

A PROGRAM OF THE FENWAY INSTITUTE



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

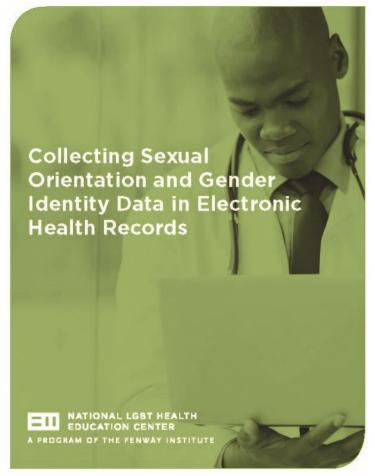
This presentation will enable you to:

- 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



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

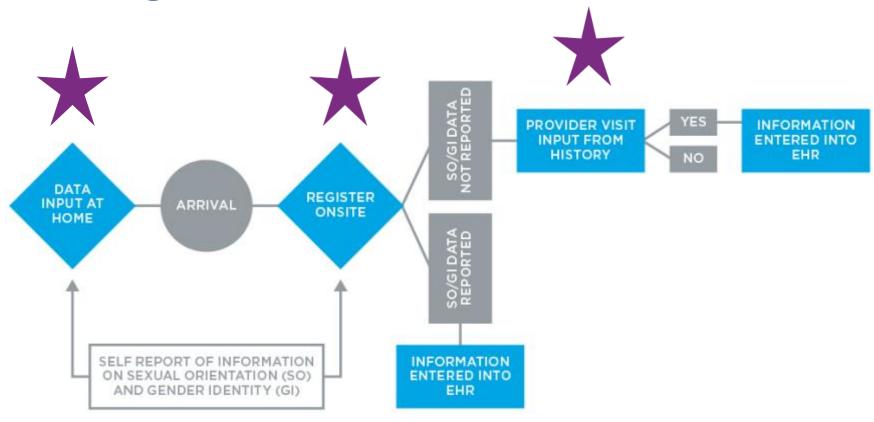


Fig. 2. Diagram from "Fenway Guide to Lesbian, Gay, Bisexual, and Transgender Health." 13

Sample Registration Form

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

FENWAY 🖽 P	HEALTH and	e information in your medical record is co d is protected under Massachusetts Gene . 111, Sec 70. Your written consen juired for release of information except in a court order.	t will be (For office use only)
Legal Name* Last	First	Middle Initial	Name used:
Legal Sex (please check of "White Fenway recognizes a number unfortunately do not. Please be aw- used on documents pertaining to in- pronouns are different from these, p	er of genders / sexes, many insuran are that the name and sex you hav surance, billing and correspondence please let us know.	ice companies and legal entities e listed on your insurance must be e. If your preferred name and	ronouns:
Date of Birth Month Da	/		
		ach you quickly and discreetly	
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 N	Name Are you covered under	
Emergency Contact's Nam	e Phone N		Yes No Relationship to you
		bills, to your mailing address. H	Relationship to you ow would you prefer to recei Letter Other
his information is for demo	graphic purposes only and	will not affect your care.	
1.) What is your annual inco	me? 2.) Employment Statu	s 3.) Racial Group(s)	4.) Ethnicity
□ No income 1a.) How many people (include)		(check all that apply) African American / Black Asian Caucasian / White Native American / Alaskan	☐ Hispanic/Latino/Latina ☐ Not Hispanic/Latino/Latin 5) Country of Birth ☐ USA
you) does your income suppo	Other	Pacific Islander Other	Other
6.) Preferred Language (choo one:)	policelf as:	8.) Marital Status Married Partnered	10.) Referral Source Self Friend or Family Member
□ English	homosexual	Single	☐ Health Provider
□ Español	□ Straight or	□ Divorced □ Other	□ Emergency Room □ Ad/Internet/MediaOutreac
□ Français	heterosexua		WorkerSchool
□ Português	□ Bisexual □ Something else	9.) Veteran Status	Other
□ Русский Other	□ Don't know	□ Veteran □ Not a Veteran	
	40.1140	13.) Do you identify as	
11.) What is your gender? □ Female □ Male	12.) What was your sex assigned at birth Female		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

