Cancer Health™

How to Improve Cancer Outcomes for LGBTQ Patients

An NCCN summit highlights the barriers to high-quality care that LGBTQ people with cancer experience.

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On December 2, the National Comprehensive Cancer Network (NCCN)—an alliance of leading cancer centers—hosted its annual NCCN Patient Advocacy Summit. This year's dialogue was focused on sexual orientation and gender identity (SOGI), and the many barriers that can prevent LGBTQ+ people with cancer from accessing high-quality care. The impact of homophobia, transphobia, and social determinants of health have been shown to result in worse outcomes for vulnerable populations, particularly when intersecting with the effects of systemic racism. Speakers at NCCN's patient advocacy summit examined interpersonal and systems level inequities that drive poorer outcomes for this community along with opportunities to improve care access and quality.

"We can't say this enough, there is no high-quality cancer care without equitable cancer care. That means recognizing and addressing the specific hardships facing members of the LGBTQ+ community that can prevent people from having supportive and affirming experiences with health care," said Robert W. Carlson, MD, Chief Executive Officer, NCCN. "Cancer care providers work hard every day to stay up-to-date on the latest innovations, research, and guidelines. Making sure we provide inclusive care is just as impactful, if not more-so, for improving outcomes and helping all people with cancer live better lives."

The summit included a welcome message from Admiral Rachel L. Levine, MD, Assistant Secretary for Health, Department of Health and Human Services, and a keynote address from Dora Hughes, MD, MPH, Chief Medical Officer, Centers for Medicare and Medicaid Innovation.

Panel discussions on breaking barriers and best practices for advancing equity were moderated by Clifford Goodman, PhD, Senior Vice President, The Lewin Group and included Earl Fowlkes, President/CEO, Center for Black Equity and Bláz Bush, MEd, Executive Director, LGBTQ+ Health Program, Stanford Medicine.

"Many gaps in our understanding of sexual and gender minority health persist due to insufficient, inaccurate, and inconsistent data collection on sex, gender identity, and sexual orientation;" noted panelist Karen L. Parker, PhD, MSW, Director of the Sexual & Gender Minority Research Office (SGMRO), National Institutes of Health (NIH). “To improve cancer-related health outcomes for sexual and gender minority communities, we must first ensure that data on sexual orientation, gender identity, and variations in sex characteristics are collected, analyzed, and reported so that our understanding of potential health disparities and outcomes is enhanced.”

Many speakers discussed personal experiences of their own and others, where implicit or explicit bias and discrimination, mistrust, and misunderstanding contributed to negative care experiences or skipping necessary care. They also cited research and data further confirming ongoing issues impacting the quality of care.

“There continues to be bias against the LGBTQ+ community in a clinical setting; something must be done," said Paula Chambers-Raney, colon cancer survivor and Fight Colorectal Cancer Hope Coordinator. “We must acknowledge that discrimination plays a factor in patient care. We need more access on all spectrums of the patient experience and equality for all in medical care.”

“One-third of LGBTQ+ patients, and more than 60% of transgender patients, reported experiencing discrimination in health care in a 2020 national survey,” explained Sean Cahill, PhD, Director of Health Policy Research, The Fenway Institute. “Such discrimination negatively affects physical and mental health, and causes patients to delay or avoid accessing care, including preventive cancer screenings. If we want to reduce cancer disparities affecting LGBTQ+ patients—such as higher risk of breast and ovarian cancer among sexual minority women—we should support policies that reduce discrimination in health care.”

Discriminatory experiences could range from direct insults, outright denial of care, and rejections from family, to more micro-aggressions involving which work-up tests to perform (such as skipped pap smears or added pregnancy tests), or gender-coded informational materials. Speakers detailed instances where people avoided necessary screening and treatment out of fear of either having to come out of the closet or go back in, in order to access care. In places where gender-affirming care is being threatened, advocates are seeing a drop-off in access to all types of health care for trans people.

