ADVANCING PATIENT-CENTERED CANCER CARE

EVENT SUMMARY

November 9, 2021

MERCK FOUNDATION

SCHOOL OF NURSING
UNIVERSITY OF MICHIGAN

ALLIANCE
FOR HEALTH POLICY

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Overview

The Alliance for Health Policy, in partnership with the national program office of the Alliance to Advance Patient-Centered Cancer Care (AAPCCC), hosted a virtual summit to highlight innovations and policy opportunities to improve patient-centeredness in cancer care.

Clinicians, hospitals, and health systems are searching for new ways to improve the oncology patient experience and promote health equity. The ongoing pandemic has complicated this push for improvement, as providers and health systems have had to change care delivery practices dramatically to protect patients from COVID-19. Furthermore, health disparities have received significant attention over the past 18 months and spotlighted the desperate need for improved equity in all facets of health care, including the ways we interact with, include, and treat patients with cancer.

This summit convened and informed health policy and oncology research communities about these critical issues and offered lessons, strategies, and policy approaches for the short and long term. Sessions explored best practices to improve patient-centered cancer care, the relationship between patient-centered practices and health equity, as well as policy implications and levers. Panelists included providers, researchers, policy experts, and cancer storytellers and survivors who each offered their unique perspectives throughout the summit.

Session Summaries & Key Takeaways

Patient-centeredness should be valued in all care and especially in care that is as complex as treatment for cancer. Patients who are being treated for cancer oftentimes have multiple specialty providers, potentially spread across several offices and health systems, as well as interprofessional care teams that support them. During the summit, several expert stakeholders in cancer care—including providers, researchers, and patients—came together to share their vision for an improved system that listens to patients and puts them at the center.

Throughout the day's discussions our panelists returned to several themes and topics, including the role of the social determinants of health, how to improve health equity in cancer care, the importance of listening to patients, and how to make tangible policy improvements. The following section contains quotes and discussion contributions that underscore the below key takeaways, shared by our expert speakers, from each session.

Audience members learned:

- Health disparities were prevalent prior to COVID-19 and were laid bare, and even widened, during the course of the pandemic. **Promoting health equity and addressing the social determinants of health** is one framework to eliminate these disparities.
- **Clear, open communication** is a central tenet of patient-centeredness, not only between patients and their providers, but also between care team members, peers, and colleagues, in order to share learning and best practices.
- Patients and their families and caregivers should be **involved in every step** of care to offer their thoughts, input, reactions and hesitations about their care plan and goals.
- All members of a care team, including patients and their families, should **consider themselves advocates and become involved at the institutional and government levels** to advocate for patient-centeredness.

Session 1: Innovating to Improve Patient-Centeredness

In this roundtable discussion, experts discussed key lessons learned from ongoing health services intervention projects to improve patient-centeredness in cancer care. Panelists focused their remarks answering the query “What does an equitable cancer care delivery system looks like?” Other discussion topics included strategies to connect with patients and their caregivers, provider training and care delivery innovations, as well as tools and practices to support patients and their caregivers.

Opening remarks, delivered by Dr. Eliav Barr, touched on the impacts of the pandemic on cancer care and the importance of addressing the social determinants of health to bridge disparities and improve health equity. Dr. Barr shared the importance of patient-centered care during his mother’s cancer treatment and his hope to make her experience the standard for all patients.

Speakers:

- **Eliav Barr, M.D.,** Senior Vice President and Head of Global Medical and Scientific Affairs at Merck Research Laboratories *(opening remarks)*
- **Heidi A. Hamann, Ph.D.,** Associate Professor, Department of Psychology, University of Arizona; Member, Cancer Prevention and Control Program, University of Arizona Cancer Center
- **Michael Holtz,** Nine-Year Cancer Survivor, Patient Advocate
- **Roland Matthews, M.D.,** Professor and Chairman, Obstetrics and Gynecology, Morehouse School of Medicine; Medical Director, Georgia Cancer Center for Excellence at Grady
- **Reginald Tucker-Seeley, Sc.M., Sc.D.,** Vice President, Health Equity ZERO-The End of Prostate Cancer *(moderator)*

He underscored critical diagnosis and treatment gaps due to pandemic-delayed care stating, “last year, many services were closed and routine visits and screenings were canceled or delayed and that means that many patients did not get the care they needed when they needed it and the care they did get looked really quite drastically different than before.” These delays mean that cancer patients may be vulnerable to more advanced illness prior to treatment and realize different treatment outcomes.

