CenterLink

✓ Nonprofit founded in 1994

✓ Helps develop strong, sustainable LGBT community centers with national network of 180+ organizations

✓ Builds a thriving network of centers for healthy, vibrant communities

✓ Recognized by the White House as a “Champion of Change”
Advance LGBT wellness by addressing LGBT tobacco and cancer health disparities

Link people with information and promote adoption of best practices

One of eight CDC-funded cancer and tobacco disparity networks

www.lgbthealthlink.org
LGBT HealthLink Partners

So No One Faces Cancer Alone®
LGBT 101
About LGBT Communities

- LGBT is NOT one single community
- There are an estimated 9 million LGBT individuals in the U.S.\(^{(3)}\) across all congressional districts
- LGBT people face isolation, violence, overt discrimination and inequitable benefits and policies, including access to health services
- LGBT communities tend to lack trust with institutions and government
- Strong LGBT community structures exist that offer social support, legal assistance, health services, and provide an organized platform
- Partnership with LGBT communities is largely an UNTAPPED resource for change
Our Alphabet

• L = Lesbian
• G = Gay
• B = Bisexual
• T = Transgender
• Q = Queer or Questioning
• I = Intersex
• A = Asexual or Allies
Gender Identity

• Transgender: term to describe those whose sex assigned at birth does not match their gender identity

• Cisgender: sex assigned at birth matches gender identity (those who are not transgender)

• Gender Binary: socially constructed dichotomy of male or female

• Gender non-conforming: those who don’t fit into gender binary notion (gender expansive, pansexual, non-binary, genderqueer, gender-fluid)
## Categories & Descriptors

### SEX
- Male
- Female

### SEXUAL ORIENTATION
- Lesbian
- Gay
- Bisexual
- Heterosexual
- Queer or Questioning
- Asexual

### GENDER/GENDER ROLE
- Man/Masculine
- Woman/Feminine

### GENDER IDENTITY
- Transgender
- Transsexual
- Man
- Woman
- Non-binary
- Queer or Genderqueer
Pronouns

• Everyone has the right to determine their own appropriate pronouns

• As healthcare professionals, it is important to respect the identity and terms your client/patient uses/is comfortable with

• Pronouns may include:
  – He/Him/His
  – She/Her/Hers
  – Gender-neutral
    • They/Them/Theirs
    • Others
Cancer in LGBT Communities
Cancer in LGBT Communities

• Data is limited
  – Lack of data collection
  – Lack of an evidence base to justify policy and research attention

• Lack of data prevents identification of disparities
  – Resulting in lack of tailored resources to support LGBT population
  – Lack of specialized and culturally competent programs
  – Insufficient info to develop LGBT-specific screening guidelines
  – Lack of best practices for LGBT communities

• Alarming, due to the increasing evidence of LGBT cancer disparities
SMW & Breast Cancer

• Risks:
  – Smoking
  – Alcohol
  – Obesity
  – Fewer pregnancies and breastfeeding
  – Data contradictory but likely lower rates of mammography screenings
SMW & Cervical Cancer

• Risks:
  • Smoking
  • HIV and AIDS
  • Lower rates of Pap screenings
  • Lower rates of HPV vaccinations
SMW & Colorectal Cancer

• Risk Factors:
  • Overweight
  • Alcohol use
  • Smoking
  • Inactivity
  • Possible lower rates of sigmoidoscopy, colonoscopy, etc.
WHY ARE WE LESS LIKELY TO ACCESS CARE?
Cancer in LGBT Communities

• History of discrimination in healthcare systems
  – Avoidance of healthcare = fewer advance screenings, early detection, and treatment/survivorship
  – And LGBT people may be less likely to get cancer screenings if they feel uncomfortable or are not “out” to their provider \(^8\)
  – Indeed, 28% of transgender individuals have delayed seeking care due to fear of discrimination \(^9\)
Cancer in LGBT Communities

• Lower rates of health insurance
  – Many health insurance policies don’t cover unmarried partners. This makes it harder for many lesbians and bisexual women to get quality health care.¹

• Many employers do not offer coverage for unmarried domestic partners.
• Does she feel safe coming out to an oncologist?
• Option to join lesbian cancer support group?
• Feel safe at support group comprised of straight women?
• Female partner feel comfortable discussing effect of chemo on sex life in room full of men?
• Uninsured highest among trans
• Trans women, listed as female on insurance, not covered for prostate screening
• Same true for trans man with an intact cervix
• Little known about potential risks associated with trans hormone use
• Trans have high rates of smoking, drinking, and HIV
HOW DO WE ADDRESS THESE ISSUES?
LGBT Best & Promising Practices throughout the Cancer Continuum

• Across six stages, five cross-cutting issues:
  • SOGI Data Collection
  • LGBT Culturally Competent Workforce
  • LGBT Culturally Competent Healthcare Systems
  • Patient/Client Information & Education
  • Diversity and Intersectionality
### BEST AND PROMISING PRACTICES

Include SOGI questions on population-based surveillance instruments supported through government funds.
- For example, BRFSS, NHANES, NHIS, YRBSS

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

Ensure that disclosure of SOGI and sexual behavior is safe (confidential, private, affirming, accepted without judgment) during all individual intake and clinical/community encounters.

