

## Translating Lessons and Successes to Policy and Practice

November 9, 2021 | Transcript

Madeline Cree:

Hello. My apologies for being muted. You can tell it's been a tricky day. Welcome to the final session of our advancing patient-centered cancer care summit, and thank you for your patience. I'm Madeline Cree, health policy analyst at The Alliance for Health Policy. I'd like to remind our audience that you can still join today's conversation on Twitter using the hashtag all health live, and following us @allhealthpolicy. We want to encourage you to continue to be active participants so please get your questions ready. Here's how you do it. Please navigate yourself to the chatbox on your screen.

You can use this feature to submit questions to panelists, as well as support for any audio or technical issues like unintentional muting that you may be experiencing. Materials for this event are also going to be available below for download and a recording will be made available here on Eventtia at the conclusion of the webinar and on our website, allhealthpolicy.org in a few days. Now, I'd like to introduce our moderator for today's final panel. Ms. Jodi-Ann Burey is speaker writer and creator who works at the intersections of race, culture, and health. She draws from education, global health, entrepreneurship, and other disciplines in her work with communities of color always at the center.

She's interviewed Stacy Abrams and introduced both US Senator Corey Booker and Vice President Kamala Harris during their 2020 campaigns. In 2018 Jodi-Ann's public health and social justice worlds collided with a spinal tumor diagnosis. Along with that recovery journey, she built what she needed, a space to not feel alone. Jodi-Ann, excuse me, created Black Cancer, a narrative podcast about identity, trauma and health inequities. She also serves as a founding co-chair of the Seattle Diversity Equity and Inclusion Community of Practice. We are so honored that Jodi-Ann could join us today to lead this discussion. And Jodi-Ann, I turn it over to your very capable hands.

Jodi-Ann Burey:

Thank you so much for the introduction, Madeline. Before we get started in the discussion, I would like to introduce our panelists. First, I'm joined by Ms. Candace Henley. Candace is a tireless advocate for colon cancer prevention and support. She was a single mother raising her five children. She lost her car and home while battling colon cancer. Her own battle and the devastation it left in her life, and that of her children, inspired her to create The Blue Hat Foundation. The organization is founded on unconditional support and compassion for people fighting colon cancer. Their mission is to provide education, information, and free screenings for colon cancer in minority and medically underserved communities.

Next, we will have Dr. Jose Trevino, the Walter E. Lawrence junior, a distinguished professor of surgical oncology. Chair of the division of surgical oncology, associate professor of surgery, and surgeon in chief of the Massey Cancer Center in Virginia Commonwealth University. In his role as chair, Dr. Trevino leads one of the largest divisions in the department of surgery. As a surgeon, as surgeon in chief at Massey, he serves as the lead oncology surgeon and demonstrates significant innovative approaches to cancer surgery. Dr. Trevino's interest in cancer health disparities and minority health is reflected in his pancreatic research. In addition to caring for patients and teaching, he's an accomplished scientist who currently leads and collaborates on multiple R-level grants from the National Institutes of Health, NIH, as many of you know, and awards from the Florida Department of Health.

Finally, we're joined today by Dr. Beverly Moy, clinical director of the breast oncology program, director of cancer equity, and medical oncologist at Massachusetts General Hospital, and associate

professor of medicine at Harvard Medical School, Dr. Moy specific research interests included breast cancer clinical trials, and racial and ethnic disparities in cancer care. She has co-authored more than 100 articles in peer review journals. She's an investigator on multiple research grants, examining cancer care equity, including those funded by the Kraft and Trefler Foundations, Merck Foundation, and the National Cancer Institute.

She served as the chair of the American Society of Clinical Oncology's Ethics Committee and the Health Disparities Committee, and as chair and panelist for multiple breast cancer guideline panels. She's also the community outreach section editor for *The Oncologist*. An incredible panel, absolutely esteemed panel. As the creator and host of the Black Cancer podcast, I personally connect with so many people of color across race and ethnicity about their cancer experiences as survivors, patients, caregivers, and loved ones. It's more than trauma, it's more than health inequities when we talk about people's stories.

What matters to me most about the podcast are the stories that people so generously share about all aspects of their experiences, navigating the highs and the lows of their journey, and who they're becoming, and who they're becoming now as a result of cancer's impact. From their stories and my own story, and from what I've learned back in the day at University of Michigan in my training and work as a public health professional, centering the person, the patient, the families, the actual human beings impacted, is mission critical to transforming cancer care and healthcare as we know it today. I want to start, and by hearing from all of our panelists know, if you can provide introductory remarks that can help ground us in the opportunities to center patients in policy development, in policy implementation.

From each of you, from your particular vantage point, what's your vision for patient-centeredness in cancer policy making, and why is it so critical for a successful and more equitable care? In your explanation, if you please give an example of a key patient experience and how it can be transformed through effective policy solutions. So, Candace, I would love to start with you.

Candace Henley:

Hi, thank you so much for having me. This is such an important topic. I would venture to say that, if we're going to make patient-centeredness part of policy making, 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 fit all. My journey as a colon cancer survivor is different as 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. So often, I mean, within the last few years, yes, we're starting to listen to patients, but still policies are still being made without the patient perspective. They're being made from the scientific perspective, from the medical perspective, but the patient perspective is missing.

How about you listen to what we're experiencing, what we say our challenges are, what our barriers have been, and then enact policies around what we're saying that we need you to do. Then, but listen, don't just go, "Okay. I assume you said." Because we get that a lot. I think I heard you say. No, that's not what I said. We have to have that active listening, and then in addition to that, also realizing that the experience is not a one size fit all because of insurance as well. We have different insurance plans. That's a huge issue because if I have Medicaid and another person has traditional health insurance, guess what? That person with that PPO insurance, they're going to get top of the line care. The doctor's not going to worry about having to submit any paperwork because they know they're going to get paid.

With the person that's on Medicaid, they have to worry about whether or not they're going to get paid, if they're going to get paid on time pretty much. The care is different, and it shouldn't be, and

I've had both experiences. The challenges, it shouldn't be, whether or not, depending on the insurance that you have, there should be a care across the board, and is not, and that's why we're having an equitable treatment. But everyone deserves the opportunity to fight cancer and live the best life they possibly can regardless of insurance.

