Join the ME/CFS Research Involvement Hub

Thank you for your interest in joining the PRIME ME/CFS Research Involvement Hub.

PRIME's full name is 'Building Infrastructure for Patients, Researchers and Industry for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome'.

It's 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 to deliver Patient and Public Involvement.

What is Patient and Public Involvement?

Patient and Public Involvement (PPI) means researchers working with patients, carers and members of the public to design, develop and improve research — rather than research being done about or for people without their input. PPI contributors help make research more relevant, inclusive and impactful.

PPI doesn't mean taking part in the research itself:

- participation is when people are the *subjects* of a study
- PPI is when people with lived experience *work with* researchers to shape and influence the study.

What is the ME/CFS Research Involvement Hub?

The PRIME ME/CFS Research Involvement Hub is a group of people who are interested in helping to design and develop research in flexible ways. After joining the Hub, you may be invited to take part in activities such as responding to short questionnaires, joining online discussions, or working more closely with research teams to coproduce research projects. You can choose how much, or how little, you'd like to be involved.

Who can join?

We welcome applications from people with a personal connection to ME/CFS who are living in the UK, including:

- People with ME/CFS
- People with Long Covid who have ME/CFS-like symptoms
- Carers, family members, and close supporters of someone with ME/CFS

You do not need any previous research experience to join — your perspective and experiences are what matter most.

About this application form

This application form contains around **20 questions, most are tick box,** and takes about **15-30 minutes** complete. You don't have to answer everything in one go.

If you wish to use our online form please visit https://primehub.fillout.com/sign-up

More information

You may find it helpful to read our **Information Pack**, which includes more detail about PRIME, the ME/CFS Research Involvement Hub, and what involvement might look like.

If you have any questions or need support to complete this form, please contact us at **prime@actionforme.org.uk** or phone Action for ME on **0117 927 9551** and leave us a message with your name and number, mentioning your call is about the PRIME Hub.

1. Are you filling in this form for yourself or on behalf of someone else?

☐ Myself
☐ Someone else

If you are filling this in on behalf of someone else, please assume all future questions relate to the person you are filling this in for. Thank you.

2. Do you consent to your data being stored and used in line with Action for ME's privacy policy? Available at actionforme.org.uk/privacy-policy

   We will send you emails about involvement opportunities. You can unsubscribe at any time, thereby removing yourself from the Hub.

☐ Yes
☐ No

3. Would you like to subscribe to Action for ME's newsletter?

   This is optional, and separate from the emails you will receive offering opportunities to get involved. You can unsubscribe at any time.

☐ Yes, I want to receive the newsletter

4. How old are you? *

   .....

You must be 16 years or older to join the PRIME Hub.

5. Are you able to fill in this form, or do you need another way to communicate?

☐ I can fill in this form myself, or with help from someone I know (go to question 7)

☐ I cannot fill in this form (go to question 6)

6. If you cannot fill in this form, please tell us the best way to get in touch with you, so that we can help you to sign up.
   For example, you might say a phone call between 10am and midday. We will do our best to adapt to your needs, and if we can't meet a request fully, we'll work with you to find practical alternatives that make participation easier.

   .....

   .....

   .....

Contact details

7. Your first name: .....
8. Your last name: .....
9. Your email: .....
10. Your preferred phone number: .....
11. Your postal address:

    .....

    .....

If you cannot fill in more of this form, please send it back to us with just the above information, and we will get in touch with you via phone or text.

Please post forms to:

PRIME, FAO Action for ME
Unit 2.2 Streamline
436-441 Paintworks
Bristol
BS4 3AS

If it is easier, you can send photographs of the form to prime@actionforme.org.uk

12. Do you have any accessibility needs that we should know about?
    Most of our work will be online, so we are particularly asking about needs relating to this, and not relating to travel or in-person activities. We will do our best to adapt to your

needs, and if we can't meet a request fully, we'll work with you to find practical alternatives that make participation easier.

.....

.....

