

MS Treatment and Care Strategies for Nurses & Allied Health Professionals, Digital Literacy and Telemedicine in MS Nursing, 30 May 2022, Digital

Transcription of digital webinar

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Welcome (0:00)

MOD: Hello everyone. Welcome to the World MS, officially marked today as the World MS day, connecting the global MS nurse and allied health professionals community together. We are here to share stories, raise awareness and campaign for everyone affected by multiple sclerosis. This event is the last in the three-part series on MS treatment and care strategies for nursing and allied health professionals and it is on digital literacy and telemedicine in MS nursing. Allow me to introduce myself, I'm Paru Naik. I'm the Director of health professional programmes for the MS trust in the UK. We are here, dedicated to help people living with MS now. We provide trusted, positive, free information informed by the experts to anyone affected by MS and we distribute over 50,000 free books, 50% of which is worldwide. We answer people's questions about their MS by phone, email, social media. We're the only organisation in the UK who fund nurses, additional nurses, in the areas of greatest need. We train all MS nurses and therapists with an interest in MS and we give them MS specialists resources they need to help people with MS and we also pay for our unique role that we have been piloting, which is an advanced MS champion role, to look at those out in community that don't have access to acute care but have a greater need.

Our website is the MS Trust website, and you can visit there, and you can see everything from A–Z, so please do visit that.

We also have an MS Trust Decision Tool, which you can find about all about those complex drugs, which I know is particularly difficult, and we recognise that and we have a tool that you may find useful.

So please do go to our MS Trust Information Service, where we have the A–Z, we have many tools online and if you'd like to talk to us about any of the things that we do, then we are available on ask@mstrust.org.uk and we have a number below.

So welcome to ECTRIMS: European Committee for Treatment and Research in Multiple Sclerosis, non-profit independent representative European-wide organisation. This serves Europe and is the world's largest professional organisation and you can register for ECTRIMS on the website as shown.

So ECTRIMS hosts a range of scientific and educational events, including an annual Congress with a dedicated MS nurse session, and a professional fellowship programme for nurses and allied health professionals. The goal is to expand expertise in MS through practical experience and training in a mentored MS environment in Europe. The application season for 2023 programme opens in July and citizens of any country are open to apply.

So, MS Treatment and Care Strategies for Nurses and Allied Health Professionals webinars. This is the third in that series now and, as you can see, there are two more that you can watch on ECTRIMS on the online library and this one should also be available within a day or two as well.

So, nurses and allied health professionals play vital roles in the treatment and care of people living with multiple sclerosis. We believe no person with MS should be alone and we know and hear frequently that specialist nurses are a lifeline for people living with MS. This webinar is designed for nurse practitioners and registered nurses to learn more about digital strategies in their work with MS patients. Joining us today are two speakers. First of all, Professor Francesco Pastore, who is nursing at the University of

Bari in Italy. He teaches evidenced-based nursing and has been specialising in MS nursing for over 15 years. He is President of the Italian Multiple Sclerosis Nursing Society, is a member of the International Organization of Multiple Sclerosis Nurses and a former ECTRIMS nursing fellowship recipient. Mr Pastore has a specific skill set in the management of disease-modifying treatments for multiple sclerosis, having participated as a study nurse in nearly all of the experimental studies of the main MS drugs. During his ECTRIMS fellowship, he developed a telemedicine project called SMcare 2.0, which we will be hearing about shortly.

Our second speaker, Denise Bruen, a Virginia, US native, is an adult nurse practitioner, Board-certified, as well as a certified multiple sclerosis nurse. She specialises in caring for those living with MS. She has been a nurse practitioner at the University of Virginia since 2004 and has worked in multiple sclerosis since 2010. In addition, she is the Medical Director for the MS clinic. In 2020, Miss Bruen started her term as President of the premier International Organization of MS Nurses (IOMSN), a group she has been involved with since 2012. Miss Bruen has spoken multiple times for IOMSN regional meetings as well as at CMSC annual meetings. So, let's kick off first with Francesco and learn more about digital literacy. Thank you.

