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Appendices

Appendix A: Generic topic guide

Topics to cover
- How the participant heard about the group
- Motivations for joining the group
- Experience of attending the group for the first time
- Their involvement in research projects
- Composition of the group
- Their reasons for why PPI is important
- Impact of group on research
- The impact of motor neurone disease on participating in the group

So to start with, can you tell me about how you heard about the motor neurone disease research advisory group?

How long have you been a member of the group?

Why did you decide to join the group?

Can you tell me about what it was like attending the group for the first time?

What motivates you to continue attending the group?

What do you think enables people to get involved in PPI?

Who is in charge of the group?

What do you think of the organisers?

Who else attends the group?

As I understand the group receives monthly emails, do you feel obliged to read everything that is sent to you?
- Are people given the option not to read all of the paperwork?
- If they do not have to read everything – does someone discuss the documents with them at the face-to-face meeting?

Do you all share similar opinions or are there ever any disagreements?
- If so, are all views taken into account by the facilitators?

Can you tell me about any patient and public involvement activities that you have been involved in?

- E.g. identifying research priorities, helping with designing studies, carrying out research, helping with analysis and helping with dissemination of findings.

Is there any training available to you so you understand what is expected of you when reviewing protocols and things?

Have you engaged in any training?
- If yes, was it useful?

Do you think your views and opinions, as well as those of the other members of the group, should be listened to?
- If yes, why do you think patient and public involvement is important in research?

Do you feel like your views and opinions are used in research?
- If no, have you received feedback, so has anyone told you about things that have changed due to opinions of the group?

Do you think it is important to gain feedback from the organisers as to how opinions of the group have influenced research?

Can you describe a time when the opinions of another member of the group had an impact on research?

Can you describe what happened in the last meeting you attended?
- Is it always like that?

Do you think motor neuron disease affects your/people's involvement in patient and public activities?
- If so, how do you think it affects your/their involvement?

Do you think being involved in the group has benefited your personally?

Are there any negative impacts of patient and public involvement?

Is there anything that you know off that stops or discourages people from participating in the group?

What do you think facilitates effective patient and public involvement?

Is there anything that you think should change in order for the group to run more effectively?

Would you recommend joining the group to other people?

Appendix B: Study protocol

Exploring the experiences of those participating in Patient and Public involvement in motor neurone disease.

Protocol

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Protocol version 2 14th March 2016

Lay summary

Background

In the last few years the involvement of members of the public in medical research has increased. Patient and Public Involvement (PPI) involves consulting members of the public on ways in which research is conducted. This might involve deciding which research should be prioritised, advising on how clinical studies are carried out or sharing the findings of the research with the public. Based in the Sheffield Institute for Translational Neurosciences, the Sheffield Motor Neurone Disease Research Advisory Group (SMND RAG) is the first and only group to specialise in motor neurone disease in the UK. This panel has been working with researchers for over five years. Members include patients, family members, carers and volunteers.

Methods

This research aims to explore the experiences of those involved the Sheffield MND research advisory group, the challenges they face and the things that may help or stop people taking part. A successful project may be able to recommend ways to make this and other PPI groups more successful and enable more people to take part.

This research will interview members of the Sheffield Motor Neurone Disease Research Advisory Group along with researchers, clinicians and scientists who have worked with the group. Interviews will be either face-to-face, telephone, Skype or email interviews depending on the interviewee preference and can be alone or together with e.g. a carer. The researchers will also attend the Research Advisory Group as impartial observers to gain an understanding the group processes.

Results

Interviews will be audio-recorded and transcribed before analysis by the Sheffield MND research team. Results will be discussed in future SMNDRAG meetings prior to publication. The results will be shared with other PPI groups in the UK using posters or at conferences.

Nature of research

This research study is to be conducted by the SITraN clinical research team including a University of Sheffield Clinical Neurology MSc student, under the supervision of the Sheffield MND clinical research team including chief investigator (Esther Hobson).

Abstract

Background
The importance of patient and public involvement in research is now recognised and is a requirement for most medical research. However, panels, such as the Sheffield Motor Neurone Disease Research Advisory Group (SMNDRAG) have only recently been established and it is only recently that members of the public have been involved in aspects of research such as development and oversight of research methods and analysis and dissertation of the results. The most effective way of involving the public to deliver a positive impact has not yet been established.

