‘We R Rare’ – Patient, Family and Carer Steering Group: Expression of Interest Form

### **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.

### Members of this Group will use their lived experiences to provide advice to the Manchester Rare Conditions Centre and the NIHR Manchester Biomedical Research Centre. They will have a key role in shaping projects, research and services related to rare conditions across Manchester and the North-West.

If you have any questions or need any help completing the form, please email Sinduja at sinduja.manohar@mft.nhs.uk and she’d be happy to help.

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 let Sinduja know (sinduja.manohar@mft.nhs.uk) and she can arrange it for you.

Please note, the information you provide in this form will only be seen by four members of staff who are working to set up the We R Rare Group and will not be shared more widely.

|  |  |
| --- | --- |
| **Name** |  |
| **Town or City** *(Please note this opportunity is specific to those in Manchester and the North-West)* |  |
| **Email Address** |  | **Telephone number** |  |
| **Where did you hear about this opportunity?** |  |
| **Please briefly tell us about your experiences of rare conditions (up to 250 words).** *For example, do you have a rare condition yourself or are you a carer or family member? Please note, a rare condition is defined as affecting less than 1 in 2000 people. If you are unsure if your experiences relate to a rare condition, please do get in touch and we’d be happy to discuss further.* |
| **Please tell us more about why you want to get involved and what you’d like to bring to We R Rare, referring to the role profile where relevant (up to 400 words).***This could relate to your personal experiences of rare conditions as well as any experiences or skills you may have from any voluntary or professional roles you’ve had in the past.* |
| **Important Dates:**  * Deadline for ‘Expressions of Interest’ – **end of day** on **Sunday 28th September 2025**
* Informal chat with the team, over Zoom at a **mutually convenient time** between **6th – 14th October 2025**.
* Induction for new We R Rare members – **Thursday 13th November from 2.30 – 4.00pm** *– this is an approximate date and we will be flexible to meet the needs of new group members*
* ‘We R Rare’ Steering Group meeting on **Thursday 27th November 2025 from 6.00 – 8.00pm.**

**Are there any dates or times that we have outlined in which you are unavailable?** *This will not be used to inform any decisions and is purely to enable us to plan accordingly.*  |
| **Do you have any needs or existing / regular commitments we should be aware of to better support you to get involved?** *This will be used by the team at Vocal only to* *support you to get involved in the process and to provide ongoing and tailored support if you become a member of the We R Rare Group. This will not be used for any other purposes and will not be used inform any decisions.* |

Please emailthe completed formto**sinduja.manohar@mft.nhs.uk** **by the end of the day** on **Sunday 28th September 2025**. We will get in touch the following week to let you know next steps.