



Health Disparities and Parkinson's: Inequities in Parkinson's Research

with Drs. Jonathan Jackson and Nabila Dahodwala

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Davis Phinney Foundation

Melani Dizon (Director of Education, Davis Phinney Foundation):

Hello and welcome, everybody, to "Health Disparities and Parkinson's: Inequities in Parkinson's Research" with Nabila Dahodwala and Jonathan Jackson. And also I'm here with our moderator, David Leventhal. Hi, everybody. Great to have you here; really excited to have this conversation and expand the conversation that we had earlier this year on understanding the issue of health equities. We had a lot of people that reached out to us and said, "We want more from those panelists. We want to talk about this more. We want to learn more." And so today we're really happy to bring that to you and to make that happen.

Now I'm going to pass it over to David Leventhal. David is, among many other things, the program director of Dance for PD, which is part of the Mark Morris Dance Group, and is on the Board of Directors for the Davis Phinney Foundation. Thank you so much for being here with us today, David.

David Leventhal (Program Director, Dance for PD)

Mel, thank you so much for the introduction and thank you for hosting this important and what I know will be an informative conversation. You know, when we started this series in August we were treated to an incredible panel discussion that really covered the breadth of this topic of health disparities. But I think what we craved after that initial session was to go a little bit more depth in specific areas.

Today we're going to be focusing on the area of research, which I know is such a fundamental element and interest of all those of those of us working in the world of Parkinson's, those living with Parkinson's, those of us in the world of Parkinson's foundations. And when it comes to advancements in Parkinson's, we know that research is fundamental and key. However, what happens when access to participation in research studies is limited? And what happens when we lack diversity in those research studies that is truly reflective of the communities in which we work and live? What are the effects of that kind of limitation, and how does it affect all of us? And those are sort of the questions we're going to be looking at today. Primarily why does a diverse participation in research matter? What do researchers get wrong about designing and recruiting for diverse participations? What are leaders and health disparities and Parkinson's research are focusing on right now?

You're going to hear that from two experts. And what role does research play when it comes to



changing equity and access for Parkinson's care? These are enormous questions, but fortunately we have two incredibly informed experts to share their thoughts and really to have a conversation about this. And it's my pleasure to introduce Nabila Dahodwala and Jonathan Jackson. Nabila is the Director of the Parkinson Foundation Center of Excellence and the Movement Disorders Fellowship Director at the University of Pennsylvania. Jonathan Jackson is the founder and executive director of the Community Access Recruitment and Engagement Research Center, known as CARE, at Massachusetts General Hospital.

It's my great pleasure to welcome you both. I'm going to turn it over to you to spark the conversation between you and I'm very much looking forward to learning about this area from both of you. At the very end, we will invite questions from our attendees. You are invited to put any questions into chat along the way. I know sometimes when I'm listening to webinar, it's hard to wait for the end. You want to put your question in. As soon as it comes up, please feel free to do that. We will be tracking questions along the way. And in about 35 minutes I will come back and help to moderate a conversation based on those questions. So without further ado, I'm going to turn it over to Dr. Jonathan Jackson and Dr. Nabila Dahodwala. Thank you so much for being with us today.

Dr. Nabila Dahodwala, MD (Director of the Parkinson Foundation Center of Excellence and the Movement Disorders Fellowship Director at the University of Pennsylvania):

Thank you, David. Yes, it is really exciting to be here today. And when the Davis Phinney Foundation asked me to be participate, I was most excited to be able to talk one-on-one with Jonathan Jackson. So thank you, Jonathan, for agreeing to do this as well. It's, you're really a leader in this field and I think learning from your insights will be super helpful for everyone. And I wanted to start off by just getting a sense of asking you, what got you into this field? What drew you to this?

Dr. Jonathan Jackson, PhD (Founder and Executive Director of the Community Access Recruitment and Engagement Research Center at Massachusetts General Hospital):

Yeah. So it's actually a pretty long story. But I did my original training in cognitive neuroscience, where I thought a lot about Alzheimer's disease and how it affects the way that we think and how it affects certain parts of our brain, specifically white matter integrity. But as I moved through my post-doc and started my tenure-track career at Mass General Hospital here in Boston, it became more and more apparent that the breakthrough clinical trials that I was working on in Alzheimer's disease and cancer, in Parkinson's disease, in precision medicine—that it was not reaching everybody equally. And so I started off trying to help with this problem a little bit. And I think through a combination of my own interest and others' interest in me, I got kind of moved more and more in this direction until the point where I had to make a decision about whether I would pursue equity in clinical research full-time or whether I would go back to the safety of my little scientist's cave and, and you know, work on computational models of white matter integrity.

So I decided to do this instead and you know, I have to say it really feels like a frontier science. There's so much that we have to explore and learn and do in this space. But I think the most rewarding part is that it's high touch. I get to interact with people from all over. I get to talk to communities that otherwise wouldn't have any kind of voice in the research space. And that really keeps you motivated. And it's really, really rewarding.