Methods
Semi-structured qualitative interviews will be conducted with members of the SMNDRAG and clinicians, researchers and scientists who have interacted with the participants. Interviews will be conducted until data saturation is reached, or a maximum of 20 interviews have been conducted. Thematic analysis will identify relevant themes.

Results
The results are expected to provide suggestions which may improve the participating in and impact of the SMNDRAG and will be relevant to other patient and public involvement activities as well as advising how to improve interactions between researchers and the public.

Background

Until recently it was uncommon for members of the public to be involved in the conduct of research. More recently Patient and Public Involvement (PPI) has become a necessary requirement in virtually all clinical research conducted in the NHS. PPI may include individuals or panels of people who have experience living with the disease. With their unique knowledge they can use their expertise to identify priorities for research which may be different from clinician/researcher priorities (1,2). They can also advise (and potentially improve) methods of communication, recruitment and retention of patients within studies. They may also be involved in the study oversight and methodology, facilitate analysis and dissemination, particularly in ways that appeal to a patient or member of the public rather than a researcher (3,4).

PPI may be conducted by panels and individuals may be involved in research management, funding decisions or undertake some of the research themselves. Some PPI panels are disease specific and others generic. The Sheffield Motor Neurone Disease Research Advisory Group (SMNDRAG) was established in 2009. It consists of patients, carers, parents or family members, volunteers or members of charities such as the Motor Neurone Disease Association. It is the only group supporting research in motor neurone disease (MND) and as a result now supports research throughout the UK. The group meet quarterly and some times communicating between meetings. Some participants are unable to attend meetings and communicate by email or Skype. Members of the group have been co-applicants in grants or members of research management groups and have supported co-design projects such as the development of a neck collar: the Sheffield Support Snood (5).

With PPI being a relatively new phenomenon there are many areas of uncertainty. There is some evidence for the developmental role of public involvement, such as enhancing awareness, understanding and competencies among lay participants. The evidence of it’s impact on the research conducted remains scarce (6). Those participating in PPI may face physical, psychological or financial challenges. These may apply to all conditions but the SMNDRAG will face challenges unique to MND and there is requirement to support PPI members to enable them to participate effectively.

Aims and objectives

The aim of this study is to explore the experiences of those participating in, organising and working with the Sheffield MND Research and Advisory Group.

The objectives of the study are to:

- Conduct a literature review of patient and public involvement
- Conduct and analyse semi-structured qualitative interviews of participants, staff and researchers working with the Sheffield MND Research Advisory group. These interviews will explore:
    - The experiences of attending the group
    - The motivation for joining and participating in the group.
    - The barriers and enablers to participation, both physical and psychological
    - The role of the group as a whole to the individual participants
    - The experiences of clinicians and scientists who interact with the group
    - The perceived impact the group has on research in MND both within SITraN and beyond

The results of this study may recommend ways to improve participation and impact on research. The results will be relevant to other future MND panels as well as other PPI groups facing similar challenges.

Plan of investigation

This is a qualitative study conducting semi-structured interviews with SMNDRAG participants and research staff.

Prior to the interviews the following will occur in order to prepare interview topic guides and guide the subsequent interview analysis:

1. A literature review of the subject, examining the INVOLVE (7), academic and grey literature of PPI in other diseases
2. Observation of the PPI group in progress by LM, who will take reflective field notes and feed back to the CI
3. Brief feedback from the PPI group about the good and bad aspects of the group (already completed in preparation for the study).

Inclusion criteria:

1) Members of the Sheffield MND Research Advisory Group past or present
OR
2) Staff who have interacted with the group for research purposes (usually employees of either Sheffield Teaching Hospitals NHS Trust or the University of Sheffield).

Exclusion criteria:

Those who are unable to give informed consent or undergo an interview/questionnaire due to severe ill health, language or cognition difficulties.

Recruitment

Participants will be approached in person, by letter or email (according to their usual method of communication). They will be provided with a participant information leaflet and given at least 24 hours to consider the study. They will be invited to discuss the study further with the study team.

