NATIONAL LGBT HEALTH EDUCATION CENTER

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

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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

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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

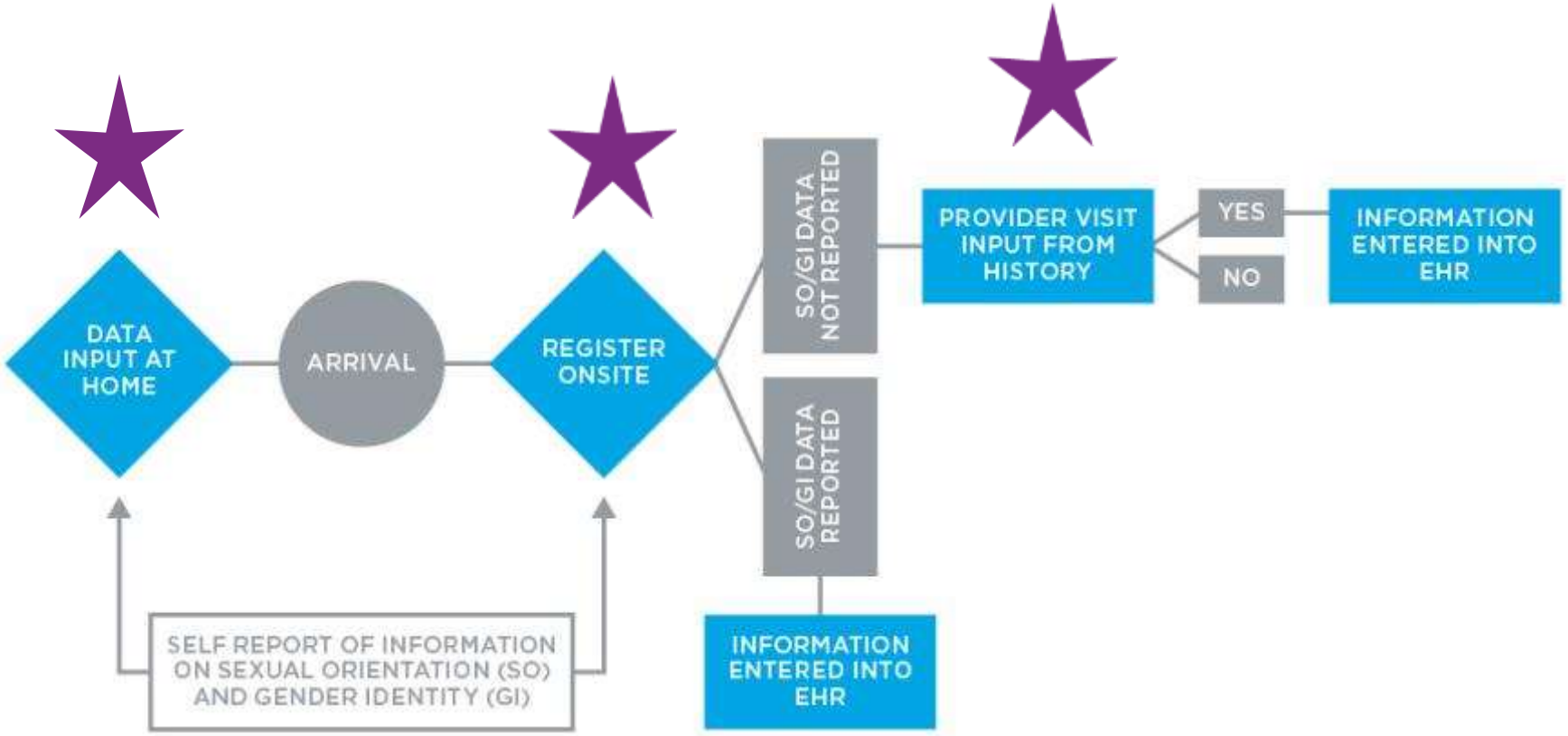
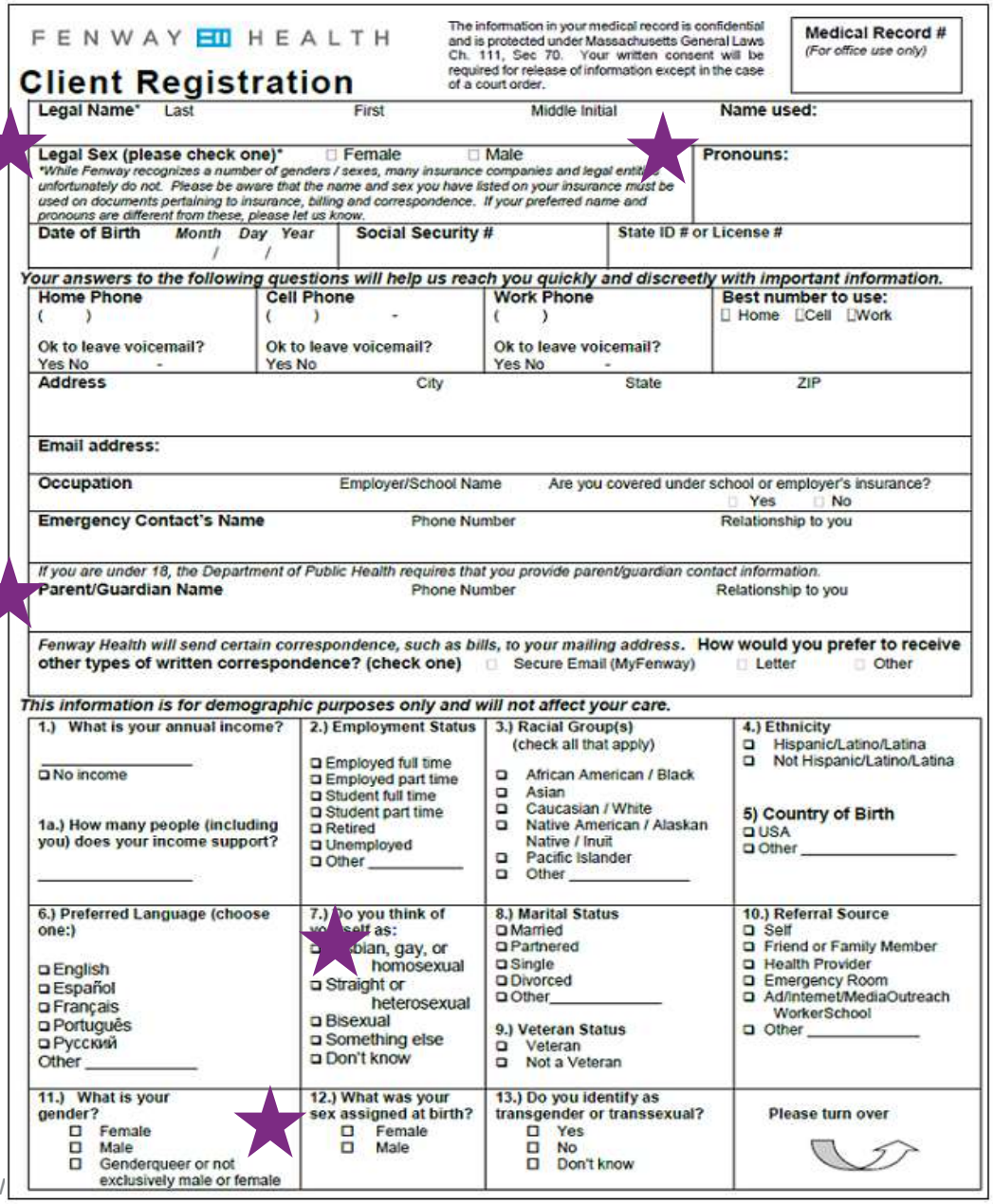