Your connection to ME/CFS

13. What is your connection to ME/CFS? Tick all that apply

☐ I have ME/CFS (please fill in section "Your ME/CFS")
☐ I have Long Covid with ME/CFS-like symptoms (please fill in section "Your ME/CFS")
☐ I care for someone with ME/CFS, or Long Covid with ME/CFS like symptoms (please fill in section "Your Close One's ME/CFS")
☐ I am a close supporter of someone with ME/CFS e.g. a family members or friend who provides regular support (Please fill in the section "Your Close One's ME/CFS)
☐ Other, please specify:.....

Your illness (only for those who tick I have ME/CFS or Long Covid)

14. Which description most closely matches the severity of your illness **over the past three months**?

☐ **Mild**: People with mild ME/CFS care for themselves and do some light domestic tasks (sometimes needing support) but may have difficulties with mobility. Most are still working or in education (often with reduced hours) but to do this they have probably stopped all leisure and social pursuits.
☐ **Moderate**: People with moderate ME/CFS have reduced mobility and are restricted in all activities of daily living. They have usually stopped work or education, and need rest periods, often resting in the afternoon for 1 or 2 hours.
☐ **Severe**: People with severe ME/CFS are unable to do any activity for themselves or can carry out minimal daily tasks only (such as face washing or cleaning teeth). They may depend on a wheelchair for mobility, are often unable to leave the house, and may spend most of their time in bed.
☐ **Very severe**: People with very severe ME/CFS are in bed all day and dependent on care. They need help with personal hygiene and eating, and are very sensitive to sensory stimuli.

15. Do you experience the following symptoms? Please select all that apply.

☐ **Debilitating fatigue** that is worsened by activity, is not caused by excessive cognitive, physical, emotional or social exertion, and is not significantly relieved by rest.
☐ **Post-exertional malaise** (PEM). This means that your symptoms get worse after (physical, cognitive, emotional) activity, and the reaction is out of proportion to what you did. PEM is often delayed in onset by hours or days. It has a prolonged recovery time that may last hours, days, weeks or longer.
☐ **Unrefreshing sleep** and/or **sleep disturbance**. For example, feeling exhausted or flu-like when you wake up, experiencing broken or shallow sleep, or an altered sleep pattern.
☐ **Cognitive difficulties** (sometimes described as **'brain fog'**). These may include problems finding words or numbers, difficulty in speaking, short-term memory problems, and difficulty concentrating or multitasking.

16. What year did you become ill?
☐ .....

Your close one's illness (only for those who are carers or close supporters)

17. Which description most closely matches how severe the illess of the person you are supporting has been **over the past three months**?

☐ **Mild**: People with mild ME/CFS care for themselves and do some light domestic tasks (sometimes needing support) but may have difficulties with mobility. Most are still working or in education (often with reduced hours) but to do this they have probably stopped all leisure and social pursuits.
☐ **Moderate**: People with moderate ME/CFS have reduced mobility and are restricted in all activities of daily living. They have usually stopped work or education, and need rest periods, often resting in the afternoon for 1 or 2 hours.
☐ **Severe**: People with severe ME/CFS are unable to do any activity for themselves or can carry out minimal daily tasks only (such as face washing or cleaning teeth). They may depend on a wheelchair for mobility, are often unable to leave the house, and may spend most of their time in bed.
☐ **Very severe**: People with very severe ME/CFS are in bed all day and dependent on care. They need help with personal hygiene and eating, and are very sensitive to sensory stimuli.

18. Does the person you are supporting experience the following symptoms? Please select all that apply.

☐ **Debilitating fatigue** that is worsened by activity, is not caused by excessive cognitive, physical, emotional or social exertion, and is not significantly relieved by rest.
☐ **Post-exertional malaise** (PEM). This means that your symptoms get worse after (physical, cognitive, emotional) activity, and the reaction is out of proportion to what you did. PEM is often delayed in onset by hours or days. It has a prolonged recovery time that may last hours, days, weeks or longer.
☐ **Unrefreshing sleep** and/or **sleep disturbance**. For example, feeling exhausted or flu-like when you wake up, experiencing broken or shallow sleep, or an altered sleep pattern.
☐ **Cognitive difficulties** (sometimes described as **'brain fog'**). These may include problems finding words or numbers, difficulty in speaking, short-term memory problems, and difficulty concentrating or multitasking.

