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## Background

People with progressive MS (PwPMS) often have a high disease burden. There are a wide variety of symptoms that can affect them, and these are often complex and interrelated. Management of symptoms is essential for effective self-management leading to improved quality of life and reduced secondary complications. Current clinical guidelines state all people with MS should have a regular review of their symptoms with a specialist healthcare professional (HCP) (1). Cognitive impairment is higher in PwPMS than in relapsing remitting MS (RRMS). Research reports it to be as high as 74% in primary and 86% secondary progressive MS. Cognitive impairment in progressive MS commonly affects short term memory and information processing (2). This is just one of several symptoms that can impact on the ability of PwPMS to recall and retain information in clinic appointments.

Mobile apps are advocated as a technology that could improve healthcare access, delivery and to support self-management in long-term conditions (3). So far, the evidence in MS is limited, research that has been conducted often excludes PwPMS and those with more complex disabilities. Further to this many studies have recruited using digital platforms. These issues have resulted in the opinions of an older, more complex and less digitally active group of patients is being missed.

## Method

**Participants:**  
 Purposive sample of adults with primary or secondary progressive MS.

**Recruitment:**  
 Via three charities: The MS Society, Shift.ms and The MS Trust,

**Procedure:**  
 Focus group (n=6)  
 Semi-structured interviews (n=6)

**Data analysis:**  
 6-step thematic analysis (4)



## Aims

- Determine what strategies if any PwPMS use to recall and retain symptom information.
- Determine what the attitudes are of PwPMS to using mobile apps for symptom management.

## Findings

- Participants used a variety of strategies to support them in appointments such as taking someone with them and making notes. Strategies used were not always successful.
- Participants were motivated and interested in apps for symptom monitoring. Many were concerned they would not have the skill to use apps successfully.
- Participants were older and had lower level of smartphone ownership than previously studied with high incidence of memory impairment reported (n=9).
- Most participants struggled to understand the benefits of symptom management and felt review appointments to be a waste of time. Participants reported stories where HCP has supported this view.

*My phone is a £26 Tesco phone. It does all I want it to do.*

*I do write things down on a bit of paper. I went to see my MS nurse the other day and forgot to get it out.*

*A lot of the time you forget about things, if you were able to put things in an app and take it to your neurologist that would be brilliant.*

*My wife comes to physio. She helps so I don't forget the important bits.*

*In the progressive stage where there is basically nothing that can be done, my appointments are short and I come away thinking it's a waste of time to be honest.*

## Conclusion

- Researchers must make greater effort to include these older less “tech savvy” populations, otherwise we risk leaving them behind in a wave of technological advancements.
- HCP need to understand the challenges PwPMS face when recalling and retaining information in clinics. Patients and HCP need support to understand the positive impact good symptom management can have.
- Apps could facilitate, engage and motivate PwPMS to monitor and share symptom information more efficiently.

### References

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