Fig. 2. Diagram from "Fenway Guide to Lesbian, Gay, Bisexual, and Transgender Health."[13]

Sample Registration Form

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



FENWAY HEALTH

The information in your medical record is confidential and is protected under Massachusetts General Laws Ch. 111, Sec 70. Your written consent will be required for release of information except in the case of a court order.

Medical Record # *(For office use only)*

Client Registration

Legal Name* Last First Middle Initial **Name used:**

Legal Sex (please check one)* ☐ Female ☐ Male **Pronouns:**

**While Fenway recognizes a number of genders / sexes, many insurance companies and legal entities unfortunately do not. Please be aware that the name and sex you have listed on your insurance must be used on documents pertaining to insurance, billing and correspondence. If your preferred name and pronouns are different from these, please let us know.*

Date of Birth *Month Day Year* / / **Social Security #** **State ID # or License #**

Your answers to the following questions will help us reach you quickly and discreetly with important information.

Home Phone	Cell Phone	Work Phone	Best number to use:
( )	( ) -	( )	☐ Home ☐ Cell ☐ Work
Ok to leave voicemail? Yes No	Ok to leave voicemail? Yes No	Ok to leave voicemail? Yes No	

Address City State ZIP

Email address:

Occupation Employer/School Name Are you covered under school or employer's insurance? ☐ Yes ☐ No

Emergency Contact's Name Phone Number Relationship to you

If you are under 18, the Department of Public Health requires that you provide parent/guardian contact information.

Parent/Guardian Name Phone Number Relationship to you

Fenway Health will send certain correspondence, such as bills, to your mailing address. **How would you prefer to receive other types of written correspondence? (check one)** ☐ Secure Email (MyFenway) ☐ Letter ☐ Other

This information is for demographic purposes only and will not affect your care.

