



Department
of Health &
Social Care

Survey - interim delivery plan on ME/CFS (print version)

This consultation seeks views on an interim set of actions to improve the experiences and outcomes of people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) that have been developed in collaboration with people living with, working or interested in the condition. It will inform the development of a final cross-government delivery plan on ME/CFS.

Most people choose to [complete the survey online](#).

Alternatively, you can:

- print this document
- write your answers on the printed survey
- send us the completed survey by post

Please return your completed to survey to:

ME/CFS interim delivery plan
Department of Health and Social Care
39 Victoria Street
London
SW1H 0EU

Completed surveys posted to this address will be destroyed once scanned to create a digital copy.

In your response to questions in the consultation, please do not include any information that could identify you or somebody else. For example, do not include anyone's name, age, job title or email address where it is not asked for.

[Read full details of this consultation on GOV.UK.](#)

The survey closes at 11.59pm on 4 October 2023.

The survey is open to people aged 13 and over, who live in the UK.

About you

To help the government address health and other disparities and to support the development of the Interim Delivery Plan we would like to know some personal details about you. This helps us to learn more about the people who are providing views on the interim delivery plan and also those who haven't participated. The information we ask for includes questions on your sex, gender, age, ethnicity, where you live and your experience of ME/CFS.

If you are answering on behalf of someone else, please enter demographic information of the person you have in mind.

1. In what capacity are you responding to this survey? (mandatory)

- As an individual sharing my personal views and experiences
- On behalf of an someone else
- As an individual sharing my professional views
- On behalf of an organisation **Go to question 16** |

2. Where do you live in the UK? (mandatory)

- England
- Scotland
- Wales
- Northern Ireland
- I live outside the UK
- Prefer not to say |

If you live outside of England, your views will be shared with officials from that nation's government/executive, so that they can consider your views in relation to local policy.

3. Where in England do you live? (optional)

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

4. What is your age? (optional)

- 13 to 15
- 16 to 24
- 25 to 34
- 35 to 44
- 45 to 54
- 55 to 64
- 65 to 74
- 75 or above
- Prefer not to say

5. What is your sex? (optional)

- Female
- Male
- Prefer not to say

6. Is the gender you identify with the same as your sex registered at birth? (optional)

- Yes
- No
- Prefer not to say
- Not applicable – I am under 13 years of age

This question should only be completed if you are aged 16 or older. If you are aged under 16, please select “Not applicable”

7. What is your ethnic group? (mandatory)

- White – includes British, Northern Irish, Irish, Gypsy, Traveller, Roma or any other white background
- Mixed or multiple ethnic groups – includes white and black Caribbean, white and black African, white and Asian or any other mixed or multiple background
- Asian or British Asian – includes Indian, Pakistani, Bangladeshi, Chinese or any other Asian background
- Black, black British, Caribbean, African or any other black background
- Other – includes Arab or any other ethnic group
- Prefer not to say

If you are responding as an individual sharing your professional views, **go to question 14**

8. Which of the following best describes you? (optional)

- I have suspected or diagnosed ME/CFS
- I had ME/CFS in the past but am now in remission or recovered
- I am an unpaid carer for someone who has ME/CFS or has had ME/CFS in the past **Go to question 11**
- I am a family member, friend or other supporter (including advocate) of someone with ME/CFS, without regular caring responsibilities **Go to question 11**
- Prefer not to say

9. How would you describe the severity of your symptoms, on average over the past 3 months? (optional)

- Mild
- Moderate
- Severe
- Very severe
- In remission
- Recovered
- Don't know
- Prefer not to say

If you are unsure, please refer to the National Institute for Health and Care Excellence definitions of severity

<https://www.nice.org.uk/guidance/ng206/chapter/Recommendations>

10. How long have you had ME/CFS? (optional)

- Less than a year
- 1-5 years
- 6-10 years
- 11-20 years
- Over 21 years
- Prefer not to say

11. What age is the person with ME/CFS that you care for or support? (optional)

Select all that apply, if you provide care or support to more than one person with ME/CFS

- Under 13
- 13 to 15
- 16 to 24
- 25 to 34
- 34 to 44
- 45 to 54
- 55 to 64
- 65 to 74
- 75 or above
- Prefer not to say

12. How long have you been an unpaid carer or supporter of the person with ME/CFS? (optional)

- Less than a year
- 1-5 years
- 6-10 years
- 11-20 years
- Over 21 years
- Prefer not to say

13. How would you describe the severity of their symptoms, on average over the past 3 months? (optional)

Select all that apply, if you provide care or support to more than one person with ME/CFS

- Mild
- Moderate
- Severe
- Very severe
- In remission
- Recovered
- Don't know
- Prefer not to say

