LGBT Best and Promising Practices

Throughout the Cancer Continuum

LGBT HEALTHLINK
THE NETWORK FOR HEALTH EQUITY
A PROGRAM OF CENTERLINK

national lgbt cancer network
ADVOCATING FOR HEALTH EQUALITY

March 22, 2016

It is with great pride that LGBT HealthLink: The Network for Health Equity and the National LGBT Cancer Network present the LGBT Best and Promising Practices Throughout the Cancer Continuum (BPPCa) report. This report will serve as a resource for the many health system leaders looking to adopt cancer control best practices for the LGBT population.

Cancer has indelibly left a disproportionate mark on the Lesbian, Gay, Bisexual, and Transgender (LGBT) communities. We understand more than ever how the stress and stigma experienced by sexual and gender minority communities interacts with cancer, one of the most devastating of health challenges. We understand more about how discrimination can lead to behaviors that increase cancer risk, such as tobacco and alcohol use. We understand more about how discrimination drains our vitality, leaving us less energy to live as healthy lives as our non-LGBT brothers and sisters. We know more about the long history of discrimination in the health care arena, a primary cause of our avoidance of health care that could provide us with advance screenings and early detection. Finally, we know that LGBT people who are diagnosed with cancer struggle to receive culturally competent care, adding to the already unreasonable strain of cancer treatment and survivorship.

This document has been created at a unique time in our national history. Three factors intersect to create a level of opportunity that is unprecedented. First, there is increased attention to the importance of culturally appropriate care broadly across workforce and health care systems. Second, decision makers are paying a new level of attention to LGBT equity in many arenas. Third, there is a surge of new research documenting the toll stigma takes on LGBT health. Spurred by these phenomena, providers are more willing to examine their practices. The best of them want to know how to better serve LGBT people before, during, and after their cancer diagnoses. If you are among the growing number of health professionals, decision makers, and educators who are committed to reducing the disproportionate burden of cancer on LGBT communities, then let this report inform and guide your efforts.

It is an enduring challenge to identify best practices in an arena without a robust complement of research and evaluation activities. There is an absence of randomized clinical trials comparing “LGBT Cancer Intervention A” with “LGBT Cancer Intervention B”. But knowledge is built at all stages of programmatic development. We employed expert guidance to create and review the content that has been developed through clinical experience, trial and error, and community innovation. We raised up the most worthy of the lessons learned, then sorted them and packaged them for use by decision makers, health care providers, and public health systems.

We are greatly indebted to our LGBT BPP Cancer Committee for this project. Without their sage voices we would have been unable to cull the information to present here. But the real value of this document now rests with you. You are the ones who will take this information and create better systems, policies, and practices out of these best and promising practices found in this report. It cannot happen soon enough.

Sincerely,

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A Program of CENTERLINK

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This report will improve the health of LGBT communities and reduce cancer disparities by providing the tools, i.e., best and promising practices, to improve the prevention, screening, diagnosis, treatment, survivorship, and end of life care for cancer.

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Part 1

Introduction & Methodology

My support system, many of whom are trans and gender variant people, were made to feel very uncomfortable by my doctors and medical staff due to disregard for pronoun use, sideways glances, and overall awkward responses. My friends composed my entire support system and were critical to my care. The reluctance to respectfully interact and, in some cases, communicate clearly with my friends was extraordinarily difficult for me and lead to much added stress. I already felt so alone without my family.

Introduction

To date, there has been little progress in the ability to measure cancer incidence, prevalence, and mortality among lesbian, gay, bisexual, and transgender (LGBT) communities. The lack of any substantial advancement towards reducing cancer morbidity and mortality continues to persist even after the 2011 Institute of Medicine report emphasized the continued lack of cancer data for LGBT communities to be problematic [i]. While there has been progress in adding sexual orientation and gender identity (SOGI) questions to a limited number of federal, state, and city population health surveys [ii], neither the National Cancer Institute(NCI)'s Surveillance, Epidemiology, and End Results (SEER) Program or the CDC's National Program of Cancer Registries (NPCR) collect SOGI data because data are not available to these cancer registry systems. Between NCI's SEER and CDC's NPCR there is a cancer registry funded in every state and together these surveillance systems collect data on cancer incidence and mortality for the entire U.S. population. These data are critical for health agencies, public health professionals, and researchers to report on cancer trends, assess the impact of cancer prevention and control efforts, and conduct research. Each cancer registry abstracts the data directly from patient medical records that usually includes some demographic data such as age, gender, and race/ethnicity. However, SOGI data are usually not included in patient medical records and therefor are not able to be systematically collected by either SEER or NPCR.

