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**COGNITIVE ASSESSMENT IN MULTIPLE SCLEROSIS CLINICAL CARE: A QUALITATIVE
EVALUATION OF STAKEHOLDER PERCEPTIONS AND PREFERENCES**

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ABSTRACT

There is a growing consensus that cognitive assessments should form part of routine clinical care in Multiple Sclerosis (MS). However, what remains unclear is which assessments are preferred by “stakeholders” (including people with MS, family members, charity volunteers, clinicians, and healthcare commissioners), in which contexts, and in which formats. Therefore, the aim of this study was to collect and synthesise stakeholders’ perceptions of the assessments that are acceptable and feasible for routine administration in the UK healthcare system.

We interviewed 44 stakeholders and held one focus group (n=5). We asked stakeholders about their experience with cognitive impairment and assessment, and their views on how cognitive assessment could be implemented within routine clinical care.

Using framework analysis, we summarised three themes: the current cognitive screening situation; the suitability of commonly used assessments; and feasibility aspects, including modality and location of testing. All participants acknowledged that cognitive impairment could have a significant impact on quality of life, but assessment and monitoring is not routine. Barriers and enablers were described, and most participants reported that brief, routine screening with tests such as symbol substitution was acceptable. Electronic, self-administration of cognitive screening would be beneficial in minimising clinic attendance and staff time.

INTRODUCTION

Cognitive impairment is a common symptom of Multiple Sclerosis (MS), with estimates of up to 86% experiencing problems in domains such as processing speed, executive function and working memory (Fischer et al., 2014). Research examining cognitive impairment in MS has revealed the impact this has on quality of life, employment, and medical implications such as medical appointment attendance, or medication adherence (Shevil & Finlayson, 2006). Qualitative interviews with people with MS have found that cognition is a ‘neglected symptom’ in their MS care, and although they placed importance on this symptom, this is rarely addressed by their MS clinicians, unless it is severe (Mc Auliffe & Hynes, 2019).

There are several available assessments for cognitive impairment, both generic and specific to MS. Reviews have provided overviews of neuropsychological batteries and individual assessments (for example Hansen & Lautenbacher, 2017), and offered recommendations for brief screening to be routinely administered, followed by a more extensive assessment for ‘conspicuous’ results. Although a full neuropsychological evaluation within clinical care would provide detailed insight into cognitive impairment, research has shown that cognitive screening is not routine in United Kingdom (UK) neurology services (Klein et al., 2018). The feasibility of such a programme may be likely due to the lack of time, staffing, and other resources within clinics. Emphasis is therefore placed on briefer assessments that are still effective at measuring cognitive impairment (Cullen et al., 2007) to ensure that cognitive assessment is practicable and efficient (Amato & Zipoli, 2003).

Previous approaches to standardised cognitive assessments for people with MS have used expert consensus recommendations (e.g., Benedict et al., 2002; Kalb et al., 2018; Lensch et al., 2006), which do not appear to take into account the preferences of people with MS, their family members, or clinicians for how they should operate. Indeed, despite these recommendations, a recent survey found that commonly used assessments for people with MS in UK healthcare included generic measures or measures developed for dementia, such as (MoCA) and the Addenbrooke’s Cognitive Examination (ACE-R), and were not standardised across clinical services (Klein et al., 2018). Furthermore, recent research has shown that people with MS often refuse to complete one of the most commonly used and recommended measures in MS, the Paced Auditory Serial Addition Test (PASAT; Cortés-Martínez et al., 2019). People with MS with greater cognitive impairment are more likely to reject the PASAT, causing challenges in being able to effectively identify and monitor cognitive problems and provide appropriate care.

Some recommendations have highlighted that brief, computerised assessments which can be self-administered at home could be beneficial in implementing regular, routine screening for all people with MS (Kalb et al., 2018). A recent overview of digital neuropsychological measurement highlights a number of benefits, including reduced costs and greater accuracy in results, but there are also challenges

in adapting traditional assessments to electronic measures, including ensuring ecological validity and accessible design to increase user engagement (Germine et al., 2019). The Topol Report emphasises the importance of involving patients in developing digital medicine for the UK National Health Service (NHS) to improve their own experience and ensure that it is appropriate for their needs (Topol, 2020). A proof of concept study suggested that people with MS prefer a self-administered, computerised tests to the traditional technician-administered Symbol Digit Modalities Test (SDMT, Patel et al., 2019). Some assessments can be developed as an electronic test more readily than others. However, adapting tests to an electronic format may require substantial procedural changes, such as how stimuli are responded to, and will need to ensure that people are not put off or disadvantaged by the testing modality.

