



Name of group: Sheffield Motor Neurone Disorders Research Advisory Group

Title: Terms of reference 10th June 2019 v5

Purpose / role of the group:

The Sheffield Motor Neurone Disorders Research Advisory Group (SMND RAG) will have communication on a regular basis (monthly via email/newsletter and quarterly face to face meetings) to discuss and review proposed, active and ongoing research projects; either being undertaken by members of the Sheffield MND care centre, or using/engaging with the patient population or clinical or research facilities. The group was established in September 2009 with the aim of bringing together patients and carers who wish to be actively involved in ensuring patient and public involvement in South Yorkshire & Humber MND research.

The aims of the Research Advisory Group are to:

- Enable patients and carer's perspectives' to be included in research proposals
- Provide knowledge from each member's experiences with MND
- Identify and prioritise research topics from the patients' prospective
- Improve recruitment to research studies
- Help in identifying improved treatments from research results
- Give patients and carers a more authoritative voice
- Help build public credibility and trust in clinical research
- Improve the input from patients and carers to research projects
- Identify any barriers to patient's effective involvement in research
- Comment on "Patient Information and Research Results Sheets"
- Help write lay summaries for research proposals
- Raise public awareness of general MND research

Membership:

SMND RAG welcomes membership from a variety of backgrounds, united by the common goal of fighting MND. It is open to patients, public and Health Care Professional's interested in MND research. There is also the option of **Associate Membership:** An initiative which allows people to join SMND RAG entirely remotely without the need for travel to Sheffield for our quarterly meetings. All they need is access to email and an enthusiasm to get involved. There are no restrictions on numbers to the group and the period of membership is for as long as the individual wishes as it is voluntary. Members are asked to complete a full application form and also to provide references to support their application.



Sheffield Motor Neurone Disorders
Research Advisory Group

Accountability:

Individual members of the group are asked to feedback to researchers on projects put forward for review within a period of 2 weeks. This feedback is returned to Annette Taylor via email who will forward feedback to the researchers on the groups behalf.

Review:

Documentation relating directly to the group or developed by the group is reviewed on an annual basis or sooner if new material comes to light that needs to be included.

Working methods / Ways of working:

Decisions will be made by the group taking into consideration individual's opinions in the group. Sub-groups maybe convened with agreement of the group to work on projects outside of the meeting times.

Meetings:

Face to face meetings are held quarterly in SITraN. The chair and Annette Taylor will organise these meetings and researchers can apply to have their projects reviewed at the meeting or issues to be placed onto the agenda. Agenda items for the meeting and other relevant paperwork will be circulated via email prior to the meeting and made available for individuals at the meeting. Non-members of the meeting will be invited to present their research or give a talk as relevant. Annette Taylor is the main point of contact for the meeting. The group is quorate when there is the chair and 4 other members of the group present, if there is less than this to attend the meeting the meeting will be rearranged for an alternative date.

Sharing of information and resources (including confidential materials):

Each member of the group is asked to sign a confidentiality agreement when they join the group.

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