TRANSCRIPT – Your Stories: Conquering Cancer – "Implementing Change" feat. Dr. Karen Winkfield and Dr. Don Dizon

Dr. Dizon: This podcast is brought to you by Conquer Cancer, the ASCO foundation. Our mission is to accelerate breakthroughs and lifesaving cancer research and empower people everywhere to conquer cancer. You can help by donating at CONQUER.org/podcast. Welcome to *Your Stories*, the podcast where we hear candid stories from people conquering cancer. I am privileged to be your host. My name is Don Dizon.

We know that black patients in the US have the highest death rate of any racial or ethnic group. And we're talking today about why and most importantly, what's being done to reverse this disparity. I am very, very honored, and we are very fortunate to have gotten on the calendar of Dr. Karen Winkfield, a radiation oncologist and overall amazing human being with a passion for health therapy. Hello, Dr. Winkfield.

Dr. Winkfield: Hello Don, it's so great to actually be on this call with you and talking about this very important issue, which I am incredibly passionate about. So thank you so much for allowing me the privilege and the honor to chat with you today.

Dr. Dizon: I should just preface this for the listeners that Dr. Winkfield and I have grown up in oncology for many years. And every time we talk, it's like seeing a very good friend. But it's an amazing trajectory that you've had. And just to highlight a shout out, an important and brilliant and fills me with pride, shout out that Dr. Winkfield is a national leader in health policy and has just been named to the President's Panel on Cancer. So congratulations.

Dr. Winkfield: Well, thank you. I appreciate it. And the sentiment goes right back at you. I've been watching you on TikTok and all of your fabulous ways that you are changing how we engage with communities. And yes, I was recently named by President Biden to the National Cancer Advisory Board. And actually, as we speak, I'm in Washington, DC, was asked to be present at today's announcement regarding the Moonshot 2.0. So I'm really thrilled to be able to represent our patients, our communities that oftentimes don't have a voice to be front and center just the same way that you are. So I am excited. I think we need to get into this because you and I can go back with accolades all day long.

Dr. Dizon: Okay. That's definitely get into it then. So I know you're based in Nashville, and I also know that you travel the country engaging communities in important conversations about how to implement change and also break down barriers that they might have locally and the ones that we also see nationally, the barriers that keep racial and ethnic minorities and other underserved populations from equitable health care. Why don't you take this opportunity to tell us about that work, that important work that you do.

Dr. Winkfield: So the importance of the work that I do is centered around engaging the communities that often times are underrepresented excluded disenfranchised. And yes, that does include racial ethnic minorities, but it is very inclusive. We know there are issues in rural communities with LGBTQ+ communities, with adolescent/young adult communities with respect to accessing health care. This

conversation, while I hope we're going to frame it around the Black population, because as you've stated, the Black population has some of the worst cancer outcomes. And in fact, we are recording this during Black History Months. While that may frame some of the conversation, we do need to keep in mind that the issues are not just specific to the Black population. And so 1 of the things that is really important about the work that I do is it helps us to hear from the voices of the communities that are the most disenfranchised. It's boots on the ground. It's having conversations with communities. And yes, while I'm based in Nashville, you know, I had been in Boston, I'd also been in Durham, North Carolina, in Winston Salem. The black community is not monolithic just the same way that any other community.

So it's not a 1-size fits all. And the opportunities, barriers, issues that were specific to the Black diaspora that was in Boston is very different from what I experienced in Winston Salem, which is very different from what I've experienced in Nashville or what I hear from my colleagues in California. And as I travel hearing about the differences in terms of what are some of the barriers and therefore, what are some of the opportunities that we have to help uplift populations, helps us to recognize that the strategies that are implemented must, in fact, be designed around the communities we hope to serve. Again, can't just lump everybody in the entire nation into 1 big bucket. You have to say what's happening locally. And this is why I like to use the phrase “think globally but act locally.” Because while this issue related to the African American and the Black population, the United States is broad it's across the board, where we see worse outcomes for cancer in some particular cases, worse incidents or more incident cases. It is a global issue, but we have to figure out how to implement change on the local level.