These issues can be addressed by understanding stakeholders' motivations and concerns about cognitive assessments being used in usual clinical practice. However, few studies have qualitatively evaluated 'how' specific tests or batteries are used. An investigation into patient preference for routine cognitive screening found the people with MS were supportive of routine cognitive screening and for their clinicians to manage both physical and cognitive symptoms (Mortensen et al., 2020). Participants perceived the SDMT to be less demanding and fatiguing than the other brief assessments included in the BICAMS (Brief International Cognitive Assessment for MS). Although valuable, this research used a small select sample of Danish patients, some of whom were already volunteering in a study of cognitive screening, which only included participants who scored between 20-60 on the SDMT. Additionally, this study did not include patients who refused to complete the SDMT, or elicit the opinions of those who scored outside of the score boundaries mentioned, which could have been valuable in determining how to engage all patients in cognitive screening. Furthermore, this study only focussed on people with MS, and did not include other stakeholders such as clinicians.

The aim of the current research was to explore which cognitive assessments may be acceptable to administer, in which modality (for example electronically), and which settings, amongst key stakeholders based in the UK. Key stakeholders are those who are involved in the process of cognitive screening to ensure its success within the UK healthcare system. These include: (i) people with MS who need to be capable, motivated, and have the opportunity to complete tests, (ii) carers or family members of people with MS to support them in completing tests, (iii) clinicians who need to implement the screening in clinical services and help interpret the results of the tests to plan future care, (iv) commissioners who fund clinical services within the NHS, amongst others. Using qualitative methods, we believed we would be better able to identify stakeholders' perceptions of the assessments that are acceptable and feasible to be administered in routine UK healthcare systems.

METHODS

Interviews and a focus group were conducted to gather qualitative data regarding aspects of cognitive screening in MS. Both methods were used to enhance the richness of data (Lambert & Loiselle, 2008). Ethical approval was obtained from the University of Nottingham's Division of Psychiatry and Applied Psychology's Research Ethics Committee (reference number: 0233) and the University of Nottingham's Faculty of Medicine and Health Sciences Research Ethics Committee (reference number: 263-1903).

Data were collected as part of an ongoing National Institute for Health Research (NIHR) programme, Neuropsychological Evaluation and Rehabilitation in Multiple Sclerosis (NEuRoMS www.neuroms.org). NEuRoMS aims to develop and evaluate a cognitive screening pathway and rehabilitation for people with MS.

Participants and recruitment

Based on recommendations of determining sample size for qualitative research (Vasileiou et al., 2018), we determined that a sample size of 40-50 participants across two participant categories: (i) people with MS, family members and charity volunteers; and (ii) clinicians working in MS and commissioners, would be sufficient to address our aims. However, we reviewed the sample size on an iterative basis to ensure data saturation, and to ensure we did not collect more data than necessary. Saturation was operationalised as the point where there were no new data being generated which supported ongoing theme development or creating the possibility for a new theme. We and the wider research team regularly reviewed the data to determine whether data collection had reached this point, and whether the analysis would benefit from further interviews.

We used a purposive convenience sampling strategy to recruit participants. All participants invited to participate if they were 18 years old or older, could communicate in English, and were able to give informed consent to participate. People with MS had to have a diagnosis of MS; family members had to have a relative or care for a person with MS, and charity volunteers had to be affiliated with MS charities such as the MS Society, Overcoming MS, or the MS Trust. These participants were recruited through Patient and Public Involvement (PPI) networks, online advertisements (using relevant communities and forums on Twitter, Reddit and Facebook), contacts at MS charities, and by word of mouth.

Clinicians, identified through professional networks of the research team, representing different healthcare professionals working in MS were invited to participate. Commissioners were invited to participate if they were a service commissioner working within the Clinical Commissioning Groups that fund NHS services.

Materials

A brief video was produced which showed computerised administrations of three commonly used screening assessments: a symbol substitution test, a Stroop test, and a paced addition test. We also provided participants with a document showing screenshots of the tests to facilitate the discussion. This document also contained verbal administrations of a word list learning, verbal fluency test, and written administrations of a trail making task, and the first ten items of a questionnaire, the Multiple Sclerosis Neuropsychological Screening (MSNQ, Benedict et al., 2003). The seven measures were selected because they: (i) are commonly applied both as individual assessments and within batteries such as BICAMS and the BRB-N (Benedict et al., 2002; Langdon et al., 2012); (ii) demonstrate different modalities (electronic, written and verbal); (iii) and provide examples of both subjective and objective measures. Clinicians and commissioners were also shown an a priori preliminary logic model and asked for feedback. The logic model was developed based on literature, behaviour change theories, consultations with PPI, clinical experiences and service realities.

Two semi-structured interview schedules, one for people with MS, family members and charity volunteers, and one for clinicians and commissioners, were developed using a preliminary logic model (developed as part of the NEuRoMS programme and shown in supplementary materials), as well as input from a PPI group. The NEuRoMS programme proposes a pathway of cognitive screening and management of cognitive problems, thus participants were asked about the different elements of this, as well as their 'journey' through the pathway as a whole. The interview schedule was amended on an iterative basis if the interviewers found that some questions required clarification or further areas needed to be investigated. The interview and focus group schedules consisted of both general and specific questions, and probing questions to clarify responses or to ask further questions if needed.

