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?