



“Is there anything you would like to tell us about your experience today?”

A Content Analysis.

Polly Swain<sup>1\*</sup>, Lauren A Taylor<sup>2,1</sup>, Haley Morris<sup>1</sup>, Nikos Evangelou<sup>1,2</sup>, Roshan das Nair<sup>2,3</sup> on behalf of the NEuRoMS collective.

<sup>1</sup>Nottingham University Hospitals NHS Trust, Research and Innovation, Nottingham, UK, <sup>2</sup>Mental Health and Clinical Neurosciences Unit, School of Medicine, University of Nottingham, Nottingham, UK, <sup>3</sup>SINTEF Digital, Trondheim, Norway.

\*Polly.Swain@nuh.nhs.uk

Background:

- The NEuRoMS project (www.neuroms.org) invites all people with MS (pwMS) to complete a brief online cognitive screening as part of a new clinical pathway, ahead of their MS clinic appointment. This screening facilitates discussions between patients and their clinician regarding their cognition.
Patients are also invited to provide open comments (limited to 250 characters), to encourage them to raise any health concerns and offer feedback about NEuRoMS.
There is a need to investigate concerns that patients highlighted during screening, to identify where support from MS clinical services should be prioritised, and how to incorporate their feedback.

Aims:

To explore patient responses to:

- Gain insight into their experiences, with the aim of improving MS healthcare and ensuring support offered is informed by patient need.
Assess the usability and acceptability of an online cognitive screening tool in clinical care.

Cognitive difficulties affect up to 70% of people with MS<sup>1</sup>.

Patients are asked: ‘Is there anything you would like to tell us about your experience today?’

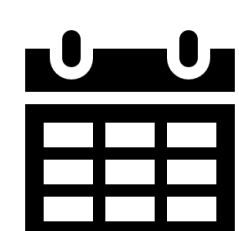
Treatments for pwMS are typically focused towards physical illness with limited psychological provision.<sup>2</sup>

Methods:



