Article:

Musson, L.S. orcid.org/0000-0002-1246-2734, McDermott, C.J. orcid.org/0000-0002-1269-9053 and Hobson, E.V. orcid.org/0000-0002-8497-2338 (2019) Exploring patient and public involvement in motor neuron disease research. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 20 (7-8). pp. 511-520. ISSN 2167-8421

https://doi.org/10.1080/21678421.2019.1643373

Exploring patient and public involvement in motor neuron disease research

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Abstract

Objectives
Patient and public involvement (PPI) is a relatively new practice whereby researchers involve patients and the public in the conduct of their research. The Sheffield Motor Neurone Disorders Research Advisory Group (SMNDRAG) is one of the first groups to specialise in motor neuron disease (MND). Its members include people living with MND, carers, relatives, volunteers, clinicians and scientists. Our aim was to explore the experiences of those who participate in, organise and work with the SMNDRAG.

Methods
We conducted 13 semi-structured interviews: ten with members of the SMNDRAG and three with researchers who have worked with the group. We used thematic analysis to identify ways in which the group influenced research and the barriers and enablers to PPI.

Results
A number of motivations for participating in the SMNDRAG were reported but the majority were altruistic. The SMNDRAG offered individuals psychosocial and intellectual benefits. The SMNDRAG has overcome a number of practical and psychological barriers to develop a successful and effective collaborative partnership resulting in a positive impact on research and researchers at each stage of the research process. For example, the group identified research priorities which ensured that research was patient-focused. However, several barriers remain, including the lack of diversity within the group and the perception that PPI participation requires a "certain type of person."

Conclusions
PPI can make a valuable contribution to all aspects of research and can have a positive impact on those involved. We recommend ways in which PPI can, and should be incorporated into research.

Key words: Motor neuron disease; amyotrophic lateral sclerosis; patient and public involvement; research advisory group; thematic analysis

Introduction

Traditionally, patients and the wider public had a passive role in research, as participants (1). However, researchers now work with patients and the public to improve the conduct of their research, a practice known as patient and public involvement (PPI). PPI comprises individuals or groups who have experience with health conditions and can use their unique perspective to influence research. It is argued that the public have a right to be involved in research as consumers and funders (2, 3) and most funding bodies now require PPI. Despite this, some still consider PPI to be tokenistic or that it is difficult to incorporate PPI in a meaningful way (4). One analysis of 90 clinical trials found that only 54% had PPI activities reported and less than a third had involvement in shaping the design (5).

The Sheffield Motor Neurone Disorders Research Advisory Group (SMNDRAG) is based at the Sheffield Institute for Translational Neuroscience (SITraN). It is one of the first PPI groups to specialise in motor neuron disease (MND), also known as amyotrophic lateral sclerosis (ALS). The SMNDRAG includes people with MND (pwMND), carers/ex-carers, friends**,** family members, volunteers for the MND Association, a scientific and clinical representative and an administrator. The group aims to enable perspectives of pwMND to be included in research proposals, to identify/prioritise research, to assist in writing documents, to improve recruitment and to help raise awareness of research (6). Members receive informal training via an introduction, support from staff and talks from researchers. Quarterly meetings are held and members receive monthly email updates that include documents to review. Other PPI groups exist but differ in their setup. In North America, the Northeast ALS Consortium's (NEALS) Clinical Research Learning Institute (CRLI) is a much larger system which has trained 300 patient/carers to be "Research Ambassadors" so they can shape and advocate for research (7). In the UK, whilst the SMNDRAG has been active since 2009, more recently, other small groups have formed to enable people to contribute to research (8, 9). This study aimed to understand the conduct and impact that PPI can have on MND research as well as barriers and enablers to PPI by exploring the experiences of members and those who work with the SMNDRAG.

