

A PROGRAM OF THE FENWAY INSTITUTE

Collecting Sexual Orientation and Gender Identity (SOGI) Data

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Our Roots

Fenway Health

- Independent 501(c)(3) FQHC
- Founded 1971
- Mission: To enhance the wellbeing of the LGBTQIA+ 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 and transgender health services

The Fenway Institute

Research, Education, Policy



LGBTQIA+ Education and Training

The National LGBTQIA+ 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, queer, intersex, asexual, and all sexual and gender minority (LGBTQIA+) people.

- Training and Technical Assistance
- Grand Rounds
- Online Learning

WWW.LGBTQIAHEALT

- Webinars, Learning Modules
- CE, and HEI Credit
- ECHO Programs
- Resources and Publications

www.lgbtqiahealtheducation.org



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- Alternatively, e-mail us at education@fenwayhealth.org for less urgent questions.

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- If you cannot hear through your computer speakers: Navigate to the bottom toolbar on your screen, go to the far left, and click the arrow next to the phone icon.
- Choose "I will call in."
- Dial the phone number and access code.

When the webinar concludes:

- Close the browser, and an evaluation will automatically open for you to complete.
- We very much appreciate receiving feedback from all participants.
- Completing the evaluation is <u>required</u> to obtain a CME/CEU certificate.

CME/CEU Information

This activity has been reviewed and is acceptable for up to 1.0 Prescribed credits by the American Academy of Family Physicians. Participants should claim only the credit commensurate with the extent of their participation in this activity.

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Nurse Practitioners,Physicia n Assistants,Nurses, MedicalAssistants	AAFP Prescribed credit is accepted by the following organizations. Please contact them directly about how participants should report the credit they earned. •American Academy of Physician Assistants (AAPA) •National Commission on Certification of Physician Assistants (NCCPA) •American Nurses Credentialing Center (ANCC) •American Association of Nurse Practitioners (AANP) •American Academy of Nurse Practitioners Certification Program (AANPCP) •American Association of Medical Assistants (AAMA)
Other HealthProfessionals	Confirm equivalency of credits with relevant licensing body.

Learning Objectives:

- At the end of this session, participants will be able to:
 - Identify methods for incorporating SOGI data into workflow, including the use of the EHR, and quality improvement techniques.
 - Discuss strategies for engaging and educating staff on the importance of collecting and using SOGI data to study the impact on health disparities.
 - Apply strategies to increase recruitment, hiring, and retention of LGBTQIA+ staff through informal collection of SOGI data and the promotion of a culture where employees feel safe to disclose.

Where the rubber meets the road: Our experiences



Getting Started....

You don't have to be LGBTQIA+ to do this well, and don't assume LGBTQIA+ people don't need training too!

Are Patients Likely to be Offended by SOGI 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 SOGI 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).

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

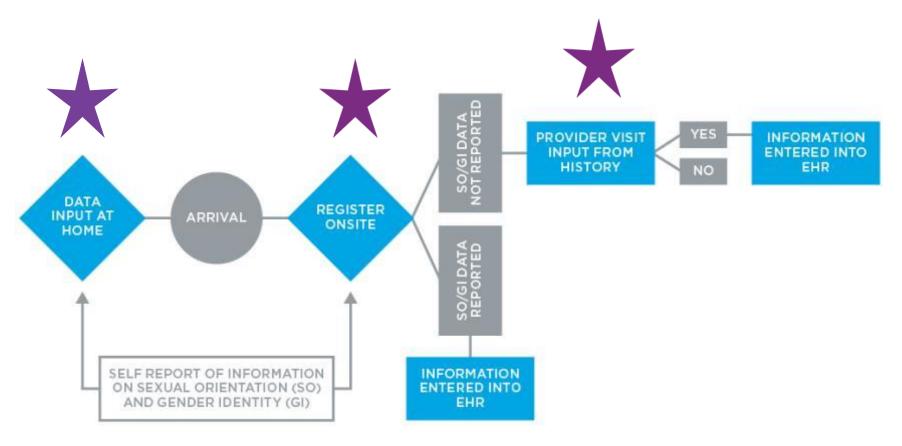


Fig. 2. Diagram from "Fenway Guide to Lesbian, Gay, Bisexual, and Transgender Health." ¹³