1.) What is your annual income?
_____
☐ No income

1a.) How many people (including you) does your income support?
_____

2.) Employment Status
☐ Employed full time
☐ Employed part time
☐ Student full time
☐ Student part time
☐ Retired
☐ Unemployed
☐ Other _____

3.) Racial Group(s) (check all that apply)
☐ African American / Black
☐ Asian
☐ Caucasian / White
☐ Native American / Alaskan Native / Inuit
☐ Pacific Islander
☐ Other _____

4.) Ethnicity
☐ Hispanic/Latino/Latina
☐ Not Hispanic/Latino/Latina

5) Country of Birth
☐ USA
☐ Other _____

6.) Preferred Language (choose one:)
☐ English
☐ Español
☐ Français
☐ Português
☐ Русский
Other _____

7.) Do you think of yourself as:
☐ Lesbian, gay, or homosexual
☐ Straight or heterosexual
☐ Bisexual
☐ Something else
☐ Don't know

8.) Marital Status
☐ Married
☐ Partnered
☐ Single
☐ Divorced
☐ Other_____

9.) Veteran Status
☐ Veteran
☐ Not a Veteran

10.) Referral Source
☐ Self
☐ Friend or Family Member
☐ Health Provider
☐ Emergency Room
☐ Ad/Internet/Media Outreach Worker School
☐ Other _____

11.) What is your gender?
☐ Female
☐ Male
☐ Genderqueer or not exclusively male or female

12.) What was your sex assigned at birth?
☐ Female
☐ Male

13.) Do you identify as transgender or transsexual?
☐ Yes
☐ No
☐ Don't know

Please turn over

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 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

	Medical Dept	Lab	Pharmacy	Patient Services
Medical Dept	• Add preferred name to printed materials	• Add preferred name to the label to order	• Send preferred Name in "Note To Pharmacy" field within script. Would need to do this for scripts sent to Fenway only • Need to add preferred name to scripts sent to outside pharmacy	• Increase font size and prominence of preferred name on the Patient Profile • Add preferred name on label or electronic submission for referral services

Task and Workflow Issues

	Patient Search	Phone Calls	Schedule	Chart Summary	Patient Banner	Labels	Letters/Bills/Emails	Other
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**	***Only able to see Patient's first and last name** ^☖ Add preferred name to the schedule	***First and Last Name** ^Add preferred name	***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) *DPH forms –uses Chart name	***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		*no mechanism to indicate which name should be used in correspondence	*Can include preferred name on HDAP forms

Pronoun Color Code

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

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

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

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

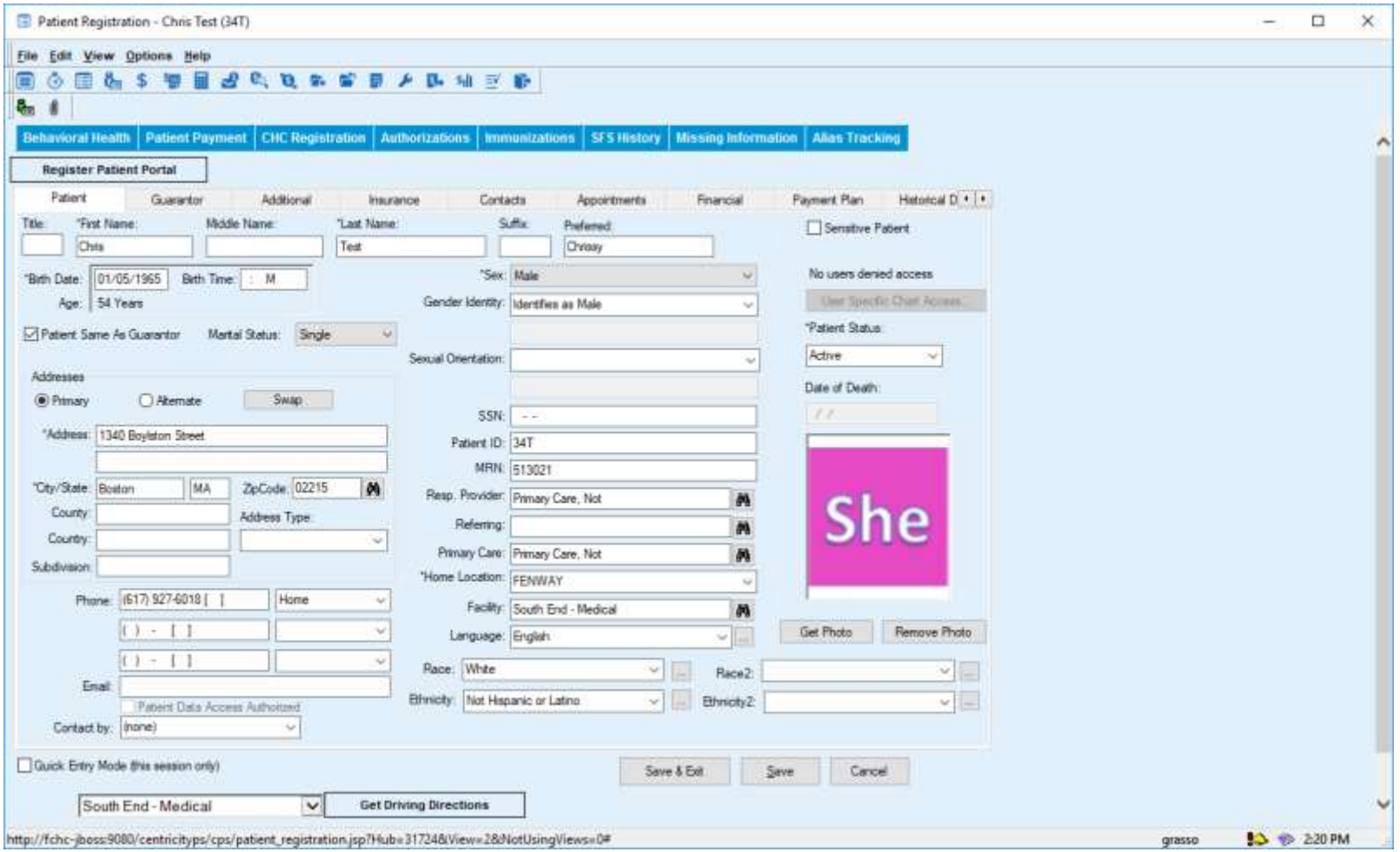
Use this pronoun color block when patient does not want any pronouns used

