



Enhancing Diversity in Cancer Clinical Trials

For decades, there has been an alarming lack of diversity in cancer clinical trials. Why does this happen, what can we do about it and how can we increase minority representation in these potentially life-saving trials are some of the questions we are trying to answer in this discussion.

Clinical trials are an integral part of the delivery of cancer care. It is an opportunity to access therapies and diagnostics that may improve quality and potentially duration of life. Yet, participants in cancer research continue to not reflect the patients diagnosed with cancer. Low participation means that underserved populations are less likely to benefit from the latest scientific discoveries and best hope for cure.

Inclusion in clinical trials for gender, racial, and ethnic minorities is an oncology-wide effort in the United States. We are talking to Dr. Hala Borno from UCSF Helen Diller Family Comprehensive Cancer Center on her innovative approaches to tackle diversity, equity, and inclusion in cancer clinical trials. Joining Dr. Borno is patient advocate Tiffany Williams to bring in the patient perspective.

Full Transcript:

Priya Menon: Hello and welcome to CureTalks. This is Priya Menon, your host. Today on CureTalks, we are discussing the very significant issue of enhancing diversity in cancer clinical trials. We have with us Oncologist. Dr. Hala Borno from UCSF Helen Diller Family Comprehensive Cancer Center. Dr. Borno's research focuses on understanding causes of inequalities in cancer prevention, treatment, outcomes and clinical research participation. Joining up Dr. Borno on the panel today is advocate Tiffany Williams. Tiffany was forced to retire following myeloma diagnosis from a career as an Assistant Professor for the College of Nursing at the Medical University of South Carolina. Tiffany's advocacy interests include health disparities affecting children and adolescents, health advocating for African Americans living with cancer and their caregivers. Welcome to CureTalks everyone.

Dr. Hala Borno: Thank you for having me.

Tiffany Williams: Thank you.

Priya Menon: For decades, there has been an alarming lack of diversity in cancer clinical trials. Why does this happen? And what can we do about it? And how can we increase minority representation in these potentially lifesaving trials, are some of the questions we are trying to answer today. Dr. Borno my first question to you, can you talk a little bit about why it's so important to have diverse participation in clinical trials? And why is it significant in terms of cancer trials?

Dr. Hala Borno: Yeah, I know I really appreciate this question and you putting the spotlight on this problem. So, you're exactly right, disparities and inequities and access to clinical trials is a long-standing problem. And in fact, in 1993, there was a mandate, the NIH Revitalization Act that mandated the inclusion of racial ethnic minorities and women in clinical trials. But yeah, we still have so much work to do in this problem continues to persist and frankly the covid-19 pandemic also further put the spotlight on inequities and access to clinical trials. And it was a moment where we uncovered the fact that clinical trials are really a social good with vast impact, where the covid-19 vaccine clinical trials led to our ability to access to vaccines, reduce our risk of mortality associated with the virus, that showed that clinical trials are really a social good and diverse



representation, accelerated recruitment, inclusion of everyone leads to maximum benefit. So, I think we are at a moment where the conversation has changed, where there's an acknowledgement of the role of clinical research to advance the well-being of all and cancer precision medicine, which is the tide in the direction that oncology is moving. I truly believe that we have to have a huge commitment and focus in achieving equity and clinical trials, because if we do not, we will see a widening in differences and clinical outcomes based on race ethnicity in the United States. So, we know that a patient that is of white... race ethnicity is going to live longer than a patient of other racial ethnic categories. We have racial ethnic disparities in clinical outcomes in the United States and that's unacceptable. Cancer precision medicine is really about developing individualized treatment plans. We often think about biomarkers selected clinical trials, using the underlying awareness of the biology of a person's tumor, the rest of their system to tailor therapy. And if we do not ensure that the clinical trials that are developing these novel therapies, are inclusive of all biologies, are inclusive of all populations, we are going to develop therapeutics for subset of patients that prolonged their survival, improve their quality of life and leave others behind. We will see a widening in the differences in survival in the United States. And that is something that I think all of us can agree on is not, okay. It is something that we need to address and strategies to promote inclusive clinical trials are critical and we have to be accountable. When we think about factors that are driving this, this lack of diversity in clinical trials, there's a multitude of factors, but I think fundamentally a lot of it has to do with structural racism and not addressing social determinants of health that are leading to gates and an individual's ability to access a clinical trial. When I say social determinants of health, I mean the conditions in which a person lives that influences their health outcomes. If we don't actually assess an individual's context and address factors that are structural than those are gates that lead to bias and also a differential access to clinical trials.