Sample Registration Form

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

FENWAY III H	IEALTH and it	nformation in your medical record is con sprotected under Massachusetts Gener 111, Sec 70. Your written consent red for release of information except in t yourt order.	al Laws will be (For office use only)			
Legal Name* Last	First	Middle Initial	Name used:			
Legal Sex (please check on 'While Fenway recognizes a number unfortunately do not. Please be awa used on documents pertaining to ins pronouns are different from these, please.	of genders / sexes, many insurance re that the name and sex you have l urance, billing and correspondence, ease let us know.	companies and legal entities isted on your insurance must be If your preferred name and	ronouns:			
Date of Birth Month Day	/					
Your answers to the following						
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 Na	me Are you covered under s	chool or employer's insurance?			
Emergency Contact's Name	Phone Nu	mber	Relationship to you			
			ow would you prefer to receive Letter Other			
This information is for demog	raphic purposes only and v	vill not affect your care.				
1.) What is your annual incom	ne? 2.) Employment Status		4.) Ethnicity Hispanic/Latino/Latina			
□ No income	☐ Employed full time ☐ Employed part time ☐ Student full time	African American / Black Asian	□ Not Hispanic/Latino/Latina			
1a.) How many people (includi you) does your income suppor		Caucasian / White Native American / Alaskan Native / Inuit Pacific Islander Other	5) Country of Birth			
6.) Preferred Language (choos one:)	vo self as:	8.) Marital Status Married	10.) Referral Source Self			
□English	o soian, gay, or homosexual	□ Partnered □ Single	☐ Friend or Family Member☐ Health Provider			
D Español	□ Straight or	□ Divorced	□ Emergency Room			
□Français	heterosexual	Other	□ Ad/Internet/MediaOutreach WorkerSchool			
□ Português	 □ Bisexual □ Something else 	9.) Veteran Status	Other			
□ Русский Other	□ Don't know	□ Veteran □ Not a Veteran				
11.) What is your gender?	12.) What was your sex assigned at birth?	13.) Do you identify as transgender or transsexual? ☐ Yes	Please turn over			
☐ Male ☐ Genderqueer or not	☐ Male	□ No □ Don't know				

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?

Privacy and Confidentiality

- How do you keep SOGI information private and confidential?
 - In the Electronic Health Record?
 - Auditing
 - Patients have a right to know who has viewed their record
 - EHRs allow for restrictions on who can view patient records
 - In conversations?
 - HIPAA
 - In small communities?

Pronoun Color Code



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



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



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



Use this pronoun color block when patient pronouns are either He or She



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



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

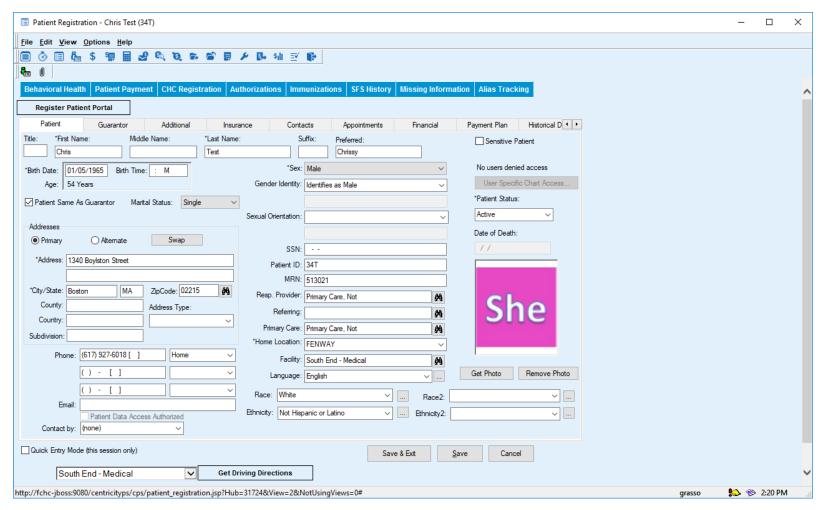


Use this pronoun color block when patient pronouns are fluid or not He/She/They series

