Voices Raised Through Research: National African Americans with MS Registry

Presented by:

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Yahaira Rivera:
Good evening, everyone. Welcome and thank you for joining MSAA's live webinar, Voices Raised through Research: National African-Americans with MS Registry, presented by MS specialist Dr. Mitzi Joi Williams, MS specialist Dr. Annette Okai, and MS advocate Victoria Reese. This webinar is part of MSAA's New Direction series. My name is Yahaira Rivera, and I'm Director of Mission Delivery and Program Development for MSAA and your host for the program.

Before we get started, I would like to take a moment and share some background information about MSAA and some housekeeping items. As you may know, MSAA is a national nonprofit organization dedicated to improving lives today through vital services and support for the entire MS community. Our services include a national helpline providing English and Spanish services Monday through Friday 8:30 a.m. to 8 p.m. Eastern Time, an Equipment and Mobility Distribution program with products designed to improve your safety, mobility, and to also help with heat sensitivity, an MRI access program for individuals who qualify for assistance, educational programs, online tools, publications and digital resources to help you and your care partners stay informed. We also offer support through community connection to help you stay connected with other members of the MS community. All of our programs are available to people living with MS nationwide. To continue learning more about our programs and services, we invite you to visit our website, mymsaa.org.

During tonight's program, you will have the opportunity to ask questions by typing them into the chat box or by using the Q&A. We'll do our best to answer your questions during the Q&A portion of tonight's webinar. At the end of the program, we ask that you please complete a brief survey. Your feedback is extremely important and will help us in developing future programing and content. A link to the survey will also be included in the chat box. And please know that this program is for educational and informational purposes only and does not constitute any formal recommendations. Please speak with your doctor or healthcare provider team if you have specific questions or concerns. We'd like to take a minute to thank our sponsors. This program is made possible through the generous support of Biogen, Genentech, Sandoz and Sanofi.

And now, without further ado, I would like to introduce to our speakers this evening. We are honored to have Dr. Mitzi Joi Williams, a board certified neurologist and fellowship trained multiple sclerosis specialist who serves as a founder and CEO of the Joi Life Wellness Group Multiple Sclerosis Center in Georgia. She is considered a subject matter Expert in urology and in MS and she is a chairperson of MSAA's African-American Advisory Board.

Also joining us tonight, Dr. Annette Okai, board certified neurologist and fellowship trained in multiple sclerosis. She's a director of neuroimmunology and multiple sclerosis research at North Texas Institute of Neurology and Headache in Plano, Texas. And she's also a clinical associate professor of neurology at Texas Tech University Health Science Center. Dr. Okai is also a member of MSAA's Healthcare Advisory Council and African-American Advisory Board.

Last but not least, we are honored to have Victoria Reese with us tonight. She is a renowned influencer, expert in patient engagement and advocacy, and founder and president of We Are Ill. Since her diagnosis of multiple sclerosis in 2012, Victoria has tirelessly worked to amplify the patient's voice and challenge the existing norms in healthcare. We want to welcome our wonderful speakers. And now I would like to pass the mic to Dr. Williams, who will lead tonight's discussion. Dr. Williams.

Dr. Mitzi Joi Williams:
Thank you so much for those introductions and good evening to everyone. I'm very excited to be with my esteemed panelists and discussants, and we are going to have a great time this evening. So we're going to go ahead and jump right into the discussion. So let's go to the next slide. So this is what we're talking about. We're talking about research. And we're talking about why it matters, why it's important, the value of participating in research. And there are two types of research that we're going to focus on this evening. One type is clinical trials, and then the other type is registries, which you'll hear a little bit about later, including the National African-American MS Registry. So we have an action packed discussion, and I'm looking forward to it.

So why should we even have this type of discussion? Well, I think it's important to recognize that research is going on all around us all of the time. And often times we are engaging in research on a fairly regular basis. When you're looking for that new car, what do you do? You do research. You talk to other people. You look on the websites. You compare different specs. How many car seats does it have? What are the safety features? If you're looking for a new hairstylist, if you're looking for a school for your children, these are all ways that we engage in research on a regular basis.

And when we talk about scientific research, it's kind of similar research, but we have certain goals in mind. So things that we look at in scientific research, particularly clinical trials and registries, are we're looking to find better ways to detect a disease as early as possible. We want to be able to diagnose different conditions accurately. We want to be able to treat them to the best of our ability. And ultimately, we love to prevent them from even happening. And so these are things that we look at and different types of research trials. And this is important because it helps us to better serve communities. And then I think another form of research that's becoming much more important is really understanding people's lived experiences. So it's not enough to talk about a condition and the, you know, biology, etc., But we need to know how are people doing in the real world. Are the things that we're doing and creating in the scientific community really serving people? And kind of where do we go from here? So these are all things that we can learn by engaging in research.

So let's start off our first point of discussion. So when we talk about the value of research, you know, of course we know it advances disease, but let's kind of bring it down to a granular level. Let's bring it home, so to speak. So what is the value for a person who's participating in research? So we as scientists want everybody to be involved. But I start and kick the discussion off to Victoria. What is the value for patients to participate in research studies or projects?