Consent

Written consent is required but in those patients who are unable to provide written consent, verbal consent or using a communication aid can be taken witnessed by a family member or friend.

Sample size

The SMNDRAG consists of a total of 20 members. When consulted on this study all those who had attended the group indicated they would be interested in participating. Ideally interviews would continue until data saturation is reached (as judged by the research team) but it is estimated that a representative sample of 10 interviews involving patients, family members, volunteers plus 3-4 researchers would provide a reasonable dataset. This is a student project with limitations on time and therefore a maximum of 20 interviews will be conducted. Patients will be able to be interviewed with a carer, as if often preferred in this population.

Withdrawal

Participation will not impact on care patients or families receive and confidentiality will be discussed as part of the consent process. Participants will be given two weeks following the interview to withdraw from the study to allow them to reflect on what they discussed. If they withdraw all data collected with be destroyed. After this data will be retained for analysis.

This is made clear in the participant information leaflet and consent form. Participants will also be offered to redact aspects of their transcript either after the interview or before dissemination of results.

Interviews

Semi-structured interviews will be conducted at the Royal Hallamshire Hospital, SITraN, an alternative private area or at the participants home (whichever is most convenient to the patient). The interviews will be conducted by Lucy Musson (LM), an MSc in Clinical Neurology and supervised by Dr Esther Hobson (EH).

LM will receive training on interviewing, listen to examples of qualitative interviews and the audio recording of each of the first two interviews and subsequent transcripts will be reviewed EH to ensure the interviews are being appropriately conducted, the data gained rich and any participant concerns addressed.

Interviews will be audio-recorded and transcribed. Interviews duration will depend on the participant, their disease and may range from very short (10-15 minutes if the patient is very frail but wishes to be involved) to approximately one hour if the participant wishes to expand on their answers. The Sheffield MND team has experience in conducting qualitative interviews in MND and is able to adapt interviews with MND in mind. We will also offer to conduct telephone, Skype or email interviews and allow participants to expand on their answers by providing written answers after the interview.

The interviews will be conducted using a topic guide based on a literature review and input from the SMNDRAG and results from early interviews will inform later interviews.

Fields notes will also be taken by the interviewers and Lucy Musson will also attend the SMNDRAG as an impartial observer.

Results

Data analysis

Results will be analysed using thematic analysis (8). This will involve the following steps

1. Familiarisation with the data using line-by-line coding (EH and LM)
2. Independent coding for initial themes (EH and LM separately)
3. Searching for themes (EH and LM together)
4. Reviewing themes (EH and LM together +/- separately if further coding required)
5. Triangulation of data from the staff and PPI member interviews (EH and LM) (9)
6. Defining themes (LM and EH)
7. Writing up (LM +/- EH)

Results will be discussed in research meetings with the wider MND team and the SMNDRAG and participant and staff interviews triangulated to explore complex themes such as research impact and participant-staff relationships.

Dissemination and potential impact

The results will be presented to the SMNDRAG to enable the group to input into the analysis and to disseminate the research to other patients/families. An academic paper will be submitted for publication and a "blog" article included on the SITraN website.

The results will be provided to the SMNDRAG who may wish to implement any suggested changes to the group. The experiences and potential changes may be relevant to other PPI groups, both with SITraN and other groups.

Limitations and ethical considerations

This study is examining a limited group of participants but at present, this is the only MND research advisory group to examine. However the results will be compared to other studies of PPI groups e.g. stroke (10). The interviewers have no influence on any of the potential participants and whilst Dr Esther Hobson has been involved with the SMND RAG in the past, Lucy Musson has not.

The interviews may cover sensitive or potentially upsetting topics. The Sheffield MND clinical team have extensive experience in qualitative research in patients, carers and members of staff. It has developed successful methods of ensuring participation is possible for patients with significant disabilities and can support participants who may be discussing potentially distressing topics. The research team and the SMNDRAG have experience in supporting participants in these circumstances. The "ground rules" for qualitative interviews will be explained prior to commencing interviews and interviews terminated should participants become distressed, tired or at their request.