Procedure

We emailed participants copies of all the interview materials, and a link to the video of computerised assessments, and details of the assessments. Participants were asked to review all materials before their interview.

Interviews were conducted by four researchers. Interviews with people with MS, volunteers and family members were conducted by HE, a female PhD student with a MSc in Psychological Research Methods who had no prior relationship with participants. Interviews with clinicians were conducted by JMM, a female postdoctoral research fellow who has expertise in neuropsychological rehabilitation in MS, and has experience in qualitative research methodologies, including semi-structured interviews. She knew some of the participants prior to the interview through her professional networks. Interviews with commissioners were conducted by RdN, a male professor and clinical psychologist, with experience in interviewing people, and NE, a male academic consultant Neurologist with experience in interview

methodologies. The participants interviewed were known to RdN and NE through their professional networks prior to the interview.

One focus group was run for people with MS and was co-facilitated by three researchers (HE, KH and PL) and a PPI partner (CB). Facilitators had different expertise and experience, including psychological research methodology (HE), qualitative methodology and focus groups (PL, CB), technology and digital health (KH), and lived experience of MS (CB). After introductions and providing some background on the study, participants were shown the materials and encouraged to participate in the focus group. Researchers guided the focus group using the same interview schedule as used for the interviews.

Interviews were held at participants' homes (people with MS), place of work (clinicians), or over the phone. The focus group was held at a convenient time and place, and participants were offered breaks. At the beginning of the interview or focus group, consent was obtained, and interviewers explained the research aims and procedure, and what would happen during the interview or focus group. Demographic information was collected for each person with MS, family member and charity volunteer. All participants we approached agreed to take part, and no participants dropped out of the study. We showed the brief video and assessment document to participants at an appropriate time during the interview.

Analysis

Audio recordings of the interviews and focus group were sent to a professional transcription service for verbatim transcription. All transcripts were anonymised, imported into NVivo software (version 12), and analysed using framework analysis, a hierarchical, matrix-based method which aims to systematically approach the data with the predetermined objectives of the logic model (Pope et al., 2000).

The logic model was used to develop an initial thematic framework for analysis, and through an iterative process, this was refined to capture the themes derived from the data. The logic model is presented in the supplementary materials, and also described in a further paper regarding the implementation of the NEuRoMS programme (Smith et al., 2020).

During the data collection and familiarisation of the data, two researchers (HE and JMM) developed iterations of the framework, with feedback from two other researchers who were familiar with the logic model and methodology (PL and GT). The framework was developed using a situation, inputs, processes/outputs, mechanisms and outcomes model (Wyatt Knowlton & Phillips, 2012). These categories contained a number of subcategories that explored how cognitive screening currently operates within UK healthcare, opinions of different assessments, and practical aspects such as how and where the assessment should take place.

Data were indexed and coded in NVivo by four researchers (HE, JMM, LS and GT) and charted to a matrix that mapped to the thematic framework. We wrote summaries to correspond to each data point for each case and overall summaries were produced for the two participant groups. These summaries were mapped onto the pathway and presented to the NEuRoMS research team and a PPI group for feedback and to sense-check the final framework and interpretation of the data.

RESULTS

Participant demographics

Forty-nine people participated in the interviews and focus group. The demographics of the people with MS, family members and charity volunteers are given in Table 1. Participants have been assigned a code which is given in Table 2 together with individual level demographic and MS characteristic information. Seventeen clinicians were interviewed: four each of MS nurse specialists, neurologists, occupational therapists (OTs), and neuropsychologists, one neuro-physiotherapist, and three commissioners. The focus group lasted 125 minutes and all participants contributed to the discussion. All interviews lasted an average of 52 minutes.

i. Cognitive Problems in MS and Current Identification

All participants recognised cognitive problems as a prevalent symptom for many people with MS, which impact upon daily life, employment, and social life. Memory, processing speed, decision making, concentration, and communication were all highlighted as affected cognition domains for people with MS. Clinicians also acknowledged that cognition, fatigue and quality of life are interlinked in MS. Despite cognition being perceived as an important symptom of MS, both people with MS and clinicians reported that discussion or assessment of cognitive symptoms does not routinely occur in clinical care, as other symptoms take priority. Some neurologists interviewed did ask people with MS about their cognition in annual appointments, but due to the competition for time in routine appointments, other symptoms often took priority over ‘invisible’ symptoms such as cognition.

