



Exploring Patient and Public Involvement in Motor Neurone Disease



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Introduction

- Patient and public involvement (PPI) is a practice whereby patients and the public are involved in the conduct of research. There are political ¹, moral ², epistemological ³ and consequentialist ⁴ arguments for the importance of PPI.

Aim

- To explore the experiences of patients, carers, volunteers and researchers who participate in, organise and work with the Sheffield Motor Neurone Disorders Research Advisory Group (SMND RAG).



Sheffield Motor Neurone Disorders Research Advisory Group

Methods

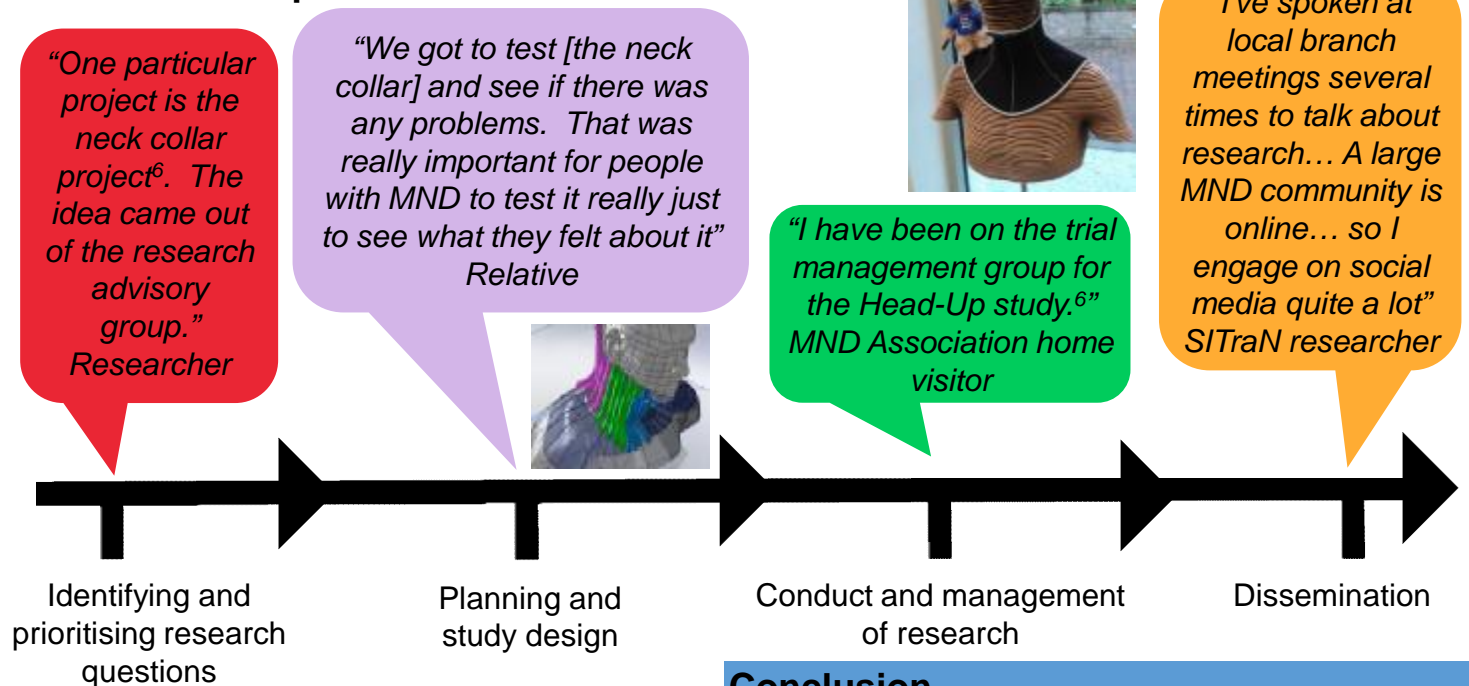
- Semi-structured interviews with 10 members of the SMND RAG and 3 SITraN researchers.
- Topic guide was based on themes found in the literature review and input from the SMND RAG.
- Interviews were audio-recorded, transcribed verbatim and analysed using thematic analysis ⁵.



What is the Head-Up project?

The Head-Up project⁶ aimed to develop a product to provide head support for people with Motor Neurone Disease. The neck collar, often referred to as the **Sheffield Support Snood**, was developed in collaboration with SMND RAG, patients, their families and healthcare professionals.

The potential value of PPI throughout all stages of the research process



Recommendations for successful PPI in Motor Neurone Disease research

- PPI groups benefit from a broad range of individuals with experience of MND, including patients, relatives, charity workers and volunteers.
- Induction, support and training should be provided and tailored to the individual.
- A successful group can take ownership of their contribution and the research in which they are involved.
- Researchers should engage fully with PPI members.
- Funding bodies should allow sufficient time and funding for PPI.

Conclusion

PPI can have a positive impact on many aspects of research and also on those involved. Successful PPI requires a supported, collaborative approach between people with experience of MND and researchers.

We thank the members of the Sheffield Motor Neurone Disorders Research Advisory Group and the researchers who have taken part in this study.

References

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- 2 Carter et al. 2013. *Contemporary Social Science* 8:307-20
- 3 McKeivitt. 2013. *Evid Policy* 9:113-130
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- 5 Braun & Clarke. 2006. *Qual Res Psychol* 3:77-101
- 6 Reed et al. 2014. *J Med Eng Technol* 39:404-10

Dr E Hobson is an NIHR doctoral research fellow. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.