Using What Works: Implementation Science to Optimize MS Care for All

Presented by:

Maria Fernandez, PhD

Kate Durack:
Hello, everyone, and welcome and thank you for joining MSAA's webinar: Using What Works - Implementation Science to Optimize MS Care for All. I'm excited to be joined by Dr. Maria Fernandez, an expert in implementation science. And today we're diving into what implementation science is and how it can transform care for everyone living with MS. My name is Kate Durack, and I'm the Director of Communication and Patient Focus and the MSIN program for MSAA and I'm also living with MS. Next slide please.

In case this is the first time you're joining one of our programs, I'd like to share information about MSAA and review housekeeping items. MSAA is a national nonprofit organization dedicated to improving lives today through vital services and support for the MS community. Our initiatives are designed to advance educational, wellness and supportive resources. Our free programs and services include a national helpline, safety and mobility equipment, distribution program for cooling equipment, educational programs, award winning publications, shared management tools, peer to peer online forum and more. For more information about our programs and services, please visit our website at mymsaa.org. Next slide please.

Okay, during tonight's program, you'll have the opportunity to submit your questions by using the Q&A chat box. As time permits, questions will be addressed during the Q&A portion of tonight's webinar. Also, please know that this program is being recorded and will be available as an on demand video on our MSAA video library within the next few weeks. At the end of the program, we ask that you please complete a brief survey. Your feedback is extremely important and it helps us develop future content and programs, and a link to the survey will be included in the chat box and will also pop up when the webinar ends. And we're going to send you an email reminder for that survey. All right. Next slide please.

As a friendly reminder, this program is for educational and informational purposes only and does not constitute medical recommendations. Please speak with your health care team for specific questions or concerns. Next slide please. And with that I'm pleased to introduce our guest speaker for this evening. Welcome, Dr. Fernandez. Could you please introduce yourself?

Dr. Maria Fernandez:

Yes. Thank you so much. Hello, everyone. It's a pleasure to be here. I'm Maria Fernandez. I'm the Vice President of Population Health and Implementation Science at the University of Texas Health Science Center, Houston, UT Health Houston. I also co-direct our UT Health Houston Institute for Implementation Science. I'm also a professor at the School of Public Health and lead a center for health promotion and prevention research. So it's a pleasure to be here. And thank you so much for the invitation.

Kate Durack:
Thank you so much, Dr. Fernandez. It's really nice to have you here. And to start things off, I just want to share how I understand implementation science. And for me, it's about closing the gap between research and real world care, making sure that proven treatments and strategies actually reach people like me living with MS. In my own experience with MS, I've seen just how different the approach to MS care can be depending on where you go and who you see. Those differences have a real impact, and not just on treatment, but on how supported and understood we all can feel. And so tonight, with Dr. Fernandez's help, we're going to explore how implementation science can make a difference. So stay tuned to get ready to learn about how we can work together to improve MS care. And with that, I would like to turn it back to Dr. Fernandez to walk us through what implementation science looks like in action.

Dr. Maria Fernandez:
Great. Thank you so much. So I always like to start with this slide when I'm talking about implementation science. And it's a quote from Kahlil Gibran that says “A little knowledge that acts is worth infinitely more than much knowledge that is idle.” And unfortunately, we have much knowledge that is idle. And we're going to talk today about how to move that knowledge into practice. How do we make sure that we have knowledge that is actionable and that acts and that improves lives, health, and quality of life?

So you've probably heard, about this sort of quote, “If you build it, they will come.” If any of you have seen Field of Dreams, that's sort of something that the main character keeps hearing over and over - “If you build it, they will come.” And unfortunately, even though a lot of times when there's new discoveries in science, when things that are amazing or potentially amazing are developed, unfortunately, just building it does not necessarily mean that they will come.

