ASSOCIATION OF
CANCER CARE CENTERS

MULTIDISCIPLINARY APPROACHES TO ADDRESSING THE NEEDS OF PATIENTS WITH GYNECOLOGIC CANCERS

A CALL-TO-ACTION SUMMIT

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EXECUTIVE SUMMARY

ACCC
ASSOCIATION OF CANCER CARE CENTERS™

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A Call-to-Action Summit

EXECUTIVE SUMMARY

Background

Gynecologic cancer refers to a group of malignancies that begins in the female reproductive organs.[1] The 5 main types of gynecologic cancers involve the cervix, ovary, uterus, vagina, and vulva. These malignancies, while less common than other cancer types, affect over 100,000 patients annually in the United States.[2] Approximately 32,000 patients died from gynecologic cancers in 2023.[2]

Advanced stages of gynecologic cancers can lead to bowel obstruction, malnutrition, blood clots, impaired organ function, extreme fatigue, severe pain, fluid overload, and other distressing symptoms. Patients not only face disease complications, but they can also suffer from toxicities related to treatment. Radical surgeries and procedures, radiation therapy, and systemic chemotherapy or immunotherapy can cause a variety of adverse effects. Furthermore, many patients have chronic comorbidities that may impair their overall health outcomes.

In addition to disease and treatment-specific complications, health disparities related to socioeconomic status, education level, ethnic background, and geographic location may impact patients with gynecologic cancers.[3] Financial toxicity also remains a substantial concern because of the associated costs of subspecialty appointments, surgeries, hospital admissions, systemic treatments, and potential lost work time. Until these complex barriers are addressed, disparities and compromised health outcomes will persist.

Summit Highlights

The Association Of Cancer Care Centers (ACCC) held a Gynecologic Oncology Summit in Chicago, Illinois, on September 27, 2023. The half-day live summit brought together a multidisciplinary panel of experts in gynecologic cancers and representatives from patient advocacy organizations from across the United States. These participants discussed challenges and opportunities and identified potential actionable solutions for patients with gynecologic cancers.

What motivates you to improve equity and care for patients with gynecologic cancers?

- "It's personal for patient advocates."
- "The gynecologic cancer community is special, and (I) want [us] to help fill those gaps together for every individual to have access to care without barriers."
- "Bringing new hopes and ideas to not just help our patients but [to] find ways to get creative and put gynecologic oncology at the top of cancer care."
- "The patients and the families inspire me to help empower them, but the burden should not fall solely on them."
- "The data shows that marginalized patients will have a worse outcome than their White counterparts."
- "Sexual health education for all patients— we must do more for the LGBTQIA+ (lesbian, gay, bisexual, transsexual, queer, intersex, asexual/ally, and others) community!"

As the session opened, the providers were asked about factors that motivate them to improve equity and care in patients with gynecologic cancers. Their responses ranged from bridging the gap to overcoming care barriers in underserved cities. Further, they stressed that gynecologic cancers often are overlooked, and awareness needs to be brought to the forefront.The general session also included a presentation by ACCC's project advisory committee chair, Premal H. Thaker, MD, MSc, professor of gynecologic oncology at the Washington University School of Medicine in St Louis, Missouri. Dr. Thaker reviewed the current landscape in caring for patients with gynecologic cancers.

Statistics in Gynecologic Cancer Care:[4]

- **66,000** patients were diagnosed with endometrial cancer in 2023. Trends show this continues to rise year after year.
- **19,000** patients are diagnosed each year with ovarian cancer; 13,270 will die from it.
- **13,000** patients will die this year from uterine cancer.
- **4,300** patients in the United States will die from cervical cancer.

TABLE 1. 5-Year Survival Rates by Race in the US, 2012-2018[a]

	White %	Black %	Absolute Difference %
All Sites	69	64	5
Breast (female)	92	83	9
Esophagus	65	60	5
Colon and rectum	22	15	7
Melanoma of the skin	94	70	24
Non-Hodgin lymphoma	75	70	5
Oral cavity and pharynx	70	52	18
Ovary	49	41	8
Prostate	97	97	<1
Urinary bladder	78	65	13
Uterine cervix	67	56	11
Uterine corpus	84	64	20

[a]Five-year relative survival rates are based upon patients diagnosed in the Surveillance, Epidemiology, and End Results 1B registries from 2012 to 2018 or followed through 2019.

