



National Comprehensive
Cancer Network®

Patient Advocacy Summit

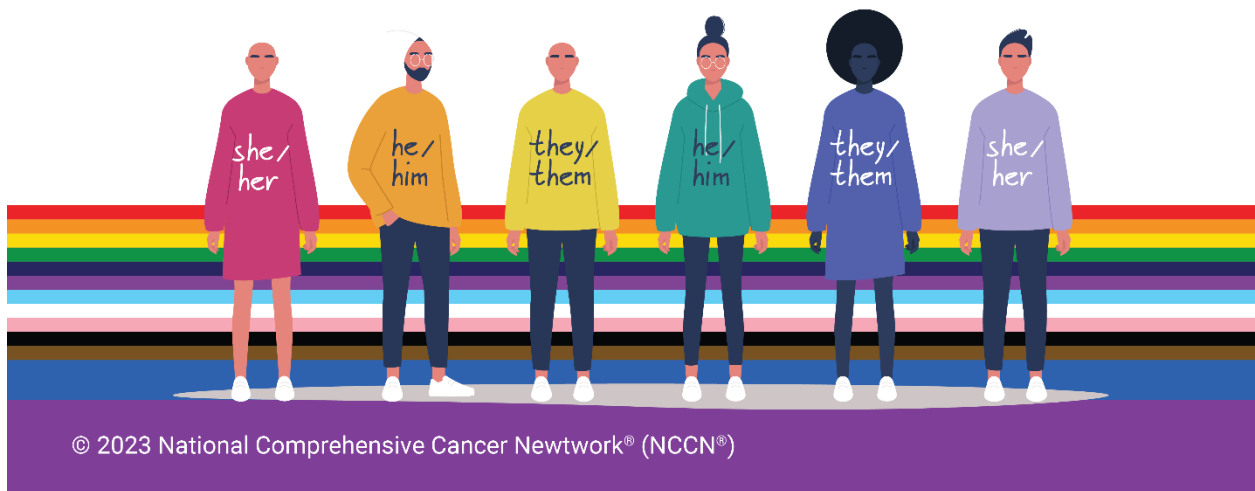
Best Practices and Policies for Addressing the Health Needs of LGBTQ+ Cancer Patients and Survivors

Summary Report

Friday, December 2, 2022

8:30 AM – 3:30 PM

Presented at The National Press Club, Washington, DC
and Virtually



Purpose of the Summit

Patients with cancer often have widely divergent care experiences from screening through survivorship. Differences in care delivery and outcomes may be due, in part, to varying patient preferences, patient needs according to varying intersectional identities, and implicit or explicit bias in care. The National Comprehensive Cancer Network® (NCCN®) Patient Advocacy Summit provided an opportunity for a varied group of stakeholders including patients, providers, payers, patient advocacy organizations, and industry to thoughtfully discuss the importance of providing quality, effective, efficient, equitable, and accessible cancer care to LGBTQ+ identifying patients.

Where/Attended by Whom

The NCCN Patient Advocacy Summit was held Friday, December 2, 2022, 8:30 AM - 3:30 PM at The National Press Club in Washington, DC. Virtual attendance was also available. **A total of 300 people attended.** Attendees included patients, providers, payers, patients, patient advocacy organizations, and industry representatives.



Learning Highlights

What are the Barriers Experienced by the LGBTQ+ Community?

People who belong to the LGBTQ+ community often face barriers to accessing appropriate and affirming cancer screening and treatment. A landscape analysis with key stakeholders revealed several root causes of this disparity. Driving factors include:

- Clinical staff often lack trauma training for this specific population which can lead to harmful/re-traumatizing interactions.
- Participants report that transgender and non-binary patients often experience misgendering by clinicians and find that their healthcare providers often do not take appropriate time to learn and use their preferred pronouns.
- Many clinical staff are not collecting data on sexual gender minorities; This is sometimes due to medical staff not feeling comfortable asking the questions and other times it is due to EHR infrastructure issues that do not allow the option of capturing this data.
- Patients of color (intersectional identities) tend to have lower rates of mammograms/paps/etc. and greater lack of social supports.