Jodi-Ann Burey:

That is such a big deal. I'll say, really personal to me, I was treated at Memorial Sloan Kettering in New York City. And when the pandemic started, I got laid off, started working for myself, and just recently rolled off my Cobra for my previous employer's insurance. Then I'm calling Sloan Kettering, I'm trying to figure out, for the first time in my life, I have to navigate health insurance outside of an employer plan and Sloan Kettering doesn't take anything off the exchange. For me, I've had stellar, stellar treatment at Sloan Kettering. And as a black woman navigating the healthcare system, that is a really big deal to find the healthcare team that I trust and that like matters to me.

I feel like I can just lay everything to bear and they'll take care of me. It is absolutely terrifying that I, just in an instant, will lose my entire healthcare team that I've had for four years. What does that look like to try to find good providers and find good healthcare? Because we know and we've experienced, and we've heard that, that healthcare is not standardized across regardless of who your insurance provider is and what you get, and how changes to that, even in changing jobs, could impact your care, particularly for folks who have a long term engagement with the healthcare system. I really, really appreciate you raising that because that is ... It's like personally terrifying for me right now in navigating the implications of that for my care and for my life.

Candace Henley:

Oh, it's a major issue. It's a huge impact. I've had the experience myself, and I had the experience where I actually had to fight an institution to stay after an inpatient surgery because I'm a cancer survivor. So, my treatment had to be a little bit different. I couldn't do outpatient surgery, and they were trying to put me out of the hospital. Yes, this is something that I have to raise the alarm about because this should not be happening.

Jodi-Ann Burey:

No, it shouldn't. And it happens at such, even a micro level too. For the podcast, I chatted with someone who also received her treatment at Sloan Kettering, but because she has Medicaid or Medicare, she has a different insurance plan. I was trying to bond with her over how amazing the food is at the Sloan's cafeteria, and she's like, I've never even been in that building. She goes to other buildings to receive her care. The inequities, it's so present, and we know disproportionately, it'll impact people of color and people with a lower socioeconomic status or who have nontraditional employment plan. So, thank you so much Candace for your remarks and for seeing me, for seeing me right now, and seeing a lot of people who are navigating what healthcare looks like with that battle of insurance.

Dr. Trevino, I would love to hear from you. What's your vision for patient-centeredness in cancer policy making? Why is that so critical? Do you have an example of a key patient experience and how that could be transformed through effective policy solutions?

Dr. Jose Trevino:

Yeah. I hate to say it is, but in terms of, unfortunately a lot of the policy is made by people that aren't affected by this disease. It's amazing how things change when the policy makers get afflicted by this, by the disease process when it comes to cancer. And however, all of a sudden the focus changes. Or the

focus on whichever political agenda is pushed forward or political party takes role. I think that's the sadness of where we are today, that there's a shift, that there can be a shift, excuse me, guys, that there can be a shift in the way we treat patients just based on, as I said, a political a party.

I would tell you that the most amazing thing I've ever seen is when groups get together and they actually make appointments to meet with their senators, their representatives at the state government, at the national government level. They're there and the groups are there. In groups such as PanCAN, who has done an amazing job, and other groups in pancreatic cancer, and that's primarily my focus of interest of study and clinical work, they've done an amazing job where they come together as a group, and then they will affect policy change by sitting down with the policy makers and letting them understand their struggle, their personal struggle.

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. For me, as a physician who treats patients with cancer, seeing their plight in the clinics is remarkable. Some days, there's happiness, and obviously there's days of sadness. And it's that, that needs to be promoted on the level where these policy makers at the level of the national and state governments understand that there has to be continued support for this. I said earlier, it fluctuates. 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.

That we need to push the envelope forward for people to understand that everybody, everybody deserves the best care. There have been names out here about Memorial Sloan Kettering, MD Anderson, Moffitt Cancer Center, VCU, what have you, you name it, we can put names out there, but I think in this country, in this day and age, in 2021, everybody should receive the best care in cancer therapies. As we both know, and as all of us know here, that's not always the case. My personal example is I know patients that get told, when they have a particular type of cancer, that they should go home and get their affairs in order.

While I'll see them a week later and I'll tell them, "No, we don't quit. We don't quit. We fight." We fight until it's over, and it isn't over until we both say it is. It's a team process. There's a lot of things that need to change, education empowerment of the people, and just overall policy, national policy to really reveal cancer care in this country and make it better.

Jodi-Ann Burey:

Yeah. I love that. It's not over until we both say it is. I really do appreciate that, and to hear that from a professional as yourself, surgeon, you just got out of surgery for folks who don't know. You're on the front lines helping people and supporting them in some of the worst experiences of their lives, and to just know that there's someone there fighting for you right in the surgery, in the operating room. Absolutely. But how can we ensure that our representatives are fighting for us? Maybe even if they haven't personally navigated it, elevating our stories, elevating those experiences, getting connected to what's happening on those front lines. That could be a way to push that urgency, to push that political will, to ignore the noise of whatever's happening in our political discourse, and understand that there are patients lives and families lives on the line. So, I really appreciate your remarks on that.

Dr. Jose Trevino:

No, I will tell you that, and I'll say one last thing, 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. We're talking

individual families that are coming from all over the country, and what the policy makers understand, I think is very, very important, is that these are ... While it be two or three people, they're from their community that elect them to be at that national level. If they 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. They lose the election, they lose their power. They lose their power, they lose their job.

All these things are important. I think that everybody, to the single person, has the ability to change this world, to change this country and change the dynamics of how we do things. That's been shown time and time again. It's just we need to understand our own importance when it comes to these topics and really push the envelope forward.

Jodi-Ann Burey:

Yes, absolutely. Thank you so much, Dr. Trevino, and I would love to hear remarks from Dr. Moy on your vision for patient-centeredness and why is it so critical in effective policy making?

Dr. Beverly Moy:

I could not agree more with what Dr. Trevino and Ms. Henley have said so far. I think what I would love to see come out of this discussion today is to kind of encourage and inspire all of the patients and oncology clinicians that are listening today to get involved with policy and advocacy. It is absolutely true that our policy makers often make policy in a vacuum. There are a lot of things that we see that are at play here. What is often lacking is the true understanding of what the patient is going through. So, it really is our responsibility as an oncology community to get in front of those policy makers and tell them our stories and tell them exactly how their policies and laws are affecting our patients.

I can think of one time, I've had the good fortune to be able to speak to lawmakers on Capitol Hill and at the Massachusetts State House. I was telling several of the senators and representatives about a patient of mine who had paged me in the middle of the night because she had metastatic breast cancer, was put on a new pill that was working. She had, had some serious disease, got some scans three months later, and there was an incredible response that she was feeling wonderful. About two weeks after she got her scans, she was called by her insurance company and pharmacy that they would no longer cover that medication and that she would be responsible for \$10,000 a month out of pocket.

