

## **‘We R Rare’ – Patient, Family and Carer Steering Group: Role Profile**

**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. We are currently looking to recruit new members, with a particular focus on men as well as individuals from diverse backgrounds, to ensure we better represent the full spectrum of lived experiences.

If you are interested in getting involved but would like to do so without the commitment of an ongoing group, please get in touch and we can discuss the different options!

### **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 will 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 all 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. We’ll work together to set priorities and decide where we should be focusing our energy. 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 meet and build relationships with others affected by rare conditions.
- Through our various activities, you can develop new and existing skills.
- 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 insights through your lived experiences to shape healthcare and research in rare conditions across North-West England.
- Contribute in a constructive 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 the NIHR Manchester 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 supports the work of the Manchester Rare Conditions Centre and NIHR Manchester Biomedical Research Centre.
- Willing to share personal insights and experiences to shape research and services 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 have different 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 that 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

<b>Time commitment</b>	<p>Group members are asked to attend meetings every two months for two hours – usually in the evening to suit availability of members but we will take a flexible approach as new members join.</p> <p>You may be asked to read a brief document to prepare for the meeting which could take about 30 minutes.</p> <p>There will also be projects to support in-between meetings (optional) and could either be through written feedback or additional discussions.</p>
<b>Where will the meetings be?</b>	Most meetings will be online, and we'll run two face-to-face meetings per year – we'd like to hear your thoughts on what would work best.
<b>Length of role</b>	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.
<b>Expenses and Payments</b>	<ul style="list-style-type: none"> <li>• We offer payments of £25 an hour for all members of the 'We R Rare' Steering Group.</li> <li>• We offer a £5 data allowance to cover data / internet charges when joining online meetings.</li> </ul>

	<ul style="list-style-type: none"> <li>We cover reasonable travel expenses across North-West England when meeting in person.</li> </ul>
<b>Support</b>	<p>We want to ensure everyone is supported to get involved.</p> <ul style="list-style-type: none"> <li>We'll always send out information about meetings a week in advance.</li> <li>We'll process your payments as quickly as possible.</li> <li>We can cover carer and/or childcare costs as needed.</li> <li>Provide lunch and refreshments during in-person meetings.</li> </ul> <p>We want to hear from you about anything else we can do to help – this could be for you personally or for the group.</p>
<b>Training</b>	<ul style="list-style-type: none"> <li>An 'introduction' session in November 2025 to meet others in the group and hear more about the work you'll be doing.</li> <li>You'll have a key contact who will provide you with information, updates and can answer any questions you might have.</li> <li>If you feel you would benefit from any training to get involved, let us know and we can work together on next steps!</li> </ul>

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

Email Sinduja Manohar at [sinduja.manohar@mft.nhs.uk](mailto:sinduja.manohar@mft.nhs.uk) by **the end of the day on Sunday 28<sup>th</sup> September 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](mailto:sinduja.manohar@mft.nhs.uk)) and she can arrange it for you.

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:

Monday 6 <sup>th</sup> – Tuesday 14 <sup>th</sup> October 2025	30 mins for an informal chat over Zoom
Thursday 13 <sup>th</sup> November 2025 from 2.30 – 4.00pm	We R Rare Induction meeting over Zoom (we can be flexible on the date and time to suit the availability of group members)
Thursday 27 <sup>th</sup> November 2025 from 6.00 – 8.00pm	We R Rare Steering Group meeting over Zoom

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

**We're looking forward to hearing from you!**