YOU'VE BUILT IT… NOW WHAT?

APPLYING SEXUAL ORIENTATION AND GENDER IDENTITY DATA TO CLINICAL QUALITY IMPROVEMENT AND DECISION SUPPORT

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INTRODUCTION

Why Collect Data on Sexual Orientation and Gender Identity?

Since 2016, health centers have been required to collect sexual orientation and gender identity (SO/GI) data of adult patients 18 years and over and report the data to the Uniform Data System (UDS) annually. On a national level, SO/GI data are helping to provide a better understanding of the populations that health centers serve, such as how many lesbian, gay, bisexual, transgender, and queer (LGBTQ) people are accessing health centers. Individual health centers can use SO/GI data to identify differences in health outcomes among LGBTQ subgroups, and to monitor whether clinical services are being provided equitably to LGBTQ patients. Like other vulnerable populations, LGBTQ people have unique health disparities that can be targeted through clinical quality improvement strategies. In this publication, we will walk you through three steps for effectively and efficiently using SO/GI data to reduce health disparities among your LGBTQ patients:

Step 1: Check the integrity of your SO/GI data

Step 2: Run clinical quality reports using SO/GI data

Step 3: Use SO/GI data to guide decision support

STEP 1

CHECK THE INTEGRITY OF YOUR SO/GI DATA

As with any data collection and entry, health center teams will want to routinely assess the quality and integrity of SO/GI data in the electronic health record (EHR) system. Checking for missing data is a good place to start. Figure 1 provides an example of a monthly demographic data report that shows counts and percentages of missing data. After running the report, the team will want to ask the following questions:

- What number and percentage of patients are missing SO data?
- What number and percentage of patients are missing GI data?
- How do these percentages compare to other demographic data?

Figure 1. Example of a monthly report with missing demographic data

Total Appointments: 2,510		
Field	**# Missing**	**% Missing**
Email	63	3%
Language	16	1%
Race	4	0%
Ethnicity	17	1%
Income	664	26%
Sex Assigned at Birth	1	0%
Sexual Orientation	755	30%
Gender Identity	215	9%

In the example given in Figure 1, 30% of the patients seen at the health center during the monthly measurement period were missing sexual orientation data, and 9% were missing gender identity data. Missing sexual orientation percentages are only slightly higher than missing income percentages, but much higher than other demographic data elements. Teams can improve the collection of sexual orientation data by asking registration staff or clinical staff (depending on who is collecting the data) about any challenges they are seeing with data collection and entry. Do language or cultural differences among patients cause challenges in interpreting the questions? Have patients made comments about the questions? Are clinical staff uncomfortable asking about sexual orientation? If some departments exhibit better performance in data collection than others, representatives from these departments can report on their methods and perhaps train the other departments. Health centers can also access online training and resources from the National LGBT Health Education Center at www.lgbthealtheducation.org/sogi.

Other ways to ensure data quality are to routinely cross-check paper forms with data entered into EHRs (if paper forms are being used). Another is to run reports of all sexual orientation and gender identity categories to look for anything surprising or unusual.

STEP 2

RUN CLINICAL QUALITY REPORTS USING SO/GI DATA

Once health center teams are confident in the integrity of their SO/GI data, they can begin using those data to identify potential disparities in health outcomes and health services to LGBTQ patients. The end goal is to determine if tailored interventions are needed to improve care for LGBTQ patients or subgroups of LGBTQ patients. For example, a summary quality report of hemoglobin A1c levels among patients diagnosed with diabetes can be stratified by demographic factors such as age, race, ethnicity, sexual orientation, sex assigned at birth, and gender identity. The report may indicate significantly worse outcomes among specific subgroups (e.g., bisexual men compared to straight men; Black/African American women compared to White and Hispanic/Latina women, etc.).

Example: Cervical cancer screening and sexual orientation

Research studies on LGBTQ populations have indicated disparities in cervical cancer screening for lesbian/gay, bisexual, and queer (LBQ) women.[1-3] Therefore, health centers may choose to run quarterly quality reports on cervical cancer screening across sexual orientation categories. Figure 2 shows an example of a quarterly cervical cancer screening report. In this example, women who identified as straight had a higher screening percentage compared to women who identified as lesbian/gay, bisexual, or something else. These findings suggest a potential disparity in cervical cancer screening for LBQ women who receive care at this health center. The health center should closely monitor screening in subsequent quarters to see if disparities persist. In addition, the health center's medical care team may wish to address the less than optimal screening rates among all women patients, while also exploring the possible reasons why the rates are even lower in LBQ women.