Dr. Barr also named specific disparities that have persisted before and during the pandemic and shared that, “… as we speak about the future of patient centered care, a key lesson from COVID-19, I think, is that health equity must be front and center in the policies and programs… We know that there are unacceptable disparities in cancer outcomes in this country… disparities exist in mortality rates and they persist across racial and ethnic identities… Approaching cancer care and treatment through health equity lens helps us recognize and plans for the needs of patients and their caregivers.”

During the roundtable, Dr. Reginald Tucker-Seeley lead expert panelists Dr. Heidi Hamann, Mr. Michael Holtz, and Dr. Roland Matthews through a discussion about how to achieve a more equitable health care system that engages cancer patients in their care.

Cancer survivor Michael Holtz shared his experience in treatment for stage 3b rectal cancer and the challenges he faced understanding his illness and care stating, “…in treatment for rectal cancer, I'm having a side effect that I [don’t recognize] … Is this normal? Is this the way this is supposed to happen? Until I asked the question, nobody told me that what I was experiencing was normal… Should I be experiencing this… And so having someone that you can call on to help you put those pieces together, that you can trust would also be beneficial.” This story resonated with other speakers, who underscored the importance of listening to patients, as well as their family members and caregivers, and offered examples of patient-centered strategies from their own work.

Dr. Heidi Hamann suggested “a forum [for researchers and providers] to communicate across county lines, state lines and the like to have best practices out there that can work for systems similar to ours and just in general, to be able to take from others.” This forum was a cornerstone of the University of Arizona Cancer Center project to expand patient-centered cancer care for under-served patients in southern Arizona. Dr. Roland Matthews built on this idea, stating, “I think we have to find a way to get the ‘public’ involved in what we are trying to do here… And we need to communicate what that is and how that can be done to the public so that they can also advocate.”

Dr. Matthews continued to reflect on practices that showed positive results in his own health system, the Georgia Cancer Center for Excellence at Grady Health System. He shared, “… one of the things that we did through the [AAPCCC] work and at our cancer center at Grady is to start what we call a PFA, which is a patient-centered… group of patients, providers, staff, but mostly [patients] and caregivers to help advise the system as to what makes sense for the patient.” This integration of patient and caregiver input, not only in cancer care practices but across the health system, is just one way health systems can build more patient-centered care.

In regard to national policy, Michael Holtz shared, “… a piece of legislation that I'm particularly passionate about is called the Palliative Care and Hospice Education and Training Act… it's legislation that one, educates people on the difference between palliative care, which I think is the definition of patient-centered care and hospice. And it trains medical professionals, but it also educates the public so that members of the public when they hear those words, "You have cancer," they know what to ask for.”

Finally, the importance of care coordination and care navigation were raised by all of the panelists. Dr. Matthews shared examples from his team’s work, stating, “… the patients have been very much appreciative of being able to have the significant input that we have given them into how their care is delivered. And I think part of what made that work well, at least in our system is that we employed navigators to help us with that… Some of our navigators were survivors themselves. And so that really helped us to connect well with the patient…” Michael Holtz followed up with his own experience transitioning through his cancer and post-cancer treatment and emphasized the value of well-coordinated care, explaining, “… there needs to be a strong handoff. The day that my surgeon freed me from his care after five years was both the best day and the worst day of treatment because he was kind of a linchpin in my follow up care… my primary care physician knows how I was treated, what I was treated with so that if I come to him with an issue that has arisen now, for example, my calcium is running really high and that typically means one of two things, one of which I don't want to think about. But we're working through that process.”

