Sexual and Gender Minority Inclusion in State Comprehensive Cancer Plans

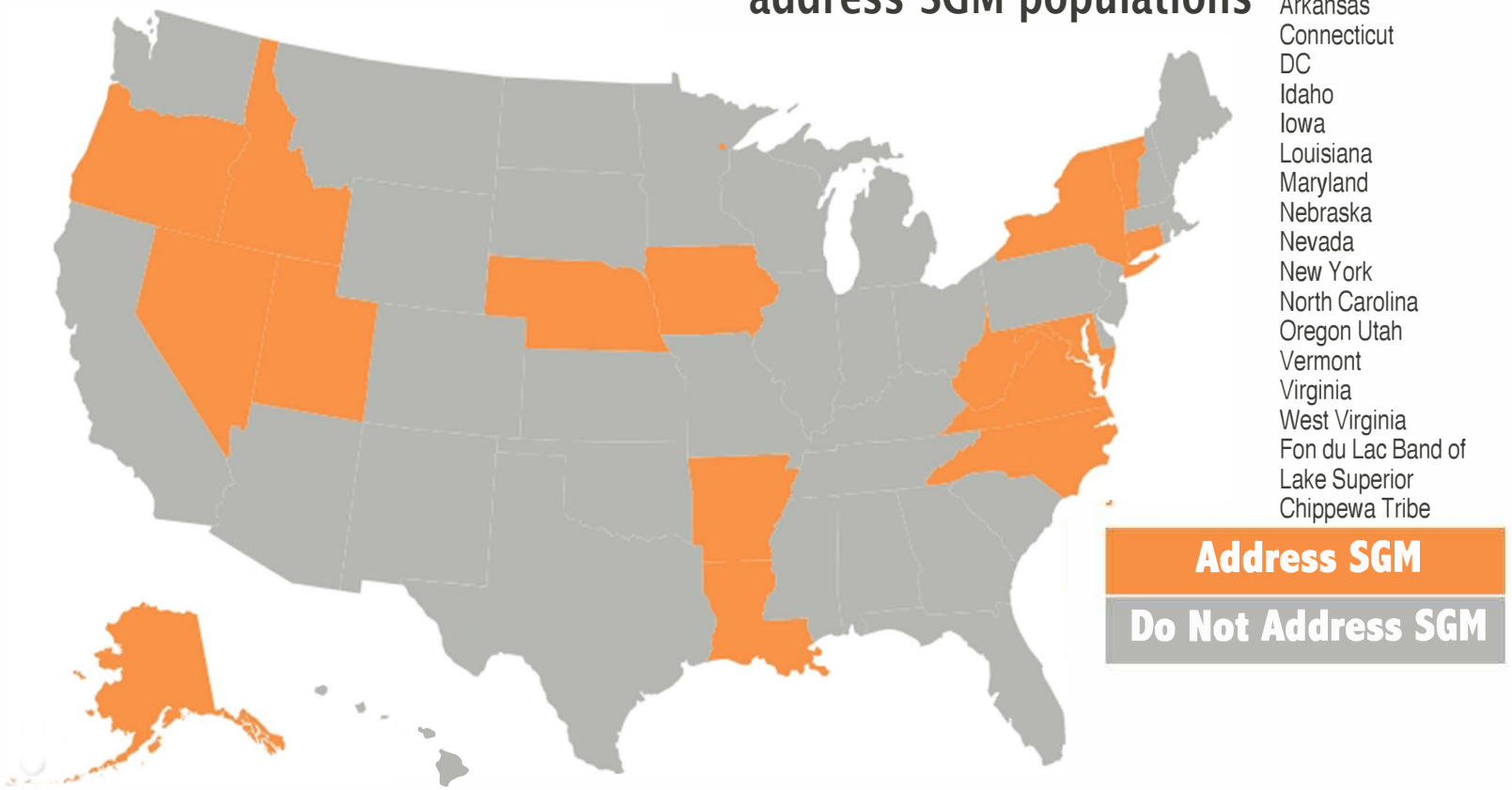
lgbt national cancer network

TOBACCO RELATED CANCER PROJECT

We reviewed states most recently released cancer plans for inclusion of sexual and gender minorities (SGM). Plans were assessed for health disparity information, data collection, and action areas (prevention, screening, treatment, survivorship).