Materials and methods

Recruitment

Members of the SMNDRAG and staff at SITraN received a personal invitation and a participant information sheet via email, face-to-face or telephone. Purposive sampling involved searching the SMNDRAG website (6) to ensure we invited members representing various backgrounds. We continued to invite participants until data saturation was reached (10). Whilst staff experiences were not the primary focus, in response to emerging themes, we sought additional researchers to gain more information. Informed written/witnessed consent was taken.

Data collection

Semi-structured interviews took place May-July 2016 at SITraN (nine participants) or at home (four participants). LM conducted each interview. EH observed the first interview and reviewed each transcript. A topic guide was informed by a literature review and the SMNDRAG (see Appendix A). It included motivations and experiences of joining/participating in the group, barriers and enablers to participation, the role of and perceived impact the group has had on research. Results from early interviews informed the questions for later interviews.

Data analysis

Interviews were audio-recorded and transcribed verbatim by LM. Long pauses, non-verbal communication and post-interview reflections were documented. Thematic analysis was used (11). LM and EH read the transcripts to familiarise themselves with the data. They analysed the data independently using line-by-line reading and open coding. Findings were discussed to agree on codes. They then searched for overall themes, reviewed them and developed sub-themes. The data was then imported into NVivo version 11 (12). LM categorised the codes into key themes and links were discussed.

Patient and public involvement

The study idea was presented to the SMNDRAG. Members showed interest and identified topics through discussion and completing a short form describing things they liked and disliked about the group. The protocol (Appendix B), participant information sheet and consent form were reviewed by the SMNDRAG and feedback integrated. The transcripts were not returned to participants to reduce burden but they reviewed the manuscript to check content validity and contextualise the findings.

Ethics

The South West–Central Bristol Research Ethics Committee provided approval (16/SW/0096). Individual quotes are used but they are identified only by participant's background (e.g. pwMND) to preserve anonymity. This report adheres to the Consolidated Criteria for Reporting Qualitative Studies checklist (13) (Appendix C).

Results

Seventeen people were approached for interviews. Fourteen responded, one of whom declined participation. One carer and patient did not respond but this was not followed up as the patient was very unwell. Thirteen interviews were conducted. Data saturation was reached by the 13th interview when LM and EH independently concluded that no new themes had emerged (10). Ten members of the SMNDRAG and three researchers were interviewed alone (see Appendix D for participant characteristics). The interviews ranged from 14-35 minutes. The mean age was 54 years (range 35-82). The majority were female (61.5%). All participants had qualifications and the majority were educated at university level (76.9%). CMD was interviewed by LM as part of the study.

Five themes were identified: motivations for joining/participating in the SMNDRAG, personal benefits of PPI, barriers and enablers to participating in PPI, barriers and enablers to effective and meaningful PPI and perceived impact of PPI on research. Additional quotes supporting the findings are shown in Appendix E.

Theme 1: Motivations for joining and participating in the SMNDRAG (see Figure 1)
The predominant motivation was a desire to help others, even if it would not help them directly.

"If you could help in any possible way to MND research or helping people. It's this that I wanted to do." (Ex-carer/relative)

Others wanted to raise awareness of research/MND and bring their personal perspective to research. Some felt strongly that pwMND should have a voice in research.

[Insert Figure 1]

Theme 2: Personal benefits of PPI (see Figure 2)
Psychological benefits
Members enjoyed the group, particularly hearing researchers' presentations. Being involved had empowered one pwMND who had previously felt helpless due to their disability and provided a sense of hope. Participants felt valued and the group had a positive impact on participants' self-worth.

"I benefit from it from feeling that I've actually done something to actually contribute." (Ex-carer/relative)

Interacting with the group gave researchers a sense of inspiration. This was particularly important for basic scientists who rarely interact with patients, making it difficult for them to realise the future benefits of their research.

Intellectual benefits
Several participants said they gained knowledge about MND, potential treatments and current research. Researchers learnt about the perspectives of pwMND and developed their lay communication skills.