[Francesco Pastore: Digital Literacy in MS Nursing \(5:58\)](#)

FP: Thank you, Paru, for your lovely introduction. Good morning everyone. First of all, I would like to thank ECTRIMS for hosting these three very interesting webinars. Today is MS International Day and we are proud to be here with you to speak about multiple sclerosis, because we must not forget that the overall goal is to give the best care for our patients and people with multiple sclerosis and this is a really good opportunity to share opinions with all healthcare professionals that work in multiple sclerosis. I am Francesco Pastore, I am an MS nurse I work at Clinical Centre at the University of Bari. So here we go with my presentation.

The topic of my presentation will be to explain what digital health literacy is and why it's very, very important in multiple sclerosis, why digital literacy is very important and how all healthcare professionals can improve digital literacy in people with multiple sclerosis. You know that telemedicine is a very good way to deliver MS care and, after my presentation, Denise will explain much better than me the importance of telemedicine before and after COVID and the

pandemic. We know that the digital ecosystem includes many aspects of eHealth, such as eHealth governance, electronic health records, telemedicine, mobile health, big data, social networks and digital health literacy. So we have a lot of items here in digital ecosystem.

[Digital Literacy in MS Nursing \(7:52\)](#)

But the question is, “What is digital health literacy and why is it important for health?” Well, the digital health literacy includes the ability to search, access, understand, appraise, and validate online health information by patients as well as the ability to formulate and express questions thanks to digital devices for our patients with multiple sclerosis because, don't forget, that today the internet is the first opinion and sometimes the second opinion for our patients, so it is very important to improve digital literacy in our patients.

The global strategy of 2020–2025 of the World Health Organization is to improve eHealth for everyone and build a digital solution to prevent, detect and respond to the health needs of patients. One of the strategic targets of the World Health Organization is to improve digital health literacy in all patients, especially in patients with chronic conditions such as multiple sclerosis. The aim is to develop a digital health training or Massive Open Online Courses to improve eHealth literacy, so the global strategy is focused on improving eHealth literacy for everyone.

In 2020, here in Europe, the World Health Organization Europe carried out a large-cross-sectional multi-centre study called Digital Health Literacy in Europe. The aims of this study was to measure literacy in Europe, in all population of Europe, and after, found there is a significant number of people who have low digital health literacy and that there is a social gradient for digital health literacy in most countries and that digital health literacy is associated with health-relevant indicators. Digital health literacy and equity is very closely related; people that have a lower social gradient tend to have a higher disease burden and health needs, so it is important for us to understand digital health literacy.

[Understanding Multiple Sclerosis in the Age of the Internet \[00:10:27\]](#)

But if we focus on multiple sclerosis, the question is: Can people now with multiple sclerosis understand what they read in the internet age? Well, it's hard to answer this question, because the internet is the first source of information for our patients, but online searches are frequently not mentioned by patients during clinical visits. For example, in the study of Marcello Moccia,

the study showed that the most visited website by people with multiple sclerosis have low readability levels and they need to be discussed carefully with all healthcare professionals. This aspect was confirmed in this other study, which tells us what is the preferred source of health information in people with multiple sclerosis. The results of this study are that healthcare professionals remain the most trusted source of health information in people with multiple sclerosis and this is an important implication for us, so we have to pay attention to this important study.

Healthcare professionals are very important to improve digital health literacy in people with multiple sclerosis. I want to show you this very interesting study, Estimating Patient Empowerment and Nurse's Use of Digital Strategies: eSurvey Study. Healthcare professionals and nurses fulfil a really important role in education and digital health literacy of people with multiple sclerosis. In this study, the authors measured how the use of digital devices can improve patients' empowerment and digital health literacy and the study showed that digital tools are not used to provide health information to the patients sometimes and this caused a lowering digital health literacy in patients. So, we must pay attention to these important topics during our visit.

A question that I often ask nurses, and the question I want to ask you is, "In a typical week, how many days do you use the digital resources for giving health information to your patients?"

