



Researcher Information Pack

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What is PRIME?

PRIME (Building Infrastructure for Patients, Researchers and Industry for ME/CFS) is a UK MRC-funded initiative (2025–2029) to accelerate research on ME/CFS. PRIME’s three goals are to catalyse 15 new research collaborations, build international scientific connections via two new research consortia, and to creation of the first network of people with lived experience of ME/CFS, trained and supported as Patient and Public Involvement (PPI) contributors to work alongside researchers.

What is Patient and Public Involvement and Why Does it Matter?

Patient and Public Involvement and Engagement (PPIE) means researchers and people with lived experience of ME/CFS working together as partners throughout the research process—from shaping questions to sharing results. It goes beyond simply seeking feedback after decisions are made; PPIE embeds patient insight at every stage.

Why does it matter for ME/CFS research?

- **Better Design:** People living with ME/CFS understand the practical realities of the condition. Their input helps ensure study methods, recruitment strategies, and materials are accessible and usable.

- Greater Relevance: Research priorities reflect what matters most to patients, improving the chances that findings will have real-world impact.
- Ethical and Transparent: Patient and Public Involvement aligns with UK PPI Standards and NIHR guidance, promoting respect, inclusivity, and accountability. It builds trust between researchers and the community.

In short, patient and public involvement makes research more robust, meaningful, and ethical—shaping studies with those most affected, not just for them.

What is the PRIME ME/CFS Research Involvement Hub?

Our Hub combines two key aspects:

1. A virtual network of people with lived experience of ME/CFS ready to provide insight, feedback, and collaboration opportunities.
2. Advice, support and matching processes to help researchers deliver PPI effectively

Through the Hub, PRIME will connect researchers to people with lived experience of ME/CFS.

This Hub will:

- Ensure ME/CFS research is shaped with and by people with lived experience
- Provide researchers across the UK with access to trained patient and public involvement contributors
- Offer tailored training and guidance for both contributors and researchers
- Build on Action for ME's recognised excellence in patient and public involvement, including the MRC highlighted DecodeME model

The goal: an ecosystem of patient and public involvement that supports both researchers and those with lived experience.

What Does the PRIME Hub Offer Researchers?

- Access to a diverse Hub of individuals with lived experience of ME/CFS and Long Covid
- Help matching members to your project needs
- Guidance on:
 - Best practice for research involvement
 - Working with people with energy limiting conditions
 - Budgeting for involvement, including use of a [downloadable Excel budgeting template](#) to help plan for public contributor time, staff time, and activity costs

How Can Researchers Use the Hub?

The Hub is here to support a variety of researcher needs. Our two roles are to match people with lived experience of ME/CFS with projects that require their input, and to provide training and advice on best practice around PPI.

Types of involvement you might consider utilising as part of your project:

- **Quick consultations:** Surveys, feedback on participant materials
- **Focus groups:** Small group sessions to explore specific issues, usually via video calls
- **Full co-production:** Collaborators, advisory group members or co-investigators embedded in your team

Examples of tasks:

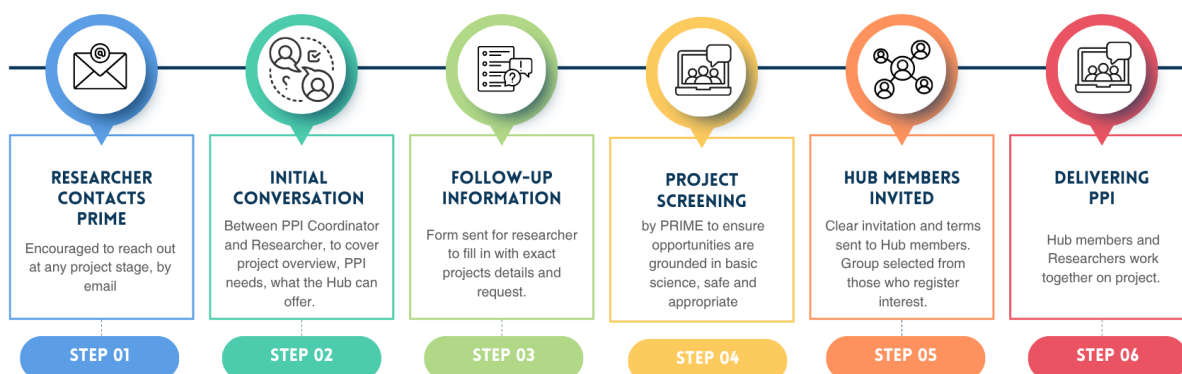
- Reviewing participant information sheets and consent forms
- Advising on recruitment strategies and accessibility
- Shaping research questions and outcomes
- Co-authoring papers and lay summaries
- Developing dissemination plans

Request Process

Simply reach out to us on prime@actionforme.org.uk to set up an initial conversation about your work and what involvement you need.

