

NCCN Digital Booklet of Patient Advocacy Resources



PATIENT ADVOCACY SUMMIT: Best Practices and Policies for Addressing the Health Needs of LGBTQ+ Cancer Patients and Survivors

The NCCN Digital Resource Booklet includes information from 6 patient advocacy organizations on programs and resources to support people with cancer in the LGBTQ+ community.

This Booklet was developed in conjunction with The National Comprehensive Cancer Network's® (NCCN®) Patient Advocacy Summit: Best Practices and Policies for Addressing the Health Needs of LGBTQ+ Cancer Patients and Survivors on December 2, 2022.

To view a broader list of advocacy and support groups on the NCCN website, visit [NCCN.org/patients/support-groups](https://www.nccn.org/patients/support-groups).

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Cancer Support Community

The Cancer Support Community (CSC) is a global non-profit network of 175 locations, including CSC and Gilda's Club centers, health-care partnerships, and satellite locations that deliver more than \$50 million in free support services to patients and families. In addition, CSC administers a toll-free helpline and produces award-winning educational resources that reach more than one million people each year. Formed in 2009 by the merger of The Wellness Community and Gilda's Club, CSC also conducts cutting-edge research on the emotional, psychological, and financial journey of cancer patients. In addition, CSC advocates at all levels of government for policies to help individuals whose lives have been disrupted by cancer.

Website: CancerSupportCommunity.org

Resource or Program Information

Frankly Speaking About Cancer: HIV & Cancer

If you or a loved one is living with HIV and has been diagnosed with cancer, you may feel overwhelmed, scared, or confused. We offer information and tips that can help you navigate this experience, including treatment planning, questions to ask your healthcare team, and ways to cope.

Website: CancerSupportCommunity.org/sites/default/files/fsac/FSAC_HIV_and_cancer.pdf

Phone: CSC Helpline: 888.793.9355

CSC Primary Contact: Claire Saxton, Vice President, Patient Experience: 202.650.5370

Email: Claire Saxton, Vice President, Patient Experience Csaxton@CancerSupportCommunity.org

Share Your Voice: Take the Cancer Experience Registry Survey!

The Cancer Experience Registry (CER) from Cancer Support Community is an online research study that uncovers the emotional, physical, practical, and financial impact of cancer to help patients, survivors, and caregivers get the support they need. The study is open to any adult living in the U.S. or Canada who has been diagnosed with cancer at any point in their life or has been a family or informal caregiver to someone with cancer. The CER aims to elevate the voices of ALL people impacted by cancer to influence real-world outcomes. Data from the CER is regularly used to influence healthcare policies, enhance cancer care, and improve support services. Share your voice and help change the future of cancer support!

Website: CancerSupportCommunity.org/registry

Phone: CSC Helpline: 888.793.9355

CSC Primary Contact: Claire Saxton, Vice President, Patient Experience: 202.650.5370

Email: Claire Saxton, Vice President, Patient Experience Csaxton@CancerSupportCommunity.org



The Chrysalis Initiative

Provides patients from disparate groups with mentoring and resource navigation. Their BC Navi app offers education, a supportive online forum, one-on-one coaching tailored to where you are on your breast cancer journey, a personalized dashboard, and the ability to find and create reviews and ratings about the quality of care provided at healthcare centers in your area.

Website: thechrysalisinitiative.org

Resource or Program Information

BC Navi

BC Navi is a website and app that works to erase the line of healthcare inequality for Black women by providing resources to recognize and address racism in their breast cancer care. Together, we will hold healthcare providers accountable and ensure every patient receives the care they deserve. One-on-one coaching informs and empowers patients throughout their treatment, helping them to feel confident and in charge by managing the worries and challenges specific to their experiences. Through this social support and evidence-based information, Black women are given the tools they need to recognize bad practices in breast cancer healthcare and reimagine treatment and screening protocols for more equitable outcomes. This tailored relationship helps patients learn to advocate for equitable quality of care and, ultimately, better treatment outcomes. No more waiting on a biased system.