1017 patients completed the online cognitive screening

Nottingham University Hospitals NHS Trust



Responses were given between 10/09/2021 – 09/01/2023

61.06% chose to respond to the open question

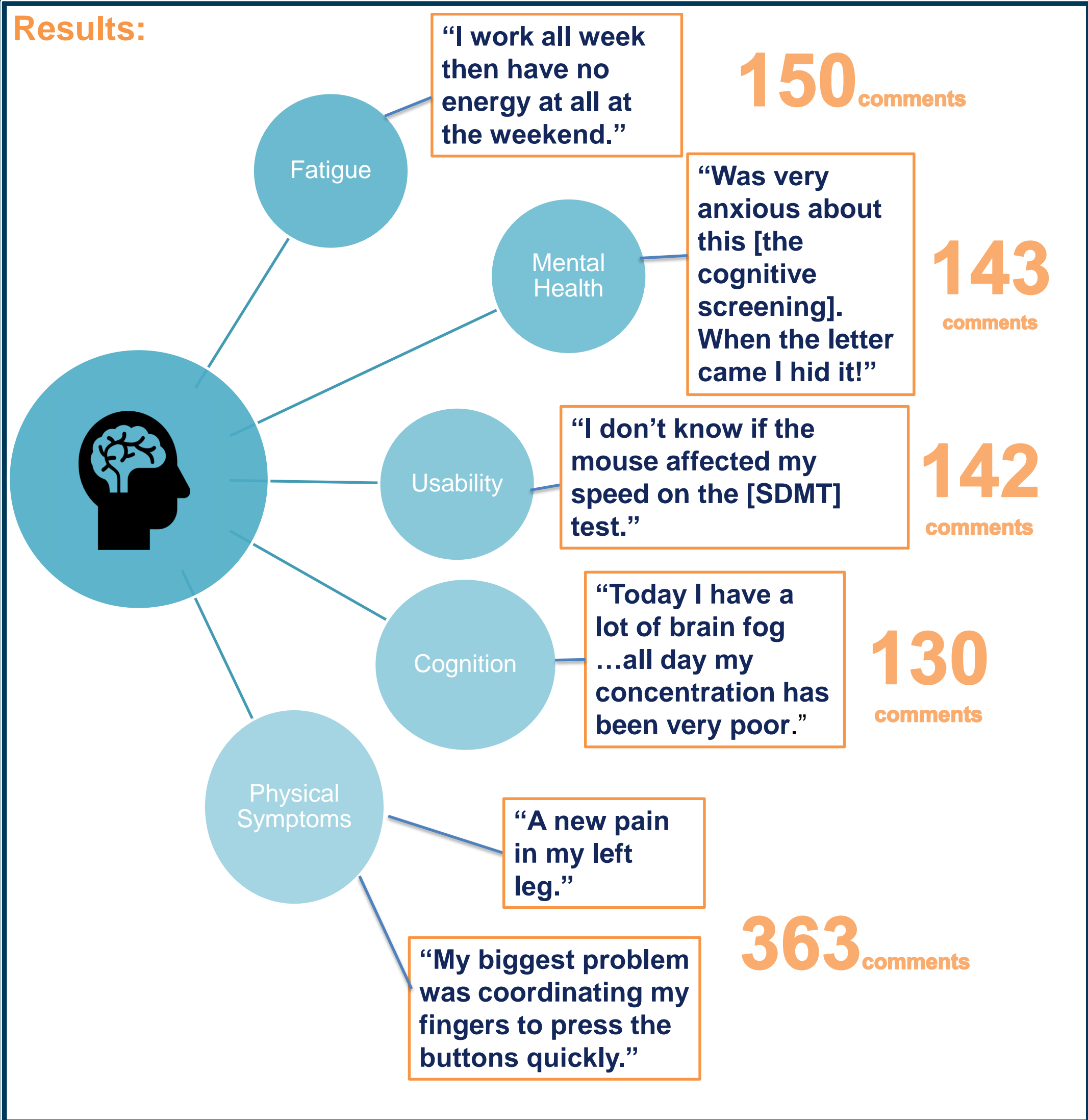


- We conducted an inductive content analysis of responses by 621 pwMS who completed the cognitive screening<sup>3</sup>. Three reviewers independently coded the data and five categories were synthesised collaboratively.

Patient and Public Involvement:

The NEuRoMS online cognitive screening was developed in collaboration with stakeholders including people with MS and care providers as well as members of the MS clinical team.<sup>2,4</sup> The inclusion of a free-text open question was informed by stakeholder feedback that an opportunity for nuance and context should be given<sup>4</sup>.

Results:



Discussion:

- Overall, the online screening tool was found to be acceptable. However, there is a need for adaptations in the screening for those with vision and dexterity difficulties.
In addition to cognitive difficulties, patients also reported on their physical symptoms, mental health, and fatigue (that might have affected the screening).

Implications:

- The findings highlighted the interdependence of cognitive difficulties with changes to mood and fatigue and shows a subsequent need for the development and implementation of multidisciplinary interventions such as a tailored psychological or fatigue management service to increase the support patients receive in a tertiary service.

Acknowledgement: This study is funded by the National Institute for Health and Care Research (NIHR) under its Programme Grants for Applied Research Programme (RP-PG-0218-20002). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

References

- 1. Julian LJ. Neurol Clin 2011; 29: 507-525. doi: 10.1016/j.ncl.2010.12.003.
2. Smith L, et al. Mult Scler Relat Disord 2021; 49: 102563. doi: 10.1016/j.msard.2020.102563.
3. Elo, S. and Kyngäs, H., 2008. J Adv Nurs. 62(1),107-115. doi: 10.1111/j.1365-2648.2007.04569.x
4. Elwick H, et al. Neuropsych Rehab 2022, 32.7: 1456-1474. doi:10.1080/09602011.2021.1899942