[Searching for information online to solve a health problem \(14:20\)](#)

So, if you want to respond? The study result said that, for a good digital health literacy for patients, we must use a digital device to give information to our patients at least once a day. So, we have to use digital devices to give information and communication to our patients at least once a day, if you want to improve digital health literacy and digital culture in our patients. The second question that I want to ask is, "Is it easy or is it difficult for you to search the online information to solve a health problem?" This is another important question that I want to submit to you. It is very important for us to know. Thank you for your responses. Yes, it is very easy to search online, and this is a good point, that we can improve the digital literacy in our patients, a good point to start.

But if we focus on multiple sclerosis, I want to show you this study that the authors evaluated the level of digital health literacy in people with multiple sclerosis. It was a very interesting

observational study published in the British Medical Journal that measured the digital health literacy using the eHealth digital literacy scales. The study showed that patients have a good level of digital health literacy and most of them use a smartphone to speak with a healthcare professional. The result of this study highlighted how healthcare professionals could improve digital health literacy in people with multiple sclerosis using not only digital devices, but traditional methods. So, if we use traditional methods and digital devices, we can improve, with this mixed method, the digital literacy in our patients.

[Instruments to measure the digital health literacy in pwMS \(16:23\)](#)

In literature, we have several instruments that we can use to measure the digital health literacy in our patients. The most important that I want to show you is the digital literacy instrument invented by Van der Vaart et al. in 2017, the Digital Health Technology Literacy Assessment Questionnaire and Digital Health Literacy 19 and most important is the eHealth literacy scale by Normann et al in 2006. This is very interesting instrument that we can use in clinical practice for measuring digital health literacy of our patients.

But what can we do to improve digital health literacy in our patients? Well, there are best practices that we can use such as use of new technology in clinical practice. We have to use smart phones, digital devices to give information to our patients. The development of the skill of all the nurses and all healthcare professionals and attitudes to use telemedicine and communication technology and the improvement of health communication between the nurses and patients, this is another important item that we can use. So, improving digital health literacy in using and understanding digital health technology and systems, as well as the health data and validate tools for the whole population.

This is a very interesting instrument that Paru suggested to me and it is a very interesting webinar that was built by Patient Information Forum. The healthcare professional— to improve digital health literacy— can use this very interesting webinar to improve their skills. The skills which are acquired after the course are: a better understanding of eHealth and digital health literacy, so it is very interesting; the ability to carry out eHealth literacy habits of their organisation; and the ability to understand who is at risk of digital inequality, because we have to pay attention to digital inequality in our patients; and ability to learn about the legal requirements to use digital devices; these are all the aspects of digital literacy in our patients.

To give you a take-home message, I can say that digital health literacy is considered a part of multisectoral actions in multiple sclerosis and digital health literacy is an essential element for the successful transformation of healthcare systems in multiple sclerosis and digital health literacy in multiple sclerosis can have a positive effect on efficacy and sustainability of our health systems all over the world. Thank you very much for your attention. Denise will now speak about telemedicine in 2022. Thank you, Denise.

Denise Bruen: Telemedicine in MS Nursing [00:20:28]

DB: Thank you, Francesco. So as Paru said before, my name is Denise Bruen. I am an adult nurse practitioner and I have done the majority of my career focusing on patients living with multiple sclerosis and other neuroimmunology disorders. Today I will be talking about what telemedicine looks like in 2022. So, to start I first have a polling question, so this first question is, "Prior to the pandemic, was your clinic or institution doing any teleHealth?" So, about a third of yours were doing teleHealth prior to the pandemic but the majority were not; 66% were not doing teleHealth and we will come back to this question.