Priya Menon: Thank you. Dr. Borno, I feel that as you said barriers to healthcare are really rooted in segregation. And unless the root causes addressed, it will be difficult to find Solutions. So, what are some of the main causes of under-representation in cancer clinical trials? I know you mentioned a structural problem and not taking into consideration social determinants of health. Could you talk a little bit more about that?

Dr. Hala Borno: So, the main problem is again multifaceted. But I would say, there is a key gate that we need to think about, which is the provider, myself, my peers, my colleagues that are practicing medicine, that are making treatment recommendations. 77 percent of patients that enroll in a clinical trial do so because their provider recommended it. Providers are gatekeepers that influence treatment decisions and patients are entrusting us to help guide them through their treatment journey, to help them select the right treatment at the right time and to create a sequence that helps prolong their lives and improve their quality of life. They trust us. And so, it is up to the providers to help address these inequities. And there are a variety of mechanisms that can support providers to do this of course, the role of implicit bias training is important but there is also a role of technology to help with informational silos that make it difficult to offer clinical trials at the point of care.

Priya Menon: Absolutely. I'm so happy. You said, that provide those are the gatekeepers and the trust factor and the sharing of information from the providers can actually really help the situation, a very complex picture here. But it'll sometimes when I was reading up, trying to understand this problem as a whole, it was extremely daunting, Dr. Borno, I know, you're right into this, your recent venture The Trial Library addresses diversity. I really want to understand how to start to untangle these various threads, right? And also, it'd be great if you could talk about your Trial Library and understand the successful strategies that you're implementing to make sure that recruited patients are representative of a diverse community? It would be great to hear about all this.

Dr. Hala Borno: Yeah, absolutely. So, Trial Library is a public benefit company that I spun out from the University of California, San Francisco. It's a software that is really focusing on engaging providers, to help them identify clinical trials at the point-of-care integrated with technology enabled navigation services, and those navigation services are primarily trying to serve the patient, to help them access clinical trials. We know that in the United States only about 30% of oncologists, engage in clinical research, the vast majority of whom practice in academic medical centers. But yet 85% of patients are diagnosed and treated for cancer or treated for their cancer in community oncology settings. And so how do you actually engage patients



where they are being treated? How do you actually provide resources and tools for providers that help them identify clinical trials? That's fundamentally what Trial Library is doing, it is engaging providers and community oncology settings with clinical trials, and then taking care of their patients, through a navigation program. Our navigators are called The Ally Navigators, they practice critical allyship, they use technology tools to engage with patients, but what they fundamentally do is an evaluation of social determinants of health. As I said before really figuring out the conditions in which a person lives trying to identify barriers and they intervene upon three barriers food and security, travel and lodging to provide navigation support so a patient can be evaluated for clinical trial if it's not within their local clinical environment where they're receiving their care. And so, this multifaceted approach is actually formed by almost a decade of research that I conducted as a clinical researcher at UCSF. So, it is really evidence driven approach to engage populations that are not conventionally offered a clinical trial opportunity. And what my research has shown is this type of model accelerates recruitment to clinical trials, overall, but is primarily in service of patients for more diverse, socioeconomic backgrounds. And so that's really what I'm trying to do is to make research more efficient because that's good for everyone but to make sure that everyone is also offered an opportunity to engage in a clinical trial if it's the right opportunity for them.

Priya Menon: So, if there is somebody out there who is listening to this, and they want more information or they want to check if they are eligible for a trial. What do you recommend they do?

Dr. Hala Borno: For patients?

Priya Menon: Yes, for patients.