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

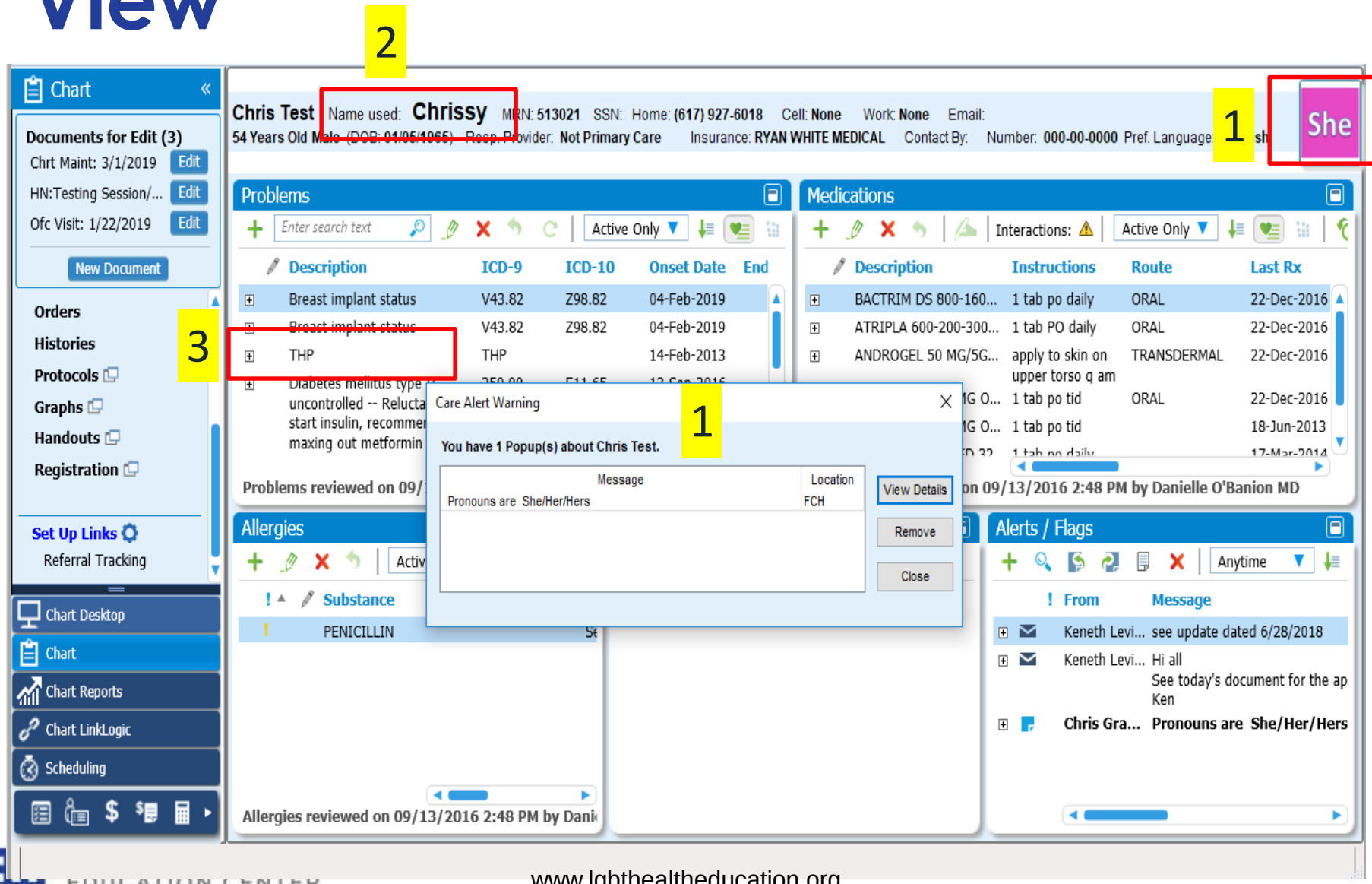
Use this pronoun color block when patient pronouns are fluid and He or They are okay

Use this pronoun color block when patient pronouns are fluid and She or They are okay