Pre-pandemic telemedicine (21:30)

So, at my institution pre-pandemic, we had this great idea of doing telemedicine for treating our patients living with MS. I live right in the middle of the state. It can be very rural; a lot of our patients don't have the means, especially with the price of gas right now, driving to the clinic, depending on their disability, getting into the car, transferring. It can be a lot for our patients to go several hours to an appointment. So the idea was that we would be offering telemedicine eventually and the thought was that we would have satellite clinics in Virginia where a patient could go there instead of coming all the way to our clinic in the middle of the state and that at that satellite clinic they could then log on with the camera and meet with their neurology provider and that we in the meantime would train a medical assistant at the satellite clinic to do the neurological exam. So, the benefits of this were, primarily, less driving for our patient and that they would be able to access neurology services even if they lived in an area that was just a desert for access. The con of it was that the patients still had to drive somewhere and some patients, if they are going to have to drive, they may as well come all the way to our centre to be seen, but for some patients this was still a nice option if it was only

a 15 or 20 minute drive to a satellite clinic versus several hours. The other con was that we were still depending on a medical assistant to do the exam. Sometimes it can be very subjective doing motor or sensation that kind of thing and there is a lot of coordination that was still needed, because we would still need to coordinate the patient going to the satellite clinic, having somebody there, having us be able to be on the camera. So there were still not great ways of doing this, but it was still a dream of ours.

So then March 2020 comes along and then everything pretty much shutdown. All of our in-person appointments abruptly stopped. We didn't know how long the pandemic would last. We were very concerned about our patients living with MS, especially because of the treatments we had them on, a lot of them are immunosuppressant therapies and we are trying to avoid them being exposed. We really didn't know much about what this was going to look like. However, patients still need care. Relapses still were happening, we still needed to assess our patients, we still needed to do symptom management and figure out how they could still get their treatment. So in the beginning when we were all quarantining at home, we did a lot of phone calls or we would use cell phones, features like FaceTime, but this was frowned upon because they weren't always secure networks and billing was very questionable, would we be able to be reimbursed for this, for our time, and still see patients. Not all of our patients have internet access. This has been a moving target point during the pandemic of trying to make sure that this is just like having electricity and water that people have internet access, but it still allowed patients to have some sense of care and still having a touchpoint for being able to access their healthcare provider.

[Summer 2020: Virtual Appointments Becoming the Norm \(25:29\)](#)

So by the summer of 2020, virtual appointments became the norm. We had identified several secure platforms, such as Doxy.me or Zoom networks; however, it was still problematic for patients that had poor to no internet access. We had some patients that internet and technology is just very intimidating to them; they couldn't figure it out. At my facility, we see patients who are incarcerated or living in skilled nursing facilities so again, a lot of coordination with how to get care to them. A lot of the prisons were not set up with telehealth. People living in skilled nursing facilities, what does that look like in terms of patient being able to go to the nurses station to access the computer or perhaps bringing an iPad to the patient so we could see them. The other downside of all of this that we figured out was that our institution's malpractice insurance only allowed us to offer teleHealth visits if the patient was physically in

the state of Virginia. So I have patients that come from many states away and it seemed like the perfect option right, if they're coming 8 or 9 hours, oh we can just do teleHealth especially if it was just a check in, but, unfortunately, they have to be in the state. So oftentimes they would still drive just over the border. I'm sure there's probably some patients that told me they were in the state and maybe were not, but there was still that, even though it seemed like a great option. Of course, doing the physical exam, I still have never found out a way to make this easy, I tried to have patients show me what they can do physically or show me their eye movements, smile for me, something you can get out of just being on the camera. However, I had some patients where it was just a very poor connection or they went to show me something and I was looking at the ceiling the whole time and it was kind of almost a waste of time to try to do a physical exam, at least in its entirety.

[Present: what we have learned \(27:20\)](#)

So at present, luckily things have started to calm down. We have opened up to seeing patients in person, but what we've learned is that patients really love virtual appointments, especially when they are feeling okay and it's just a check in to do a med check or see where they are at with needing to get MRIs or blood work done. So with this, they don't have to travel, they are not getting exposed as different variants come along, they don't have to take time away from their work and family and also again now with the price of gas, this is a huge saving for patients if they don't have to drive 2 hours for a 20-minute appointment for us to say, "It looks like you're doing great." We still can do much in a virtual appointment. We can do medication checks, we can discuss disease-modifying therapies, symptom management. If the patient is able to show me something that is going on with them that is concerning for a relapse, those sorts of things we can still do on a virtual appointment.