Summit participants identified many challenges in this area including:

- Costs associated with childcare and caregiving
- Lack of care coordination for genetic testing
- Nonstandard implementation of SDOH screening tools
- Inequitable knowledge of and/or access to community resources.

"We need to make sure to say people, individuals, or persons when talking about gynecologic cancers, because, yes, a patient could identify as a woman but…another may not." – Summit Participant

Attendees also identified practice struggles such as lack of funding for clinical trials and difficulty in enrolling diverse patients. Insufficient diversity among providers is also of concern; some breakout group members addressed the need for multidisciplinary team training around the effects of explicit and implicit bias.

Group 3. Community Support and Patient Advocacy

Individuals diagnosed with gynecologic cancers need high levels of supportive care as shown by continuing challenges in community support and patient advocacy expressed by Summit participants.

Summit participants identified the following challenges:

- Insufficient access to care
- Need to bring gynecologic malignancies to the forefront
- Lack of community awareness and education

"We have to find community resources that can help provide financial aid to patients." – Summit Participant

In addition to the challenges listed above, participants were concerned about a lack of patient educational resources after treatment, the need for program funding, and policy implications for genetic testing and insurance coverage. Resources concerning sexual dysfunction, financial needs, and navigation of resources were specifically identified. Genetic testing concerns stemmed from customized treatments that are often needed in smaller communities.

Opportunities

Following the first breakout session, participants were asked to brainstorm potential opportunities to address the identified challenges.

Group 1. Social Drivers of Health

To improve health among the population, equity must be prioritized and measures integrated to reduce disparities.[7] The first step is to assist patients in identifying any barriers present. This can be done through screening methods such as the core 5 SDOH screening tool, which evaluates factors such as food insecurity, housing, utilities, transportation, and safety.[8] When challenges are identified, opportunities for improvement can be initiated.

Summit participants identified the following opportunities to address SDOH:

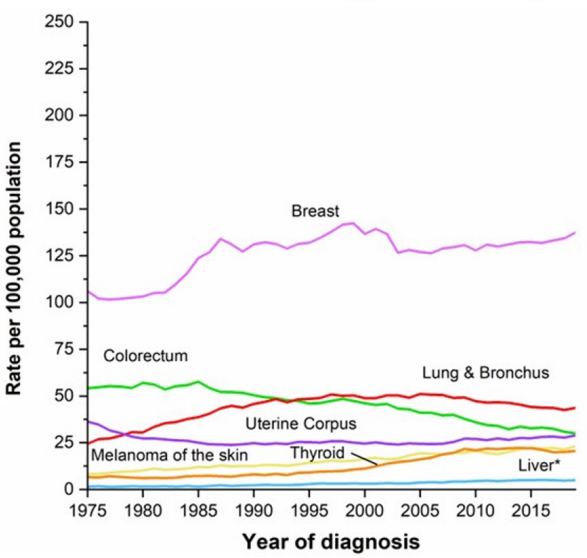
- Advocate for comprehensive cancer care delivery within insurance provider networks
- Increase funding for health equity initiatives
- Expand access to services by advocating for telehealth payment parity
- Promote a diverse workforce and leadership
- Streamline detection of multiple cancers and related diagnostic testing

Social media was also mentioned to educate patients, to disseminate important information about leveraging existing clinical services, and to provide greater awareness of inclusivity. Participants touched on opportunities to expand access to care including the NCI's Community Oncology Research Program that offers patients an opportunity to take part in clinical trials and study interventions to improve care.

Group 2. Multidisciplinary Care, Workforce, and Patient Navigation

This group was asked to discuss the broadest category—patient care, health care workforce needs, and navigation resources.

FIGURE 1. Trends in Cancer Incidence Among Females in the United States, 1975-2019[a]



[a]Trends are age-adjusted to the 2000 US standard population and are adjusted for delays in reporting.
[b]Includes the intrahepatic bile duct

Dr. Thaker shared a trend report from the National Cancer Institute's (NCI's) Surveillance, Epidemiology, and End Results program that included data from 1975 to 2019. Trends show uterine cancer has been increasing since the 1990s. Dr. Thaker also noted the drastic disparities in 5-year survival rates by race (**Table 1, Figure 1**). She offered reasons for these disparities, including biologic, environmental, and access inequities for underserved populations.