That was a direct result of some policies made about oral anti-cancer therapies versus intravenous anti-cancer therapies, and obviously something that we need to fix, because the great thing about cancer treatment in modern times is that we do have some great oral therapies with less side effects and more convenience to the patient. Yet, how she was faced with an impossible decision. It was working, she was feeling better, but could not afford it. So, she said to me, should I go bankrupt and pay for this medicine? That's something that policy makers aren't hearing enough. It is our responsibility to tell these stories so that they understand what regular people in their constituency are going through.

Inevitably, when you tell these stories, their eyes feel with tears because suddenly they understand. There's this empathy there. We have seen meaningful change result from these conversations. I was just talking to one of the State House in Massachusetts' representatives recently, and I asked her bluntly, I said, "How can physicians be helpful in helping you advance policy, especially when it comes to health equity" she was so happy to hear that question because she said, "Absolutely, we need your voice." Many of us individually want to advance these policies, but are met with resistance from colleagues or people on the other side of the aisle.

And we need you here to tell these stories, to really kind of pressure people to understand, yes, you've got all these stresses and blah, blah, blah, blah, blah, but we need to do right by people effective with cancer. That's why patient-centeredness is really important when it comes to policy and advocacy,

and that's why more of us need to be involved in the front lines to try to advocate for our patients and for our families.

Jodi-Ann Burey:

Yeah. There's something in your story too, that's kind of like, I don't know, making me a little anxious, right? Because I have also benefited from my doctors and my care team who've extended their phone numbers and outreach, and I'm contacting them at sometimes weird hours, freaked out about something, what-have-you. And I think about how important your presence is as my care team in my life, supporting me as a patient, being available for me. Then I see the work that these same physicians have to do in advocating for changes on the policy level. So, it's almost like, wait, are you going to spend time with this politician or are you going to spend time with me? And this pulling on physicians of seeing the whole chain of influence, from the very front lines to what's happening in the Capitol buildings where people are making decisions about lives of people that they don't even know.

What's that experience like for you as the physician to be straddling these worlds of super, super deeply patient centered and so personal into a space where, maybe you have two minutes to try to be compelling to get someone to just check a box or do something differently that could have such a huge impact in people's lives? How do you navigate that as a physician?

Dr. Beverly Moy:

Well, I think that it's all connected, right? Because the fact of the matter is, and I'm so glad that we're having this conversation today, the fact of the matter is that policy is what is really the overarching solution to so many things dealing with cancer equity. We need to provide the stories, the evidence to inform meaningful policy changes to make patients lives better and to remove barriers to quality cancer care. I feel a responsibility to my individual patients to speak to them, to the policy makers 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. Doing that kind of work makes me a better cancer physician to my patients because you really can see the good that other people are bringing to the table.

Jodi-Ann Burey:

Yeah. Thank you so much for that, Dr. Moy. Thank you everyone on this panel for setting the stage and sharing your initial thoughts. I want to dive into some more follow up questions. At this time I want to remind everyone here in the audience that you can submit your own questions to us via the chat, and we will get those questions answered, hopefully all of them at the end of this section, but I have my questions first. Candace, I want to start back again with you. So, you, similar to me, you have had both the experience of understanding the healthcare system from these two sides as a patient and as a public health professional. I see you also have your masters in public health, MPHs, very excited about that.

I'm curious for you, how do you think our healthcare system sometimes overly relies on patient education and patient self-advocacy, and how can policy changes fill in those gaps and mitigate that dependency?

Candace Henley:

I think the healthcare system totally relies on us to find out information, and pretty much because there's not enough time spent in the office with the physicians, right? We know that when we're ... I guess it depends, 10 to 13 minutes, so how much information can be relayed in that amount of time for a patient to ask questions and for the doctor to feel comfortable in answering questions and making sure that we understand and know where to find information? And the insurance companies are threatening not to pay if you're spending too much time and it is scrutinizing everything. So, the insurance company has too much control over the health of patients. As long as insurance companies are saying, you can't spend more than 12 minutes at a time with this patient.

Well, guess what? This patient had metastatic cancer. She just had scans come in. I have to go over the scans. We have to go over this. We have to switch the medication. Maybe we have to talk about surgery. You can't do that in 13 minutes. You can't do that in amount of time. There has to be, is some way where we can take the power out of the insurance companies, because that's an issue. You're controlling whether or not ... I mean, and this may seem extreme, but you're controlling how well I live or die based upon the information that I'm able to receive and obtain for a certain amount of time. And then, after I leave, I have to think about, what did I not say? What did I not hear? Okay, so then I have to call back to the office, and hey, I have some questions. And depending on the time, can they call me? Can the physician call me back in a certain amount of time?

Will it be 24 to 48 hours? We're looking at all of this where the insurance company is in the middle of this, and it's causing the issue. The literacy is that we're depending on patients after they leave the doctors, that they understood everything that they said, and now they're going to go to Dr. Google and read Dr. Google, and Dr. Google is going to say everything across the board, and they're not going to understand any of it. Then there's a science piece of it, right? Because I mean, who hasn't researched their type of illness, to see what that looks like? You've looked at YouTube to see the surgery, but we're seeing-

Jodi-Ann Burey:

Yes.

Candace Henley:

Yeah. Okay. Exactly.

Jodi-Ann Burey:

I did the same thing.

Candace Henley:

Yeah. So, we're left to try to understand all of these technical terms that we're reading, that we don't understand what these words mean. So, we're sitting there, then we're Googling the words, and then we're trying to put them all together. I'm not a physician. I didn't go to school for this. If I put it all together, and based upon what I read and what I read on Google, it says I'm dying next week. We are sending the patients out into the world to depend on what they're getting from the internet versus having information that's saying, "Hey, listen, we might not be able to finish this conversation, but here's some information, take a look at it, write your questions down. Here's my email address. Email me, and send any questions that you have, and we can answer it. And if there's any questions that we didn't get a chance to talk about, here."

I mean, but policy changes is that we have to take the power that the insurance company has, that is keeping us from having enough time to understand our diagnosis so that I'm not going home telling my family that I'm dying and I'm not.

Jodi-Ann Burey:

Yeah. No, I hear that. I mean, I talk to so many people for the podcast, and like that same energy, like the stress 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.