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.

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.
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).

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).

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.

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.

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.
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 care and 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

<table>
<thead>
<tr>
<th>Recommendations for Public Health Departments</th>
<th>Cross-cutting Issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>Include SOCI 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.</td>
<td><img src="https://via.placeholder.com/150" alt="Image" /></td>
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<tr>
<td>Identify LGBT liaison(s) (point person) to provide cross-cutting subject matter expertise on LGBT issues.</td>
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<tr>
<td>Collaborate with community partners on LGBT-tailored prevention and health promotion activities.</td>
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<tr>
<td>Seek and fund programs and campaigns that address LGBT cancer prevention and health promotion.</td>
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</tr>
<tr>
<td>Enhance patient navigation projects (where available) to provide culturally relevant services for LGBT cancer survivors.</td>
<td><img src="https://via.placeholder.com/150" alt="Image" /></td>
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<tr>
<td>Implement and support LGBT-tailored programs, messages, and policies that improve access to physical activity, nutrition, obesity prevention, smoking cessation, cancer awareness, cancer prevention (i.e., human papillomavirus (HPV) immunizations), and chronic disease programs.</td>
<td><img src="https://via.placeholder.com/150" alt="Image" /></td>
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<tr>
<td>Include LGBT communities in state cancer plans.</td>
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</table>
Work with the local LGBT communities to identify and reduce regional and specific barriers to timely cancer screening.

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.

Include LGBT individuals’ support networks (i.e., family of choice) whenever possible during screening process and procedures.

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

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.
# Early Detection/Screening

## Recommendations for Public Health Departments

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<tr>
<td>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.</td>
<td>Data</td>
</tr>
<tr>
<td>Provide management, leadership, and coordination for LGBT-centered screening promotions.</td>
<td>Workforce, Systems, Information, Systems, Information</td>
</tr>
<tr>
<td>Adopt federal model (per Executive Order 13672) of requiring LGBT non-discrimination policy statements for all Health Department-funded entities.</td>
<td>Systems</td>
</tr>
<tr>
<td>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.</td>
<td>Systems, Information</td>
</tr>
<tr>
<td>Support culturally competent delivery of services that increase access to and utilization of cancer screening.</td>
<td>Systems, Diversity</td>
</tr>
<tr>
<td>Support recruitment and utilization of patient navigators that are culturally competent and sensitive to the disparities and needs of the LGBT population.</td>
<td>Systems, Diversity</td>
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### Best and Promising Practices

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<tr>
<td>Collect relevant diagnostic SOGI data in SEER, NPCR, and other population-based registries and databases.</td>
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<td>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.</td>
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<tr>
<td>Include LGBT individuals in research trials of diagnostic tests.</td>
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<tr>
<td>Ensure health care providers are knowledgeable of unique health care needs of LGBT individuals.</td>
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<tr>
<td>Develop guidelines for culturally competent LGBT patient navigation programs including training for all patient navigators.</td>
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<tr>
<td>Train all staff who interact with patients/caregivers (including clerical, technicians, patient navigator, pharmacy, housekeeping, food service, etc.) in LGBT cultural competence.</td>
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</table>
## Diagnosis

### Recommendations for Public Health Departments

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<tr>
<td>Educate about the need for NAACR standards to include SOGI</td>
<td>Data</td>
</tr>
<tr>
<td>Collaborate with NPCR, SEER, ACS, and others on the reporting of SOGI data as part of cancer incidence and mortality publications.</td>
<td>Data</td>
</tr>
<tr>
<td>Support policies and programs that address LGBT compliance with established clinical time intervals from screening to diagnosis.</td>
<td>Systems</td>
</tr>
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<tr>
<td>Include SOGI categories as part of core demographic data in clinical studies/trials and a requirement for human subject research.</td>
<td></td>
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<tr>
<td>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.</td>
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<tr>
<td>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.</td>
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<tr>
<td>Ensure compliance with treatment guidelines regardless of SOGI or gender transition care.</td>
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<tr>
<td>Ensure nondiscrimination on the basis of SOGI in hospital visitation, surrogate medical decision making, etc. for Centers for Medicare &amp; Medicaid Services and Joint Commission Accrediting Standards.</td>
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</tr>
</tbody>
</table>
Include LGBT topics in all cultural competence training across the health care treatment workforce (including clerical, technicians, patient navigator, pharmacy, housekeeping, food service, etc.).