Victoria Reese:
Yeah, So I think that... first, I'm a person who was taught, like, be a part of the change you want to see. And I think if you are any, let's say, adult over 18 and you do your research, attend webinars like this, learn about the space and the patient experience, I think we all could say some changes are needed, right? And I think that what I try to do with my patient advocacy work is really champion for the patient to be active participants in that change. I think it's very easy to read and complain about things, but you know, my doctor this or oh, the healthcare industry that. But I think that, you know, some of those things are out of our control. But the things that we can control, at least from the patient perspective, is trying to be active participants in that change we want to see.

And I know for me, I didn't realize how much research really affected me on a day to day. So like when I started, when I got diagnosed, I started to do my research. I'm looking for data, ultimately statistics, you know, in articles. My first thing is I'm going to Google it, and then when I get to an article, it's going to give me some stats and figures for me to kind of get a lay of the land of what's going on. Well, usually it's like studies and clinical trial evidence that's in there that they're referencing. So I think that when you think about it holistically, that participation is bigger than we realize. It affects us as patients more than we realize. So we're active participants and we will see more information that applies to us. So that's why.

Dr. Mitzi Joi Williams:
I love that. I love that. Anything you want to add, Dr. Okai?

Dr. Annette Okai:
Sure. I'd like to bring it from a clinician perspective from the exam room. So when a patient comes into the exam room and agrees to participate in research, one of the advantages of that is that individually you are getting access to cutting edge research, you are on the crux of what most people don't have access to yet. And another thing that someone gets when they participate in research is that they get more monitoring associated with that treatment. They get more face-time with healthcare professionals, be it their primary investigator who is the doctor they're seeing, the research coordinator. They get more labs, more frequent MRI. So attention, the spotlight, is really on the patient, on you as a patient in every aspect of your care when it comes to what you are participating in.

It is slightly different if you're newly diagnosed or if you're seeing a doctor, You come in every 3 to 6 months, depending on your doctor's schedule and in the interim there, you may not have contact with your doctor's office. But with research, a spotlight is on you. And that's a good spotlight to be in because every aspect of your care is being monitored very closely and more face-time interaction. And for some people, that is what they need to even help them on their journey. So that's just one part of the individual benefits. And then we can talk about the community benefits afterwards.

Dr. Mitzi Joi Williams:

Yeah, So those are excellent points. I love what you said, Victoria, about how you didn't recognize that research really affects you in your day to day life. You know, I think it's important when we're looking for answers, when we're looking to try to understand a condition like MS, you know, we're trying to understand why maybe it's affecting certain populations that we thought it didn't affect or affecting them disproportionately or more severely. The answers to help us understand that is in research, Right? That's how we get to the bottom of what is really causing some of these disparities that we see and why are we seeing MS, for instance, so much in the black community where we didn't see it before? And so, you know, as a clinician, you know, I look for those answers, but I can imagine also people who are living with MS are like, well, where's the data about me? Or where are the people that look like me? You know, where is the information about me? And one of the ways that we find that is by having people become more involved in research and in the research process.

And so you talked a little bit, Dr. Okai, about the individual benefits - access to cutting edge care, access to treatments before they come to market that no one else has access to except for people in the study. But let's talk also about the community benefit. So what are the benefits to the community when one person participates in a research study or research project?

Dr. Annette Okai:
So like you mentioned previously, you know, you want information about how, let's start with, medications or the disease affects you and people that look like you. And just like you brought the real world analogy about looking for a car, looking for a house and the research that you do, when you are diagnosed with this, you look for people that look like you and see their experiences. And if you don't find that it creates, I will say, more confusion for you as to “why me?” and “why is my disease looking like it is in me and not like other people?” So when we have people of different background, of different race, of different ethnicity, participating in clinical trials, then we can apply that data, the statistics, like Victoria mentioned, to that and have it make sense.

If we do not have that, then there are lots of unanswered questions for the clinician and for the patient themselves. So it's a community wide effort. You are helping your community as a whole to answer questions before things come up that we didn't know about because we had no representation. If different backgrounds, people aren’t represented, then we do not have data that we can apply to that we're going on, I wouldn't call it luck, but we are going on data that really we can transfer to one group.

And in research we call it generalization, we cannot make general statements about it because it's quite different. Start with the disease course itself, right? Some people may have a different disease course, they may look fine, don't need a whole lot, other people may need walking aides, other people may need wheelchairs. Why is that different between all the races, all the ethnicity? We don't know if we do not have people that are participating to get that information. And until we even answer some of those questions, we can not address it to say, okay, we need to slow it down this way. So that's one way that you can help your community, by participating in research.

Dr. Mitzi Joi Williams:
Okay, perfect. And before we move on from this, I do want to ask you, Victoria, one more question. So we're talking a little bit about clinical trials, Dr. Okai, in the next little section is going to talk a little bit about the difference between clinical trials and registries. But I wanted to go back to that piece about the lived experience. Tell us a little bit about why it's important for us

as a scientific community to make sure that we are also studying and understanding the lived experience of people with multiple sclerosis, particularly those from diverse backgrounds.

