‘We R Rare’ – Patient, Family and Carer Steering Group: Role Rofile

We are looking for up to 8 patients, carers and family members with direct experience of rare conditions across Manchester and North-West England to join our established We R Rare Patient, Carer and Family Steering Group!

Our priority is to work with everyone who is interested in getting involved. To help broaden the diversity and perspective of the We R Rare Steering Group, we’re especially keen to hear from men with direct experience of rare conditions as well as those from diverse ethnic backgrounds.

What are Rare Conditions?

- A rare condition is one that affects less than 1 in 2,000 people.
- More than 3.5 million people in the UK are affected by a rare condition.
- Two-thirds cause long-term disability and over three-quarters affect children.
- Most rare conditions have no treatment.

We know rare conditions impact patients across all ages, sexes, socio-economic and ethnic backgrounds. We will only achieve our goals by working in partnership with people affected by rare conditions across North-West England to ensure the work we do meets their needs.

As a member of the ‘We R Rare’ Steering Group, what difference will I make by getting involved?

As a member of the ‘We R Rare’ Steering Group, your involvement can have a big impact. There is lots of ongoing work in Manchester and the North-West that will shape future treatment, diagnosis, and research of rare conditions.

Your lived experience is essential to ensuring we ask the right questions and implement the approaches that will best meet the unique needs of those living with rare conditions, their carers and their families. As a ‘We R Rare’ member, you will be part of a legacy where people affected by rare conditions can benefit from work being done now and in the future.

We want to make sure that you are personally benefitting from getting involved too:

- You’ll get to meet other people affected by rare conditions.
- Through our various activities, you can develop new skills and further boost your existing ones.
- Your role within ‘We R Rare’ can be a valuable addition to your CV, and we're happy to provide references as well.

As a member of the ‘We R Rare’ Steering Group, what would I be asked to do?

- Use your lived experiences to shape healthcare and research in rare conditions across North-West England.
- Contribute in a constructive and thoughtful way to give your opinion and advice on topics such as:
    - Engaging with people living with rare conditions, their families, their carers and the public in ongoing conversations about projects, research and services focused on rare conditions.
    - Communicating the impact and outcomes of research to the public.
    - Being accessible and inclusive of diverse communities and groups.

- Talk to people affected by rare conditions to better understand their needs and priorities, reflecting their views in discussions with the Steering Group.
- Help promote the work of the Manchester Rare Conditions Centre and Biomedical Research Centre.

- Attend and actively participate in Steering Group meetings.
- Prepare for each meeting by reading any papers required in advance.
- Respond to emails between meetings to support us in driving our activities forward.
- Where necessary, maintain confidentiality.

What experience and skills do I need to get involved?

- Lived experience of a rare condition – either as a patient, carer or family member.
- Based in North-West England - this role is to specifically support the work of the Manchester Rare Conditions Centre and Manchester Biomedical Research Centre.
- Willingness to share personal insights and experiences to shape research in rare conditions across North-West England.
- Feel comfortable speaking openly in a group and sharing your own opinions clearly and constructively.
- Be open to engaging in discussions with people who may hold differing opinions.

Interests:

- Using lived experiences to advise and shape work focused on rare conditions.
- Collaborating with diverse group of people to improve health and care.
- Role people with rare conditions, their families and their carers play in ensuring work in rare conditions meets their needs.
- Understanding and learning from the lived experience of others.
- Willingness to learn about rare conditions and the language and terminology used.

Additional Information	
Time commitment	We'd like for you to attend group meetings every two months for 2 hours. You may be asked to read a brief documents in preparation for the meeting which could take about 30 minutes.
Where will the meetings be?	It will be a mix! Most meetings will be online, and we'll run two face-to-face meetings per year – but we'd like to hear your thoughts and ideas on what would work best.
Length of role	Initially, members will be invited to join for 12 months, at which point we'll review the role with you to ensure it's the right fit for everyone. You'll then have the option to extend your role for another two years.
Expenses and Payments	• We offer payments of £25 an hour for all members of the 'We R Rare' Steering Group. • We offer a £5 data allowance to cover data / internet charges when joining online meetings. • We cover reasonable travel expenses across North-West England when meeting in person.

Support	We want to ensure everyone is supported to get involved. • We'll always send out information about meetings a week in advance. • We'll process your payments as quickly as possible. • We can cover carer and/or childcare costs as needed. • Provide lunch and refreshments during in-person meetings. We want to hear from you about anything else we can do to help – this could be for you personally or for the group.
Training	• An 'introduction' session in September 2025 to meet others in the group and hear more about the work you'll be doing. • You'll have a key contact who will provide you with information, updates and can answer any questions you might have. • If you feel you would benefit from any training to get involved, let us know and we can work together on next steps!

I'm interested in getting involved, what next?:

Email Sinduja Manohar at sinduja.manohar@mft.nhs.uk by **the end of the day on Monday 25th August 2025** with a **completed expression of interest form** *(see We R Rare webpage for the form)* outlining your experience and interest in this role.

If you would like to talk to an existing member of the We R Rare Steering Group to find out more about their experiences of being involved, please do let Sinduja know (sinduja.manohar@mft.nhs.uk). She can then arrange a Zoom call between you and an existing We R Rare Steering Group member at a mutually convenient time.

We may not be able to invite everyone who expresses their interest to join the Steering Group. As such, we will be inviting those who have been shortlisted to have an informal chat with the team over Zoom at a mutually convenient time. We will have other ways for you to get involved in the future too so do keep an eye out!

Please do keep the following dates free if possible:

- w/c 1st September 2025 = 30 mins for an informal chat
- Thursday 18th September 2025 from 2.30 – 4.00pm – We R Rare Induction meeting (we can be flexible on the date and time)
- Tuesday 23rd September 2025 from 6.00 – 8.00pm = We R Rare Steering Group meeting

If you have any questions or would like to find out more about the role, please do email Sinduja (sinduja.manohar@mft.nhs.uk) and she'd be happy to help.

We're looking forward to hearing from you!