“As an oncology nurse, it is clear to me that there are structural issues in our health care system that bar LGBTQ+ people with cancer from receiving the care they need,” said Ryne Wilson, DNP, RN, OCN, RN Care Coordinator, University of Minnesota Physicians. “The key area of concern for me is protections for caregivers of LGBTQ+ people with cancer. Often times LGBTQ+ people have chosen families and, although they may not be biological, they still deserve the same employee protections as a biological family member for medical leave to care for their loved ones.”

Ultimately, improvement comes from showing patients more trust and respect, while not making assumptions.

“Trust me that I know my gender, sex, and sexuality. Ask me if you don’t know,” said Archana Pathak, PhD, Associate Professor, Virginia Commonwealth University. “When we say we need to treat the whole person, for the LGBTQ+ community, that means understanding the differences between sex, gender, sexuality, and the complex ways in which those are interrelated in our lives. But keep in mind that our communities are vibrant, complex, and diverse. Just because someone has explained their experience to you, it doesn’t mean that it completely translates to my life.”

“We need to understand how historical discrimination and social stigma have led to maladaptive coping, but we also need to be sure we are not stereotyping patients. Knowing the heightened risks of patients is important, but we must balance that with asking questions to ensure we don’t assume behaviors based on someone’s sexual orientation or gender identity,” agreed Mandi L. Pratt- Chapman, PhD, Associate Center Director for Community Outreach, Engagement and Equity, GW Cancer Center, Associate Professor of Medicine, GW School of Medicine and Health Sciences, Associate Professor of Prevention and Community Health, GW Milken Institute School of Public Health, The George Washington University.

Dr. Pratt-Chapman continued: “It is critical to collect SOGI data in all research to guide the best clinical care for sexual and gender minorities in the future. Right now, we have very little evidence on which to guide clinical care management due to an historical lack of SOGI data collection. In a recent study for which I was a co-investigator, we found that the act of collecting SOGI data in oncology practices was associated with a belief in the importance of these data to the delivery of quality care, as well as leadership support and dedicated resources to support SOGI data collection. Data is important to highlight disparities; but let’s not stop at deficits—we must also look at examples of resiliency.”

The speakers were quick to point out that there is a lot of progress being made. They highlighted the eagerness of most providers to learn and improve, and the introduction of some welcoming policies and procedures. That said, there is still much more that can be done.

“By working same-gender couples and gender diverse people into existing training scenarios, we will normalize diversity while increasing knowledge and comfort without the need to find time for additional training,” said Chasity Burrows Walters, PhD, RN, Senior Director, Patient & Community Education, Memorial Sloan Kettering Cancer Center. “Using gender-inclusive language in cancer screening guidelines is important not only for conveying accurate information, but also for creating a sense of welcoming and acceptance.”

Scout, Ph.D., Executive Director, National LGBT Cancer Network agreed: “We know very few cancer survivors see anything in their providers’ offices that is welcoming to the LGBTQ+ community—but having that welcoming environment is highly correlated with good care experiences. We feel that bridging this gap is one of the biggest opportunities to improve care for this underserved population.”

Numerous efforts are underway to provide resources that bridge that gap. Several programs were presented during the summit as examples of best practices, and a guide to relevant resources was shared with attendees and the public at NCCN.org/patient-advocacy-resources.

The presentations included an overview of the respectful and inclusive language being used in NCCN Guidelines for Patients—free books that support patient and caregiver empowerment with an overview of the latest treatment recommendations. The NCCN Guidelines for Patients were recently honored by the Cancer Patient Education Network (CPEN) with the 2022 Excellence in Cancer Patient Education Award, specifically for their unique support of diversity, equity, and inclusion in breast cancer resources.

Learn more about NCCN’s patient information program, which includes books, webinars, and more, at NCCN.org/patients. Learn more about the NCCN Policy Program at NCCN.org/policy, and view videos from past policy summits at NCCN.org/summits.

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