Of 51 State Comprehensive Cancer Plans, 8 US Territory/Pacific Island Jurisdiction Cancer Plans, and 8 Tribes/Tribal Organization Cancer Plans:

17 states and **1** tribal organization address SGM populations



14 contained information related to health disparities in SGM populations

6 discussed data collection to assess SGM populations and cancer risk

3 outlined strategies for cancer prevention among SGM populations

2 provided tools for cancer screening among SGM populations

2 contain treatment methods for SGM populations

1 provided strategies related to survivorship for SGM populations

How were SGM included across comprehensive cancer plans?

14 contained information related to health disparities in SGM populations

Health disparity information discussed SGM as an at-risk population using national and state-specific data. Topics included risk behavior, barriers, cancer prevalence, and related adverse health conditions among SGM communities.

Example(s)

In Utah, smoking rates are higher among the LGBTQ (Lesbian, Gay, Bisexual, Transgender, Queer) community than the heterosexual community. Cigarette smoking prevalence is 16.2% among homosexuals and other members of the LGBTQ community and 10% for heterosexuals.

-Utah Comprehensive Cancer Prevention and Control Plan 2016-2020

The specific preventive and health care needs of members of the lesbian, gay, bisexual, transgender and queer (LGBTQ) community have overwhelmingly been overlooked in the past. [...] LGBTQ people smoke cigarettes at a rate that is 68% higher than the rest of the population. Additionally, LGBTQ people face continued discrimination and stigma within health care settings.

-Iowa Cancer Plan 2018-2022

6 discussed data collection to assess SGM populations and cancer risk

Information on data collection with SGM populations included identification of gaps in data collection and goals for future inclusion.

Example(s)

"BRFSS and YVS collect data on a variety of risk behaviors annually..." '..challenges include inconsistent inclusion of optional questions in BRFSS and VYS, delay in including data on emerging risk factors such as LGBTQ cancer risk and burden..."

-Virginia Cancer Plan 2018-2022

GOAL 1: Increase and analyze the data available on vulnerable (underserved) populations, to include but not be limited to: persons with disabilities; Hispanic residents; and lesbian, gay, bisexual, and transgender (LGBT) residents.

-Delaware, The Next Five-Year Plan, 2017-2021

3 outlined strategies for cancer prevention among SGM populations

Idaho, Virginia, and North Carolina plans contained suggestions and tools for cancer prevention among SGM communities through education and strategy promotion, such as:

Example(s)

Strategy 6.2 b. Provide education to physicians and other healthcare providers on issues related to cervical cancer screening in LGBTQ communities.

-Virginia Cancer Plan 2018-2022

Support and promote implementation of evidence-based strategies to decrease disparities in gender, racial/ethnic populations, LGBT people and rural communities related to tobacco use.

-Idaho Comprehensive Cancer Strategic Plan 2016-2020

2 provided tools for cancer screening among SGM populations

Virginia and Louisiana were the only states that addressed strategies for cancer screening through education with SGM communities and training for healthcare providers.

Example(s)

"Visits with primary care physicians are important, as the majority of patients will be screened or be recommended for screening during these visits. If an LGBT patient feels that she or he will be treated unfairly or poorly because of their identity, they may not visit a primary care physician, and therefore may not receive the recommended screenings. To engage this issue, provider education on LGBT cultural competence is increasingly important:'

-Louisiana Comprehensive Cancer Control Plan, 2017-2021

How were SGM included across comprehensive cancer plans?

3 plans contain treatment strategies for SGM populations

New York, Alaska, and Louisiana discuss treatment strategies for SGM through cultural competency training and engagement.

Example(s)

Objective 4.1: Provide the highest quality of cancer care and support for all patients and their families. [...] Strategy 9: Increase engagement with LGBTQ cancer survivors and provide training for welcoming oncology offices.

