

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)