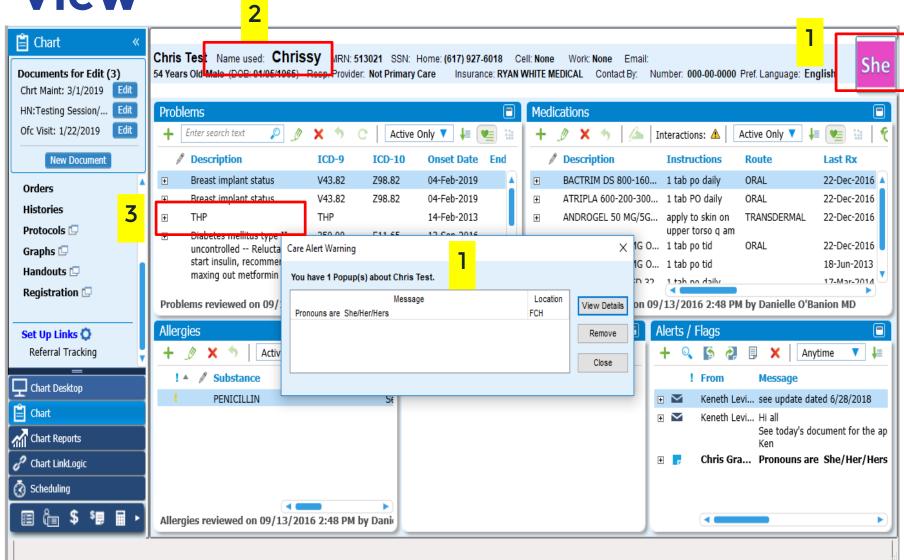


Use this pronoun color block when patient pronouns are either She or They

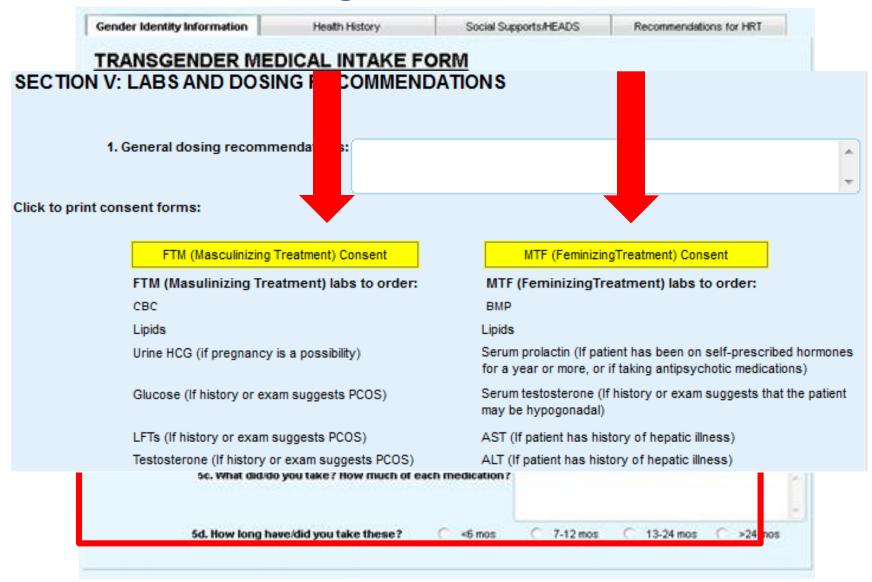
Current Practice: CPS Registration Screen



Current Practice: Modified Chart View



Forms: Transgender Intake



EHR Form: Organ Inventory

Organ Inventory							
<u>BREAST</u>							
Congenital Absence							
Chest Reconstruction							
Bilateral Mastectomy							
Unilateral Mastectomy, R							
Unilateral Mastectomy, L							
Breast Augment/Implant(s)							
CERVIX							
Congenital Absence							
OVARY							
Bilateral Salpingo-Oop <mark>v</mark> orectomy							
Initatoral Salpingo-Oophorostomy, D							
Unilateral Salpingo-Oophorectomy, L							
PENIS PENIS							
Phalloplasty/Metoidioplasty/Penile Transplant							
Erectile Device							
PROSTATE PROSTATE							
Prostatectomy							
<u>TESTIS</u>							
Testicular Implant(s)							
<u>URETHRA</u>							
<u>Urethral Lengthening</u>							
<u>UTERUS</u>							
Hysterectomy - Cervix Removed							
Hysterectomy - Cervix Remains							
<u>VAGINA</u>							
Colpocleisis - Closure of the Vagina							
<u>Vaqinoplasty</u>							
Prev Form (Ctrl+Pallp) Next Form (Ctrl+PaDn)							

