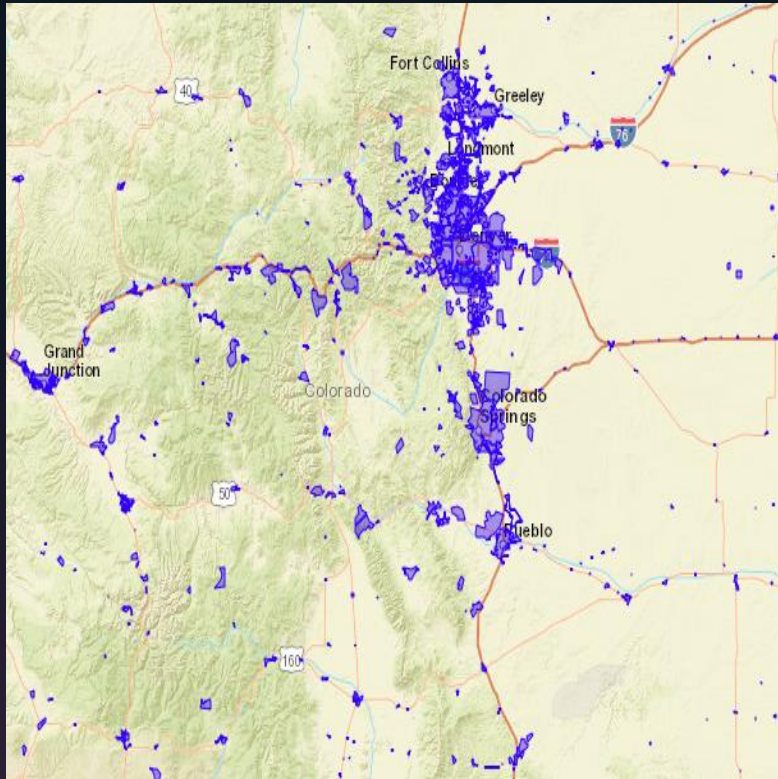
- FQHC within a Level 1 Trauma Center
- Cares for thirty-three percent of Denver's population annually
- 18 School-based health centers
- 11 community-based health centers (more to come)
- EIS Clinic, PLWH expanded to EISN 7/2017:
  - 50% increase in patients seeking PrEP and Gender Affirming Care