How can we, as you're talking about, this like insurance piece and the oversight that we have for insurance companies is giving them way too much power in our lives, which not only impacts us, but it can impact our relationship with our physicians. I think, for me, even personally, I feel like I have to do all the research, have all the language, turn the personality way, way up so this physician can feel compassionate for me, and maybe give me a little bit more than the 13 minutes. But all of that work is so exhausting. As we had talked about before, absolutely not standardized, which can only exacerbate these inequities. So, thank you so much for elevating what are the policy changes that we need that can mitigate or eliminate the control that insurance companies have in our health and in our relationships with our physicians who want to help us. So, thank you so much for that.

Dr. Trevino patient-centeredness is typically discussed in the context of care delivery and reform, but I'm curious, based on your vantage point, what are some of the recommendations for how we can make policy that's patient centered as well? So, yes, we have our doctors that can be incredibly patient centered, but what does policy look like when it is patient-centered?

Dr. Jose Trevino:

I think that, at the end of the day, when we're looking at patient centered kind of policy, we have to really think about what we're doing for these patients. I think I'm going to just follow up a little bit in what Ms. Henley mentioned earlier, and I'll bring up a term that I thought was resonating over and over as she was talking, a term by the name of financial toxicity. Financial toxic is an incredible term that I heard years ago at a conference and nobody was touching upon it. And it was just kind of one of this thing that was just barely being touched on because it wasn't basic science. It wasn't this real kind of envelopment of what we understand in terms of cancer biology, for those that that play around with cancer cells and do the stuff that we do here at VCU and research realm.

This was a completely different realm for me. And I thought, what an interesting topic, that your finances and what goes around it, and the economic hardship and the social hardships of everything could have an effect on your outcome. If you think that a lot of has changed in this country since the inception of this country has been based around hardships, that the idea that we could think about patient centered policy change can be based around that and that alone. There are countries out there that suppress their people because they know that the moment that they understand the hardship, that the people understand their hardship and come together as one, everything changes.

These are what revolutions are about, and this country was based upon that, for that reason alone. When you want to talk about patient centered policy change, you have to think of it in that context. Think of it, if what we're doing to our patients is giving them nothing more than hardship based upon their inability to pay for their therapies, their best therapies. And we're not providing the best



therapies in medicine, in cancer medicine in the year 2021. What in the heck are we doing? We can't just sit idly by and say, well, you know what? It happened to mom. It happened to dad. We couldn't do this. We couldn't do that. That's not how policy changes here.

When you think about the politicians and you think about why they change the things that they change, it's because of the pressure from these hardships that occur. There is no question in my mind, none that this financial toxicity affects patient's lives. Your stress levels based upon the diagnosis of cancer are already high. That stress causes you to become immunosuppressed, your inability to fight cancer because your body is a unique modality that fights off anything that it interferes as foreign. It recognizes foreign, and cancer's one of them. But you drop that inability to fight it, you will have progression of disease. Not only will it affect other parts of your physiology, cardiac, pulmonary, what-have-you, it affects everything.

We cannot, as a country, allow that to happen. And when we do, we fail our patient population. When we come together as one, we're strong. Again, that's how revolutions happen. We're not asking that people overthrow the government, but we just want the people to come together and say, enough's enough, that I want the care that they're getting over there and I think that's the best care, and we want here and over there and. There's no reason why the care in one side of the city should be any different than the care on the other side of the city. Mind you, most of the time, there's differences in socioeconomic status at each one. That doesn't make any sense to me at all, especially in the United States of America in the year 2021.

Jodi-Ann Burey:

Yeah. There's this almost kind of the stress of everything. You can have this casual acceptance of inequities. I remembered I was at like a fundraising event. I was working there because I worked at the organization who knew needed the funds, which means I interacted with a lot of people who had the funds, and had a cane at the time. The issue of my diagnosis had come up and the guy casually mentioned, there are just so many targeted therapies now for your genetic code and all of this stuff, he was saying, and I'm like, "Oh, that's so cool that you think I'd have access to that." In a sense, like making a joke to exit out of that conversation, but we don't have to accept the realities of this disproportionality in access to lifesaving resources, financial or otherwise. I appreciate you invigorating us with how much power we have as patients, as loved ones to compel policy making.

But also, I would love to see policy making that doesn't rely on my sad story, to just understand that inequities are not okay. That is not what we should want or have in this country, and definitely not for our healthcare.

Dr. Jose Trevino:

Absolutely.

Jodi-Ann Burey:

Yeah. Dr. Moy, I'd like to turn to you because, and I want to dig a little bit more in racial inequities when it comes to healthcare and then cancer care. It seems that more and more, even talking about race is not only becoming toxic to our public discourse, but it is bringing both a literal and figurative toxicity into people's lives. I think, Dr. Trevino, in talking about financial toxicity, the experience of racism is also something that can erode our health as people of color. When those disproportionalities show up and then those inequities show up in our actual healthcare, that can have a felt and material impact on our lives.

Dr. Moy, if you could ground us in what equity in cancer care actually looks like, I think that would be really helpful for this discussion. I would love for you to share your thoughts on why equity is so critical, mandatory even, when it comes to changing our cancer policy as we know it today.

Dr. Beverly Moy:

Thank you for that question. I think that, when we talk about cancer equity, I think that first we have to face the cancer inequity issue to be much more blunt and candid about the problem. The fact is if you are black and have cancer, certain types of cancer, certainly breast cancer, prostate cancer, some GI cancers, you're almost twice as likely to die from your cancer as somebody who's white with the same cancer. That, in my opinion, is a failure of the health system. There are many reasons going into that, but certainly access to quality care is a huge part of that. Until we understand that there is a huge disparity here, we can't really talk about equity because it's, frankly, it's not present right now.

Then we need to really think about why these things are occurring and if there is the political will to start improving the situation. I think that, when you talk about cancer research or cancer care, a lot of people talk about discovery and delivery. A lot of times the attention is focused on that new drug that improves overall survival by a couple percent. But if we actually improved the disparity that exists between races and cancer, we would achieve so much more than the sexier developments and discoveries that have happened over the last few years. It's really time to focus on these issues more.

I think that one of the silver linings that have come because of this horrible pandemic is really how the healthcare disparities have been laid bare, when we see people of minority races disproportionately dying of COVID because they're in the hospitals more. At Mass General, we had a lot of COVID patients here, and most patients didn't speak English. They were essential health workers. They couldn't stay home. They couldn't quarantine. People finally saw what is really happening in terms of healthcare. In cancer, we're really failing our patients. How do we start figuring this out? I think there are so many things that we need to do, but we need to improve access, remove insurance barriers as Ms. Henley talked about.