Social benefits
Members enjoyed being part of a supportive group with shared goals.

"We had that shared experience and there was a lot of comradery." (SITraN employee/relative)

Face-to-face meetings gave members the opportunity to hear from others in the same position and tackled the sense of isolation caused by MND. Staff and volunteers passed on information to the wider community.

[Insert Figure 2]

Theme 3: barriers and enablers to participating in PPI

Participants experienced and/or identified barriers to participation and ways of overcoming these (Figure 3).

[Insert Figure 3]

Psychological factors

The main barrier was a lack of awareness and understanding about PPI as people may be unsure of the contribution they could make.

"Not knowing exactly what it involves... and feeling that they have nothing to offer." (MND Association volunteer/ex-carer)

Staff thought the group was good at promoting itself (e.g. through word-of-mouth) but patients and relatives thought more awareness was needed. The MND Association was seen as helpful for raising awareness about the role people could play in PPI.

Despite assimilating into the group, some felt somewhat of an outsider compared to founding members. Therefore, participants anticipated that people might lack confidence to join an already established group. Participants recognised that people might be discouraged from participating if they believed research to be impenetrable. However, participants agreed that an informal induction was useful for increasing people's confidence, whilst face-to-face meetings and presentations facilitated participation.

Practical factors

SMNDRAG meetings are held in SITraN: some liked that the meetings took place at a research unit but one pwMND thought this might make people feel *"intimidated."* Time commitments and difficulty using technology were seen as potential barriers but participants were supported by the administrator and none felt pressure to attend every meeting or review all documentation. Furthermore, participants felt they benefitted so the time commitment was not a barrier to them (ex-carer/relative).

Factors associated with MND

The majority thought the group could benefit from more pwMND but recognised that as a disabling and terminal disease, prolonged membership was not possible for most. MND posed an emotional challenge as the group worried that members with MND would die. They anticipated that people might not attend if they do not want to be reminded of MND.

Location, access and parking were facilitators but participants spoke of the difficulty for people to travel to meetings if they were disabled or lived further away. Members used email and were enthusiastic about using Skype as it allowed pwMND to continue to contribute. One pwMND reported feeling self-conscious due to their physical limitations and said the meetings can be tiring. Encouraging carers to attend was valued because they could offer additional support. Travel expenses were helpful but one pwMND stated they would prefer funds went to *"more useful causes."*

Theme 4: Barriers and enablers to effective and meaningful PPI

Participants discussed the group dynamics, collaborative partnership and barriers and enablers to effective PPI (Figure 4).

[Insert Figure 4]

Group dynamics

There was a strong sense of ownership and members felt bonded through their shared experiences and goals. Members agreed that the group was friendly and supportive, making it a *"safe place"* (MND Association volunteer) to give honest opinions. This group cohesion was important for recruiting members. A common belief amongst members and researchers was that there is a *"certain type of person"* (pwMND) needed for PPI. However, no one explicitly said what this kind of person was. Inferred properties appeared to be someone who would be well-educated and confident with research and participating in groups. Some mentioned that members need to be open to listening whilst those who were not confident talking about their feelings would find it difficult. Training was seen as helpful for increasing members' confidence and gaining an understanding about research. However, participants' felt only basic training was needed. Nevertheless, all members were keen for more people to join and stressed that anyone with experience of MND could make a valid contribution.

"The most important thing is knowing about MND!" (MND Association volunteer/ex-carer)

The collaborative partnership

Developing a collaborative member-researcher partnership was key to effective PPI. Researchers recognised the potential for tokenistic attitudes to prevent this. However, it was clear the SMNDRAG was treated as worthwhile partners.

"I know loads of scientists who aren't interested in PPI... I think it's a matter of educating people and keep drumming it home that PPI is really, really important." (Researcher)

Members felt supported to gain the knowledge they needed to be effective partners. However, when asked to comment on research, members wanted to be told what was expected of them. This did not always happen. Feedback from researchers was seen as important to maintain the partnership. Not all members recognised they received feedback (pwMND) but those who did, valued it because it made them feel worthwhile.