Website: bcnavi.com

URL: thechrysalisinitiative.org

Phone: 800.929.4979

Email: info@thechrysalisinitiative.org



The Fenway Institute

The Fenway Institute is the research, education and training, and policy arm of Fenway Health. The mission of The Fenway Institute is to optimize health and well-being for sexual and gender minorities (SGM) and those affected by HIV.

URL: fenwayhealth.org/the-fenway-institute

Resource or Program Information

National LGBTQIA+ Health Education Center

We Are The National LGBTQIA+ Health Education Center. We provide educational programs, resources, and consultation to health care organizations with the goal of optimizing quality, cost-effective health care for lesbian, gay, bisexual, transgender, queer, intersex, asexual, and all sexual and gender minority (LGBTQIA+) people

URL: lgbtqihealtheducation.org

Phone number: 617.927.6354

Email: education@fenwayhealth.org

Contact email for review: scahill@fenwayhealth.org

Search for cancer to find up half a dozen archived webinars and issue briefs on different kinds of cancer prevention and care with LGBTQIA+ patients. lgbtqihealtheducation.org/?s=cancer

Recent Publications (Journal Articles, Issue Briefs):

Rosser BRS, Polter EJ, Chandiramani N, Cahill S, Wheldon CW, Konety BR, Ryan CJ, Haggart R, Kapoor A. **Acceptability and Feasibility of Collecting Sexual Orientation and Expanded Gender Identity Data in Urology and Oncology Clinics.** *LGBT Health.* 2021 Aug-Sep; 8(6):420-426. PMID: 34348045.

Richgels C, Cahill S, Thompson J, Dunn M (2021). **State bills restricting access of transgender youth to health care, school facilities, and school athletics threaten health and well-being.** Boston: The Fenway Institute. fenwayhealth.org/policy-briefs/anti-transgender-bills-threaten-to-harm-the-health-of-trans-youth-by-limiting-access-to-health-care-denying-access-to-athletic-activities-and-contributing-to-stigma-and-discrimination

Cahill S. (2018). **Legal and policy issues for LGBT patients with cancer or at elevated risk of cancer.** *Seminars in Oncology Nursing.*

Dragon C, Erdem E, Haffer C, Laffan A, Cahill S, Kenefick D, Ye J (2017). **Health indicators for older sexual minorities: National Health Interview Survey, 2013-2014.** *LGBT Health.* 4(6): 398-403.

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The Fenway Institute *continued*

Cahill S, Wang T, Geffen S (2017, December 11). **Executive branch actions promoting religious refusal threaten LGBT health care access.** Boston: The Fenway Institute. fenwayhealth.org/policy-briefs/executive-branch-actions-promoting-religious-refusal-threaten-lgbt-health-care-access-pdf

Burkhalter JE, Margolies L, Sigurdsson HO, Walland J, Radix A, Rice D, Buchting FO, Sanchez NF, Bare MG, Boehmer U, Cahill S, Griebing TL, Bruessow D, Maingi S (2016). **The National LGBT Cancer Action Plan: A white paper of the 2014 National Summit on Cancer in the LGBT Communities.** *LGBT Health.* 3(1); 19-31.

Cahill S & Vargas H (2015). **Policy and legal issues affecting LGBT health.** Makadon H, Mayer K, Potter J, Goldhammer H (eds.). *The Fenway Guide to LGBT Health.* Philadelphia: American College of Physicians. Second edition. 519-538.

Cahill S (2014). **Community resources and government services for LGBT older adults and their families.** Orel N, Fruhauf C (eds.). *The Lives of LGBT Older Adults: Understanding Challenges and Resilience.* Washington, DC: *American Psychological Association*, 2014. 141-170.

