



SUMMARY OF RESEARCH

# Summary of Research: Collaboration Between Healthcare Professionals and People with Multiple Sclerosis to Develop Communication Tools to Improve the Standard of Multiple Sclerosis Care

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## ABSTRACT

This is a summary of a previously published paper: Joint Healthcare Professional and Patient Development of Communication Tools to Improve the Standard of MS Care. It describes a collaboration

between people with multiple sclerosis (PwMS) and healthcare professionals (HCPs) to identify challenges in multiple sclerosis (MS) care and design tools to improve communication during consultations.

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### Key Summary Points

This Summary of Research Article overviews a previously described collaboration between people with multiple sclerosis (PwMS) and healthcare professionals (HCPs) to identify challenges in multiple sclerosis (MS) care and design tools to improve communication during consultations.

PwMS feel more satisfied with their care if they have good communication with their HCP.

In reality, PwMS often feel disconnected from their HCP because of poor communication, resulting in suboptimal outcomes.

A group of PwMS and HCPs collaborated to identify current challenges and design tools to improve communication during consultations.

Through workshops and a survey, the group identified key issues in communication between PwMS and HCPs, including a lack of time in appointments to explore the priorities of PwMS, and information not being presented in a clear and appropriate way.

With these findings, the group developed two communication tools—“myMS priorities” and “myMS commitments”—to help PwMS and HCPs best utilize their consultation time, and to encourage open and honest communication.

## INTRODUCTION

This Summary of Research Article overviews a previously described collaboration between people with multiple sclerosis (PwMS) and healthcare professionals (HCPs) to identify challenges in multiple sclerosis (MS) care and design tools to improve communication during consultations. PwMS feel more satisfied with their MS treatment if they have good communication

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with their HCPs and are involved in shared decision-making [1]. However, the communication between PwMS and their HCPs can sometimes be poor:

- PwMS often feel they do not get enough quality information from their HCPs during their consultation.
- Some HCPs may misjudge PwMS sensitivity about discussing certain topics, including sexual problems, incontinence, and walking ability.
- Some HCPs can use a one-size-fits-all approach, rather than tailoring consultations to suit individual needs.
- PwMS and HCPs' treatment priorities can differ; from the perspective of PwMS, some HCPs focus on risks and adverse effects associated with treatment, rather than the impact of treatment on symptoms and disease progression.

Therefore, communication between PwMS and HCPs needs to improve to improve treatment satisfaction. Some communication tools already exist for PwMS and their HCPs, including the “MS symptom and impact diary” which aims to help PwMS understand the impact of their symptoms. However, there is still room for improving the communication between PwMS and HCPs, and communication tools could address this.

In this group, PwMS and HCPs worked together to:

- Identify issues in communication between PwMS and HCPs through workshops and surveys.
- Create solutions to these problems in the form of two communication tools.

## WHO TOOK PART IN THESE WORKSHOPS AND THE SURVEY?

The group involved members of the international initiative “MS in the 21st Century” (MS21), which is led by 12 PwMS and 15 HCPs who specialize in MS. Five workshops were held with various members of MS21 between March 2016 and July 2017.

A survey about MS care was answered by 143 PwMS and 296 HCPs at various neurology and PwMS meetings held between 2016 and 2018.

## WHAT WAS DISCUSSED AT THE WORKSHOPS?

In the first workshop, the group discussed recent successes and areas for improvement in MS care, and how MS treatments affect the lives of PwMS.

The group then developed a survey to gather more opinions from PwMS and HCPs about different aspects of MS care, including diagnosis, disease progression, treatment decisions, and communication.

Over another four workshops, the group analyzed the results of the first workshop and the survey. They then discussed possible ways to improve communication in MS care. In the end, two communication tools—myMS priorities and myMS commitments—were developed. The two tools were then presented at neurology and PwMS meetings to gain further feedback.

## WHAT WAS THE OUTCOME OF THE WORKSHOPS?

### Part 1: Identifying Issues in Communication Between PwMS and HCPs

In the first workshop, PwMS and HCPs listed similar issues in current MS care (see Table 1), but there were some key differences in opinion. For example, PwMS tended to focus on mental wellbeing and treating the “whole person”, not just the physical symptoms of disease. But these topics were not mentioned by HCPs.