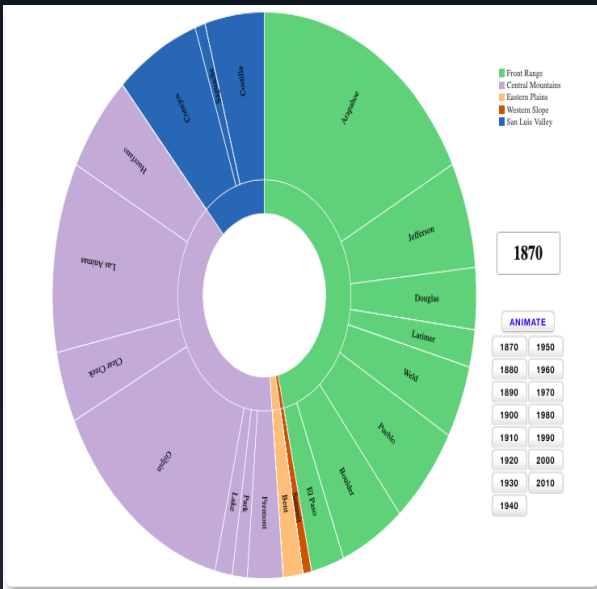
# Panel demonstration of geography



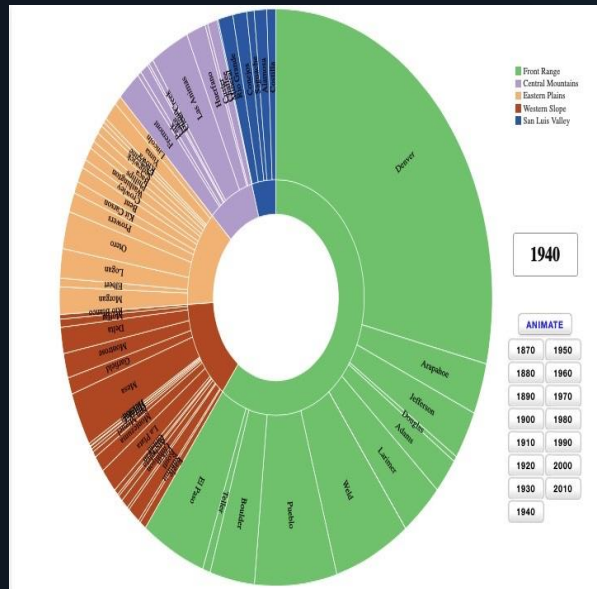
# Disadvantaged communities



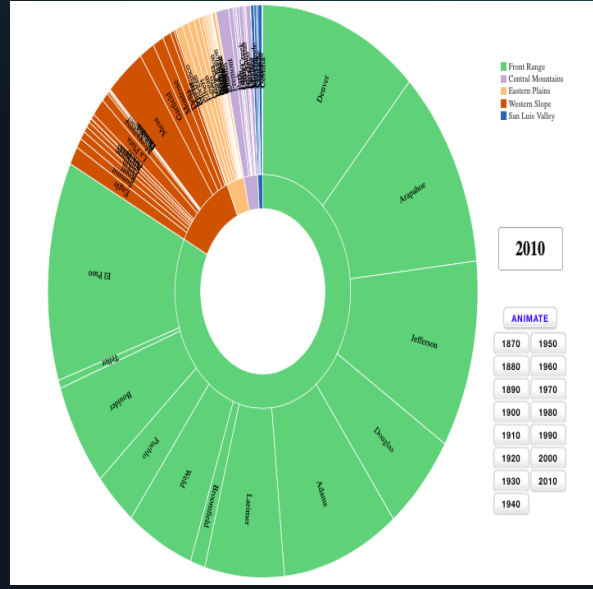
<https://www.udsmapper.org/HealthLandscape.cfm>



1870



1940

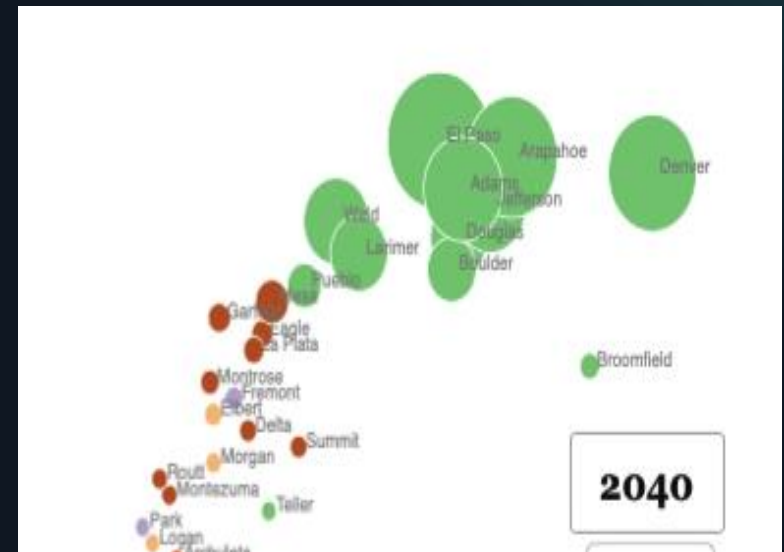
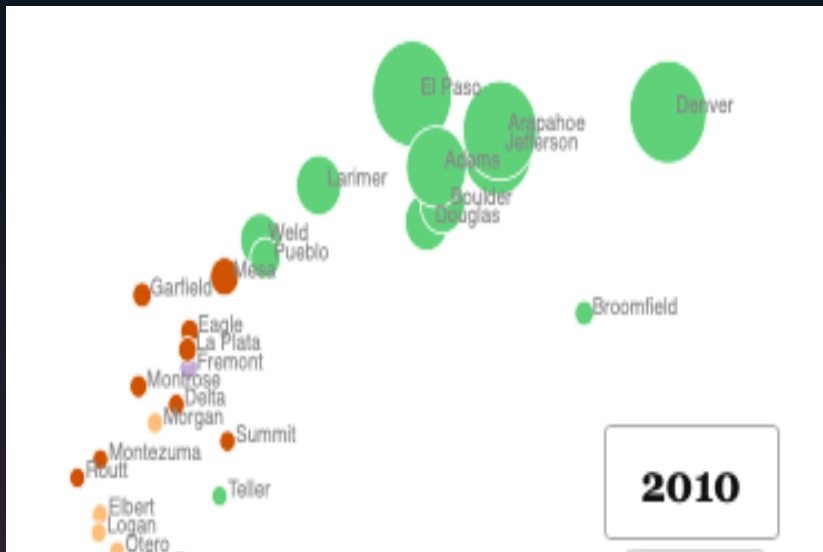