Custom Forms: PrEP

General Discussion Initiation First Maint Maintenance Termination										
Prior nPEP History None Rx outside Fenway Study outside Fenway Rx at Fenway Study at Fenway from another's prescription Primary Reason for visit: HIV/STI evaluation										
Does patient receive primary care elsewhere than Fenway? Yes No										
Is this patient's first primary care visit at Fenway? Yes No										
Is this patient's first primary care visit at Fenway in the last year? Yes No										
Prior PrEP History Rx outside Fenway Study outside Fenway Rx at Fenway Study at Fenway from another's prescription										
Is patient presently homeless? Yes No										
Is patient presently in an insecure housing situation Yes No										
Has patient been a sex worker in the last 12 months? Yes No										
Level of PrEP knowledge Basic ▼										
PrEP Status: Taking										
PREP Risk Group: WSM DU Heterosexual sex										
Sexual Behaviors										
Receptive oral intercourse: Yes No Didn't Ask Doesn't Recall										
Insertive oral intercourse: Yes No Didn't Ask Doesn't Recall										
Receptive anal intercourse: Yes No Didn't Ask Doesn't Recall										
Insertive anal intercourse: Yes No Didn't Ask Doesn't Recall										
Receptive vaginal intercourse: Yes No Didn't Ask Doesn't Recall										
Insertive vaginal intercourse: Yes No Didn't Ask Doesn't Recall										
Condom use for anal/vaginal sex with casual partners: Inconsistent (Less than 100%) Condom use for anal/vaginal sex with primary partner: Consistent (100%)										
Notes Notes										
Relationship status: Partnered (not living together)										
Monogamy status: Non-monogamous										
Gender of partner: Male										
Notes										
Is patient in an HIV serodiscordant relationship with a spouse, partner or regular sexual partner? Yes No Is HIV positive partner on ART? Yes No Unknown Not Documented If partner on ART, for how long? Less than 1 mon 1 mionth or more Unknown If partner on ART, what is their adherence level? no missed doses one missed dose per week or less										

Clinical Decision Support (CDS)/ Health Maintenance

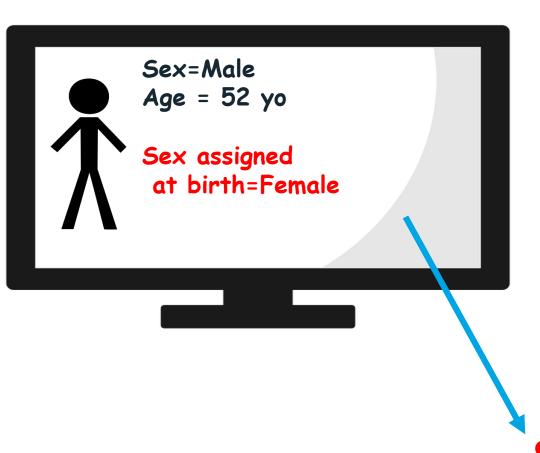
Current Variables:

- 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

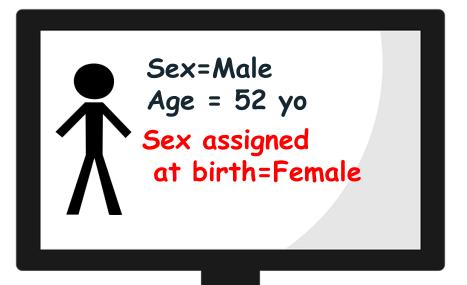


Patient Due For:

- LDL
- HDL
- TRIGLYCERIDE
- CHOLESTEROL
- HGBA1C
- STD
- HEP C

• ??????