Ensure the inclusion of LGBT individuals in all private and public human subjects cancer research.

In the absence of LGBT-specific treatment guidelines, follow standard of care/current treatment data to meet the standard of care.

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.

Provide gender neutral diagnostic facilities and programs for all cancers, including cancers traditionally treated in gender-specific facilities.

Address sexual intimacy and other quality of life (e.g., fertility, gender reassignment surgery) concerns as they relate to treatment options.

Be aware of and responsive to barriers based on SOGI in symptom management.
## Treatment

### Recommendations for Public Health Departments

- Educate appropriate bodies about the importance of LGBT cultural competence training as part of provider licensing.

- Support policies and programs to improve LGBT compliance with established clinical time intervals from screening to treatment.

- Collaborate with hospitals and other health care systems to include LGBT issues in Patient Bill of Rights.
### BEST AND PROMISING PRACTICES

**Fund and conduct research on the effectiveness of multiple intervention strategies with LGBT cancer patients/survivors.**

**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.**

**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.**

**Avoid gendered assumptions (e.g., breast reconstruction always being desired), including battle metaphors (e.g., fighting cancer) when providing services to LGBT cancer survivors.**

**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.**
Provide cultural and age appropriate cancer services to LGBT youth survivors.

Recognize the complexity of disclosure for LGBT survivors who must negotiate whether and how to come out to multiple providers about being SOGI and to potential sexual partners about their cancer status. Respect that sometimes withholding is safer.

Address directly (or via referral) the legal and financial impact of cancer on LGBT individuals and their families of choice.

Develop protocols for protecting the fertility options of LGBT cancer patients prior to treatment and include survivors in decision making about fertility.

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.
## Survivorship

### Recommendations for Public Health Departments

1. Eliminate barriers to access.

2. Collaborate with hospitals and other health care systems to include LGBT issues in Treatment Summaries and Cancer After Care Plans/Survivorship Care Plans.

3. Develop and maintain a list of LGBT culturally competent support groups, programs, and resources.

4. 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.).

### Cross-cutting Issues

- Systems
- Information
<table>
<thead>
<tr>
<th>BEST AND PROMISING PRACTICES</th>
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</thead>
<tbody>
<tr>
<td>Create open-access registries with ratings of hospices’ and health care organization’s cultural competence in caring for LGBT patients.</td>
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<tr>
<td>Include SOGI variables in quality of care metrics and professional organizations, and consumer surveys.</td>
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<tr>
<td>Collect SOGI data for all patients at initial encounters, and create individualized plans in regard to disclosure or nondisclosure of SOGI to others.</td>
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<tr>
<td>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.</td>
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</tr>
<tr>
<td>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.</td>
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</tr>
<tr>
<td>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.</td>
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<tr>
<td>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).</td>
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</tbody>
</table>
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.

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.

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.

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.

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.
# LGBT Best & Promising Practices throughout the Cancer Continuum

## End of Life/Palliative Care

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<thead>
<tr>
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<tbody>
<tr>
<td>Support training for palliative care and hospice providers on LGBT cultural competence.</td>
<td><img src="image1" alt="Workforce" /> <img src="image2" alt="Diversity" /></td>
</tr>
<tr>
<td>Eliminate barriers to access.</td>
<td><img src="image3" alt="Systems" /></td>
</tr>
<tr>
<td>Support policies, systems change, research, and programs that increase the availability of culturally competent end-of-life and palliative care for the LGBT community.</td>
<td><img src="image4" alt="Information" /> <img src="image5" alt="Diversity" /></td>
</tr>
<tr>
<td>Support LGBT-tailored interventions and health promotion.</td>
<td><img src="image6" alt="Information" /> <img src="image7" alt="Diversity" /></td>
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</tbody>
</table>
Success Stories: Strategies to Reach Out to the LGBT Communities

- Leadership
- Provision of care, treatment, and services
- Culturally Competent Workforce
- Data collection and use
- Patient, family (family of choice), and community engagement
Closing Thoughts

• LBT stressors can lead to risk behaviors
• Lack of insurance and lack of trust are LGBT barriers to care
• Physicians must set welcoming and accepting tone with open-ended questions and without judgement
• Use trusting relationship for open dialogue around LBT risks
• Patient, family (family of choice), and community engagement
• ACA & same-sex marriage ruling have helped but more needed
JOIN THE MOVEMENT TO ACHIEVE LGBT HEALTH EQUITY!

www.myLgbthealthlink.org

HealthLink members have access to:

• Weekly LGBT Health News Roundup
• Scholarships to help support and promote leadership in LGBT health
• Members-only online networking groups
• Exclusive webinars and resources available for download
• Co-branding opportunities

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