-Alaska Comprehensive Cancer Control Plan 2016-2020

1 plan provided strategies related to survivorship for SGM populations

Utah was the only state that contained a strategy for addressing survivorship among SGM populations.

Example(s)

Strategy C: Improve access to treatment options, symptom management, and follow-up care for cancer survivors. [...] Support partners in developing specific patient navigation programs addressing the needs of disparate populations including adolescent and young adult survivors, rural and frontier populations, racial and ethnic minorities, LGBTQ individuals, etc.,

–Utah Comprehensive Cancer Prevention and Control Plan 2016-2020

Other Highlights

(Appendix A) The Louisiana Comprehensive Cancer Control Plan (2017-2021) contains a "A Spotlight on Lesbian, Gay, Bisexual, and Transgender (LGBT) Health and Cancer". This provides a thoughtful, in-depth look into cancer risk in the LGBT community.

(Appendix B) The Fond du Lac Band of Lake Superior Chippewa plan includes a narrative on cancer caregivers for SGM community members that highlights life at the intersection of Indigenous and LGBT identity.

Two states discussed SGM in previous cancer plans, but did not in the current cancer plan. It is essential that states both include content related to SGM and ensure the sustainability of this information in future plans.

national lgbt cancer network
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Appendix A:

A Spotlight on Lesbian, Gay, Bisexual, and Transgender (LGBT) Health and Cancer

According to US Census 2010 data, Louisiana had approximately 8,100 same-sex couples, or 4.7 same-sex couples per 1,000 households (Gates & Cooke, 2010). Many same-sex couples are concentrated around larger cities: New Orleans, Baton Rouge, Lafayette, and Shreveport. While these specific statistics are available, limited publications and statistics are available on gay and bisexual health in the nation or in Louisiana. Of the publications that are available, many are related to HIV/AIDS issues and few are published on the array of other issues that surround LGBT health. Cancer statistics for Louisiana's sexual minority population statistics are scarce and prevention strategies are deficient as of 2016. Terminology regarding sexual orientation and gender identity in this section is referred to in the same terminology in which it appears in the source document referenced in that instance.

The LGBT community often does not receive health treatment that is comparable to their heterosexual counterparts. This is largely due to a lack of data in the LGBT population, generic treatment plans that often best suit heterosexual persons, and a stigmatization of the LGBT population (Blank, 2014). These same issues can be seen in public health; the majority of CDC data and resources focus on sexually transmitted disease (STD) and HIV testing (CDC, 2014). This absence of information contributes to health disparities in the US.

LGBT persons seeking treatment for cancer are faced with issues of inadequate data, routine treatment plans, and stigmas that can ultimately result in increased mortality. In one of the few studies published on LGBT communities, the CDC's National Center for Health Statistics developed questions that were subsequently added to the National Health Interview Survey (NHIS) (CDC, 2013). This survey is administered randomly to residents throughout the US and is often used for health statistics. The 2013 NHIS recorded that among US adults ages 18 and over (N=34,557), 1.6 percent identified as gay or lesbian and 0.7 percent identified as bisexual (Ward, Dahlhamer, Galinksy, & Joestl, 2013). Of adults between the ages of 18 and 64 who identified as gay, lesbian, or bisexual (LGB), 29.5 percent reported being current smokers, which is higher than those who identified as straight reported currently smoking (19.6 percent). Those identifying as LGB also reported having five or more drinks in one day at least once in the past year (41.5 percent), more than their straight counterparts (26.0 percent). From the NHIS data, an increase in risk-taking behavior (e.g. smoking and binge drinking) is observed; risk-taking behavior in LGB men and women is also cited throughout published literature (Blosnich, Jarrett, & Horn, 2010) (Rosario, Scrimshaw, & Hunter, 2006). These behaviors can lead to an increase in cancer of multiple sites, some of which are more common in LGB persons than others (Lemp et al., 1994). The National Cancer Institute's SEER (Surveillance, Epidemiology, and End Results) Program, has yet to collect information on sexual orientation of individuals diagnosed with cancer.