So if you build it, they won't necessarily come. And we know that this is a major problem. And the reason it's a problem is because to have an impact on population health depends not only on whether an intervention or an innovation is effective, but it also depends on what is the reach in the population. So if only a few people get something that's very effective, it's not going to impact population health, right? It's only going to be those few lucky people that get access to it. So when we're thinking about how do we truly improve health at a population level, we have to think about reach. And there are some good examples of that. But we know that there are many, many more examples of things that we know work but are not necessarily implemented and disseminated widely to benefit the most people.

So, for example, we know that there are programs targeting fatigue or physical activity that have been shown to be effective. And people living with MS may like these programs to manage symptoms. We know that they've worked. They've been studied. However, they don't always reach patients. Patients might not be aware of them. Providers might not be aware of them, or even if they are they’re not systematically recommending them. And these are some of... this is an example of where implementation science can help.

So first let's talk a little bit about some definitions. Evidence based interventions or evidence based practices are things, innovations, it could be a policy, a practice, a program or some other type of innovation, could even be a treatment, that has evidence that will show that it can positively impact outcomes. And sometimes those outcomes are psychological outcomes, physical outcomes, you know, usually health outcomes. So there's evidence that it works. And that's what makes it an evidence based intervention. Right? There's other terms that have been used that are evidence informed or knowledge based or practice based. But essentially, evidence based interventions is the thing that we're interested in implementing. Right? And so, it's the practice, innovation or policy that you want to adopt, implement or sustain.

Unfortunately, we know that a lot of products from research don't actually get to implementation. There are... there's original research that's done and then it's submitted for publication if the finding was positive. A big problem that we have in science is that when things don't work, a lot of times they don't get published. And that's a problem because if we don't know what doesn't work, that limits our advancement in trying to understand what does work.

So there's a lot of things that are never published. Even when things are published, and it usually doesn't take that long, maybe a year to a year and a half for a new finding to actually get published in a scientific magazine, and then it gets to databases, but from there to actually being used in practice, for actually it to be included in guidelines and recommendations and what doctors are actually doing, it takes much longer. And so this analysis that was done showed that it takes 17 years to turn only 14% of original research to the benefit of patient care. That is too long. And fortunately, this was actually a study that was done over 20 years ago and people started paying attention to this. So funders like the National Institutes of Health and the centers for Disease Control and Prevention and other groups started saying, well, wait a second, we're investing all of this money into discovery, but it's not necessarily reaching who it needs to reach to improve health of people in our country and beyond.

And so, implementation science can help actually change this scenario, change it so that we can more effectively and more rapidly use what we know works or what we think might work. So what is implementation science? It's the study of ways to promote the adoption and integration of evidence based practices, interventions and policies into routine practice. So it really essentially continues the job of clinical research, of public health research, taking these evidence based innovations and then doing things like testing strategies and doing other things to get them into practice. So if you look at this picture here, you know, there's what we know and what we practice and there's this gap, right? Sometimes we call it the “know-do gap” and implementation science focuses on how do we fill that gap.

So just to get some language that might help in understanding these concepts, and this comes from a paper that a good friend of mine published a few years back, Jeff Curran, and he said, okay, let's just call the intervention or the practice or the innovation, let's call that the thing. And effectiveness research looks at whether that thing works. And it's usually does that thing work to improve health? Does that thing work to improve behavior? Right? And then dissemination and implementation research looks at how best to help people in places do that thing. And when we say do that thing, we mean deliver that thing. Right? So there's this innovation and there's patients over here and then there's somebody who has to deliver that to the patients and make it available to the patients. And then implementation strategies are the stuff we do to help people in places do the thing. And then we're always measuring, well, to what extent have we done this?

So how does implementation science help then? Well, one thing is that it can help identify the factors that influence whether an innovation gets used or not. And when I'm talking about whether an innovation gets used, think of it not so much from the patient perspective but from like the provider perspective or the organizational setting. Right? Because they're the ones who usually are finding out about innovations and changes in practice that can improve patient care. Right? So, one way that implementation science can help is that it can help understand what are the things that are influencing the reason why these practices, these providers are using these innovations and the reasons why they're not. And understanding is really the first step in improving the situation. Right? Another area that is very common in implementation science is an adaptation to understand how things might need to be adapted to fit new populations and settings. And probably the most important part of implementation science, and I'll talk a little bit more about this in a few minutes, are strategies and the strategies that we use to improve adoption and implementation and sustainment of these innovations.

