THE IMPACTS OF INCLUDING A PPI EMBEDDED PATIENT RESEARCHER ON CLINICAL TRIALS FOR MULTIPLE SCLEROSIS

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INTRODUCTION

Traditionally, public and patient involvement (PPI) in research has included people with multiple sclerosis (MS) in consultation roles rather than deeper levels of 'involvement'. There has also been limited evidence regarding the impact that such involvement has on the person living with MS or on trials which employ people living with MS, as part of the research team. Here we report on the experiences of a person living with MS who is embedded in a clinical trial throughout the lifetime of the project - an embedded patient researcher (EPR).

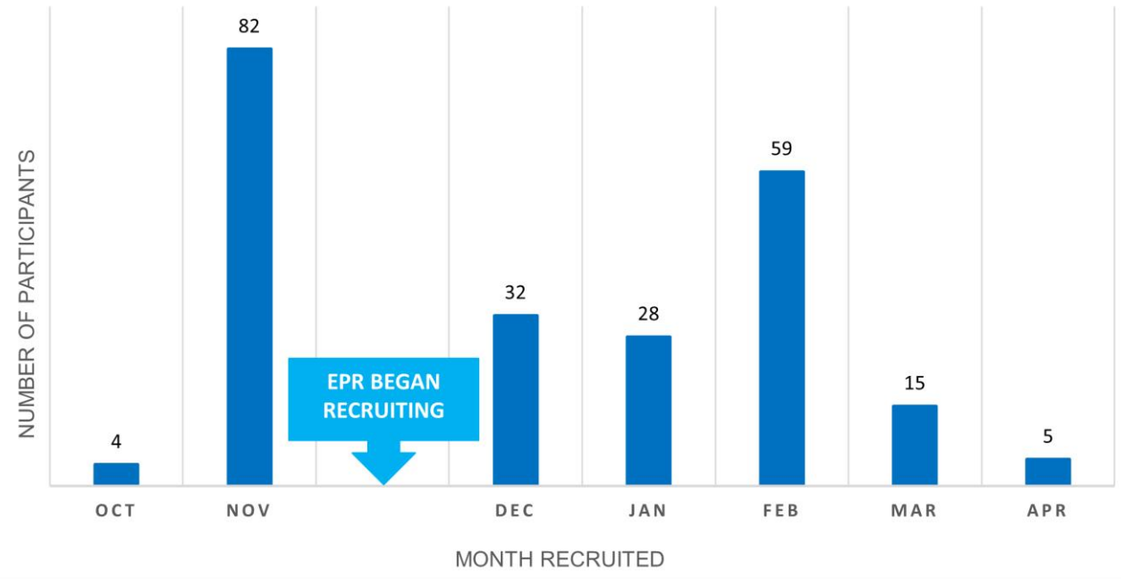

FIG. 1. TIMELINE OF TRIAL PARTICIPANT RECRUITMENT (2019-2020)

AIMS & OBJECTIVES

The aim of this research is to explore and present an embedded patient researcher's (EPR) perspective on PPI integration within a feasibility trial of a Cognitive Occupation-Based programme for people living with MS (COB-MS) [1], with respect to the PPI impact on trial feasibility and potential success.

METHODS

This presentation is focused on three specific examples of EPR impact, regarding recruitment, trial materials and adapting to the impact of SARS-CoV-2 on the trial. Due to the high level of PPI integration within COB-MS, significant amendments were made.

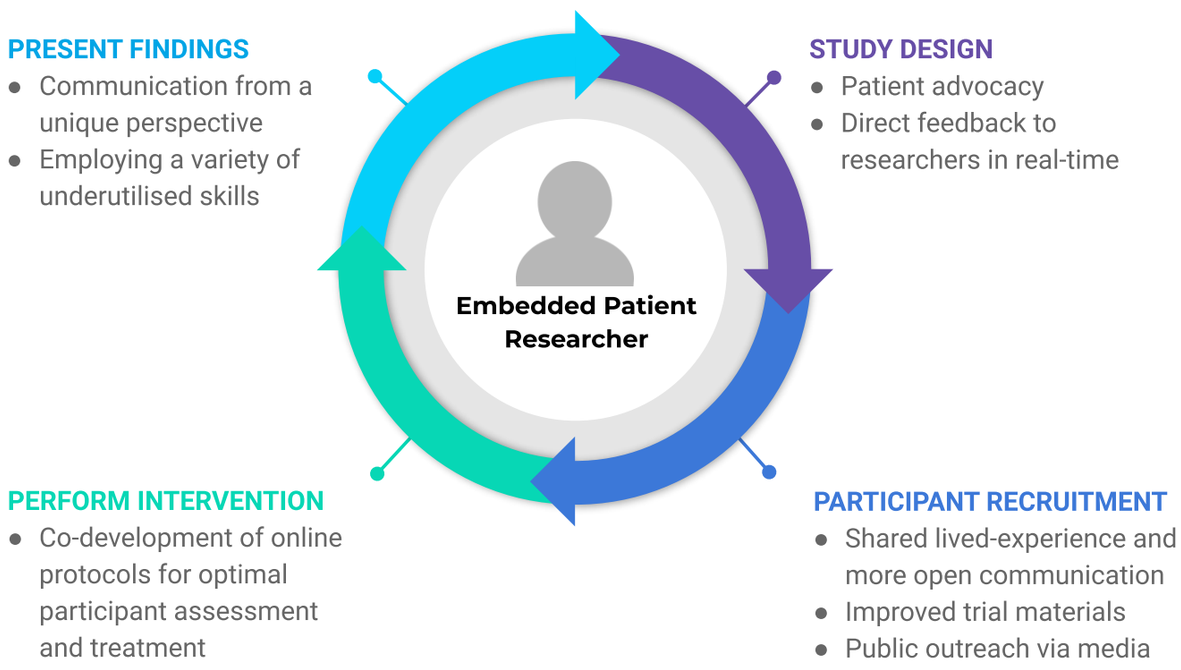

FIG. 2. THE VALUE OF THE EPR IN THE RESEARCH PROCESS

RESULTS

As a result of a high level of PPI integration, the research team identified the recruitment of between 34% - 62% of participants as a result EPR involvement (Fig. 1), which also influenced the decision to extend the role of the EPR to include Patient Advocacy. The EPR's involvement facilitated the development of more accessible trial materials for participants with MS and the development of online protocols for the treatment and assessment of participants (Fig. 2).

CONCLUSION

When fully integrated into a trial, PPI – along with the inclusion of an EPR – has the potential to improve participant recruitment, trial material development and adaptability as a result of external factors impacting the trial (with respect to being more suitable for participants with MS.) It has also encouraged the EPR to develop further as a Patient Advocate, by sharing their experience with patients wanting to become more involved in research as well as researchers and educators who want to incorporate PPI in their research or training.

Reference

1. Dwyer *et al.* Evaluating the feasibility and preliminary efficacy of a Cognitive Occupation-Based programme for people with Multiple Sclerosis (COB-MS): protocol for a feasibility cluster-randomised controlled trial. *Trials* [online]. 2020 [Accessed 28 September 2021];21(1):269. Available from: https://trialsjournal.biomedcentral.com/articles/10.1186/s13063-020-4179-5