Medical <u>Dept</u>	Patient Search *Only able to search by First and Last name. Cannot search by preferred Name ^△ Add preferred name to the search	* Nurse Call center ^search feature – which is the correct name to use when contacting	*Only able to see Patient's first and last name ^_ Add preferred name to the schedule	Chart Summary *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)	*Patient profile has first, preferred and last name ^Increase the font size for preferred name on Patient profile
	*Only able to search by First	the patient	*Acupuncture – patient's		*Has Patient's first, last and		*DPH forms – uses Chart name *no mechanism to indicate which	*Can include preferred name
BH Dept	and Last name. Cannot search by preferred Name ^△ Add preferred name		sign in and introduce themselves *Only able to see Patient's first and last		preferred name ^Increase size of preferred name in the Banner		name should be used in correspondence	on HDAP forms
	to the search mechanism		name ^△ Add preferred name to the schedule					

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



She 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 always They series



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

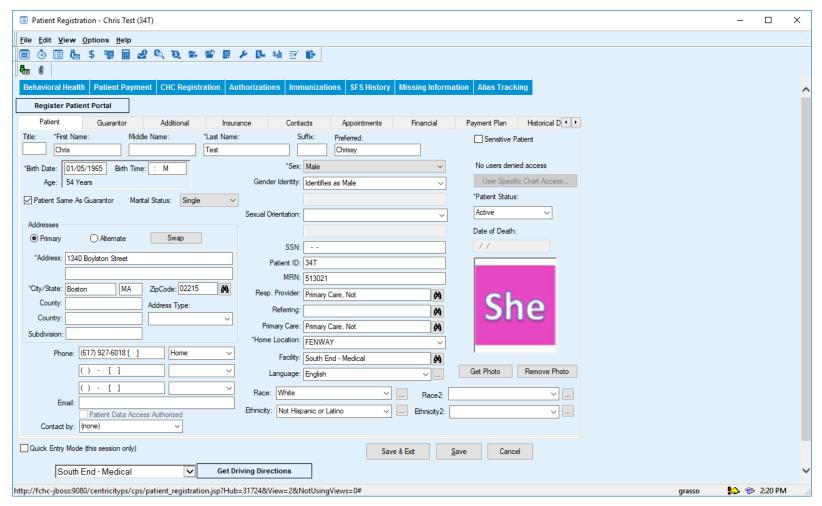


Use this pronoun color block when patient pronouns are fluid or not He/She/They series

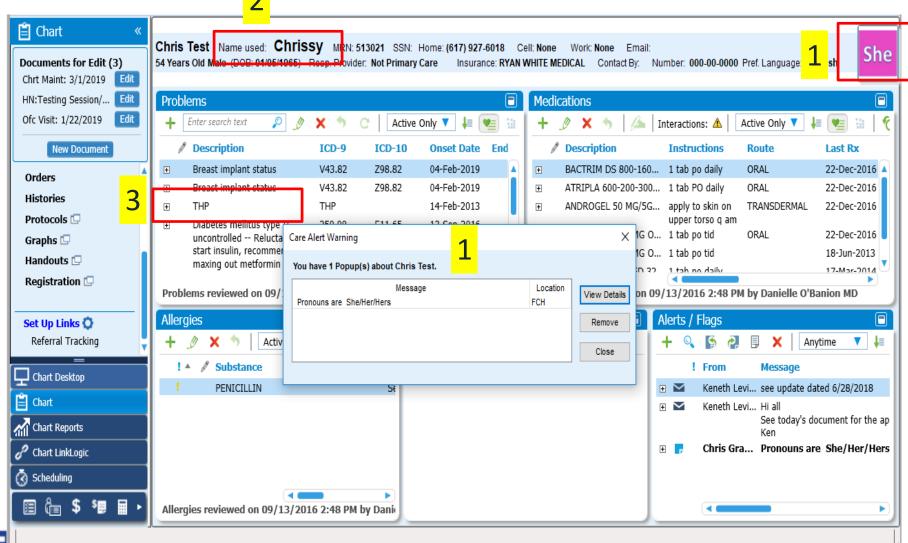


Use this pronoun color block when patient pronouns are fluid and She or They are okay