2010

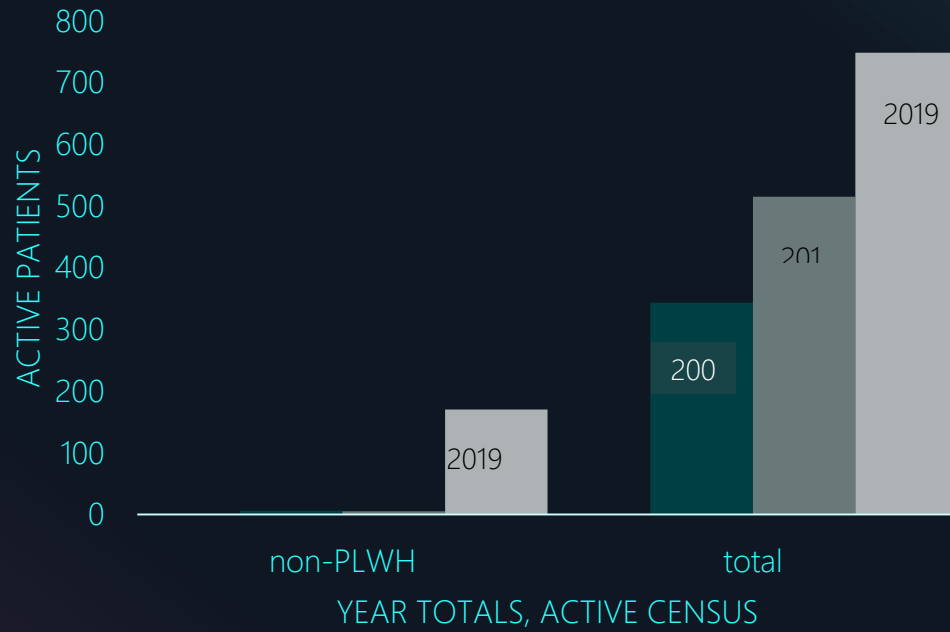
Photo credit: The Gender Spectrum Collection, Zackary Drucker (2019)

# The Rural and Suburban Migration from Denver

Population per Square Mile (Logarithmic Scale)