Another area of implementation science is De-implementation. And what that means is that sometimes there are things that we've done in healthcare, and for example, I'll give you one, they used to do dental X-rays almost at every single visit. And then it was found that that's an over use of dental X-rays and it's unnecessary. So let's stop doing it. Let's de-implement it. Now, some of you out there are probably thinking, well, every time I go to the dentist, they do an X-ray. Right? And so, that's an example of even though there's been recommendations to not do that, they're still doing it. And so de-implementation is another really important area in implementation science. And then finally dissemination and scale up. So sometimes we really know that something works. We even know how to implement it in practice. And now we just need to spread it so that everybody is getting it.

Okay. So I wanted to say something about implementation science and health equity. I really like this drawing that explains a little bit the difference between these words, like “equality” and “equity,” and the ones on the left, you know, the one on the left and the one in the middle, those are commonly seen, and I'll tell you about the one on the right in a minute. But what it's showing is that you can give everybody the same thing, but that doesn't mean that they're going to have the same access. And so equity is really when you are giving people what they need to have access. And Implementation Science is really important in this regard, because when new... when innovations become available, who do you think gets them? Usually it's people with resources. Usually it's the people that are most connected, not people that may be in rural settings or people that might have lower resources, or worse insurance. And so a focus on equity and making sure that everyone has the opportunity to access these new innovations, these things that that can work better and improve health and quality of life, that's a really important part of implementation science.

The picture on the right is just like imagining a time where there are no barriers. Right? And I think we're a ways away from that, but we can certainly strive for getting there. And in the meantime, like, really focusing on equity and equitable implementation is a very important focus on Implementation Science. And there are many examples of inequitable implementation. If you think about during Covid, telemedicine was an innovation, right? It had been around for a while, but being used as broadly as it was during Covid, that was an amazing innovation, right? Do you think that it was accessed equitably? Probably not. In fact, we know it wasn’t. There were people with not a lot of digital literacy, right? Their ability to kind of understand and get online. There was, or they had unreliable internet coverage or they didn't have a computer to use. Right? So that, even though that technology was there, it was inequitable.

And then there's also other things like, I don't know if any of you use healthy food delivery services in the past. I did, I tried this, as a way to, you know, try to eat a little bit more healthy. But they're expensive. Right? And so, only certain people, even if they can be beneficial, only certain people had access. And then testing for Covid-19, for example, at the beginning there were a lot of testing sites available and stuff, but then that sort of tapered off. And if you wanted to test yourself on Covid, and currently this is the situation, you had to buy it, you had to purchase it. And so obviously that situation also increases inequities. So, I wanted to mention this, I'm going to not talk so much more about this right now, but to just as a highlighting that when we think about implementation strategies, which I'll talk about in just a minute, we have to think about strategies that can increase equity.

This is just a diagram for those of you who are interested and maybe familiar with different kinds of research to show you where research and implementation lies. So if you look at this diagram, you can see that, over here on the left, where you're looking at efficacy studies or pre intervention studies, you're trying to answer the question of could a program work. And then in effectiveness studies you're answering the question does a program work. But in implementation studies that are really focused on getting organizations to adopt and implement and sustain innovation, that's really studying how do we make a program work.

So commonly asked questions about, like, evidence and when it's time to be in that yellow box to study implementation. It's like, well, do we have to have perfect evidence that something works before we can study implementation? And the answer is, as, you know, in many things, is it depends. Right? And what does it depend on? It depends on how pressing the health issue is. Right? If it's an epidemic or something, or a pandemic, sometimes we have to start promoting things that we might know are safe, but we're not 100% sure how efficacious it's going to be. Another question is, is it going to be implemented regardless? Even if there's not a tremendous amount of evidence, if there's a lot of excitement and possibility around something, it might be implemented or there might be a new policy that it's going to be implemented. Is it a priority for the community? Is this something that people want and are asking for? And are there resources to implement that evidence based program?