People with MS were not always directly told about cognitive problems during their appointments. Consequently, some participants thought that younger or newly diagnosed people may be unaware that cognitive problems could be an MS symptom, and that some people could be in denial of their problems by “*burying their head in the sand, just not willing to accept*” (Volunteer 01). A charity volunteer acknowledged that, although cognitive issues had not affected them, it would still be beneficial to be informed by their clinician about potential cognitive problems: “*I think this [cognitive problems] might be quite handy to actually hear it from somebody clinically saying, you know, you need to do something about this*” (Volunteer 01).

Some people with MS thought that their neurologist “*doesn’t think [cognitive problems] actually even exist*” and that cognitive problems were not “*taken seriously*” (Patient I 11). Neurologists and MS

nurses largely perceived addressing cognitive problems the responsibility of neuropsychologists and OTs, and referrals to primary and secondary care were being prioritised for those with severe or advanced problems, or when cognitive problems were having an adverse impact on employment or education. Neurologists and nurses thought factors such as mood and medication should be managed prior to referrals for cognitive problems.

OTs and psychologists reported using the Repeatable Battery for the Assessment of Neuropsychological Status (RBANS), BICAMS, SDMT, MoCA, Addenbrooke's Cognitive Examination III (ACE-III), Rivermead Behavioural Memory Test (RBMT) and/or Test of Everyday Attention (TEA) if required, but these were not routinely administered for all people with MS. The neuro-physiotherapist interviewed reported using the SDMT as part of a larger battery of assessments, and used it to aid discussion with the people with MS about their perception of cognitive changes.

ii. Perceptions of Cognitive Assessments

OTs and neuropsychologists emphasised that assessments should encompass the domains of processing speed, working memory, executive function, and attention.

Most people with MS thought that cognitive assessments were acceptable and would complete them if required. However, one person with MS strongly opposed completing the cognitive tasks, expressing a negative reaction towards the tasks, but would complete questionnaires. Another thought questionnaires would be less intimidating as *"you feel like it's not being done to you, you have got some control over what's actually happening"* (Patient I 11). Clinicians suggested that subjective measures can add further insight into cognitive impairment, and the perceived difficulties of people with MS. However, there were concerns about recall periods, and whether questionnaires were nuanced enough, with one person with MS thinking they might be *"too subjective, a bit too fluffy... unless I've got a space for text which gives nuance, these are worthless"* (Patient F 02). One person with MS thought that *"when you go through a questionnaire, you don't really want to revisit the symptoms that you feel and the changes that have come about in you as a person"* (Patient I 04). Similarly, both patient and proxy-reported measures were considered acceptable: *"it would be quite interesting getting both of you, the family member and yourself and see what the difference is"* (Patient I 04), but one clinician had concerns that family members may not want to fill in proxy-reported measures.

Some participants thought that symbol substitution was relevant and had ecological validity. One person with MS reported that it was *"like looking at a spreadsheet isn't it! [Laughs] Making sure your data is correct"* (Patient I 09), although conversely, one person with MS felt that the task would benefit from extra context about the test, and would benefit from a *"simple explanation of 'this is what this test is looking for'"* (Patient I 11). This was a common theme from participants who were shown the measures, with another person with MS stating *"I think it's really, really important to provide people that*

information because otherwise you don't know if people just look at it and go 'oh it's just another one of these things that I have to fill in and then never hear back about'" (Patient I 13).

Many people with MS found the paced addition style tasks difficult, fatiguing and potentially anxiety inducing. One participant reported they would *"probably hate to do that one"* (Patient I 02), others were also unwilling to complete it, stating *"I'm not doing that. I've more important things in life, that's what I'd think"* (Patient F 01) and *"I wouldn't even enjoy doing it, so why would I bother"* (Patient I 07). Some people with MS indicated that they would still try to complete the task, despite possibly struggling with it and believed that their premorbid mathematical ability may have more of an impact than their cognitive impairment *"the reason the score's so low is because I just can't do it!"* (Patient F 02). A neuropsychologist agreed that *"the resounding feedback for the PASAT with patients is a 'no!'"* (Psychologist 05).

iii. Practical Aspects of Cognitive Screening

(a) Mode of delivery

All stakeholders felt that online administration of cognitive tests was an acceptable option, and digitisation may fit in well with other electronic systems such as patient records. However, there were concerns from clinicians that it may lead to non-completion, *"there will be a big chunk of people that don't do it. But that is just in relation to general kind of self-management, I suppose, and how well... kind of engaged people are with that"* (OT 01). People with MS and their family members thought that other people with MS may have challenges with electronic completion, especially older individuals, and those lacking confidence with technology or not having the appropriate equipment. However, none of those interviewed thought they themselves would experience difficulty with technology.

