

SPRING 2022 CANCER POLICY ROUNDTABLE: EXECUTIVE SUMMARY

SURVIVOR KEYNOTE:

Jamie Ledezma, JD

15-year Breast Cancer Survivor

NCCS Cancer Policy & Advocacy Team (CPAT) Steering Committee Member

In the opening keynote, Jamie Ledezma, a 15-year breast cancer survivor, recounted her survivorship journey and the impact it has had on her family. Her family has an extensive history of cancer and at 27 years old and 14-weeks pregnant, she received the news that she had triple-negative breast cancer, an aggressive form of cancer with few individualized treatment options. She shared her appreciation for her care team and oncologist who helped her seek additional opinions before she received chemotherapy while pregnant. After six months of chemotherapy, she gave birth to a healthy son.



Now with no evidence of disease, she strives to raise awareness of the gaps in survivorship care. In the keynote, Ms. Ledezma called attention to the challenges of transitioning from active care to survivorship care as well as living one's life after a cancer diagnosis, emphasizing the importance of providing interventions along the continuum of survivorship in varying doses and different stages of life. She drew attention to the existence of barriers within systems, including the healthcare system, drawing on her family's move to a new city as an example. After her move, Ms. Ledezma had to assemble a new care team and build trust with a new provider, and she discovered that some treatments were out of her reach. When describing the doubt her family later felt about moving, she said, "How can the fate of our family's wellbeing be contingent on where we live and the quality of care we're receiving in one community over the other? How can our family's wellness and sense of ability to move forward be dependent on our zip code?"

Ms. Ledezma stressed the need for whole-person care, arguing that care must encompass the mental, emotional, and physical needs of patients as well as their financial wellbeing. She acknowledged that the cancer community has made progress but admitted that much more work still needs to be done. To help with this effort, she shared several important

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recommendations for providers. First, providers should speak with their patients about survivorship from the beginning, addressing fear and giving patients permission to hope. They should also help prepare patients for mental, emotional, and physical transition from active treatment to survivorship, making sure to avoid an abrupt handoff. Finally, providers should embrace the whole person when talking about survivorship, invest in coordination of care, and demand the inclusion of patients at the table, especially patients who are historically marginalized.



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— Jamie Ledezma, JD

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SESSION ONE:

Cancer Care During the Pandemic and Beyond: Where Do We Go from Here?

Justin E. Bekelman, MD

Penn Center for Cancer Care Innovation
Abramson Cancer Center

Norma L. Day-Vines, PhD

Hurdle
Johns Hopkins School of Education

Ana Maria Lopez, MD, MPH

Sidney Kimmel Cancer Center
Jefferson Health New Jersey
NCCS Board Member

Shelley Fuld Nasso, MPP (moderator)
CEO, NCCS

Jamie Ledezma, JD

15-year Breast Cancer Survivor

NCCS Cancer Policy & Advocacy Team (CPAT) Steering Committee Member

A panel of health care professionals, cancer survivors, and technology innovators convened to discuss cancer care during the pandemic and options for improving cancer care and survivorship care delivery.

Dr. Bekelman helped launch UPenn's Cancer Care at Home program during the pandemic, allowing patients the option to receive chemotherapy or immunotherapy at home rather than in a hospital or clinic. Before the pandemic, the program's vision was to change the status quo of cancer care and deliver up to 20% of therapies in the patient's home. However, the pandemic grew the program 700% in just 6 weeks as immunocompromised patients saw an opportunity to receive treatment at home rather than risking exposure to COVID-19 in a clinic. Dr. Bekelman hopes to normalize home infusion and expand this treatment across the country.

Ms. Ledezma and Dr. Lopez both expressed their appreciation for telehealth, Ms. Ledezma as a cancer survivor and Dr. Lopez as a provider. Dr. Lopez highlighted telehealth as a valuable



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innovation that increased in popularity during the pandemic and helped providers meet patients where they were. However, she cautioned against its ability to fuel disparities and shared ways that her cancer center sought to ease barriers. Since every person may not have a device with the best capacity, her cancer center helped patients access telehealth by providing technical assistance as needed and utilizing grant funding they received to provide devices with internet to patients who needed them.

Dr. Day-Vines introduced the audience to the start-up company Hurdle, for which she is a clinical advisor, which provides culturally intentional tele-mental health services for Black, Indigenous, and people of color. She cited alarming statistics that 50% of counseling sessions with minorities end prematurely, which can be attributed to the fact that these populations do not feel understood or heard when they receive mental health services. She also highlighted the stigma around counseling that is present in the Black community and the importance of centering patients' issues around race, ethnicity, and culture rather than avoiding them.

