

# action

## Highlights from the ACORI Call to Action Summit



In 2021 the Association of Community Cancer Centers launched the ACCC Community Oncology Research Institute (ACORI), which is building on ACCC's existing mission to achieve equitable cancer care for all patients by forming key community partnerships. As part of this mission, ACCC hosted the ACORI Call to Action Summit, a two-day virtual event held Sept. 13-14, 2021.

The summit brought together a diverse group of stakeholders—including community oncology professionals, research team members, patient advocates and advocacy groups, clinical trial sponsors, industry leaders, research networks, cooperative groups, and government and regulatory agencies—to explore practical ways to strengthen and diversify oncology clinical trials.

In opening the packed agenda, Michaela Marchi—a singer, songwriter, cancer survivor, and patient advocate—shared her powerful story about her lifelong experience with cancer. Of Pueblo, Filipino, and Italian descent, Marchi (along with most of her family) has Lynch syndrome (also known as hereditary non-polyposis colorectal cancer), and she was diagnosed with Stage IV colon cancer in 2016. With a long family history of cancer, Marchi was the first of three generations to survive after diagnosis. She credits her survival to taking it upon herself to independently identify and enroll in a clinical trial targeting patients with Lynch syndrome diagnosed with Stage IV colon cancer. Marchi received immunotherapy, and her tumors disappeared within a year. Since then, Marchi has dedicated her life to advocating for patients who traditionally do not have access to clinical trials and giving them the education necessary to participate in trials. Through her sobering tale, Marchi articulated the mission of the summit: to understand the experiences of historically disadvantaged communities and build effective relationships with them to further cancer research and health equity.

### Representation

ACCC gathered expert panelists who discussed the current research landscape and the need to create and run more inclusive clinical trials. “The diversity of trials must represent the diversity of cancer,” said Sybil Green, JD, RPh, MHA, the diversity and inclusion officer at the American Society of Clinical Oncology. Green laid out the current oncology and clinical trial landscape:

- Four percent to six percent of patients on clinical trials are Black.
- Three percent to six percent of patients on clinical trials are Latinx.
- American Indians experience the highest mortality rates compared to all other groups.

Linda Burhansstipanov, MSPH, DrPH, president of Native American Cancer Initiatives, and Rodney Haring, PhD, MSW, director of the Center for Indigenous Cancer Research at Roswell Park Comprehensive Cancer Center, both highlighted the many barriers Indigenous communities face regarding access to equitable healthcare (i.e., common misconceptions regarding the use of casino funds and general distrust of western medicine).

“They [Indigenous communities] desperately need partnerships with cancer programs to help,” said Dr. Burhansstipanov. By partnering with Indigenous communities, oncology staff and researchers can target current barriers and build long-term trust. A 2021 *Oncology Issues* article demonstrated how Dr. Haring’s team at Roswell Park Comprehensive Cancer Center has successfully partnered with native populations to guide its clinical research.<sup>1</sup>

Similar barriers and needs exist in Black and Latinx communities. Panelists agreed that the largest barrier to equitable representation in cancer clinical trials is not asking traditionally underserved populations to participate in them. For this to happen, oncology staff must have dedicated time to spend with their patients to educate them about clinical trials and invite them to participate. Patients cannot be expected to make informed decisions about participating in clinical trials if they do not understand how these trials work, the travel or costs associated with participation, or how a trial may impact their communities in the long term. Education about clinical trials should be done in layman’s terms to meet patients where they are, and it should be in a patient’s native language. To support these efforts, ACCC developed a digital glossary of clinical research terms that helps establish a standardized understanding across cancer care team members and serves as a tool to improve patient education and encourage shared decision-making conversations. Explore this online tool at [acori-glossary.accc-cancer.org](https://acori-glossary.accc-cancer.org).

Duron warns against making any assumptions about patients’ communication preferences. “[Healthcare professionals] need to ask patients what language they prefer, not what language they speak,” she explained.

### Building Community Partnerships

In all panel discussions throughout the day, one question repeatedly emerged: How do we build trusting and effective community partnerships to engage marginalized groups in cancer research? Many panelists agreed that each patient’s community is part of their identity, especially those in the Black and Latinx population. For Indigenous groups, Dr. Haring shared that cancer programs and practices need to understand each tribe within their

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community, including their long histories, to build relationships with them. Panelists suggested that education should be bi-directional. Patients must be appropriately educated about their disease and potential clinical trials, and staff must be educated about the communities they wish to engage.

Shonta Chambers, MSW, executive vice president of Health Equity and Engagement at the Patient Advocate Foundation said that researchers “cannot separate a patient from the social context of their community.” That context is key. For example, social determinants of health to consider in disadvantaged populations can include food security, socio-economic status, access to transportation, and so much more. “For community engagement to be successful, it takes time and resources,” said Venus Ginés, MA, P/CHWI, chief executive officer and founder of Día de la Mujer Latina. Panelists identified the need for cancer programs and researchers to engage with communities long before a trial is designed or patients are asked to participate. In doing so, researchers should partner with grassroots organizations within the community that may already have a footprint among community members and/or host community education activities.

In all, the day’s panelists agreed that to achieve true diversity within cancer clinical trials, we must begin before a study or trial is thought of and engage in these communities with the intention to build or restore trust between them and their healthcare providers.

ACCC will publish an executive summary of the summit that will speak on the day’s themes and their usability, feasibility, and degree of potential impact to guide the future of the Institute. Meanwhile, browse resources available in the ACORI Summit Resource Library ([accc-cancer.org/ACORI-library](http://accc-cancer.org/ACORI-library)), including:

- *All Together Now for Inclusive Cancer Trials*. A program developed in partnership with Stand Up to Cancer, the LUNGevity Foundation, Moffitt Cancer Center, and Platform Q
- The Stand Up to Cancer Resources Toolkit
- National Black Family Cancer Awareness Week #BlackFamCan; Social Media Toolkit for the FDA’s Oncology Center of Excellence Project Community Initiative
- U.S. Cancer Centers of Excellence Strategies for Increased Inclusion of Racial and Ethnic Minorities in Clinical Trials, Regnante et al.
- Promoting Inclusion of Members of Racial and Ethnic Minority Groups in Cancer Drug Development, Lola Fashoyin-Aje, MD, MPH; Julia A. Beaver, MD; Richard Pazdur, MD
- Let’s Tackle the Hidden Real-World Reasons for Poor Clinical Trial Diversity
- FasterCures, Engaging Patients in Research.

#### Reference

1. Patton A. Center for Indigenous Cancer Research at Roswell Park Comprehensive Cancer Center. *Oncol Issues*. 2021;36(3):22-28.

## ACCC Welcomes Its Newest Members

### **Montrose Memorial Hospital San Juan Cancer Center**

Montrose, Colo.

Delegate Rep: Dean Putt, MBA

Website: [montrosehospital.com/medical-services/san-juan-cancer-center](http://montrosehospital.com/medical-services/san-juan-cancer-center)

### **Baptist Health Corbin**

Corbin, Ky.

Delegate Rep: Lisa Gomez, RN

Website: [baptisthealth.com/corbin](http://baptisthealth.com/corbin)

### **Parkland Hospital, Parkland Cancer Program**

Dallas, Tex.

Delegate Rep: Umber Dickerson, MPH

Website: [parklandhospital.com/cancer](http://parklandhospital.com/cancer)