I've liked it because it gives me a glimpse into what the patient's home situation is like. You can assess a lot of what's going on around the patient, what kind of devices they maybe have at home that they don't usually bring to clinic, they can show you. I often have patients that, as I ask them if they need refills of anything, they can just run to the medicine cabinet and pull stuff out, so it gives you that inner glimpse to what their situation is like at home, which can be really nice. Again, for patients that have trouble with transportation, either they can't drive or because of their MS and disability, it's quite a bit to get them into the car and transfer and just energy and that kind of thing and again the price of gas, it can really lighten the load to just pivot and do a teleHealth visit instead of an in-person. It can also do an easy transition if the

in-person appointment needs to be changed due to weather, if you have snow or bad rain and patients don't want to drive. We've had an issue of lack of staffing. I think it's kind of an international thing with nurses and medical assistants. Who knows where they went and we don't always have the staff to room patients, so it can lighten the clinic load, as well we're still giving care. Unfortunately, some areas or insurance might stop paying the virtual appointments and this has again been a moving target here in the US where insurance companies might eventually not pay for them anymore. Again, we still have some areas that have poor internet access and, as I mentioned before, we just don't have good tools right now that I'm aware of, to do a remote visit examination in terms of checking strength and reflexes and that sort of thing.

Polling Question: Does Your Clinical Institution Offer TeleHealth? [00:30:16]

So, I have another polling question, "Will your clinical institution continue to offer teleHealth or has it thought about offering this platform to patients since the pandemic?" So how have things changed for your institution? The other nice thing I didn't mention about doing teleHealth, is when I do see patients in person, we are still wearing masks, so doing teleHealth I can actually see the person's full face and they can see mine, which is nice. Okay, so 100% of people said that they will still be offering telehealth, so that's really interesting. So, pre-pandemic, only a third; post-pandemic are doing it, or thinking about it, 100% so maybe this is a good thing that came out of the pandemic, is making this kind of pipe dream a reality and offering this care to our patients and just, again, being creative with how we can still offer care to them. So, I think now we have questions and answer session.

Question and Answer Session

Discussion: Thoughts about privacy and digital (32:15)

- FP: It was a very interesting presentation, Denise. I have a question if there aren't questions for you, the privacy about teleHealth, what do you think about privacy and digital, it's very important here in Europe to collect data and teleHealth with privacy?
- DB: Do you mean privacy that no one can hack into the line with the patient or privacy just where I'm sitting and where the patient is sitting?
- FP: The privacy of data protection, when you make a teleHealth visit monitoring your patients, the privacy is very, very important for us in Europe, and in the United States, is it the same?

DB: It is the same and that's why, in the beginning, when we were trying to figure out how to do this, they discouraged is doing FaceTime or even just calling on the phone. That's also a different way of insurance billing, a telephone call versus a video call too. And then we've had a couple of reiterations of how we do our teleHealth visits. So we were doing this Doxy.me where I would log on to Doxy.me and have a virtual waiting room and the patient can log on. So that was a secure site. The downside was that if a patient had a family member, if somebody else wanted to join in at a different location, they couldn't. So we have a medical record system at my institution called Epic. I'm not sure if it's worldwide or not, but they recently integrated at my institution a Zoom link so the patient has to log onto their MyChart, which is secured, and then from there they get the Zoom link and then they can share that to have other family members to join in too. So that's a secure way that we've been doing it now.

[Discussion: Difference between eHealth literacy and digital health literacy \(34:25\)](#)

MOD: Hi Denise, hi, Francesco. Sorry there's always technical issues isn't there, but I think I'm back. So thank you, that was fascinating as ever because teleHealth and digital is the way forward isn't it and I wonder Francesco, we had a dialogue about what the difference is between eHealth literacy and digital health literacy, can you expand on that first bit?