Although we still lack estimates of the cancer burden for LGBT communities from national and state cancer registries, as well as from large population studies, other studies in the scientific literature continue to produce findings showing that LGBT adults (compared to non-LGBT adults) are at higher risk for certain cancers and/or experience higher morbidity and mortality in relation to specific cancers [iv] [v] [vi] [vii] [viii]. Researchers are also beginning to find that LGB adolescents have significantly higher cancer-related risk behaviors associated with specific cancers when compared to their straight counterparts [ix]. These cancer-related risk behaviors are estimated to put LGB adolescents at a higher lifetime risk for certain cancers [x]. One follow up study, looking at a potential driver for cancer-related risk behaviors disparity for LGB adolescents, showed that a significant mediator is the amount of peer violence victimization experienced due to sexual orientation [xi]. Just as the scientific evidence continues to mount, so does the communities' anecdotal evidence documenting LGBT individuals experiencing discrimination and other barriers in accessing and receiving appropriate cancer care [xii]. This is exacerbated by research findings that reveal inconsistent or suboptimal cancer care of LGBT patients due to providers' lack of training to provide such care [xiii].

Unfortunately, the limited health data, including information on cancer, for LGBT communities is not new but has an ongoing effect on the ability to develop best and promising practices (BPPs) for the LGBT community. The result is that research and intervention programs, prevention and health care practices, and resources and policies that specifically address cancer in the LGBT communities are significantly lacking. The lack of BPPs that focus on LGBT cancer is even more alarming in view of the increasing research evidence highlighting cancer disparities for the LGBT communities. In fact, that alarm on cancer in LGBT communities was sounded four years ago by the Institute of Medicine in the 2011 report *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding* but remained unheeded. The same call was made 12 years earlier in the 1999 Institute of Medicine Report addressing the health of lesbians [xiv]. This report represents an intermediate step to address the continuing existing gaps throughout the cancer continuum and public health to better address cancer disparities in the LGBT communities.

Methodology

Harvesting promising practices and programs throughout the cancer continuum presents a challenge. The type of innovation associated with promising practices usually emerges in the programmatic world, through communities of cancer survivors, their support systems, prevention and health care providers, and allied organizations. These innovations usually serve an expressed need, but they rarely carry the level of rigorous evaluation necessary for a traditional best practice determination [xv]. As a result, this report utilized a multi-pronged approach to identify, collect, and assess these promising practices and programs. Many times the promising practices and programs are a direct derivative or modification of established best practices and comprehensive programs; at other times they are a result of needs not addressed by traditional academic research or government Agencies. In putting together the approach and the process to collect BPPs for LGBT cancer, the strategy used was adapted from the knowledge brokerage field where a component of the model is the syntheses of community knowledge and practice with general and specific research knowledge, with the goal of translating into practical applicability [xvi]. That method is built on Systematic Screening and Assessment (SSA), whose purpose is to identify, vet, and assess promising innovative programs [xvii].

The conceptual framework and approach provided by the knowledge brokerage field and the methods provided by SSA were modified in order to arrive at a collection of BPPs throughout the cancer continuum and public health systems for engaging LGBT communities. A panel of 13 experts from community and academia, prevention and health care systems, and public health met periodically by phone and twice in person over the course of 15 months. The LGBT BPPs Cancer Committee members work in different areas of the cancer continuum (from prevention to palliative care) and represent diverse viewpoints, interests, and knowledge about the LGBT community and cancer. Through an iterative process of looking at different cancer continuum models and federal and state cancer plans and models, the panel arrived at the six stage cancer continuum being used in this document and the five cross-cutting issues.

Six stage cancer continuum model

- Prevention and Health Promotion
- Early Detection/Screening
- Diagnosis
- Treatment
- Survivorship
- Palliative Care and End of Life

Five cross-cutting issues

- Sexual Orientation and Gender Identity (SOGI) Data Collection
- LGBT Culturally Competent Workforce
- LGBT Culturally Competent Health Care Systems
- Patient/Client Information and Education
- Diversity and Intersectionality