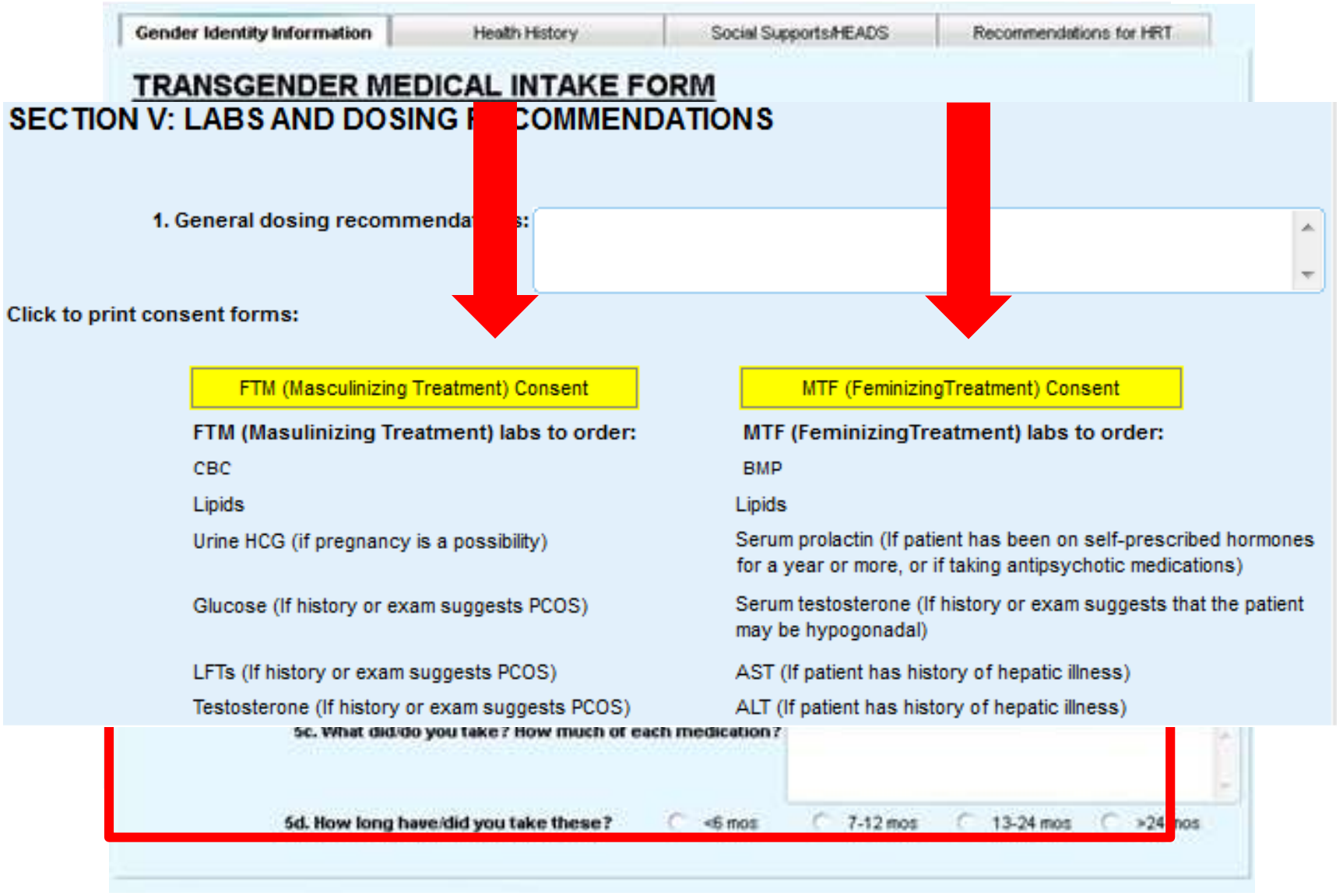
Current Practice: CPS Registration Screen