Attendees then transitioned into breakout sessions and were tasked with defining challenges and opportunities in 3 key areas:

- Social Drivers of Health (SDOH)
- Multidisciplinary Care, Workforce, and Patient Navigation
- Community Support and Patient Advocacy

Key Challenges

During the first breakout session, members of each group were asked to identify key challenges in providing quality gynecologic cancer care.

Group 1. Social Drivers of Health

Social and environmental factors affect health outcomes.[5] Social factors include resources needed for daily living such as food, housing, transportation, finances, and childcare, among others.

Challenges identified among Summit participants included:

- Financial toxicity related to treatments
- Distance traveled and transportation for patients
- Establishment and maintenance of patient care

"How do you establish and maintain care with patients who struggle with coverage and financial toxicity?" – Summit Participant

Beyond factors already highlighted, responsibility for tackling SDOH and understanding the need to set a threshold intervention to reduce burden were discussed. Health care teams may not be equipped to address some drivers and must rely on public or social service agencies to support barriers identified. ACCC supports these concerns by promoting relationships with community resources that can help to meet ongoing patient needs.

Group 2. Multidisciplinary Care, Workforce, and Patient Navigation

Multidisciplinary care requires professionals from various fields to convene and provide patient-centered services.[6] This can be difficult, since staff can be limited by retirement, burnout, or specialty training requirements. Patient navigation, while not always available due to funding or resources, may help to reduce health disparities.[7]

Opportunities for improvement include:

- Prioritization of diversity, equity, and inclusion
- Provision of clinical pathways and advancement in treatment options
- Increase in access to genetic counseling and testing through telehealth services
- Flexibility of clinical trials
- Bolstering of employee recruitment and retention programs

Workforce strategies focused on diversity, equity, and inclusion protocols and increased incentives for workforce retention. An identified goal for multidisciplinary teams is to broaden diversity into sexual and reproductive care programs to encompass health care providers of varied racial, ethnic, and cultural backgrounds.

Clinically, institutional administrators have opportunities to make clinical trials more flexible, to advocate for increased access to genetic counseling and testing, and to support patient navigation, SDOH triage, caregiver education, and automation by using wearable technologies and other modalities. One example of a best practice already in a pilot phase is a sexual health clinic based in Pennsylvania; staff at that clinic provide education and support for patients who experience disruptions to their sexual health.

Group 3. Community Support and Patient Advocacy

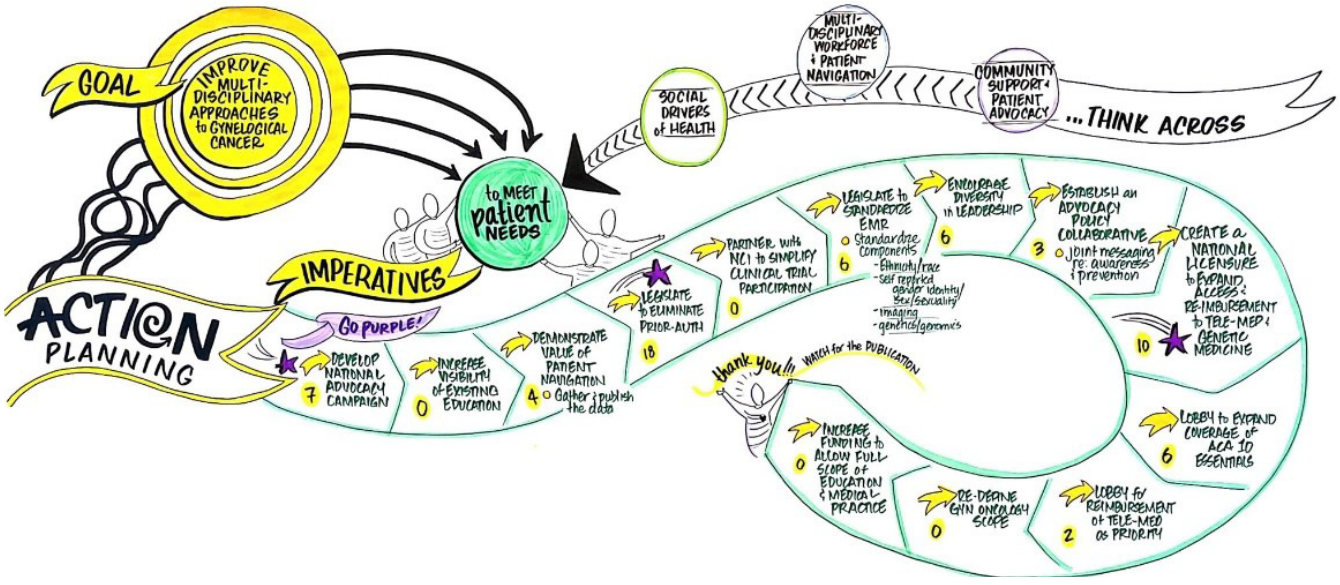
Sometimes a solution is as simple as promoting a service or services that already are available. Communities and health care institutions can benefit through partnerships that help to spread resources and awareness. Additionally, health care institutions need to advocate for national policy change for genetic and/or genomic testing and health insurance coverage for care-related transportation and other patient needs. These topics will be normalized when they become common to everyday conversation.