Increased Risks

Literature for site-specific cancer among LGBT persons is inadequate to date. However, the few existing publications provide insight into sexual minority cancer status. Breast, lung, and colorectal cancer incidence has been shown to be different in areas that have a higher sexual minority density (SMD) than in those with a higher density of heterosexual persons (Boehmer, Miao, Maxwell, and Ozonoff, 2014). As noted previously, the tobacco industry targets LGBT populations with marketing, and smoking rates among LGBT persons are higher than among the general population; this ultimately increases risk for lung and other tobacco-related cancers. HIV/AIDS can also increase a patient's risk of developing Kaposi sarcoma or non-Hodgkin lymphoma, two cancer types that are associated with the lymphatic system (International Agency for Research on Cancer, 1996; Oksenhendler, 2002).

According to the Louisiana HIV/STD Program, 65 percent of new HIV diagnoses in 2014 were among men who have sex with men (MSM), and the majority of those diagnoses were among Black men. HIV and STDs disproportionately affect Black men, especially Black MSM in Louisiana (Louisiana Department of Health and Hospitals, 2014). Being HIV positive increases a person's risk for other infections, including other sexually transmitted infections and viruses. HPV infection is a viral infection that causes various cancers. HPV can cause of cervical and other cancers in females, and it has recently been implicated in the increased incidence of anal cancers in males; in fact, the incidence of anal cancer among gay or bisexual men is higher than the incidence of cervical cancer among women (Chin-Hong et al., 2005). Persistent HPV infection is frequent among HIV-positive MSM (Krueter, A., Wieland, U., 2009). For men and women (lesbian and bisexual), the number of lifetime oral sex partners increases the risk HPV-related oropharyngeal cancers (Brouwer, A. F., Eisenberg, M. C., & Meza, R., 2016). Women identifying as lesbian or bisexual are also at risk of HPV infection and the possible consequence of cervical cancer, despite common belief that they are at lower risk because they do not have sexual contact with men (Bailey, Kavanagh, Owen, McLean, & Skinner, 2000) (Marrazo, Koutsky, Kiviat, Kuypers, & Stine, 2001). Ultimately, increased HPV-vaccination will reduce new HPV infections and HPV-related cancers among men and women regardless of sexual identity or gender orientation. At present, according to the CDC Sexually Transmitted Diseases Treatment Guidelines, the data are insufficient to recommend routine anal cancer screening for persons with HIV infection or MSM without HIV infection (CDC, 2016).

Future Work

Cancer registries need to start collecting data on sexual orientation and identity, since major cancer registries such as SEER do not do so to date (Bowen & Boehmer, 2007). Without data, adequate research cannot be conducted on cancer trends among sexual minority groups. While some national surveys, such as the BRFSS, have begun to ask questions to identify sexuality, it is imperative that all national self-reported surveys begin to include these questions as well. (Baker & Hughes, 2016)

The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) has recently updated policies to include transgender women who have taken or are taking hormones and meet all program eligibility criteria for breast cancer screening (Maril, 2013). Although the CDC has not made any specific screening recommendations for this population, these women are eligible under federal law to receive appropriate cancer screening. With more research, proper recommendations can be made and early detection programs can include more sexual minority groups.

Visits with primary care physicians are important, as the majority of patients will be screened or be recommended for screening during these visits. If an LGBT patient feels that she or he will be treated unfairly or poorly because of their identity, they may not visit a primary care physician, and therefore may not receive the recommended screenings. To engage this issue, provider education on LGBT cultural competence is increasingly important. Providers may not be aware that certain cancers present at a higher frequency and with more complications in LGBT patients and may not recommend the correct screenings because of this. Provider education on communicating with LGBT patients is also important. Primary prevention—such as regular visits to a physician, healthy diet, exercise, reduced obesity, and smoking cessation—is key in reducing cancer incidence and mortality in the LGBT community, just as it is in any other community.

More culturally appropriate prevention strategies for the LGBT community are needed. Because current prevention strategies may not fit the needs of gay, lesbian, bisexual, or transgender Louisiana residents, research and prevention strategies must be developed to fulfill these needs. With more data collection and research on how cancer affects sexual minorities, specifically in Louisiana, better recommendations for cancer prevention will be made.