Although quotes used in dissemination will be anonymised given the limited number of participants it may be possible for participants' responses and quotes to be identifiable. Full transcripts will only be available to the interviewer and Dr Esther Hobson who will use their discretion when reporting the results if the responses are identifiable or upsetting and will exclude responses if any risk of harm to the participant is possible. They will also take into account any potential impact the responses may have on participants' research and employment if they are staff participants. If required they will allow the participant to decide whether to include a particular response. This will be explained in the participant information sheet and consent form.

Ethical and sponsor approval is required for this study.

The study aims, protocol, patient information sheet and consent form have been reviewed by the SMNDRAG and clinical research team to ensure the study is acceptable to potential participants. The group members indicated that it was a worthwhile study.

Data entry, security and confidentiality

Data (including audio-recordings) will be collected and retained in accordance with the Data Protection Act 1998 and Caldicott Principles. Data will be anonymised prior to entry onto a database and stored on the secure Sheffield University intranet which is password protected. Study documents will be retained in a secure location during and after the study has finished according to SITraN SOPs. Personal data (consent forms, recruitment log) will be held for up to 12 months and research data up to 10 years.

Adverse events

No adverse events are expected in this study. As such all adverse events (including serious adverse events) will be recorded and reported to the CI and MND research team and sponsor.

Access to source data

Monitoring and audit by the relevant health authorities will be permitted by the sponsor. These include the Research Ethics Committee and local R&D departments. The sponsor will be allowed to monitor and audit the study at each site and be allowed access to source data and documents for these purposes. Intellectual property generated by University of Sheffield researchers is managed by the University of Sheffield Research Office.

Project management

Weekly oversight through the Sheffield MND clinical research team.

Costs

Publication costs will be met by student fees. The student will transcribe initial interviews but if required, student fees can cover a small number of transcriptions.

Service users

The SMND RAG have reviewed the study principles, participant information and given guidance on topic guides.

Target dates:

The project will commence in April 2016 following ethics and sponsor approval.
Initial report to the research team will be submitted in August 2016 following which the results will be prepared for academic publication.

Staff underpinning the study: The study will be conducted by Ms Lucy Musson, MSc student with day-to-day supervision from Dr Hobson. She has received Good Clinical Practice training and holds an honorary contract with Sheffield Teaching Hospitals NHS Trust.

Other investigators expertise: Dr Esther Hobson is an NIHR Doctoral Fellow and specialty registrar in neurology. She also has experience caring for patients with MND and other chronic diseases and conducting qualitative research in MND. She holds an honorary contract with Sheffield Teaching Hospitals NHS Trust and works in the Sheffield MND care and research centre.

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Appendix C: COREQ checklist

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual in Health Care* 2007;19(6):349 – 357.

No	Item	Guide questions/description	Reported in section(s)
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	Materials and methods
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	Acknowledgements and declarations
3.	Occupation	What was their occupation at the time of the study?	Acknowledgements and declarations
4.	Gender	Was the researcher male or female?	Authors
5.	Experience and training	What experience or training did the researcher have?	Acknowledgements and declarations
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	Materials and methods, Acknowledgements and declarations
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.*g. personal goals, reasons for doing the research*	Materials and methods, Acknowledgements and declarations
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*	Acknowledgements and declarations
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory,*	Materials and methods

		discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	Materials and methods
11.	Method of approach	How were participants approached? e*.g. face-to-face, telephone, mail, email*	Materials and methods
12.	Sample size	How many participants were in the study?	Materials and methods
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	Materials and methods
Setting			
14.	Setting of data collection	Where was the data collected? e*.g. home, clinic, workplace*	Materials and methods
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	Materials and methods
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	Materials and methods, Appendix D
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Materials and methods, Appendix A
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	Materials and methods
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Materials and methods
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Materials and methods
21.	Duration	What was the duration of the interviews or focus group?	Materials and methods
22.	Data saturation	Was data saturation discussed?	Materials and methods
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Materials and methods

Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	Materials and methods
25.	Description of the coding tree	Did authors provide a description of the coding tree?	Materials and methods
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Materials and methods
27.	Software	What software, if applicable, was used to manage the data?	Materials and methods
28.	Participant checking	Did participants provide feedback on the findings?	Materials and methods
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e*.g. participant number*	Results, Discussion, Appendix E
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Results, Discussion, Conclusion, Appendices
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Results, Discussion
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Results, Discussion

Appendix D: Characteristics of the participants.