Opportunities to make changes for normalizing these topics include:

- Advocating for national policy change relating to access to genetic and genomic testing and counseling and associated care
- Coordinating and supporting patient advocacy for health equity in gynecologic care
- Building or strengthening patient navigation programs
- Developing delivery roadmaps for integrative and palliative care
- Promoting early screenings to reduce risk factors

Patient advocates shared the financial impact of restricted funding and limited grants and the need to standardize patient navigation across centers to improve access to care and community awareness for unmet patient needs.

FIGURE 2. Planning for the Call to Action



ACA, Affordable Care Act; EMR, electronic medical record; NCI, National Cancer Institute; prior-auth, prior authorization; tele-med, telemedicine.

CALL TO ACTION

The Summit wrapped up with a call to action in which providers proposed steps to establish, plan for, and provide solutions for providers and key stakeholders over the next 2 to 3 years (**Figure 2**). They identified 13 distinct priorities that ranged from expanding coverage to developing a national advocacy campaign, increasing visibility of existing education, and creating an education library. They identified 5 key areas to address.

Legislate to eliminate burdensome prior authorizations.

Advocate for policy change to eliminate onerous prior authorization requirements and highlight models that have been successful at the program and/or state levels and that can be replicated.

Create a national licensure system to expand access to and reimbursement for telemedicine and genetic testing.

Expand access to reimbursement and telemedicine by creating a national licensure system. Development of joint messaging about disease awareness and prevention specific to gynecologic cancer is imperative.

Develop a national advocacy network to campaign for awareness of gynecologic cancer.

Develop a national awareness campaign about gynecologic cancers, like campaigns for. Additionally, advocacy is needed to garner more research funds and other resources for patients with gynecologic cancers.

Legislate to standardize electronic medical records (EMRs).

Expansion of priority EMR components were mentioned to make standardization of imaging, genetic, and genomic findings and self-reporting of gender identity, ethnicity, and race mandatory.

Empower diversity in leadership.

Partnerships with professional societies encourage health systems to mirror the communities they serve.

Summit participants shared ideas about creating care teams with diverse cultural backgrounds to treat gynecologic cancers to enhance innovation and decision-making and reach a broader patient population. They also shared ways for current providers to embrace diversity; these included continually learning about unconscious bias, being an active listener, communicating with clarity, and serving as an example for peers. In addition, participants recognized a need to advocate for changes in managing prior authorizations, to expand coverage of the Affordable Care Act's 10 essential health benefits[8], and to demonstrate the value of patient navigation using data.

Conclusion

The Gynecologic Oncology Summit brought together experts across many disciplines with the same goal—to face barriers and challenges head on and identify actionable solutions. Through the initiative Multidisciplinary Approaches to Addressing the Needs of Patients With Gynecologic Cancers, ACCC will continue to work with partner organizations to identify, develop, and disseminate resources to support multidisciplinary care teams as they provide optimal care for patients with gynecologic cancers.

Testimonials from Summit Participants

> "I thoroughly enjoyed participating in the summit. It was engaging and rewarding listening to the group's ideas. Thank you again for the opportunity."
> Pharmacist

> "I enjoyed the summit! It was such a great opportunity to network and collaborate with such amazing oncology professionals."
> Clinical Manager

To learn more about ACCC's work on gynecological cancers, please visit **accc-cancer.org/gynecologic-cancer-care**

Acknowledgements

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In partnership with:

SGO Society of Gynecologic Oncology | OCRA ovarian cancer research alliance

This project is made possible by support from:

AstraZeneca | GSK

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