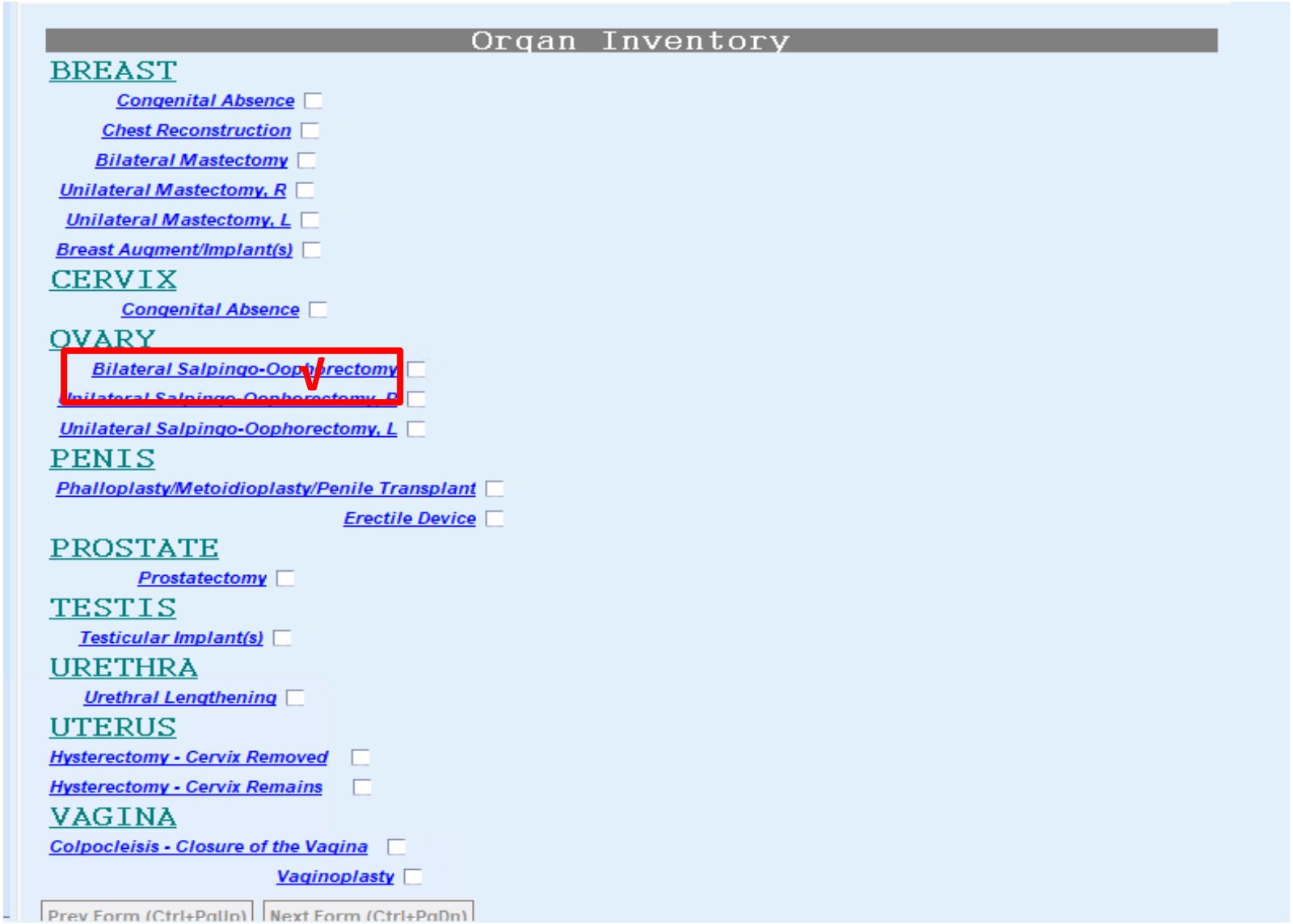
Current Practice: Modified Chart View



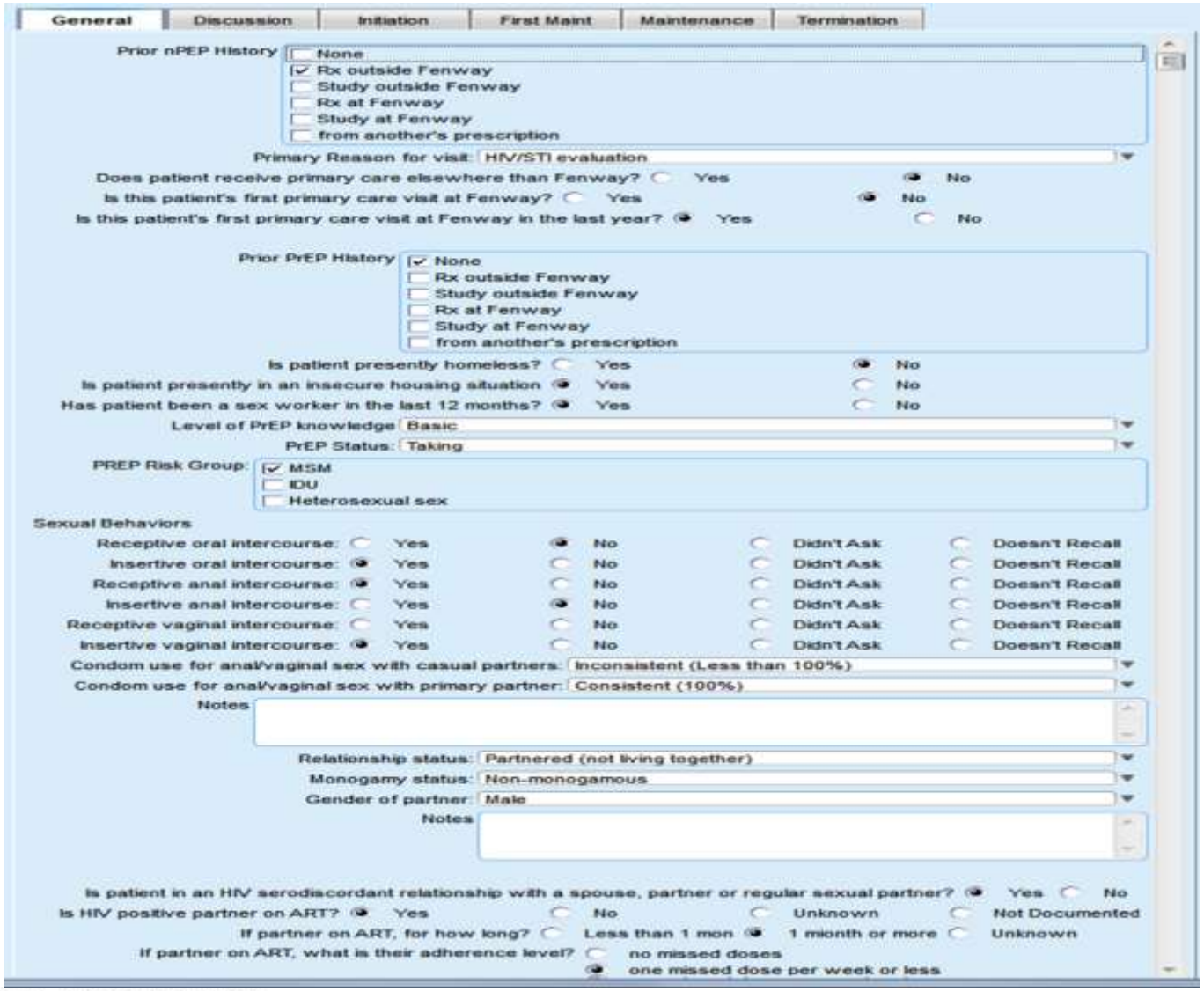
Forms: Transgender Intake



EHR Form: Organ Inventory



Custom Forms: PrEP



Clinical Decision Support (CDS)/ Health Maintenance

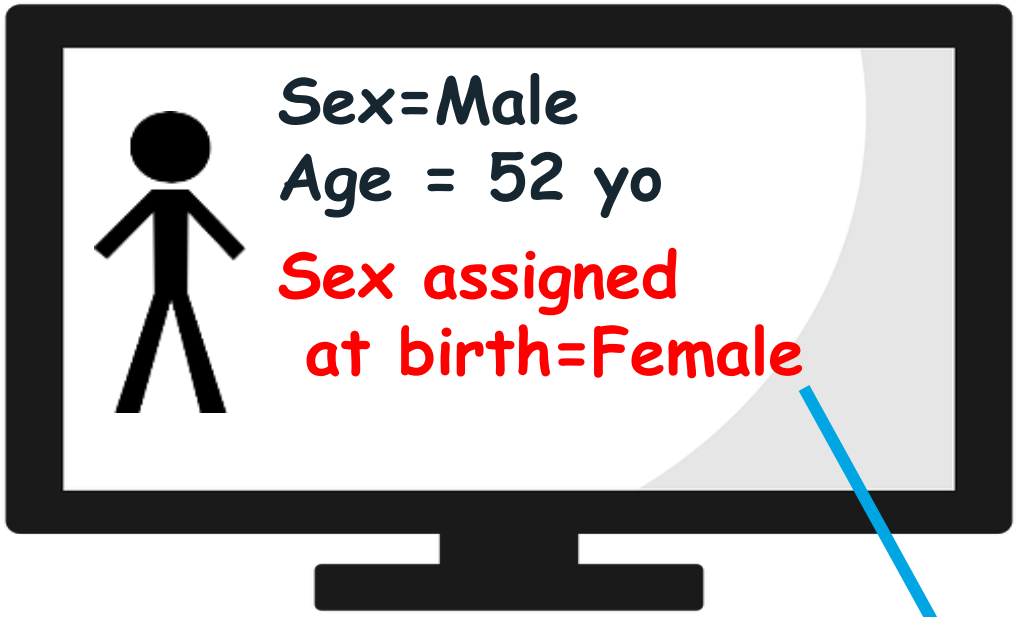
Current Variables:

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