Dr. Nabila Dahodwala:

Yeah, I would agree. I think that's largely what drives me. That's a big leap from cognitive neuroscience to here. Although I think probably a lot of the principles are the same of, you know, how you design a study and conduct research? So let's dive in. Why is this important? Why does it matter that we have diversity in research?

Dr. Jonathan Jackson:

Yeah, so I think that the best way to understand it is that we embrace diversity in every other aspect of our lives. So we recognize that, just for one example, the medicine of the future, the medicine of the present in certain sectors, is something that is personalized and something that is very precise. And so that feels like it's something out of science fiction, but it's, in other ways, it's something that we do every day. So you might have noticed, for those of you who can see me, that I'm wearing glasses. And when we go and get glasses, it's not just sort of one prescription, or you don't just get one prescription that you try for a few weeks and then go back and try another one. And then you have to wait six or seven years before you can see. You know, we have a process of determining exactly what it is that helps us out.

You know, when you go to the shoe store, if you go to Foot Locker or Nordstrom or Macy's and try on shoes, you get mad if you can't find your shoe size. And so we, we have that expectation that we can find something that fits for us in lots and lots of other spaces. So there is no reason why, when it comes to clinical research, when it comes to the medicine that we put in our bodies, that we shouldn't embrace a similar kind of diversity. And unfortunately, unlike the examples that I just mentioned about your glasses or your shoe size, there are things that matter, you know, so in the Parkinson's space, it, you know, it, it matters what stage of the disease that you're in, when you were diagnosed. It matters what your skin color is. It matters where you grew up. It matters what kind of education you had.

And we simply don't see a lot of these people represented in clinical research. And so what that means to me as a research scientist is that we may not have a complete view of what Parkinson's really is and what it looks like. You know, we found out this past summer that people of color may have a completely different, or at least a subtly different, presentation of Parkinson's symptoms. It may be more cognitive than motor, for example. And so if we don't have everybody represented in clinical research, not only can we not treat everybody, but it means that we may not be understanding the disease as much as we think we do. So it's one of those things where it's a, win-win for science, it's a win-win for the community. So we just need to find a way of getting this,

right?

Dr. Nabila Dahodwala:

Yeah. I say, I think one of the most frustrating things as a clinician is when you see a patient and you want to give them a treatment and you say, "Well, and in clinical studies, it helped 50% of people. I don't know if you're going to be the one it helps, or it doesn't help. I don't know if you're going to be the one who has side effects or not." And to really being able to personalize our treatment to the specific person in front of us would be amazing. And I think what we often forget is that Parkinson's disease is so different amongst all people. So no two people with Parkinson's disease will have the same course of the same symptoms, the same trajectory, and the only way really going to understand all how to predict different project trajectories.

The other first question I get from people when I first diagnose them is "What's going to happen to me? What can I expect in five, 10, 15, 20 years?" And that's very hard for me to answer because Parkinson's is so different. And until we have more diverse representation in our studies of Parkinson's disease, we won't be able to answer these questions that I think everyone, that it's important to everyone. But I think we both agree that it's really important, but it still doesn't happen. Right? What are the barriers? What are we doing wrong in designing our studies and recruiting people and setting them up? Where are we making mistakes?

Dr. Jonathan Jackson:

Yeah. So, I mean, I'm happy to answer this, but if you don't mind, I would love to turn it around and hear what you have seen as well. So you know, I can kind of talk about this from a very academic perspective because I don't run my own Parkinson's clinical trials. I just work very closely with people who do. And I think that there was a really great paper published by Marina Picillo and colleagues back in 2015, so about five years ago, that really outlined the set of barriers to participate in Parkinson's research studies. So you know, for those of you who have access to journals, I would recommend and going and reading that particular paper. It kind of outlines four different categories of problems.

And so one is that there may be a trouble on the site of the participant or the person who's involved in the study. And so one of the barriers is on the participant side, or at least one cluster of them. So somebody may not have the right eligibility criteria. They may not be able to get into the study. They may have issues with trust or awareness of research. We know that there are provider characteristics. So you know, we expect our doctors, our neurologists, our sub-specialists, to know about the latest research. And many of them just don't have that opportunity. So there may, you know, the doctor that you met that you may be seeing may not be aware of research studies, or they may be aware of a couple, but maybe those couple aren't right for you.

You know, there are also some well-documented trust issues on the part of providers, you know, for one reason or another. And there's a whole political thing that we can get into about those

kinds of issues.

And then there are barriers related to the structure of research itself. We know that most clinical trials, and this is true in Parkinson's as well as anything else, they tend to happen in relatively wealthy large academic medical centers that are on the east or west coast of the United States. If you live anywhere else, it's going to be a little bit harder for you to even hear about a trial, much less get to one. And so there are a lot of these structural issues as well, that really play a role.