FP: Yes, this is a very intelligent question because we spoke about this, the difference between digital health literacy and eHealth digital literacy. eHealth literacy is the ability to search, access, understand and validate and apply the information that patients have found online but today with digital culture, the new technology, such as digital assistance, remote monitoring, artificial intelligence, the big data, the blockchain, as well as wearable devices, we must speak not about eHealth literacy but the digital health literacy. So the difference is this, another important topic is that the patient's digital health literacy is not just collecting information online but to use digital devices by the patients and to answer and communicate with healthcare professionals with digital devices. So, the difference is from digital eHealth is this.

[Discussion: Confidence-building among health professional \(35:53\)](#)

MOD: Thank you. I think this made it much more clearer for us. One of the things that seems to come out is that the confidence to use this because Denise you've talked about this, and I think we will become acquainted with Zoom, but is confidence-building amongst health professionals on the other side?

DB: I think so. I think for some patients it has as well. I think just like we had some difficulties here with cameras, patients have understood that sometimes things don't work. Sometimes we need to again pivot how we meet up at the assigned time. I know in the beginning, I had been doing in-person appointments scattered in with virtual appointments and appointment times run over and when we are in the clinic, we can go in or our nurse can go in and say, "Hey 5 more minutes I'll be in there." But when someone is waiting in a virtual platform, you can't really do that. I'm late because things happen so sometimes I have patients that will log off or will think they're in the wrong domain, so I've changed how my clinic is, where I try to have a set block just for virtual appointments and then set blocks for in-person to avoid that kind of back and forth, because it just gets a little too crazy on my end. Sometimes, though, a patient at last minute will say, "I have an impersonal appointment with you Monday but could we, for whatever reason, do virtual?" and if I know I'm running late just because of the patients ahead of them, I will try to send them an email or a message to their MyChart saying, "Hey, log on at our time, but chances are I might be a little bit late." I think as we've been doing this now for 2 years; patients know that even a 10 o'clock appointment virtual, it is not going to be right at 10 am, hopefully but not always. So that's been a challenge versus in-person appointments and then of course vital signs and that kind of thing, we just can't get those on our patients and sometimes that's important to also assessing their care but I think again, one of the things that's being expedited because of the pandemic, is how do we get tools like that, so that patients can be evaluated at home for some of those simple things such as just their vital signs.

[Discussion: Using algorithms \(38:00\)](#)

MOD: So, building on that, particularly with people with MS that could be anywhere on their pathway with MS, have you done any sort of algorithms of who you would see virtually or who you would ask to come into the clinic?

DB: For sure, obviously patients that haven't been seen at all in 2 years, I think we probably all have those that have just been hiding out waiting. Obviously if somebody has symptoms of a concerning relapse that I just want to be able to assess or feel comfortable assessing, ruling out other differential diagnoses that I wouldn't be able to do virtually, knowing the patient and how accurate they are to be able to tell you what's going on with them and being able to distinguish, is this a relapse or something else, a herniated disc or migraine, that kind of thing, so it is very valuable to see them in person. Sometimes again, I think those patients that it's a

real, I don't want to say hassle, but a lot of trouble with getting them into a vehicle and getting them here and then transferring, those are probably our patients that are more disabled that it can just be very difficult to transport them. So sometimes for those patients also, like if they're prone to bed sores and they're going to be on a gurney. Trying to avoid all those things, there could just be a ripple effect, for a check in virtually. I have also heard from patients that they do really miss just being touched, so there are some patients that, although we offer them a virtual appointment, it's just not the same thing as being in person, touching them, feeling the human connection. A lot of patients have really missed that, regardless of how severe or benign their MS is.

[Discussion: Feeling of loneliness with moving to digital \(40:06\)](#)

MOD: Yes, it feels like it's going to be rather bespoke, isn't it going forward, even if we are very digital-literate. Is there any feeling amongst people living with MS, is there any more feeling of loneliness or despair with moving to digital or is that coming out in any way?

DB: You know in some ways, actually the opposite. I can think of a patient who is very disabled from her MS and during the pandemic was the first time she was able to attend her support group because they were doing it virtually and that was huge for her to be able to see these faces of people she hadn't seen in years because she couldn't really get out of the house. So in some ways it's really opened that up, with us coming to the patient right where they are instead of them always coming to us, so in some ways it's been a positive thing in that way.