Electronic versions may overcome obstacles, such as anxiety induced by face-to-face administrations. One volunteer said *"I'd be a bit worried, I'd be a bit panicky, and then I'll be sitting there thinking I can't think... in a face-to-face situation I think it could be quite intense"* (Volunteer 04). Electronic versions may also overcome dexterity issues. One volunteer thought they would have difficulties with pen-and-paper assessments, which could lead to inaccurate scoring, as *"pressing a screen is a lot easier than holding a pen for me... I would struggle more... I would definitely be slower"* (Volunteer 01).

Clinicians raised concerns that some tests, such as figure copying, word list learning, and verbal fluency tests would be challenging, if not impossible to digitise, and the change in modality would require new normative data to be collected for assessments. One neurologist emphasised that handheld administrations need further work by *"looking to see how the tests perform in mobile versus tablet and what kind of people use one or the other or how it compares to the two"* (Neurologist 03).

More difficulty was ascribed to using a keyboard and mouse rather than touchscreen devices, which people with MS reported to be more familiar with, and felt *“it’s most convenient, it’s easier”* (Patient I 13). Clinicians agreed that tablets would be easier to use in clinic than a laptop or desktop computer but restricting assessment to this format may preclude people from self-administration, however, traditional verbal or written tests could be made available.

(b) Location of testing

Most people with MS preferred the option of completing the screening at home electronically and emphasised the potential benefits of this. These included saving time and being more comfortable at home, thus providing a better reflection of their “true” cognitive ability. An OT agreed with this, saying *“we probably would get more honest information if people had time to give it at home, and bring the results with them”* (OT 02).

MS nurses thought in-clinic testing would be impractical. Waiting rooms were viewed as inappropriate for assessment – both people with MS and clinicians perceived them as too busy, loud and unsuitable to complete tests: *“just think chaos”* (Volunteer 05). Screening during appointments was also perceived as inappropriate due to time constraints. One participant was very resistant to spending any more time in clinic than they had to, saying that before and after their appointments they are *“angry and all it does is give me a hard time dealing with my illness”* (Patient I 07).

Participants agreed that it was important to still have the option of completing the screening in clinic, if people with MS could not complete it at home. There were also perceived advantages to completing in clinic, including having *“all assessments and results in hand and patients don’t forget about it”* (MS Nurse 05). The results of the screening may be anxiety inducing, and people with MS may want reassurance about their results as soon as possible:

“If they feel that they’re a bit isolated and they’re not going to know for a while what the results are, if they – I guess it’s a bit different than doing it kind of face to face and getting reassurance straight away of you” (OT 01).

Resources in clinic are limited, especially in terms of time and staff. Clinicians reported that most neurology appointments are time limited, and often over-run, however OT appointments were longer and potentially more suitable. These appointments are unlikely to be routine for most people with MS, so it is not feasible to rely on OTs for screening.

(c) Time associated with cognitive assessments

People with MS thought that screening should be brief enough to prevent fatigue and a lapse in concentration, and 2-5 minutes of screening would be acceptable, but a few people with MS felt tests

could be up to 60 minutes long if they needed to be. Stakeholders thought that brief screening would encourage people with MS to complete screening at home and ensure they were not too tiring:

“These tests are requiring a great deal of commitment and input and, as I said, I have to be very careful about how I spend my energy and I would probably end up at the end of the day feeling a little hard done by because I’d done that and I wanted to do something else” (Patient I 07).

The lack of time during appointments with clinicians was also reflected when asked about who should feedback results to people with MS. Some people with MS thought that their neurologist would be the best person, especially if the results indicated cognitive decline, to afford an opportunity for people with MS to ask questions, and discuss the results face-to-face. One carer stated that *“it’s very important this trust element, that is vital, but you can only create this trust if the professional has got the correct information”* (Family member 09). Some people with MS stated a preference for their results to be given by an MS nurse, as they had a better relationship and longer appointment times with them compared with their neurologist.

Clinicians observed that the discussion would have to be brief to fit into existing appointments with neurologists or MS nurses. MS nurses reported not having enough time in their current workload to contend with cognitive problems, and some viewed this as the job of other healthcare professionals, such as OTs, while they saw their remit focusing on DMTs and managing physical symptoms. One OT thought *“that wasn’t the most effective use of [OT’s] time”* (OT 02). Neurologists thought that other healthcare professionals such as physiotherapists, psychologists or OTs, or volunteers could be trained to administer the screening. All participant groups thought that volunteers could play a part in the screening, including providing help and support to complete the assessments. People with MS felt it was important that the person administering the cognitive tests should understand MS and be able to explain the rationale and provide support for completion.

Clinicians also thought that administrative staff could be involved and trained to administer the screening pathway. Commissioners and neurologists felt that the screening programme could increase the workload for administrative staff:

“You could provisionally have a trained receptionist to give a tablet, and say can you do this, and then can you give the tablet to me please, so I can give it to the next patient. That of course, you know, implies some cooperation and willingness of the receptionist to facilitate” (Neurologist 01).

