



# The ME/CFS Priority Setting Partnership

## Your Top 10 ME/CFS Research Priorities

### What is this survey for?

In a survey earlier this year, we asked people with ME/CFS, their carers, and health and care professionals to tell us their comments and questions about ME/CFS.

We did this because we want to influence where research funding is spent in future. We want it to be spent in the areas that matter most to people with ME/CFS and the people who care for them.

Thank you to everyone who sent comments and questions. We have taken all of them into account.

The questions that can be answered by research, but haven't already been, were summarised and are listed in this new survey. Others will be used in different ways and will not be lost.

You can see more about the project here [www.psp-me.co.uk/](http://www.psp-me.co.uk/)

## Who should take part in this survey?

This survey is for the following people living in the UK. Please tick the boxes that best represent you. When we say ME/CFS, we are also including ME, CFS/ME and CFS. **(This question requires you to tick at least one answer)**

- Anyone aged 16 or older who has been diagnosed with ME/CFS at any time
- Carers, friends, family and supporters, including parents of children with ME/CFS
- Health and care professionals who work with people with ME/CFS
- Other (please describe below)

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## What are we asking you to do?

This survey has 2 sections.

1. Read the list of 59 suggested future research questions and tick up to 10 that are important to you.
2. Tell us some information about yourself. This is optional but will help us ensure we are reaching a broad range of people.

If you need help filling in this survey it's fine to talk to someone about it and ask them to help you.

If you would like to complete this survey by phone, please contact xxx at the 25% ME Group on xxxx and she will help you do that.

Please ask other people to complete this survey too. We want to make researchers aware of the issues that matter to lots of people.

**The survey closes at 5pm on 13<sup>th</sup> December 2021.**

### **Is it confidential?**

This is a confidential survey. The reason we ask for some information about you is so that we can understand what types of people are completing the survey and whether we are hearing from a wide range of people.

You do not have to leave your name, address or email address when you complete the survey unless you want to hear from us again.

You will not be identified in any of the survey results and we will keep the information you give us secure. If you do give us your name and address or email address we will destroy our records of these at the end of the project.

### **What will happen next?**

After this survey has closed, we will use the survey responses to work out which are the most popular questions.

We will then hold a workshop for people with ME/CFS, their carers and the health and care professionals who work with them.

At the workshop they will discuss the most popular questions in more detail and agree the Top 10 questions that need researching.

## Choose your priorities

Here is the list of 59 questions for ME/CFS research. **Please tick up to 10 questions that you would like researchers to answer, based on your own experience.**

Please take your time and have a break if you need to, but do read all of the questions. We have added headings as a guide to the different types of questions in each group. There are 8 groups of questions.

Please tick up to 10 boxes on the list on the following pages:

### Causes and prevention

- Is there a genetic link to ME/CFS? If yes, how does this affect the risk of ME/CFS in families? Could this lead to new treatments? (1)
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- Why do some people develop ME/CFS following an infection? Is there a link with long-COVID? (2)
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- Is ME/CFS caused by a faulty immune system? Is ME/CFS an autoimmune condition? (3)
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- Are there factors that increase the risk of developing ME/CFS (such as stress, trauma or exposure to toxic chemicals)? (4)
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- Do hormonal imbalances (such as thyroid hormone or cortisol imbalances) cause ME/CFS and/or affect symptoms? Could this lead to new treatments? (5)
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- Can ME/CFS be prevented? (6)
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- Is ME/CFS infectious? Can it be transmitted to others? (7)
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- What causes ME/CFS to become severe? (8)
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- What can be learnt about the cause of ME/CFS from clusters of cases? (9)
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## Diagnosis

- How can an accurate and reliable diagnostic test be developed for ME/CFS? (10)
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- How can the current approach to diagnosing ME/CFS be improved, to reduce delays and include other conditions commonly linked to ME/CFS, such as Postural Orthostatic Tachycardia Syndrome (POTS), Ehlers-Danlos syndromes (EDS) and Mast Cell Activation Syndrome (MCAS)? (11)
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## Lifetime risks and course of the illness

- What is the typical course of ME/CFS over a lifetime, for children and adults? What influences this? (12)
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- Why do symptoms vary between people with ME/CFS? Why are there short term and long term changes in ME/CFS symptoms? (13)
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- Why are women at greater risk of ME/CFS than men? (14)
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- Are there different types of ME/CFS linked to different causes and/or how severe it becomes? Do different types of ME/CFS need different treatments and/or have different chances of recovery? (15)
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- How do some people recover from ME/CFS? How might this understanding help others? (16)
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- Do hormonal changes (such as during the menstrual cycle, pregnancy and menopause) affect ME/CFS symptoms? Does ME/CFS affect menstrual cycles, risks around pregnancy or menopause? (17)
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Which conditions are commonly linked with ME/CFS, such as Ehlers-Danlos syndromes (EDS), Postural Orthostatic Tachycardia Syndrome (POTS), gut disorders and Mast Cell Activation Syndrome (MCAS)? Do they have the same root cause or does one cause the other? (18)

