INTERNATIONAL PROGRESSIVE MS ALLIANCE

DIGITAL TOOLS WORKSHOP

25-27 June 2025 | Philadelphia, USA

MEETING REPORT

Unlocking the Potential of Digital Tools in Progressive MS: Highlights from a Global Workshop

Digital tools – such as mobile apps, wearable devices and online platforms, have the potential to improve care and outcomes for people living with progressive multiple sclerosis (MS). They could serve as measures to evaluate new treatments in clinical trials, and be used in everyday care to support treatment, monitoring, or self-management. To make the most of these tools, we need a better understanding of how well they work and reflect the lived patient experience in real-world settings. We also need to ensure the they are carefully built, tested, and maintained over time to bring the most benefit possible to people with progressive MS, healthcare providers, and scientists.

The current and future landscape of digital tools in MS was the focus of a scientific workshop held in Philadelphia, Pennsylvania, USA, in June 2025. The workshop was hosted by the International Progressive MS Alliance as part of the Alliance's mission to accelerate the development of effective treatments for people with progressive multiple sclerosis that improve quality of life worldwide.

Organized by a Scientific Meeting Planning Committee* convened by the Alliance, the 2-day workshop brought together MS experts, foundations, pharmaceutical and biotech companies, donors, and people affected by progressive MS from around the globe to discuss topics critical for the effective development and adoption of digital tools for progressive MS.

Presentations, panel discussions, and breakout groups considered the current state of digital tools, the opportunities for using them in clinical trials and clinical care, potential challenges and limitations moving forward, and critical next steps to ensure that digital tools can be used to their full potential to accelerate MS research and improve outcomes for people living with progressive MS.

Where We Are Now: Digital Tools in MS Care and Research

Following a workshop introduction by Dr. Ruth Ann Marrie (Co-Chair, Dalhousie University, Canada) and Cory Turner (Member, People Affected by MS Engagement Coordination Team, Canada), Dr. Jennifer Graves (Co-Chair, University of California, San Diego, USA) kicked off the meeting with a session that focused on the current landscape of digital tools, including the common categories of digital tools currently used in the MS field.

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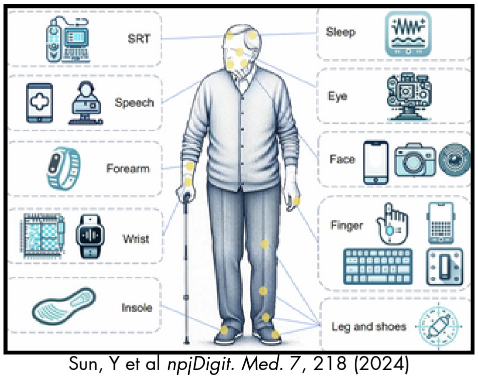
*Planning committee members were Dr. Ruth Ann Marrie (Meeting Co-Chair, Dalhousie University, Canada), Dr. Jennifer Graves (Meeting Co-Chair, University of California-San Diego, USA), Dr. Douglas Landsman (National MS Society, USA), Dr. Michelle Ploughman (Memorial University of Newfoundland, Canada), Dr. Nikolaos Sfikas (Novartis, France), Dr. Sarah Sternbach (National MS Society, USA), Cory Turner (Person affected by MS, Canada), Dr. Kathleen Zackowski (National MS Society, USA), and Dr. Paola Zaratin (Italian MS Society, Italy).

Digital tools may collect data through wearable sensors, touch screen interaction on mobile apps, or through ambient or video-based collection methods. The data can be collected passively or actively. Passive monitoring collects information in the background without requiring an individual to perform any additional task, such as smartwatches continually collecting accelerometry data (things like step count, walking speed, and sleep patterns). Active monitoring requires an individual to engage with a tool, such as interacting with apps that have finger tapping exercises, participating in walk tests, or completing questionnaires.



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Many of the wearable technologies, websites, and apps detect and often predict changes associated with MS symptoms or outcomes, suggesting usefulness for monitoring and managing symptoms, assessing treatment response, and tracking disease progression over time. For example, clinical EDSS (Expanded Disability Status Scale) score tends to worsen as the average daily step count decreases. Performance on a finger and foot tapping task can distinguish people with relapsing-remitting MS from people with progressive MS and can capture changes in function over time. Analysis of finger-drawn shapes on a touchscreen reliably measures functional impairment in MS. These examples show that digital tools have real potential to improve how we understand and treat progressive MS, but more work is needed to improve and bring them into research and clinical care.