MOD: Wow, that's actually quite powerful. So your poll showed prior to the pandemic, a third were doing teleHealth and now it seems that those who have taken it or adopted, it are going to be using it, now obviously a small sample, probably, but very indicative of how we're moving now, isn't it?

DB: Yes, I think so. And I think you are getting back to Francesco's presentation, as patients are more used to what the internet holds, being able to understand more about digital literacy, what options are out there, even not even signing forms anymore. We're doing all that virtually now, so patients have had to educate themselves and if it is intimidating, kind of overcome that, going to appropriate sources so that they're not just finding whatever information they

want on the internet, which can be a downside, but realising what a powerful tool it can be to educate themselves.

[Discussion: What tools are we missing in digital health literacy? \(42:05\)](#)

MOD: Francesco, is there anything you would like to see developed more in this world, are there things that you think we are missing that we could be doing?

FP: I want to talk about the tools that nurses and all healthcare professionals can use to improve digital health literacy, because I want to stress this important topic of today. I call these instruments, the soft skills of eHealth and eHealth soft skills of the nurses and of all healthcare professionals because the first skill that we have is the communication with our patients, we have to understand the user that we have in front of us when we speak with a patient, because we have to understand his problem and not dwell on appearance. We have to choose the best communication with our patients and to make sure that our patients understand what we can do thanks to eHealth and telemedicine. It is the topics that I would stress.

MOD: Great. I do ask the audience, if there's any questions you particularly want to ask, then there is the chat function and we do go into the Q&A functionality. If you'd like to ask any questions, that will help us take this conversation forward even more, particularly if you want to know more in terms of clinically how we manage these patients, Denise, and more about the kind of information that we can produce and help with literacy. Do you think that people living with MS, I think in your slide, you said that it's the number one information source now for people living with MS, how can we build on that, because in a way it's positive and in a way it is a little bit scary as well, isn't it?

FP: Yes, I think that is very important because you know, digital health literacy for our patients is important but it's important for healthcare professionals too. When I make my presentation, I searched online for a lot of instruments we can use for digital health literacy. Particularly I found four instruments that we can use in clinical practice. I want to talk about the Digital Literacy Assessment Questionnaire that we can use in clinical practice every day with our patients. In particular the Digital Health Technology Literacy Assessment Questionnaire is a questionnaire validated by Yoon in 2022 in an important study and includes 34 items with two domains: digital functional and digital critical literacy and four categories. So it is important for healthcare professionals to improve digital literacy, but these four categories that is,

information, communication, technology icons, for example the use of applications, the evaluation, availability and the relevance of information.

MOD: Yes, that's very interesting. So, are you planning to do anymore research around this, Francesco? Are there any more studies that you're involved in?

FP: Yes, we carried out a very important large study here in Italy. We want to expand in Europe, maybe into the United States. It's very hard but we want to measure digital health literacy in all patients with multiple sclerosis, because we want to build an instrument for people with multiple sclerosis that we want to call Digital Health Literacy in People with Multiple Sclerosis. So we play hard in this direction with my professor and it is very, very important topic in the future because telemedicine is very important for the future and for all healthcare professionals and people with multiple sclerosis too.

[Discussion: Collaborating with like-minded health professional \(47:10\)](#)

MOD: That would be very interesting, I think especially if there was a collaboration of these like-minded health professionals who was struggling with the same things but actually wanting the same things. So, are you someone that they could contact and think about doing something a bit wider?

FP: Yes, physiotherapist, for example, psychologists, occupational therapists, a lot of healthcare professionals because this webinar is for all healthcare professionals. And ECTRIMS, I think ECTRIMS facilitate all healthcare professionals because the patient with multiple sclerosis is a complex patient and not only nurses are important for people with multiple sclerosis but when disability is high and the patients can't go into a hospital, it is very important to share this knowledge with all healthcare professionals so physiotherapists, occupational therapist, psychologists, this is the way for us.

