Strengthening your PPI Section
Insights from PPI Reviewers:

Through two rounds of Seed Funding applications, we've learned a lot about what matters most to Patient and Public Involvement (PPI) partners. Our expert PPI reviewers have shared their insights and observations, and this resource shares takeaways from their feedback. We hope this will help future applicants better understand what good PPI looks like and how to strengthen their applications. Whether you're new to PPI or looking to improve, these insights can help you build more meaningful and impactful involvement.

Relevance and Impact - Show that your study question matters to people living with rare conditions, and explain how it will benefit them

- Describe how your research might address current challenges (lack of treatments, poor symptom tracking, gaps in support)
- Explain how your results could improve care, even in small but meaningful ways
- Make clear how your research relates to priorities of people living with the condition
- Balance long-term goals with short-term impacts that matter to patients
- Use real examples or quotes from patients, family members, or advocates
- Where relevant, show the broader relevance for related rare diseases

Language and clarity - these are important throughout the application, and particularly in the lay summary. Tip: Ask someone without a research background to read your summary.

- Your lay summary should clearly describe the condition being studied, who it affects, and what the research is aiming to change
- Explain it simply and avoid jargon
- Simplify medical terms, or consider putting a description in brackets beside the medical term (e.g., edema [swelling])
- Use plain, everyday language (e.g., replace "comorbidities" with "other health conditions")
- Visit resources like National Adult Literacy Agency (NALA) for plain English guidance
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Study design - make it clear that taking part in your study will work for the people it's meant to help. Consider patient needs, study acceptability and the practicalities of participation. Tip: Talk to people about what it would be like to be a participant in your study

- Explain what study participation will involve (e.g., procedures, time commitment, travel, use of sensitive data)
- Demonstrate that you've considered the additional burdens that may fall on people living with rare conditions
- Describe your efforts to ensure your methodology aligns with patient priorities and needs
- Patient groups provide pools of expertise, and collaborations with them are viewed favourably

Dissemination and feedback - for people living with rare diseases, access to new knowledge and research is crucial. Reviewers want to see well-planned strategies for feedback

- Craft dissemination plans in partnership with PPI contributors
- Explain how these plans will share results of the research with the rare disease community.
- Ask people how *they* would like to hear results, and use that in your approach
- Some specific ideas:
    - Plain language summaries via email or newsletters
    - Social media posts or infographics
    - Patient stories or videos
    - Public talks
    - Updates through patient organisations and support groups