One of the things that when we have something that we think is very promising, but we can't yet call it an evidence based program because there's still studies that are trying to figure out if it works or not, we ask the question, is it possible to study both effectiveness and implementation simultaneously? And we call that a hybrid study because it's a hybrid between just effectiveness and just implementation. And the reason that this is really important is that if you just study effectiveness, but it's kind of like not in the real world, then even if it works, it's going to be a bigger leap to get it to where it's ready to be implemented. Whereas if you're studying whether it works or not, and you're also studying whether or not you're able to implement it with certain strategies, then you get a lot more information and it's much more ready to actually be used once you get the information about whether it works.

There are a lot of different frameworks in implementation science, and one of the most widely used is this one called RE-AIM. And RE-AIM stands for reach, effectiveness, adoption, implementation and maintenance. And the gist of RE-AIM is that we need to think beyond "does it work?" We have to think about how do I reach the population that is in need and to what extent will this innovation be able to reach that population. And we have to think about things like adoption. How do I develop support to deliver this new innovation? How do I ensure that it's going to be delivered properly and equitably, like we were just talking about. And then once it's implemented, how do you incorporate it? How do you integrate it? So that's delivered not just now when we have a new thing that we're all excited about, but over the longer term, and that's

what maintenance is about. So this framework helps guide a lot of research questions and work that we do to design strategies.

Another theory that I wanted to tell you a little bit about, because this is actually a theory that was developed in the 1950s, and it was one of the first times that people started talking about diffusion of innovations. And Everett Rogers, who I had the pleasure to meet many years ago, was the developer of this theory. And he really started looking at, and he was in the Midwest and he was visiting farms, he was studying communication and things like that, and he noticed that in some farms they were using certain technologies for harvesting or for animal, you know, for animal husbandry and other things. Right? And other farms weren't doing that. And so he wondered, well, why is that? Why is this farm over here doing these things that are improving their outcomes but this one isn't? And he started studying the diffusion of innovations and described this theory of how ideas, products and behaviors become norms.

And he looked at multiple levels. He looked at interpersonal level, individual, organizational. And what he found and how, this is part of the theory, is that success is determined by a number of different things. What is the innovation? What's the nature of the innovation? What are its characteristics? What communication channels exist? You know, how much time do you have to adopt something, and what's the social system that's involved? And so he, sort of, developed this model that had all of these different things influencing diffusion, and also talked about the characteristics of different individual adopters. Now, you can think about this at an organizational level like we usually do in implementation science. But you can also think about it as an individual level. So I want you to just take a moment and think about a technology. Right?

So, how about we think about smartphones. Right? So I have my smartphone here. So smartphones, like, think about a smartphone. And I know that some of you are very young and you probably have never known anything but a smartphone. But, some of us are a bit older and, you know, haven't always had any kind of mobile phone, and then maybe started off with a flip phone or something else. Right? So think about when the smartphone came out. Where would you put yourself on here? Are you an innovator? Were you one of the first people that you knew that got a smartphone? These people are usually venturesome. They have the shortest time between when they find out about something and when they get it. Then there's early adopters that typically are opinion leaders, and they might not be the first, but they're pretty early. Then there's like sort of the early majority. They're swayed by opinions of others, and by the time, you know, they hear about it and they hear about good outcomes of adopting that innovation, then they go ahead. Then there's those folks who are a little skeptical, and they need more to be convinced. Right? They're sort of tied to what they had. They loved their flip phone or their BlackBerry or whatever. And they, you know, they need a little bit more convincing. And then there's the laggards. Right? They need much more outreach, much more hand-holding to be able to switch.