Decision Support/Health Maintenance



Anatomical Inventory

- **✓** Cervix
- Vagina
- **Uterus**
- Ovaries
- **M** Breasts

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 LGBTQIA+ 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 LGBTQIA+ 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

What is your current gender identity? 💢 Male □ Female Transgender Male/Trans Man/FTM Transgender Female/Trans Woman/MTF GenderQueer Additional Category (please specify) ____ 2. What sex were you assigned at birth? □ Male □ Male □ Female Female Decline to Answer

PCMH Missing Demographic Data Report

Total Missing ÷ Total Appts = %
Missing

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	700	20%								
birth	700	28%								

Quality and Integrity Checking

Examples of Stratification by other Socio-Demographic Data

- Gender Identity by:
 - Country of birth

Compare data proportionally and within categories to identify problem areas

- Age group
- New medical patients
- Social determinants of health

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

Quality Report Example: Cancer Screening

MRN	Patient first	Patient last		/ Chart Sex	Age	Screening	Cancer Screening
1111	Donald	•	Smith MD, Joseph	M Curr Gene	gigt So	rreening Screen	Needed
5555	Genny	Test	Smith MD, Jane	F (31	Non-Compliant	N/A
5555	Ger ikiy thiyest	Srnith MD, Test Jahe	Sor Sor Else	nething Fem	SIS C	on- Non-Co rNp/M ant ompliant	Non-Compliant
3333	Paul	Test	Smith MD, Jane	М	6	N/A	N/A
8888	Pau Mad Unet	Sinith MD, Jahe st	Makath MD6gosepay	ian, Male nosexual	66 N	M/A N/A	N/A ✓
9999	Sammy	Test	Smith MD, Jane	F	49	Compliant	Compliant

Quality Reports: Rates of HIV Testing Stratified by Gender Identity, Sexual Orientation, Race and Ethnicity

Patients tested for HIV

		White/No	. BIPOC and/or Latinx									
		White/ Non-hisp	Asian	Hispanic/ Latinx	Black/ African-A	Multiracial	AI/AN & NHPI					
Cisgender	LGB/Q	43.85%	46.34%	47.78%	63.55%	45.54%	56.00%					
Female	Straight or he.	36.75%	36.96%	42.89%	54.83%	42.42%	29.03%					
Cisgender	LGB/Q	83.79%	88.50%	87.95%	89.72%	91.01%	82.46%					
Male	Straight or H	47.33%	43.41%	52.96%	56.33%	57.43%	40.74%					
Genderqu	LGB/Q	45.25%	38.60%	52.38%	56.16%	50.62%	28.57%					
	Straight or H	23.53%	50.00%		100.00%							
Transgende r Female	LGB/Q	46.61%	59.26%	58.46%	76.92%	59.02%	88.89%					
	Straight or he.	44.57%	56.25%	68.00%	80.00%	100.00%	33.33%					
Transgende	LGB/Q	40.34%	42.50%	56.82%	51.72%	55.77%	25.00%					
r Male	Straight or he.	31.63%	27.59%	46.51%	62.96%	66.67%	100.00%					

Stratifying UDS Measures by SOGI

		Sexual Orientation Categories							Gender Identity Categories						
Key UDS Measures by SO/GI Category	Lesbian/ Gay	Bisexual	Straight or Heterosexual	Something Else	Don't Know	Not Disclosed / Unknown		Cis Women	Cis Men	Trans Men		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
- A Ninbhes
- **EPERSON**
- Screenings
- Ecological Properties
- Federal poverty level
- Insurance
- New/Returning
- Location of care

