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Who's Missing from Multiple Sclerosis Research?

Ashley Baker:

Welcome to *NeuroFrontiers* on ReachMD. I'm Ashley Baker, and joining me to discuss her recent study on equity, diversity, and inclusion in multiple sclerosis, or MS, research is Dr. Ruth Ann Marrie. She's a Professor at Dalhousie University and holds the Gillian's Hope Multiple Sclerosis Clinical Research Chair.

Dr. Marrie, we're so glad to have you here today.

Dr. Marrie:

Thanks so much for the invitation to join you.

Ashley Baker:

Let's start with the big picture, Dr. Marrie. When you looked at the current MS research landscape, what gap did you see this study filling?

Dr. Marrie:

So, we have seen a growing number of studies that have shown us a pretty broad array of characteristics of an individual person with MS related to their identity and social position that affect health outcomes—gender, ethnicity, religion, education, and so on. A lot of research studies aren't very diverse in terms of who participates. We see that in clinical trials, whether it's for disease-modifying therapies or rehabilitation interventions. We also recently looked at the body of literature in Canada and found that observational studies also don't have a very diverse group of participants.

But we need those research studies to include everyone if we're going to have the necessary information to meet the needs of all people with MS. So, we thought if we were going to try and fix those gaps, we really needed to set some priorities that could allow us to move forward in future research and do a better job.

Ashley Baker:

So, from my understanding, this research brought together people with lived experience, clinicians, and equity, diversity, and inclusion researchers. Why was it important for you to hear from all of these groups, and how did the modified e-Delphi technique help you achieve these goals?

Dr. Marrie:

So, we thought it was really important to have multiple perspectives for a couple of reasons. So first, in terms of getting people with MS to participate, this work is for people with MS, so they need to have a say in setting the priorities. When we're thinking about the EDI researchers, they have the expertise in this area. They understand best practice, measurement, and where we should be headed. But then, when we're thinking about clinicians, they're also living within the health system. They may be identifying and recruiting people for research, and they're also dealing with the health system day to day, so they're potentially going to have a different set of perspectives.

So, we thought to really come up with a set of priorities that were going to be meaningful, we needed to have this diverse set of perspectives, and that's where the e-Delphi comes in. So often, when you have people in a room and you're trying to all agree and you have different perspectives, it can sometimes be difficult to reach consensus. And if you do in-person meetings in those settings, the person who is loudest or is most senior—you create these group dynamics, and they may be most likely to carry the day in terms of

what happens, and maybe you don't hear enough about those other differing perspectives.

So, Delphis are a type of consensus process that get away from those group dynamic problems when you're dealing with complex topics because you do things like allow anonymous voting and iterate. So, you get everybody's input, and people hear from everybody else, but there isn't that pressure to agree with a particular person. It allows you to really integrate all those different perspectives and come up with consensus that you can be confident reflected the input of all of those different individuals.

Ashley Baker:

Well, with that in mind, let's dig into the results. The first thing I want to discuss is that most priorities were rated as achievable rather than core. What stood out to you about these ratings?

Dr. Marrie:

When we did this, we asked people to rate things at different levels. So, core were the things we thought everybody should do all the time. Achievable were the ones we thought people could get to with a little bit of work. And aspirational were the ones that really only a small proportion were going to get to.

So, I was actually a little surprised at how few items came up as core. For instance, one of the things we asked about was, what characteristics of people with MS should we be measuring—knowing that most studies when we looked in the Canadian literature, for instance, just reported age and sex. And really, age was the only thing that came up as core—that minimum standard. And yet, there's some of these other characteristics like gender identity and things you could easily ask. So, I was a bit surprised that they were labeled as achievable rather than core. But I wonder if some of this is people's concern about sensitivity and about how to ask for these questions. Some of the people were clinicians, so in a clinical setting, they may have been worried about the time constraints. So, I think that we need to understand a little bit more about that, but at least they were achievable, which means people think we could get to a place where we could look at those.

