

## **Improved Data Collection for Our LGBTQ Population is Needed to Improve Health Care and Reduce Health Disparities**

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Providing the best possible health care and interventions to Delawareans requires us to understand the health disparities that may exist among populations. When data collection efforts include demographics for lesbian, gay, bisexual, transgender and questioning (LGBTQ) individuals, our health systems can become more culturally responsive and inclusive. However, information on health conditions by sexual orientation and gender identity is hard to find because the data are not routinely collected.

Approximately 4.5 percent of the U.S. population identified themselves as LGBT in an analysis of 2017 Gallup poll data by Williams Institute of the School of Law at University of California, Los Angeles (UCLA).<sup>1</sup> Overall, 5.1 percent of women and 3.9 percent of men identified as LGBT. LGBT identification is also higher in those with lower incomes, and among racial and ethnic minorities.<sup>2</sup>

Survey data on LGBT populations are available and collected in several national and state surveys such as the Centers for Disease Control (CDC)-funded Behavior Risk Factor Surveillance System (BRFSS) and the Youth Risk Behavior Survey (YRBS). Among Delaware adults, about 5.2 percent identify as LGBT, according to the 2017 Delaware Behavioral Risk Factor Survey (BRFS), an annual survey of about 4,000 adults that reports both state and national data. It has only been in the last four years that BRFS has included questions which allow individuals to identify as LGBT. Much of Delaware's state-level data related to LGBT individuals are suppressed, meaning that they cannot be used to interpret data specific to this population when looked by a single year because the sample size is not large enough to be valid. Eventually, DPH will be able to aggregate three or four years of data and do rolling averages for adults.<sup>3</sup>

The Delaware YRBS that is completed every other year in public high schools asks questions about LGBTQ, with the Q referring to "Questioning" – which is much more common in this age group. Eleven percent of respondents to the 2017 High School YRBS identified as lesbian, gay, or bisexual; an additional three percent were unsure of their sexual orientation and just over one percent identified as transgender.<sup>4</sup>

Asking about sexual orientation is slowly becoming more common in surveys. Federal health forms typically do not include sexual orientation questions, and gender questions are limited to male/female. Eight national data systems collect sexual orientation data, including the National Health Interview Survey (added in 2013), and the National Survey of Drug Use and Health (added in 2015).<sup>5</sup> A gender identity question was included in the Health Resources and Services Administration's 2013 and 2014 National Health Service Corps Patient Satisfaction Surveys and the 2014 NURSE Corps Participant Satisfaction Survey.<sup>6</sup> Public health workers generally agree that sexual orientation and gender identity data are limited and mainly regard adolescents.

The LGBT companion document to *Healthy People 2010* recognized the need for sexual orientation and gender identity data “to document, understand, and address the environmental factors that contribute to health disparities in the LGBT community.”<sup>7,8</sup> The Institute of Medicine raised the need for further gender minority research in the 2011 report, *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*<sup>9</sup> as well as in a 2012 workshop summary.<sup>10</sup> Its authors, a committee of experts, recommended collecting sexual orientation and gender identity data in U.S. health surveys and other federally funded surveys, in electronic health records among other demographic information collected. HHS’ Agency for Healthcare Research and Quality has included LGBT information in its National Healthcare Quality and Disparities Reports since 2011, but in 2017 noted that few databases support LGBT analyses.<sup>11</sup> Currently, the nation’s Healthy People 2020 (HP 2020) initiative contains seven LGBT data objectives. Objective LGBT-2.2 is to increase the number of states, territories, and the District of Columbia that use a provided module on sexual orientation and gender identity questions in the BRFSS from 20 in 2014 to 22 in 2020. Objective 2.3 is to do the same in the Youth Risk Behavior Surveillance System (YRBSS) from 28 in 2015 to 31 in 2020 (see Table 1).<sup>12</sup>