			ous Year: 2017	YTD	YTD: 2018		Q1 (JAN-MAR)		Q2 (APR- JUN)	Q3 (JUL- SEP)	Q4 (OCT- DEC)
Total	in Panel	3	454	2	179		21	.79			
AGE		n	%	n	%		n	%			
	N egotalej/ndRaneli sk				Ш	34	2179			2179	
18-19 20-29	Mild/Risky Use Moderate/Problema	Type									
	Settement Disourchement Ha	æs									
	Not screened DAST 10 (Drug Abuse) h									
50-59	Ne%acine∮ellotinizing	horm	ones		\blacksquare						
60-69 70+	Mild/Risky Use % On both horm Moderate/Problemat	ones c Use									
RACI											
Amer	Not screened ican indian of Alaskan PHQ 9 (Depression)										
Δsian	No#Deaptriesnitsn23 and										
Black	Middlernesionvical	РАР м	vithin las	t 3							
Hispa	Moderately Severe				\blacksquare						
	padinlas BAP within				+						
isiand	Seleweilappe Ripificiti Not screened	nin la	st 3 year	S							
	GAD 7 (Anxiety)										
Unkn	Jaw Anxiety				$\parallel \parallel$						
White	Mild Anxiety				Ш						
ETH	NICITY	NO LUG	orgors								
Hispa	Notestileened	JU DIS	oruers								
Non-	lispanic/non-Latinx										
SEXU	JAL ORIENTATION										
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Homo	Milselened	ייט מיי	Спероп	о''							
	know				\top						
Unkn	own										

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 (SOPs)
- Include in other quality reports and initiatives
 - For example: Patient-Centered Medical Home, Meaningful Use both monitor demographics – add SOGI as an integral 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 Healthcare Effectiveness Data and Information Set/National Committee for Quality Assurance (HEDIS/NCQA) Quality Measures and the United States Preventive Services Task Force (USPSTF) guidelines 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 health information systems, e.g., Consolidated Clinical Document Architecture (C-CDA) and Health Level Seven (HL7)
- Insurance/Billing Forms

SOGI data for recruitment, hiring and retention of LGBTQIA+ staff

Mason Dunn, JD

Affirmative recruiting language

- Language: "We are seeking dynamic candidates with experience improving care for the LGBTQIA+ community, or who are committed to learning about LGBTQIA+ health"
- Gender-inclusive pronouns in posting and job descriptions
 - They/them
 - He/him or she/her
 - Encourage diversity: "LGBTQIA+ identified persons are encouraged to apply"
- Equal opportunity employment (EEO) "Fenway Health is deeply committed to include all applicants, regardless of gender identity, race/ethnicity, veteran status, and/or disability"
- Images on company website and recruiting materials

Affirmation in the workplace

- All-gender restrooms
- Personnel records and badges reflect name used
- Employees have the option to display pronouns on badges, email signatures, & business cards
- Organizational policies
 - Develop gender affirmation guidelines and policies
 - Include gender identity and gender expression in Discrimination, Harassment,
 Sexual Harassment and Workplace Bullying Policies
 - Ensure the personnel manual includes policies that protect those employees who are gender-diverse or in the process of affirming their gender. For example, dress codes shouldn't be gender specific
- Accountability Ensure policies are not just for show
 - Continual checks for accountability
 - Reporting systems
- Inform and educate supervisors

Retention

- A 2018 Human Rights Campaign survey found that:
 - 20% of LGBTQIA+ respondents had searched for a different job because they did not find their employer to be welcoming and accepting
 - 25% stayed in a job primarily because the environment was very accepting of LGBTQIA+ people
 - The top reason LGBTQIA+ workers don't report negative comments they hear about LGBTQIA+ people: They don't think anything will be done about it

Importance of leadership

- Leadership sets the tone for the entire organization by clearly communicating their commitment to diversity, including patients and staff of all gender identities
- Must take an active role in building a workplace culture that is inclusive by:
 - Updating policies and procedures
 - Developing programs to support LGBTQIA+ inclusion
 - Encouraging affinity groups and employee resource groups for transgender and gender-diverse staff and allies
- Participation and visibility for major LGBTQIA+ events:
 - Pride month/events
 - LGBTQ+ History Month
 - Coming Out Day

Sexual Orientation/Gender Identity (SOGI) data collection for employees

- Affirmative action forms
 - Frame the question federal form
 - Provide a separate form with additional gender categories
- Opportunities for self disclosure
 - Employee satisfaction survey
 - Data can be used for advocacy insurance, other benefits
- Disclosure is part of a culture where it's safe to be yourself
 - Employee resource groups
 - Policies and procedures + Accountability
 - Regular, mandated training



NATIONAL LGBTQIA+ HEALTH EDUCATION CENTER

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The Education Center is 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 LGBTQIA+ focused health centers.

- **617.927.6354**
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- mww.lgbtqiahealtheducation.org
- www.acponline.org/fenway

