

2021 SPRING CANCER POLICY ROUNDTABLE

EXECUTIVE SUMMARY

Throughout the pandemic, NCCS has heard from many survivors who feel especially vulnerable due to their history of cancer treatments. To set the stage for our first Cancer Policy Roundtable of 2021, NCCS advocate Julia Maués shared her experience of living with metastatic cancer during the pandemic. Julia said cancer survivors are uniquely prepared for COVID-19 because they know what it's like to have their world turned upside down. Julia's patient keynote laid the foundation for important discussions on what has been learned from COVID-19, and how cancer care has changed in the last year.

"I urge you to listen to different patient experiences, especially listen to those patients who experience the worst outcomes. When you go back to your work, make sure you bring in to bring diverse patient perspectives. That same spirit of shared decision-making that we talk about all the time between patients and doctors needs to be brought over to research. Patients want a seat at the table where decision are being made. After all, our lives are the ones that are on the line." – Julia Maués

PANEL ONE: EXPERIMENTATION IN CANCER CARE: INSPIRED (OR FORCED) BY THE PANDEMIC?

Shelley Fuld Nasso, MPP | National Coalition for Cancer Survivorship
Julia Maués | Co-Founder, GRASP

As the saying goes, "*Necessity is the mother of invention.*" In the first panel, experts shared the benefits and challenges of experimentation in cancer care inspired by the pandemic. One of the immediate responses was providing telehealth services.

Drs. Mishra and Dillion discussed ways providers adjusted cancer care. Dr. Dillion said, "*we made Zoom our ally. We got creative and now we can Zoom with patients' entire family present.*" Brenda Nevidjon, CEO of the Oncology Nursing Society echoed this sentiment, saying, "*Zoom is very different than a phone call with a family member. Having that visual has been a positive.*" Ms. Nevidjon also addressed the challenges facing nurses during COVID. She explained that nurses are beginning to leave the profession and that we will likely see a weakened supply post-pandemic, particularly in rural areas.

Dr. Deborah Schrag shared a silver lining of the pandemic, which was an opportunity to slow down and talk about personal issues with patients in a more intimate way. She said she hopes that as we emerge from the pandemic, providers can continue this focus on the patient and expand their role as healers. Dr. Mishra shared that although her institution has been successful in providing telehealth, equity and digital availability are issues that need to be addressed. "*Too many patients still don't have access to digital services,*" she said.

Dr. Karen Winkfield agreed that telemedicine has been critical in providing good care during but that challenges still exist. *“Telehealth needs to stay, but it’s not a panacea. It needs to be used appropriately and we need to achieve the right balance.”* Part of this balance is addressing the inequities in care. Dr. Winkfield explained how systemic inequality hurts patients of color and she said, **“There has been an increased attention to racial issues and inequities in this country, but there’s a lot more to do. We have to think about structural injustices, and we have to think about the patient in front of us.”**

PANEL TWO: MENTAL HEALTH AND CANCER SURVIVORS

Melissa Dillmon, MD | Harbin Clinic Cancer Center

Julia Maués | Co-Founder, GRASP

Asmita Mishra, MD | Moffitt Cancer Center

Brenda M. Nevidjon, MSN, RN, FAAN | Oncology Nursing Society

Deborah Schrag, MD, MPH | Dana-Farber Cancer Institute

Karen Winkfield, MD, PhD | Meharry-Vanderbilt Alliance

Shelley Fuld Nasso, MPP (Moderator) | National Coalition for Cancer Survivorship

The second panel brought together experts and advocates to discuss cancer survivors’ mental health challenges, including depression and anxiety. Survivors report that the cancer care system is not always responsive to their mental health needs, and that there is poor coordination of care and communication among providers. The pandemic has exacerbated mental health issues for some, and the isolation of the pandemic has posed a challenge for all cancer survivors.

Dr. Tamryn Gray explained creative solutions to help cancer survivors gain access to mental health services, palliative care, and proper care coordination following treatment. She said it is critical that we ensure we are not leaving people out who do not have access to digital technology. Hybrid care approaches using technology, telephone, and in-person are key to providing quality care.

NCCS advocate Patsy Hinson shared that although no two cancer survivors are the same, many patient advocates share similar challenges. She said, *“I don’t think we can overstate how important that is to hear, ‘How I experienced this is different than how you experienced it, but let’s find a way to help each other find some relief.’”*



Oncology social worker Susan Hedlund discussed the parallels between a cancer diagnosis and the pandemic. She said cancer survivors as well as many individuals during the pandemic experience post-traumatic growth. *“When we get through a very traumatic experience, such as cancer, such as a pandemic, we may see that we have a renewed perspective on what’s truly important for us,”* Ms. Hedlund said.

NCCS advocate Wenora Johnson explained that it is not just care delivery that has been disrupted but also care giving. She calls herself a “virtual caregiver” for her brother who suffers from late-stage colon cancer and mental illness. Ms. Johnson said that having virtual check-ins makes a big difference for her brother in feeling supported.

The panelists agreed that there is a huge need for mental health support for cancer survivors, but with shortages in the workforce, we have to be creative in making sure patients have support. This support can come in a variety of ways, including support groups, community organizations, and professionals, ideally with expertise in the mental health challenges that cancer patients face.

KEYNOTE ADDRESS: COVID-19, CANCER CARE, AND CANCER RESEARCH
Norman (Ned) Sharpless, MD | Director, National Cancer Institute

Shelley Fuld Nasso, MPP (Moderator) | National Coalition for Cancer Survivorship
 In the closing keynote, Dr. Ned Sharpless, Director of the National Cancer Institute (NCI), provided updates from NCI about the effects of the pandemic on cancer care and research.

Although there is much to be optimistic about in cancer care, the reality is that the pandemic has disrupted cancer care significantly, and its effects will be felt for years to come. Dr. Sharpless explained that there are dramatic decreases in new cancer diagnoses at major cancer centers and these decreases are related to the disruptions in screening. The graphs below from Dr. Sharpless’ presentation show how significant these screening declines have been during the pandemic.

With the Cancer Moonshot implementation, the 50th Anniversary of the Cancer Act upon us, and President Biden’s aspiration to “end cancer as we know it,” the future of cancer care is an exciting and encouraging one. Dr. Sharpless walked us through key Cancer Moonshot efforts in survivorship care, NCI’s appropriations, and grant funding.

