Methods

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

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).

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

Identifying and prioritising research questions

“One particular project is the neck collar project6. The idea came out of the research advisory group.”
Researcher

Planning and study design

“We got to test [the neck collar] and see if there was any problems. That was really important for people with MND to test it really just to see what they felt about it”
Relative

Conduct and management of research

“I have been on the trial management group for the Head-Up study.6”
MND Association home visitor

Dissemination

“I’ve spoken at local branch meetings several times to talk about research… A large MND community is online… so I engage on social media quite a lot”
SITraN researcher

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.

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References

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