

Collecting Sexual Orientation and Gender Identity Data to Reduce LGBTQ Health Disparities



June is LGBTQ Pride month and as healthcare organizations work to increase health equity and form a more inclusive environment, it is important to capture sexual orientation and gender identity (SOGI) data. LGBTQ healthcare consumers have unique healthcare needs and community health centers are positioned to offer equitable, inclusive, and quality services to these individuals.

Nationwide, Community Health Centers have been charged with collecting SOGI data since HRSA added this component in 2016 to the annual UDS. However, a study published in the American Journal of Public Health in 2019 found that SOGI data was missing from annual UDS reports for 77.1% and 62.8%, respectively, of patients served by community health centers (Grasso et al., 2019)

In West Virginia Community Health Centers, according to public-facing 2019 UDS data, there were 114,729 patients or 24.3% missing sexual orientation data and 89,077 patients or 18.87% missing gender identity data <https://data.hrsa.gov/tools/data-reporting/program-data/state/WV/table?tableName=3B> .

Line	Patients by Sexual Orientation	Number (a)	% of Known
13.	Lesbian or Gay	2,515	0.78%
14.	Straight (not lesbian or gay)	315,976	98.32%
15.	Bisexual	2,383	0.74%
16.	Something else	514	0.16%
		Number (a)	% of Total
17.	Don't know	114,729	24.31%
18.	Chose not to disclose	35,906	7.61%

Line	Patients by Gender Identity	Number (a)	% of Known
20.	Male	145,348	39.40%
21.	Female	222,669	60.36%
22.	Transgender Male/Female-to-Male	485	0.13%
23.	Transgender Female/Male-to-Female	384	0.10%
		Number (a)	% of Total
24.	Other	89,077	18.87%
25.	Chose not to disclose	14,060	2.98%
26.	Total Patients (Sum of Lines 20 to 25)	472,023	100.00%

Source: 2019 WV CHC UDS Table 3B <https://data.hrsa.gov/tools/data-reporting/program-data/state/WV/table?tableName=3B>

Collecting SOGI information can be difficult for health centers to accomplish and depending upon the staffs comfort level with these types of questions, making it routine can be a challenge.

SOGI data collection is important for reasons stated above for the LGBTQ community but collecting gender identity is also important for the female patient population. When health centers are missing important gender data for females, certain preventive health screenings such as breast cancer screening and cervical cancer screenings can be missed. When a gender is not identified, EHR algorithms do not trigger preventive screening alerts and these patients will not be listed in EHR or population health care gap reports.

The Fenway Institute, a leading authority in capturing SOGI data and caring for the LGBTQ community has great resources specifically for community health centers.

Resources from the Fenway Institute:

[Helping Your Organization Collect Sexual Orientation and Gender Identity Data!](#) helps healthcare organizations begin the process of SOGI data collection by explaining the benefits and motivating factors to convince key stakeholders that SOGI data collection is necessary.

[Eight Tips for Building Coalition Support and Moving SOGI Data Collection Forward in Your Organization](#) provides helpful tips and strategies to continue to build momentum and support for SOGI data collection after initial buy-in from key stakeholders.

[The Nuts and Bolts of SOGI Data Implementation: A Troubleshooting Toolkit](#) provides tips and approaches to solve real world implementation issues from healthcare organizations that have already successfully implemented SOGI data collection.

If you need assistance with workflow redesign to collect SOGI data, please contact Emma White RN, Clinical Quality Improvement Coordinator emma.white@wvpca.org