DISCUSSION

All participants showed awareness that cognitive impairment was a symptom of MS, and the majority of people with MS reported experiences of cognitive impairment. The impact of cognitive impairment was varied, but many people with MS explained how it had affected their employment, relationships, the management of their MS, and quality of life. People with MS perceived that all aspects of their memory (including working, prospective and episodic memory), attention and concentration, processing speed, and language skills were affected. Clinicians agreed that these cognitive domains were altered. It was also clear that cognitive symptoms were closely related to mental health issues and fatigue.

Like in Mortensen et al. (2020), we found that routine cognitive screening was seen as valuable for both people with MS and clinicians. Both objective and subjective cognitive assessments were viewed as appropriate. However, despite the prevalence and perceived importance of cognitive impairment, both clinicians and people with MS in our study did not routinely discuss this, and referrals to specialist services were infrequent. Time constraints of appointments, and physical symptoms (such as bowel and bladder problems) reportedly took precedence in appointments over cognitive problems. Very few people with MS had received a referral or assessment for cognitive problems. Clinicians also reported a lack of staffing and resources, such as private rooms in MS clinics, making administration of cognitive assessments challenging. Clinicians' disinclination to discuss cognitive problems in routine appointments could be because of the lack of appropriate cognitive assessments or management clinics/services available to refer their patients to.

The existing situation suggests that the implementation of routine cognitive screening would need to take these resource limitations into consideration. Participants agreed that self-administered electronic screening completed in patients' homes would mitigate some of these obstacles.

A screening programme would need to be managed carefully to ensure sustainability within the UK healthcare system. Participants were clear that a cognitive screening programme should be administered with a rationale as to why people with MS were being asked to engage with it, as well as what would happen after the screening in terms of getting results, and potential cognitive treatment or management that could be offered.

It is critical to establish which forms of assessments people with MS would find acceptable to complete, and clinicians to administer. The paced addition style task was the only assessment that people with MS viewed negatively. This was echoed by clinicians, who reported that participants often refused this test, and is consistent with research findings (Cortés-Martínez et al., 2019). Other assessments, such as a symbol substitution, were more widely accepted, and an enthusiasm for self-administration is also reflected in other studies (Patel et al., 2019). People with MS showed an understanding of the rationale of the assessments and thought they reflected relevant cognitive domains they had difficulty with, but

would not be so challenging that they would reject completion. Some people may reject assessments they are asked to complete outright, and an assessment programme should take this into account. Rejection of objective assessments could lead to cognitive impairments not being identified, and not receiving appropriate care if they are experiencing cognitive problems. This suggests that clinicians should have other methods of identifying impairment, such as subjective questionnaires, and discussions with their patients. Despite their limitations, subjective questionnaires, such as the MSNQ, may be more familiar and less intimidating than objective assessments of cognition. Some people with MS also thought that people may feel anxious about discussing cognitive problems, and may not want to examine this sensitive topic, either in their medical appointments or in conversations with researchers.

Electronic self-administration at home was acceptable to all participants and reflects recommendations for brief screening in MS (Kalb et al., 2018). Self-administration could protect clinic time, and for people with MS, reduce the time spent at the hospital. However, care should be taken to ensure that a lack of technology, or an unwillingness or inability to complete the assessments, does not preclude people with MS in receiving treatment for cognitive problems. The development of an electronic, self-administered cognitive screen would require careful consideration and evidence of its validity, and new normative data for interpretation (Bauer et al., 2012). UK healthcare is moving towards a digital future, and the role of the patient is important to ensure that this meets their needs (Topol, 2020). It is likely that due to changes in neurology clinics during COVID-19, and for the foreseeable future, telemedicine and digital assessments will be adopted more frequently (Mummery & Kipps, 2020). Traditionally, the administration of neuropsychological assessments is restricted by test publishers to those with specified neuropsychological expertise and experience (Puente et al., 2006). However, digitisation can automate the administration and scoring of screening assessments, and widen administration to include MS nurses, and other clinic staff. This could overcome some of the resource constraints that were reported by clinicians in coordinating and assisting patients to complete cognitive screening assessments. This will also be facilitated by other aspects of digitisation such as sending a link to patients, and directing digital results to clinicians, which could form a part of routine administration by staff. However, formal neuropsychological assessments should continue to be administered, scored, and interpreted only by those trained to do this.

These conclusions are limited by some methodological considerations. The overarching research programme of NEuRoMS encompasses a proposed pathway of both cognitive screening and management of cognitive problems provided in routine care within the UK NHS. We have focused on the cognitive screening element within this paper, but it is important to note that participants were aware that screening forms a part of a pathway that could offer cognitive rehabilitation as opposed to screening presented as a discrete undertaking. In addition, the focus of the pathway's implementation within the UK healthcare system may have limited applicability to different countries, and/or different systems.