And then in the work that I've done personally in the Parkinson's space, we've discovered another set of barriers, which is the fact that many research studies excuse me but they don't reach out to communities. And so there's no work to raise awareness of what Parkinson's disease even is among many underserved populations, as well as thinking very carefully and cautiously about how to build up trust and good will and to be trustworthy researchers. So there's a lot of problems that make it difficult.

I think, you know, if you want to step back and provide a summary, the way that I like to think about it is that we think about diversity and clinical research as a problem to solve. But I think it's not one problem. I think it's at least seven problems that you have to solve. And if you don't solve all seven, you're not going to see that needle move. And so I think that's what makes it particularly challenging because you have to have so many stakeholders involved and you really have to rethink the structure of the way that we do clinical research for a lot of reasons.

But again, that's my sort of very nerdy academic take. And Nabila, you've been on the front lines. You're right there at the forefront, you know. What have you seen that makes it difficult? It's not like people are sort of hopelessly, you know, guarded or territorial. It's like, there's nobody that's saying, you know, "We don't want diversity." I think it's hard for a lot of other reasons.

Dr. Nabila Dahodwala:

Yeah, I would agree. I mean, running clinical trials, being a principal investigator on trials, I would say everything that you mentioned, I have seen. And just to be more specific in terms of the patient side, there can be very stringent eligibility criteria on trials, where by age, by having a care partner, by comorbidities or other health conditions, that you have that really limit who can participate.

There can be issues related to what our expectations are of the patients in terms of coming in for extra visits. And I mean, we ask a lot of participants during the study. So the burden that we put on participants to travel, to miss work, we often don't reimburse for some of these issues. Some of these problems like people might not be able to take care of—might need help with caregiving during participation in a trial.

I think that from the provider side, our incentive, I mean, we're seeing patients at the same time that we're enrolling patients into a clinical trial. So expediency is probably like the number one thing we're looking for. Like, easy and fast. And I think a lot of what we think is easy and fast is based on our prior experiences. And then we end up having a biased view of who would be a good research participant, who we would approach for research. And it perpetuates this cycle of the same types of people getting enrolled in trials, because this is who was enrolled before. And this is who we think will participate. And for sure, the structural side, you know, the sponsors of the study have their own incentives and milestones. They want us to reach, they usually want it to be done quickly.

They usually want to see a positive, I mean, they always want to see a positive result, which means they really want homogenous population. They want the people in the study to be as similar as possible so they can see the effect of their drug. But then as we were talking about before this, it wouldn't apply to everyone with Parkinson's disease. It would only apply to that small group of people that were part of the study. So there's this competing interest of how much money and resources and time does this, like a pharmaceutical company, want to spend on a study versus, you know, getting a quick FDA approval and then they can worry about the rest.

But I think people are starting to care about this. I think the government and the NIH, which is the National Institutes of Health, and they sponsor a fair amount of clinical trials, have put in some, you know, some policy measures to try and ensure more diversity in research. There's not a ton of teeth behind it. They can't—there's not punishment if you don't do it. But I think it is a step in the right direction. Some newer studies or more recent studies have tried to incorporate, actually have targeted enrollment, where there is a conscious effort to have more diversity in recruitment.

That kind of actually segues into this next question. What are leaders in health disparities in Parkinson's research focusing on right now? Where is the landscape for how we can change this and where's research in this area?

Dr. Jonathan Jackson:

Yeah. So you know, again, I think this is one of those questions that maybe we should both chime in on, but from my perspective, I'm seeing two things in particular. So number one, I'm seeing some interest in trying to figure out who has Parkinson's disease, who suffers from parkinsonism. So for a long time, there's been this debate in the literature that kind of goes back and forth that really seems to suggest, you know, "No, it really *is* the people that we're seeing in our clinics. It really tends to be white people and maybe, you know, people with different kinds of Latinx heritages may be more likely to get Parkinson's than other groups. And then there's, I think, this emerging view that these may be the individuals who are most likely to get diagnosed. And maybe, you know, there is an overlap, you know, there is an overrepresentation of these populations, but it's not as dire as what we're seeing in our clinics."



And so there are lots and lots of underserved populations that are simply not being diagnosed.

And so I want to pause and say that this goes way beyond race and ethnicity. You know, one of the groups that is routinely under-diagnosed, and of course, Nabila, you know this as well as I do, you know. A CIS gender woman who can't get a diagnosis because many general practitioners, men, even general neurologists, will sort of look at their profile of symptoms and say, "Well, you're, you're a woman. And you know, I haven't seen Parkinson's in too many women." And so that becomes sort of the end of the conversation. So I would say that there is kind of this emerging view that we need to have a better handle on understanding how prevalent Parkinson's really is in our society.

The other thing that I see is sort of a much more thoughtful approach to the way that we design and fund research studies looking at Parkinson's disease. So looking at basic mechanisms, looking at genetic components that may play a role in risk. And so I'm doing a pair of studies with the National Institute of Health and with the Michael J. Fox Foundation that are looking at redesigning research trials from the ground up to try to be much more diverse from the get-go. So we're thinking about not just designing a trial and saying, "How do we get more people of color?" for example. But it's more saying, you know, "What is it that we need to do?" So we're starting from the perspective of we want the diversity, and then we're kind of designing the study from that kind of very foundational bedrock principle.