In 2014, the LGBT BPP Cancer Committee generated the initial set of BPPs for each of the six cancer continuum stages. Considering the importance of state and national public health leadership in addressing these issues, the Committee elected to separately address best practices for public health departments across each of the six stages. The cancer panel was also instrumental in knowledge synthesize and pressure testing the BPPs while incorporating input from the community. To solicit innovation from the community, the process included two waves of collecting input beyond the LGBT BPP Cancer Committee – thus in this case, "community" was defined broadly (e.g., cancer survivors and their support networks, professionals working in the area of cancer, and public health educators, decision makers, scientists, and health care providers). Community input was obtained mostly online, with a few exceptions where small in-person meetings were held. The first wave of online community input was hosted by the National LGBT Cancer Network. Multiple invitations asking for input were sent out by the National Cancer Network and LGBT HealthLink using various channels of communication (e-mail blasts, Facebook, Twitter, newsletters, postings on list-serves, and professional organizations alerts) with the goal of reaching a broad range of community members. The second wave of community input was purposely narrowed, and it targeted 60 cancer experts working in diverse disciplines ranging from prevention to palliative care who participated in the first ever National LGBT Cancer Action Plan Summit held in New York City on January of 2014 by the National LGBT Cancer Network.

Throughout the different stages of the process, the LGBT BPP Cancer Committee members assessed the weight of the evidence for the final list of BPPs and cross-cutting issues as well as associated each of the BPPs with the appropriate cross-cutting issues.

How to Use This Report

The LGBT Best and Promising Practices Throughout the Cancer Continuum report contains 68 BPPs across the six stages of the cancer continuum and 33 BPPs for public health departments. The implementation of these BPPs across different cancer prevention and treatment programs and facilities truly has the potential of making a significant impact in LGBT cancer health disparities. This report is created for health care providers, public health systems, and decision makers, enabling them to identify changes that would have the largest impact on the cancer risks and experiences of LGBT communities and offering clear guidance on implementing these BPPs throughout the cancer continuum. Equally, this report was created to be used by LGBT cancer survivors, those at risk, and their support networks as a tool to educate about the need for culturally competent care throughout the cancer continuum.

One of the main goals of LGBT HealthLink is to inform as many decision makers as possible about these best practices. LGBT HealthLink will be using this report as a guideline for technical assistance to LGBT community centers, governmental health departments, and allied cancer leaders. Contact LGBT HealthLink via e-mail at HealthLink@lgbtcenters.org or by calling 954-765-6024 for technical assistance to support implementation of these best practices. Visit our website at www.lgbthealthlink.org to download a free copy of this report and to access the web interface.

Part 2

Cross-Cutting Issues & Best and Promising Practices

Including SOGI in clinical records of cancer treatment patients creates the opportunity for measurement and improvement – including reducing disparities in access to care and health outcomes.

Cross-Cutting Issues

This report includes five cross-cutting issues, sometimes called overarching themes, which cut across the six stages of the cancer continuum and the public health section. Instead of just listing the cross-cutting issues for this document each of the best and promising practices (BPPs) has been associated with the pertinent cross-cutting issue(s). The five cross-cutting issues are not exhaustive but the five that are listed below are the most inclusive and universal among the BPPs in this report.

The five cross-cutting issues can also be found in different state cancer control plans, scientific literature, and as focus areas of work in various government agencies. These five issues were determined via an iterative process where each of the cross-cutting themes emerged from the initial collection of BPPs found in this report, then were reinforced via the weighing of the evidence using both the scientific and gray literature.

Data

Sexual Orientation and Gender Identity (SOGI) Data Collection – Collecting LGBT data as a core demographic variable, similar to race/ethnicity data in surveys and registries, should become the standard, not the exception, across the cancer continuum. The continued lack of SOGI data collection exacerbates LGBT invisibility and perpetuates LGBT cancer disparities, despite evidence of multiple disparities across the cancer continuum.

For example, successful data collection includes collecting SOGI measures in the following arenas:

- Research
- Evaluation
- Surveillance
- Clinical records and insurance claims data

Workforce

LGBT Culturally Competent Workforce – A requirement for providing a minimum standard of care for LGBT patients, clients, and their support systems of choice is a workforce that is culturally competent in meeting the needs of LGBT individuals, caregivers, and communities across the cancer continuum.

For example, the components of an LGBT culturally competent work force include:

- Training and continuing education on LGBT cancer topics for all levels of providers who have contact with patients and caregivers, including administrative and security staff
- Specific training on respectful and effective practices and communication

Systems

LGBT Culturally Competent Health Care Systems – Best practices call for changes in prevention and health care systems to improve health information, communication, informed decision making, and access to health services. Systemic changes in cancer care must be addressed separately from training the individuals who work within the system.