MOD: I agree, I think that's a really good point that you've made because one of the things that Denise talked about is that it's a very rural area and we find in the United Kingdom that we have the same problems. Out in rural sticks, it's hard to get to an acute centre, there's travel as you said you've hit the nail on the head, gas is going up exponentially but also sign-posting to different services because it's not just about MS, is it, there's so many other things going on with patients according to their disability. So we found

that actually navigating the system is quite hard, so how do you think navigating the system through a virtual way, how would we do that?

FP: I think the virtual is very important, but we don't forget that that the personal visit is best practice. So we can use telemedicine and telehealth, but we don't forget that people and in person is very important because we want to touch our patients with our hands we want to see, we want to see them with our eyes, because it is very important to not lose this professionalism that we have as nurses, as physiotherapists, as occupational therapists so teleHealth is very important but is a part of all the clinical practice in multiple sclerosis. What do you think, ladies?

DB: I completely agree with you. I mean, I think as soon as we walk in the room, we are smelling common we are assessing right. You can walk in and say, "Well, this patient has a urinary tract infection." Or their hygiene, what's going on differently? We're using all those different skills soon as we go into the room with the patient that we are assessing, which obviously gets missed doing it virtually. But I think it's still a great option, again for patients where it's just an easy check-in appointment. Again I think those are the high-yield type of patients to be doing virtual health with, but some of our sicker patients, if that's all we have, that's all we have, but there's so much that we get out of the in-person appointment. I had a question for you, Francesco. This might be out of the domain of what you are studying, but I know that sometimes when I go to Google a medication, the search engine, they pay, different companies pay, to come up sooner on the search engine, so let's say I look up an infusible therapy for MS and the first thing that comes up is an oral therapy, say, because the company has paid to be higher up on the chain, I don't know if it's really a question I have or more of a comment, but it was very shocking to me and I can only imagine for patients being wait, it can be confusing, no I Google this, why am I being shown this other information?

[Discussion: Healthcare professionals as advocates \(51:36\)](#)

FP: Well, this is a very important problem, because here the healthcare professional can play an important role because the role of our advocacy of healthcare professionals can help the patients to research online and verify online the correct message about therapy. I know that is a problem of healthcare, teleHealthcare and Google, but I think healthcare professionals can play an important role because if we give the skills, the instruments to research online

information about therapy to our patients we can promote the digital literacy and the research about this important topic that is the therapy.

MOD: Thank you, Denise and Francesco. We're going to come to an end and wrap this up now, but let's leave with maybe the two take-home messages that you would like to give our audience today, Denise and Francesco.

FP: Well, my take-home message is to read about digital health literacy to share with your colleagues, your psychologists, and your patients the importance of digital health literacy because we want to build an important topic in the field of multiple sclerosis, that digital health literacy is important and we have to learn our patients, all the stakeholders and our colleagues to improve digital health literacy and acknowledge the internet, to fight this infodemic.

DB: I would say teleHealth is definitely here to stay; there's pros and cons to it. I think primarily pros, because again we are bringing more healthcare to our patients and the same thing, I think educating our patients, how to get the most out of their teleHealth appointment is really important, preparing for it, what can be done, what cannot be done. I think as we continue with this more, hopefully we will have more tools to get more out of these teleHealth appointments whether that's even just better internet connection to be able to assess for nystagmus or that kind of thing but just tools to have it as close to an in-person appointment as possible.

MOD: Thank you, Denise, thank you, Francesco, for a very, very positive conversation around digital health and it absolutely is the way forward. The challenges in the sector, and indeed the last 2 years, has catapulted us hasn't it, into evolving this digitally and how we can deliver. So I want to say thank you to everyone for joining us today and leave you with a few words from our CEO that always echo in my head and that's, "The easiest thing would be for us to press control alt delete and just reset but we've now got an opportunity to embrace the changes and evolve even more so let's not lose this moment in time." Join us again in the future for some probably even more enhanced digital tools and digital health emerging. Thank you.

FP: Thank you, panel.

[Audio end](#)