The group agreed that the main reasons for poor PwMS and HCP communication are:

- PwMS may have a lack of knowledge about the disease and/or information is not presented in a clear and appropriate way.
- HCPs may lack the ability to explain complex information to PwMS.
- HCPs may not fully understand the individual priorities of PwMS and instead use a one-size-fits-all approach in consultations.
- There is a need for more educational resources available addressing these issues for both HCPs and PwMS.
- There is a need for more time in consultation appointments.

### Part 2: Developing Communication Tools to Address Issues

Once the group understood the possible reasons for poor communication in MS care, they were able to design two tools to help improve communication between PwMS and their HCPs.

myMS priorities is a checklist designed to help PwMS and HCPs make the most of their consultation time. In this tool, PwMS can write down what they

want to focus on in their consultation, including any questions or changes in their symptoms, medication, or lifestyle. These notes can then be shared with the HCP before the consultation so that the doctor can prioritize conversations that are important to the PwMS and prepare and plan referrals ahead of time if needed. Furthermore, the tool may help PwMS initiate discussions about potentially embarrassing or invisible symptoms.

myMS commitments is a disease management contract, designed to encourage open and honest communication between PwMS and HCPs. This tool outlines the responsibilities that both PwMS and HCPs have in the management of MS, encouraging shared decision-making. The contract covers four aspects of MS care: education about MS, how to get the best from appointments, MS treatment and management, and how to get the best out of life. This tool also provides PwMS with a realistic idea of what they can expect from their healthcare team.

Once the tools were developed, the group gained feedback from other HCPs and PwMS at neurology and PwMS meetings to understand the possible limitations of the tools:

- HCPs felt they may not have the time to read myMS priorities before each appointment. They were also worried that copies of the tool may get lost.
- PwMS were concerned that PwMS may change their mind about their priorities before the appointment. They also felt that any physical or cognitive difficulties due to MS may make it harder for PwMS to use the tools.

## WHAT ARE THE NEXT STEPS FOR THESE COMMUNICATION TOOLS?

Testing the communication tools in real consultations with PwMS and HCPs to see if they can improve communication, encourage shared decision-making, and improve the standard of MS care.

## WHAT ARE THE MAIN TAKE-HOME MESSAGES?

- There are some key issues in communication between PwMS and HCPs that may affect the delivery and outcome of care.
- The main reasons for these issues in communication include a difficulty in either communicating

**Table 1** PwMS and HCPs' perspectives on current issues in MS care

| Topic  | PwMS  | HCP   |
|--|---|---|
| What areas of MS care need more focus/support?           | <ul style="list-style-type: none"> <li>Monitoring “invisible” symptoms and mental wellbeing</li> <li>Being able to see or speak to HCPs</li> <li>Educating HCPs</li> <li>Thinking about the person with MS as a whole person (including social and mental aspects), not just treating the symptoms of disease</li> <li>Tailoring care and treatment to individuals</li> <li>Educating patients and giving them suitable information</li> <li>More awareness of MS among the general public</li> </ul> | <ul style="list-style-type: none"> <li>Being free from disease</li> <li>A cure</li> <li>Continuity and quality of care</li> <li>Financing medical treatment for hospitals and clinics</li> <li>Access to treatment for hospitals and clinics</li> <li>Neuroprotective measures to reverse or prevent further nerve damage</li> <li>Tailoring care and treatment to individuals</li> <li>Better treatment for progressive MS</li> <li>Getting patients involved in making decisions about their own care</li> <li>Supporting and speaking up for PwMS</li> </ul> |
| What are the most important recent successes in MS care? | <ul style="list-style-type: none"> <li>More PwMS support from healthcare teams</li> <li>New and more varied treatment options</li> <li>More focus on quality of life</li> <li>Global online PwMS community</li> <li>More focus on progressive MS</li> <li>Hope for PwMS from treatment, support, research, etc.</li> </ul>  | <ul style="list-style-type: none"> <li>More treatment options</li> <li>Better care from a team of HCPs from different departments</li> <li>Better treatments</li> <li>Better teamwork between individuals involved in MS treatment and care</li> <li>Advances in scientific research</li> </ul>   |
| How do treatments affect the lives of PwMS day-to-day?   | <ul style="list-style-type: none"> <li>Balancing the risks and benefits of treatment</li> <li>Access to treatment</li> <li>Not enough time with HCPs</li> <li>Lack of regular review and monitoring by HCPs</li> <li>PwMS get different treatment options depending on where they live</li> <li>PwMS sticking to treatments</li> </ul>  | <ul style="list-style-type: none"> <li>Side effects</li> <li>Cost of treatment</li> <li>Not enough support for PwMS</li> <li>Balancing the risks and benefits of treatment</li> <li>Uncertain future for PwMS</li> </ul>  |