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What causes people with ME/CFS to relapse and their symptoms to get worse? Are there ways to prevent or minimise relapses? (19)

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Does ME/CFS affect life-expectancy? (20)

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Are people from ethnic minorities at greater risk of developing ME/CFS? What barriers do they face getting a diagnosis and treatment? (21)

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Are there long-term effects of repeated post-exertional malaise (symptoms caused or made worse by physical, mental or emotional effort, which can be delayed)? (22)

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## **Treatment and management**

Can prompt treatment and advice when diagnosed prevent ME/CFS from getting worse over time? What does this mean for people whose illness starts gradually? (23)

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Which existing drugs used to treat other conditions might be useful for treating ME/CFS, such as low dose naltrexone, or drugs used to treat Postural Orthostatic Tachycardia Syndrome (POTS)? (24)

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Do complementary & alternative therapies benefit people with ME/CFS? (25)

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How does ME/CFS impact on people's physical health, and does their physical health impact on their ME/CFS? What can people with ME/CFS safely do to maintain their physical health? (26)

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Does changing diet or taking supplements help people with ME/CFS? (27)

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Is there a way for people with ME/CFS to monitor and manage their activities (such as using a heart rate monitor) to avoid triggering post-exertional malaise (symptoms caused or made worse by physical, mental or emotional effort, which can be delayed)? (28)

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Are there ways to objectively measure how severely someone is affected by ME/CFS and whether their symptom levels are changing over time? (29)

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## **Underlying mechanisms and their treatments**

What is the biological mechanism that causes post-exertional malaise (symptoms caused or made worse by physical, mental or emotional effort, which can be delayed) in people with ME/CFS? How is this best treated and managed? (30)

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What causes the central and peripheral nervous systems (brain, spinal cord and nerves in the body) to malfunction in people with ME/CFS? Could this understanding lead to new treatments? (31)

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How are mitochondria, responsible for the body's energy production, affected in ME/CFS? Could this understanding lead to new treatments? (32)

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Does the immune system continue to over-function or under-function in some people with ME/CFS to cause symptoms? What does this mean for treatment & risks from infections and vaccinations, including COVID-19? (33)

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What happens to muscle function in people with ME/CFS? (34)

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What causes some people with ME/CFS to become intolerant to alcohol, chemicals and/ or medicines? (35)

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What are the links between nervous, digestive and immune systems that could cause ME/CFS symptoms? (36)

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How is the transport of nutrients/electrolytes in and out of cells affected in people with ME/CFS? Could this understanding lead to new treatments? (37)

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Does poor delivery or use of oxygen within the body cause ME/CFS symptoms? If so, how is this best treated? (38)

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Does continuing viral or bacterial infection cause ME/CFS symptoms? If so, are antivirals or antibiotics effective treatments? (39)

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## **Health services**

What would be the make-up of a high-quality specialist service for people with ME/CFS? Would this improve the treatment and care of people with ME/CFS? (40)

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Why don't some health professionals accept ME/CFS is a serious illness? What would help them to recognise and respond appropriately to people's symptoms? (41)

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How can the needs of people with ME/CFS best be met when accessing and using health and social care services (for example while in hospital)? (42)

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Based on people's experiences, what does ongoing monitoring and care for people with ME/CFS need to include? (43)

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## **Causes of symptoms and their treatment**

What causes sensory problems in people with ME/CFS (such as sensitivity to light, noise, smell and touch)? How are these best managed and treated? (44)

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What causes orthostatic intolerance (e.g. feeling dizzy or unwell on standing or sitting up) or problems controlling body temperature? How are these best managed and treated? (45)

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What causes headaches and migraines in ME/CFS? How are these best treated and managed? (46)

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What causes skin problems in ME/CFS? How are these best treated and managed? (47)

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What causes sleep problems and sleep pattern changes in people with ME/CFS? How are these best managed and treated? (48)

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What causes ongoing fatigue (tiredness or exhaustion) in people with ME/CFS? How is this best treated and managed? (49)

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What causes gut problems, difficulties with swallowing and eating in people with ME/CFS? How are these best managed, for example with tube feeding for people who are very severely affected? (50)

