

PPI in RDCTN: How We Operate

Having a dedicated role within the network is a declaration to our stakeholders that we take PPI seriously and value its importance in all our activities. Our PPI Liaison Officer is dedicated to ensuring all our efforts align with the genuine needs and priorities of those affected by rare disease.

Recruitment Mechanisms

Contributors are recruited through mechanisms like:

- Social media
- Our website
- PPI Ignite Noticeboard
- Online community hubs
- Chance meetings and outreach

Initial Engagement

After submitting an Expression Of Interest, contributors are offered a one-to-one chat with the PPI Liaison Officer to discuss:

- Type of experience with rare disease
- Communication and acknowledgement preferences
- Motivation and expectations
- Competencies and constraints

Levels of Involvement

Recognising the time constraints of those affected by rare diseases, we offer flexible involvement:

- Ad hoc group passively receives information and opportunities
- Advisory group commits to serving terms, attending regular meetings, and providing strategic insights

Guidance and Structure

Contributors are guided by a governance structure they helped develop, with key structures in place, including:

- Expression of interest
- Terms of reference (available to share)
- PPI Strategy
- Role descriptions will be developed as the group expands in size and commitments

Involvement Examples

Contributors are involved in many projects, ranging from information sharing to collaboration:

- Contributes to network governance groups like the management committee
- Presents at international meeting
- Reviews seed funding applications
- Influences conference programme, speaker selection and themes
- Develops content and priorities for the network website and social media profiles

Operational Management

PPI activities are managed by full-time a PPI Liaison Officer within the RDCTN

This role sits between the RDCTN and HRCI, bridging the clinical and charity health research sectors

The liaison manages recruitment, onboarding and coordination of contributors, as well as providing PPI workshops and training for contributors and researchers

This role is guided by our vision that PPI is at the heart of our network