Victoria Reese:
Yeah, I think that, I guess for me, I'm from Detroit, raised by a single mom, first person go to college in my family, I knew about certain illnesses in my family, diabetes, things like that. But I didn't know about MS. I think that if, you know, I had a different experience and more people around me talked about MS, or there were at health fairs at the school, I don't know, I'm just trying to bring up my make up. Like if it was more in my face, people talked about it, if it came to my neighborhood, maybe I would know more about it, and I wouldn't feel that only... or maybe no one would have told me only white people get MS or black people don't get MS.

So if people have those types of experiences, that is really... the doctor may not be thinking about that, but if the person has these experiences of people telling them black people don't get MS, or, you know, ignoring their symptoms, I think like this makeup of me I'm influenced, that influences my experience. I'm coming... or let's say clinical trials. If my grandmother told me, don't be a guinea pig, I don't want to be a guinea pig and I'm not asking any questions about it, because my grandmother told me not to be a guinea pig. And then my aunt said, you know, they're going to steal your identity, then I'm not going to ask any questions because this is what was talked about in my house.

So I say all that to say, these are the things that people, I guess, at least me, a black girl from Detroit, this is in my head already before I'm asked. So I think if clinicians were to think about the makeup of that individual person, their background and things like that, then it's like, how am I approaching asking about clinical trials? How am I approaching offering it or inviting them to participate or just even questioning about it? You know, I think we have to take those things in consideration. That was a long answer, but.

Dr. Mitzi Joi Williams:
That was an excellent answer. I mean, and I mean, so many good things you said. I mean, we could finish the whole discussion about that, but I know we got to move on. But what I will say is that what I'm hearing you say is that it will help us as a research community learn how to interact when we know about the background and different experiences. But it also exposes things that our colleagues need to be educated about, right? Because obviously MS does occur in anyone, anyone can get MS. And so it's important that when we examine or research, you know, or talk to people about those lived experiences and publish data based on it, that we can help educate the community as a whole. We can help educate the patient community, but also help educate the scientific and clinician community so that hopefully people that come behind those who participated in research won't have the same experiences if they were not positive experiences. So with that being said, we're going to move on to the next part where Dr. Okai is going to talk to us a little bit about the difference between clinical trials and registries.

Dr. Annette Okai:
Well, it's been a great discussion already, so this part I'd just like to touch on two types of research. There are many different types, but things that come to mind when we talk about research, the number one is clinical trials. And like Victoria mentioned in certain communities, in certain households, that is very scary, and for good reason because the scientific community treated people from diverse backgrounds, especially African Americans, and there are lots of other backgrounds, ethnicity that were affected by unethical research trials. And coming out of that, because that happened, now there are guardrails and very strict guidelines in place for

people doing clinical trials. So let me break that down. When we talk about clinical trials, the first thing that comes to mind is old “we are going to test the medication on you.” Yes, in a way that's true. It's not approved and is being tested. But what is seen is that this has gone through several phases and we'll go through the phases later - phase one, phase two, phase three, before it's brought to the wider community.

So before a new treatment comes to market, it has gone through, at the minimum, at least five years of testing. And it starts small, it starts in a small group of people under 100. Then it goes to about 100 to 150. And before you open it to hundreds and to probably a thousand, thousands of patients, and they are designed to look at the drug that we are testing either against placebo, and that's a bad word, too, for some people, because placebo can mean sugar pill. But in our MS community today, we do not use placebo in the U.S. because we have good medications that work. So the new drug that is being tested is being tested against a drug that is already approved for MS. And we're very focused on answering certain questions. First, we see that it’s safe in 50 people and we see that it’s safe in 150 people. Now, is it safer in 700 to 1000 people, do we see any new signals? Is it doing what we want it to do? So this is where clinical trials you've been enrolled in drugs that test medications or devices or even try to answer questions like how can we improve fatigue, all of this falls under clinical trial.

Contrast that to what we call registries. Now, one thing about clinical trials, it goes through rigorous testing and you have to go through what we call inclusion and exclusion criteria. So in a way, patients are being cherry picked for this trial. You have to meet this. You can't have this disease. And we put you in this trial for the other. So very strict inclusion and exclusion criteria. But guess what happens when the clinical trial ends and the medication is approved. It comes to a wider community and we do not have those inclusion and exclusion criteria. So if in a clinical trial you had high blood pressure and we couldn't enroll you in that trial, when a drug comes to market, we are not excluding you from taking that drug. You have high blood pressure, you can take the drug. But we didn't study that in the clinical trial.

So now that brings us to registries. So registries allows us to answer certain questions and look at common themes amongst groups and through lived experiences as well, things that we cannot, we do not have the ability to look for in clinical trials because our group is very pristine. Now we can do it in a larger community and by asking questions directly. So to patients, that's the first thing. And sometimes to researchers, it's a “what do your patients look like when you put all these characteristics together?” And usually this is over time. For most, a registry is either a yearly survey that you are filling out on a variety of topics, from how your disease is looking, how it is progressing or not progressing, to what medications you have been tried on in the past and the reasons for the medications, or how’d this exercise affect us. All of that is asked in registries, so it's real time, it’s with people living with the disease, it’s people’s experiences and we can glean more information from there to answer questions. So both are types of clinical trials, but it helps us gain more insight, one, probably to the granular level of the disease, and the other to, OK, how are our patients living and what are their experience with the disease?

