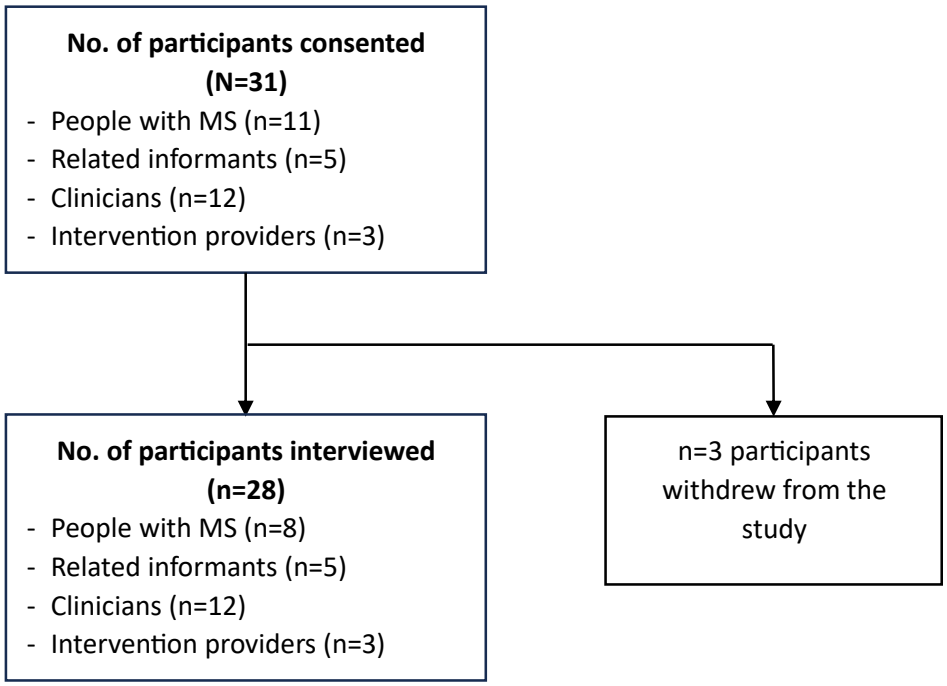
NEuRoMS
Neuropsychological Evaluation and Rehabilitation in Multiple Sclerosis

Nottinghamshire Healthcare NHS
NHS Foundation Trust

University of Nottingham
UK | CHINA | MALAYSIA

Neuropsychological evaluation and rehabilitation in multiple sclerosis – qualitative case study: Summary Findings

Participant Flow



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Baseline characteristics

Participant demographic and clinical characteristics

	People with MS (*n*= 8)	**Related informants (*n*=5)**	**Clinicians (*n*=12)**	**Intervention providers (*n*=3)**
Mean age (range)	60 years (47-72)	45 years (27-59)	48.9 years (35-60)	28 years (25-31)
Gender:				
Woman	62.5%	80%	50%	66.7%
Man	37.5%	20%	50%	33.3%
Ethnicity				
Asian/Asian British			8.3%	
Other ethnic group			16.7%	
White	100%	100%	75%	100%
Mean time since diagnosis (range)	8.9 years (2-16)	n/a	n/a	n/a
Type of MS		n/a	n/a	n/a
Relapsing remitting MS	37.5			
Secondary progressive MS	37.5%			
Primary progressive	12.5%			
Not known	12.5%			
Relationship with people with MS	n/a		n/a	n/a
Child		60%		
Partner		40%		
Mean duration of support provided (range)	n/a	3.6 years (0.5-8)	n/a	n/a
Job role	n/a	n/a		n/a
Consultant neurologist			75%%	
MS nurse			16.7%	
Occupational therapist			8%	
Mean years of experience working with people with MS (range)			18.8 years (1-31)	

	People with MS (***n***= 8)	**Related informants** (***n***=5)	**Clinicians** (***n***=12)	**Intervention providers** (***n***=3)
Prior experience working with people with neurological conditions Yes				100%
Prior experience of cognitive screening and management Yes No				66.7% 33.3%