So you know, in reviewing grants for the Michael J. Fox Foundation and in conjunction with my research center, is redesigning the research review process, where we ask tough questions about a recruitment plan, about community engagement, about ensuring that they have a representative research sample, you know, with respect to race and ethnicity and gender and staging of the disease. And sort of just recognizing that we need to normalize the fact that our research participants will be diverse rather than trying to come up with some arbitrary quotas.

So that's something that's going to be a little bit more behind the scenes compared to, to initiatives that are a little bit more community facing. But I really think it is it's these structures that, that need to change the most in order to pave the way for a future where we do have research representation that looks like you know, the, the public that, that is willing to kind of come out and speak on this disease. So I think that's what I've seen. I mean, I could go on and on about a lot of other things, but Nebula, what, what are you seeing in the Parkinson's space?

Dr. Nabila Dahodwala:

I agree. I've seen more of the community engagement of, you know, trying to leave our academic bubbles and go more into communities where more patients who are underrepresented in our trials are living with Parkinson's disease and getting care outside of the center. So I think that I've seen more of that. I think we can learn a lot from diseases outside of Parkinson's disease, where they have been doing this for a little bit longer than we have. And thinking about incentives

on the patient side and how we cannot—I think the issue we as researchers often have with incentives is we worry about it being coercive, that we're unduly influencing someone's participation in study. But in fact, there's actually been a lot of research on different incentive structures that you can use for participants. And it doesn't even need to be a lot of money or even money, but it's being creative with how we think about “what's the benefit for precipitate participating in the trial?” And how can we make that clear for patients or participants?

I think another thing is how you mentioned study design, how we kind of structure the study. So you don't have to necessarily spend more time or more money because of the increase in diversity that we have in this study. So there's these adaptive study designs that can kind of continue to adjust based on the findings. There are more real-world or pragmatic studies where you don't have to worry as much about the comorbidities or other health conditions that people have. And I just think we need to be more open-minded about it. I think Parkinson's clinical trialists have used the standard template over and over and over again. And I really like how you said, like, just start from scratch and rethink from a different perspective how we set up everything. And I just think it just takes it a new perspective. Really. I don't think it's an “I'm thinking about what the diversity is” that we were looking for.

Dr. Jonathan Jackson:

Yeah. And so I think that's the point that I think is not often visible to people who aren't doing clinical trials themselves, which is you know, we have a standard template for Parkinson's disease, clinical trials, which is different than our standard template for cancer clinical trials. That's different than our standard template for COVID clinical trials. That's different than our standard template from Alzheimer's clinical trials. You know, there are these silos that we kind of get involved in, and you know, this, the work that I'm doing and that I think the work that many people are doing, especially in trying to move the needle on diversity and inclusion in research trials, is to learn from from from other successes. And so one of the areas that I think that has done a lot of work—there are two sectors that have done a lot of work.

So one is the work that was done in HIV and AIDS back in the eighties and nineties when there was a heavy stigma around the disease. People didn't want to talk about it. People didn't want to get tested or diagnosed. They didn't want to get treated for it. They didn't want to. They didn't trust the medical establishment to look after their needs. And so, you know, you had a lot of these communities that we call “hard to reach,” which doesn't mean that they're actually hard to reach. It just means that we can't reach them. So there were a lot of innovations in that space over the eighties and especially through the nineties about different ways of building trust and reaching these different populations and doing so in a way that respected both the needs of the study and the needs of the community.

So you build in things like community health workers, research navigators. You build in an incentive structure that allows the community to derive some kind of value. One of my favorite

researchers on this topic is named Consuelo Wilkins. She, and I actually just had a paper that came out yesterday that talks about this concept of return of value and making sure that people are getting something positive out of a study. But I think a summarized quick version of it is that there are three things that we can offer in our research studies. We can offer money; we can offer time; we can offer information. And all three of these are commodities. The best studies, the ones that, you know, will achieve lasting diversity and retention over time, will offer all three.

You don't need to offer a lot of money, but you need to offer some. Recognize that you are paying people for their time. But giving them your time, your expertise, your information as research scientist, it doesn't have to cost a lot of money. But recognize that these are three commodities that people simply don't have, and designing our research studies so that people get all three or at least two out of the three. It seems to be a really great place to get started in terms of, of achieving diversity.

So there is a lot of nuance. There's a lot of comparative effectiveness science, and we can get into the details, but I think at the end of the day, if you can offer some combination of those three things to research participants, and you can do that continually over the course of the study, that makes certain things really self-evident. Like adaptive trials or open-label designs where if you find that the medicine works, you give it to everybody or you give everybody the chance to opt in.

And so these things—it's not exactly rocket science, but it does require us to look outside of the places and sectors that we've normally looked, that we've already looked to. And so it's just a matter of kind of exploring a new frontier in this space.

