

Sheffield Motor Neurone Disorders Research Advisory Group

Promoting Patient and Public Involvement in MND Research

Emily Goodall¹, Hannah Hollinger¹, Alison Proctor¹, Ann Quinn, Jane Evans, Michael Hickman, Olga Bannister, Sarah Wyatt, Stan Bedford, Annette Taylor¹, Colin & Alison Fenwick, Alison Pickard, David Booker, David Stelmach, Julie Drakeley, Lindsay Lonsborough, Mbombe Kazoka¹, Patrick Gleeson, Mary Pluke, Stacy Young¹, Dr Chris McDermott¹ and Professor Dame Pamela Shaw¹

¹Sheffield Institute for Translational Neuroscience (SITraN), University of Sheffield, 385a Glossop Road, Sheffield, United Kingdom, S10 2HQ

Our Group

SITraN researchers believed it was vital for researchers to understand patient/carer perspectives when developing research proposals. Hence the Sheffield MND Research Advisory Group (SMND RAG) was created in 2009 to ensure patient needs and views are reflected in the research strategy.

The group meets face to face quarterly and has monthly contact via email correspondence with all members.



SMND RAG currently has 19 full members and 3 Associate members with a variety of backgrounds and experience, united by the common goal of fighting MND. Associate membership, which is managed entirely remotely, permits patients with progressive disability to join. All that's needed is access to email and an enthusiasm to get involved.

All members are required to be UK residents and to complete confidentiality agreements upon joining the group.



Face to Face meetings are 3 hours long and speakers are invited to present their research and gain feedback from the panel members.

Members of the group are recruited via a number of methods:

- Website
- Word of mouth
- Publicity and advertisement of the group on a variety of databases and websites
- Links with the Local MND Association Branch
- MND Clinics

Our Research

Motor neurone disease (MND) is a rapidly progressive neurodegenerative disease causing loss of motor neurones, or nerves, in the brain and spinal cord. This leads to muscle weakness, wasting and often difficulties with speech, swallowing and breathing. Over time it causes severe and unpredictable forms of paralysis then death, typically within 2-5 years of symptom onset.

Our main activity is to advise researchers from the Sheffield Institute for Translational Neuroscience (SITraN), a state-of-the-art research centre dedicated to researching motor neurone disorders. However we have recently expanded our remit and will provide PPI support to any MND project within the Yorkshire and Humber region. We offer clinical and scientific researchers feedback on their research proposals, ideas to improve patient involvement and assistance in communicating their research to wider audiences.

We have reviewed over 35 applications, lay review and grant applications to date.

"The SMND RAG represents the patients and their families which is at the heart of all our research. Their feedback helped shape both the planning, carrying out and the findings of our research."
Dr Esther Hobson
NIHR Research Fellow

"PPI allows us to develop our research programmes to match the priorities identified by individuals affected by MND."
Dr Chris McDermott, Consultant Neurologist

"Lay summaries are exceptionally important so receiving feedback from a lay audience has been extremely helpful and constructive."
Dr Laura Ferraiuolo, Research Associate

•SMND RAG is situated in the Sheffield Institute for Translational Neuroscience (SITraN)

•SMND RAG

SITraN, B12
385a Glossop Road
Sheffield S10 2HQ
United Kingdom

T: +44(0)114 222 2289

F: +44(0)114 222 2290

E: smndrag@sheffield.ac.uk

www.smndrag.group.shef.ac.uk



Follow @SMNDRAG

Key Successes

- ❖ Established a core panel to represent those affected by MND
- ❖ Developed strong links with clinical and scientific researchers
- ❖ Set up feedback protocol for reviewing documents
- ❖ Reviewed numerous research proposals
- ❖ Improved recruitment to studies
- ❖ Directed researchers to focus their results on improving standards of care
- ❖ Increased awareness of MND and our research
- ❖ Publicity on local radio, newspapers and NHS literature
- ❖ Evolved group identity via a logo and website
- ❖ Presentations about the group's work locally and internationally
- ❖ Raised money to support the group
- ❖ Expanded our remit for review to support Yorkshire and Humber in the new Local Comprehensive Research Network
- ❖ Development of Associate membership which gives individuals with increasing disability or altered time commitments the capacity to maintain links with the group and its activities
- ❖ Member of the panel has been a co-applicant on a successful research grant and remained involved in the project throughout
- ❖ Capacity for Skype participation

The Future

The group aims to become a resource for pharmaceutical companies to access specialist PPI advice.

We hope SMND RAG acts as a model for other groups to be established and support research into MND and other conditions.

