



Member Information Pack

What is PRIME?

PRIME's full name is 'Building Infrastructure for **P**atients, **R**esearchers and **I**ndustry for **M**yalgic **E**ncephalomyelitis/**C**hronic Fatigue Syndrome'

It is an initiative aimed at enhancing and accelerating research on ME/CFS. It's funded by the UK Medical Research Council from 2025-2029, and aims to catalyse 15 new research collaborations, build two international research consortia, and establish an ME/CFS Research Involvement Hub.

What is the PRIME ME/CFS Research Involvement Hub?

The ME/CFS Research Involvement Hub is a virtual space bringing together people with lived experience of ME/CFS, researchers, and other partners. Our goal is to make sure research is shaped by the voices of those it affects most.

We know that the best research happens when everyone involved shares ideas, listens to each other, and collaborates from the very beginning. That means people with ME/CFS are not just consulted—they are part of the team, helping to design, plan, and guide projects.

Through the Hub, PRIME will connect people with lived experience of ME/CFS to research projects that need their input. Research teams will also be able to ask questions of people that are part of the Hub, via surveys, focus groups and even 1-1 discussions, to get feedback on key issues. They will be able to work with specific groups if they need to, such as those with severe ME/CFS, to ensure they hear the voices of those who are often excluded from research.

Members of the Hub are not research participants but are there to provide personal feedback and insight aimed at shaping and improving research.

Who can join the Hub?

We are recruiting people with lived experience of ME/CFS to join the Research Involvement Hub.

You can join the Hub if you are a:

- Person with ME/CFS
- Person who suspects they have ME/CFS but has not been able to access a formal diagnosis, including those with Long Covid whose symptoms resemble ME/CFS
- A carer of someone with ME/CFS
- A close supporter of someone with ME/CFS (e.g. family members or friends who provide regular, ongoing support)

You must also:

- Reside in the UK
- Be aged 16 or over

Health or social care professionals, researchers, and students are not eligible to join because the goal of the Hub is to ensure that the voices of lay people are heard by those groups.

We warmly encourage people from minority or marginalised groups* to join our Hub as their unique experiences are extremely valuable and underrepresented in many research projects.

*Including but not limited to people with severe or very severe ME/CFS, people from minoritised ethnic groups, and people with low socio-economic status.

How involvement in the ME/CFS Research Involvement Hub works

Once you've signed up to join the Hub, you will be asked to confirm you have read and agreed to our Value and Principles Member Agreement. We also plan to send an initial training video and quick quiz **on Patient and Public Involvement and Engagement (PPIE) in research.**

Following this you could be invited by email to engage in different activities, including:

- Responding to surveys asking your opinion on specific aspects of a research project
- Joining small focus groups to discuss a particular project

- Becoming a collaborator on a specific project, to help design and deliver it

There may be times where more opportunities come through, and times where you don't hear from us for a while. All opportunities will clearly explain what is involved - whether that is video calls, feeding back on a document, or filling in a short survey. We'll include information about time frames and commitment. If an opportunity isn't right for you, just don't respond. For longer term involvement opportunities, we may hold interviews.

All Hub members are encouraged to pace any involvement, and to ask for support where this is needed. Anyone can step back at any point without needing to explain why, as we recognise people's life circumstances, health and capacity will fluctuate.

We will prioritise matching those who complete the training and quiz as collaborators for upcoming research projects. We'll aim to make training available in multiple formats to meet different needs. And we hope to offer further training sessions in time.

Our goal is to have at least 100 people who are ready to become part of co-producing research. If you become a collaborator on a project, you are likely to need to engage more intensively with the research team, such as through meetings and small group discussions, or emails and Microsoft Teams. However, we will advise projects on adapting processes to be accessible to those with severe ME/CFS or other needs. We can also support you to advocate for your own needs if we match you with a project.

How will researchers use the Hub?

Researchers will be able to request involvement from members of the Hub.

All requests will be screened by at least one member of the Action for ME research team, at least one ME/CFS researcher from PRIME, and at least two lived experience representatives from PRIME, before invitations are sent out to members of the Hub.

When submitting a request, researchers must clearly outline what they need from Hub members and the most appropriate way to gather this insight (for example, a short survey to gather views, or inviting Hub members to act as co-investigators on a study).

Every researcher request will be screened to check it is:

- ✓ grounded in a basic understanding of PPI
- ✓ safe and appropriate
- ✓ accessible for people with ME/CFS

- ✓ based on a reasonable scientific rationale
- ✓ transparent about expectations

If a project does not fully meet our screening criteria but is still considered valuable, we will work with the research team to bring it up to standard.

Once approved, the opportunity will be shared with members of the Hub, along with a timeframe for expressing interest. If more people volunteer than a project requires, we will recommend suitable Hub members based on lived experience, demographics, location, and relevant interests. For longer term involvement opportunities, we may hold interviews.

Benefits and Limitations

Benefits:

- **Influence research that matters to you**
- **Learn about research processes and co-production**
- **Connect with others who share your experience**
- **Develop new skills and confidence**
- **Feel valued and heard**
- **Flexible involvement**
- **Contribute to meaningful change**

Limitations:

- **We cannot guarantee involvement in a project**
- **Engagement may vary over time**
- **Some research materials may be technical**
- **Not all suggestions can be implemented**
- **Timings may be tight**
- **Energy and health limitations**

Even with flexible options, involvement may not always be possible during symptom flares and we strongly support people in prioritising their own health, or the health of their close one.

Payment

Becoming a member of the Hub does not automatically mean you will receive payment.

Most opportunities—such as **surveys, quick feedback tasks, or one-off focus groups—will not include payment.** These activities are usually voluntary because they are short, low-burden, and often take place before funding is secured.

However, some Hub members may be offered **paid opportunities**, particularly when they are invited to take on a more substantial or ongoing role within a research project (e.g., acting as a collaborator, co-investigator, or advisory group member).

We encourage and support research teams to budget for public involvement in line with [NIHR guidance on payment of fees](#).

During early stages of research, such as the development of grant applications, researchers may not be able to offer payment, and involvement at this stage is typically voluntary.

If a grant application is successful, the project team should then have the resources to compensate the Hub members working with them throughout the project. These thank-you payments are often **around £27.50 per hour**, reflecting your time, skills, and lived-experience expertise. This is not a wage or salary, but an acknowledgement of your contribution.

Before inviting any Hub member to take part in a research opportunity, we will make sure:

- the terms of payment (if any) are clearly explained
- the process for claiming payment is provided
- you have the option to decline payment if that is your preference

Hub members can always choose whether to take part in any opportunity depending on what feels right for them. They may also choose to participate but turn down receiving payment for any reason.

More information

For updates about the PRIME ME/CFS Research Involvement Hub go to actionforme.org.uk/prime

Get in touch

If you have any questions, you can reach out to us on prime@actionforme.org.uk