Please note, examples are not listed in a particular order of priority in the table  
*HCP* healthcare professional, *MS* multiple sclerosis, *PwMS* people with multiple sclerosis

(HCP) or understanding complex information (PwMS), differences in priorities (and awareness of such differences), a lack of time in appointments, and lack of educational resources.

- The myMS priorities tool is a checklist designed to help PwMS and HCPs make the most of their consultation time so that both parties feel heard and the needs of both are met.
- The myMS commitments tool is a disease management contract designed to encourage open and honest communication between PwMS and HCPs and establish expectations and responsibilities for MS care.
- Both tools are available in the supplementary material.

## QUESTIONS FROM THIS RESEARCH THAT CAN BE USED TO TALK TO YOUR PWMS ABOUT THEIR MS CARE

- What does this information mean for them?
- How can they use these communication tools in consultations with their HCPs?

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**Data Availability.** The datasets during and/or analyzed during the study discussed in this summary are available from the corresponding author on reasonable request.

## Declarations

**Conflict of Interest.** **Celia Oreja-Guevara** has received honoraria from Biogen Idec, Novartis, Sanofi Genzyme, Almirall, the healthcare business of Merck KGaA, Darmstadt, Germany. **Diego Centonze** is an advisory board member of Almirall, Bayer Schering, Biogen, GW Pharmaceuticals, the healthcare business of Merck KGaA, Darmstadt, Germany, Novartis, Roche, Sanofi-Genzyme, Teva and has received honoraria for speaking or consultation fees from Almirall, Bayer Schering, Biogen, GW Pharmaceuticals, the healthcare business of Merck KGaA, Darmstadt, Germany, Novartis, Roche, anofi-Genzyme, Teva. He is also the principal investigator in clinical trials for Bayer Schering, Biogen, the healthcare business of Merck KGaA, Darmstadt, Germany, Mitsubishi, Novartis, Roche, Sanofi-Genzyme, Teva. His preclinical and clinical research was supported by grants from Bayer Schering, Biogen Idec, Celgene, the healthcare business of Merck KGaA, Darmstadt, Germany, Novartis, Roche, Sanofi-Genzyme, Teva. **Gavin Giovannoni** has received compensation for serving as a consultant or speaker for or has received research support from AbbVie, Aslan, Atara Bio, Biogen, BMS-Celgene, GlaxoSmithKline, Janssens/J&J, Japanese Tobacco, Jazz Pharmaceuticals, LifNano, Merck & Co, Kenilworth, NJ, the healthcare business of Merck KGaA, Darmstadt, Germany/EMD Serono, Moderna, Novartis, Sanofi and Roche/Genentech. **Sven Schippling** receives research grants from US EMD Serono. **Pieter van Galen** has received honoraria from the healthcare business of Merck KGaA, Darmstadt, Germany for MS in the 21st Century activities, and has received consulting and speaking fees from Johnson & Johnson, Novartis, Merck N.V.-S.A., Overijse, Belgium, an affiliate of KGaA, Darmstadt, Germany, Celgene R&D Sarl, F. Hoffman-La Roche, NV Roche SA, Mylan GMBH and Excemed.

**Ethical Approval.** This article is based on findings from previous studies and a debate; it does not report any new studies with human participants or animals performed by any of the authors.

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