Jodi, and you mentioned someone talking to you about targeted therapies, right? These targeted therapies didn't just come out of nowhere. They came from clinical trials and research. So much of modern cancer treatment is focused on patients' molecular markers. That means that patients have to have access to this kind of scientific testing. Sometimes if you identify these markers, the best treatment that's available targeting that marker is only available in clinical trials, but disproportionately, people of minority races cannot get to these trials because they don't seek care or receive care in places that have these kinds of trials, or their physician may not be aware of those trials because they're just not available in that immediate site.

There are so many reasons why these inequities are perpetuated. Therefore, we need people like us providing the evidence of interventions and solutions that work, and then we need to go in front of the policy makers, the lawmakers, industry who fund these trials, to finally turn the whole way we do things, in terms of cancer care, on its head, so that we can view things from an equity lens and do things differently, because the way we're doing things now are not working for huge swaths of our population. That's why we need policy changes to really make those things happen, because without policy changes, unfortunately the same things will happen over and over and over again.

Jodi-Ann Burey:

Oh my gosh. I think that's such a critical point to dial in on, right? That yes, everyone's looking for new innovative technologies and solutions to address cancer. Maybe we're looking too much over there because anytime you'll introduce a new solution, a new treatment, those inequities will still be there, if

not expand. So, we can do more for cancer care as a whole by leveling out these inequities, even as we might have some folks that are looking towards new solutions. I think that's such a critical aspect of this. Like how can we address the inequities? Alongside yes, of looking for new solutions, but there's already so many innovative solutions out there that people just don't have access to.

One thing I do want to double click on too, as we talk about COVID, that there was a period of time when people were saying, okay, more folks of color are dying, are getting sick from COVID. It's them. They don't trust the doctors. They don't trust the system. They just have bad health. They're not taking care of themselves. It was just so kind of patient centered in the wrong way of just looking at individual behaviors. But I think what you're elevating here and what we're all talking about here is, well, let's look at the system, right? What created this environment to create these inequities, and how can we address that if we want to move forward in a serious way to change what we know about how we treat cancer and cancer incidents in the United States and across the world? Thank you so much for that.

Woo. Let's keep going. I have a couple more our questions and then we'll get to our audience questions. But Candace, I do want to come back to you in your work founding and running The Blue Hat Foundation. I'm sure, similar to me, you encounter a lot of patients and survivors and loved ones of people who've been impacted by colon cancer, and even other cancers as well. What do you think is a part of the patient, the caregiver, or that loved one's experience that policymakers often ignore or they have the least access to, that would better support people in their journey?

Candace Henley:

Well, Dr. Trevino spoke on it earlier, and I was like, well, thank you, Dr. Trevino. And that is the financial toxicity. It is not talked about enough. When I went through my journey in 2003, I had no idea that, that surgery that led to saving my life also took my life, because I gainfully employed great insurance, house, backyard, cars. My kids had the American 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. They talk about, well, patients paying for treatment.

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 at that time, in 2003, colon cancer was not on the list of cancers for social security. Then there was the services that the city, wherever you live in, the city and state offers, it was in a summertime, so they only offered gas and electricity, and then you, 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 of trying to rob Peter to pay Paul, and trying to support your family.

Then in addition, the other thing is too, and this is a question I always ask the doctors, does the treatment match the life? My surgery was an emergency surgery because I came in with a bowel blockage. However, I never left the hospital. So, for 10 days, I was in that hospital, and everything was going on. Life kept going. My kids had to eat. The rent had to be paid. All of that kept going, but there were times where I have to say, was it actually an emergency? Could they have gotten me together enough where I could have maybe moved some things around to get life in place, fill out my [inaudible 00:47:10]. So, everything I did after my surgery was behind, but I always ask the doctors, does the treatment match the life? Because if someone works at McDonald's, can they afford this surgery right now?

Can they take off to have this surgery now? Are there other therapies that might be able to be offered that, hey, that's not going to be so impactful for this person's life. When we are talking about the patient and caregiver experience, we have to acknowledge the financial impact that it is putting, and

that stress. It is to the point where it's not only financially stressful, it's emotionally, and it's mental. And if you don't have the right systems in place, the only time they ever offered me psychosocial support was when they told me I had cancer, but no one called me afterwards. I disappeared from the whole system.

That journey is a lonely journey and there ... 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 navigators could be handling. In addition to working with social services, asking that patient, is there anything that might prevent you from continuing your treatment?

Is there anything that might prevent you from making your appointment on time? Is there anything that might prevent you just from coming to the ... I mean, so there are not enough questions asked, there's not enough thought put on how the family is impacted by this.

Jodi-Ann Burey:

Yeah. I often say, as the patient, you're both the project and the project manager, and how stressful that is. I think you're raising a really good point here that you have to think about this person in the context of their whole life. I think we do have lots of patient stories, but I always think of all the stories we'll never have because of people who just drop out of the system who can't sustain being the project and the project manager at the same time. There's so much that we don't know that just isn't captured. I want to actually go a little bit more into stories with you, Dr. Trevino, because I feel that doctors and scientists and researchers have incredible access to data, right? More data than I can even pronounce, a lot of the words and things that you're dealing with.

And you have that ability to turn your data into information. What I think the challenge is, is that so much of our political lives are influenced and moved by stories. We can turn data into information, but it's hard to turn that information into stories. How can policy makers work best with researchers and medical professionals, and vice versa, to turn that data into information, into stories that can change a policy landscape to make a material difference in the lives of patients and their loved ones?

Dr. Jose Trevino:

It's almost you threw me a softball after Dr. Moy and Ms. Henley's comments here because ... I'll try to make it simple because I think that this is, sometimes can be complicated for some people to fully understand, especially when we talk about looking further and further into tumors and based upon how specific they are to a particular patient or a particular race and ethnicity. I think Dr. Moy mentioned this slightly, and was touching on this, and I'll dive a little bit deeper. In this country, therapeutics are based on clinical trials. The clinical trial involvement from people of black, we're going to stick with black and Latinx background, in this country, in the year 2021 is about 8%. That's the enrollment in cancer therapies.

We know this because we are putting together a paper that's hopefully going to be published very soon in the point that it's almost an embarrassment that we know that blacks and Latinx patients are just as likely to get cancer in this country and have, in some cases, worse outcomes. So, how is the therapies that we're developing, these major clinical trials only have 8% to 9% participation. If you look even further, they're mostly from white males that are participating in this. So, we even have a gender

disparity within that component as well. Okay. Let's just make the assumption over the past 60, 70, 80 years we've been having clinical trials on cancer therapies.