So I hope that you were able to place yourself on here. And please share if you want to share with us where you think you are in terms of where you were in terms of the smartphone. But this concept also translates to organizations that are considering adopting or implementing new things. And it also... and when I say organizations, like health systems or insurers or or even providers, and so there's different characteristics of individuals and also there's characteristics of the innovation itself.

And so what Rogers talked about was, you know, there are differences, there are reasons why certain innovations spread more quickly than others. And, some of them, I won't go through all of these, you can just sort of look at these, but, they include things like the relative advantage.

How is this better than what I'm currently doing? How compatible it is with your own values, belief, needs, right? How complex is it? Right? Things that are complex are harder to adopt and implement sometimes, you know. And can you see the results? Right? So all of these things are characteristics of innovations that influence whether or not they're adopted and implemented. And so in Diffusion of Innovation, Rogers talked about how there needs to be change agents and opinion leaders and clear communication channels for this to to happen, for people to adopt and to implement new things. So Diffusion of Innovation was really a groundbreaking theory. And many of the other theories and frameworks that have been developed to help implementation have been based on this.

Another really important, another important foundational process of designing strategies to improve implementation is community and stakeholder engagement. So we know, you know, I'm a health promotion scientist, and we know in health promotion that you always engage communities to try to develop health promotion materials and processes and protocols and programs. Right? Well, it's the same with implementation. You need to engage communities. And in this case, communities are those adopters and implementers and maintainers. So they're those people that are responsible for making decisions about are we going to use this innovation or not. And they also are the ultimate beneficiaries. So they also include patients. And here's an example of an article, a recent article using participatory action research to develop a new self-management program. And so this is an example of how you use community engagement for the design of a program. And also informing its implementation is really important, too.

Okay. So now I'm going to switch and talk just a little bit about those strategies that we use to improve adoption, implementation and sustainment. Remember I said the design and the testing of strategies is a very important part of this field. And in Curran's language, it's the stuff that we do to help people in places do the thing, to help people and places implement the innovation. And there are discrete strategies. And then there's multifaceted strategies. Usually you have to do a number of different things, because when you're implementing something, there's different people involved, and sometimes at different levels.

So there was a lot of work that was done around trying to identify what do people do to implement things. Right? And one of the most well known created a compilation of implementation strategies called the ERIC Strategies, and it stands for Expert Recommendations for Implementing Change. And basically what they did was they looked around at the literature and they said, what have people done and then how can we kind of group them together? So if you look on the right, these are some things that they had found worked to improve implementation. So it's things like, you know, evaluating what... think about it from the perspective of like a clinic, a practice. So what are they doing and how can they improve, provide interactive assistance, adapt and tailor to their context, you know, support clinicians, engage consumers, use financial strategies to incentivize implementation. So these are some of the categories that they found were important. And so now that this list exists a lot of times people are sort of choosing from the list, you know, when they say, okay, we want to implement this new innovation, so let's choose one of these strategies.

Well, even though most people agree that basically you have to understand what influences implementation in a particular setting and then develop strategies, picking from a list of strategies is a little bit too simple. And I like this quote from Einstein that says, "Make everything as simple as possible, but not simpler." And what that means is that if you make something too simple, then you might, and you probably are, wrong. Right? And so we need ways of deliberately planning implementation strategies that take into account theories and models and

frameworks like what we just saw with diffusion of innovation and RE-AIM, we need processes that include partners like patients and providers. And we also need evidence of what's been used before in order to carefully plan implementation strategies. And we developed this process called implementation mapping that is being used, you know, all over to plan implementation strategies and implementation mapping helps us think through who's going to make the decision to use this new program or policy or practice change or innovation. Just think about it as an innovation. Who's going to decide whether or not they're going to use it, who's going to implement it, and who will make sure that it continues, and what will they need to do, and how can we support them in doing so? So, that's kind of the process that we typically use for planning, implementation strategies.