We convened a panel, experts from around the country a couple of years ago to discuss where some of the gaps in cancer care are for lots of different types of disenfranchised communities. And in January of last year, 2021, we actually published a paper that was specifically outlining an actionable framework for reducing healthcare disparities in the United States. It did talk about the importance of thinking locally, but it gave a broad, evidence-based framework that individuals who are truly interested in making a difference in their communities, they have something to go to. There now is a go-to paper.

Dr. Dizon: I think that's such an important concept that you bring up about the idea that minority communities in the sex and gender community, and I've come to embrace it. It's a sexual and gender minoritized community because it's not like we wear a lesbian trans on our sleeves, that people are like, oh, yes. So in a sense, it's the system that has minoritized that community. But yes, none of these underserved communities are monolithic. So in a sense, speaking globally does work. But when you're giving those talks locally, do you ever get the sense of sensitivities and maybe even landmines so that you know, you're either going to confront or you know, you need to try to avoid? Is that ever something you think about on a local level?

Dr. Winkfield: That's an interesting question. One of the things that I've been very intentional about, even in my work with the American Society of Clinical Oncology in some of the work that I do to raise awareness is the importance of seeing the person who's in front of you. And so I use this concept of humility. A lot of folks like to say cultural competence, which I cannot stand because it implies that you are going to get it all, that you have watched a 20 minutes video and now check box. You are now competent coming in with this concept of humility, cultural humility, where you are saying to this

person sitting in front of you, I may not know you that well, but I'm interested. Help me understand your perspective, help me understand the things that you value. And frankly, if we do that to each and every person and with each and every person, it doesn't matter what their sexual orientation or gender identity or what their race or ethnicity is. We are asking that individual what their concerns are, but that does require a systemic change. Just even asking the question, allowing people to self-identify, you very well know that most institutions do not even capture SOGI data, right, sexual orientation, gender identity. We are still not getting race and ethnicity data correct. So we've got to look at each individual person that will avoid some of the landmines that can come out of making assumptions about a population or a people and allow people to self-identify? I'm laughing a little because when I was in Boston, we had a very large immigrant population and there was a patient who had come in and was asked to meet with a nutritionist after following their cancer diagnosis. And the nutritionist said, you need to really be careful about not eating so much fried foods and all these things, an African American gentleman. But it turns out that this African American gentleman was actually African. And so his diet was comprised of mostly fruits and vegetables. He happened to be pescetarian. But there was an assumption made that this black man sitting in front of this healthcare provider ate horrible food and just wasn't into their nutrition or whatever it is, and it just cracks me up. So I think we need to be very mindful of the fact that, again, thinking globally can indeed be problematic if we're not sensitive to the fact that we must have that culture of humility, that we must be culturally appropriate, and that requires looking not only locally but also on the individual level.

Dr. Dizon: So much of what you're saying is so relevant. No one walks into these positions or into this work with the answer. But I think your point is so critical because we all need to start asking the questions. So I have to think that I love that. All right. Moving on, my friend. As oncologists, we know that some people, no matter their race or ethnicity, have biological markers that make them more likely to get cancer. And if you go back to the fact that black people, who make up 13% of the US population, lead in cancer death rates in America, what are some of the things that people need to know about why Black people are less likely compared to White people to survive cancer?

Dr. Winkfield: This is a big question. So if you look at the data that's collected, Blacks have the worst cancer mortality of all racial and ethnic groups. In fact, probably the only group that we have less information on in terms of race/ethnicity is our Indigenous populations, because oftentimes we're not collecting their data appropriately. And we know that they also have been a very highly disenfranchised and excluded population. So I'll state that but listen, we've got to look along the entire cancer continuum about where the issues and the gaps fall in terms of health care. There's a lot of distrust in the healthcare system for individuals who are black, particularly those who are descendants of slaves, because they have been excluded, and we understand the structural barriers that have been placed. If we think about prevention, screening, diagnosis, treatment, survivorship and end of life care, there are gaps all along the entire care continuum. And the way that our healthcare system is set up is problematic because we do not pay the health care system for preventive care. Okay. So we pay providers to treat disease, we do not pay providers to work on prevention.

