

Expression of Interest Form for Patient and Public Involvement

Development of a National Rare Disease Strategy

The Minister for Health recently announced the establishment of the National Rare Disease Steering Group. The Steering Group have been tasked with developing a new Rare Disease Strategy for Ireland that sets out the vision for Rare Disease services and research in Ireland and the actions required to achieve this.

As part of the development of this new Strategy we are seeking to strengthen and expand our patient and public involvement (PPI) and public engagement activities, and broaden our network of people, especially those living with a rare disease, carers of people living with a rare disease, and health workers, who are interested in contributing and partnering in the development of a new National Rare Disease Strategy.

Furthermore, as part of the development of the new Strategy, a Patient Forum is being established to ensure the voices and lived experience of people living with rare diseases and their families remain central to the development of this strategy. The Patient Forum will be chaired by Ms Vicky McGrath (Rare Diseases Ireland) and Dr Derick Mitchell (IPPOSI) and the input collected through the Patient Forum will feed directly into the work of the Steering Group in developing the new Strategy.

This survey is for people who are interested in the future of rare disease services in Ireland, have experience accessing these services, live with or care for someone with a rare disease, or are interested in contributing in a tangible way to the creation of more trusted, and more efficient, relevant rare disease services and research in Ireland. It is not about access to services or being a participant in research. Rather, it is about helping us to shape services and research for the future. Completing this 'expression of interest' will allow us to alert you to new opportunities to engage with the work of the Steering Group and the level to which you would like to be involved.

On this form, we ask you to share some of your personal experiences of rare disease services and/or research. Please feel free to share as much or as little as you are comfortable with; your responses will only be used by the National Rare Disease Steering Group to enable us to match people with suitable opportunities, helping to ensure any experience in participating in the envisaged PPI activities is a positive one.

Please note that participation in PPI and engagement activities with the National Rare Disease Steering Group and Patient Forum is voluntary.

We very much look forward to hearing from you.

Privacy Policy:

The lawful basis for processing this information under the GDPR is: 6(1)(e): processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller.

The information collected in this survey will enable us to invite interested persons to take part in future Patient and Public Involvement (PPI) and public engagement initiatives for the purpose of informing the development of the National Rare Disease Strategy. This is the only way in which your information will be used.

All information supplied will be treated sensitively, with access limited to relevant staff working within the National Rare Disease Steering Group. All information will be held until August 2024, following which it will be disposed of subject to the Department's obligations in accordance with the National Archives

PERSONAL DETAILS

1. Name:
2. Age:
3. Gender:
4. Email:
5. County:

MOTIVATION

6. How would you describe your motivation for wishing to take part in patient and public involvement (PPI)? Tick all that apply
 - a. I have accessed rare disease services
 - b. I have been involved in research on rare diseases
 - c. I am living with a rare disease
 - d. I am caring for a person or people with a rare disease
 - e. I am interested in improving healthcare in Ireland
 - f. I am employed in the healthcare sector in Ireland
 - g. I am interested in rare disease services and research
 - h. Other (please state): [open ended]
7. Have you previously participated in PPI activities or acted as an advocate for someone living with a rare disease?
8. In what ways would you be interested in participating in PPI and public engagement activities to improve the design and delivery of a new National Rare Disease Strategy? Tick all that apply
 - a. Complete the occasional survey by email
 - b. Participate in focus groups or other structured discussions with peers (either online or in person)
 - c. Become a member of a Patient Forum (meeting virtually approximately once a month)

- d. Share your story with the National Rare Disease Steering Group in writing or via voice/video recording (we will contact you with submission details in January 2024) with the goal of inspiring positive change.
 - e. Other
9. Which of the following areas would you be interested in contributing to? Tick all that apply.
- a. Care Pathways, Integrated Care & Service Delivery
 - b. Diagnostics and Newborn Screening
 - c. Technology and orphan medicines, including novel advanced medicines.
 - d. Electronic health records, Data and Registries
 - e. Health & Social Research & Industry Partnership
 - f. Other – please suggest topics
10. What knowledge, skills, or perspectives do you hope to contribute through PPI activities?
11. Do you have any concerns about participating in PPI activities?
12. Are there any other comments you would like to include in this expression of interest?

Motivation statement: Why I would like to be a member of the Patient Forum

(ONLY REQUIRED FOR THOSE SEEKING TO JOIN THE PATIENT FORUM)

- *Please tell us why you want to become a member of the Patient Forum and include any specific contribution that you feel you can make. A specific contribution may be related to your personal background, your lived experience and knowledge, or your interest in service improvement/research. Please share with us any further information that you feel is relevant for this role.*
- *You can send a motivation statement as a document or you can create a video or audio recording, or you can send us a document and a video or audio recording. Written statements should be less than 500 words. Audio or video recordings should be shorter than 3 minutes. Longer recordings will be accepted from any person with special communication needs.*