So I'm just going to give you a very quick example and then we're going to, in a few minutes, like, move to some questions and answers and any discussion that you'd like. So, there aren't a lot of examples, believe it or not, in terms of implementation or implementation studies related to MS. There are some, and so we just... this is sort of like a hypothetical example of how you might use a particular evidence based product and get it adopted and implemented.

Okay. So decision support tools for disease modifying therapy are some products that exist out there, some programs. Right? So we know that there are many disease modifying therapies or DMTs that have been approved. Providers may know some, but not all. And patients and providers must navigate the choice, or they should navigate the choice, together. And sometimes patients are left navigating the choice alone. And the issue then is that despite the availability of an intervention like DMTs that has a lot of evidence of working, the process for deciding or even discussing varies widely across providers and clinics. So that's a problem. And MSAA has developed this Ultimate MS Treatment Guide, and there's information if you're interested in accessing it, if you're not familiar with it. But today I'm just using it as here's a tool that, you know, can improve decision making between providers and patients that now maybe should be adopted and implemented more widely.

So, one of the things, as I mentioned, that implementation science can help us do is to understand, okay, why would it not, what are some of the barriers that may exist for why this innovation, this tool that is helpful, is not being used, and try to analyze that as a way to then address those barriers. Right? So, these are just some that could influence, you know, whether or not there are policies or laws that exist about the need or guidelines related to shared decision making. You know, these are things that can influence whether it's adopted and implemented. And also not even whether those guidelines exist, but to what extent are people aware of those guidelines. Whether there's funding. You know, there's a cost to everything, so there may need to be funding available. And if there's not funding that could be a barrier. There might be barriers just related to lack of motivation among staff or communication barriers, staffing shortages. There may be issues around patient workflow and the electronic health record, and how that needs to be integrated into adopting and implementing something like this tool. Right? Like the treatment guide.

But then there's also facilitators. There's, you know, materials and equipment, there could be funding, there could be connections and partnerships and access to knowledge and information that can make it much easier for an organization to adopt and implement a tool like the guide. And so we analyze these in implementation science, and then we start designing strategies to help address the barriers and capitalize on the facilitators. So, these pictures are from another project where we developed different strategies. But, just to give you an idea, you know, some of the strategies that have worked have been you identify early adopters, so you might identify

clinics that have been successful in implementing this tool and highlight them and have them give testimonials about how it went. You can identify and prepare champions.

So you you may have heard the term “clinical champions” before, but essentially a champion is someone who's in an organization, and I'm talking about clinics a lot, but it can really be any kind of organization that's adopting and implementing something new. Right? But, so champions are people that are there as a resource to answer questions or help and promote and motivate people, like, Yeah, we should use this, or, you know, talking about the tool like, This tool is great for me and my conversations with patients, like, maybe you should try it. That's what we mean by a champion. And then there's of course like other strategies related to data and giving feedback about how well something is being implemented. This is a number of different, common strategies, you know, assessing readiness for implementation, you know, conducting educational meetings, audit and feedback. Right? See how people are doing, give them feedback, capturing and sharing local knowledge. These are all strategies that have been used and have been effective for influencing adoption and implementation and maintenance.

So I wanted to give you that example of like how we design implementation strategies. And now I'm just going to turn to telling you a little bit about a relatively new practice based research network related to MS. And, but first, what is a practice based research network? So a practice based research network are networks of healthcare professionals or clinics that work together to try to advance science and to advance knowledge, but also implementation. And they've been used a lot in implementation science to try to make sure that the needs are being met. Right? Any changes in practice or things that need to be adopted and implemented, and then at the same time we can study that process so that it can help others. So the Multiple Sclerosis Implementation Network is a network of MS specialists, MS sites. And currently we have 14 sites. The mission is to improve care quality, value and outcomes for people living with MS through implementation and implementation science in this practice based network. And ultimately, we want to empower people living with MS to become informed leaders in their own care. And by creating this network, we can share information across providers and patients can learn more about what are the innovations coming out and how can we get access to them.