And that's a massive issue. There are 2—the top 2 modifiable risk factors for the development of cancer are smoking and obesity. If we take the latter, if we look at the black population, 70-75% of the Black

population in the United States is obese or overweight, which means that their cancer risk is much higher. The risk of them developing cancers is much higher. You think about for breast cancer, colorectal cancer, where we know that there are these clear connections, prostate cancer, maybe less so. But certainly we know that there's a risk factor with obesity in general and then smoking, which Black men have one of the highest smoking rates in the country, and they're being targeted. Right? Advertisements, et cetera. There's specific targeting for that. And both men have the highest rates of many of the cancers that we are really working hard, lung cancer, prostate cancer, to really reduce risk for them. So that's on the prevention side. But it also means are we getting screening? And the COVID-19 pandemic has highlighted the access issues for people who may not have ever noticed that they were there before. Right. You and I have been working in this field for a long time. We understand the barriers have existed, but some are like, oh, my goodness. Wow, this is novel. Well, no, it's not. So there are these gaps, and a lot of it is related to socioeconomic status. Let's put that on the table.

Dr. Dizon: Correct.

Dr. Winkfield: Wealth matters in this country. The capacity, the ability of individuals to access health care is absolutely tied to socioeconomic status, their income, their occupation and their education. And it's not just education about whether or not you have a degree or not. It's also talking about health education and health literacy. So we'll put that out there. But occupation, if you get paid by the hour and have to travel an hour and a half to go get your mammogram, for instance, and then have to travel another hour and a half to get back to work, that's half a day. So we've got to think about that. We've got to think about access. We've got to think about the people who may be paid per hour, and if they missed that half a day of work, they're not going to be able to put food on the table because remember, in the United States, we do not pay people living wages. And that disproportionately impacts the black community because of structural racism. Oops, did I say racism? I did, yeah.

So we've got to be clear. There are barriers built into the system that prevent black Americans from accessing the healthcare at the point where they potentially could have improved outcomes. We know early detection is key. We know that screening and prevention is the way to go in early detection. But we're even struggling with getting people there because of the systemic barriers.

Dr. Dizon: Yeah. I think that again, the point about wealth just meaning so much in terms of access in this country and high income countries all over the world. But you and I have sat with people who underwent screening, who traveled the 1 hour, who got off work from their hourly job and then were diagnosed with cancer. And the look of absolute fear, not even because am I going to live through this? It's more like, how am I going to do this if I cannot work?

Dr. Winkfield: Yes. That to the point where I've had patients tell me that breast cancer patients would come up to me and say I elected to get a mastectomy because that was the only way I could foresee doing this for my family. If they had to get radiation therapy, that at the time was a six week long course of treatment every day. They said there was no way to do that. So they elected to have a mastectomy so that they could go back to work sooner, which is it freaking blows my mind. Right.

Dr. Dizon: Right.

Dr. Winkfield: That's not an easy surgery. And yet some people were forced to do it and go back to work after just one or two weeks of being out.

Dr. Dizon: Right. And I think that the trajectory of the cancer experience, it's all builds on each other. So that 1 decision you make because you need to feed your family has repercussions years and years later on your body image and how you see yourself in the society, how you see yourself in your family, how you define the role you play, it's all together. When I think about and there's a term that maybe we can get into a little bit of, intersectionality, it's true. The struggle is the same with the folks I meet who are white, who are just socioeconomically disadvantaged, and the struggles that they face are the same, yet they're very different as well. I think you're right. It is very complicated. And applying that local lens to this issue, I think that has to be one of the things that you spoke of. But it's just so important.

Dr. Winkfield: Yeah. Your point about intersectionality is really important. And it's just understanding how the different categories are communities that individuals find themselves in. And I'll say communities because I think that's where we really need to focus in on if, for instance, an individual is a member of the black community that has with it all sorts of connotations from a social context. Imagine then, if they're both Black and of the LGBTQ+ community, that adds another layer of complexity. And what if that person also lives in a rural setting, like, hello, all three of those things, being part of LGBTQ+, being Black and also being in a rural community may put them in a situation where they are actually, some of them may have the lowest capacity in terms of economics than anyone else. Right. And I say that because all 3 of those categories are overrepresented in poverty. Okay. In lack of insurance. Right. Yeah. I think that these situations can compound one on the other.