The other place where I was surprised was that a lot of the strategies designed to enhance participation of underrepresented groups that we asked about, like community engagement and tailoring materials to those groups, were listed as achievable. And just in thinking about those and looking at the literature, we thought perhaps some of this relates to the additional time and resources, like funding, that are needed to do that type of work, and maybe people haven't been adequately trained to do that kind of work. We thought a lot of it really pointed to gaps in the tools and expertise people may need in order to be able to carry out some of these kinds of priorities.

Ashley Baker:

For those just tuning in, you're listening to *NeuroFrontiers* on ReachMD. I'm Ashley Baker, and I'm speaking with Dr. Ruth Ann Marrie about how equity, diversity, and inclusion can be better integrated into multiple sclerosis research.

So, Dr. Marrie, we know that your research identified a wide range of characteristics—things like race, gender identity, housing, and even food security. From your perspective, how can researchers realistically collect and report this kind of data without overwhelming studies?

Dr. Marrie:

So, fortunately, for most of these things that we're talking about, these are things that people with MS can report. They can complete questionnaires, which could be done on paper, or they can be done on smartphones or tablets, and many of them can be answered with a single question. So, conceivably gathering substantial portions of this information could be done in 10 to 15 minutes at the outset of a study. We think that should be feasible for most kinds of studies.

Ashley Baker:

One point that really comes through is that this work isn't just on individual researchers. Could you expand on that—particularly what roles participants saw for funders and journals in helping move equity, diversity, and inclusion forward?

Dr. Marrie:

Thanks for bringing up that point. So, research is done in a broader ecosystem, and we recognize that researchers need resources, so there were lots of priorities related to funders. For example, the funders can set guidelines for what kind of information about diversity needs to be in research proposals. Because tailoring recruitment materials to different groups and reaching out to underrepresented groups takes more time and takes more funding, the willingness to provide funding to support that kind of behavior to support community engagement is important. Funders can play a really important role in saying that it's valuable to do research that looks at health inequities, to support training the next generation of researchers, and to know all of these things and how to do them.

So that then gives researchers some of those resources and tools to do the right thing from a journal's perspective. Of course, once you get your findings, you're publishing them, and journals have an opportunity to influence the type of work that comes in, how it's shared, and how it's perceived. And so journals, again, came up in our study; there's value in ensuring editorial boards are diverse so that they respect diverse perspectives. The editorial journals, boards, and editors can be transparent about the diversity of their existing boards. They can use double-blind peer review to deal with some of the unconscious bias that can affect how certain types of research are perceived. And journals can do a better job explaining some of the limitations in studies with respect to EDI considerations so that people develop a better awareness and, over time, start moving toward meeting some of the priorities that we have proposed.

It all takes some work, but I think if everybody contributes, we are likely to continue to improve on what we're currently doing now.

Ashley Baker:

Before we wrap up our program, Dr. Marrie, let's look ahead for a moment. What do you see as the most important next step to move from consensus to real-world change in MS research?

Dr. Marrie:

There are several. I think people who serve on editorial boards hopefully can take this work to their annual or semi-annual editorial board meetings, bring up the topic, and hopefully generate discussion and continue to move journals in these directions. We're fortunate to be funded in this work by MS Canada, so we've, of course, shared this with them in the hopes that they will be interested in integrating this into some of their planning and priorities as they fund future work. And we'll share it with other MS organizations as well.

And then, from a training perspective, all of us who are training the next generation of researchers also need to make this important and help ensure that our trainees have the time and are given access to the appropriate resources to learn about those things.

So, I think these are some fairly straightforward initial steps that can be taken.

Ashley Baker:

With those final thoughts in mind, I want to thank my guest, Dr. Ruth Ann Marrie for joining me to unpack new priorities for equity, diversity, and inclusion in multiple sclerosis research.

Dr. Marrie, it was great having you on the program.

Dr. Marrie:

Thanks for having me.

Ashley Baker:

For ReachMD, I'm Ashley Baker. To access this and other episodes in our series, visit *NeuroFrontiers* on ReachMD.com, where you can Be Part of the Knowledge. Thanks for listening.