Appendix B:

A Caregiver's Story

My younger sister Nada K. Joseph was diagnosed with Stage IV breast cancer in 1997—she fought the demon until she no longer could and walked on in 1999. I made a promise to her that I would continue her fight until my last breath.

We have a large family (nine children) and I was closest to her. Not only was she a member of the Fond du Lac Band of Lake Superior Chippewa but she was also a member of the Lesbian/Gay community. She was an athlete, a nonsmoker who took care of herself, and I believe an experience of this magnitude is even more difficult knowing you've always been "healthy."

She asked me to help—to become her caregiver and I was, and am honored. First of all most of us really know so little about this "demon" except we immediately think of death. I jumped in and began to do my own research. The medical jargon alone is overwhelming and because there is no "cure" for cancer, I observed many of her healthcare providers debate over which treatment plan would be the best and then leave it up to her. While we were actively involved in her healthcare decisions, this aspect of her journey was probably the most frustrating. All treatments and protocols were gut wrenching decisions.

This experience is almost indescribable but think of every verb that describes sadness, helplessness and any other emotionally crippling pain—that is how a caregiver feels. To navigate through the "unknown" is scary enough but to know deep in your heart and soul that Stage IV patients rarely survive never leaves your thoughts.

There is no magic answer as to what is right or wrong in caring for a cancer patient. Most of the time I felt paralyzed but somehow I had to step up to the plate and offer her what help I could. One really has to keep an open mind and heart throughout the journey for there will actually be good days as well as those bad days that rear their ugly heads. The hardest for me was to not take things personally. My sister, like so many who are fighting this disease, would have days of anger and rage, days of total silence, days of great hope and days of little hope, days of joy and far too many days and nights of unpredictability.

Most everyone had incredibly high expectations of her—I suppose because she was such a gregarious and healthy person. It was difficult for them to see her in a weakened state but these daily expectations took their toll on her very quickly as she felt it was her duty to "counsel" everyone who was feeling bad. That exhausted her and one day she said to me, "Don't they realize I'm fighting for my life?" It was then that I had to change her daily schedule and "thin the herd" as we called it. I put a voice mail message

on the telephone offering a daily update and that most often she was resting and unable to come to the phone. I screened all visitors, including family members, which was perceived as "being shut out." All of her energy had to focus on the battle.

Even though she had a bone marrow (stem cell) transplant she was never totally cancer free and had three recurrences. When she first called to tell me I was packed and in the car in fifteen minutes. Five hours later I walked into her kitchen and she was wearing this sleeveless white tee shirt. That "lump" drew me directly to it but I refused to allow it to disrupt our usual greeting of hugs and kisses. My sister then took my hand and placed it on the evil spot and I was shocked and felt sick to my stomach as I tried to maneuver it around, but it wouldn't budge! Huge as a grapefruit and hard as a rock. Because I had lost eight close friends and colleagues to breast cancer in the past three years, I had some familiarity with the "stages" but this scared the daylights out of me. When the biopsy was done and the syringe produced no liquid from the area my heart sank. I knew then that she was terminal. I never spoke those words out loud to anyone and this is the first time I've publicly stated this.

Early detection is KEY! Mammograms and breast self-examinations can save your life. My sister knew she waited too long to go in . . . she only told me that once during her two year struggle. At that time we couldn't find any American Indian support group much less any resources in the Lesbian community. There is a huge need for support in all forms that is culturally appropriate for our people including two spirited people.

When she had her stem cell transplant at Karmonos Hospital on the Wayne State University Campus in Detroit, she was the first American Indian person to ever participate in that program. The head of the program was so intrigued he came to visit Nada often, which we were told was rare. He eventually asked me to ask Nada if she would be interested in being interviewed by all three local television stations (NBC, CBS and ABC). The interviews not only focused on her cancer but on the importance and impact her cultural beliefs and traditions had on her as she prepared for battle each day, and then finally as she prepared for her spiritual journey.

Bonnie Wallace, Giidaagahbinesikwe (Spotted Eagle Woman)