But even if you look at rural communities and you look at rural Whites versus rural Blacks, rural Blacks still have worse outcomes, outcomes health care. Right. So this is a lot of it, again, is really important not to dismiss any of the communities, but if you start to focus on the community, the community that has the worst access, there have been studies that have shown that if you implement programs to support the communities that have the worst access to health care, that it actually elevates health care for everyone at that center in that region, in the state. You may recall, actually the state of Delaware did that study where what they did was they looked at colorectal cancer screening. They found that African Americans had the worst colorectal cancer screening and said, let's put together a statewide level, a program to help improve colorectal cancer screening. And by doing so and after implementation, not only were they able to raise the colorectal cancer screening rates for African Americans, they also raised it for the entire state.

So part of it is, again, thinking about what's the community, where is the greatest need? What can we do, how do we engage that community in bi-directional communication to say, what are the levers that need to be pulled? Because as you've stated, that intersectionality poverty is oftentimes is really the root of these issues. And if we can actually provide access for the individuals who are struggling the most, then we have the potential to elevate care for everyone in that region.

Dr. Dizon: I mean, there's a lesson for society right there. All right. Moving forward, what do you see? Health systems doing to help black patients, and how can we meet those communities? How can we

actively meet the communities? And you mentioned the Delaware experience, which is a great example. But what else have you seen and heard of in the work you're doing?

Dr. Winkfield: Not enough. Yeah, don't get me started. So I mentioned that paper that was published in Journal of Clinical Oncology Oncology Practice, JCO Oncology Practice, against stakeholders from around the country were pulled together. There are some best practices, some of which have been published in the past. Others are just from boots on the ground experience and kind of show what can be done. Obviously, navigation is one of the things that I am a huge proponent of. We do not have enough navigators. We do not have enough community health workers. We do not have enough lay, health advisors, all of them really under the umbrella of navigation. If you think about what Harold Freeman intended with the navigation program. Right. So Harold Freeman, this amazing surgeon in Harlem, noticing that his black patients presented with more locally advanced disease and had worse outcomes simply by training someone who's from and of the community, a layperson, not a nurse, not a physician, not a PA, someone who's from and of the community, a trusted individual in the community, training them about the importance of breast screening. What is mammography? How do we kind of move people from through the system? That education piece really being key.

He was able to actually improve the overall survival from 30% to 70%. What? Overall survival! So navigation is really something that people say, well, we don't know what the return on investment is. I'm sorry, how about life? How about lives saved? That's a return on investment. But if you want to put a dollar amount on that, then yes, we need to do some of that work and show, oh my goodness, we've been able to improve people's access. We're not getting people at late-stage disease where it costs more money to the system. Right. We're catching them early where they might have an early-stage cancer that can be cured with either surgery alone or very little, a shorter treatment course. I don't understand why our focus is has to be on the business part of medicine. I know that that was a policy decision that came out several decades ago where they've tied—our health care is no longer a right in this country. Right. It's now tied to capitalism, and that makes it a challenge. So I do think that there are some programming folks can take a look at that paper because it actually does highlight many of the things that need to be done.

But I also think it's really important for individuals and for institutions and organizations to understand what their role is because a lot of this is this is all social justice. Right. Health care is a justice social justice issue. And when we think particularly around Blacks, I mean, George Floyd's murder highlighted this for many people in a way that—I'm telling you, if COVID wasn't here, we would not have had the same response because people were sitting at home with nothing to do because everything was shut down. They got to watch an 8 minute plus video of someone getting murdered. And all of a sudden there's a groundswell.

Dr. Dizon: And you could not ignore it. That was the thing. You couldn't not have seen it. You know, you didn't have the luxury of saying, I didn't see it.

Dr. Winkfield: Yes, it highlighted, the antiblack racism that still exists. It's still so pervasive because it started those conversations. And our nation has not had the conversations. And it needs to the United States needs to just acknowledge, wow, we had slavery for 200 plus years. That was a race-based system. And for 401 years total, there's been disenfranchisement of a specific singular population. I mean, just acknowledging that alone could go a lot towards having conversations that can help to then say, what do we need to now do? Right. And so my colleagues and I, after the George Floyd incident, we wrote a paper that said, Why racial justice matters in radiation oncology. Now, we said radiation oncology, but could be oncology in general.