Participants thought scientists used appropriate language and were open to questioning, allowing them to establish a relationship. Conversely, one pwMND felt nervous about participating in the group after listening to a presentation where the researcher used complex jargon.

Participants recognised the importance of having PPI early in the research process for it to be meaningful. However, tight deadlines for grant applications meant PPI could be rushed or forgotten about.

Practical matters

Members said the administrator helped the group run *"smoothly"* (MND Association volunteer) whilst the chairperson ensured the group kept to the agenda and avoided members dominating the discussion. Participants thought the discussions enabled good balance between individuals' own experiences and those of others. Despite disagreements, members believed the group worked well because they had *"the same aim"* (MND Association volunteer/ex-carer).

Theme 5: Perceived impact of PPI on research

Both members and researchers described the impact of the SMNDRAG in all stages of research (Figure 5).

[Insert Figure 5]

Positive impacts included grant capture, publications, influencing guidelines, clinical material and websites and helping researchers gain a broader perspective on MND. Research prioritisation ensured research was patient-focused. The SMNDRAG identified the need to improve neck support and access to specialist care, both of which developed into projects where members were involved (e.g. Head-Up, Box 1 and developing a telehealth system for remote monitoring (18)). Members also helped to improve study recruitment by being involved themselves and by amending documentation so it was more acceptable to lay people. Members were heavily involved with dissemination through formal channels (e.g. charities and social media) and also informally by word-of-mouth. One ex-carer/relative described how they had raised money for future research at SITraN by promoting research.

[Insert Box 1]

Discussion

PPI can offer value throughout the research process. Similar to findings in other studies, the SMNDRAG has made research more patient-focused and relevant (19). PPI can improve recruitment (20), the credibility of projects (21) and accessibility of the findings (22). PPI members translate research into lay-terms and can access patient networks (23). By endorsing the research, PPI has the potential to have a positive impact on outcomes, future research, funding and government policy.

PPI offers empowerment, increased self-worth and social contact (24). Whilst altruism is a clear motivator (24, 25), participants also wanted to put their experiential knowledge to good use and to learn/raise awareness about research. PPI offered a feeling of self-efficacy and hope to those living with what is currently an untreatable terminal disease.

The collaborative partnership is key to the success of PPI (26). Being embedded within the research unit and working together means members and researchers felt valued (27). The group has a strong sense of ownership through their shared goals. However, the group's success depended not just on its dynamics but also on the fundamental infrastructure. This included the provision of administrative and organisational support, flexible participation and adequate time. These vital components should be appreciated by researchers (e.g. providing feedback), healthcare providers (e.g. supporting groups), funders (e.g. ensuring sufficient time/funding for PPI) and journals (e.g. requiring the reporting of PPI (28)).

A recurring theme was that there is a *"certain type of person"* (pwMND) needed to participate in PPI. The SMNDRAG is predominantly female, highly educated and many have healthcare backgrounds. The demographics of this group are not a full reflection of all pwMND. This problem is unlikely to be limited to this group and is likely to reflect the characteristics of healthcare volunteers and how PPI tends to be conducted (e.g. daytime commitments, formal meetings). The involvement of charity volunteers may help improve representation through their involvement with a diverse range of people and offering different ways to participate. An element of training was seen as important but members thought no formal training was needed. Members agreed that personal experience was the only qualification needed and the level of information training was sufficient to enable participation. This supports the concern that providing specialist training risks producing 'experts' who are not lay representatives of the community (29).

We propose recommendations that are consistent with the standards published by the National Institute for Health Research (30). For example, we recommend advertising widely and promoting flexible participation. This will promote inclusivity and help ensure involvement reflects the diversity of the population. We also recommend that groups collect demographic data and be aware if, and why, the group does not reflect the population. This may be particularly important in self-governed groups where members may recruit others like themselves. A careful balance should be sought between enabling members to actively participate and producing highly educated 'experts' who are not representative. Groups should attempt to quantify their impact and annual reviews would be beneficial for monitoring/reviewing their progress.