And moving to the next slide, we see that here, as I said, and I touched on this, it requires very detailed planning and you can receive either, you have inclusion and exclusion criteria. And we test our question, does this drug help, MS? Does it reduce MRI lesions? Does it reduce relapse rate? In most clinical trials, people are assigned, like I said, to receive the treatment that we're testing or can receive a control medication, or in other trials, a placebo. As I said, in MS trials in the US, we don't use placebo these days, we use control medications. And this is the gold standard because this eliminates most of the biases that we have when it comes to testing drugs. Next, slide, please.

So the choice is yours. So we as clinicians, we are asking you to give your time. We're asking you to give your... for us to test you, but it's your choice. And before you make that choice, you have to ask as many questions as you need to feel comfortable participating in the trial. And if it means more than one visit to the investigator office, two or three, consulting with your family members and see what they say. It is important that you understand what you are being asked to participate in and you are comfortable with it. I have to say that if you give a consent, that consent is valid, but you can withdraw your consent as well, for whatever reason, and that should not affect your relationship with your primary care neurologist, and the neurologist can also take you out of the trial if they feel it's not the right one for you. And these are the things that you need to be educated about when you're making this. So like Victoria mentioned, it wasn't a conversation that was, you know, commonly had in her household, correct, Victoria? It was do not participate or they are going to steal your information and that was case closed, if that's what I gleaned from it. But, with more education some of those barriers can be overcome and help you understand more what is being done and what is put in place for your safety when you decide to participate in these trials. Next slide.

Dr. Mitzi Joi Williams:
Absolutely. That was a great set up, Dr Okai. We're set up for this discussion and we're going to go through this one a little bit quickly because we've got some other discussions at the end. And we also want to save some time at the end for questions. But I think you covered very nicely, you know, some of the things that have been put in place to try to ensure safety. You know, it has to be recognized that if Dr. Mitzi wants to give you a survey about something, we have to go an IRB before we can ask you a question. We have to go to the research board. It has to be reviewed, all of that stuff. So, you know, please recognize that there are many things put into place to make sure that research is conducted ethically, that we're not doing things that we're not supposed to do, that we are not infringing on people's rights.

And as Dr. Okai said, it's important to recognize that if you do decide to become involved in a study that at any time you can withdraw your consent. So it's not like you sign on the dotted line and you sign away your life and your first born and all of that, right? If you feel uncomfortable for some reason or if you're not doing well, you know, that is a reason to, you know, to talk about it again and to potentially come out of that study. But what other questions do you think are important, Victoria, for people to ask if they're considering being involved in a research study?

Victoria Reese:
Yeah. So I wrote down a few and I added one at the very top because I think that it's a fair question. One question is like, will I turn into a zombie after this? You know, what's going to happen to me if, you know...? Because I think a lot of people... I'm so glad Dr. Okai talked about how the, you know, the drug has been tested for five years before you're even getting it. I think a lot of people think that someone's stirring it up, you know, in the back and then giving it to you in a capsule from your doctor. And, you know, that's just not correct. I wish it was more broadly discussed. So I've jokingly added, will I turn into a zombie as my first question? But I do think you want to make an informed decision.

So you want to ask the right questions. And I think some of mine would be, you know, would I be monitored really closely? Like, I think it was mentioned as well, you know, we're not seeing our neurologist every day or every week. You know, most people may not be. So if you're not going on a weekly basis, then that's not as closely monitored. Well, under a clinical trial, you would be heavily monitored, which is a great incentive. And I think we all wish we were being checked on every day. I know, me too, Doctor... Hint, hint. Dr. Mitzi. I'm just kidding. Then, I

think another question is like, if I have adverse effects or, you know, if it doesn't work well on me, if I get sick or something like, what does that mean? Do I still have to keep doing this? That would be a question. And I think one for me, I'm a fairly new mom, so I'm thinking, what's the time commitment? You know, do I got to sit in traffic? Do I have to miss work? Do I have enough PTO days for this? And then what about childcare? I think those are very valid questions to have, I know those would be first for me. So I know these questions aren't true for all, but I think they're some practical questions to consider if you were considering participating in a clinical trial.

Dr. Mitzi Joi Williams:
Absolutely. So those are excellent questions. You know, I think you hit the high points for sure. You know, there is a process called informed consent. Doctor. Okai touched on this a bit, but informed consent really tells you about the study, the risks, you know, a little bit about what the time commitment and those things are. And so really to make sure you understand kind of the scope of the study before you decide whether or not you want to get involved, but certainly making sure you're clear on what are the risks, what are the benefits, what's the goal of this trial, you know, what is the time commitment? Is there going to be a cost to me? You know, is there any incentive? In some cases, you know, people may receive reimbursement for transportation or for childcare costs. You know, and that's important because, you know, as a scientific community, we are asking you to lend your time, in some cases, your body, samples from your body, etc.. And so we have to make sure that we're compensating people for the time that they're missing doing other things. You know, so those are all excellent questions. And what we're going to do is we're going to talk a little bit more about the National African-American Registry. So we'll move to the next slide and Dr. Okai is going to go into a little bit more detail about registries.