Dr. Nabila Dahodwala:

As we're talking about this, I started thinking, I think studies that are being generated from the Fox Foundation or Davis Phinney, or from academic institutions, will probably or hopefully aim to achieve some of these goals, but what about industry-sponsored studies? What sort of leverage do we have with them?

Dr. Jonathan Jackson:

That's a great point. And I am not sure that everyone watching kind of appreciates the nuance. You know, I think most people feel like scientists like you and me run the studies. Unfortunately that's not how it works. So it's not like we get any kind of major financial incentive or benefits for doing this studies. So sometimes, somebody like Nabila will have a great idea and she'll pitch it and she'll get funded and she can run a trial but many, many times, and it depends on what you're studying. But sometimes more frequently, sometimes less frequently, a company will say, "We've got a good idea. We're going to pick somebody to run the study. We're going to pick a few places to help us out, and we're going to do it that way."

And so the difference is that these industry sponsored trials play by by and large the same set of rules. But there are some small differences. For example, NIH, the National Institutes of Health, do have some requirements about reporting the race and ethnicity and the age of the people who participate in the study. Industry-sponsored trials don't usually have that kind of oversight. You know, they don't have to do it. And so what that means is that if we're talking about something like diversity, there's not necessarily that built-in incentive structure. My guess, though, is that this is, if we get this right, if we learn how to do this from investigator-initiated trials or NIH-sponsored trials, that industry will have to adapt to keep up.

You know, I think that what we'll find is that if you can achieve a diverse trial, and this is sort of the big bet that I'm making with my research, that you will also find a way to run an efficient trial. You'll get your recruitment much—you'll get it done much faster. You'll have better generalize-ability. You know, the research findings will hold up. And you're more likely to get people who will stick with the study long-term.

So, you know, I think that these are positive changes that materially impact the finances of industry trials. So my guesses are, my hope is, that we can demonstrate that caring about diversity, caring about represented research samples, is not just a matter of social justice. It's just the way that you can do really good, efficient, cost-effective science. And so I think that those are, those will be the levers that do push this forward.

Although there is an outside chance that state legislatures or federal agencies, you know, may require some evidence of diversity before submitting for FDA approval. But I think that's probably going to be a long way off.

Dr. Nabila Dahodwala:

Yeah. So I think, I guess kind of related to this, is what is the role of research in changing or in helping to reduce inequity in the disparities that we see in Parkinson's disease? Across all care, not just in research? Can research play a role in combating the inequities in healthcare, outside of participation in research itself?

Dr. Jonathan Jackson:

So I would say yes and no. From my perspective, the way that we design research trials reflects a lot of the inequities that we see in getting access to clinical care. So the hypothesis that I have been operating under—and this is testable, we don't know if it's right or wrong, but I think it's right—is that if you can get somebody to trust and engage with a clinical research study, then you will have identified and overcome a number of the barriers that make it hard for them to get access to good clinical care. And so that would mean that you would have to run a clinical trial in a way that was appealing, that was efficient, that was accessible. And so that might mean that you have to explore new kinds of research designs, like decentralized trials or virtual trials or clinical trials that were within reach of most people.

So running a clinical trial where you could do a part of the study visit, or most of the study visits, at your local community health center, or at a Walgreens or a CVS. Making it easy for people to participate, I think, will expose solutions to gaps in equity and access.

But I think that one of the biggest problems that we have in Parkinson's is just getting people diagnosed, you know? And so we recognize that for most people, you have to talk to a primary care doc, and then you have to go see a general neurologist, and then you go see a sub-specialist. And, and, and. For many people because of insurance or because of time and other competing interests, that's a process that takes several years to figure out even when you identify.

And do you have to be on a waitlist for several months? So I think that that makes it hard to even talk about clinical research because you're spending so much time and effort trying to be understood for something that's going on in your own life. So you don't have any energy left for a clinical research study. So I would think that exposing some of these solutions and some of these processes that make it easier to participate in research would help with many aspects of clinical care.

But that would also mean, or it would also imply, some duty to dismantle some of these barriers. And that's where things I think can become a little bit more political and tricky and complicated. But I'm hoping that this research will highlight some of those barriers to care.

Dr. Nabila Dahodwala:

Yeah, I would agree. I think, you know, I thought, I think more about how to reduce inequities in clinical care than in research and, I think they're very similar. I think a lot of it starts with the clinical care side before you can get to research. It starts with identifying patients, identifying what the barriers are to getting appropriate care. You know, networking, I think, with physicians in the community. And I thought—I haven't come up with any formal plans, but would there even be a way to recruit for research from within primary care offices? And I think, I mean, it's possible, but I think the first step is making those community connections and building more of a pathway to getting the expert consultations when needed. And then the research will kind of follow along with that.