Burkhalter J, Cahill S, Shuk E, Guidry J, Corner G, Berk A, Candelario N, Kornegay M, & Lubetkin E. (2012). **At the Intersection of HIV/AIDS and Cancer: A Qualitative Needs Assessment of Community-Based HIV/AIDS Service Organizations.** *Health Educ & Behavior*

Policy Briefs

Improving Human Papillomavirus vaccination rates in the U.S.: Recommendations for health professionals and policy makers fenwayhealth.org/policy-briefs/improving-human-papillomavirus-vaccination-rates-in-the-u-s-recommendations-for-health-professionals-and-policy-makers

Promoting Cervical Cancer Screening Among Female-to-Male Transmasculine Patients fenwayhealth.org/policy-briefs/trans-men-cervical-cancer-screening-pdf



GW Cancer Center

The GW Cancer Center is a collaboration of the George Washington University, the GW Hospital and the GW Medical Faculty Associates to expand GW's efforts in the fight against cancer. The GW Cancer Center also incorporates all existing cancer-related activities at GW, with a vision to create a cancer-free world through groundbreaking research, innovative education and equitable care for all.

Organization URL: cancercontroltap.smhs.gwu.edu

Email: mandi@gwu.edu

Resource or Program Information

Together Equitable Accessible Meaningful (TEAM) training

This training aims to improve health equity by supporting organizational changes at the systems level. The training will help organizations implement quality improvements to advance equitable, accessible and patient-centered cancer care through improved patient-provider communication, cultural sensitivity, shared decision-making and attention to health literacy.

URL: cme.smhs.gwu.edu/gw-cancer-center/content/together-equitable-accessible-meaningful-team-training#group-tabs-node-course-default1

"I Want You to Know" Printable Cards

This "I Want You to Know" printable card can help patients begin a conversation with their provider about their identity and care preferences. Versions of the cards are available in English, Spanish and Chinese (simplified). Interested in branding the cards with your organization's logo? There's a blank version so your organization can insert their own logo and contact information if needed. A GW Cancer Center-branded version is also available.

URL: cancercontroltap.smhs.gwu.edu/news/i-want-you-know

Prostate Cancer: Resources to Take Charge of Your Health

Transgender women and gender non-conforming individuals have health care needs that are often not talked about. It may be uncomfortable to think about parts of the body that may still be there after you have transitioned. This fact sheet is only a starting point. It can help you talk with your doctor if you have prostate cancer. There are also tips for you and your partner(s) to help manage the effects of treatment. The resources list on the back has more information.

URL: cancercontroltap.smhs.gwu.edu/news/prostate-cancer-resources-take-charge-your-health

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The GW Cancer Center *continued*

Living with Prostate Cancer: Resources to Take Charge of Your Health

Gay and bisexual men have health care needs that are often not talked about. This fact sheet is for men who have sex with men and have been diagnosed with prostate cancer. This fact sheet is only a starting point. It can help you work with your health care team and help you manage the effects of treatment. The resources list on the back has more information for you and your partner(s).

URL: cancercontroltap.smhs.gwu.edu/news/living-prostate-cancer



Malecare

National Gay/Bisexual and Transgender women cancer patient advocacy organization

Website: malecare.org

Resource or Program Information

Gay men with Prostate Cancer Support Group

Providing a safe space for gay men to talk about their life with prostate cancer

Website: malecare.org/support-groups



National LGBT Cancer Network

The mission of the National LGBT Cancer Network is to improve the lives of LGBTQ+ individuals on the cancer journey and those at risk through educational, training and advocacy initiatives.

Website: cancer-network.org

Resource or Program Information

LGBTQ+ Cancer Virtual Peer Support Groups

In 2021, we launched our first-ever, virtual LGBTQ+ cancer peer support groups. We know that many LGBTQ+ cancer patients and survivors often do not feel welcome or understood in mainstream support groups, and transgender survivors are especially excluded. Individuals who live further from major metropolitan areas are also unlikely to find a support group at all. A study conducted by the National LGBT Cancer Network confirmed that LGBTQI+-specific support groups were the top request made by LGBTQI+ cancer survivors.

These are free Zoom peer-support groups for LGBTQ+ individuals who have or have had cancer. They are offered three times a week. A promotional flier is available and can be co-branded for posting in your cancer center.

Website: cancer-network.org/programs/support-groups-for-survivors

Phone number: 212.675.2633

Email: info@cancer-network.org

Welcoming Spaces: Treating Your LGBTQ+ Patient

Welcoming Spaces is an updated and expanded version of our flagship LGBTQ+ Cultural Humility training designed specifically for healthcare professionals. Developed in collaboration with the Society of Gynecologic Oncology, the eight modules are each 45 minutes long, available for Continuing Education (CE) Credits, and free for the remainder of 2022.

