



## The ME/CFS Priority Setting Partnership

# Have your say in ME/CFS research

---

The ME/CFS James Lind Alliance Priority Setting Partnership aims to identify the Top 10 priorities for future research. The partnership is led by people with ME/CFS, their carers and health professionals. With your help, this survey can help change the research agenda for ME/CFS. For more information about this partnership see [www.psp-me.co.uk](http://www.psp-me.co.uk).

If you would like to complete this survey by phone or text, please contact the 25% Group on 07392 403591 and they will help you do that.

### Who should take part?

This survey is for the following people in the UK. Please tick as many boxes as apply to you, to help us see the types of people we are hearing from. When we say ME/CFS, we are also including ME, CFS/ME and CFS. **\*This question requires you to select 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)

---

---

---

### About this survey

This survey has 2 sections. In the first section you can submit your questions and ideas. The second section has tick boxes where we ask for some information about you.

**The survey closes on 5<sup>th</sup> July 2021.**

## Your questions

Please think about what impact ME/CFS has on you and what you would like research to find out.

If you are a professional working in the field of ME/CFS, please consider what research would make a difference to the delivery of care to people with ME/CFS.

We want to hear your questions and ideas, no matter how big or small. Please do not include any personal details in your questions and ideas.

If you are helping a person with ME/CFS to complete this survey, the responses should be their own ideas. You can complete the survey again yourself as a carer or supporter.

For example, you may have questions about:

**Understanding ME/CFS** – Causes, Prevention, Risk factors, Diagnosis, Prognosis, Related conditions including post viral illnesses.

**Living with ME/CFS** – Associated disability, Issues for carers, Services relevant to the condition and access to services, Monitoring activity.

**Treatment or management of ME/CFS** – Drug treatments, Symptoms, Relapses, Measuring improvements.

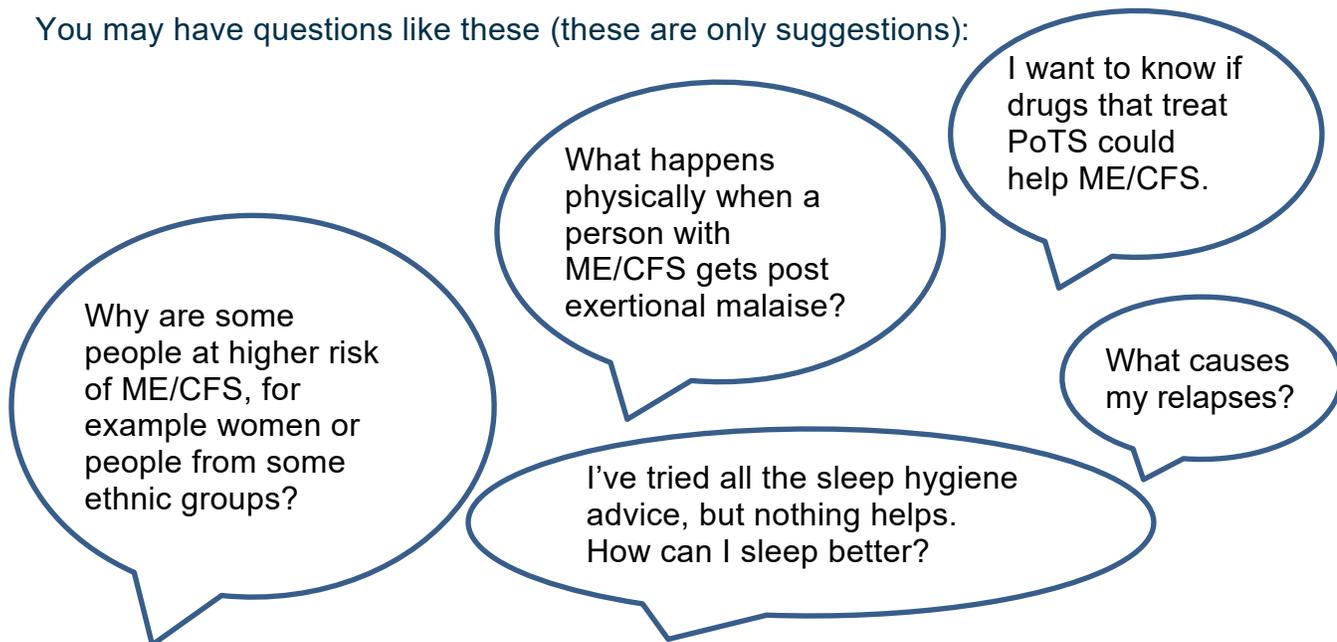
Or you may have ideas or questions about other areas of ME/CFS.



## Do I have to write a research question?

No. The most important thing is to draw on your own personal or professional experience of ME/CFS. Write as much or as little as you like. It is enough to write a short sentence about something that is important to you.

You may have questions like these (these are only suggestions):



**Please write your questions or comments in the boxes below.**

**My first question or comment is:**

**My second question or comment is:** *(Optional)*

**My third question or comment is:** *(Optional)*

## Do you have any other ideas or questions based on your experience of ME/CFS?

Please write them in the box below. *(Optional)*

We hope you understand that we can't respond to 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 [www.forward-me.co.uk/linked-organisations-and-associates](http://www.forward-me.co.uk/linked-organisations-and-associates)



This survey will collect your questions for research about ME/CFS in these boxes. The James Lind Alliance will then work with our Steering Group to find out which of these questions have already been answered and which haven't. This will be followed by a second survey where we ask which of the unanswered questions are most important. We hope that you and others like you will complete that second survey.

The most important questions will be brought to the attention of researchers and research funders, so that we can ensure research is relevant to people dealing with ME/CFS every day.

## Some questions about you

These 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.

## The questions on this page 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 one box that is the closest fit)  
(Optional)

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



Mild - Able to manage activities of daily living with occasional assistance. Able to walk outside. Most are still in work or education.

Moderate - Limited mobility when outside and may require wheelchair assistance. May require help with activities of daily living but not all of the time. Most have stopped work or education.

Severe - Housebound. May be able to manage personal care but needs assistance with other activities of daily living such as housework and meal preparation.

Very severe - Bedridden and needs assistance with all activities of daily living.

In remission - Experience no symptoms, even during or after strenuous activity.

**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:

---

---

---

## The questions below are for everyone:

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

- England
- Northern Ireland
- Scotland
- Wales
- Other (please describe below)

---

**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

**Please tell us how you heard about this survey if you can** *(optional)*

---

## Would you like to hear more from us?

To hear about the progress of this project and how you can get involved in the next stages of choosing which of the questions we receive are the most important, please add your contact details below:

|   |  |
|---|--|
| Name:   |  |
| Email address:  |  |
| Postal address if you prefer to be contacted by post: |  |
|   |  |



Questions and comments that you give us may be included anonymously in any published results of the project. It will not be possible for anyone to identify who the comments or questions came from.

You don't have to give your contact details unless you want to. If you do, we will keep them securely, separately from your answers.

## How we will keep your information safe

By taking part in this survey you are agreeing to us publishing your questions anonymously. Your personal information (for example your gender or ethnic group) is held and used in compliance with data protection regulations. Any personal information that you give us will only be used in relation to this project. If you give us contact details, they will be kept separately from your survey response so that your survey response is anonymous.

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 5<sup>th</sup> July 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.**

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

**Twitter:** [@PSPforMECFS](https://twitter.com/PSPforMECFS)

**Hashtag:** #PrioritiseME

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

**Telephone:** 0117 927 9551