Table 1. Healthy People 2020 LGBT Data Initiatives

Initiative	Description
<b>1.0</b>	<b>Increase the number of population based data systems used to monitor Healthy People 2020 objectives that include in their core a standardized set of questions that identify lesbian, gay, bisexual, and transgender populations</b>
1.1	Increase the number of population based data systems used to monitor Healthy People 2020 objectives which collect data on (or for) lesbian, gay and bisexual populations
1.2	(Developmental) Increase the number of population based data systems used to monitor Healthy People 2020 objectives which collect standardized data that identify lesbian, gay and bisexual populations
1.3	Increase the number of population based data systems used to monitor Healthy People 2020 objectives which collect data on (or for) transgender populations
1.4	(Developmental) Increase the number of population based data systems used to monitor Healthy People 2020 objectives which collect standardized data that identify transgender populations
<b>2.0</b>	<b>Increase the number of states, territories, and the District of Columbia that include questions that identify sexual orientation and gender identity on state level surveys or data systems</b>
2.1	Increase the number of states, territories and the District of Columbia that include questions on sexual orientation and gender identity in the Behavioral Risk Factor Surveillance System (BRFSS)
2.2	Increase the number of states, territories and the District of Columbia that use the provided module on sexual orientation and gender identity in the Behavioral Risk Factor Surveillance System (BRFSS)
2.3	Increase the number of states and territories that use the provided module on sexual orientation and gender identity in the Youth Risk Behavior Surveillance System (YRBSS)

Other than BRFS and the YRBS, which are administered through the Division of Public Health (DPH), our agency does not collect sexual orientation or gender identity data on its forms and data surveys, but may gather such data via risk assessments and key informant surveys. Whenever possible, DPH analyzes sexual orientation data and includes it in data reports, data briefs, and professional articles when the sample sizes are large enough. Small data pools prevent the analysis of risk factors, diseases, and lifestyles, especially if there is already low prevalence. For the most accurate data representations, researchers must aggregate several years of data to overcome wide confidence intervals. For example, DPH is aggregating multiple years of BRFS data and reviewing the LGBT responses to determine adult LGBT smoking prevalence in comparison to the general adult population.

“By asking these questions, you are legitimizing the LGBT community,” said Salvatore Seeley, Director of Health and Wellness for CAMP Rehoboth,<sup>13</sup> a 501(c)(3) nonprofit community service organization dedicated to creating a positive environment inclusive of all sexual orientations and gender identities. “It’s altruistic in a way, but it’s also empowering to a community that is largely excluded.”

Demographic survey questions, typically limited to binary (male/female) choices, should become more culturally appropriate and centric, Seeley said. He noted the importance of giving people the opportunity to self-describe their sexual orientation and their gender. Transgender individuals express their gender differently; others might be agender (no particular gender) or bi-gender (any two genders) individuals. CAMP Rehoboth suggests these sample answers through its culturally inclusive trainings:

- Male/Female, Prefer to self-describe, Prefer not to say
- Male/Female, Non-binary, Third gender
- Do you identify as transgender? Yes/No, Prefer not to say.

While it would be inclusive for data collection points to ask if one is heterosexual or other (lesbian, gay, bisexual), having those data might not change how we address a health problem. For instance, Delaware’s HIV Program collects “men having sex with men” data because it is a risk factor. Women having sex with women are at much lower risk. In other areas, such as infant mortality, sexual orientation variables may not be needed for health care professionals to do their work.

Expanding data collection tools to include sexual orientation and gender identity could result in the public health community being aware of disease and health behaviors that it may or may not be adequately addressing. LGBT Delawareans represent many distinct population groups, each with their intrinsic health needs. Having LGBT data to access can assist health providers and educators in streamlining their care and outreach efforts. Customized, culturally competent interventions can reduce LGBT health disparities.

“Delaware is losing out by not truly understanding the needs and wants of the LGBTQ population,” Seeley said. “LGBT people have specific health needs and we get clumped in the general group [of respondents.]”

Let's look at some of the health issues that have been identified through data collection. Nationally, among gay, bisexual, and other men who have sex with men, there are higher risks of sexually transmitted diseases, especially among communities of color. HIV prevalence among gay and bisexual men is 40 times that of sexual partners of heterosexual men. Seventy-five percent of reported 2012 syphilis cases were among gay and bisexual men.<sup>14</sup> Gay, bisexual, and other men who have sex with men are 17 times more likely to get anal cancer than heterosexual men and face major depression, generalized anxiety disorder, and bipolar disorder.<sup>15</sup> Based on national data, tobacco use is also higher among gay and bisexual men than heterosexual men.

