



Defining future ME/CFS research

2022

Appendices

The ME/CFS Priority
Setting Partnership

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Funding for this project was awarded to Action for M.E. who worked with the James Lind Alliance to facilitate the steering group in leading the process.



With thanks to our funders:



Appendix 1 - The long-list of 59 research priorities

Causes and prevention

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

Diagnosis

10. How can an accurate and reliable diagnostic test be developed for ME/CFS?
11. 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)?

Lifetime risks and course of the illness

12. What is the typical course of ME/CFS over a lifetime, for children and adults? What influences this?
13. Why do symptoms vary between people with ME/CFS? Why are there short term and long term changes in ME/CFS symptoms?
14. Why are women at greater risk of ME/CFS than men?
15. 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?

16. How do some people recover from ME/CFS? How might this understanding help others?
17. 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?
18. 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?
19. What causes people with ME/CFS to relapse and their symptoms to get worse? Are there ways to prevent or minimise relapses?
20. Does ME/CFS affect life-expectancy?
21. Are people from ethnic minorities at greater risk of developing ME/CFS? What barriers do they face to getting a diagnosis and treatment?
22. 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)?

Treatment and management

23. 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?
24. 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)?
25. Do complementary and alternative therapies benefit people with ME/CFS?
26. 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?
27. Does changing diet or taking supplements help people with ME/CFS?
28. 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)?
29. Are there ways to objectively measure how severely someone is affected by ME/CFS and whether their symptom levels are changing over time?

Underlying mechanisms and their treatments

30. 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?
31. 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?
32. How are mitochondria, responsible for the body's energy production, affected in ME/CFS? Could this understanding lead to new treatments?
33. 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 and risks from infections and vaccinations, including COVID-19?
34. What happens to muscle function in people with ME/CFS?
35. What causes some people with ME/CFS to become intolerant to alcohol, chemicals and/or medicines?
36. What are the links between nervous, digestive and immune systems that could cause ME/CFS symptoms?
37. 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?
38. Does poor delivery or use of oxygen within the body cause ME/CFS symptoms? If so, how is this best treated?
39. Does continuing viral or bacterial infection cause ME/CFS symptoms? If so, are antivirals or antibiotics effective treatments?

Health services

40. 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?
41. 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?
42. 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)?
43. Based on people's experiences, what does ongoing monitoring and care for people with ME/CFS need to include?

Causes of symptoms and their treatment

44. 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?
45. 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?
46. What causes headaches and migraines in ME/CFS? How are these best treated and managed?
47. What causes skin problems in ME/CFS? How are these best treated and managed?
48. What causes sleep problems and sleep pattern changes in people with ME/CFS? How are these best managed and treated?
49. What causes ongoing fatigue (tiredness or exhaustion) in people with ME/CFS? How is this best treated and managed?
50. 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?
51. Do heart problems, changes to blood cells or blood/lymph circulation cause ME/CFS symptoms? If so, how are these best treated?
52. Do postural or structural problems in the head, neck and spine cause symptoms of ME/CFS? If so, how are these best treated?
53. What causes pain in people with ME/CFS? How is this best treated and managed?
54. What causes brain fog in people with ME/CFS? How is this best treated and managed?

Social and psychological impacts and support

55. 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?
56. What are the psychological impacts of ME/CFS? How are these best treated and managed?
57. 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?
58. What practical and emotional support do carers/ parents of people with ME/CFS need and how can these needs be met?
59. What support do pupils and students with ME/CFS need to help them with their education?