Along the way, we've gone through hundreds, if not thousands, of different therapeutic. We know now that our genetics, what mutations drive our tumors are different based upon our ancestry, right? We come from all different areas, and I have this diagram on my wall where it shows the world and the migration of peoples throughout time, and the migrations are coming from everywhere, and everybody's a little bit different. Africans that come to this country are different than African-Americans that have been here for 400 plus years. The same thing goes for Latinx patients who live in San Diego versus Miami. We are not, from an ancestry point of view, similar to some degree. We have a lot of differences.

Our mutations that drive some of these genes in our tumors can be very specific toward targeted therapies. So, going back to what I said earlier, so let's just say that only 8% to 9% of blacks and Latinx patients are considered in these trials, could we have been throwing away tons of therapies that in all actuality might have affected a certain population better than another? Because again, we're different. God made us all incredibly different, and special is what I look at it, but our tumors are different and are sometimes driven by different genetic mutations.

I look at that and I just scratch my head sometimes, and I say, God, so many therapy, so many millions of dollars that we spent. And where we're just not having enough diversity within the clinical trial to really say that there might have been a success. We learned that lesson when we started to realize that in a small focused clinical trial, that maybe 15% of patients had efficacy to a particular drug. Then someone said, "Wait, wait 15%. Wow. That's not great, but what about that 15%? What makes them so special that they had efficacy?" Instead of throwing that drug away because it wasn't going to be something that the pharmaceutical companies or the trial list were going to gain some financial or reputation or academic prowess, we looked at that 15% and actually discovered so many things about those patients that could theoretically change the entire dynamics of how we did cancer therapies and targeted therapies for gastrointestinal stromal tumors is a perfect example.

Or looking at the mutations in colorectal cancer is another great example of the fact that, when we look deeper, we find therapeutics at work. But until we diversify the clinical trials in this country, and actually open up and say to our policymakers, you have to have a diverse population to make this clinical trial something worth pursuing. Until we change that, we might be missing a great deal of success because we're not really representing this country, and that's the importance of that.

Jodi-Ann Burey:

Yeah. Thank you so much for throwing that out there. Actually, I want to dig a little bit deeper in that if you don't mind. So, a couple months ago I was doing a talk for an organization that ran clinical trials. Everyone on this call, deep in the cancer space, running trials, researchers, clinicians, what-have-you, people who have very deep expertise when it comes to this work. One of the audience questions, for me, I've had my little masters in public health, worked in global health for a couple of years, but by no means know anything about clinical trials. They asked me, "Hey, Jodi-Ann, how can we get more people of color in clinical trials?" I'm like, "Why are you asked me that?" I was like, "The fact that you could ask me that question, here's my question for you, have you ever asked yourself that question?"

You, researchers, people who know how to ask questions and find the answers to it, have you ever put your team around the table and said, "Hey, how can we get more people of color in clinical trials? What are we doing to diversify our population?" I think another thing that I want to dig into here too, with your comment, is how do we evaluate like the data points? With this 15% efficacy, do we look at what's happening with people of color as outlier because it's not happening to most people or do we

have it in us to dig a little bit deeper in that and see what the true story is there? And maybe there is more to it than maybe we can see just in that 15%.

I'm curious for you, if you have anything more to say around the responsibility to build in equity practices, in equity approach, in our patient-centeredness, when we're thinking about setting up clinical trials, when we're thinking about how we evaluate these numbers, and who it's good for, and whether we get to determine if 15% is good enough.

Dr. Beverly Moy:

Could I take a stab at that one?

Dr. Jose Trevino:

[crosstalk 00:57:28] away please.

Dr. Beverly Moy:

I can certainly start. I mean, I think that the way that we do cancer clinical trials currently, it's no wonder that we have such low minority participation. From the very beginning of the design to the inclusion exclusion criteria, Candace put in the chat, is the inclusion criteria too rigid? Oh yes, absolutely. To not asking patients if they're interested in trials. That is a huge one, right? If you were to ask ... There's a lot of evidence that if you ask people of color with cancer, if you're interested in this clinical trial, oftentimes they'll say, yes. It's just a matter of getting over potentially that implicit bias of thinking they might not be interested, right?

To the actual enrollment into the trial, and after you get them on the trial, the burden of trial participation is tremendous. 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 parking, and the gas, and the childcare. This is really also not just for you, it's for the benefit of generations afterwards. So, why are these people paying a financial burden to help us in the cancer community?

This is the state of clinical trials today. Until we turn it around and make it easier for people to participate, we're not going to get any better. I think that there has been some traction in improving the situation because people have started to really recognize this as an issue. Really, for the first time, a lot of our into history and former partners are making big changes in how things are being done. Institutions are changing and prioritizing this very issue. And the NCI and FDA are prioritizing this as an issue because it's a real, in my view, social justice issue.

If people are being deprived of these therapies, that's a real problem. It's going to take a lot of will to examine the clinical trials process from start to finish to start really making a dent in this issue.

Dr. Jose Trevino:

I think Dr. Moy made a bunch of great comments, but I had to say that Ms. Henley wrote down in her comment, the clinical trial criteria is sometimes too rigid. Well, Ms. Henley, there's a paper coming out on that too. So, if you look at what's happening in this country, and ASCO, which is the American Society Clinical Oncology, the big kind of umbrella to this country for clinical trial development, and just really looking at how we structure ourselves as clinical oncologists, has stated that, that we have to relax a

little bit. Because again, a Latinx patient and a black patient and a white patient, we all come from different backgrounds, different ancestry, different cultures. We carry different comorbidities, different than others.

Blacks have a higher tendency to be hypertensive and have diabetes. Hispanics have their issues with diabetes as well, and sometimes issues with liver disease is more common than others. Then there are some populations that have higher infectious disease rates, and we exclude patients. The best example I can give you is that we've been excluding patients with HIV, which has been a disease that is somewhat well controlled. And we exclude patients from clinical trials in oncology because they have HIV because people who develop these are scared that something about that virus and something about that disease won't give them a good outcome, and might skew the results.

We have to stop doing that because it's not just based upon the successes of the clinical trials. It's based upon our understanding of what we're doing and better for the populations. There's clearly a lot of uproar on the exclusion and inclusion criteria in clinical trials. I think that's one of the first steps we have to do, because if we don't do that, then we exclude such to a great population of people just based upon something that culturally might be a part of them and that you can't change. To exclude someone because they have uncontrolled diabetes is ridiculous, as one of my medical oncology colleagues says, "We just have to control their diabetes."