Dr. Jonathan Jackson:

Yeah. So I think a clear example of where this has been effective, and I think this may get at some of the questions that are popping up in the chat, is comes from the Muhammed Ali Center in Phoenix, Arizona, where I was lucky enough to spend a week there last year in 2019. And what we saw was, you know, treating everybody the same way. So everybody comes in and they go through the same process of diagnosis, disclosure, of being introduced to research. And you find that when you do that, you end up getting a lot more people involved in research. So not just people of color, not just minorities, not just women, but everybody is much more just into participating in research. And so the fact that they have standardized some aspects of intake,

some aspects of disease management, and some aspects of talking about research, you know, I think is the key to kind of overcoming some of the biases that we've actually seen in the Parkinson's world around talking about research.

So there are solutions out there. They're not complicated. They don't mean that we have to completely change our workflow or throw millions of dollars at the problem. It's just about literally designing a protocol where we treat everybody the same way. Hi, David. Is our chat over?

David Leventhal:

It will continue. But I did want to make sure that we had a chance to address some of the really thought-provoking questions that are coming up in the chat. So think of this as just a brief pause while I introduce some of those questions, and then I'm going to let you just continue your conversation around those questions, some of which have been addressed already. But I actually wanted to start with that question of implicit bias, because we just were just talking about it. To have it in the protocol is one thing; this particular listener is just wondering sort of how we also—is there training that needs to happen among clinicians as they're implementing that protocol, as they're recruiting, as they're speaking with people, to ensure that there isn't implicit bias in how they're approaching potential research subjects?

Dr. Jonathan Jackson:

Yeah. Do you want to go first?

Dr. Nabila Dahodwala:

Yeah, I mean, I totally agree with that point. I think we—although probably the literature and knowledge about implicit bias has been out there probably for decades—we, I feel like it just came to our health system this year. And so we had, I just recently completed an implicit bias training for our health system, and it didn't even touch on research. So I think we're just starting to get there. But I think the more we can talk about it, the more we're aware of it, the better it will be. But I think that'd be a great idea to have training around how our biases affect how we recruit and retain patients in research.

Dr. Jonathan Jackson:

And then I would say, you know, one thing that we've learned in 2020 sort of with language is the fact that when it comes to discrimination, when it comes to disproportionate opportunities, implicit bias plays a role. But I think a much larger role is played by structural factors. And we do need to be trained about how to eliminate it, but a much larger slice of the pie is due to systemic and structural factors. So implementing things like fairly relatively standard protocols where everybody's treated the same way, at least at first, or given an equitable set of opportunities for disease management and follow-up gets around a large set of the issues that would then allow us to further, you know, close the gap by doing implicit bias training. But my two cents is that we probably won't see a lot of improvement from implicit bias training until we have addressed the

structural and systemic factors. So I think that, you know, we have to take care of that source of variance—I'm going to be a really nerdy scientist for a minute—we have to take care of that source of variance before we can see the variability and the variants contribution from implicit bias training.

David Leventhal:

Thank you. Moving on, there was a question about the after-effects of mistrust from experience such as the Tuskegee and others among minority communities. And if so, are you aware of strategies being used to help attenuate that mistrust in order to increase enrollment? When you talked about reaching out, really going into the community for study recruitment, are there strategies that are intentionally trying to, as this participant says, attenuate that mistrust and really deal with this head-on?

Dr. Jonathan Jackson:

Oh boy, have I got a set of answers for you. If you don't mind, I'm going to go. There's a lot. All right. I'm going to do this as quickly as I can. The first thing that you need to do is Google "Consuelo Wilkins" and I'll put her name in the chat. She is out of Meharry and Vanderbilt, and she has made a wonderful career out of building trust in communities that have previously not trusted medical enterprises, especially researchers. She pioneered about five or six years ago a technique called Community Engagement Studios, or CE studios. And so the CE Studios have been proven to build trust in communities that that have had problems, you know, like Tuskegee. And actually a lot of others. I have given a few talks about medical abuses against Black Americans in particular, and it turns out there was a lot more than Tuskegee. That's sort of the tip of the iceberg.

There's a book called *Medical Apartheid* by Harriet Washington and it's an unflinching look at a huge number of abuses that have actually continued into pretty close to the present day.

The other thing that I would say is that historical mistrust is not the only mistrust. It turns out that when you do really interesting surveys and polls, it is the older generations that think about Tuskegee as the major source of their distrust. But for younger generations—so if we're talking about people on the younger end of being diagnosed with Parkinson's, so like the newly diagnosed people; so when I say young, I don't mean people in their twenties. I don't mean millennials. I mean, people like in their forties and fifties—they are folks that generally feel that their ongoing current experiences, the experiences of their family and their loved ones, are the primary source of mistrust because of, you know, everybody's got a story that they have experienced where they have felt that they have not been listened to. They see the disparities in maternal mortality. And so that is kind of the ongoing source of medical mistrust.

And so I think that building ways to address that is really important. And so I've got two more things to say.