	Participant type	Age	Gender	Ethnicity	Education level	Number of years in the SMNDRAG	Communication difficulties
P1	PwMND	50s	Female	White British	Masters degree	3	No[a]
P2	SITraN employee/relative	30s	Female	White British	Doctor of Philosophy	7	No
P3	MND Association volunteer	50s	Female	White British	Masters degree	7	No
P4	Ex-carer/relative	80s	Male	White British	Undergraduate degree	7	No
P5	SITraN employee	40s	Female	White British	Masters degree	7	No
P6	MND Association volunteer/ex-carer	80s	Female	White British	Undergraduate degree	7	No
P7	Ex-carer/relative	40s	Female	White British	Professional qualification	6	No
P8	PwMND	50s	Female	White British	Undergraduate degree	3	No
P9	MND Association volunteer	50s	Female	White British	Professional qualification	7	No
P10	Ex-carer/relative	70s	Male	White British	Professional qualification	7	No
P11	Researcher	40s	Male	White French	Doctor of Philosophy	N/A	No
P12	Researcher	40s	Male	White British	Doctor of Philosophy	N/A	No
P13	Researcher	30s	Male	White British	Doctor of Philosophy	N/A	No

[a] *This participant used voice recognition software to use electrical devices*

SMNDRAG, Sheffield Motor Neurone Disorders Research Advisory Group
PwMND, person with motor neuron disease
SITraN, Sheffield Institute for Translational Neuroscience
MND, motor neuron disease

Appendix E: Supporting quotes from the interviews

Motivations for joining and participating in the SMNDRAG

Help other people:
"It can't do my husband any good but it can do the future hopefully" (MND Association volunteer/ex-carer)

Raise awareness of research in neurological disease:
"I wanted to be a part of the group that would help get patients involved in the research to give them an understanding that there is this whole research community out there trying to do its best for patients… for me that was the most important bit, disseminating that information and raising awareness." (SITraN employee/relative)

To bring a personal perspective:
"I think I've got something to bring from both sides of the fence, both as a patient and as a healthcare professional." pwMND

To give something back:
"To try and give something back I think. The motor neuron [staff], all of them, were very good." (MND Association volunteer/ex-carer)

To improve care and treatment:
"Wanting to see a cure for motor neuron disease and being able to help a little bit." (Ex-carer/relative)

Think PPI is important:
"I thought it was a really good idea to bring people affected by MND into the research… because they're the people it's going to directly affect and they have a lot of very clear ideas." MND Association volunteer

Interested in research:
"I'm very interested in the research that's going on." (MND Association volunteer/ex-carer)

Learning about research in MND:
"Finding out about MND is not that easy... also, a very selfish thing about thinking if there's something going on, there's research going on or whatever, I want to know about it." (pwMND)

Personal benefits of PPI

Enjoyment:
"I really enjoy the [pause] presentations that are given." (MND Association volunteer)

Hope:
"To talk about the different angles that they're doing research on and things that they're investigating, it's incredibly interesting and uplifting as a patient to hear that." (pwMND)

Valued:
"I've been asked if I would join the steering group for [a study] which I was really chuffed about…I was like oh, I obviously must have said something that was [useful]." (pwMND)

Satisfaction:
"Yeah I always get satisfaction when I've been to a meeting and things are going well which is usually the case." (Ex-carer/relative)

Empowerment:
"It's nice to feel like you're doing something rather than doing nothing." (pwMND)

Inspired:
"Being able to talk to people, and you feel that actually what you do might serve something at some point. Which if it's just fundamental [basic research], you're not necessarily going to see any immediate outcome of your work so I think this is really positive." (Researcher)

Gain knowledge:
"It's also a good source for me to hear about potential management or treatments that are likely to be coming through the pipeline in the future, I enjoy that." (pwMND)

Developed communication:
"It's very good practice to talk to kind of... a non-scientific audience." (Researcher)