Also nationally, lesbians and bisexual women are more likely to be overweight or obese, and lesbians are less likely to get cancer screenings, according to the U.S. Department of Health and Human Services (HHS).<sup>16</sup> Transgender individuals are at risk of acquiring HIV and STDs, being victimized, having mental health issues, and attempting suicide, as well as not having health insurance. Elderly LGBT individuals must overcome isolation and at times, a lack of social services and culturally competent providers.<sup>5</sup>

Turning our focus to LGBTQ youth, it is clear that an additional set of issues present themselves, some that are addressed through a social determinants of health lens. For LGBTQ youth, interpersonal and internal conflicts – and not sexual orientation itself – may increase substance use risk behaviors and poor mental health due to stigma and stress as contributing risk factors.<sup>17,18</sup> LGBTQ youth are also more likely to be homeless.<sup>5</sup> Two meta-analytic reviews of national data found that on average, lesbian, gay, and bisexual youth were 190 percent more likely to misuse substances than heterosexual youth; and they were significantly more prone to depression and suicide attempts, as they noted that they suffered from victimization, discrimination, and stress.<sup>17,18</sup>

Data from Delaware's 2017 YRBS, which sampled 2,906 public high school students, show that the rate of current cigarette use is more than double among Delaware LGBTQ youth compared to heterosexual youth. Thirty-two percent of sexual minority youth surveyed reported using marijuana in the past 30 days, compared to 23 percent of their heterosexual peers. The reported use of prescription pain medicine in the past month was twice as high among LGBTQ students compared to heterosexual students.<sup>4</sup>

Regarding mental health, 52.5 percent reported feeling sad or hopeless for two weeks or more in the preceding year. Nearly 39 percent of LGBTQ students and 10 percent of heterosexual youth purposefully injured themselves (without intending death) at least once in the past year. Slightly more than 30 percent of Delaware LGBTQ youth planned suicide within the past year, compared to 9 percent of their heterosexual peers; and 18 percent attempted suicide at least once within the last year, compared to 5 percent of their heterosexual peers. Getting bullied on school property and electronically on social media occurred less among heterosexual students and more among LGBTQ students, who also reported being more likely to bring a weapon to school.<sup>4</sup>

How can these data be useful to health care providers? Providers who are aware of their patients' gender identity and sexual orientation are more likely to screen them for certain conditions identified based on data trends. Additionally, particularly for younger patients, providers would be more likely to monitor them for signs of struggling with emotional issues or substance use disorder, and refer them to counseling or connect them with appropriate treatment sooner.

Cultural competency plays a huge role in positive provider-patient interactions and welcoming LGBT individuals to health care delivery sites. When LGBT persons are mistreated or ostracized

by society, they tend to avoid doctor's visits. Many LGBT individuals may be reluctant to disclose their true orientation to health care providers because they fear rude and discriminatory reactions, or that their status could become public. When kindness and respect pervade care delivery sites, LGBT persons are more comfortable with disclosing their orientation, allowing providers the opportunity to screen them for relevant behaviors and conditions. Sharing sexual orientation and gender identity on a form, rather than verbally to a nurse, was nearly three times more likely to result in patients identifying as LGBTQ than among non-LGBT patients.<sup>19</sup> However, they have a very real concern that their personal information could be made public.

It would be immensely helpful if a national assembly of federal and state data professionals, would formally discuss sexual orientation and gender identity data collection and provide recommendations. State and federal agencies can be surveyed about current data collection efforts. The group can study the value and feasibility of collecting such data and issue guidance that includes model survey questions and how to interpret LGBT findings correctly, especially when numbers are small and confidence intervals are wide. The National Institutes of Health's Office of Sexual and Gender Minority Research (OSGMR), established in 2015 to increase sexual and gender minority (SGM) knowledge and remove research barriers, might be an appropriate lead agency.<sup>20</sup>

Not too long ago, it was a big step for Delaware to include persons of Hispanic ethnicity in its data collections. It's time to expand data collections to include sexual orientation and greater gender choices to enhance our knowledge of health needs that we may not be addressing – or on the flip side, of prime LGBTQ health behaviors of which we are unaware. Data collections should represent all Delawareans with dignity.

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