19. What year did your close one become ill?

☐ .....

Why do you want to apply?

Our ME/CFS Research Involvement Hub connects people with lived experience with researchers to help shape studies.

We'd love to learn more about what motivates you and what you'd enjoy bringing to this role. You don't need any previous experience in research to join – your perspective and ideas are what matter most. These questions help us understand what interests you and how we can support you to make a meaningful contribution. Please answer in a way that feels right for you – there are no "right" or "wrong" answers.

20. Why do you want to join the Patient and Public Involvement Pool? (Max 250 words, but just a few sentences are okay too. Continue on another sheet of paper if you need.)

.....

.....

.....

.....

.....

.....

.....

21. What would you enjoy bringing to this role? This could be your perspective as a patient or carer, your ideas for improving research, or any skills you'd like to use. (Max 250 words, but just a few sentences are okay too. Continue on another sheet of paper if you need.)

.....

.....

.....

.....

.....

.....

.....

22. Do you have previous experience as a Patient and Public Involvement contributor to research?

    You don't need any previous experience to join – we just ask so we can support you in the best way.

☐ Yes, a little experience
☐ Yes, a lot of experience
☐ No

23. You can get involved in the Hub in different ways. Please let us know what you would be interested in doing. You can tick as many boxes as you want.

    If you want to be involved in a certain way but might find it challenging, please do tick that box and we will adapt our processes to help you as much as we can.

☐ Responding to short surveys or questions about the best ways to develop research.
☐ Joining focus groups or discussion sessions to share your insights.
☐ Being matched with a research project to co-produce research, regularly inputting to meetings and decisions.

About you

We're keen to learn a little more about you, so that we can ensure we are building a diverse and representative Hub.

24. Which country do you live in?

- ☐ England
- ☐ Northern Ireland
- ☐ Scotland
- ☐ Wales
- ☐ Prefer not to say

25. Which region do you live in?

ENGLAND

- ☐ North East England
- ☐ North West England
- ☐ Yorkshire and the Humber
- ☐ East Midlands
- ☐ West Midlands
- ☐ East of England
- ☐ London
- ☐ South East England
- ☐ South West England
- ☐ Prefer not to say

NORTHERN IRELAND

- ☐ Antrim
- ☐ Armagh
- ☐ Down
- ☐ Fermanagh
- ☐ Londonderry
- ☐ Tyrone
- ☐ Prefer not to say

SCOTLAND

- ☐ Highlands & Islands
- ☐ North East
- ☐ Perthshire
- ☐ Borders, South and South West
- ☐ Central Belt
- ☐ Prefer not to say

WALES

- ☐ North Wales
- ☐ Mid Wales
- ☐ West Wales
- ☐ South Wales
- ☐ Prefer not to say

26. Which of the following best describes your gender?

☐ Woman
☐ Man
☐ Non-binary
☐ My gender is not listed
☐ Prefer not to say

27. What is your ethnicity?

☐ Asian or Asian British
☐ Black, Black British, Caribbean or African
☐ Mixed or multiple ethnic groups
☐ White (British, Irish, or other)
☐ Other ethnic group
☐ Prefer not to say

28. Is there anything else you want to tell us? (Max 250 words)

.....

.....

.....

.....

Thank you!

Please post your form back to:

PRIME, FAO Action for ME
Unit 2.2 Streamline
436-441 Paintworks
Bristol
BS4 3AS

If it is easier, you can send photographs of the form to prime@actionforme.org.uk

Once we've received it, we will send you an agreement to read through, that outlines the values and principles we wish to work by in the Hub. Once you've had a chance to agree to this, we'll will follow up with some training.

We will also start to share opportunities to get involved in shaping research when they arise.