Dr. Annette Okai:
Okay, So registries. So these are not what we call interventional trials. We're not giving you drugs. We're not giving you devices. We're not asking for samples. The registries are basically, one, we're asking you for your information, for your experience. Tell us about your experience. Tell us about your disease process. So we collect information from you with your consent. Okay. And usually this information is de-identified, meaning once you sign up, we take all information out that, if someone goes in, can point to you. So we make it anonymous as much as we can to get the information that you need. And it’s over time, so it's not just one time. Some may be one time. Yes. Some may just be one survey, but usually for registries, especially in MS, we want over time, because MS is a lifelong disease. Right? We want to see how you do year one versus year to versus year five, and it’s self-reported from the patient. And this is strong because this is your voice, it’s not what the researchers are saying. You are telling us how MS affects you, what the medications you take, your experience with it.

So it's a place for your voice to be heard. And that's why the questions that you, that you get are very detailed and very, very succinct to get the information that you need. But one thing I must say is that what you give us is valuable because it’s coming from the person who is living with MS and not what we assume everyone goes through. And that's what we want to get away from. We want someone who has lived through this disease, gives us the information, we synthesize it, and we put out the data that we get. So, next slide, please.

And so that's what Dr. Mitzi and I and a few other people came up with, the African American Registry. And we can talk about how the years that we were brainstorming or everything to come up with this. But we noticed that it affected a huge number of African Americans, but we weren't getting any data, Victoria, we went to the Internet, we went to our scientific journals and

we weren’t getting any data regarding... and I wouldn't say any data, but it could be like this, very... in a one inch three ring binder, like Dr. Williams likes to say, over a ten year period of time.

And so we, we, we founded that the African American Registry, and the goal is to advance care and outcomes for African American patients because, first, the MS trials that were being held had very little number of African-Americans in it and papers that were being published were on ten, two, seven patients. And that wasn't really a representation of what the entire community looks like. So there are lots of MS registries out there, and they really didn't distinguish between African-Americans, Caucasians, Asians, Hispanics. Well, we decided if this is the data that we are seeing more MS In African American patients, African American women - biggest group being diagnosed, and the disease is more progressive as has been put out there. Let's hear from the people that are really living through this disease. And this is how we came up with this registry, with the help of very generous people who gave their time. But also it took ten years of working to get this going. And so if you fall in this group, we really encourage you to look at this and help us advance the knowledge in the population, in our community for solid, patient-oriented data or to continue to answer the questions that affect us as a community. Next slide, please. And Dr. Williams, I'll turn this over to you.

Dr. Mitzi Joi Williams:
Yeah. So excellent. You know, and we'll talk a little bit more about the registry kind of as we get into the Q&A session as well. I think this was important to highlight because, you know, there are definitely some barriers to involvement in research and we'll talk about that in just a few minutes. But, you know, one of the questions, or one of the arguments that many scientists say is that, well, people don't want to be involved in research. You know, certain populations are going to say no. And this is an interesting survey that we did out of a project called The MS Minority Research Partnership Network. And we surveyed almost 2600 people, 200 black or African-American people, 188 Hispanic people. And what we found was that by and large, most people had very positive thoughts about research. And we asked kind of specific questions. We also asked kind of free form questions like, you know, do you have positive or negative thoughts, etc.. And most people from all groups had very positive thoughts about research. But some of the barriers were people weren't asked to be involved and they didn't know where to find out about research. So those were two of the bigger reasons why people weren't participating or being enrolled in trials.

Now, certainly there were some concerns from certain populations, the Black and Hispanic groups had a little bit higher concern about mistrust in terms of being involved. There was concern that maybe they wouldn't receive as good care in a clinical trial. And then, of course, some people were concerned about their insurance status as well as their legal status for those who may have been immigrants, etc.. You know, so these are all valid concerns. Let's go to the next slide.

So I want to kind of park here for a second and talk about some of the barriers to involvement in research. So certainly it's important for us to talk about, you know, the benefits, but also there are some real drawbacks or barriers for some people to being involved. Certainly lack of awareness about where to participate in studies. If you don't receive care at an MS center or with an MS specialist or with someone who conducts clinical trials or different types of research, you may not even know that this type of research exists or how to get involved. Some people don't have a clear understanding about the studies, right?

The informed consent, although it is definitely meant to give you an overview of the study, the documents are very long and thick, right? So if you go home with 50 pages, you know, and try to read it and wade through it at home, you may have some difficulty understanding exactly, you know, the whole scope of the study if somebody doesn't take the time to really walk through it with you and answer questions. Of course, there are concerns about safety, particularly if we're talking about a clinical trial where we're talking about medication, absolutely valid concerns for medications and procedures. Important to understand those. Certainly financial, you know, time away from work, etc. And then when we talk about institutional barriers, certainly there can be bias on the side of providers, right? Not asking people because you assume that a group of people is just going to say no. And that's important for us to address as well as when we look at the inclusion and exclusion criteria, we can automatically exclude whole groups of people who may have more diabetes or hypertension. If you have to be in 100% perfect health, you know, you may miss a lot of people who should be involved in the study.