We presented seven different assessments that are frequently used in MS, however this is not the full range of assessments in-use. We recruited people with MS using an opportunistic sample from our PPI network, promotion of the research through MS charities, advertisements placed on social media sites and word of mouth, and clinicians from our professional networks. This, like in most qualitative research, is not (meant to be) a representative sample. In our Participant Information Sheets, we stated that interviews lasted for up to an hour, and this could be unappealing, or not feasible for people with MS with severe symptoms, both physically and cognitively. We attempted to allay this concern by offering to conduct interviews at participants' homes, or remotely via video conferencing or telephone. Similarly, we intended to recruit a greater sample of both clinician and people with MS to conduct a number of focus groups with people with MS, and clinicians. We found that participants, particularly clinicians, preferred interviews, which had more flexibility in terms of time and place, than a focus group. The focus group had a smaller number of people with MS (five) than we were hoping to recruit. However, this study benefited from a mixture of interviews and a focus group, a large sample and a range of stakeholders.

The results of this qualitative study show that brief cognitive screening with simple assessments, such as symbol substitution, for routine administration is both feasible and acceptable for people with MS and clinicians, however cognitive assessments should be managed carefully. Patient preference indicates self-administration and electronic assessments completed on their own handheld device could overcome barriers such as limited clinic resources. However, there are challenges with this approach, including adapting tests successfully to this modality, and these need to be considered carefully. Future research should ensure modality changes from traditional written or verbal assessments are robust in their validity and reliability, as well as providing adequate accuracy in sensitivity and specificity.

References

- Amato, M. P., & Zipoli, V. (2003). Clinical management of cognitive impairment in multiple sclerosis: A review of current evidence. *International MS Journal*, *10*(3), 72–83.
- Bauer, R. M., Iverson, G. L., Cernich, A. N., Binder, L. M., Ruff, R. M., & Naugle, R. I. (2012). Computerized Neuropsychological Assessment Devices: Joint Position Paper of the American Academy of Clinical Neuropsychology and the National Academy of Neuropsychology. *Archives of Clinical Neuropsychology*, *27*(3), 362–373. <https://doi.org/10.1093/arclin/acs027>
- Benedict, R. H. B., Fischer, J. S., Archibald, C. J., Arnett, P. A., Beatty, W. W., Bobholz, J., Chelune, G. J., Fisk, J. D., Langdon, D. W., Caruso, L., Foley, F., LaRocca, N. G., Vowels, L., Weinstein, A., DeLuca, J., Rao, S. M., & Munschauer, F. (2002). Minimal neuropsychological assessment of MS patients: A consensus approach. *The Clinical Neuropsychologist*, *16*(3), 381–397. <https://doi.org/10.1076/clin.16.3.381.13859>
- Benedict, R. H., Munschauer, F., Linn, R., Miller, C., Murphy, E., Foley, F., & Jacobs, L. (2003). Screening for multiple sclerosis cognitive impairment using a self-administered 15-item questionnaire. *Multiple Sclerosis Journal*, *9*(1), 95–101. <https://doi.org/10.1191/1352458503ms861oa>
- Cortés-Martínez, A., Matias-Guiu, J. A., Pytel, V., Montero, P., Moreno-Ramos, T., & Matías-Guiu, J. (2019). What is the meaning of PASAT rejection in multiple sclerosis? *Acta Neurologica Scandinavica*, *139*(6), 559–562. <https://doi.org/10.1111/ane.13090>
- Cullen, B., O'Neill, B., Evans, J. J., Coen, R. F., & Lawlor, B. A. (2007). A review of screening tests for cognitive impairment. *Journal of Neurology, Neurosurgery, and Psychiatry*, *78*(8), 790–799. <https://doi.org/10.1136/jnnp.2006.095414>
- Fischer, M., Kunkel, A., Bublak, P., Faiss, J. H., Hoffmann, F., Sailer, M., Schwab, M., Zettl, U. K., & Köhler, W. (2014). How reliable is the classification of cognitive impairment across different criteria in early and late stages of multiple sclerosis? *Journal of the Neurological Sciences*, *343*(1), 91–99. <https://doi.org/10.1016/j.jns.2014.05.042>