Digital Tools in Other Fields

Researchers from other fields shared what they have learned from successfully developing and using digital tools, offering valuable insights that the MS field can build on. Dr. Rosalind Picard (Massachusetts Institute of Technology, USA) spoke about Embrace2, a wrist-worn sensor that detects and alerts people to possible seizures by measuring body movements and position, temperature, and how well the skin conducts electricity. The technology, now expanded into the Empatica Health Monitoring Platform, connects to a digital app and system that allows for effective data collection and analysis.

Dr. Ludy Shih (Harvard Medical School, USA) spoke about the role of digital tools in Parkinson's disease, both for everyday management and measuring outcomes in clinical trials. The Parky App uses smartwatch sensors to monitor tremors and involuntary muscle movement. It reviews user data, creates reports, streamlines communication with healthcare providers, and empowers patients to take control of their condition. Separately, a digital motor skills test was a helpful outcome measure in a small clinical trial and is now being used in a larger phase 3 clinical trial testing a drug for treating Parkinson's disease.

Dr. Graves pointed to a sharp rise in scientific publications on digital tools over the past decade, along with major financial investments expected in the future. This growing momentum is a key opportunity to focus efforts on advancing digital tools for progressive MS.

Why Digital Tools Are Especially Valuable in Progressive MS

People living with progressive MS often notice subtle changes in their symptoms and abilities that traditional physical exam based clinical endpoints like the EDSS are not sensitive enough to capture. When traditional measures don't pick up on subtle changes, clinical trials take longer, access to effective treatments is delayed, and people with progressive MS feel frustrated. By monitoring changes more often and with greater sensitivity than current clinical assessments, digital tools can address the unmet need of detecting subtle differences over time.

The Role of Digital Tools in MS Clinical Trials

For a new drug to be approved by regulatory agencies like the Food and Drug Administration (FDA) or European Medicines Agency (EMA), it must achieve its primary endpoint, the main result measured at the end of a study to see if the treatment is effective. It is very rare for digital outcomes to serve as a primary endpoint, and to date, no drug has been approved based on a digital outcome measure.

Regulatory experts from the United States (Ms. Sonya Eremenco) and United Kingdom (Dr. Khadija Rerhou Rantell and Dr. Maria Molinari) discussed the extensive process required for a digital outcome to be approved as a primary endpoint in clinical trials. The new outcome must be reliable, meaningful to people with the disease, better than other measures at showing how well treatments work and protect people's privacy and data. The progressive MS field is building new tools and testing the validity of digital outcomes.

Dr. Kostas Sechidis (Novartis, Switzerland) presented results from a clinical trial that tested a digital walking test using the Floodlight smartphone app in people with MS treated with ofatumumab. The tool was able to identify groups of people with and without EDSS progression at a level similar to the in-person walking test. Early studies showed that people with MS were engaged and satisfied with the app, and it is currently being updated based on user feedback to ensure long-term use.

Dr. Anne Helme (MS International Federation, United Kingdom) explained that patient-reported outcome measures – or PROMs – could be better than clinical measures for monitoring progressive MS by picking up changes more clearly and more often. PROMs are reported by patients based on how they feel about their symptoms, disabilities, and/or quality of life. They work well with digital tools because they can be thorough (many can be measured in one app) and personalized (people can answer what matters most to them). The global PROMS Initiative is studying which digital tools already do a good job of collecting these kinds of data and which could be helpful for clinical trials. The Initiative is also measuring how people with MS feel about using digital tools for PROMs monitoring. In a recent survey of nearly 2,000 people with MS, only 27% of respondents currently use digital tools, but over 70% of respondents said they would use them to track symptoms for clinical trials, clinical care, and self-management.

It is important to note that these studies include people with different types of MS. Additional studies specific to progressive MS are needed to find the best and most relevant outcome measure(s). Once identified, new clinical trial endpoints that use digital tools could mean that outcomes are measured over a course of months, instead of years.

Bringing Digital Tools Into MS Clinical Care

Researchers also discussed the role that digital tools may have in clinical care, either as an intervention for symptom control or as a tool for symptom monitoring:

Dr. Sarah Donkers (University of Saskatchewan, Canada) discussed non-invasive transcranial direct current stimulation of the brain for treating progressive MS. This intervention may help restore function by stimulating nerve activity in the brain. Much of what we know about it so far is from clinical trials of stroke patients, but it is now being evaluated in 14 MS studies, with one specific to progressive MS. Early results suggest that it may be effective at improving balance, cognition, fatigue, walking, and/or urinary incontinence.