And then, of course, lack of ethnically diverse researchers impacts the types of questions that are asked. Right? You know, so certainly there are some general questions we need to ask about, you know, do medications work, etcetera, etcetera. But also there are maybe more nuanced questions that may be specific to a community. And if you don't have researchers who are part of that community, there are things that may be missed. And so, you know, I think it's important for us to address these and I want to ask you, Victoria, what are some of the barriers that you hear from the patient community or that, you know, you may have encountered yourself to being involved in research?

Victoria Reese:
Yeah, the biggest one is just simply not being asked. And I think you brought up something that is valid to bring up, clinicians and healthcare providers are human too. So I could totally see someone like, I'm not going to ask this lady. I don't feel like, you know, or I don't have the words to explain so eloquently like you all have done on this webinar. You know, doctors appointments seem to be shorter and shorter every year. So I can imagine a doctor on a long day saying, you know what, this doesn't seem like the environment or the day that I want to ask about this. Maybe they're short on time. Maybe they just feel like it's not going to be a good conversation. But a lot of people feel like they're just simply not asked. And then I think that a lot of people in our community, at least that are ill, have mentioned not being in the state or in the area where this could happen. I believe they researched it maybe on a website and it was in Missouri and they were in L.A. or something like that, so maybe it just wasn't being conducted near them. So I think those could be some barriers. But I would say first and foremost, a lot of people aren't being asked.

Dr. Mitzi Joi Williams:
Yeah, yeah. Anything you want to add to that, Dr. Okai?

Dr. Annette Okai:
Yeah. From a clinician perspective, I do ask everyone. So from a clinician perspective, what I hear from people that decline clinical trial is time commitment, because, you know, you're coming to the office first. It could be every two weeks, every week. And so that's one. And the second thing is the concern, the safety concerns. But once again, I must point out that, you know, yes, we are now realizing that these things take time and we are trying to make it a little bit less burdensome on patients by trying to incorporate remote visits, or nurse visits, just for blood draw as opposed to driving to the doctor's office just to get your blood drawn.

We are also trying to make it more clear, you know, the informed consent, I sit with every patient and go all through the 36 to 50 pages of informed consent and make sure that they understand all of that, but mostly it's time commitment. And we need to work harder at reducing the burden on the patient. We can't use financial as an incentive. That is not right. That's unethical. But, to say, we're going to give you this if you participate, we cannot do that and we should not do that. And there are barriers in place for us to doing that. But we do have to recognize what it is. And we do have, and like you mentioned earlier, taking care of childcare if we have someone who has volunteered a time, if someone lives far away, Victoria, there is transportation covered or finding somewhere closer for them. So all of that is in place, but we can use that as an incentive to get people to participate in trials. But they're things in there to reduce these barriers.

Dr. Mitzi Joi Williams:
Yeah, I love that. Thank you.

Victoria Reese:
I have a quick question.

Dr. Mitzi Joi Williams:
Yeah.

Victoria Reese:
Are certain... Okay, Dr. Okai, Dr. Mitzi, you all are very passionate about clinical trials and increasing participation from patients, but are some clinicians more invested than others? Like, if you are part, like, as an investigator or something, in a clinical trial, will you be the that's more likely to ask versus a different neurologist who might not be as involved in clinical trials? Or should all neurologists be expected to ask this?

Dr. Annette Okai:
No, so mostly people who are asking are the investigators that are conducting trials at this site. Those are the people that are asking. There are lots of neurologists that take care of MS patients that do not conduct clinical trials, and clinical trials aren't on their radar. So I, as a primary investigator, I try to reach out to providers who do not participate in clinical trials with letters informing them, I have this clinical trial going, you know, if you consider sending patients, but if they do not understand what the clinical trial is about, or, you know, they are busy, like you said, time is short, they're not invested in recruiting for clinical trials.

Dr. Mitzi Joi Williams:
Yeah. So, you know, exactly what Dr. Okai said. And again, we are very passionate about it, you know, and hopefully that shines through. There are some people who are very, very interested in getting diverse patients involved. But I think again, it really is a group effort. So not just looking at ethnically diverse researchers, but also teens. So every researcher is not going to be African-American. Every researcher is not going to be Hispanic or Latino. And increasing that diversity in the scientists is going to take time. But certainly for those who don't have, you know, clinicians who are primary investigators from different backgrounds, you can look at your team, right, and find other people who are on the research team who maybe can identify with patients who are from different backgrounds, and that can help with the asking, with the asking part and being receptive to that.

So we'll quickly do the next couple questions and then we'll go into... So, let's talk first about how registries help patients and then let's talk about how they help researchers. So I think Dr.