And I'm like, "Exactly." I'm just like, "Why exclude them." I mean, these are just incredible points that are being made in this panel, and Ms. Henley nailed it, and Dr. Moy nailed it. We can bounce off each other all day long, but this is a really, really, really important topic, and I think are key things. Just so you know, Ms. Henley, these are papers that are being published at some of the higher impact journals because it's putting out a lot of controversial things that people don't want to talk about. We don't want to take a look at ourselves and be embarrassed that we're not doing the right thing, but we have to.

Candace Henley:

Well, I'm looking forward to reading them because I've lost a lot of friends that have been kicked off of clinical trials because they developed a fever, or developed an inability to walk, but it didn't impact the way the treatment was going. So, because of that, they've lost their lives from a treatment, a clinical trial that was working. It's like, are you kidding me right now? I mean, where is the compassion in that? I understand their parameters, but then, where is the empathy? Where's the compassion that this is a live human being that this drug is working, but because they developed something that was not a part of the criteria, they are now not a part of it? There's something drastically wrong with the system, and it shouldn't be. Why?

Jodi-Ann Burey:

Yeah. I mean this conversation, I mean, I'm just taking so many notes and just thinking of, again, as you said, Candace, all the lives are being impacted by rigid inclusion criteria, or our misunderstanding of the data that we're seeing and who gets excluded, who gets included, who's participating in this. So, we have one question from our audience member. It's actually a friend of mine, a friend of the Black Cancer Podcast, France. France is asking, for anyone on the panel, please pick this up. Is part of the messaging perception who the messengers are, and how critical is the diversification of clinical investigators, physicians, and research staff? Feel free anyone, if you'd like to answer that.

Dr. Beverly Moy:

I think it's crucially important. When we look at the diversity of the clinicians that are available in cancer, we are certainly not doing very well at all. In my own institution actually, we have a handful of underrepresented minority physicians. I was just talking to one of my colleagues who's absolutely terrific. He's actually a GI medical oncologist who happens to be black, and he said to me, offhandedly, he goes, "If I were ever on the other side of the bed with cancer, I would love to have the doctor walk in look like me, and I just don't see that happening." I think that there's something important about representation, about understanding about community.

I think about my own dead father who was diagnosed with prostate cancer and chose to go to a community center in Chinatown and New York City rather than going to Memorial, because there was such a level of comfort there. Certainly enable to message the things that we're talking about today, it's important for all of us to think about who those message giver are, because we really do want people to be receptive. But at the same time, I also want to avoid overburdening our colleagues who are minorities and making it their responsibility. Jodi, someone asked you, how do we improve clinical trial participation? Why was it your question to answer?

Jodi-Ann Burey:

I don't run clinical trials. You do, so you tell me.

Dr. Beverly Moy:

I think that we all have to be champions, but to work together to amplify the message at the same time.

Jodi-Ann Burey:

Absolutely. Absolutely. Anyone else want to take that before we transition to close?

Candace Henley:

I will say, yeah, it is the messenger and it is the message. We have to be careful in how you communicate the information and how it comes across. Because so often, historically, it's like, we're going to save you, it's going to fix your life. How are you going to save me? I know that sometimes it is well intended, but if you are not familiar, and I always tell researchers, "Do your research. Research for your research, know who you're talking to. Understand the taboos, the barriers, the cultural issues and things that ..." Because when you're delivering information, you need to understand why there might be pushback, you need to understand why there might be fears. When you're not doing that, and when you don't address it, see, and it goes far beyond Tuskegee and Henrietta Lacks.

When they're like saying, "Oh, I know it, I know about Tuskegee." Okay, but what else do you know? Do you know what happened when there was an anesthesia, when a surgery is performed without anesthesia, do you know this? And not just on African Americans, but so there has to be a well-rounded message and messenger that understands that you are speaking, you have to be able to speak to a diverse community, and you have to be able to understand the cultural norms and cultural barriers for the communities in that you're talking to.

Jodi-Ann Burey:

In the last two minutes, I have two questions. So, we'll start with the first one. It's a lightning round, so just one sentence for each of you. But I want to set up this dynamic of like rocks and pebbles, and rocks are these like huge hairy, scary gargantuan issues that we need to all chisel at every day versus a pebble that's more of an easy win. For the policy makers and policy influencers that are on the call right now,



for each of you, I would love for you to share one rock that you want them to be chiseling at every day. And what's one easy win that you think they should focus on after this conversation when it comes to effective patient-centered policies?

Dr. Jose Trevino:

I'll start. I think that the big rock is access to the best healthcare in cancer care. I mean there's no question about it. I mean, we want all patients to have the best access. How that's going to come about, one day we hope that we will all be able to see the disparity issue kind of go away. I think the pebble in the sense of what I would like to see every day is the active recruitment of everyone from a different race and ethnicity into clinical trials and the encouragement. I think understanding cultures, understanding people really does allow that. And yes, as Dr. Moy mentioned, it's great to see your own when you're across the table because it gives you that level of comfort, but we have to understand the different groups in this country, and with that understanding, we will make the difference. Then sometimes it's just about being empathetic and listening to the people and what their concerns are.

Jodi-Ann Burey:

Absolutely. Thank you so much. Dr. Moy, one rock, one pebble.

Dr. Beverly Moy:

I think the rock is definitely figuring out what we think should be essential care for the cancer patient, whether it be clinical trials protections, coverage for oral anti-cancer therapies, genetic testing, whatever we say it is, and to ensure that all insurers cover those essential things, whether it be Medicare, Medicaid, or private insurers. We need to make sure that there is no barriers to the essential things that help cancer patients. The pebble, I would probably also agree with Dr. Trevino about clinical trials. We're finally making some headway, and it's happening with FDA basically putting pressures on sponsors and clinical trial folks to say, and they did it with a COVID vaccine. They said, "We're not going to approve this until you have a certain amount of minorities." We're headed there, and when things like that policy-wise happen, things change. That would be my pebble.

Jodi-Ann Burey:

I love it. Candace, take us home with our rocks and pebbles. What's one rock and one pebble for you?

Candace Henley:

Well, since it's my experience, the one rock would be the financial toxicity and the pebble would be policies put in place to have those with homes, right? There is all kind of help for people who live in apartments, but when you live in a home, there's nothing. There's no safety net for you, there's no ... Nothing. So, I would love to see, just like, but they've done it since COVID right. Since COVID, they've enacted policies to help people with homes and people with apartments. Can we have this constantly for those of us who are going through major life crises to have a safety net to help us maintain our hard earned money that we've spent maintaining these homes. Our dreams are gone.

