



# HHS Public Access

Author manuscript

*LGBT Health*. Author manuscript; available in PMC 2016 October 20.

Published in final edited form as:

*LGBT Health*. 2015 ; 0(0): .

## Public Health Opportunities for Promoting Health Equity in Cancer Prevention and Control in LGBT Populations

Greta M. Massetti, PhD<sup>1</sup>, Kathleen R. Ragan, MSPH, CHES<sup>1</sup>, Cheryl C. Thomas, MSPH<sup>1</sup>, and A. Blythe Ryerson, PhD<sup>1</sup>

<sup>1</sup>Division of Cancer Prevention and Control, Centers for Disease Control and Prevention, Atlanta, Georgia.

### Abstract

Advances in cancer prevention, detection, and treatment have led to reductions in morbidity and premature mortality and improvements in quality of life. However, not all Americans have benefitted equally from these advances, and certain populations experience continued disparities in cancer care. Although research and public health efforts have highlighted the experiences of some groups, other populations have been relatively understudied, such as lesbian, gay, bisexual, and transgender (LGBT) individuals. Public health efforts in surveillance, research, programs, and partnerships can provide opportunities to advance health equity for LGBT at the population level and lead to better health outcomes for LGBT individuals with cancer.

### Keywords

access to care; epidemiology; health disparities

### Introduction

NOT ALL AMERICANS BENEFIT equally from recent improvements in life expectancy and overall health. Differences in the incidence, prevalence, and mortality of disease exist among specific population groups. While *health disparities* have been routinely characterized by race or ethnicity, the term also refers to gender, age, education, income, social class, disability, geographic location, and sexual orientation since these all have a direct or indirect impact on an individual's health.<sup>1</sup>

Members of the lesbian, gay, bisexual, and transgender (LGBT) community have specific health needs that are often associated with social and structural inequities. The U.S. Department of Health and Human Services (HHS) has worked to promote equal treatment,

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Address correspondence to: Greta M. Massetti, PhD, Division of Cancer Prevention and Control, Centers for Disease Control and Prevention, 4770 Buford Hwy NE, MS K76, Atlanta, GA 30341, gmassetti@cdc.gov.

#### Disclaimer

The findings and conclusions in this article are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

#### Author Disclosure Statement

No competing financial interests exist.

provide tailored resources, identify specific health needs, improve access to health coverage for LGBT Americans, and improve collection of sexual orientation and gender identity variables in population-based data systems.<sup>2,3</sup> As the nation's health protection agency within HHS, the Centers for Disease Control and Prevention (CDC) strives to improve the health of LGBT communities by increasing awareness of health care access issues and supporting culturally appropriate and relevant programs and science. Since LGBT populations may be disproportionately affected by certain cancer types, CDC's Division of Cancer Prevention and Control (DCPC) takes a public health approach to identify opportunities that promote health equity and to establish cancer prevention and control priorities for LGBT populations.<sup>4</sup> This article provides an overview of DCPC's current and potential future work in LGBT populations in surveillance and research, public health programs, and public health partnerships.

## Public Health Surveillance and Research

In 2011, The Institute of Medicine (IOM) identified research gaps and opportunities for LGBT populations, including the need for more LGBT-specific data.<sup>5</sup> Public health *surveillance and research* activities are critical for planning, evaluating, and building the evidence base for public health programs. DCPC uses two major types of surveillance systems for cancer data: cancer registries and behavior-based surveys.

### The National Program of Cancer Registries

CDC's National Program of Cancer Registries (NPCR) supports 48 central cancer registries to collect data on all invasive cancer occurrences. Together, NPCR registries and those funded through the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program make national cancer incidence and mortality data available through several avenues.<sup>6</sup> Numerous factors dictate the type of information that can be successfully collected on the over one million invasive cancer cases diagnosed annually, which have important implications for collecting information on sexual orientation and gender identity. One of the most critical factors is that data collection occurs by abstracting information from existing medical records. In contrast with information on age and diagnosis, sexual orientation is usually not available systematically in medical records and is not available for consistent data capture by cancer registrars. Unlike behavior-based surveys, cancer registrars do not speak to patients directly as part of state-mandated cancer reporting.

Cancer registries do collect some data on gender identity, including whether the patient is male, female, hermaphrodite, or transsexual. Recently, the North American Association of Central Cancer Registries modified sex categories to include: transgender, natal male; and transgender, natal female.<sup>7</sup> However, the validity and stability of these counts are not yet known and the relative cancer burden for these groups cannot be measured without corresponding population data from the U.S. Census.

Efforts to carefully evaluate the most effective approaches to studying cancer in the LGBT community need to continue. Until collection of sexual orientation is universally acknowledged by the medical community as critical to care and diagnoses, and clinicians consistently include this information in medical charts, nation-wide collection of these data

through modern cancer registries is likely not feasible. However, focused data collection efforts in smaller geographic areas can be used to continue to assess risk factors for cancer in LGBT populations and study how to best decrease cancer risks and barriers to care in these populations.