Okai did touch on quite a bit of this. But Victoria, I'll have you start with how do you registries, you know, which gain information about the lived patient experience or different information that we get from clinical trials, how do they help patients? How does that help patients?

Victoria Reese:
I think it just goes back to having that information. Now, I mean, I'm a different patient than I was in the beginning and I'm very proud of that because I attend webinars, and now I speak in them, but I attend webinars and I try to stay informed on what is going on. But I think that you look at a registry, you're thinking about how that information, your information, helps the information, the pool of information that clinicians need to help them determine things about our demographic or a group of people or just people living with MS. I think, you know, signing up for that is important to identify what this community is dealing with. It's not a lot of information that's needed, so I think this registry is beautiful because where you guys are asking people to volunteer their time to fill out some questions, it's not long, it's a short amount of time. But to have it all in one place so that this information can be housed somewhere, I think it's very important to be a part of that change that we want to see.

Dr. Mitzi Joi Williams:
Absolutely. Absolutely. And then from the researcher side, Dr. Okai, how do registries help researchers?

Dr. Annette Okai:
It helps us in a lot of ways. It gives the patient a voice. I said it earlier, but I'm going to... it gives the patient a voice, because even though we're sitting here talking about patients and, you know, the MSAA does all these webinars about how MS affects patients, there are some clinicians out there who think there are no difference between Caucasians and Hispanics and African-Americans. Right? So it it gives you your voice so that we get this information to say, Look, this is real. And some people need to see data. All they want is to see data. Someone can come in, they can have a room full of patients, but if you don't give them data, they're still going to be, No, that's not true. Right?

So from a researcher perspective, we get information from the patient regarding their experience and we are able to educate our colleagues about your experience so that when you walk into that example room, now they're able to identify what you are... you and your community experience and go through and make decisions based on that and not biases. So look at it. We have social media all over. You know, everything is on TikTok and everything's on Instagram, and you give information all the time, and they collect it all the time, even sometimes without your consent. Right? This is for the benefit of you, your journey, and your community. So it's important that you contribute to that and, once again, let your voices be heard. Okay? Stand up and be heard.

Dr. Mitzi Joi Williams:
Absolutely. All right. So we're going to go in the last 9 minutes we have left, we're going to go to some patient questions. And so let's hop right into it. So there is a question that someone put in the chat I think is a really good one. And I want to kick it off to you, Victoria, first, and then you have you, Dr. Okai, weigh in. It says, I want to participate in research, but I'm a very private person and the thought of sharing information about myself and my health condition makes me hesitant to participate. What can I do to ensure that my information won't be shared and will remain anonymous? And what should I look out for?

Victoria Reese:
Great question. I think it was touched on about informed consent and just that all of the parameters that have, because of medical mistrust in the past, all of the parameters that have been set in place to protect us. So I would say first, thoroughly reading that information, if it's 50 pages, it's 50 pages. I'll read 25 because... I'm going to read all 50. But, I'm going to read all 25 pages worth of where my information is going. And honestly, I think, I've never thought about this, but have an attorney, your family attorney, review it if you need to if you don't really understand what it's saying just to get a better understanding about what is happening with your information.

And just as far as being private, I respect that. I absolutely do. But I've learned that the squeaky wheel gets the oil and sometimes that crosses the boundary of your privacy. Sometimes you got to speak up and sometimes you got to trust that crossing that own personal boundary, not too much, of course, is necessary to get the change or the service or the healthcare that you need. So I will say, my own experience, I don't expect anyone to do the same thing as me, but me being the loud wheel and telling my truth and sharing my experience has been the best decision I've ever made. I'm smarter and more knowledgeable. I ask questions and I am a better patient because I open my mouth to not only share my story but to ask questions. So I implore everyone to not be so private and then kind of like it was said, we share information all the time. All the time on social media. We can find a lot about all of you on Facebook or Instagram, if we wanted to. So in comparison, you know, which one could potentially really help you in your healthcare journey as a patient?

Dr. Mitzi Joi Williams:
Yeah, I love that one. And I will add to that that when you enter into research trials, there are, again, safeguards and rails in place to protect your information. So there is a central site, your site that knows who you are and can identify you. But, you know, you get changed often to a number, you know, I can't, if Dr. Okai and I are having patients in the same study, I can't call Dr. Okai and say, Hey girl, you know about patient X, Y, Z? Did you see what she answered on such, such, such? Because you're a number, I don't know who is who. I have to even figure out ways to go backwards and find out my patients, once they're enrolled. So there are safeguards in place to de-identify your information so that we can't look and say, Ooh girl, I think that look like Victoria right there, did you see them answers? It doesn't work like that.

Okay, So we can't identify you, the people who are essentially looking at the information can't identify you, you know, and we ask information just, you know, to make sure that if there... so there is a way if there's a problem to connect the dots back to you. But it's not something where like your name and all your information is sent to all these different sites all over the country or the central site, everything is de-identified once you enter the trial. And I know you want to say something Dr. Okai, we got about five more questions.