Looking toward the future, the panelists explored new innovative ways to provide and improve cancer care. Dr. Day-Vines argued that leveraging group counseling could be incredibly beneficial to cancer patients struggling with mental health issues and fatigue, as they could interact with and learn from fellow cancer survivors at different stages. Accessing group therapy on an online platform would help normalize the helplessness and hopelessness that some survivors experience and allow survivors to draw support from others experiencing the same issues without leaving home. She also advocated for the establishment of pipeline programs to enhance cultural responsiveness and diversity in the healthcare field, and especially among doctors. She emphasized the importance of patients having the ability to receive care from people who look like them to encourage trust and eliminate fear of the healthcare system that may exist for people of color.

Dr. Lopez emphasized the need for increased community engagement and partnership, especially by leveraging community health workers who have established trust with patients, to encourage an openness between healthcare providers and minority communities. She also mentioned the existence of technology that is not yet widely available that would allow providers to examine patients and complete a full exam without being in the same room. These current examples and future ideas could go a long way in improving cancer care if adopted widely.

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Message from Senator Amy Klobuchar (D-MN)



Senator Amy Klobuchar (D-MN), a cancer survivor, shared a special message with NCCS and everyone who joined us at our first Cancer Policy Roundtable of 2022. She shared about her breast cancer diagnosis during the pandemic as well as insights into the cancer legislation she continues to champion. She announced her latest partnership with Congresswoman Debbie Wasserman Schultz (D-FL), a fellow cancer survivor, to introduce cancer survivorship legislation that would ensure a seamless continuum of care for all survivors. She emphasized that this support is critical to monitor health progress and prevent cancer recurrence. Finally, she thanked all members of the cancer community for advocating for everyone touched by cancer.

"Together, we can create better care, find new treatments, and save lives."

— Senator Amy Klobuchar (D-MN)

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SESSION TWO:

Cancer Moonshot

Danielle Carnival, PhD

White House Cancer Moonshot Coordinator, White House Office of Science and Technology Policy

Dr. Danielle Carnival shared about President Biden's Cancer Moonshot 2.0 initiative and highlighted the effort's goals. She began by calling for hope. She said there was so much reason to hope, which is why Biden reignited the Cancer Moonshot and set new goals to decrease the death rate of cancer by 50% over the next 25 years and improve the experience of survivors and families living with and surviving cancer. The Moonshot's ultimate goal is to "end cancer as we know it."

She acknowledged the decades of progress in the cancer field and celebrated the fact that more people were surviving cancer and living longer after diagnosis. However, she stressed the need for additional goals to improve care for cancer patients and their loved ones. She explained that too many patients and families had to navigate cancer and survivorship on their own and called for better support to help patients navigate cancer diagnosis, treatment, and survivorship and overcome medical, financial, and emotional burdens brought on by cancer.

Through the Cancer Moonshot and other recent developments, like the funding and creation of ARPA-H and the establishment of President Biden's Cancer Cabinet, which aims to leverage a whole-of-government response, the Biden administration plans to develop new ways to prevent, detect, and treat cancer and ensure the necessary tools reach more Americans.



"You have our commitment and our partnership to make significant progress to end cancer as we know it."

— Danielle Carnival, PhD

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CLOSING KEYNOTE:

The Impact of the Coronavirus Pandemic on Cancer Prevention, Diagnosis, Care, and Research

Norman (Ned) Sharpless, MD Director, National Cancer Institute

In the closing keynote, Dr. Ned Sharpless, Director of the National Cancer Institute (NCI), addressed the impact of the COVID-19 pandemic on cancer prevention, diagnosis, care, and research and shared more about NCI's latest work. He celebrated the steady budget increases to NCI since 2015 which reflect the broad bipartisan support for cancer research and the support from President Biden.

Despite sustained investments in cancer, the pandemic gravely impacted cancer screening, care, and treatment. Dr. Sharpless identified the disruption the pandemic caused to cancer care, sharing that NCI estimated the US would experience increases in cancer mortality over just a few years due to the disruption in care.

In response to the pandemic, NCI took part in a series of projects, including embracing innovative and popular solutions like telehealth to ensure patients could enroll in clinical trials and producing a report addressing vaccine hesitancy. NCI also partnered with the First Lady Dr. Jill Biden to direct public attention to cancer screening to counteract the disruption in screening caused by the pandemic.

Finally, Dr. Sharpless highlighted what he called a national epidemic of cancer survivors that will result from cancer interventions like the Cancer Moonshot. While these interventions will save lives, survivors will nevertheless be left with survivorship challenges. He stressed the need for survivorship research, confirmed NCI's growing interest in survivorship and discussed the accomplishments of the NCI's Office of Cancer Survivorship. In response to this focus on survivorship, NCI has continued investing in survivorship grants, which have increased exponentially in the last 20 years.



"Cancer survivorship is an area where the National Cancer Institute will continue to invest."
— Norman Sharpless, MD