So one is that I have a research fellow, AJ, who is starting a new project, so if anybody is interested, I would love to put you in touch with her. It's called "Trials and Trust," where she actually really wants to speak to individuals from underrepresented populations who have interacted with research and who have done a lot of really cool things in the Parkinson's space. And we want to talk about why, you know. What barriers did you overcome? What did you think was interesting? What did you think was not interesting? How did you get involved in Parkinson's disease research? So that study is set to kick off next year, and I think it'll be really interesting.

The last thing that I'll say is that if there's any groups that are just starting this out, and let's say you don't have the resources or access to do any of these things, what's really, really crucial is to focus on empowerment rather than trust. Trust is hard to win and easily lost. And ultimately what we don't want to do is engage with communities in a situation where they have to have faith that we'll do the right thing. We should engage with them as partners, as equal partners. And so the only way to do that is not necessarily to build up trust, although that is a part of it. It's really to ensure that they have the tools and the power to do the right thing.

So, you know, the way that I like to frame this, somewhat cynically, is that if you have power, you don't have to trust anybody. Because you know how the system works, and you know how to engage with it in an equitable way that benefits you in your community. So if we can work better about giving the tools and the resources to communities directly and, you know, I think that they will either have a sufficient empowerment rather than trust to engage with clinical research in a way that truly benefits them. Okay, I'll stop there. That was a lot, but you know, this is something that I think about a whole lot. Nabila, do you have thoughts on building trust?

Dr. Nabila Dahodwala:

Yeah, that was an extraordinary answer. I really appreciated it. So thank you very much. I think the last thing that I would say is, I agree that trust is a problem, but that it's not the answer. So I agree with the empowerment. And in fact, when you ask people of who are underrepresented in research whether they want to participate in a trial, they're actually just as likely to say yes as someone who's from a non-underrepresented group. So I don't know that's the crux of the problem. And I think the, more of the systemic and structural issues that Jonathan was referring to before, really. We just, we are putting up barriers at so many different steps of the way that I think focusing on the basic structure of this study will really make a bigger difference than the trust. But I think it's still such an important problem that our whole society is facing.

David Leventhal:

Is it fair to say that like many things in this field, there's an interrelatedness between sort of research recruitment and community relations and interactions? That it's not, you know, you can't just sort of say, "Well, I'm going to go, and I'm going to recruit with this community," without having any sort of track record of engagements, of inclusion, of a sense of belonging, right? You can't just do a cold call. And I think what I'm hearing is that we really need to be developing these

relationships for a number of reasons. Research is one of them, and obviously diverse research will be easier and more easily accessed if we have those relationships. But we should have them anyway. So you can't just walk into a community and say, "Well, we want you to be in a research study because NIH says we have to do it this now this way." But really from the ground up, developing a much more, well, trusting, but as Jonathan says, empowering attitude towards the communities with which we work. And that it's a much more systemic and holistic issue than simply the narrower research initiative that we're looking at. Is that fair to say?

Dr. Jonathan Jackson:
I think so.

Dr. Nabila Dahodwala:
I would agree. I think that's a good summary.

David Leventhal:
Sort of connected to this question is a question that came up—do researchers tend to use people who look like them or people who are easier to see, i.e., more accessible, those who come more frequently to the office or seen at events? Or perhaps—there's a question, they're not as confusing as men. I'm not sure I understand that part of the question, but is there, you know, is there a mirror? Perhaps this goes back to the issue of cognitive bias or implicit bias.

And along with this, there was a question from one of our attendees when he says, "I am an African-American male in early sixties diagnosed five years ago, I'm fairly active within the Parkinson's space to date. I can count the numbers of African-American people with Parkinson's on one hand who have attended support groups, seminars, symposiums, walks."

And these two seem related because we, you know, there's that bias of associating with, or reaching out to people who look like us, or, you know, we assume think like us. And it's just, as you said earlier, it's just easier to do that study. It's just, we, you know, it's a homogenous group. There's not a lot of incentive to kind of reach beyond that. And of course, it's just easier for researchers.

So how do we, we've talked a bit about this, but how much does that play a role, that sort of identity mirroring, and also that the fact that across the spectrum, we have difficulty finding numbers of people who are African-American in all kinds of activities, not just research. Yeah. So Nabila, I wanted to ask you—in line with some of the comments that have been coming through in the chat—are men easier to recruit? I guess because of hormones. And it looks like there was a question about menstruation, but I guess we can also throw menopause in there. Would you, do you feel that that is a driving factor in recruitment?

Dr. Nabila Dahodwala:

So I think I do think men are easier to recruit. I don't think it's necessarily because of the potential risk for contraception, for pregnancy and women because generally women with Parkinson's disease are outside of that window. And also there's also a potential risk for males, sperm. So I don't think it's an exclusive sex issue.

I think part of the reason men are easier to recruit is that many of our studies require a study partner or a caregiver, and men are more likely to have caregivers or caregivers who are available to participate. Oftentimes it's the care partner who's advocating for participation in this study. And the patient might have some cognitive impairment or apathy or depression, and they need that extra support to participate. Someone who's going to drive them for visits. Who's going to fill out other questionnaires. Who's going to make sure they're doing their home assessments.