Recommended Additional Variables:

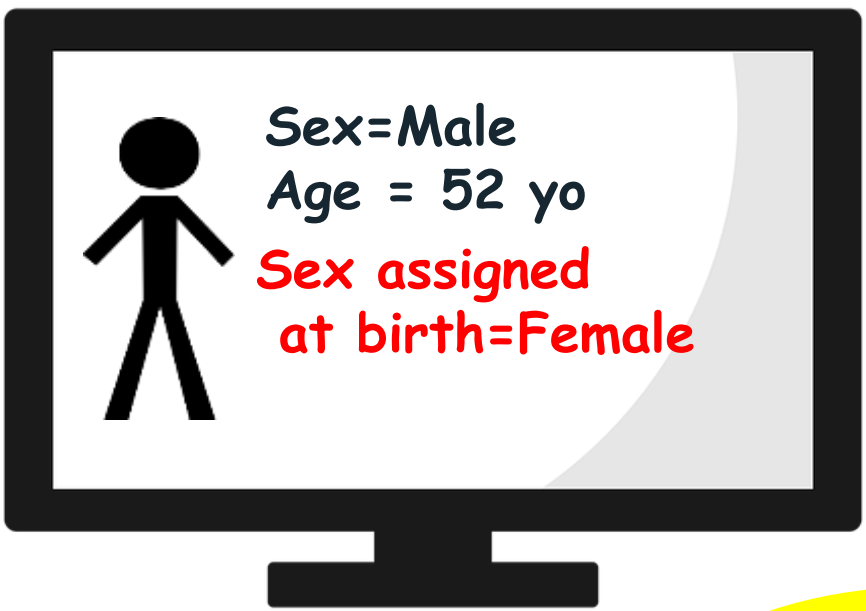
- Sexual Orientation
- Gender Identity
- Sex Assigned at Birth
- Anatomical Inventory

Decision Support/Health Maintenance



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

Decision Support/Health Maintenance



Patient Due For:

- Cervical Pap Smear
- Mammogram
- ?????????

