

Help Improve Neuromuscular Care in Norfolk & Suffolk

Join Our Stakeholder Group!

We are looking for people living with neuromuscular conditions and family carers to join a Stakeholder Group supporting a regional study of neuromuscular services across Suffolk and Norfolk. The study is called VOICE-NMD (Views, Opinions and Individual Care Experiences of people with Neuromuscular Disorders).

People with neuromuscular conditions often need care from several different teams, hospitals, and specialists. This can make the pathway complicated, and experiences can vary depending on where someone lives or which services they can access.

We are carrying out this study to understand what neuromuscular care currently looks like across Suffolk and Norfolk. The aim is to learn what is working well, where there are gaps or delays, and how services can be improved for patients and families.

What the role involves

- Attending three online meetings (approximately 1 hour) between July 2026-March 2027
- Helping shape a survey and focus groups for patients about neuromuscular healthcare
- Reviewing emerging findings
- Ensuring recommendations reflect what matters most to patients and families

Who can take part

- Adults with any neuromuscular condition or parents/carers of adults or children with neuromuscular disorders
- We particularly welcome people from underserved or under-represented communities

Support and payment

Patient and carer contributors will be reimbursed £25 per hour for their time (in line with NIHR guidance). Training and support will be provided.

Interested?

To express interest or find out more, please contact:

Research Lead: Dr Kate Maresh (Consultant Neurologist, West Suffolk NHS Foundation Trust)

Email: neurologydept@wsh.nhs.uk

Your VOICE can help shape better neuromuscular care for our region.