Dr. Dizon: It could be medicine in general. Honestly.

Dr. Winkfield: There you go. And I've actually given talks to that fact. Right. Why racial justice matters. And again, we talk about intersectionality, but the racial injustices are the ones that have really been problematic and continue to be so in a very profound and open way. It's just ridiculous. I feel like there are some communities that are gaining some leverage, some of it on the backs of what Blacks have done to try to–

Dr. Dizon: 100%, yeah.

Dr. Winfield. –But it's okay. But I just want to make it clear that this antiblack racism needs to be dealt with. And so that paper actually did outline a few principles for individuals to really say, I need to learn about this. How can I advocate, what are the things that I can do? So we've outlined clear steps that individuals need to take. But then we also said there are things that institutions, organizations, countries need to do with the Principles that include kind of acknowledging and being transparent and really implementing programs that can really help. So I would encourage folks to take a look at that paper, published in Advance, and I think it was May or June of 2021.

Dr. Dizon: Let me ask you a fairly provocative question based on all of this.

Dr. Winkfield: Okay.

Dr. Dizon: Yeah. So I think everything you said is the truth for sure. When I think about it from an institutional perspective now, having been confronted, and I'll use that word purposefully, confronted with systemic and structural racism in the communities that we are within and perhaps even in the way healthcare was approached. And let's say that there is now this very heartfelt move to engage, reimagine, re-envision, and obtain input from those communities. One of the things that I think has to be handled sensitively is that outreach, because what George Floyd's murderer did was not only bring the flashlight into racism in this country, but it ignited the fire, and I will say this, for lack of a better word, the rage that had been simmering because access to health care has been problematic, and we'll focus on health care. Access to health care has been problematic. Access has been too expensive. Access has been denied. Now the institution is coming to you and say, help us do better. How does that work when one might have that position within community leaders, for example, saying, you haven't helped me one bit, I've come to you, and now this cancer, we can even choose that my cancer is advanced

because you didn't think to help me one bit. How does one engage in that highly charged environment that we're all actually still living in?

Dr. Winkfield: So let me tell you. Well, yes, there's a fire ignited. My fear is that that flame is going to go out very quickly.

Dr. Dizon: Really.

Dr. Winkfield: Because it's not easy work. The work is not easy. I mean, you just highlighted, wow, this has been a community that has been systematically disenfranchised for centuries. And then people are like, so what do we do? We want to help. Okay, that's it. Here are the steps. And then they go, oh, like, wait, there's like, work. Yeah, there's work, there's repair, there's reparations, and I'm using that word intentionally, that needs to be made. I remember one of the institutions I worked with, I said to them, and this was early in my tenure there. I had been doing some listening tours in the Black community and said, I think what would really go a long way to help bridge the gap, to help people say, man, that institution is really interested in hearing what I have to say as a community, as a member of the Black community, is for you as an organization to simply acknowledge, simply acknowledge the past egregious activities that happened there, 1 of which was eugenics, which, as you know, was the systematic sterilization that disproportionately impacted Black women because Black race, who needs them, right, right. Whatever. But the community remembers not only because eugenics went through the 1970s.

I mean, people think it was a long time ago. O to the no, right. Just the same way that Tuskegee ran into the 1970s. This is not that long ago, folks. And people like, well, Black people need to get over it. Get over. This is my generation. This is in my lifetime that these things happened. And for institutions and all of a sudden say, oh, look, we need to help the poor Black people, first of all, make it real. And I do think there are people who are in an institution are interested. But first, acknowledge that there was past, that there's been a past, that there has been these past egregious activities, that racism has been, has impacted care, that there are still structural barriers like redlining that are creating wealth gaps that continue to grow. And again, it's hard for healthcare systems. You're like, well, I'm not in charge of the redlining. Right. So a lot of times institutions say, well, I can't impact that. But yes, you can, because you have a voice. Right. Oftentimes healthcare systems, larger ones are some of the largest employers in the region. How are you treating your employees?