And so we've developed this community of practice. And right now, this is just to give you an example of kind of what's happening now, they're getting together and they're talking about the patient journey. Right? And you'll be happy to know that, you know, MSAA is like fantastic and making sure that the patient voice is always there. So it's not just this community of practice, but there's also patients involved in, like, every aspect of this learning. Right? And the purpose of this initial discussion is, where are there gaps in care? Where are there gaps that can be filled with evidence based interventions or promising interventions that need to be more broadly implemented?

So I'm going to wrap up by just, you know, highlighting the fact that, and this was a fairly recent article in the Journal of American Medical Association, and they say that not only is implementation science really important, but it's really important for clinicians to learn about implementation science and others because it's something that's so critical for bridging that research to practice gap. Right? What we know and what we do, knowledge to action, like in this picture here. And so it's a major opportunity for training providers and for engaging providers in this kind of work. So, in summary, implementation science can help bridge this gap between research and practice by building knowledge to understand what influences implementation, developing strategies to help improve, scale up and spread of things that we know work, ensuring community and stakeholder engagement and team science approaches to make sure that the strategies that we develop are sustainable. And finally, and the most

important thing is improving healthcare and public health practice to increase population health and quality of life.

So thank you so much for your attention. We have some time now for, I think, some questions and answers. Also, please stick around for the post webinar survey, that... we'd love to hear your feedback. And in particular, we're going to ask you a question, and the question is, what are the most important innovations in MS care that need to be more widely implemented? So if you're... just anything that comes to mind, like something that you think is new or that you've heard about, but that you think is not really widely used or widely implemented, we would love to hear your thoughts on that.

Kate Durack:
Absolutely. Thank you so much, Dr. Fernandez. We're going to give it a little bit to see if we get any extra questions popping up in the chat. And I will just give it one second. Looks like we've got a couple coming in. Thank you all for being here. This was so great. And we can go back to that last slide, too. We have some questions in the chat that are very MS health specific. So we recommend reaching out to your healthcare provider. And we can also reach out to you independently and connect you with someone on our team that can assist you a little bit better. Maria, you touched on this a little bit, but I do... here's one question. What strategies exist for incorporating patient voices in implementation design?

Dr. Maria Fernandez:
Yeah, I think that incorporating patient voice is critically important. And, you know, when I talked about participatory approaches, it was interesting to me because as health, you know, someone who is trained in health promotion, you know, we've always incorporated patient voices. And I think in implementation science, it sort of it came a little later, but nevertheless over the last, you know, I would say five years or so, there's been a really, really big focus on, you know, don't forget the patients. Like even though you might be focusing your strategies on providers or you might be focusing your strategies on organizations, I think it's really important for the patients to weigh in on, you know, how they'd like to receive information, what they think about, you know, different innovations that are coming through. I think that that's really critical. And so typically there are things like including patients in planning groups. So when you're planning strategies, making sure that there's patients involved, having patient advisory groups, making sure that if there's ever any sort of pilot testing that's done on certain strategies, especially if they're related to communication with patients, that patients are involved in all of that and giving feedback.

Kate Durack:
I think that's great, Maria. And I know that we are utilizing those strategies with MSIN. I am very fortunate to be on the MSIN team as well. And as someone living with MS, I'm glad that I get to chime in about what we're doing and what we're working on. So I think that's great. I have, I think, two more for you. How does implementation science applies specifically to MS research and care?

Dr. Maria Fernandez:
That’s a great question. And I think that it applies in the sense that any new innovation, any innovation that has been shown to work but is not widely used is, sort of, the space where implementation science could improve the situation. So one of the things that we noticed, for example, is that there's a lot of need for supportive care interventions related to physical activity and other things. And there are actually ones out there that work, but they're not necessarily being offered, utilized, you know, disseminated. And so this is an area for improvement.