Comradeship:
"[The group] also gives an opportunity to listen to [others], and as I've gone longer and grown in confidence, I've learnt that [pause] people are very open to listening to 'well I've got the disease and this is what I've found or this is how I feel'." (pwMND)

Social contact:
"Yeah, yeah. I mean it's always good to talk to and meet people and be involved in groups." (MND Association volunteer)

Helpful for work:
"You have the insight to know that there are things that are going on and you can say to people what's happening." (MND Association volunteer/ex-carer)

Reported barriers to participating in PPI

Lack of awareness about PPI:
"I found out about PPI through accident." (pwMND)

Lack of understanding about PPI:
"A lack of knowledge about what the group does is potentially a, sort of, component of how people are discouraged to become involved." (SITraN employee)

Unsure of the contribution that they could make:
"They either haven't got the confidence to come along and be part of the group or think they haven't got anything to offer." (MND Association volunteer)

Lack of confidence:
"A sort of sense of, who are all these people? And how am I going to fit into this group?" (pwMND)

Think research is impenetrable:
"I think some people [pause] perhaps think that research is way above their head." (MND Association volunteer)

Intimidating location:
"Maybe the environment, although people quite like SITraN, it's still an academic establishment opposite a hospital, it's not a café… It's a biased environment, it's not a neutral environment." (SITraN employee)

Time commitment:
"I think it could be difficult for some people. We're in the fortunate situation where my husband is virtually retired... so his working hours are very flexible so he can just schedule that." (pwMND)

Progressive nature of the disease:
"I know it's a difficult disease to get people involved for any length of time." (Ex-carer/relative)

Difficulty using technology:
"We send stuff out via email for them to review, some of them, they can't just click away on a keyboard and do that, it's quite difficult." (SITraN employee)

Emotional challenges associated with progressive neurological disease:
"You do build friendships with people that attend the group and it's difficult seeing other people deteriorate… and I think that may be something else that keeps people away." (pwMND)

Fatigue:
"I think the length of the meeting is quite long... and I, particularly now as my disease advances, it's quite a long time for me to sit." (pwMND)

Self-conscious due to physical limitations:
"The first time I went was, because I can't use my arms at all I need to be given my drinks and whatever, I felt incredibly self-conscious." (pwMND)

Difficulty travelling to the meetings:
"People that have got problems with physically getting there and with motor neuron, it can need quite elaborate transport arrangements to do that." (pwMND)

Lack of parking:
"Just parking at Sheffield, that car park is a nightmare, that's probably the only negative." (Ex-carer/relative)

Reported enablers to participating in PPI

Promoting the group:
"I think a lot of it is word-of-mouth and encouraging people because some people don't fully understand it. I spoke to somebody recently and he thought it was about fundraising." (MND Association volunteer)

Involving charity representatives:
"People like myself who are visitors are a good way of letting people know about it really and that they could be [involved]." (MND Association volunteer/ex-carer)

Informal induction:
'Before the first meeting… I had already had a look around the centre which makes it better really because you know where you're coming.' (Ex-carer/relative)

Supportive group:
"I think it's a very inclusive group and everybody chats with everybody. So when new people join the group they're always made to feel... very welcome." (MND Association volunteer)

Group cohesion:
"We all realised that… we are in the same boat because we all have got somebody who either has MND or had someone die from motor neuron... so that was a sort of commonality." (Ex-carer/relative)

Research presentations:
"I think they might be… put off by the fact that they wouldn't understand the research process… It can be quite scary, but certainly in the face-to-face meetings, and the presentations work really well to break that barrier down." (SITraN employee/relative)

Having the meetings where the research takes place
"It's the atmosphere of the building, to see the researchers around, and the enthusiasm of the young people, they always impress me... their dedication." (Ex-carer/relative)

Flexible involvement:
"You're not bound to do anything, it's up to you, if you don't want to review it you don't review it, there's no pressure put on you." (Ex-carer/relative)

Administrative support:
"I mean if someone wasn't using the computer, they'd just get everything by hard copy, that would be absolutely fine." (MND Association volunteer)

Skype:
"We started up a Skype facility to make it easier for people who were progressively debilitated and couldn't make the journey and that seems to work quite well... it gives them the capacity to input even though they can't actually physically be there." (SITraN employee)