Appendix 2 - The shortlist of 18 research priorities

- A. 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?
- B. Why do some people develop ME/CFS following an infection? Is there a link with long-COVID?
- C. Is ME/CFS caused by a faulty immune system? Is ME/CFS an autoimmune condition?
- D. What causes ME/CFS to become severe?
- E. How can an accurate and reliable diagnostic test be developed for ME/CFS?
- F. 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?
- G. How do some people recover from ME/CFS? How might this understanding help others?
- H. What causes people with ME/CFS to relapse and their symptoms to get worse? Are there ways to prevent or minimise relapses?
- I. 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)?
- J. 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?
- K. 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?
- L. How are mitochondria, responsible for the body's energy production, affected in ME/CFS? Could this understanding lead to new treatments?
- M. Does poor delivery or use of oxygen within the body cause ME/CFS symptoms? If so, how is this best treated?
- N. 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?
- O. What causes sleep problems and sleep pattern changes in people with ME/CFS? How are these best managed and treated?
- P. What causes ongoing fatigue (tiredness or exhaustion) in people with ME/CFS? How is this best treated and managed?
- Q. What causes pain in people with ME/CFS? How is this best treated and managed?
- R. What causes brain fog in people with ME/CFS? How is this best treated and managed?

Appendix 3 - The surveys

First survey

See next page.



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.

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 5th 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.

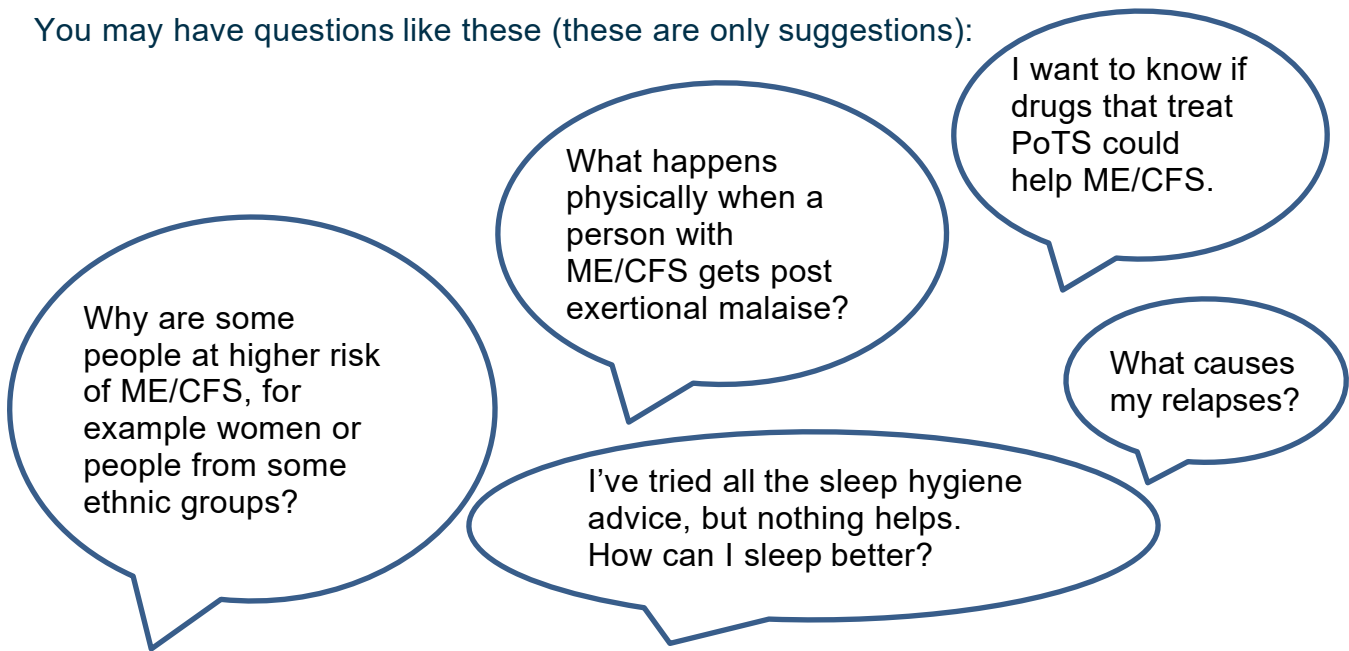
Or you may have ideas or questions about other areas of ME/CFS.