What is SOGI Data and Why is it Important?

Sexual orientation and gender identity, or SOGI, data are a critical component of accurately assessing the current problems that LGBT people experience—such as mental health and substance use disparities and barriers in access to health insurance coverage and health care—and developing effective policies and programs to address them.¹ Summit Panelists noted: *“We don’t count if you don’t count us!”*

What Can Providers do to Improve Care Experiences for the LGBTQ+ Community?

- Develop EHR infrastructure compatible with inclusivity.
- Train Staff to appropriately ask questions to gather necessary data.
- Collect, analyze and report on SOGI data; Data informs evidence bases which ultimately provides validity for much needed research funding.
- Create a more welcoming care environment through the use of visible signage (rainbow/trans flag, Black Lives Matter fist, etc.) throughout care spaces and waiting areas.
- Ensure diverse representation in pamphlets and reading materials.
- Evaluate inclusiveness of language used (i.e. renaming from “women’s clinic”).

¹ Baker K, Hughes M. Sexual orientation and gender identity data collection in the behavioral risk factor surveillance system. Center for American Progress. <https://www.americanprogress.org/article/sexual-orientation-and-gender-identity-data-collection-in-the-behavioral-risk-factor-surveillance-system/#:~:text=Sexual%20orientation%20and%20gender%20identity%2C%20or%20SOGI%2C%20data%20are%20a,developing%20effective%20policies%20and%20programs>. Published March 29, 2016. Accessed December 14, 2022.

What Can Policymakers Do to Improve Care Experiences for the LGBTQ+ Community?

- Remove barriers for caregiver support. Currently many LGBTQ+ people can't access rights under FMLA to care for a loved one. Policymakers should advocate to ensure family of choice can be recognized and protected.
- Policymakers can advocate to create and uphold health protections of LGBTQ+ identifying persons.
- Policymakers can advance policies that would require collection of SOGI by health entities.

2023 Summit Series

Cancer Across Geography

Thursday, June 15, 2023

Measuring and Addressing Health-Related Social Needs in Cancer

Tuesday, September 12, 2023

Navigating the Care Continuum from Screening through Survivorship

Tuesday, December 5, 2023

For More Information: <https://www.NCCN.org/summits>



Dora L. Hughes, MD, MPH, Chief Medical Officer, CMS Innovation Center Centers for Medicare & Medicaid Services

Appendix 1.

NCCN Patient Advocacy Summit: Best Practices and Policies for Addressing the Health Needs of LGBTQ+ Cancer Patients and Survivors

Summit Speakers

Sean Cahill, PhD, The Fenway Institute

Mandi L. Pratt-Chapman, PhD, The George Washington University

Tanya Fischer, MEd, MSLIS, National Comprehensive Cancer Network

Earl Fowlkes, Center for Black Equity

Clifford Goodman, PhD, The Lewin Group

Dora L. Hughes, MD, MPH, CMS Innovation Center Centers for Medicare & Medicaid Services

Admiral Rachel L. Levine, MD, Department of Health and Human Services

Terrance Mayes, EdD, Stanford Cancer Institute

Darryl Mitteldorf, LCSW, Malecare, National LGBT Cancer Project

Karen L. Parker, PhD, MSW, National Institutes of Health

Archana Pathak, PhD, Virginia Commonwealth University

Paula Chambers-Raney, Fight Colorectal Cancer

Scout, PhD, National LGBT Cancer Network

Chasity Burrows Walters, PhD, RN, Memorial Sloan Kettering Cancer Center

Ryne Wilson, DNP, RN, OCN, University of Minnesota Physicians

Environmental Scan Participants

CancerCare

Cleveland State University

The George Washington University

Latinas Contra Cancer

MaleCare

Memorial Sloan Kettering Cancer Center

National Institutes of Health

National LGBT Cancer Network

National LGBT Cancer Project

Stanford University School of Medicine

University of California San Francisco

University of Rochester

Whitman-Walker