Dr. Annette Okai:
Okay. Just a quick question. Yes, it's de-identified, and to unblind, it has to go to a monitoring board. It has to go to the FDA for clinical trials to unblind for anyone. So even if there's an adverse effect, it has to go through three chains for anyone to know who you are. And for being private, once again, if we do not know, we cannot help solve the problems. So, yes, I respect your privacy, but if you keep everything to yourself, medically, it could be a disadvantage in how your disease is addressed, how it is treated. And so we need to know because if you don't say, we cannot help.

Dr. Mitzi Joi Williams:
Absolutely. All right. So we got a couple more questions. I'm going to have one person answer each question so we can try to get through as many as possible. I'll send this one to you, Doctor. Okai - If you start on a clinical trial and have an adverse reaction, do they stop the medicine immediately?

Dr. Annette Okai:
Okay. So yes, let me go through this. If you have it... So when you're in a clinical trial, once again, everything is de-identified. So when it goes, when you report an adverse reaction, I have 24 hours to report that to the sponsor, to the FDA, to the monitoring board, and then they review everything. Is this expected or not? So if you took something and you had nausea or vomiting, people have heard all those - call your doctor if you have this, this, this, this, this. So if you have all of that, is this expected with the medication or is this unexpected? Unexpected? Serious? Yes. They are contacting me as an investigator and say this is what we see, reach out to the patient and let's do this. Stop. Yes, if it's severe, it's stopped and then we go through the process of determining what needs to be done.

Sometimes it may be minor and I have to come to you and say, look, this is what we see, this is expected or is minor, do you still want to continue or do you want to withdraw? If it's severe, I don't have to make that decision. The FDA and the monitoring board say, Stop, we're not going to go through with this because this is for patient safety. So there are so many levels that are put in place for your safety and protection. Yes. So in that event, yes, it happens.

Dr. Mitzi Joi Williams:
Excellent question. All right. I'm going to throw this one to you, Victoria. Participating in research seems like one more thing I have to manage on top of several appointments. What should one expect in terms of time commitment when participating in research?

Victoria Reese:
I do not know that answer.

Dr. Mitzi Joi Williams:
Okay. Okay. Maybe I'll take that one. Well, the first part sounded like it was direct to you. Okay, so I'll take that one. So it really depends on the study, you know, for instance, for registry studies like the African-American Registry, you can complete that questionnaire anywhere online, in the comfort of your home, you know, are you sitting in the waiting room waiting for somebody, to see somebody, etc. Other types of research studies, the protocols are different depending on the study. There are some where you may have to go in for frequent visits. There are some studies that are conducted online where you do assessments online. So it really is study dependent. So one of the jobs of the person explaining to you, to explain that protocol and the number of visits, but also it's important for you to understand the time commitment and, as I said, it's really study dependent.

I'm going to throw this one to you, Dr. Okai. It says... about age. Let's talk about age. Someone said, I'm interested in starting research programs, but research, it seems like it's for younger people. So let's talk about that.

Dr. Annette Okai:

Yes. So that is totally correct. For a very long time, there has been this arbitrary age caught up in MS study, and that is also frustrating for us as principal investigators. And so there has been a push recently to change that because, you know, we now see that MS doesn't only affect 20-year-olds, we are diagnosing patients after 50. So that is something that we are aware of and is not going to be a quick fix. But we are addressing it and encouraging that we extend the age because... and there are lots of reasons for this. The biology of the disease is one thing. How the disease progresses over time is also another thing. But with the newer studies that are coming out and there has been a focus on age, there has been a push to change that.

Dr. Mitzi Joi Williams:
I love it. Okay, so one more because we're out of time. How Do you participate in the National African-American MS Registry? Dr. Okai.

Dr. Annette Okai:
Great. So, the website is NAAMSR.ORG, so National African MS registry. You can go there and sign up, it's all you have to do is sign up, and then to complete the registration you will get a survey and the survey is what enrolls you in the registry. It's not just signing up to say I'm this and here's my email address. Once you sign up with your email address, you get a survey and fill it out, we call it the baseline survey, that's what gets you enrolled, and then subsequent survey is yearly. Or if we need more information, we'll send out a shorter survey. So the website was also on this slide and hopefully we can put that up after this for you to see but just Google National African American MS registry dot org and sign up and look at the survey within seven days and we appreciate you continuing to fill out those surveys.

Dr. Mitzi Joi Williams:
Awesome. Well thank you guys. Thank you so much Victoria. Thank you, Dr. Okai.

Dr. Annette Okai:
Oh, and the website can also be found on the MSAA website.

Dr. Mitzi Joi Williams:
Yeah, absolutely. It's on MSAA. So thank you all so much for your amazing insights. Thank you to our audience. I'm sorry we could not get to every question, but there are some amazing questions there and hopefully this provided some information to give you food for thought about participating in research in the future, and I will hand it back over

Yahaira Rivera:
Thank you so much, Dr. Williams, Dr. Okai and Victoria. This was such an inspiring and wonderful program and you provided the MS community with important information about research, clinical trials and the registry to our wonderful audience. Thank you so much for participating and for all the wonderful questions that you sent over. On behalf of MSAA, thank you so much and have a wonderful night. Bye bye.