For example, needed system-wide changes include:

- Eliminating barriers to LGBT access, retention, and completion of cancer prevention and care
- Altering the health care environment, e.g., adding SOGI to intake forms and EHR, providing gender neutral bathrooms
- Addressing inequalities in policies, administration, and health insurance

Information

Patient/Client Information and Education – Health literacy for LGBT patients, clients, and their support systems of choice require culturally competent health education resources. Such resources will help patients and clients to understand basic health information, navigate available services, and make appropriate health decisions throughout the cancer continuum. Targeted resources and programs need to be developed as a measurable standard across the cancer continuum.

For example, successful information and education programs include:

- LGBT-specific, tailored interventions across the cancer continuum
- LGBT-specific health promotion materials and events
- Targeted LGBT tools and referrals
- Funding and collaboration for community empowerment

Diversity

Diversity and Intersectionality – Best Practices in LGBT cancer care require an understanding of the diversity of LGBT personal and community identities. Individual LGBT identities and the LGBT communities are shaped by a host of characteristics that include, but are not limited to, race/ethnicity, social class/economic status, sexual orientation, gender identity and expression, nationality, disability, individual health care history, oppression, and discrimination. These intersectional characteristics have different significance, expression, and denote different needs throughout the cancer continuum.

For example, a successful focus on diversity and intersectionality includes:

- Encouraging disclosure of layered LGBT identities
- Recognizing the diverse family and support systems of choice in LGBT communities
- Understanding the role of social determinants of health for LGBT individuals and communities
- Addressing the multiple stigmas many LGBT patients experience in healthcare
- Sensitivity to comorbidities in the LGBT health disparities, including those diagnoses overrepresented in the LGBT communities

Prevention/Health Promotion

This section contains best and promising practices in the arena of health promotion and cancer prevention (primary through tertiary). Overall, these practices focus on ensuring a culturally competent health promotion workforce and on engaging and empowering the LGBT communities. Historically, local LGBT health promotion groups have focused primarily on HIV/AIDS and STIs (Sexually Transmitted Infections) care. Issues such as cancer, cancer risk factors, and social determinants of cancer-related health have not been identified or addressed for the LGBT community due to a lack of systematic data collection. To promote LGBT cancer-related health, we must identify LGBT individuals in the population at large, develop tailored prevention and health promotion messages in collaboration with LGBT communities, and develop interventions that address social determinants of health and cancer risk factors. Finally, we must empower individuals and communities to develop sustainable, community-based interventions to improve or maintain health. All of these best practices must be embedded within a culturally competent and culturally safe health care system operating across the cancer continuum.

PREVENTION/HEALTH PROMOTION – Best and Promising Practices	**Cross-cutting Issues**
Include SOGI questions on population-based surveillance instruments supported through government funds. • For example, BRFSS, NHANES, NHIS, YRBSS	Data
Involve culturally competent and trained community health workers to augment and/or deliver prevention and health promotion messages. • For example, health educators such as promotoras, navigators, popular opinion leaders, LGBT peer leaders	Workforce
Ensure that disclosure of SOGI and sexual behavior is safe (confidential, private, affirming, accepted without judgment) during all individual intake and clinical/community encounters.	Workforce Systems
Recognize that disclosure of layered and intersectional identities is complicated for LGBT individuals seeking health prevention services. They must negotiate whether and how to come out to multiple providers about being LGBT.	Workforce Systems Diversity
Cultural competence to conduct LGBT health promotion activities should involve measurable competencies, including but not limited to a measure of engagement with the local LGBT communities.	Workforce Information

PREVENTION/HEALTH PROMOTION – Best and Promising Practices	Cross-cutting Issues
Provide ongoing education on LGBT cultural competence to the entire health care work force, especially those that interact with LGBT patients, their family, and their chosen support person(s).	Workforce Diversity
Create a welcoming and safe environment for LGBT patients (including but not limited to gender-neutral restrooms, physical and virtual environments, forms, health literature, and in-person communications occurring in the health setting).	Systems
Acknowledge and prioritize health promotion programs in consultation and collaboration with the LGBT communities within your service area to ensure that messages are targeting the communities' perceived needs.	Systems Information
Develop and implement effective guidelines, interventions, and programs aimed at decreasing the cancer burden for LGBT populations, with intentional and careful adaptation for all segments of the LGBT communities.	Systems Information Diversity
Develop and/or implement LGBT- specific health education and prevention messages, materials (print and online), and resources, developed in consultation with community advisory boards and other consumer groups.	Information Diversity