Dr. Hala Borno: Yeah. So, I mean right now I think that we have a lot to do in terms of informational content. That is more patient accessible online. I think a lot of patients have tried to look up trials on clinicaltrials.gov, I can't even find a trial quickly on clinicaltrials.gov. It's not really designed to be a clinical point of care resource to guide you. And so, it's really hard. Patients engage in patient advocacy organizations; they find peer mentors to guide them through their journey. And then they fundamentally ask their providers for resources and opportunities. I think the current model that primarily serves patients for clinical trials, is a model that requires second opinions where a patient perhaps with more resources and the ability to explore other clinical environments goes out and gets a second opinion at one academic medical center or research center and then another until they find a clinical trial. And what is that take, that takes time, a lot of time, that takes expense, a lot of expense and that absolutely is leading to inequities in whom is actually being offered trials because you need those resources to be able to explore those options. So, there's so much work we need to do to make the system better so there aren't informational silos and so patients can figure out the right treatments for them quickly without having to expend a lot of resources.

Priya Menon: Thank you, Dr. Borno and Tiffany before you ask your questions. It'd be great if you can share how your experience has been in this regard since you've seen it from both sides, as a health care provider as well as a patient.

Tiffany Williams: Yes. Thank you, definitely. So as a patient, I have not participated in a clinical trial. My passion comes from seeing those inequities of people who could benefit but aren't offered. And in my space of advocacy, I'm trying to help encourage and educate my community on the benefits of clinical trial, but then at the same time, trying to help the clinicians understand the importance of offering clinical trials to everyone and trying to avoid some of the bias it comes with reality of healthcare today. But I have not particularly individually participated in a clinical trial.

Priya Menon: Interesting. Now, please go ahead and ask your questions Tiffany.

Tiffany Williams: Yeah, sure. Dr. Borno, thank you so much for your contribution to this discussion. I mean, it's just so, I mean, the information you gave was so impactful and very important and one of the questions that I had you touched on a little bit when you were talking about barriers, and you gave some really good insight on the providers being gatekeepers. And while I think it's important for patients to be advocates for



their own individual treatment and clinical trial awareness. As an advocate I'm with other advocates who really push this all the time and often times this with populations who are able to advocate in that way and find those resources themselves. But do you believe that the onus is ultimately on the health care team to educate patients on the benefits of clinical trial, participation or is it on the patients?

Dr. Hala Borno: Absolutely believe it's on the healthcare team. I mean patients are going through a lot, to ask a patient to expend their time when they may be feeling vulnerable, they may have responsibilities outside of their own well-being that they have to navigate. Maybe they need to figure out a child care solution because they were primarily caring for a young woman or an older adult, and they have to figure out caregiving for an older adult. Maybe they are the primary source of income for their household and there's economic opportunity loss, associated with receiving treatment for cancer. These are all just human circumstances that come up when someone is ill and to expect a patient to also, have the bandwidth and energy to educate themselves about clinical trials is not acceptable. It is a provider, it's a health system's responsibility to create transformation in order to make it accessible for patients. Of course, empowering patients with information and knowledge is something we should do. And if there's bandwidth and hunger, we should support providing patients and their families with as much resources as possible. But engaging in clinical research, should not have a dependency that the patient is already able to engage in questions around clinical research. It is really up to the provider to engage the patient and to help them where they are with available and accessible information and to help support them through their treatment journey with the decisions at hand.

Tiffany Williams: Thank you. I agree wholeheartedly as a patient. I worry sometimes there's an advocate that the message of advocacy is sort of shifting toward too much responsibility or selfcare being on patients. So, thank you for that. For many patients the discussion of clinical trials isn't shared in some months after diagnosis or sometimes even after they've exhausted treatment options. Do you think that patients should be introduced to the possibility of clinical trials earlier in their care perhaps even a diagnosis as you're talking about the whole possible treatment regimen course of treatment. Should that be introduced early? What do you think?

Dr. Hala Borno: I do. And I've actually studied this question. So, I call out a research study that funded by the California Department of Public Health where we contacted patients at time of diagnosis, we used information from electronic pathology report. So, patients who are just diagnosed with their tumor and the pathology was reported to the Department of Public Health. We contacted patients very soon thereafter with information in the form of a digital solution called, Trial Library and I really do believe that exposing patients to high quality information that is designed to be accessible to patients early in their treatment journey is important so that they can understand that clinical trials are very frequently, a wonderful opportunity to receive, a type of treatment to receive a type of diagnostic, to help answer a research question and that can happen at time of diagnosis and doesn't need to happen only in an advanced setting where a patient may be has already had cancer growth on standard of care options. So, I absolutely believe earlier is better and engaging people to deliver high-quality information at the time of diagnosis, is the right way to go.