So let's go to where we do see Black people in the healthcare system, oftentimes kind of working in environmental services, in kitchen services, maybe medical assistance, front desk staff. If you look at the institutions, have you asked yourself how are you treating your Black individuals if those are the same people who are hourly wage earners, or if you're one of those institutions like some of the ones I've worked at before, where you only allow them to work part time so they do not have health care benefits despite the fact they're working at a healthcare system. Don't get me started on it. Right.

Dr. Dizon: Yeah, 100%. But let me bring this back to another issue, which I think is also really relevant. You know, a lot of our institutions, including the ones that I've been associated with, they have their equity and diversity statements. That the care— [laughter] okay, you know where I'm going with this, that we will provide care regardless of race, of socioeconomic status, they have it. But then even

someone like a physician who's a gay parent can come into that system and meet with discrimination. And it's such an interesting thing to say, this is what you say, but this is the real lived experience. And then to have leaders to come in and say, well, in this specific case, me taking my daughter, them asking for mom's name, me saying there's no mom, them asking for adoption records.

Dr. Winkfield: What?

Dr. Dizon: Oh, yes. Oh, yes. And then me taking this to leadership, saying this is a problem and here's why. And them saying, well, she did have a mother. So there's what's posted.

Dr. Winkfield: Right.

Dr. Dizon: And then there's the lived experience. That's my example.

Dr. Winkfield: Yes.

Dr. Dizon: I'm sure you might have yours. But talk about that. Talk about holding institutions and what the community not even individual. What can the community do to hold institutions to what they have posted? And is there a way for us to do that together?

Dr. Winkfield: So you are absolutely right. Every single institution healthcare institution has their mission and vision statement that is in some way suggestive of them being inclusive. But we know that's not the case. And it's definitely not the case with respect to cancer care, if you think about the fact that there are some of our very large, prominent cancer centers that do not accept Medicaid. Right, correct. So what you're saying is, wait, so we are available and open to everyone. We want to be inclusive, except for the poor people.

Dr. Dizon: If you have the insurance, I take.

Dr. Winkfield: Right. Obviously, except for the disabled. Right. Because Medicaid is not just for poor people. Right. So that's one thing. So I do think that when it comes to this aspect of being culturally appropriate and providing culturally appropriate care, that the training, quote unquote, that institutions implement can't be a 1 and done, there has to be continual reminders. There has to be continual confrontation, if you will, of saying, listen, these are the things that are happening. And so when you have a leader who comes to you and says something ridiculous like that, they need to be immediately, there needs to be some mechanism by which they need to be taken into the corner. Right. And not just scolded. Right. And it needs to be done in a way that there is some sort of public acknowledgement, because that's the challenge. A lot of this stuff happens in private. A lot of the issues that come up with respect to the barriers to health care are done in a private setting because you're told to call risk management. Right. Or whatever as a patient and you call risk management and risk management takes care of stuff all behind the scenes. I'm like, no, we need to have a publicly facing health equity report card, period.

Dr. Dizon: That's an interesting idea. That is a really interesting idea.

Dr. Winkfield: So there has to be real intentionality in terms of what is it that you're going to measure in a health equity report card and what are the metrics? And it can't just be around how well people do clinically. I think that's 1 component of it. And the reason why I say that is because you don't want to Ding the institutions that are primarily caring for the disenfranchised and marginalized populations, right? I don't even know Boston was a majority minority city until I went to City Hospital. City Hospital is caring for all of the patients that other institutions in the region be like, sorry, you're too poor, are you too Black or you're too Brown? And they're caring for those individuals. And because of all those external pressures, all of the societal barriers, they may have worse outcomes or clinical outcomes. So you don't want to bring the institutions that are caring for them. So the health equity report card must be on more of those tangible things or the intangible things that oftentimes go unseen, like how is leadership responding to the intersectionality within their own organization that makes more.

Dr. Dizon: Yeah. I think it's also you mentioned that City Hospital here in Boston is caring for those folks. But the other reason City Hospital is caring for those folks is because that's where the community finds trust.

Dr. Winkfield: Yes.