Early Detection/Screening

This section contains best and promising practices related to cancer screening in the LGBT communities. Given that the LGBT community has higher rates of cancer-related risk factors, such as smoking and infection with HIV/AIDS and other STIs (Sexually Transmitted Infections), culturally competent screening practices are essential for this population. Incidence and mortality rates of cancer have been decreasing in the United States; research to date anticipates a correlation with a reduction in risk factors like smoking. However, we do not yet know if this trend is reflected in the LGBT communities. Implementing culturally competent practices for screening in the LGBT communities can reduce the public health burden of cancer through early detection and early treatment in this underserved group.

EARLY DETECTION/SCREENING – Best and Promising Practices	**Cross-cutting Issues**
Identify LGBT individuals who are at higher risk for cancer and revise screening guidelines to incorporate LGBT-inclusive risk assessment.	Data Systems
Train all staff (all levels) in providing culturally competent service to LGBT patients, their family, and their chosen support person(s) throughout the screening process.	Workforce
Identify, use, and refer to screening facilities known to be culturally competent in delivering health services to LGBT individuals.	Workforce
Develop and/or use LGBT-tailored cancer screening guidelines for LGBT communities.	Workforce Information Diversity
Engage culturally competent patient navigators for LGBT patients from the time of screening through the cancer care continuum.	Workforce Information Diversity

EARLY DETECTION/SCREENING – Best and Promising Practices	Cross-cutting Issues
Eliminate discriminatory and arbitrary exclusion from screening procedures due to discordance between gender markers and anatomy.	Systems
Work with the local LGBT communities to identify and reduce regional and specific barriers to timely cancer screening.	Systems
Ensure that LGBT patients receive prompt follow up after abnormal screening results, as well as timely and culturally competent coordination of transition to cancer care in order to mitigate attrition and delays.	Systems Information
Include LGBT individuals’ support networks (i.e., family of choice) whenever possible during screening process and procedures.	Systems Diversity
Tailor screening messages and utilize effective media with particular attention to diverse sub-groups within LGBT communities. • For example, involve screening messengers, ambassadors, and witnesses known as credible in their respective communities	Information Diversity
Educate the LGBT communities about the importance of cancer screening, with emphasis on malignancies that disproportionately affect LGBT individuals, using a variety of media and campaigns shown to be effective or promising with LGBT communities in general and/or with specific sub-groups.	Information Diversity

Diagnosis

This section contains best and promising practices to better serve LGBT patients and their support networks through cancer diagnosis. These practices focus on ensuring that diagnostic modalities are applied in an appropriate and culturally competent manner to the LGBT communities. Implementation of these best and promising practices may reduce disparities in access to diagnostics and disparate health outcomes including morbidity and mortality.

DIAGNOSIS – Best and Promising Practices	Cross-cutting Issues
Collect relevant diagnostic SOGI data in SEER, NPCR, and other population-based registries and databases.	Data
Collect and include SOGI data in patient intake and registration forms, medical records, patient satisfaction surveys, and health outcome measures. Then ensure SOGI data are collected in cancer registries, other population-based registries, and databases.	Data Systems
Include LGBT individuals in research trials of diagnostic tests.	Data Systems
Ensure health care providers are knowledgeable of unique health care needs of LGBT individuals.	Workforce
Develop guidelines for culturally competent LGBT patient navigation programs including training for all patient navigators.	Workforce Systems
Train all staff who interact with patients/caregivers (including clerical, technicians, patient navigator, pharmacy, housekeeping, food service, etc.) in LGBT cultural competence.	Workforce Diversity

DIAGNOSIS – Best and Promising Practices	Cross-cutting Issues
Mitigate delays and attrition between screening and diagnosis, and between diagnosis and treatment in compliance with established guidelines by ensuring timely and culturally competent coordination of care.	Systems
Provide gender-neutral diagnostic facilities and programs – particularly in relation to gendered cancers (e.g., breast or gynecological cancers) that may take place in gender-specific facilities.	Systems
Eliminate discriminatory and arbitrary exclusion from diagnostic testing (e.g., due to discordance between gender markers and anatomy).	Systems Information Diversity
Anticipate, identify, and eliminate barriers to diagnostic procedures for LGBT individuals and communities.	Systems Diversity
Include patients' support networks (i.e., family of choice) during diagnosis and decision making.	Systems Diversity
Develop and distribute culturally appropriate information materials at time of diagnosis, procedures, and at follow-up appointments.	Information

Treatment

This section contains best and promising practices to better serve LGBT patients and their support networks throughout cancer treatment. These practices focus on ensuring that treatment modalities are provided in an appropriate and culturally competent manner to the LGBT communities and that disparities in treatment outcomes are detected and eliminated by including SOGI status in relevant data collection. Implementation of these best and promising practices will reduce disparities in access to treatment and health outcomes, including quality of life as well as morbidity and mortality.