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



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)

- | | |
|---|--|
| <input type="checkbox"/> Up to 1 year ago | <input type="checkbox"/> Between 1 and 5 years ago |
| <input type="checkbox"/> Between 5 and 20 years ago | <input type="checkbox"/> 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)*

- | | |
|--|---|
| <input type="checkbox"/> England | <input type="checkbox"/> Northern Ireland |
| <input type="checkbox"/> Scotland | <input type="checkbox"/> Wales |
| <input type="checkbox"/> Other (please describe below) | |

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

- | | |
|--|--|
| <input type="checkbox"/> Male | <input type="checkbox"/> Female |
| <input type="checkbox"/> I prefer to use my own term | <input type="checkbox"/> I prefer not to say |

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

- | | |
|--|--|
| <input type="checkbox"/> White | <input type="checkbox"/> Mixed/multiple ethnic groups |
| <input type="checkbox"/> Asian/Asian British | <input type="checkbox"/> Black/African/Caribbean/Black British |
| <input type="checkbox"/> Other ethnic group | <input type="checkbox"/> 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.

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 5th 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

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

Email: questions@psp-me.co.uk

Hashtag: #PrioritiseME

Telephone: 0117 927 9551

Second survey

See next page.



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/

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)

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 Helen at the 25% ME Group on 07392 403591 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 13th 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)

- ☐ Why do some people develop ME/CFS following an infection? Is there a link with long-COVID? (2)

- ☐ Is ME/CFS caused by a faulty immune system? Is ME/CFS an autoimmune condition? (3)

- ☐ Are there factors that increase the risk of developing ME/CFS (such as stress, trauma or exposure to toxic chemicals)? (4)

- ☐ Do hormonal imbalances (such as thyroid hormone or cortisol imbalances) cause ME/CFS and/or affect symptoms? Could this lead to new treatments? (5)

- ☐ Can ME/CFS be prevented? (6)

- ☐ Is ME/CFS infectious? Can it be transmitted to others? (7)

- ☐ What causes ME/CFS to become severe? (8)

- ☐ What can be learnt about the cause of ME/CFS from clusters of cases? (9)
-

Diagnosis

- ☐ How can an accurate and reliable diagnostic test be developed for ME/CFS? (10)
-
- ☐ 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)
-

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)
-
- ☐ Why do symptoms vary between people with ME/CFS? Why are there short term and long term changes in ME/CFS symptoms? (13)
-
- ☐ Why are women at greater risk of ME/CFS than men? (14)
-
- ☐ 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)
-
- ☐ How do some people recover from ME/CFS? How might this understanding help others? (16)
-
- ☐ 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)
-

☐ 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)

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

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

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

☐ 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)

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)

☐ 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)

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

☐ 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)

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

☐ 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)

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

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)

☐ 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)

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

☐ 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)

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

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

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

☐ 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)

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

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

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)

☐ 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)

☐ 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)

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

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)

☐ 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)

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

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

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

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

☐ 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)

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

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

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

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

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)

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

- ☐ 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)

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

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

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)*

- | | |
|---|--|
| <input type="checkbox"/> Up to 1 year ago | <input type="checkbox"/> Between 1 and 5 years ago |
| <input type="checkbox"/> Between 5 and 20 years ago | <input type="checkbox"/> 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

☐ 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

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 13th 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

Twitter: @PSPforMECFS

Hashtag: #PrioritiseME

Email: questions@psp-me.co.uk

Telephone: 0117 927 9551

Appendix 4 - Link to all research ideas submitted in first survey

The below link takes you to an excel document that includes all of the research ideas originally submitted in the first survey.

We hope that researchers and others will make use of this information as they explore the prioritised questions and more.

By looking at the original ideas submitted, researchers may be able to tease out the nuances of some of the Top 10+ priorities and other questions. We hope they will use this to improve their funding applications through a more in depth understanding of the priorities of people with ME/CFS, carers and health and care professionals.

www.psp-me.co.uk/all-research-ideas



The ME/CFS Priority Setting Partnership

Keep in touch



@PSPforMECFS



psp-me.co.uk