For more resources, a transcript, and a recording of Session 1 please click here.

Session 2: Fireside Chat with Dr. Wayne A.I. Frederick

Speakers:

- **Wayne A. I. Frederick, M.D., MBA,** President, Howard University
- **Sarah J. Dash, MPH,** President and CEO, Alliance for Health Policy *(moderator)*

During this fireside chat, Dr. Wayne A. I. Frederick, President of Howard University, leveraged his expertise as a surgical oncologist to offer thoughts on the importance of equity in cancer care, including the role of patient-centeredness, and how disparities impact the lives of cancer patients and their families.

He began his remarks with a striking, regional example - "What we've learned so far is that the disparities are wide. You look right here in DC, as an example, you just look at life expectancy, overall. A white woman in DC who lives in [a predominantly white section of the city] has the largest life expectancy, but almost 20 years less for a black man living in [a predominantly black section]. And think of how small DC is, just 600,000 citizens. You would think that access, et cetera, wouldn't be an issue. The COVID-19 pandemic has exacerbated that, in my opinion."

Sarah Dash followed this thread, asking, "...in terms of specifically focusing on cancer and cancer care disparities, are there immediate actions that could be taken to improve the situation?" Dr. Frederick responded with the priorities he would address, in rank order, "first is we need a national effort to get screenings back on track. So, we need public service announcements in the same way that we encourage people to take vaccines. As our vaccination rate has increased and COVID decreases, we need to move some of our public service announcements and our public health messaging to [encourage] people to get to screenings to close that gap. Second, we need to have a focus on underrepresented minorities because of the gap that does exist, existed before, that has only [widened]. So, we need to be out in those communities, taking the message [and services] to them... And the third thing is more of a longer-intermediate to longer-term strategy. We have to start filling the pipeline of diverse health care professionals who are culturally competent and will go into some of these neighborhoods and support the work that must be done. And that work must be done immediately."

Dr. Frederick also shared his thoughts on the recent national discussions around mistrust and distrust in the medical system. He explained how responses or changes in practice due to historical actions, such as the Tuskegee experiment, are not always well communicated to the public, which may be driving further mistrust. In order to rebuild this trust, Dr. Frederick explained, "what we need to do is to say, yes, this happened. It is unacceptable that it was able to happen, and we've put things in place for it to never happen again. I think the second thing is we have to believe in our trusted messengers. And we know that our trusted messengers do not only exist in our health care systems, but they exist in our churches. They exist in our homes and our community centers. They exist in our corner stores and groceries."

As the conversation progressed, Sarah Dash asked for insights into why patient-centeredness is so important when trying to achieve health equity and what the care team's responsibility is to the patient. Dr. Frederick offered, "every question and concern, that [the care team is] here to help them. And empowering that patient to be able to take control of their destiny around their health care, I think is critical in decreasing disparities and bringing health equity, but also in increasing the, I would say the quality of the relationship with the medical establishment."

In reflecting on the role of policymakers and how they can contribute to advancing patient-centered care, Dr. Frederick explained, "I think one of the things that we have to look at is what are we providing for people where they are… Where [does the policymaker] put certain items? What [is the policymaker] thinking about in terms of… health? We don't want to hurt your bottom line, but your bottom line could still be great while you do provide a service to the community."

For more resources, a transcript, and a recording of Session 2 please click here.

Session 3: Translating Lessons and Success to Policy and Practice

Advocates and cancer care experts came together for this conversation on how best to translate small program lessons and strategies into policy and widescale practice. Panelists discussed both policy and operational approaches to providing more equitable, patient-centered cancer care, including how best to deliver care to patients and how to train our cancer care workforce effectively.