- Germine, L., Reinecke, K., & Chaytor, N. S. (2019). Digital neuropsychology: Challenges and opportunities at the intersection of science and software. *The Clinical Neuropsychologist*, 33(2), 271–286. <https://doi.org/10.1080/13854046.2018.1535662>
- Hansen, S., & Lautenbacher, S. (2017). Neuropsychological Assessment in Multiple Sclerosis. *Zeitschrift Für Neuropsychologie*, 28(2), 117–148. <https://doi.org/10.1024/1016-264X/a000197>
- Kalb, R., Beier, M., Benedict, R., Charvet, L., Costello, K., Feinstein, A., Gingold, J., Goverover, Y., Halper, J., Harris, C., Kostich, L., Krupp, L., Lathi, E., LaRocca, N., Thrower, B., & DeLuca, J. (2018). Recommendations for cognitive screening and management in multiple sclerosis care. *Multiple Sclerosis Journal*, 24(13), 1665–1680. <https://doi.org/10.1177/1352458518803785>
- Klein, O. A., das Nair, R., Ablewhite, J., & Drummond, A. (2018). Assessment and management of cognitive problems in people with multiple sclerosis: A National Survey of Clinical Practice. *International Journal of Clinical Practice*, e13300. <https://doi.org/10.1111/ijcp.13300>
- Lambert, S. D., & Loisele, C. G. (2008). Combining individual interviews and focus groups to enhance data richness. *Journal of Advanced Nursing*, 62(2), 228–237. <https://doi.org/10.1111/j.1365-2648.2007.04559.x>
- Langdon, D. W., Amato, M. P., Boringa, J., Brochet, B., Foley, F., Fredrikson, S., Hämäläinen, P., Hartung, H.-P., Krupp, L., Penner, I. K., Reder, A. T., & Benedict, R. (2012). Recommendations for a Brief International Cognitive Assessment for Multiple Sclerosis (BICAMS). *Multiple Sclerosis (Houndmills, Basingstoke, England)*, 18(6), 891–898. <https://doi.org/10.1177/1352458511431076>
- Lensch, E., Matzke, M., Petereit, H.-F., Scherer, P., Schramm, S., & Calabrese, P. (2006). Identification and management of cognitive disorders in multiple sclerosis. *Journal of Neurology*, 253(1), i29–i31. <https://doi.org/10.1007/s00415-006-1107-x>
- Mc Auliffe, A., & Hynes, S. (2019). The Impact of Cognitive Functioning on Daily Occupations for People with Multiple Sclerosis: A Qualitative Study. *The Open Journal of Occupational Therapy*, 7(3), 1–12. <https://doi.org/10.15453/2168-6408.1579>

- Mortensen, G. L., Theódórsdóttir, Á., Sejbæk, T., & Illes, Z. (2020). Patient Attitudes to Routine Cognitive Testing in Multiple Sclerosis. *Patient Preference and Adherence*, *14*, 693–704. <https://doi.org/10.2147/PPA.S245623>
- Mummery, C. J., & Kipps, C. M. (2020). UK neurology response to the COVID-19 crisis. *Clinical Medicine*, *20*(3), 266–269. <https://doi.org/10.7861/clinmed.2020-0159>
- Patel, V. P., Shen, L., Rose, J., & Feinstein, A. (2019). Taking the tester out of the SDMT: A proof of concept fully automated approach to assessing processing speed in people with MS. *Multiple Sclerosis Journal*, *25*(11), 1506–1513. <https://doi.org/10.1177/1352458518792772>
- Pope, C., Ziebland, S., & Mays, N. (2000). Analysing qualitative data. *BMJ: British Medical Journal*, *320*(7227), 114–116.
- Puente, A. E., Adams, R., Barr, W. B., Bush, S. S., NAN Policy and Planning Committee, Ruff, R. M., Barth, J. T., Broshek, D., Koffler, S. P., Reynolds, C., Silver, C. H., & Tröster, A. I. (2006). The use, education, training and supervision of neuropsychological test technicians (psychometrists) in clinical practice. *Archives of Clinical Neuropsychology*, *21*(8), 837–839. <https://doi.org/10.1016/j.acn.2006.08.011>
- Shevil, E., & Finlayson, M. (2006). Perceptions of persons with multiple sclerosis on cognitive changes and their impact on daily life. *Disability and Rehabilitation*, *28*(12), 779–788. <https://doi.org/10.1080/09638280500387013>
- Smith, L., Elwick, H., Mhizha-Murira, J. R., Topcu, G., Bale, C., Evangelou, N., Timmons, S., Leighton, P., & das Nair, R. (2020). Developing a clinical pathway to identify and manage cognitive problems in Multiple Sclerosis: Qualitative findings from patients, family members, charity volunteers, clinicians and healthcare commissioners. *Multiple Sclerosis and Related Disorders*, 102563. <https://doi.org/10.1016/j.msard.2020.102563>
- Topol, E. (2020). *The Topol Review—NHS Health Education England*. <https://topol.hee.nhs.uk/>
- Vasileiou, K., Barnett, J., Thorpe, S., & Young, T. (2018). Characterising and justifying sample size sufficiency in interview-based studies: Systematic analysis of qualitative health research over a 15-year period. *BMC Medical Research Methodology*, *18*(1), 148. <https://doi.org/10.1186/s12874-018-0594-7>

Wyatt Knowlton, L., & Phillips, C. C. (2012). *The Logic Model Guidebook: Better Strategies for Great Results*. SAGE Publications.