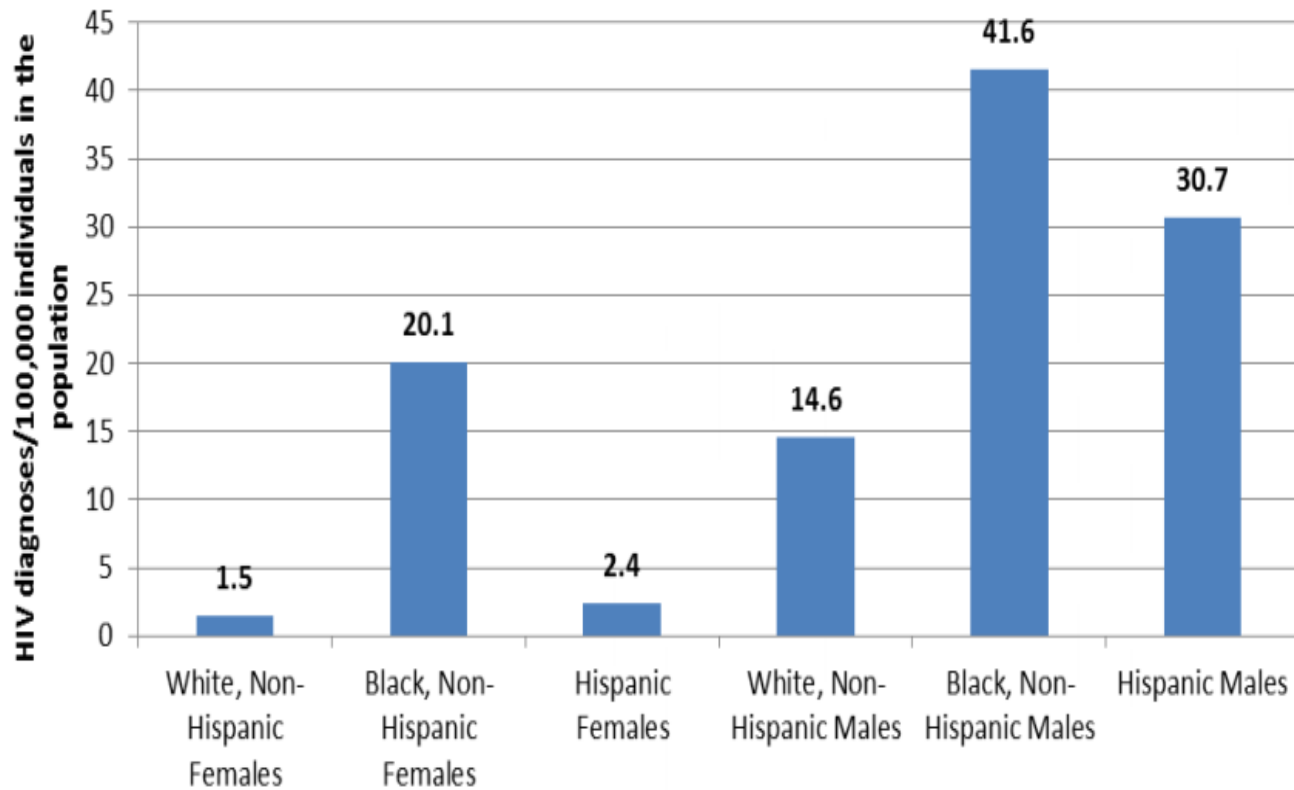


## EIS clinic growth





## Rate of New HIV Diagnoses in 2016



Overall **PrEP Awareness** was **85%**

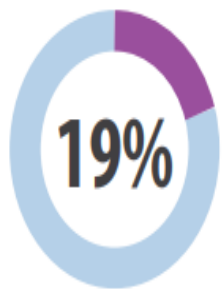
Overall **PrEP Use** was **25%**



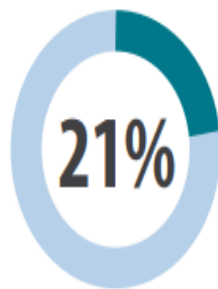
**Pre-exposure prophylaxis** (or PrEP) is a pill that, taken daily, **can protect someone from getting HIV.**



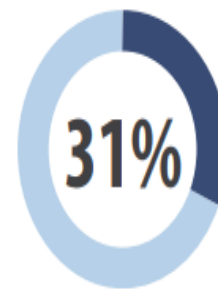
By race/ethnicity, past 12-month PrEP use was less common among **Black/African-American** and **Hispanic/Latino MSM**



**Black/  
African-American  
MSM  
took PrEP**



**Hispanic/Latino  
MSM  
took PrEP**



**White  
MSM  
took PrEP**

Indicator	2020 Target								Recent year progress
	National	2010	2011	2012	2013	2014	2015	2016	
<b>Colorado</b>									
New HIV infections	125%	390	380	410	360	380	380	490	
Knowledge of HIV+ status	90%	80.6	81.4	81.7	81.8	82.7	84.2	87.2	
New HIV diagnoses	125%	425	377	388	319	377	379	424	
Linkage to HIV medical care	85%	—	—	—	—	—	85.2	82.8	
Retention in care	90%	—	—	—	—	45.7	45.0		
Viral suppression	80%	—	—	—	—	48.7	51.0		






-  **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%

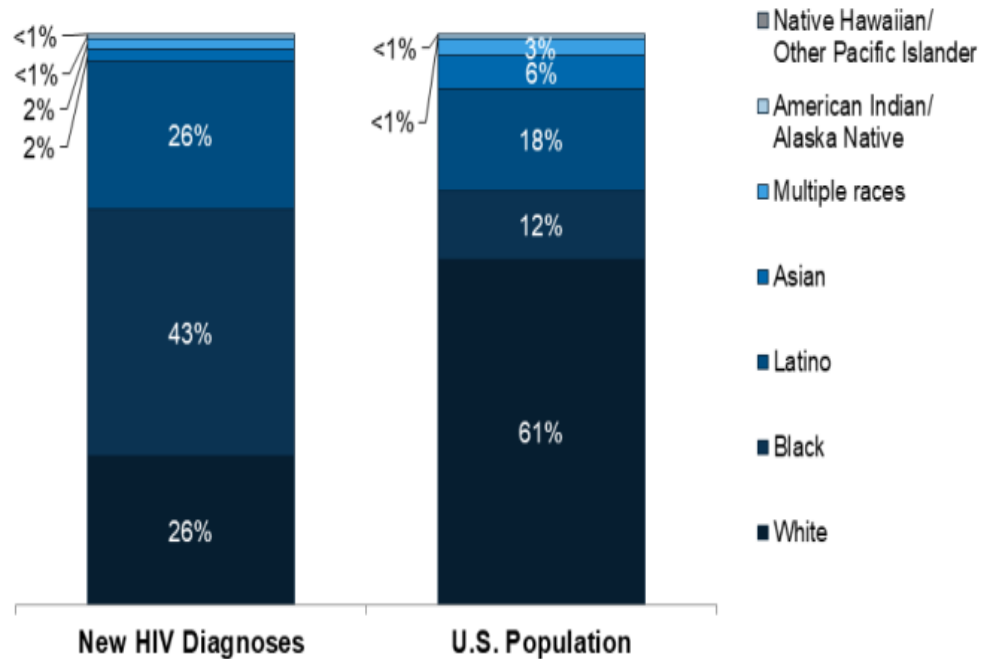
Photo credit: The Gender Spectrum  
Collection, Zackary Drucker (2019)



- Latinos+
- 21% Colorado's population
- 26% of new HIV dx
- Increase of 12 % 201

Figure 1

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



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

SOURCES: CDC. *HIV Surveillance Report, Diagnoses of HIV Infection in the United States and Dependent Areas, 2017*, Vol. 29; November 2018. HIV diagnosis data are preliminary estimates from 50 states, the District of Columbia, and 6 U.S. dependent areas. KFF. *State Health Facts*; accessed January 2019.

# CONSENT GAME

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# 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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