TREATMENT – Best and Promising Practices	Cross-cutting Issues
Collect relevant diagnostic SOGI data in SEER, NPCR, and other population-based registries and databases.	Data
Include SOGI categories as part of core demographic data in clinical studies/trials and a requirement for human subject research.	Data Systems
Collect SOGI data in patient intake forms, clinical encounters, patient satisfaction surveys, and health outcome measures. Then ensure SOGI data are collected in cancer registries, other population-based registries, and databases.	Data Systems
Maintain appropriate hormone regimens and transition-related services for transgender and gender variant patients during cancer treatment as a standard of care, in the absence of compelling data to the contrary.	Workforce
Ensure compliance with treatment guidelines regardless of SOGI or gender transition care.	Workforce Systems
Ensure nondiscrimination on the basis of SOGI in hospital visitation, surrogate medical decision making, etc. for Centers for Medicare & Medicaid Services and Joint Commission Accrediting Standards.	Workforce Systems

TREATMENT – Best and Promising Practices	Cross-cutting Issues
Include LGBT topics in all cultural competence training across the health care treatment workforce (including clerical, technicians, patient navigator, pharmacy, housekeeping, food service, etc.).	Workforce Diversity
Encourage the inclusion of LGBT subjects in all public and private cancer research.	Systems
In the absence of LGBT-specific treatment guidelines, follow standard of care/current treatment data to meet the standard of care.	Systems
Ensure timely and culturally competent coordination of care in order to mitigate delays and attrition between screening and diagnosis and between diagnosis and treatment to comply with established guidelines.	Systems
Provide gender neutral diagnostic facilities and programs for all cancers, including cancers traditionally treated in gender-specific facilities.	Systems
Address sexual intimacy and other quality of life (e.g., fertility, gender reassignment surgery) concerns as they relate to treatment options.	Systems Information
Be aware of and responsive to barriers based on SOGI in symptom management.	Systems Information

Survivorship

A small but growing body of research confirms that LGBT cancer survivors experience additional challenges in survivorship and that these needs are rarely adequately addressed by traditional health and social services. This section contains best and promising practices that will help LGBT survivors and their support networks (i.e., family of choice) to eliminate disparate health outcomes.

SURVIVORSHIP – Best and Promising Practices	Cross-cutting Issues
Fund and conduct research on the effectiveness of multiple intervention strategies with LGBT cancer patients/survivors.	Data
Offer LGBT cancer survivors access to culturally competent support services either through the creation of LGBT-specific support groups, referrals to community groups, or at a minimum training support service staff to provide LGBT culturally competent care.	Workforce Systems
Offer LGBT families of choice access to culturally competent support services either through the creation of LGBT-specific groups, referrals to community groups, or at a minimum training support service staff to provide LGBT culturally competent care.	Workforce Systems
Avoid gendered assumptions (e.g., breast reconstruction always being desired), including battle metaphors (e.g., fighting cancer) when providing services to LGBT cancer survivors.	Workforce Information
Train all staff who interact with LGBT patients/caregivers (including clerical, technicians, patient navigator, social work, pharmacy, housekeeping, food service, etc.) in culturally competent language and LGBT survivorship issues.	Workforce Diversity

SURVIVORSHIP – Best and Promising Practices	Cross-cutting Issues
Provide cultural and age appropriate cancer services to LGBT youth survivors.	Workforce Diversity
Recognize the complexity of disclosure for LGBT survivors who must negotiate whether and how to come PALLIATIVE out to multiple providers about being SOGI and to potential sexual partners about their cancer status. Respect that sometimes withholding is safer.	Workforce Diversity
Address directly (or via referral) the legal and financial impact of cancer on LGBT individuals and their families of choice.	Systems Information
Develop protocols for protecting the fertility options of LGBT cancer patients prior to treatment and include survivors in decision making about fertility.	Systems Information
Offer LGBT survivors and their family of choice culturally competent information about the impact of cancer treatment on their sexual health, intimacy, and reproductive health.	Information