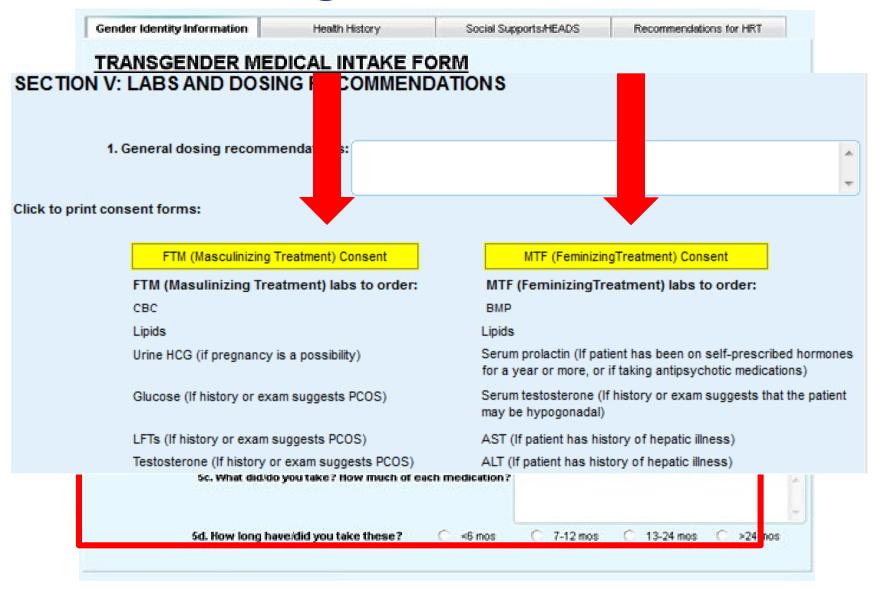
Current Practice: CPS Registration Screen



Current Practice: Modified Chart View



Forms: Transgender Intake



EHR Form: Organ Inventory

Orqan 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-Ooph rectomy
hilatoral Salningo Oophorostomy P
Unilateral Salpingo-Oophorectomy, L
<u>PENIS</u>
Phalloplasty/Metoidioplasty/Penile Transplant
Erectile Device
<u>PROSTATE</u>
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>Vaginoplasty</u>
Prev Form (Ctrl+Palln) 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? C Yes No
Is this patient's first primary care visit at Fenway? C Yes No
Is this patient's first primary care visit at Fenway in the last year? Yes No
Prior PrEP History V None
Rx outside Fenway
Study outside Fenway
Rx at Fenway Study at Fenway
from another's prescription
Is patient presently homeless? C 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:
IDU 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: C Yes No C Didn't Ask C Doesn't Recall
Receptive vaginal intercourse: C Yes C No C Didn't Ask C 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
- I
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? Ves C No
Is HIV positive partner on ART? Yes No Unknown Not Documented
If partner on ART, for how long? C Less than 1 mon ● 1 mionth or more C Unknown
If partner on ART, what is their adherence level? on missed doses
● one missed dose per week or less

Clinical Decision Support (CDS)/ Health Maintenance

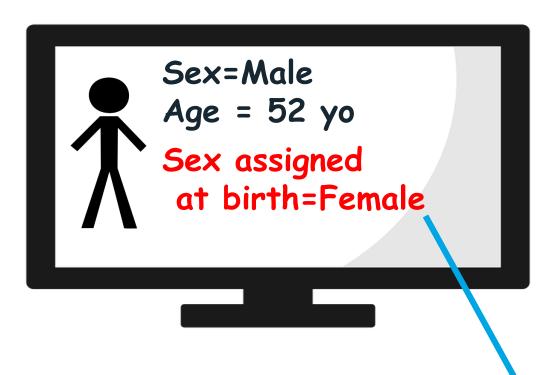
Current Variables:

- 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

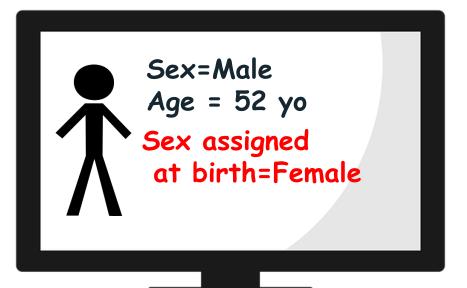
Decision Support/Health Maintenance



Patient Due For:

- LDL
- HDL
- TRIGLYCERIDE
- CHOLESTEROL
- HGBA1C
- STD
- HEP C
- ১১১১১১

Decision Support/Health Maintenance



Anatomical Inventory

- **Cervix**
- Vagina
- **Uterus**
- Ovaries
- 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 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

What is your current gender identity? 1. **Male □** Female Transgender Male/Trans Man/FTM □ Transgender Female/Trans Woman/MTF □ GenderQueer □ Additional Category (please specify) _ What sex were you assigned at birth? ■ Male **Female □ Decline to Answer**

PCMH Missing Demographic Data Report

	Tot	tal Missing ÷ Total Appts = %
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

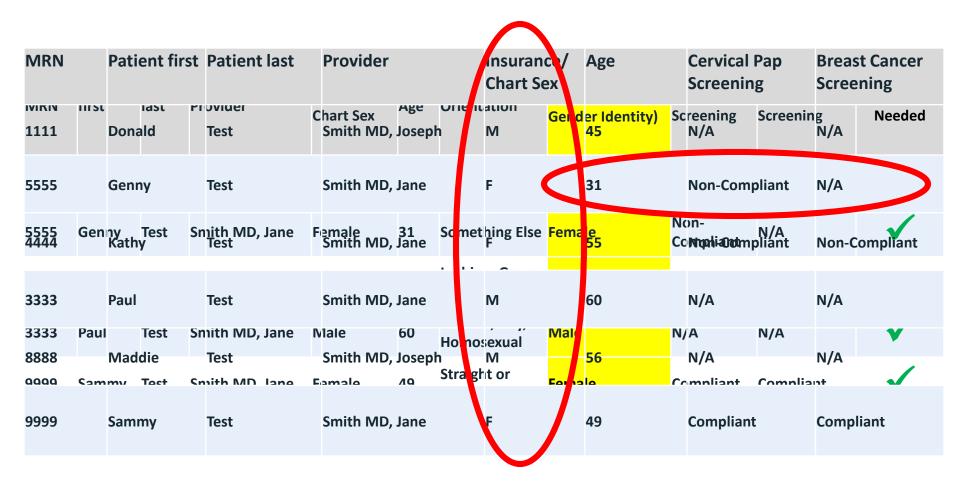
Examples of Stratification by other Socio-Demographic Data

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

Compare data propo	rtionally 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 (10/)	50
Total	367 (52%)	80 (11%)	94 (13%)	52 (7%)	30 (4%)	87 (12%)	710

Quality Report Example: Cancer Screening



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

Cervical Cancer Screen Completed?

Sexual Orientation	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

		Sex	ual Orientat	ion Catego	ries	Gender Identity Categories							
(ateanry	Lesbian/ Gay	Bisexual	Straight or Heterosexual	Something Else	Don't Know	Not Disclosed / Unknown		Cis Vomen	Cis Men			()thor	Not Disclosed / Unknown
HIV test													
Mammogram							T						
Screening, Brief Intervention, and Referral to Treatment (SBIRT)													
Cervical Cancer Screening - Patients Aged 23 through 64													
Tobacco Use: Screening and Cessation Intervention							Ī						
Screening for Clinical Depression and Follow-Up Plan - Total Patients Aged 12 and Older							1						

Quality Reports: Transgender Dashboard

- Depression
- k metanes
- ative bative

- Morbidities antation
- Federal poverty level
- Insurance
- New/Returning
- Location of care



		ou 20:	s Year: L7	YTD: 2018		Q1 (JAN-MAR)		١,		Q3 (JUL- SEP)	-	Q4 (OCT- DEC)	
Total in Panel	3	34!	54	2:	17	9	2	179					
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Not screened	162	\dashv			$^{+}$								
DAST 10 (Drug Abuse	n~ h 1				Ï								
50-59 Negacine/Pelloti atizinske	horm	or	nes		T								
60-69 Mild/Risky Use	onoc				1								
60-69 Mild/Risky Use 70+ Moderate/Problemati	c Use				#								
RACE													
American indian of Alaskan Native PHQ 9 (Depression)		+			#								
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Black Middle Pression Vical Black Moderate Depression Hispaniy Vical Action Severe		-			+								
Hispanic Latin Severe		+			#				-				
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Don't know		+			+				-				
Unknown													

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