Ms. Jodi-Ann Burey opened the discussion with a reflection on her work as the creator and host of the Black Cancer podcast and the stories her guests—survivors, patients, caregivers, and loved ones—share with her about their cancer experiences. Audience members then heard stories directly from cancer survivors and providers about the direct impacts of cancer treatment in patients' and their families' lives. Candace Henley immediately pointed to the importance of listening to the patient voice stating, "… if we're going to make patient-centeredness part of policymaking, then we need to hear from the patients. There needs to be a listening session for patients of all cancer types, because it's not one size that fits all. My journey as a colon cancer survivor is different [from] a journey with someone with breast cancer, someone with cervical cancer, someone with liver cancer. They're all different. Yes, cancer is cancer, but they're all different."

Speakers:

- **Candace Henley, MPH,** Chief Surviving Officer, The Blue Hat Foundation
- **Beverly Moy, M.D., MPH,** Clinical Director of the Breast Oncology Program, Director of Cancer Equity, and Medical Oncologist, Massachusetts General Hospital; Associate Professor of Medicine, Harvard Medical School
- **Jose G. Trevino M.D., FACS,** Walter E. Lawrence Jr. Distinguished Professor of Surgical Oncology; Chair, Division of Surgical Oncology; Associate Professor of Surgery; Surgeon-in-Chief, Massey Cancer Center, Virginia Commonwealth University
- **Jodi-Ann Burey, MPH,** Creator and Host, Black Cancer Podcast *(moderator)*
- **Christopher Friese, Ph.D., RN, AOCN®, FAAN,** Elizabeth Tone Hosmer Professor of Nursing Professor, School of Nursing, University of Michigan; Co-Director, Alliance to Advance Patient-Centered Cancer Care National Program Office *(closing remarks)*

The narrative of listening to patient stories directly was carried on by Dr. Jose Trevino, a surgical oncologist who is also passionate about patient advocacy. Dr. Trevino discussed the systemic levers that can be pulled to improve patient-centered practices, saying, "For me to walk into a room and try to explain to somebody cancer is one thing. For a patient family and a patient with cancer to explain their cancer is a completely separate entity. It's incredible how the two dynamics can work together… And that's why empowerment of communities, empowerment of people, empowerment of different racial and ethnic groups, I think, is probably the most important thing that we've seen over the past decade."

with other speakers, who underscored the importance of listening to patients, as well as their family members and caregivers, and offered examples of patient-centered strategies from their own work.

Dr. Trevino also reflected on the power of patient stories to influence the actions of policymakers, sharing, "… I've seen when I went to visit state senators and actual representatives, as well as at the national level, when I'm at the door to wait for them to see me to talk with me about policy in cancer research and cancer care, there are families there… individual families that are coming from all over the country… [and] while it be two or three people, they're from their community that elect them to be at that national level. If [policymakers] ignore or they don't really take account for what's happening in their backyard, in their home, that reputation spreads, and they lose the election."

Dr. Beverly Moy further reflected on the practical impact of sharing patient narratives and the specific role of providers as patient-centeredness and policy advocates, explaining, "I feel a responsibility to my individual patients to speak to them, to the policymakers that can come up with those solutions. I'm actually not shy about talking to my patients about the times that I'm in Capitol Hill or in the State House to talk about these things. Because then they tell me more stories like, 'Oh yeah, you should tell them about blah, blah, blah, blah, blah.' And it's a partnership really, but I think that it really is all connected. When I go to these places with other oncologists, we always leave invigorated." This direct engagement between providers and policymakers was a key piece of Dr. Moy and her team's strategy to enhance patient-centeredness at Massachusetts General Hospital Cancer Center.

The discussion, led by Jodi-Ann Burey, echoed many of her observations as a cancer storyteller and podcast host "… I talk to so many people for the podcast… and the urgency and the work of being a patient, I don't know if people didn't understand that, I didn't understand that until I was actually in it, that there are people who are sick, people who are unwell, people who are super, super stressed out, who still have to be in their hospital bed as I was on the phone with your insurance company, trying to figure out what options you have for treatment, or how many sessions of the treatment you have or how you're going to pay for it, and so you're not focusing on getting well." This burden of coordination, placed on the patient and their families, is a problem that patient-centeredness hopes to improve. Projects, like that piloted at Johns Hopkins Medicine, that aim to support patient-centered cancer care use a variety of tactics including enhanced care coordination to improve patient experience and provide higher quality care.