Palliative Care & End of Life

There is growing awareness of the bias and discrimination experienced by LGBT individuals, their partners, and caregivers. We have seen shifts in societal attitudes as well as expanded legal protections in areas such as hospital visitation rights and surrogate medical decision making. However, discrimination continues and is especially problematic when navigating health care systems including hospice and palliative care settings. LGBT individuals may distrust specific aspects of palliative medicine teams such as pastoral care because of past rejections by faith-based communities. Other barriers to culturally competent hospice and palliative care include social and familial rejection, fear of revealing minority status, lack of legal protections, and fear of discrimination at the end of life.

PALLIATIVE CARE & END OF LIFE – Best and Promising Practices	Cross-cutting Issues
Create open-access registries with ratings of hospices' and health care organizations' cultural competence in caring for LGBT patients.	Data
Include SOGI variables in quality of care metrics and professional organizations, and consumer surveys.	Data
Collect SOGI data for all patients at initial encounters, and create individualized plans in regard to disclosure or nondisclosure of SOGI to others.	Data Systems
Conduct research on the end-of-life/chronic illness experiences of LGBT patients and their caregivers, including the development of LGBT-specific psychosocial, spirituality, and existential distress measures.	Data Diversity
Provide in-person and/ or virtual access to culturally competent and/or LGBT-specific bereavement programs for LGBT support networks (i.e., family of choice), recognizing the increased risk for disenfranchised grief.	Workforce Systems
Address the increased risk of mental health problems and unique psychosocial barriers that exist for some LGBT cancer patients, and ensure that existing quality standards for pain and symptom management are met.	Workforce Systems
Provide ongoing training to all hospice/palliative care providers and staff to ensure culturally competent care to LGBT patients and families of choice in all care settings (including hospice, long-term care, and skilled nursing facilities).	Workforce Information

PALLIATIVE CARE & END OF LIFE – Best and Promising Practices	Cross-cutting Issues
Address the complex spiritual needs of LGBT patients and families of choice with awareness of the fear and distrust of faith-based communities experienced by many LGBT communities. This includes respecting the choice of not wanting spiritual/pastoral care.	Workforce Diversity
Ensure timely care coordination for LGBT patients including prompt referral to culturally competent palliative care providers soon after diagnosis to reduce distress, improve symptom management, and increase retention in treatment.	Systems
At the end-of-life, dignified death is a priority for LGBT patients. Unique topics such as continuation of hormone therapy for transgender patients as well as respect for patient choice of burial and death rituals need to be addressed.	Systems Information Diversity
Include psychosocial distress, suicide risk, financial planning, relationship with family of origin, and current families of choice when performing screening and intake of LGBT cancer patients.	Systems Diversity
Discuss and formalize surrogate decision-making during initial patient encounter, including medical proxy documentation, formalization of custody of dependent children, and hospital visitation forms. Recognize that it is a patient's legal right to include family of choice. These discussions must reflect rapidly changing laws, regulations, and accrediting standards at the national, state, and institutional levels. Advance directives and Physician Orders for Life Sustaining Treatment (POLST) should follow patients across multiple care settings.	Systems Diversity

Public Health Departments

Health Departments play a critical role in creating and supporting systems and environmental change initiatives that improve access to culturally competent care across the cancer continuum. This section contains best and promising practices for Public Health Departments to reduce barriers to health care and disease prevention as well as enhancing a culturally competent workforce to improve care.

Implementing these measures will promote health equity for the LGBT community, a historically marginalized and vulnerable population experiencing discrimination and barriers to care.

Prevention/Health Promotion

Recommendations for Public Health Departments	Cross-cutting Issues
Include SOGI data in risk and behavioral surveillance tools, Behavioral Risk Factor Surveillance System (BRFSS), Youth Behavioral Risk Factor Surveillance System (YRBSS), Adult Tobacco Survey (ATS), etc.	Data
Identify LGBT liaison(s) (point person) to provide cross-cutting subject matter expertise on LGBT issues.	Workforce
Collaborate with community partners on LGBT-tailored prevention and health promotion activities.	Workforce Diversity
Seek and fund programs and campaigns that address LGBT cancer prevention and health promotion.	Systems
Enhance patient navigation projects (where available) to provide culturally relevant services for LGBT cancer survivors.	Systems
Implement and support LGBT-tailored programs, messages, and policies that improve access to physical activity, nutrition, obesity prevention, smoking cessation, cancer awareness, cancer related vaccines (i.e., human papillomavirus (HPV) immunizations), and chronic disease programs.	Systems Information
Include LGBT communities in state cancer plans.	Systems Information Diversity