Sometimes it's related to treatments. Right? Or classes of treatments. You know, I gave the example of disease modifying therapies. We know that there's a lot that goes into that decision. But even having that conversation and even making that an option, that's something that's not necessarily used or done broadly across settings. So when we know that there's best practices that improve outcomes and it's not happening, that's where implementation science can come in and help bridge that gap.

Kate Durack:
That's great. So if... what would you recommend for someone who is just interested in getting in the weeds, hearing about things that are going on in the field and then maybe bringing that back to their care team and advocating for themselves to get something implemented for their own care? Like, how would they start? Where would you look?

Dr. Maria Fernandez:
Well, I would I would actually refer them to you for that, and the MSAA. And, you know, resources that are, you know, specifically kind of for patients and for patients to be able to be advocates for their own health. Right? I think that continues to be important. Now, if you're specifically interested, you know, in some of the things that we've been talking about, I know that there's opportunities to continue to engage patients in the work that we're doing with the implementation network. So I would say also to reach out to you all to coordinate that.

Kate Durack:
Great. Thank you. And I think there was one more. How do disparities affect implementation in MS populations?

Dr. Maria Fernandez:
Yeah. So, you know, this was actually one of the things... So I'm not an MS researcher. Right? I'm an implementation science and a health promotion researcher. And I learned, I started learning much more about MS, and particularly, like, MS care, like, I knew about MS because I have a couple friends living with MS, but I didn't really know much about the care. And one of the things that really drew me to the Multiple Sclerosis Implementation Network project was that, you know, I was informed. Right? I was educated by MSAA about the disparities that exist. So, I just remember Amanda Montague mentioning to me that, you know, you go into a clinic that's high resourced and people have had options for a lot of different medications and maybe other innovations and people, you know, you can just see it right in the waiting room. Right? People look different. They look healthier. Then going into, let's say, a rural setting that serves people with less resources and maybe less specialist care, and, you know, the people in the waiting room are like in wheelchairs or they're just, you know, sicker. And, that vision of, like, how much of a disparity there is, like, how not just unequal but inequitable it was is one of the things that really, like, I thought, my gosh, you know, if there are things that work and it's always the patient's individual decision and a decision that should be made with the provider, right, but being able to make those decisions, being able to have access to those new things that are coming out, that may be the right thing for me, that’s the thing that, where I think implementation science is very important in MS and improving the lives of people living with MS.

Kate Durack:
Great. Thank you. I think we can close. I would just like to know, Dr. Fernandez, if you had two key takeaways from tonight for people that you really hoped they would get out of this, what would that be?

Dr. Maria Fernandez:
I think that people are always drawn to discovery, right? I think that people always want to know what's the new thing, what's the, you know, what's coming down the pike? And that's normal and exciting. And I think that people forget that there's a lot that we know already. And, just because you know something doesn't mean that it's going to be used. And so maybe a key takeaway is that, yes, new things, absolutely new things. And let's look about using what works like improving like the use and maintenance of things that we already know work while we wait for the next thing to come down the pike. So that's, I think, the takeaway.

Kate Durack:
So more universally adopting the things that are currently working well.

Dr. Maria Fernandez:
Yeah.

Kate Durack:
Anything else to leave us with?

Dr. Maria Fernandez:
No. Just thank you so much, everybody. Thank you for your thoughtful questions and it was a pleasure to be here tonight.

Kate Durack:
Thank you so much. And with that, I'm going to do my closing. And that's a huge thank you to Dr. Fernandez and to all of you for being part of this important conversation. I am so excited to see how implementation science continues to shape the future of MS care and how we can work together to make sure real world treatment truly reflects what matters to people living with MS.

This concludes our webinar, and on behalf of MSAA we want to thank you for your time and participation. Remember that this program was recorded and will be archived on MSAA's website in the upcoming weeks. Please do take a few minutes to complete the brief survey. We would greatly appreciate it. We would love your feedback. Thank you everyone and have a wonderful evening. Goodbye.