Email:
"[Email] also works well in practical terms because I do still have a driving licence myself and I drive locally but I wouldn't drive as far as Sheffield, I need somebody to take me there." (pwMND)

Encourage carers to attend:
"The first time I went was, because I can't use my arms at all I need to be given my drinks and whatever, I felt incredibly self-conscious. But, the next time I went back with a carer so I had somebody there with me to give me a drink and stuff." (pwMND)

Accessible location:
"It's in a fairly central place and relatively easy access." (MND Association volunteer/ex-carer)

Reported barriers to effective and meaningful PPI

Belief that there is a 'right kind of person' needed for PPI:
"You want the PPI group to have the right skills so… you might consider interviewing for the type of people that are going to be on it, I don't think everyone, every individual would be suitable." (Researcher)

Lack of members:
"It would be good if we could recruit more members." (SITraN employee/relative)

Not representative:
"[Those] that attend the group regularly, I would say [are] educated probably to degree level." (pwMND)

Tokenistic attitudes:
"It could be very tokenistic but I suppose that depends on your values. So, I'd probably say you have a broad range of people who are really into it and think it's really important down to 'well, I've got to do this for a grant', so yes a tick box exercise." (Researcher)

PPI members unsure about what is expected of them:
"When you're asked to comment on a paper I never quite know [pause] what's the most useful way to comment and what angle they're looking for." (pwMND)

Lack of feedback:
"If you're not giving feedback then you'll find that you won't have meaningful PPI because the group will disappear." (Researcher)

Scientific jargon
"I didn't understand 75% of what he was talking about. It made me think: have I joined something I'm out of my depths here?" (pwMND)

Limited time provided to seek PPI:
"If it's for grant applications and things, everything is always so last minute, one of the things I think is it's easy to forget to do PPI in a meaningful way, you need to go and involve PPI early." (Researcher)

Dominating members:
"If you've got a very dominating person with strong opinions… it can make it difficult to work through the agenda." (pwMND)

Reported enablers to effective and meaningful PPI

Shared experience:
"It quickly became apparent that it was a very friendly group and we had that shared experience and there was a lot of, sort of comradery between us." (SITraN employee)

Group cohesion:
"We all realised that… we are in the same boat because we all have got somebody who either has MND or had someone die from motor neuron, so that was a sort of commonality." (Ex-carer/relative)

Friendly and supportive members:
"I think it's widely acknowledged within the group and that's why the group works, that, you know, all opinions are valid." (MND Association volunteer)

Researchers forming good relationships with PPI members:
"[The scientists are] very happy to be questioned about what they're doing... [One scientist] stayed for ages. He was willing to chat to people about his work and bigger pictures." (MND Association volunteer)

Positive attitudes about PPI:
"I think it should definitely be a two-way street… I think you need to be the kind of person who wants to be able to seek it out." (Researcher)

PPI members should be treated as partners:
"They're treating us as a worthwhile thing to do, as partners in the research." (Ex-carer/relative)

Provide feedback:
"The feedback is important... if they don't know whether anything's happened or acted upon, then… it makes them less interested." (MND Association volunteer/ex-carer)

Supported to gain knowledge:
"I think they might be… put off by the fact that they wouldn't understand the research process… So, it is something that we have worked on, and we do try and support new members… but certainly in the face-to-face meetings, and the presentations work really well to break that barrier down." (SITraN employee/relative)

Pitch at the right level:
"The scientists are really good at explaining what they're doing at a level of what we can understand" (MND Association volunteer)

Early involvement:
"So, really before you're writing the grant, I think it's important to have been to the PPI group even with just the seed idea so that… the group are aware of it early on and they can be a part of it as it's developed." (Researcher)

Good administration:
"I think the group is very well organised and I think we get plenty of information." (MND Association volunteer)

Effective chair:
"It involves drawing up the agenda, deciding who's coming to speak, there's quite a lot to do really… And as a chair you need to be able to focus the group on what it's actually there for." (SITraN employee)

Group discussion:
"Yeah there are differences of opinion and I think that's a good thing, that's why you need several patients and public members on the group because it doesn't want to be coming from one person." (pwMND)