Cognitive behavioral therapy (CBT) is a type of talk therapy shown to treat many symptoms associated with MS, such as depression and anxiety. Dr. Stefan Gold (Charité University Berlin, Germany) presented results from an internet-based CBT program. In a trial of 279 people with MS, internet-based CBT improved depression symptoms for up to one year. If they perform well in people with progressive MS, this and other CBT digital tools could offer quicker access to mental health care by overcoming access barriers for conventional in-person CBT delivery.

In addition to using digital tools as interventions, they may also be helpful for symptom monitoring. Dr. Ludwig Kappos from the Research Center for Clinical Neuroimmunology and Neuroscience Basel (Switzerland) presented data from the Digital Biomarkers for Multiple Sclerosis (dreaMS) project. DreaMS is an app that measures various functions often affected in people with MS (for example, movement, balance, mood, and vision) using active tests, games, and passive monitoring. Researchers are trying to identify new kinds of clinical data that can be "digital biomarkers" and support current ways of diagnosing and monitoring the disease to improve care of people with MS. Early clinical studies have shown promise, and larger studies that test their clinical meaningfulness are ongoing.

New digital tools must show more than clinical meaningfulness. For a digital tool to be used consistently in clinical practice, people with progressive MS must want to use the tool. Members of the People Affected by MS Engagement Coordination Team who are living with progressive MS provided insights and suggestions for making tools user-friendly. Key requirements include:

- Defining its value: People with progressive MS must understand the purpose of the digital tool – what is it measuring and why is the information collected important?
- Explaining the results: People with progressive MS want to know how to interpret the tool's data and results in the context of their disease, not just see data on a screen.
- Keeping it easy to use: People with progressive MS may not use the tool if it is uncomfortable, difficult to use, technologically complex, or a time burden.
- Allowing for flexibility and personalization: People with progressive MS will have different opinions on which outcomes are most important and which devices they prefer to use, so a "one-size-fits-all" approach is not ideal.

Incorporation of digital tools into clinical care could allow for greater autonomy, increased awareness of disease progression, quicker and more informative consultation with healthcare providers, and earlier access to effective treatments.

Accessibility: Making Digital Tools Work for Everyone

An ideal digital tool should be accessible to everyone, including people with progressive MS, researchers, and healthcare providers from a diversity of settings and global locations. The term "accessibility" captures not just the physical availability of the tool, but also the comfort and usability of the digital tool.

For people with progressive MS, availability of digital tools may be restricted by cost, lack of reimbursement, and limited internet access. For healthcare providers, availability may be restricted by the inability to integrate digital outcomes into electronic health records, especially when countries or different health systems have different rules and regulations.

Usability, or how easily and effectively people can use a product, is particularly important for people with progressive MS to ensure long-term and consistent use. Features specific to MS, such as dexterity and vision, must be considered. Dr. Elizabeth Gromisch (Trinity Health, USA) highlighted key considerations for digital tool development, including text size, color, touch sensitivity, navigation, and how information is laid out. She emphasized the importance of collecting ongoing feedback during development and refining digital tools so they are easy, useful, and engaging.

As an example, she spoke about people with MS who provided user feedback on the Managing MS My Way app – a self-management app that focuses on fatigue. Researchers learned that digital flash cards are preferred versus scrolling for information, and customization is important. The app was updated based on user feedback, allowing for improved design, functionality, and accessibility.

Making Digital Data Work Together

A strength of digital tools is the ability to collect and analyze large volumes of data. Creating a common system for how digital tools collect and use data (called data harmonization) would allow for better use of the information gathered. Day 2 of the workshop focused on considerations unique to data from digital tools, such as how to collect it, where to store it, and how to make sure it is analyzed consistently.

A centralized "digital platform" that gives shared access to existing tools, datasets, and analysis methods could improve coordination and avoid duplicating efforts. Attendees discussed important considerations for developing a digital platform, with key highlights below:

Data collection – What, why, and how data are collected must be considered. PROMs survey results presented by Dr. Anne Helme showed that people with MS are only willing to spend a few minutes per week actively participating in data collection, so it is important to optimize that time by collecting the most important data, or to focus more on passive data collection. Clear, upfront research questions should guide task selection to minimize unnecessary patient burden.

Devices, procedures, and file formats should be standardized to support consistency across studies and prevent siloed work. If different studies are measuring the same outcome (for example, walking based on accelerometry data), the way the data are collected should be consistent. It was noted that some flexibility will be necessary, however, as advancements in technology may require changes over time.

Data storage and sharing – Centralized locations where data are housed and managed – called data repositories – are necessary for storing information efficiently and making it easy to access and use. Many important questions still need to be answered, such as where the data should be stored, who should be the data custodian, who will have access, and how all of this will be paid for. Attendees agreed upon the importance of repositories including both "raw data" (all the data collected) and processed data (the final numbers used in analyses and reports).