Tiffany Williams: Thank you. And I think too, there's something to be said about trust with that too. If I here as a patient get introduced to that early on and I know that starting out, I'm more likely to trust it when I went to reintroduce, when I needed or it's the appropriate time because trust is a big word in this whole space of clinical trials for patients who face inequities and particular patients of color. And so it's almost impossible to talk about diverse clinical trial participation without talking about the trust between patient and clinician. So, what are some suggestions to address the issue of trust and impact people of color participating in clinical trials?

Dr. Hala Borno: Yeah, so you're totally right. I mean, we acknowledge in this sort of field, we call it the field of recruitment science, understanding factors that are that influence recruitment to clinical trials, that hereditary mistrust, fears of experimentation play a role. And how could they not? I mean we have a pretty egregious history of exploitation and experimentation of human subjects. And so, I think an acknowledgement of that history is it very important. But I think to your point, , the normalization of clinical



trials, as an integral aspect of care delivery, I think is the goal so that it's not something that's brought out and can generate concern or questions. But it's really just a standard part of care delivery that we offer you these opportunities, and you can make choices based on opportunities that are either investigational or establish a standard of care. And so, I think education is the key piece. There's been a lot of research that has shown that people of color so, for example, African American men with prostate cancer if offered clinical research opportunities engage in clinical research at high rates. So, while concerns around trust should be acknowledged fundamentally, what needs to happen is an opportunity needs to be offered to patients and the data suggest that they actually engage in research at high rates and even higher than other racial ethnic categories relative to the proportion of patients that are asked. And so I think that I worry about trust, communities trusting research places in some way blame on the community for not engaging in research, where I fundamentally think it's the health system's responsibility to talk about research early, to demonstrate the fact that it is a part of care delivery and can be an integral part of oncology and to offer opportunities in a consistent fashion so that we can see and observe that indeed diverse communities are engaging in clinical research, when asked.

Tiffany Williams: So, what can cancer patient advocates like, myself do to enhance diversity efforts in clinical trials, bi-directionally, to not only around raising awareness among diverse patient but also awareness among clinicians of clinical trials biased or diverse communities and such?

Dr. Hala Borno: It's a great question. There is initiative around just ask. Some providers asking patients about clinical trial opportunities. Patients asking providers what clinical trial opportunities exist and then to the extent that we can deliver high quality health information about clinical trials, that is accessible to the average consumer, to the average person. How can they access information that's easy for them to take in and doesn't require a lot of lift in order to find it. So I think really that's where a patient advocacy organization can really make a huge influence, is the ability to disseminate high-quality health information accessible for all and then encouraging asking about clinical trials from the provider.

Priya Menon: Thanks Tiffany. I think they were great. Dr. Borno, I know you did touch upon this but it'd be great I want to just summarize this talk. Three things that you feel causes that are the other reasons for the lack of diversity and three things that can be done to improve this.

Dr. Hala Borno: So, three things that I believe contribute to a lack of diversity in clinical trials are structural racism, not addressing social determinants of health and bias among the gatekeepers which I define as the provider who is offering clinical trials. Ways that we can address these barriers include health system transformation, so create a health system that makes clinical trials and the conversations around clinical trials an integral aspect of care delivery and bring it up early. I believe that a second opportunity is for us to deliver high quality health information about clinical trials, not only to the patient but also to the providers, especially providers caring for patients in our communities. And that navigation support, I think is key that navigation, a component of human touch to help patients during their care journey is really critical, especially if we want to ensure that we address populations with more socio-economic diversity, who may have social determinants of health that need to be addressed. I believe that those three key interventions can make a really tremendous difference in advancing equity in cancer precision medicine and in particular clinical trials, overall.

Priya Menon: Thank you, Dr. Borno. This was a very informative session. Cancer clinical trials fail to successfully enrol a racially and ethnically diverse patient population, and therefore, run the risk of leaving critical gaps in understanding regarding the effectiveness of new approaches. So, thanks a lot Dr. Borno and Tiffany, thank you for the great questions. We also thank UCSF Helen Diller Family Comprehensive Cancer Center. This talk will be available on curetalks.com. Thank you, everyone. Have a great day.

Thank you.