Prevention/Health Promotion

Recommendations for Public Health Departments	Cross-cutting Issues
Include LGBT community-based organizations in state cancer coalitions.	Systems Diversity
Integrate lessons learned from established Department of Health programs that have existing relationships with LGBT communities (i.e., HIV/AIDS, tobacco).	Information

Early Detection/Screening

Recommendations for Public Health Departments	Cross-cutting Issues
Include LGBT as a designated special population in cancer screening programs funded by Health Departments to ensure there is adequate tailored outreach, tailored services, and program monitoring.	Data
Provide management, leadership, and coordination for LGBT-centered screening promotions.	Workforce Systems Information
Adopt federal model (per Executive Order 13672) of requiring LGBT non-discrimination policy statements for all Health Department-funded entities.	Systems
Establish partnerships with multiple (3 minimum, local or national) LGBT organizations to vet and provide technical assistance in the development and implementation of screening campaigns/materials.	Systems Information
Support culturally competent delivery of services that increase access to and utilization of cancer screening.	Systems Diversity
Support recruitment and utilization of patient navigators that are culturally competent and sensitive to the disparities and needs of the LGBT population.	Systems Diversity

Public Health Departments

Diagnosis

Recommendations for Public Health Departments	Cross-cutting Issues
Educate about the need for NAACR standards to include SOGI	Data
Collaborate with NPCR, SEER, ACS, and others on the reporting of SOGI data as part of cancer incidence and mortality publications.	Data
Support policies and programs that address LGBT compliance with established clinical time intervals from screening to diagnosis.	Systems

Treatment

Recommendations for Public Health Departments	Cross-cutting Issues
Educate appropriate bodies about the importance of LGBT cultural competence training as part of provider licensing.	Workforce
Provide LGBT-focused CME trainings for health care providers.	Workforce
Establish and support incentive programs that address LGBT health care provider shortages.	Workforce
Support policies that address and encourage LGBT culturally competent treatment.	Workforce Systems
Support policies and programs to improve LGBT compliance with established clinical time intervals from screening to treatment.	Systems
Collaborate with hospitals and other health care systems to include LGBT issues in Patient Bill of Rights.	Systems Information
Create and/or expand culturally competent LGBT provider listings/registries.	Systems Information Diversity

Survivorship

Recommendations for Public Health Departments	Cross-cutting Issues
Eliminate barriers to access.	Systems
Collaborate with hospitals and other health care systems to include LGBT issues in Treatment Summaries and Cancer After Care Plans/ Survivorship Care Plans.	Systems
Develop and maintain a list of LGBT culturally competent support groups, programs, and resources.	Systems Information
Support policies, systems change, research, and programs that enhance survivorship for LGBT patients and their families (legal, psychosocial, employment, primary care, nutrition support, access to care, etc.).	Information

End of Life/Palliative Care

Recommendations for Public Health Departments	Cross-cutting Issues
Support training for palliative care and hospice providers on LGBT cultural competence.	Workforce Diversity
Eliminate barriers to access.	Systems
Support policies, systems change, research, and programs that increase the availability of culturally competent end-of-life and palliative care for the LGBT community.	Systems Information
Support LGBT-tailored interventions and health promotion.	Information Diversity

Part 3

Glossary of Terms and References

The most important thing to remember when dealing with health in the LGBTQ community...is that for many, their past experiences with health care providers have often not been pleasant. Patience and awareness when it comes to language within the LGBTQ community can be particularly helpful and comforting.

Glossary of Terms

Acronym	Meaning
ACS	American Cancer Society
AIDS	Acquired Immune Deficiency Syndrome
BPP	Best and Promising Practices
BRFSS	Behavioral Risk Factor Surveillance System
CME	Continuing Medical Education
EHR	Electronic Health Records
HIV	Human Immunodeficiency Virus
LGBT	Lesbian, Gay, Bisexual, Transgender
NAACR	North American Association of Central Cancer Registries
NPCR	National Program of Cancer Registries
NHANES	National Health and Nutrition Examination Survey
NHIS	National Health Interview Survey
SEER	Surveillance, Epidemiology, and End Results Program
SOGI	Sexual Orientation and Gender Identity
YRBSS	Youth Risk Behavior Surveillance System

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