### **Behavioral surveillance using survey methods**

Behavioral surveillance collects data directly from individuals and presents an opportunity to better understand cancer disparities among LGBT populations. CDC is collaborating with other HHS agencies to develop and test questions on sexual orientation and gender identity on population-based data systems that monitor the Healthy People 2020 objectives.<sup>2</sup> The inclusion of sexual orientation questions on surveys sometimes raises concerns that the topic is too controversial and may result in excessive missing or inaccurate data due to refusals to self-report. Research suggests, however, that refusal rates for sexual orientation questions are significantly lower than household income questions and comparable to race/ethnicity and weight questions.<sup>8</sup> Additional research has found that most patients believed it was important for their health care provider to collect sexual orientation and gender identity information and were willing to share the information with providers.<sup>9</sup>

A module that included questions on gender identity and sexual orientation was available for the 2014 Behavioral Risk Factor Surveillance System (BRFSS) questionnaire.<sup>10</sup> Thirty-one states adopted the module or used a variation on the questions and received technical and financial assistance from HHS. According to The Fenway Institute, 25 states have included some sexual orientation questions in their BRFSS surveys at least once from 1995–2011.<sup>11</sup> The collection and analysis of these questions are an important start to understanding the health behaviors of LGBT populations. Whereas health disparity measures such as race and ethnicity, age, education, and income are collected annually on the BRFSS questionnaire, sexual orientation is not currently collected by all grantees. As the need for data-driven, state-based public health programs specific for LGBT populations continues to increase, including sexual orientation as an additional health disparity measure in the demographics section of the BRFSS questionnaire would provide a better opportunity to assess disparities among sexual minorities, especially as they relate to cancer.

National-level, sexual orientation data have been collected by two population-based surveys: the National Health Interview Survey (NHIS) and the Youth Risk Behavior Survey (YRBS). NHIS is a nationally representative sample of non-institutionalized adults aged 18 and older and the YRBS includes a nationally representative sample of students in grades 9–12 attending U.S. high schools.<sup>12,13</sup> The NHIS collected sexual orientation data in 2013 and 2015 and the YRBS included sexual orientation items on the 2015 national survey.<sup>14,15</sup> Taken together, efforts to collect sexual orientation data on behavioral surveys can begin to provide the data-driven foundation for development of new or modification of existing cancer prevention and control programs tailored for LGBT populations.

### **Public Health Programs**

CDC promotes adoption of evidence-based cancer screening interventions for underserved populations who experience a disproportionate burden of cancer through two programs. The

National Breast and Cervical Cancer Early Detection Program (NBCCEDP) provides access to breast and cervical cancer screening and diagnostic services to low-income, uninsured and underinsured women.<sup>16</sup> The Colorectal Cancer Control Program (CRCCP) intends to increase colorectal cancer screening rates by implementing evidence-based, population-level strategies to promote colorectal cancer screening and providing screening services.<sup>17</sup> Since neither program includes gender as an eligibility requirement, CDC is able to address the cancer screening needs of LGBT populations who may be uninsured or underinsured. For example, transgender men and women who have taken hormones and meet program eligibility requirements may receive breast cancer screening through the NBCCEDP. Also, transgender men who have not had a bilateral mastectomy or hysterectomy continue to be eligible for breast and cervical cancer screening.<sup>2</sup>

The National Comprehensive Cancer Control Program (NCCCP) supports a collaborative, data-driven process to reduce cancer risk, find cancers earlier, improve treatments, increase the number of people who survive cancer, and improve the quality of life for cancer survivors.<sup>18</sup> One of the NCCCP priorities includes promoting health equity as it relates to cancer control. Of the 58 programs funded by CDC, there are 5 that include objectives related to LGBT populations. As the surveillance data for LGBT populations become readily available, more NCCCP programs may include objectives that specifically address this population.

## Public Health Partnerships

Based on the tenants of comprehensive cancer control, DCPC has partnered with CDC's Office on Smoking and Health to fund the Consortium of National Networks to Impact Populations Experiencing Tobacco-Related and Cancer Health Disparities (National Networks Consortium).<sup>19</sup> It is intended to address tobacco use and cancer in underserved communities in a variety of ways, including enhancing the quality and performance of public health data and information systems and public health practices and services. The National Networks Consortium supports including sexual orientation in tobacco surveillance surveys.<sup>20</sup> One of the funded National Networks Consortium partners is LGBT HealthLink and focuses on addressing health disparities in LGBT populations through building capacity for community collaborations, providing education, helping to bridge communication and outreach gaps among LGBT communities and local health providers, and disseminating research findings to support program efforts.<sup>21</sup>

## Conclusion

Identifying cancer disparities among LGBT populations and effectively monitoring efforts to reduce them has been limited by a lack of specificity, uniformity, and quality in data collection and reporting procedures.<sup>22</sup> Consistent methods for collecting and reporting health data can help advance an understanding of the nature of cancer prevention and control efforts in the LGBT community, and ultimately lead to public health efforts to reduce those disparities and advance health equity.

## Acknowledgments

The authors thank Ena Wanliss for her suggestions and input in the original conceptualization of the manuscript. This research was supported in part by an appointment (K. Ragan) to the Research Participation Program at the Centers for Disease Control and Prevention administered by the Oak Ridge Institute for Science and Education through an interagency agreement between the U.S. Department of Energy and CDC.

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