In addition to care coordination between providers, the importance of specialized navigation assistance was also highlighted. Candace Henley explained, "now they have patient navigators, but they don't have enough. Because see, they're replacing patient navigation with nurse navigation. Those are two separate entities. Patient navigation is someone that can help the patient navigate through the financial resources that they need to have outside of the hospital. Nurse navigation can help navigate resources within the hospital, and they can work together, but if you are doing away with patient navigation, you're putting too much on the shoulders of the nurse navigators to handle what the patient navigations could be handling." There is not only a need to ensure that patients are not overburdened in their coordination and navigation of their care, but that their care team members are also able to provide their specialized assistance without overstretching their individual role.

Finally, the impact of the social determinants of health were again brought to the surface. During

Finally, the impact of the social determinants of health were again brought to the surface. During discussion about the importance of patient-centeredness across the health care spectrum—from clinical trials, to treatment, and beyond—the reality of these barriers was brought into sharp focus. Candace Henley shared, “my kids had the American [dream] that I worked hard to give them, only for it to be wiped out after a cancer diagnosis. It wasn't simply because of treatment, because I hear that a lot when doctors talk about financial toxicity…. No, it's patients paying for life, right? Life. My disability insurance at my job only paid $184 a week. Social security denied me because… colon cancer was not on the list of cancers for social security. Then there was the services that the city… offers, it was in a summertime, so they only offered gas and electricity…, and then you either had to be a senior or you had to be disabled. Of course, I wouldn't declare disabled because guess what? Social security didn't acknowledge me as being disabled. So, it's an endless vicious cycle.”

Dr. Moy expounded on this and shared her observation as a clinician, stating, “it's hard enough having cancer and going through regular treatment, as we already heard, but when you're on a trial, the logistics and the schedule of required visits, sometimes you have to stay overnight and get a blood draw the next day. You have to come in, maybe once a week sometimes. You have to get scans every two months, and you have to travel farther, because maybe the place that does the trial is an hour away and you have to pay for the time off of work, and the park getting, and the gas, and the childcare.”

As the day closed, Dr. Christopher Friese reflected on the lessons learned and shared, and offered a call to action to the audience to continue to learn and advocate for patient-centered cancer care.

For more resources, a transcript, and a recording of Session 3 please click here.

Selected Experts

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Glossary of Terms

Care Continuum: Per the Primary Care Development Corporation: "In health care, the continuum of care describes how health care providers follow a patient from preventive care through medical incidents, rehabilitation and maintenance."

Health Disparities: The Healthy People 2020 initiative describes health disparities the following way: "Although the term disparities is often interpreted to mean racial or ethnic disparities, many dimensions of disparity exist in the United States, particularly in health. If a health outcome is seen to a greater or lesser extent between populations, there is disparity. Race or ethnicity, sex, sexual identity, age, disability, socioeconomic status, and geographic location all contribute to an individual's ability to achieve good health."

Health Equity: The CDC states that health equity is "achieved when every person has the opportunity to "attain his or her full health potential" and no one is "disadvantaged from achieving this potential because of social position or other socially determined circumstances."

Patient-Centeredness: The Institute of Medicine or IOM (renamed the National Academy of Medicine in 2015) defines patient-centered as: "Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions."

Social Determinants of Health: Healthy People 2030 defines the social determinants of health as "the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks" and groups these determinants into five domains: economic stability, education access and quality, health care access and quality, neighborhood and built environment, and social and community context.

Survivorship: Per the NIH National Cancer Institute, survivorship focuses on the health and well-being of a person with cancer from the time of diagnosis until the end of life.