

Patient and public members of the Sheffield MND Research Advisory Group

The SMND RAG Group:

- Advises on the development of strategies, activities and approaches to MND research within the Sheffield area
- Oversees the strategic planning and implementation of research studies
- Monitors research governance - ensuring good quality research

Patient and public involvement in SMND RAG is gradually developing, and getting it right will be a learning process for us all. What we don't get right now, we will hope to change in the future.

The core role of patient/public representatives

The core role of a patient/public member is to contribute to the development of MND research locally from the point of view of someone with direct or indirect experience of MND.

Patient/public members on the Group will be able to contribute to the development of the Research as follows:

- Attend relevant meetings
- Work constructively as part of the SMND RAG to foster the aims of the group
- Read through the papers and other items beforehand
- Read and consider consultation documents, to provide comments on the consultation documents where appropriate from a patient/public perspective
- Discuss and comment on items during meetings, and raise issues for consideration
- Take into account the responsibilities, viewpoints and expertise of other members
- Provide a patient/public perspective on research deliberations
- Consider methods for wider patient and public involvement in the strategic development of Sheffield MND research
- Contribute to the training of new staff
- Respond to virtual sub-group meetings if appropriate, or external events/conferences and report back to the group
- Advise on SMND RAG newsletters and general publicity for the SMND RAG and on dissemination of research results
- Respect any requests for confidentiality, and declare any conflicts of interest if they arise.
- Contribute to reviews and evaluations of the SMND RAG's work

The person

People interested in becoming patient/public members will come from different backgrounds. Below is a wide-ranging list of skills and qualities for the role. It is recognised that individuals will have different combinations of skills to contribute. Selection will aim at balancing different characteristics, although obviously not all will be included.

Essential skills and qualities of patient/public members

The most important personal skill for the role is a willingness to bring to the committee a balanced understanding of the wide range of different perspectives which MND patients, carers and the wider public will have.

Patient/public members should have direct or indirect experience of MND or Neurodegenerative conditions in one of the following ways:

- as a patient, carer, ex-carer, family member, or friend of those who have been a patient and/or who have participated in research,
- as a member of the public who may be involved in clinical and health research programmes related to MND, or affected in other ways by health or clinical research issues in MND
- as a member of the wider public with relevant experience of patient and public involvement

Other essential qualities

- Able to give a balanced viewpoint, including an understanding of a range of different perspectives on MND
- Able to travel to attend meetings, and to carry out other activities, such as reviewing documents.

Desirable personal qualities of patient/public members

- Medical charity experience is helpful, although patient/public members - like other members - are chosen because of their individual experience, not because of their affiliations or relationships with other organisations
- Experience of patient and public involvement
- Keen interest in MND healthcare in the UK
- An understanding of clinical research processes
- Good communication and team-work skills, and a potential willingness to speak in public
- Experience of committee work
- Experience of running things, and management experience
- Patient/public members will find it highly advantageous to have access to email, the internet, and a printer, and be reasonably proficient in their use.
- Self confidence in a mixed group of individuals

Duration

It would normally be hoped that patient/public members would commit to up to three years, or at least one year. However, to ensure a full range of patient's health considerations can be taken into account, planned duration of membership may be shorter or open-ended.

Remuneration

Membership of the SMND RAG is unpaid. Reasonable travel expenses, that are agreed, will be reimbursed in accordance with SMND RAG Expenses Policy or local policies where indicated and lunch will be provided at meetings.

Raising concerns

If there is something about the Group or meetings that makes the person feel uncomfortable, to approach the Chairperson or someone else appropriate.

Conflicts of interest

Members shall be required to disclose any involvement with individuals, government bodies, commercial interests or third parties which could lead to a conflict of interest with the work of the SMND RAG. A conflict of interest doesn't stop someone from being a patient/public member.

Confidentiality

Some papers circulated for SMND RAG meetings are considered to be confidential, even if not marked as such. Many patient/public members will be in contact with other patients and people affected by a particular condition, and will feel there are general issues, arising from the meeting, that they would like to discuss. Indeed this will be an important avenue to provide a broader patient/public perspective on many issues.

Things that may be discussed with others outside the meeting could, unless indicated otherwise by the Chairperson, include identifying priorities for research activities, progress in a particular area of research, and publicly available details about proposed trials.

Members should not communicate any potentially confidential information that they learn as a result of being a member of the group. In particular, proposed trial-specific information should only become public once the protocol is published. Members should always seek clarification first from the Chairperson if unclear.

Mentoring

The formal responsibility for arranging a person to offer support lies with the Chair, in agreement with the relevant parties. The chair can support the group members identifying training needs, providing relevant information, assisting to resolve outstanding issues, ensuring that there are opportunities to link with other lay members.