Other valuable assets seen in the SMNDRAG that we recommend adopting are its effective chair and administrative support. Recruitment strategies should seek to address people's concerns and highlight the benefits identified in this study. An introductory guide to participating in PPI would be welcome (30). Researchers should consult early in the process (31, 32), use appropriate language and be explicit in their expectations (24). A collaborative approach should provide feedback as this enables members to feel valued (27) and results in meaningful PPI (26). A full list of our recommendations are presented in box 2. The SMNDRAG has overcome significant barriers and has become a successful, self-funding, self-governing collaborative partnership. Adopting their strategies and our recommendations is likely to improve any PPI group.

[Insert Box 2]

Strengths and limitations

The use of qualitative interviews enabled us to explore the workings of the group in depth, to identify experiences, barriers/enablers to PPI, and to understand these from a range of perspectives in this fairly new research practice (33). MND is a relatively unique disease and this was a small study that examined only one PPI group. Whilst it is likely that many of our findings will be applicable in other groups, we make no comment on whether there is a 'best' way to conduct PPI. Qualitative research does not aim to represent all experiences (34). Therefore, future research should explore whether our findings are replicated in other groups and examine the perspective of researchers, funders and consumers of research.

Conclusion

PPI is valuable and vital as it offers a positive impact on research and benefits those involved. It seems to work best in a collaborative partnership between PPI members and researchers. However, measures should be taken to ensure it is inclusive and captures the breadth of experiences. Future research should examine the different ways in which PPI can be delivered in different disease areas and how truly reflective these groups are of the population they seek to represent.

Acknowledgements

The authors are grateful to the members of the Sheffield Motor Neurone Disorders Research Advisory Group (SMNDRAG), based at the Sheffield Institute for Translational Neuroscience for their support throughout this project. EH was funded by the National Institute for Health Research (NIHR) Doctoral Research Fellowship award (DRF-2013-06-076) and later an NIHR/Health Education England Clinical Lecturer award. CMD is funded by the NIHR Sheffield Biomedical Research Centre (Translational Neuroscience) IS-BRC-1215-20017. This paper presents independent research funded by the NIHR. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

EH was a specialty registrar working in MND research with experience working with the SMNRAG and in the MND clinic. CMD is a consultant neurologist working in the MND clinic. He set up the SMNDRAG and also participated in the study. Both EH and CMD have an interest and experience in qualitative research in MND. LM was a student completing an MSc in Clinical Neurology and is interested in MND research. LM received training in interviewing by reading transcripts, practicing and observing interviews. She had no prior involvement with the SMNDRAG and her independent conclusions were supported by the co-authors and the SMNDRAG itself.

Declaration of interest statement

The authors report no conflict of interest.

Additional data can be made available at reasonable require.

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Figure 1. Reported motivations for joining and participating in the SMNDRAG.
MND, motor neuron disease

Figure 2. Personal benefits of PPI.
MND, motor neuron disease

Figure 3. Reported barriers and enablers to participating in PPI.
MND, motor neuron disease

Figure 4. Reported barriers and enablers to effective and meaningful PPI.
PPI, patient and public involvement

Figure 5. Stages of the research process that participants reported the SMNDRAG had been involved in and supporting quotes.
MND, motor neuron disease
PwMND, person with motor neuron disease

Box 1. The involvement of the SMNDRAG in the Head-Up project.
SMNDRAG, Sheffield Motor Neurone Disorders Research Advisory Group
PwMND, person with motor neuron disease
MND, motor neuron disease

Box 2. A list of our recommendations for those organising and running PPI groups, researchers and funding bodies.
PPI, patient and public involvement