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

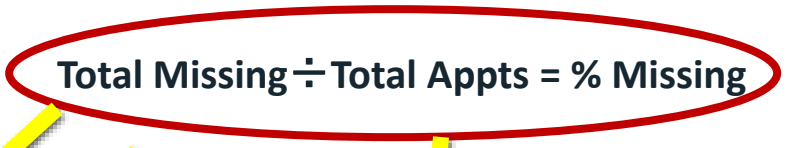
- Sexual Orientation ≠ Gender Identity
  - Everyone has both a Sexual Orientation and Gender Identity
- Be careful not to lump all LGBTQ people into every denominator or numerator for every question
- Important to differentiate between the two in data quality checking
- You will need to use **BOTH Sex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

Using Gender Identity and Sex Assigned at Birth Questions

1. What is your current gender identity?
   - [x] 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
   - [ ] Decline to Answer

PCMH Missing Demographic Data Report



Total Appointments in June: 2,510

Fields with Missing Value	Total # missing	% Missing
Email	63	3%
Sex	0	0%
Language	16	1%
Race	4	0%
Ethnicity	17	1%
Income	664	26%
Sexual Orientation	**700**	**28%**
Gender Identity	**715**	**28%**
Sex assigned at birth	**700**	**28%**

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

Compare data proportionally and within categories to identify problem areas

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

Quality Report Example: Cancer Screening

MRN	Patient first	Patient last	Provider	Insurance/ Chart Sex	Age	Cervical Pap Screening	Breast Cancer Screening
1111	Donald	Test	Smith MD, Joseph	M	45	N/A	N/A
5555	Genny	Test	Smith MD, Jane	F	31	Non-Compliant	N/A
4444	Kathy	Test	Smith MD, Jane	F	55	Non-Compliant	Non-Compliant
3333	Paul	Test	Smith MD, Jane	M	60	N/A	N/A
8888	Maddie	Test	Smith MD, Joseph	M	56	N/A	N/A
9999	Sammy	Test	Smith MD, Jane	F	49	Compliant	Compliant

Quality Reports: Rates of Cervical Cancer Screening Among Patients By Sexual Orientation

Sexual Orientation	Cervical Cancer Screen Completed? Yes (%)	No (%)	Total (%)
Lesbian/Gay			
Bisexual			
Straight/Heterosexual			
Something Else			
Don't Know			
Missing			
Total			

Quality Reports: Rates of HIV Testing Stratified by Ethnicity and Sexual Orientation

Sexual Orientation	Hispanic/Latino/ Latinx # (%)	Non-Hispanic/Non-Latino/ Non-Latinx # (%)	Unknown # (%)	Total # (%)
Lesbian/Gay				
Bisexual				
Straight/Heterosexual				
Something Else				
Don't Know				
Missing				
Total				

Stratifying UDS Measures by SOGI

Key UDS Measures by SO/GI Category	Sexual Orientation Categories						Gender Identity Categories					
	Lesbian/ Gay	Bisexual	Straight or Heterosexual	Something Else	Don't Know	Not Disclosed / Unknown	Cis Women	Cis Men	Trans Men	Trans Women	Other (Genderqueer)	Not Disclosed / Unknown
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												

Quality Reports: Transgender Dashboard

- Depression
- Age
- Hormones
- Anxiety
- Race
- Preventative
- Tobacco
- Ethnicity
- Screenings
- Sexual
- Co-Morbidities
- Alcohol
- Orientation
- PrEP
- Drug
- Federal poverty level
- Insurance
- New/Returning
- Location of care

	Previous Year: 2017		YTD: 2018			Q1 (JAN-MAR)		Q2 (APR-JUN)	Q3 (JUL-SEP)	Q4 (OCT-DEC)
Total in Panel	3454		2179			2179				
AGE	n	%	n	%		n	%			
<18										
18-19										
20-29										
30-39										
40-49										
50-59										
60-69										
70+										
RACE										
American Indian or Alaskan Native										
Asian										
Black or African American										
Hispanic/Latinx										
Multi-racial										
Native Hawaiian or Pacific Islander										
Other										
Unknown										
White										
ETHNICITY										
Hispanic/Latinx										
Non-Hispanic/non-Latinx										
SEXUAL ORIENTATION										
Bisexual										
Heterosexual or Straight										
Lesbian, Gay, or Homosexual										
Something Else										
Don't know										
Unknown										

Total in Panel					34	2179			2179	
HORMONES by Type										
# on any hormones										
% on masculinizing hormones										
DAST 10 (Drug Abuse)										
% on feminizing hormones										
% on both hormones										
PHQ 9 (Depression)										
# Patients 23 and older										
Anal or Cervical PAP within last 3 years										
Anal PAP within last 3 years										
Cervical PAP within last 3 years										
GAD 7 (Anxiety)										
HIV+										
Depression/Mood Disorders										
Patients with an active PrEP prescription during the reporting period										

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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