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Do heart problems, changes to blood cells or blood/lymph circulation cause ME/CFS symptoms? If so, how are these best treated? (51)

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Do postural or structural problems in the head, neck and spine cause symptoms of ME/CFS? If so, how are these best treated? (52)

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What causes pain in people with ME/CFS? How is this best treated and managed? (53)

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What causes brain fog in people with ME/CFS? How is this best treated and managed? (54)

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## Social and psychological impacts and support

- What are the impacts of ME/CFS on people's quality of life, including work, finances and family and social life? What practical support would be most effective, particularly in terms of social care and welfare benefits? (55)

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- What are the psychological impacts of ME/CFS? How are these best treated and managed? (56)

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- What harms do people with ME/CFS experience as a result of the lack of professional recognition and stigma from the condition? How can these best be addressed? (57)

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- What practical and emotional support do carers/ parents of people with ME/CFS need and how can these needs be met? (58)

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- What support do pupils and students with ME/CFS need to help them with their education? (59)

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Thank you for your help in choosing the most important questions.

If you have individual questions or concerns about ME/CFS, there are a number of voluntary organisations and charities that may be able to provide support and you can see a list of these here <http://forward-me.co.uk/linked-organisations-and-associates.html>

## Some questions about you

The following questions are optional, but we would appreciate knowing a little about you, to help us make sure that we hear from a wide range of people.

These answers are confidential. No individual will be identified when we present the results.

Any personal information that you supply will only be used in conjunction with the ME/CFS Priority Setting Partnership.

## These three questions are for people with ME/CFS and their carers only:

What is the severity of your ME/CFS, or the person you care for, at the moment? Please note, this is not a question about how severe your suffering is, but of how badly affected you are in comparison with other people with ME/CFS. (Please tick the box that is the closest fit)  
(*optional*)

- Mild
- Moderate
- Severe
- Very severe
- In remission

Approximately how long ago did you, or the person you care for, first become ill with ME/CFS? (Please tick one box) (*optional*)

- Up to 1 year ago
- Between 1 and 5 years ago
- Between 5 and 20 years ago
- Over 20 years ago

How old are you? Or if you're a carer, please tell us how old the person you care for is. (Please tick one box) *(optional)*

Under 16

16 – 24

25 – 34

35 – 44

45 – 54

55 – 64

65 – 74

75 – 84

85+

Prefer not to say

**This question is for health and social care professionals only:**

If you are a health and social care professional, please note your job title/role here

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**The questions below are for everyone:**

Where do you usually live? (Please tick one box) *(optional)*

England

Scotland

Northern Ireland

Wales

Which best describes your gender? (Please tick one box) *(optional)*

Male

Female

I prefer to use my own term

I prefer not to say

Which best describes your ethnic group? (Please tick one box)  
(optional)

White

Mixed/multiple ethnic groups

Asian/Asian British

Black/African Caribbean/Black British

Other ethnic group

Prefer not to say

### **Would you like to hear more from us?**

Yes, I would like to hear about the results of this project.

Yes, I would like to hear more about taking part in the workshop to choose the final list of priority research questions.

We communicate mostly by email. If you have ticked 'Yes' to one or both statements above, please add your name and email address below:

Name:

Email address:

Postal address (please only leave a postal address if you cannot be contacted by email. We prefer to send emails where possible to save money on postage, so as much money as possible goes to helping people with ME/CFS):

## How we will keep your information safe

Your personal information (for example your gender or ethnic group) is held and used in compliance with data protection regulations and will only be used to help us understand which types of people are responding. Any personal information that you give us will only be used in relation to this project. We will not pass your details to any third party and you can ask us to remove your details from our database at any time by emailing [questions@psp-me.co.uk](mailto:questions@psp-me.co.uk)

Do you agree to your personal information (for example your gender or ethnic group) being used in the way we have described above? **(This question requires an answer)**

Yes

No

**Please return this survey by 13<sup>th</sup> December 2021 to:**

**FREEPOST Plus RTJR-TREB-AXGY**

**42 Temple Street**

**Keynsham BS31 1EH**

**Help us to prioritise ME/CFS by sharing this survey with anyone who might be interested. Thank you. This survey can be completed online at the website below or further paper copies can be requested by email or telephone.**

**Website:** [www.psp-me.co.uk](http://www.psp-me.co.uk)

**Twitter:** @PSPforMECFS

**Hashtag:** #PrioritiseME

**Email:** [questions@psp-me.co.uk](mailto:questions@psp-me.co.uk)

**Telephone:** 0117 927 9551