Outcome measures

Primary outcome measure	Findings
1. Improved understanding of how the NEuRoMS screening and management pathway is integrated within routine clinical practice (e.g. contextual factors which influence its delivery, those mechanisms which influence its affect and those outcomes which are described by interviewees) through qualitative data; measured throughout data collection by reviewing notes from monthly teleconferences/videoconferences with clinicians and supervision sessions with intervention providers, and at interviews with patients and related informants (within approximately 2 weeks of completing the intervention), and at interviews with clinicians and intervention providers (after experiencing different elements of the pathway; 3-8 months post patient recruitment).	People with MS were able to complete screening online at home without needing any support or assistance from their clinical team. However, some of the related informants noted that other people with MS may struggle to use a computer to access screening or may not own a computer, suggesting that not all people with MS will be able to complete screening at home. Overall, clinicians said the cognitive screening and management pathway helped them to better support their patients by aiding both the identification and management of cognitive problems for people with MS. However, implementation of the pathway also highlighted some gaps in the MS NHS services, such as lack of time during appointments to discuss the cognitive screening results and the lack of psychology services to refer patients identified as needing more specialist support for mood or cognitive problems.
2. Improved understanding of how the NEuRoMS intervention programme is experienced by those who deliver and receive it (e.g. behavioural elements of the intervention, essential resources needed for, and barriers to screening and intervention delivery) through qualitative data; measured throughout data collection by reviewing notes from monthly supervision sessions with intervention providers, intervention audio-recordings, and at interviews with patients and related informants (within approximately 2 weeks of completing the intervention) and intervention providers (after experiencing different elements of the intervention; 3-8 months post patient recruitment).	People with MS said that they found the cognitive management sessions beneficial. They also told us that some of the topics discussed during sessions were overwhelming to people with MS, with discussions feeling rushed. Specifically, the section that looked at cognitive problems and setting individual goals. The suggestion was to split this section over at least two sessions. Intervention providers also agreed that more time should be spent on setting goals during sessions. All people with MS were happy that they could choose how the sessions were delivered (videoconference, over the telephone or face-to-face) where possible due to COVID-19 restrictions. People with MS said that they had experienced changes since receiving the programme, which the related informants observed as well. For example: they started using a wider range of strategies to help with their cognitive problems that had been discussed during the sessions; they became more aware of their cognitive abilities and limitations (e.g., need for pacing themselves, understanding the effect of fatigue on cognitive function, need to be more mindful

	and in the moment, need for a more relaxed outlook).
Secondary outcome measures	**Findings**
1. Patient, related informant and intervention provider views of the intervention resource book, measured throughout data collection by reviewing notes from monthly supervision sessions with intervention providers, intervention audio-recordings, and at interviews with patients and related informants (within approximately two weeks of completing the intervention) and intervention providers (after experiencing different elements of the intervention; 3-8 months post patient recruitment)	General feedback about the format and layout of the booklet for people with MS included that there needed to be more space provided for making notes, and simplifying some of the diagrams.
2. Intervention provider views and experiences of the staff training package, measured throughout data collection by reviewing notes from monthly supervision sessions with intervention providers and at interviews with intervention providers (after experiencing different elements of the intervention; 3-8 months post patient recruitment)	Intervention providers reported that the training package was comprehensive, with the role-playing component the most useful part of the training they had received. Suggestions for revisions to the training package included spending more time on goal-setting and delivering training over a longer period of time.
3. Appropriateness of fidelity tools measured throughout data collection by reviewing notes from monthly supervision sessions with intervention providers and at interviews with intervention providers (after experiencing different elements of the intervention; 3-8 months post patient recruitment)	Intervention providers gave suggestions on how to improve the session record forms they were required to complete following each session (part of the fidelity tools), which better suited the person-centred approach to intervention delivery.

Adverse events

There were no adverse events associated with this study.