We will usually do this via a Teams video call. Once we've worked out together what your requirements are, we will send you a form to fill in giving us more detail about your project in your own words.

All projects will be screened by a small team from PRIME, including one researcher, one PPI member and one Action for ME research department staff member. Following this, Hub members will receive a clear invitation about your project, and we will match a diverse group to get involved.



You are welcome to get in touch at any stage of your project, and while we encourage early involvement, please don't let this put you off if you are already a way in.

If you have something specific you would like to ask about, just want an exploratory chat, or would value advice on involvement approaches, you are also very welcome to get in touch.

Payment and Budgeting

We strongly recommend budgeting for patient and public involvement in line with [NIHR guidance](#), and offering thank you payments to those you involve.

To help with this, we have developed a [downloadable Excel budgeting template](#) to support researchers think through costs such as public contributor time, staff time to organise involvement activities, accessibility needs, and other practical delivery costs.

We recognise that it is important to involve people with lived experience during grant development, but that funding may not always be available for this. We also recognise that providing thank you payments may depend on the type of involvement you are looking for. We will work with you to think about what is and isn't appropriate, and how best your project can recognise the contributions of people with lived experience.

Contact and Support

- PRIME PPI Team contact details: prime@actionforme.org.uk
- Researchers with specific queries, or who would like advice on involvement, are very welcome to get in touch.
- Training for researchers, and potentially drop-in PPI sessions, are being developed and will be shared when available.

Learn more about PRIME at actionforme.org.uk/prime

FAQs

- **How do I start if I've never done PPI before?** Get in touch with us for an initial conversation. We can help you think through what kind of involvement would be most useful, when to involve people, and what good practice looks like for your project.
- **What if my project is very technical?** That is not a problem. People with lived experience can still offer valuable insight on relevance, acceptability, accessibility, language, recruitment, and study design, even in highly technical projects.
- **How do I handle confidentiality and data protection?** We can offer general advice on good involvement practice, but researchers remain responsible for ensuring that any involvement activity is managed appropriately and in line with their organisation's policies and requirements.
- **Can PRIME connect me to international contributors?** No, not at present. The PRIME Hub is currently focused on involving UK-based contributors.
- **Can PRIME help me find participants to be subjects in my study?** No. PRIME supports patient and public involvement, not participant recruitment for research studies.
- **Can PRIME coordinate involvement for my study?** No. We can provide advice and match researchers with lived experience contributors, but researchers need to coordinate the involvement opportunity themselves, including arranging meetings, managing thank you payments, and supporting contributors to get involved. Some larger projects contract this work to charities such as Action for ME. If your project would like Action for ME to consider taking on this work, please contact research@actionforme.org.uk directly.
- **Who can use the PRIME Hub?** The PRIME Hub is for researchers looking to involve people with lived experience of ME/CFS in their work. We expect most requests to come from UK-based researchers or research teams, and the Hub is currently focused on involving UK-based contributors.
- **At what stage of a project should I get in touch?** At any stage. We encourage early involvement wherever possible, especially when shaping research questions, study design, or grant applications, but it is still worth contacting us if your project is already underway.
- **Is there a cost to using the Hub?** There is no charge for contacting us, discussing your needs, seeking advice, or being matched with contributors. However, researchers should plan and budget appropriately for involvement activity itself, including thank you payments, accessibility needs, staff time, and any practical delivery costs.
- **How long does matching usually take?** This will depend on the type of opportunity, the number of contributors needed, and how specific your

requirements are, but we aim to have fast turnaround times once we have all the information necessary from you. We will always aim to be clear with you about likely timescales and encourage you to get in touch as early as possible if you are working to a deadline.

- **What kinds of involvement opportunities are suitable for the Hub?** The Hub can support a range of involvement opportunities, from one-off feedback requests to ongoing advisory roles. This might include reviewing participant-facing materials, shaping research questions, advising on accessibility and recruitment, contributing to dissemination, or being part of an advisory group.
- **Can contributors review participant-facing materials only, or be involved more deeply?** Both. Some researchers need quick feedback on documents such as participant information sheets or consent forms, while others want longer-term involvement through advisory roles, workshops, or co-production. We can help you think through what level of involvement is most appropriate for your project.
- **What if I do not yet have a budget for involvement?** Please still get in touch. This is a common issue, especially during early-stage or grant development work. We can talk with you about what may be feasible, what good practice looks like, and how to plan for involvement costs in future funding applications or project budgets.
- **Can PRIME advise on accessible ways of involving people with energy-limiting conditions?** Yes. We can advise on practical ways to make involvement more accessible and inclusive for people with ME/CFS and related energy-limiting conditions, such as thinking carefully about meeting length, pace, format, communication methods, notice periods, and follow-up support.