Website: cancer-network.org/welcoming-spaces

Phone number: 212.675.2633

Email: erin.o'connell@sgo.org

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National LGBT Cancer Network *continued*

Tailored Outreach Materials & Technical Assistance

Direct members are eligible for direct technical assistance from us. Organizational membership is free. We currently have over 450 tobacco and cancer control national, state, and local agencies, academic institutions or projects that are members. Our short- and long-term technical assistance focuses on a variety of topics including: provider trainings, best practices for reaching and engaging our population, and enhancement of data collection.

The National LGBT Cancer Network provides customized graphics for social media platforms, flyers, postcards and other print materials via our online resource library. These materials are available free of cost to our members and address a variety of topics and issues. One of our most popular bundles aims to raise awareness about colorectal, breast, lung, skin, and cervical cancer among members of the LGBTQ+ community. And our most recent set of graphics focuses on colorectal cancer screening guidelines for people of all genders. Interested members can add their logos to these media materials; we provide the graphics in the necessary formats. Our content is also available to state health departments via the Media Resource Campaign Center which is operated by the CDC.

Website: cancer-network.org/programs-2-3/resource-library

Phone number: 212.675.2633

Email: info@cancer-network.org

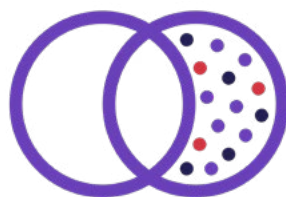
LGBTQ+ cancer resource pages

At the National LGBT Cancer Network, we aim to address the needs of our communities across the cancer continuum. Our prevention initiatives include one of the few LGBTQ+ cessation Quitline portals designed to provide community-specific motivation and encouragement to LGBTQ+ people who use tobacco products. For transgender and gender non-conforming cancer patients, our TRANSforming Cancer Microsite offers support, resources and personal stories. Lastly, we recognize that LGBTQ+ individuals affected by cancer, whether they have been recently diagnosed or are in remission, lead full lives. Thus, our sex after cancer microsite, Frankly, addresses the impact of cancer on the sex lives of members of our communities. Frankly is on a mission to dispel the myth that queer people on the cancer journey are just happy to be alive. We know people with chronic illness are sexual and desire sex. This space is for LGBTQ+ folks to share stories about their sexual desires and changing needs, the challenges disabilities can have on relationships and breakthrough discoveries about how to reclaim intimacy and gain sexual satisfaction. From prevention to remission, we are proud to offer tailored resources for LGBTQ+ communities across the country.

Website: cancer-network.org

Phone number: 212.675.2633

Email: info@cancer-network.org



National LGBT Cancer Project

National LGBT Cancer Project

World's first nonprofit organization focused on the survivorship needs and challenges of LGBTQ+ people diagnosed with cancer.

Website: lgbtcancer.org

Resource or Program Information

Information and support groups for all LGBTQ+ people diagnosed with cancer



SAGECare

SAGECare is the LGBTQ+ Aging Experts™ providing training programs and strategic guidance to help improve the lives of LGBTQ+ older adults.

Website: LGBTQ+ Aging Training and Consulting for a Better Workplace - SAGECare (sageusa.care)

Resource or Program Information

LGBTQ+ Aging Cultural Competency Training

SAGECare is a leading LGBTQ+ aging cultural competency provider that offers training programs and strategic guidance to help improve the lives of LGBTQ+ older adults. Through experience from decades as a leading educator, we create high-trust virtual spaces for action-oriented learning to put service provision back in balance and encourage increased empathy and awareness.

Website: LGBTQ+ Aging Training and Consulting for a Better Workplace - SAGECare (sageusa.care)

Phone: 212.741.2214

Email: sagecare@sageusa.org



For more information on the NCCN Oncology Policy Program,
please visit [NCCN.org/policy](https://www.nccn.org/policy) or contact:
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