Dr. Dizon: So it's both if you know, it's just like, yeah, you might want to serve that community, but they don't trust you.

Dr. Winkfield: Yes.

Dr. Dizon: You need to recognize that and then we can approach it. But if you don't even recognize that, then we will never get anywhere. So we're running out of time. I did want to ask you about the clinical trials issue. We look at who enrolled in our trials, and it's remarkable, shocking that few underserved people are still going on clinical trials. So the question to you is what do we do? And what can you tell this audience about that under representation of Black people on our studies?

Dr. Winkfield: Yeah. Let me just state in general, we don't do a great job in this country of enrolling in clinical trials in general.

Dr. Dizon: Correct.

Dr. Winkfield: We may have 9% or so of individuals who are involved in clinical trials in the nation. And so we appreciate all 9% of them. We appreciate them so much. But you would think that even with something as scary as cancer can be, that people might say, I want to consider doing, finding ways that may help improve not only my care, but the care for future generations. But that's not always the case. And when you use the terminology of clinical trials, that in of itself can turn people off instead of talking about clinical research or clinical studies because trial indicates that there is some uncertainty. And while we know that as researchers, if you're doing a phase III clinical trial or even phase I, any of the phases, that there certainly can be some degree of uncertainty. But it's really about how you couch it and making sure that individuals who are coming in for cancer in particular know that if there is a standard of care option, they will always at least get that if it's a randomized controlled trial, they will

always at least get standard of care. Now, if they're palliative and there's nothing else that they have, then maybe the standard of care is nothing, but they're always going to get the standard of care and so they will always get some degree of treatment.

But it's really important to acknowledge even that fact because of the past, as I mentioned, even the Tuskegee study, which happened well into the 70s. Okay, so there are individual communities that worry about being guinea pigs, so there is some education that needs to be done at the community level before people have a cancer diagnosis. So one of the things that I've been doing in my engagement activities is to always talk about the importance of research and making sure we're at the table. However, what I hear back from my community members is I wanted to, I have prostate cancer, I wanted to enroll in a clinical trial and I was never asked or I want to enroll in a clinical trial, but they had some weird exclusion criteria, so I wasn't eligible. Again, remember we talked about the obesity thing. If BMI is one of the things that you have as an eligibility requirement and you have a BMI less than 25, you're going to exclude most of the US population. I'm just saying. So you might want to look at that. So part of it is looking at eligibility requirements as well.

But let me tell you, there was a paper that was published in the Journal of Cancer in 2020 and I saw Vickers was 1 of the co-authors of this paper and it was talking about bias and stereotyping amongst researchers and clinical professionals and they actually did 91 qualitative interviews. Interviews with 91 different individuals from across the different stakeholder groups. And what they found was that the individuals, the researchers and the clinicians actually had bias like Duh. Right. The reason why I'm talking to patients, I might even be offered because providers and clinicians oftentimes think that the recruitment interactions with minority populations are going to be more difficult or challenging or they're not perceived as good candidates, they may not be compliant. Right. Instead of saying, well, how can we make this easier for the patient? How can we become more patient-centered in the way we design clinical trials, which includes thinking about eligibility, thinking about access. Do we really need that fifth CT scan? Maybe we don't. Right. Maybe the patient can get their blood draw closer to home or we can send somebody to their home. Right. Being more patient centric in the way we do it. So I think clinical research is really one of the areas that I've been focused in on. If you think about language even being a barrier. Right. Don't just make the assumption that because someone does not speak English, they are not going to want to participate in a clinical trial.

Dr. Dizon: I think that's accurate, and I'm actually glad you sort of framed it this way. Clinical trial is an enterprise, and there's multiple steps within that enterprise. And you can't just fix one thing and expect more under represented people, more Black people, more gay and lesbian people to enroll in your studies. In the world of sex and gender minority folks, we are trying to decouple gender from a cancer. So why does your studies say you're excluded if you're not a woman with ovarian cancer? This is a trans man with ovarian cancer. So technically he can't enroll in your study. Why do you have to say men with prostate cancer? Did you think about that? And I think it goes to this thing that you also mentioned of that sort of implicit bias, that sort of nothing that we're conscious of, but they guide how we interact with each other. It's that reason why you're looking at this woman, this Black woman saying, no, I'm not even going to discuss the trial because she's not going to do it.

