



National Comprehensive
Cancer Network®

Oncology Policy Summit

Sexual and Reproductive Health and Its Impact on the Cancer Care Experience

Policy Report

Monday May 6, 2024

9:00 AM – 3:00 PM

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



May 2024 Oncology Policy Summit Policy Report: Sexual and Reproductive Health and its Impact on the Cancer Care Experience

Patients will face numerous issues and decisions throughout their care experience when they receive a cancer diagnosis. Gender can have a profound impact on a person’s care journey, and can also lead to additional considerations and difficulties in both their sexual and reproductive healthcare as a result of treatment options. Such problems are present during diagnosis, throughout the course of their treatment journey, and also persist well into survivorship. Further complications and considerations now exist as the public policy landscape, particularly around women’s healthcare access, has changed drastically in recent years. To explore these issues and potential policy solutions, The National Comprehensive Cancer Network® (NCCN®) hosted its 2024 Policy Summit entitled, Sexual and Reproductive Health and its Impact on the Cancer Care Experience. The summit provided an opportunity for a varied group of stakeholders including patients, providers, payers, patient advocacy organizations, policy makers and industry to thoughtfully discuss diverse perspectives related to the impact of cancer care on sexual and reproductive health considerations. The learnings of this summit as reported by participants are detailed in this policy report.

NCCN CEO Crystal S. Denlinger, MD, welcomed attendees to the NCCN Policy Summit on May 6, 2024.



Tamika Felder, Founder and Chief Visionary of Cervivor, Inc., gave a keynote presentation during the NCCN Policy Summit on May 6, 2024.



Challenges Associated With Access to Sexual and Reproductive Healthcare

Lack of Training: There is a lack of training on how to discuss sexual function challenges and as a result, a lack of experts available to instruct on the topic. Summit participants report that sexual function training is not an expected or formal part of training for fellows. Participants additionally report that restrictive reproductive laws can impact the ability to adequately provide OBGYN training which impacts the workforce available in some states. Summit participants also discussed the need for additional training on approaches to care for the LGBTQ+ community as it relates to this population’s needs around sexual function and reproductive health.



Communication Challenges: Patients may assume that healthcare professionals will bring up issues regarding sexual impact and may not feel empowered or comfortable to do so without being prompted by their care team. Healthcare professionals may also lack the tools to comfortably speak to patients regarding such topics. Additionally, providers who only discuss a narrow range of potential side effects could miss the opportunity for the provider and patient to discuss broader side effects that extend outside of physical impact and include mental ones as well.

Insurance Coverage Issues: Treatments addressing sexual health problems face variability in insurance coverage and affordability. Although treatments to address sexual health problems may be available, access to these treatments may be limited due to coverage issues or high out of pocket costs. The cost or coverage gaps may limit a provider's ability to prescribe therapies as recommended by clinical practice guidelines, as a patient may not be able to afford the high cost of care. Ultimately, variability in coverage of therapies addressing sexual health problems impacts a patient's access to guideline-concordant care, which has been demonstrated to improve cancer outcomes.

Legislative Barriers: The panelists at the summit reported that restrictive reproductive healthcare laws in certain states may cause delays in treatments for patients who are pregnant or become pregnant during the course of their cancer care journey. Participants noted that pregnant patients may face issues around receiving certain recommended treatments or delays due to pregnancy, and that can directly impact care outcomes. Legislative barriers in the reproductive healthcare space also mean that providers are increasingly confused about what care they can provide due to the ambiguity and lack of clarity in these laws. Summit speakers discussed how legislative barriers also exist for the LGBTQ+ community, and restrictive laws around their healthcare can also impact the type of treatment and care they are able to receive during a cancer diagnosis.

Lack of research in SOGI: Unfortunately, there is a dearth of Sexual Orientation and Gender Identity (SOGI) data and research available for this population, especially in the context of impact on sexual function of a cancer diagnosis. The use of certain gender and sex terminology in this research space can complicate the discussions around care and can impact the progress made towards collecting SOGI data. For example, the way certain cancers might be discussed as a "men's health cancer" or a "women's health cancer" could exclude those who may be living and identifying as one sex, but have a different set of reproductive organs. Participants noted that a lack of this data impacts screening and approaches to discussions on how to treat or actively surveillance patients who might have already undergone gender affirming care. Sexual function measures in research are also mostly geared towards heterosexual patients, which can lead to assumptions in data collection. In one study it was found that only 40% of oncologists felt it was important to find out a person's sexual orientation, and only 66% thought it was important to know a patient's gender identity.