Figure 2. Example of a quarterly report on cervical cancer screening across sexual orientation categories

	Received Cervical Cancer Screening	
Sexual Orientation	Yes (%)	No (%)
Lesbian/Gay	65	35
Bisexual	70	30
Straight/Heterosexual	75	25
Something Else	65	35
Don't Know/Missing	70	30

Because some health disparities differ across sexual orientations, it is best to analyze each sexual orientation category separately, as shown in Figure 2. Health centers that have smaller than average percentages of LBQ women (say, less than 2% of the total patient population), may need to group lesbian/gay, bisexual, and something else together.

Example: Cervical cancer screening and gender identity

Transgender men are another LGBTQ subgroup that experience disparities in cervical cancer screening.[4-6] The term transgender men refers to people who identify as male and whose assigned sex at birth was female; they may identify themselves as transgender males/men, transmasculine, female-to-male, male, or other gender identities. Most transgender men have a cervix and require the same cervical cancer screening guidelines as non-transgender women.[4,5] Transgender men, however, may receive Papanicolaou tests less frequently than cisgender (non-transgender) women, a disparity that may relate to provider discomfort, patient anxiety regarding anatomy that does not align with the patient's gender identity, and increased pain from androgen-induced vaginal atrophy.[4,6] For these reasons, it is recommended that health centers run quarterly reports on cervical cancer screening according to gender identity in order to detect potential disparities in services to transgender men.

When running a report with gender identity data, however, it is important to also look at the data field for sex assigned at birth. The reason is because gender identity does not provide information about a patient's anatomy, nor does it always indicate if someone is transgender; for example, some transgender people have a male or female gender identity (as opposed to transgender male or transgender female), and some people are gender fluid or otherwise have non-binary gender identities (i.e., people who identify as neither male nor female, as a combination of male and female, or as something else).

Figure 3a provides an example of issues that can occur when a report only generates gender identity. In the case of patients 1 and 3, it is not clear if services were appropriately provided to the patients because we do not know if these patients had a cervix at the time of their visit. In Figure 3b, the addition of data on sex assigned at birth provides a more complete picture. Here it is shown that patients 1 and 3 were assigned female sex at birth, and therefore have a cervix, unless surgical history tells otherwise. These patients were therefore due for a cervical screening that was not performed. In addition, the sex assigned at birth data has revealed that patient 2 was assigned male sex at birth, and therefore is not due for cervical screening, unless the patient has undergone surgery to create a vagina and/or neo-cervix; most transgender health guidelines suggest that these patients receive cervical screening according to guidelines for all women.

Figure 3a. Cervical cancer screening according to gender identity

Patient	Gender identity	Age	Received cervical cancer screening	Compliant?
1	Transgender Male	52	No	?
2	Female	45	No	No
3	Genderqueer	27	No	?

Figure 3b. Cervical cancer screening according to gender identity and sex assigned at birth