Data analysis – As new trials begin and more people with progressive MS use digital tools, researchers and clinicians will collect increasing amounts of digital data. How those data are analyzed and interpreted must be consistent, and transparency about the analysis process is an important consideration. Raw data must go through many steps of processing just to get to the one or two data points that are reported. This processing involves eliminating many data points that may be "noise" (data that are not important for identifying important differences). To make results reliable, researchers should share in detail how they clean and process digital data before using it in studies. However, researchers must also be careful to correctly categorize what is noise and what is true signal to avoid missing important data.

Dr. Mia Tackney (University of Cambridge, United Kingdom) described potential challenges and provided an example of "missing data." When collected over time, data should be continuous, but if a person does not always want to wear a digital sensor or forgets to do a task, data will be missing. An important consideration will be how to handle those situations during calculations and analyses to avoid introducing bias that could lead to incorrect data interpretation.

Artificial intelligence (AI) has great potential for assisting with data analysis. Dr. Cristina Granziera (University of Basel, Switzerland) highlighted how it has been successful with lesion detection from brain scans. Her group is establishing new measures to define its reliability, such as a "trustworthiness" score, before their AI image analysis tool is widely adopted.

Collaboration is the Catalyst for Progress

Underlying nearly every workshop presentation and discussion was the idea that digital tools cannot reach their full potential if they are used in isolation or not connected with other tools and systems. So, a collaborative approach to digital tool application for progressive MS is necessary to make sure digital tools are useful, easy to access, long-lasting, compatible with each other, and truly make a difference. At a minimum, new and emerging digital technologies should engage researchers, clinicians, engineers, software analysts, industry partners, regulatory authorities, and people living with MS throughout the development, assessment, and implementation process.

Turning Barriers Into Action

Despite the significant opportunities digital tools can bring to the progressive MS field, several barriers and limitations exist that risk slowing progress. At the conclusion of the workshop, participants broke into smaller groups and brainstormed strategies to ensure progress will be made toward transitioning digital tools into clinical trial outcomes, using digital tools in clinical practice, and harmonizing data. Some key suggestions are below.

How Can We Transition a Digital Outcome to Clinical Trials?

- Incorporate digital outcomes as endpoints in small or early phase clinical trials to increase regulatory agencies' familiarity and comfort with digital outcomes measures.
- Conduct clinical trials specific to people with progressive MS that use digital outcomes. Ensure participants are supported when using unfamiliar digital tools, and limit participant burden.
- Consider trials that enroll participants from a diversity of settings and global locations.
- Encourage advocacy efforts that may highlight the importance of adopting digital outcome measures into clinical trials.
- Form a group of experts from different fields that can collaborate to create guidelines that standardize how digital tools are used and analyzed. Update the guidelines as needed to keep current with advancements in the field.
- Provide training and guidance to people with MS, researchers, and clinicians as new tools emerge on their appropriate use.

How Can We Advance Digital Intervention into Clinical Practice?

- Engage people living with progressive MS, health administrators, and clinicians throughout the stages of tool development to ensure it is useful, valuable, accessible, and easy to transition into clinical practice.
- Reduce burden on healthcare providers and health systems by creating simple, universal approaches that allow different technology systems to communicate and digital data to integrate into electronic health records.
- Learn from the successes of other fields to guide tool development and refinement.
- Reimbursement will be key for widespread adoption of a digital tool. When planning studies to show how well a tool works, consider what type of evidence insurance companies need to see. Before developing a new tool, review existing tools to understand what is reimbursed and not reimbursed.

How Can We Optimize Data Collection, Analysis, and Harmonization?

- Create a shared data platform that allows widespread access to digital tools, data, and analyses, while prioritizing security and ethical concerns.
- Develop standard procedures and guidelines for data collection and harmonization (like file formats and data points) and analysis (including data cleaning and processing steps).
- Dedicate funding to support a data repository that can store and analyze the data from digital tools.

The Road Ahead for Digital Innovation in Progressive MS

In summary, digital tools hold great promise to solve the big problems in progressive MS. Although it may not be a quick journey, and many limitations and barriers were discussed, Dr. Jennifer Graves concluded that "The challenges are surmountable, and the opportunity for digital tools is too great not to pursue."

Through its global collaboration of MS organizations, researchers, clinicians, industry partners, and people affected by progressive MS, attendees agreed that the International Progressive MS Alliance is uniquely positioned to be a catalyst for many of the action items discussed during the workshop. Learnings from the workshop will guide future Alliance initiatives that work toward developing, validating, and implementing digital tools to support shorter and faster clinical trials and improve well-being and clinical care for people with progressive MS.

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