An afternoon panel discussion during the NCCN Policy Summit on May 6, 2024 focused on policy's impact on sexual and reproductive health in cancer care.

What Can Policymakers Do to Improve Care Experiences?

Provide funding for training: The summit panelists reported the high need for training across various areas. Whether it's for sexual function, SOGI collection and treatment of LGBTQ+ patients, or reproductive health access, investing in properly training medical professionals to truly address a patient's needs throughout their cancer care journey is critical to improving sexual and reproductive health during and after cancer treatment. Participants felt that requiring sexual healthcare as a component of oncology resident and fellow training as well as sensitivity training for SOGI data collection would help to provide a better care experience for patients.

Pass comprehensive fertility coverage: There is a significant lack of insurance coverage for fertility preservation across the United States. For general infertility, there are only fifteen states that have a law that would require health plans to cover any type of infertility treatment. However, for iatrogenic infertility, which is infertility induced by a medical treatment such as chemotherapy, only eight states currently have coverage laws specifically addressing this. In support of those whose fertility could be impacted by a cancer diagnosis, lawmakers should pass comprehensive fertility coverage laws that allow cancer patients timely access to the reproductive healthcare they need.

Support policies that provide better access to care: Cancer affects about 1 in 1,000 pregnant individuals. There are a limited number of therapies that could be administered during a pregnancy, even in the second and third trimester, and almost all cancer therapies pose at least some risk to the safety of the pregnancy and fetus. Variability across states in abortion restrictions



following the Dobbs decision may result in treatment delays or impact treatment outcomes for pregnant patients in some states. Currently, twenty-one states ban abortion or have laws that are more restrictive than the standard set by Roe v. Wade. Additionally, laws aimed at creating barriers to healthcare access for LGBTQ+ patients have also been on the rise, with close to 50 bills having been introduced this year that could impact this patient population's ability to access needed care. Summit participants noted that there should be more support for policies that provide those with a cancer diagnosis with the ability to work with their providers on the best course of treatment for them without fear that their care could be restricted due to state laws. Advocating for more accessible care and inclusive healthcare policies would benefit patients who are already dealing with the stress of a cancer diagnosis.

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- i. <https://ascopubs.org/doi/10.1200/JCO.18.00551>
 - ii. <https://www.kff.org/womens-health-policy/issue-brief/coverage-and-use-of-fertility-services-in-the-u-s/#:~:text=Only%20a%20handful%20of%20states,preservation%20in%20their%20Medicaid%20plans.>
 - iii. <https://www.allianceforfertilitypreservation.org/state-legislation/>
 - iv. Silverstein J, Van Loon K. The Implications of the Supreme Court Decision to Overturn Roe v Wade for Women with Pregnancy-Associated Cancers. *JAMA Oncol.* 2022;8(10):1394–1395. doi:10.1001/jamaoncol.2022.3785
 - v. Suran M. Treating Cancer in Pregnant Patients After Roe v Wade Overturned. *JAMA.* 2022;328(17):1674–1676. doi:10.1001/jama.2022.13668
 - vi. <https://www.nytimes.com/interactive/2024/us/abortion-laws-roe-v-wade.html>

APPENDIX 1

1. **Laila Agrawal, MD**, Norton Cancer Institute
2. **Tamika Felder**, Cervivor, Inc.
3. **Cecile Ferrando, MD, MPH**, University of California, San Diego
4. **Mindy Goldman, MD**, Carol Franc Buck Breast Care Center, University of California, San Francisco
5. **Clifford Goodman, PhD**, Health Care Technology and Policy
6. **Sean Kern, MD**, Murtha Cancer Center, Uniformed Services University and Walter Reed National Military Medical Center
7. **Jennifer Barsky Reese, PhD, FSBM**, Fox Chase Cancer Center
8. **Joyce Reinecke, JD**, Alliance for Fertility Preservation
9. **Scout, PhD, MA**, National LGBT Cancer Network
10. **Kristin Smith, BS**, Robert H. Lurie Comprehensive Cancer Center of Northwestern University
11. **Ana Tergas, MD, MPH**, City of Hope National Medical Center
12. **Tracy Weiss**, The Chick Mission