

# NCCN PATIENT ADVOCACY SUMMIT: NAVIGATING THE CARE CONTINUUM FROM SCREENING THROUGH SURVIVORSHIP

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This is the first blog post is on the [National Comprehensive Cancer Network \(NCCN\) Patient Advocacy Summit: Navigating the Care Continuum from Screening Through Survivorship](#). This event was held virtually and in person in D.C. on Tuesday, December 5, as part of the NCCN's annual policy summit series.

For their final policy summit of 2023, the NCCN invited multidisciplinary stakeholders to Washington D.C. for a discussion focused on patients with cancer receiving comprehensive and equitable care. “Patients navigating the cancer care continuum often encounter several barriers and needs as well as issues associated with care transition, disparities across healthcare coverage and best practices in patient navigation,” said Crystal Denlinger, MD, FACP, CEO, NCCN, in delivering the summit’s opening address.

“The speakers today will highlight the vital role of patient navigation and care coordination.” According to Dr. Denlinger, the issues plaguing cancer care—cost being chief among them—are far too complex to address in one day. However, she shared her hope for this meeting to serve as a springboard for health equity initiatives in 2024 and beyond.

## Cancer Care in Immigrant Communities

“Today, we are going to talk about navigating social justice and equity,” said Francesca Gany, MD, MS, chief of Immigrant Health and Cancer Disparities Services for Memorial Sloan Kettering Cancer Center while delivering the summit’s keynote address. “We look at language, literacy and the digital divide, employment, housing, food security, and what it takes to establish trust.”

Dr. Gany began by highlighting the unique challenges of delivering cancer care in immigrant communities. “In New York, our foreign-born population sits at 37% and that was important to consider as we developed our patient navigation,” she said. “We have a large undocumented population, and they are often the last to come in for care, so we make sure they get screened.”

According to Dr. Gany, 50% of patients in their catchment region were struggling to make ends meet even before their cancer diagnosis. “More than 50% live below the poverty level; 14% are food insecure, and that is about the same around the country,” she explained. “Patients have to decide between coming in for treatment and feeding their family.” Of perhaps greater concern is the result of a study conducted by Dr. Gany and her team in

their safety net clinic. “We found that 17% of patients with limited English proficiency did not know their own cancer diagnosis. That is—1 in 5 of our patients did not know what their cancer was, let alone be able to discuss their treatment with their providers.”

Language is a significant but underreported barrier to patients receiving cancer care. One [study by the NCCN](#) revealed linguistic disparities in cancer care access due to barriers present prior to a patient receiving an evaluation from a physician. The study found that simulated Mandarin-speaking and Spanish-speaking patient callers were provided with the next steps to access their cancer care in only 27.5% and 37.7% of the calls, respectively—remarkably less than the 93.5% of English-speaking patient callers. Given that patients with limited English proficiency remain [underrepresented](#) in cancer equity literature, additional research is needed to understand how pervasive this barrier to cancer care truly is. Dr. Gany went on to discuss another significant barrier to cancer care: food insecurity.

## Food Insecurity

“More than 25% of people with cancer in the United States are food insecure,” Dr. Gany said. “This often affects people from underserved communities.” According to Dr. Gany, food insecurity leads to delays in care, reduced treatment adherence, and poorer treatment outcomes. Thus, it is it is especially important to develop strategies to tackle this issue.

“The NCCN—yay—added food insecurity on the distress survey. What is not yet known is how often we should be asking about food insecurity. We know it’s not enough to just ask on the first visit, as financial insecurity increases as care progresses,” she said. “At MSK [ Memorial Sloan Kettering Cancer Center] we ask quarterly, and we found so much food insecurity among our patients, we decided to start a food bank.” While the pantry yielded positive results, Dr. Gany said patients desired a degree of personal agency. So, the Memorial Sloan Kettering Cancer Center developed a food voucher program and established a grocery delivery service.

According to Dr. Gany, the benefits of these initiatives far outweigh the costs. The food pantry costs \$63 per patient in a cohort of 12 and \$52 per patient in a cohort of 50. The food voucher program costs \$81 per patient per week, while the grocery delivery service costs \$71 per patient. Both include weekly pantry access. “When we think about the dollars spent in cancer care in the US, and the small amount this represents commensurate to the effects, we need to think about doing this across the country,” she said.

## The Digital Divide

In conclusion, Dr. Gany examined the need for cancer programs and practices around the country to address the digital divide. “MSK partnered with a tech[nology] company to refurbish and distribute devices to patients,” she said. “This partnership has provided 346 devices to patients, and we have helped 186 patients receive home internet through the [Affordable Connectivity Program](#).” Six months following program implementation, 99% of patients reported healthcare satisfaction, while 98% reported improved provider trust, and 97% indicated they were better able to attend appointments and receive treatment. Further, there was an 80% increase in first-time patient portal users. However, perhaps it is this patient story that adequately summarizes the impact these initiatives have had on the cancer center’s patients:

*RB is retired supervisor with Stage IV breast cancer, living in the Bronx. She received a laptop through the Access to Telehealth for Underserved Breast Cancer Patients program and extensive navigation on how to use her patient portal. In an email, she expressed thanks to the navigator who has worked close with her: “As I told you during the day we met, ‘You were an angel who walked into my life that day.’ I am sitting on my new laptop with all smiles and excitement. This cancer is hard to deal with, but you’ve eased some of my emotional pain.”*