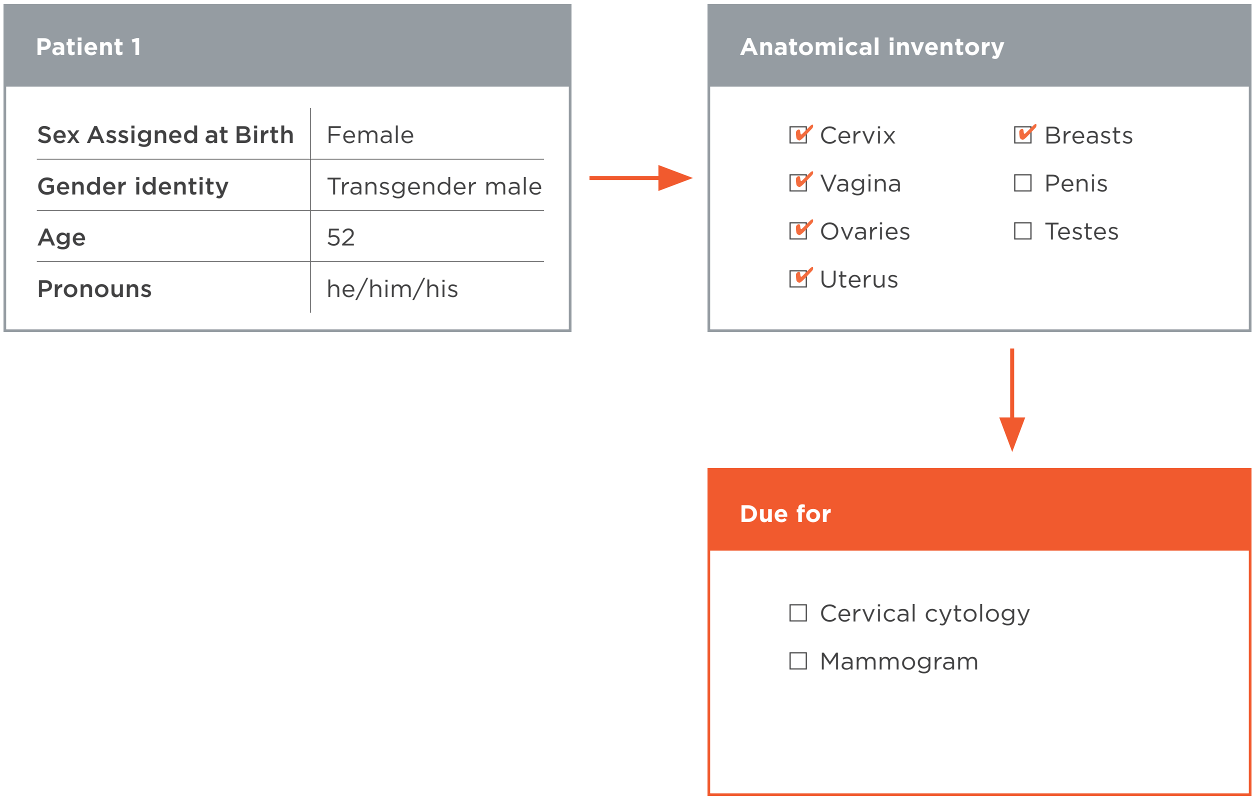
Patient	Sex assigned at birth	Gender identity	Age	Received cervical cancer screening	Compliant?
1	Female	Transgender Male	52	No	No
2	Male	Female	45	No	N/A
3	Female	Genderqueer	27	No	No

STEP 3

USE SO/GI DATA TO GUIDE DECISION SUPPORT

As shown in the cervical cancer screening example above, both surgical history and current anatomy would have provided additional important information to assess whether a patient needed to receive cervical cancer screening. When creating systems to determine which clinical services a patient is due for, similar issues arise. For this reason, we recommend that health centers take anatomical inventories of patients and link these inventories to clinical decision support tools. EHR vendors may need to be contacted in order to modify the system to accommodate these inventories. Figure 4 illustrates how the anatomical inventory—rather than sex assigned at birth or gender identity—guides the clinical decision making for screening services.

Figure 4. Flow chart for using anatomical inventories to guide clinical decision making



Patient 1

Sex Assigned at Birth	Female
Gender identity	Transgender male
Age	52
Pronouns	he/him/his

Anatomical inventory

☑ Cervix
☑ Vagina
☑ Ovaries
☑ Uterus
☑ Breasts
☐ Penis
☐ Testes

Due for

☐ Cervical cytology
☐ Mammogram

RESOURCES

Collecting and entering SO/GI data into EHRs provide an important opportunity to identify and address potential inequities in quality of care for LGBTQ patients. Additional resources to support health centers in collecting high-quality SO/GI data and applying that data to reduce health disparities include the following:

- Ready, Set, Go! Guidelines and Tips for Collecting Patient Data on Sexual Orientation and Gender Identity (SO/GI)
  https://www.lgbthealtheducation.org/wp-content/uploads/2018/03/Ready-Set-Go-publication-Updated-April-2018.pdf

- New Sexual Orientation and Gender Identity Questions: Information for Patients
  https://www.lgbthealtheducation.org/wp-content/uploads/2016/08/NLHEC-3_SOGI-Patient-Handout_updated-12_18.pdf

- Sexual Orientation and Gender Identity Data Collection Demonstration Videos
  http://www.lgbthealtheducation.org/sogi/ (click tab: Demonstration Videos)

- Grasso C, McDowell MJ, Goldhammer H, Keuroghlian AS. Planning and implementing sexual orientation and gender identity data collection in electronic health records. J Am Med Inform Assoc. 2019;26:66-70.

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