Dr. Winkfield: Yes. There's the automatic assumptions to the point where I've even and look, I am now at an HBCU. Right. Faculty appointment. But even in the way that we on the tumor boards, people were just like, this is a 68 year old black man or 59 year old white woman. Why does his or her race matter? Why does the race matter in this discussion? Just to say my question, like, can we divorce gender from the conversation can we divorce race, ethnicity and really, again, hone in on this particular individual, what their needs are, not just lumping them into a category. And so I actually brought that up. And it's funny because we're trained often times in medicine that part of the history of present illness or the chief complaint they actually put in all this crap that doesn't matter. It's superfluous. And so we've got to retrain not only the medical students and the residents, but we've got to train the folks who've been in practice. We've got to retrain them because they're the ones who are modeling the bad behaviors. In many ways, I think the younger generation is more woke, but it's really important to I love what you're saying, and that's a really great example because I have clinicians that struggle, how do I take care of a trans person? And I'm like, really?

Dr. Dizon: Well, why don't you just accept who they are, call them by their name, that they wish to be called by and start there. And then you can treat them like a person, not a patient. Treat him as a person. Let's start there. All right. So to conclude here, Karen, what research would you like to see within the next 5 years to specifically try to close that gap in cancer care for Black people?

Dr. Winkfield: I think we've got to move away from the descriptive science that happens all the time. People doing these large database analysis to say, oh, look, Black people are underserved. Oh, look, we don't capture this data. Well, yeah. Well, how about we start to couple that with implementation science? I'm a basic scientist. I'm a biochemist. And back in the day, you could simply kind of describe a protein. Look at this protein, a new protein I found. Right. You can't do that anymore. You can't just publish a gene's DNA, what the DNA sequence is. That is no longer allowed. It was early on. But we know disparities exist. There's no need to describe and so papers and journals that allow people to just write in papers and saying, oh, look what we found. There's a disparity. Well, yeah. How about we now move to the next level just the same way that as a basic scientist, you now need to say, what does that protein do? What are its partners? How does it interact even kind of potentially think about its structure. So we've got to stop the descriptive research. I really would love to have more community engaged research that's focused on developing sustainable programming to reduce barriers and explore the implementation of that in different types of settings. Right. We talked about the difference of what happens in the Northeast versus the Southeast versus on the West Coast. So you might come up with something that might work in your town and your region at your institution. Let's look at implementation broadly.

Dr. Dizon: I love that idea and I think it's the only way we are going to see progress. I mean, you need to make sure that the leadership understands all the way down to the people who are saying hello at the front desk.

Dr. Winkfield: Yes.

Dr. Dizon: If you don't have all of that, if you don't train all of that, you can train all the docs. You want to be as sensitive to all of this. It takes one interaction, one to blow it all up. I agree with you. Everything that we're doing, we've got to ask the questions about implementation Because if we can't sustain something, if we cannot sustain change, then I worried like you do. That the flash of activism. Some say anger, some say awareness that's going to extinguish because nothing has been sustained. I think that's what we need.

Dr. Winkfield: Yes, agree.

Dr. Dizon: I think it's going to get there on the backs of folks not acting in their own interests.

Dr. Winkfield: Right there.

Dr. Dizon: It's like you and I are sort of in this field but we're taking people with us. We're taking people with us. We're growing them. But we're also you know what, once you reach that academic echelon where I mean, I can't believe it. I'm saying where we both are now. It's like you don't need more accolades. What you want to see is change.

Dr. Winkfield: There you go. Love that.

Dr. Dizon: Well, there are some tweetable moments here in my tweet for us, but okay. Thank you for listening to this podcast brought to you by Conquer Cancer, the ASCO Foundation. For doctor-approved patient information, please visit Cancer. Net, which is supported by Conquer Cancer donors. Conquer Cancer is creating a world where cancer is prevented or cured and every survivor is healthy. You can help by donating now at conquer.org/podcast. Participants of this podcast report no conflicts of interest relevant to this podcast. Full disclosures can be found on the episode page on CONQUER.org.