So, I would like to see policies enacted to help those who have homes maintain their homes while they're going through cancer or a major life policy. I don't want to just leave it to cancer because every life event is important. So, how can we do that? How can we talk to our policy makers to make this a constant, not just during COVID, but how can we continue this after COVID?

Jodi-Ann Burey:

Yeah. Thank you so much for that. This is an incredible list, right? Access to patient care, active recruitment for clinical trials, understanding people and culture, figuring out what is essential care for a cancer patient, ensuring that all insurances cover that. Financial toxicity addressing that and supporting people in homes. We have a good list in just a minute of what our policy makers who are in this discussion right now could be focused on. But I have to bring my mother into this room, and often growing up, she would say to me, "Well, are you hearing me or are you listening?"

This distinction between, are you just listening, like hearing the words that are coming out of my mouth, or are you listening in the sense that I will see your behavior change? My question for all of the policy makers and policy influencers in this conversation right now is, are you hearing us or are you listening? How can you uptake these recommendations, this conversation, into what you can do in your everyday life to really change the face of cancer policy as we know it today? I will leave you all with that to make sure that you're actually listening to this conversation, identifying that there are going to be barriers to you making this happen, but isn't that what we always do, is overcome barriers for the things that we care about and for the thing that we value?

Thank you so much for our panel. I'll actually give a few seconds if there's any final thoughts that any of you would like to share before we turn it over to close.

Dr. Jose Trevino:

Jodi-Ann, I have something to say. I say this a lot. Every time I give a talk at a grand rounds or a get invited to give a talk at a department or an institution, I always have one picture at the end of one of my diplomas. I've done a crazy life of education and training, what-have-you, but I say, that's not why I do this. And if you look behind me, right here, this right here is probably one of the most important things that has ever been given to me. I display this for everyone to see. This is a drawing of one of my patients that I did a pancreatic resection for, for pancreatic cancer. Obviously it depicts who she is and where she comes from and what her culture is.

Then this one over here, at this end, is the same one. It's an Asian one. And again, another patient. Those are the most, for me, outside of my books, are the most important things for me. Because again, this is what the policy makers need to know. It's not a matter of degrees, it's not a matter of where you are. It doesn't matter the power you have in this country. It's a matter of the patients that you affect, the people that you affect, the people that you represent that should matter the most to you. I'd rather get a drawing from a child or a picture from a patient. It means much more to me than you could ever imagine, because that tells me that they put their life and trust in you. I say it all the time. I mean, this is what makes me proud to do what I do and keeps me going every day, waking up every day to do the right thing. Those are my last words.

Jodi-Ann Burey:

Thank you, Dr. Moy, Candace, if you have anything, quick remarks. If not, it's okay.

Candace Henley:

It's okay. You are in a position of service, if you are not servicing the people that you got into this position for, then you are a part of the problem and not the solution, and you need to get out of practice.

Dr. Beverly Moy:

I would just quickly say, seek out to your professional societies, patient advocacy organizations so that you can advocate together because together we can make change.

Jodi-Ann Burey:

Oh my gosh. That's an incredible way to wrap. Thank you so much, Candace, thank you so much, Dr. Moy, thank you so much, Dr. Trevino. I want to thank all of our speakers for joining us this afternoon and sharing their experiences, their thoughts, and their expertise. For everyone in the audience, you'll be receiving a survey via email later this afternoon, so please help The Alliance plan future events by filling that out. Thank you for joining us. And before we end our conversation and the summit today, I would like to invite Dr. Christopher Friese to join us for some closing remarks. Dr. Friese.

Dr. Christopher Friese:

Well, thank you so much, Jody-Ann, for your wonderful leadership. It was stimulating and exciting to hear all the great work and the insights of the panelists. I want to thank all of our panelists and moderators for joining us today to really set a very bold, ambitious, but important agenda on how we can advance cancer health equity and improve patient-centeredness for patients with cancer and their loved ones. I think, as we began the day with Dr. [Barr's 01:16:54] remarks, there's an urgent need and an opportunity to better meet the needs of patients with cancer and their loved ones. And we really do need to challenge ourselves as a broad community to critically examine what we're currently doing, what's working and what's not, to best meet the needs of patients and families.

In our first panel, we learned about the need for a paradigm shift in cancer care delivery and coordination through collective learning and collaboration and partnerships, and the need to really reset the factors that we consider when we think about quality and the value of cancer care. It's not just a simple mathematical formula. We also learned of the power of navigation services, whether they be clinician navigators, or lay navigators, or other coordinated services, that really help make sure that the rapid discoveries in cancer care are equally available to all patients regardless of their background circumstances.

I think Dr. Frederick's important fireside chat exposed the fault lines of the COVID pandemic and how external factors and societal factors don't ignore patients with cancer. And we're living through a very challenging times for patients with cancer, and we can come out the other side of this using the tools that we have developed by several of the interventions that The Alliance, to advance patient-centered care interventions have led to important improvements in the patient experience and reaching historically underserved populations.

Then finally, in our final panel, we learned about practical strategies and the importance of bringing our stories collectively to policymakers and to payer communities at the local state and federal levels to make sure that their policy decisions align with the needs of patients and families that we center the work on patients and families, and those at most in need. We have a tremendous opportunity, I would say, and an obligation to do that work and to continue that work knowing as I think, Jodi-Ann really aptly described, there are pebbles and there are rocks, and we need to pay attention to both the short-term wins that we can make immediate improvements, but we also can't forget the important long-term work that our patients and families deserve.

If we truly want patients with cancer and their loved ones to receive equitable evidence in patient-centered care, we need to work at these levels and include the payer community to implement interventions that we know work, and to develop new models of care that integrate these interventions that we know work so that our cancer care delivery system, regardless of where you're treated in the country, everyone can receive the same care. If we don't do that work, the important discoveries, the

new tests and treatments that we have for cancer will be moot because we will not achieve our goal of improved outcomes for all people who unfortunately, are diagnosed with this disease.

Please join me in thanking today's amazing panelists and moderators. I want to especially thank our colleagues at The Alliance for Health Policy for their outstanding work in leading today's event. Finally, I want to thank the Merck Foundation for their support for The Alliance to advance patient-centered cancer care over the last five years. You can learn more about those interventions on our website. We also want to thank The Foundation for sponsoring today's event, and finally thank all of you for your time and attention and your commitment to advancing patient-centered cancer care. Thank you so much. (silence)