I think we tend to see more men in our clinic than women. So they're just the population that we're serving and where we're recruiting from. 'Cause we tend to recruit from our clinics, not from the community. Mostly we see more men. And in terms of that question of whether we are more likely to recruit someone that looks like us, I'm not sure. I mean, I haven't thought about that. I've never thought about that question. I think someone who would look like—I don't see that many people that look just like me—but maybe people that I connect with in terms of how we communicate, because if we are communicating in the same way, the visit is generally going much smoother. We've built a rapport. And then it's easier to bring up research.

Because you know, generally, you're bringing it up during a visit, like an encounter when you're treating them for their symptoms. And then you're adding in research like, "Oh, by the way, we have this research study, do you want to do it?" But if we haven't had great communication, I don't tend to bring it up at the end. I don't bring it up for every patient. And so that I can say for sure, there's some bias in me and it may be a time issue alone. But I think how I communicate in a visit varies a lot. And the rapport that's built. But that could definitely have some bias built into that.

Dr. Jonathan Jackson:

And I'll give a quick response. So again, from a research standpoint, we have to recognize that the world of clinical research is based on what we call samples of convenience. You know, we design trials that are pretty grueling sometimes, you know, require a lot of visits, require an available study partner, you know, require people to be able to do the study. And so those of us who have the opportunity to recruit people into research studies, there's always this conversation in the back of our heads, "Can they do the study?" And so that is where you get a bit of unconscious bias because of course you are going to select people who can do the study. But you usually will select people who already know all about what research is. These are people who tend to be relatively privileged.

They have a lot of support. They can get to and from the study. They may be retired clinicians or researchers themselves. You know, they are people that kind of understand what it's all about. You can sort of anticipate that they're likely to stick with a two- or three-year study where you have to come in for say, monthly infusions.

So this concept of whether people can do the study really leads people to select who they ask or who they ask more than once. And so here can be, well, there is—there is a bias that really creeps in there. And this has been demonstrated in Parkinson's disease research studies for lots of reasons. And so it's not like, you know, they're thinking, “I want to get my friends in.” It's more like, you know, “I want somebody who won't be stressed out, somebody who could stick with it, somebody who's likely to benefit.”

And unfortunately, when you have this interior life of constraining who that is, you tend to end up with very privileged populations. And in the Parkinson's world, that tends to be disproportionately relatively wealthy, well-educated white men who have had a diagnosis for more than seven years, who live in an urban center along the east or west coast United States. And if you not all of those at the same time, you are much less likely to be asked or to be involved in a research study.

David Leventhal:

Nabila, that hearkens back to your point about just trying to find a way to make the process easier, to make it less arduous. You know, Jonathan, as you were talking, I was thinking about a parallel to the another kind of trial, which is a jury trial and jury service, and sort of those same demands that we place on a jury, of having to be there, having to miss your job, having to find childcare which can be much more arduous for people who have, who have pressures, economic pressures, family pressures, work, pressures that come from not being privileged in those positions. So it's, I think for those of us who are having trouble understanding that perspective, it may be a useful parallel.

We have unfortunately come to the end of our hour, and I'm sure we all feel that we could probably do another hour on this topic with the same expert speakers. But I'm going to wrap it up there and I'm going to start with a very humble and deep thanks to you both for sharing your thoughts and perspectives with us today. So Jonathan, Nabila, thank you very, very much for being part of this. I'd like to thank the Davis Phinney Foundation and Dance for PD for hosting and bringing this convening together.

I would like to encourage everyone to reach out to the Davis Phinney Foundation with additional questions related to this topic, and also other requests for topics in this series. There have been some wonderful ideas that have come through. And in fact, some things that you suggested are already on the schedule. Consuelo Wilkins will be appearing as part of this series early next year. So stay tuned for that.



But if there are questions that you really want answered that we didn't have time for today, please write to us at the Foundation, and we will make sure those questions get addressed. And I know that's true because I had a question from a webinar I did that didn't get answered and it came right through to me from Mel. So they, we, really do make an effort to get those questions answered.

Our next webinar will be coming up just after the first of the year, so please stay tuned for that. And I also want to remind everybody that we will be sending you a video and audio recordings of the proceedings from today, as well as a transcript. So if you missed any part of that, if your internet went out, if you want to share it with a friend, that will be available to you in a little bit, as soon as we get that together.

And above all, thanks to our attendees. Thank you all so much for joining us today. It really is incredibly gratifying to be able to share this information and these perspectives with you, from such a wonderful speakers. And you, our audience, are what make these webinars tick. We are deeply grateful to you for joining us, and I'm going to turn it back to Mel to wrap things up. But thank you all so much.

Melani Dizon:

Yes. Thank you, Jonathan and Nabila and David. We are so grateful. Thank you, everybody. I put my email in the chat, and we will be in touch very soon. Thank you. Have a great day, everyone.

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