If you are unsure, please refer to the National Institute for Health and Care Excellence definitions of severity
(<https://www.nice.org.uk/guidance/ng206/chapter/Recommendations>)

14. Where do you work as a professional? (optional)

If you work outside of England your reviews will be shared with officials from that nation's government/executive so that they can consider your views in relation to local policy

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

15. Which of the following best describes your area of work? (optional)

Select all apply. If you are retired or not currently working, please select the option(s) which are closest to your profession the last time you were in employment

- Primary care
- Community healthcare
- Secondary healthcare
- Mental health
- Specialist ME/CFS services
- Occupational Health/Human Resources
- Adult social care
- Children's social care

Question continues on the next page

- Primary education
- Secondary education
- Higher/further education
- Welfare support
- Employment support
- Research or related field
- Other (*please specify*)

- Prefer not to say

16. Where does your organisation provide services? (optional)

If you provide services outside of England your views will be shared with officials from that nation's government/executive so that they can consider your views in relation to local policy

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

17. What is the name of your organisation? (optional)

18. Which sector best describes your organisation? (optional)

- Public sector
- Private sector
- Voluntary or third sector
- Not for profit
- A mix of sectors
- Other (*please specify*)

- Prefer not to say

Email – contacting you

As part of this survey there are a few reasons we may require your email address:

- if you need to contact us about amending or deleting your response the only way, we can verify that it is your response is via your email address
- if you didn't have time to finish the survey, we can send you a reminder before it closes.

If you are responding on behalf of an organisation, please provide your organisational email address. Your email address will not be shared with anyone outside of the department.

19. Are you happy to share your email address with the Department of Health and Social Care?

Yes

No

20. What is your email address?

Your contact details will not be shared with anyone outside the consultation team.

About the interim delivery plan

Chapters 2, 3 and 4 of the interim delivery plan set out the key problems to be addressed, some proposed descriptions of the future vision to be achieved and best practice principles for everyone to be aware of. Chapter 5 lists the agreed actions setting out what will happen to address the problems identified.

Research

The plan concludes that the research community has a low capacity and capability to respond ME/CFS research needs, and that awareness of those research needs is low. The level of biomedical research on ME/CFS that has been funded is also low.

The government is keen to build on the work already done by the National Institute for Health and Care Research and Medical Research Council, such as the DecodeME study, and the James Lind Alliance Priority Setting Partnership's top ten research priorities.

The plan sets out proposed commitments to action in three areas: research strategy, capacity and capability in the research community and building awareness and trust between stakeholders

21. To what extent do you agree or disagree with the contents of this chapter? (optional)

- Strongly agree
- Agree
- Disagree
- Strongly disagree

22. What, if anything, do you think could be improved about this chapter? (Optional)

Select all that apply

- Some content is missing
- Some content does not reflect my experience
- Some content could be simpler or clearer
- Some content could be more detailed

Do you have further comments? 250 words maximum (optional)

Use this free text box to tell us more about your responses above, for example how you think the chapter could be changed or improved. Do not include any information in this space that could identify you or somebody else.

Attitudes and education

We have heard that many children and adults with ME/CFS feel they have not been believed, supported or treated equally across all settings and professional groups. There is limited evidence as to what the attitudes towards ME/CFS are among professionals currently. Some people with ME/CFS have had positive experiences with professionals but other people with personal experience do not feel that professionals always fully acknowledge or understand the impact of ME/CFS on their daily life.

There are limited education and training opportunities for any professional groups on ME/CFS. Professional awareness of the updated NICE Guideline on ME/CFS (NG206) could be improved. We aim to make progress to improve education and training opportunities, to increase awareness and understanding of ME/CFS and its impacts among professionals and for people with ME/CFS, their families and carers to feel listened to, supported and treated fairly.

23. To what extent do you agree or disagree with the contents of this chapter? (Select one option only)

- Strongly agree
- Agree
- Disagree
- Strongly disagree

24. What, if anything, do you think could be improved about this chapter? (optional)

Select all that apply

- Some content is missing
- Some content does not reflect my experience
- Some content could be simpler or clearer
- Some content could be more detailed

Do you have further comments? 250 words maximum (optional)

Use this free text box to tell us more about your responses above, for example about how you think the chapter could be changed or improved. Do not include any information in this space that could identify you or somebody else.)

Living with ME/CFS

Quality of Life

We heard that quality of life is often significantly reduced for adults and children with ME/CFS, and for their families and other unpaid carers who support them. We aim to raise more awareness of ME/CFS and its impacts on daily life for those with the condition as well as their families and carers.

25. To what extent do you agree or disagree with the contents of this chapter? *(Select one option only)*

- Strongly agree
- Agree
- Disagree
- Strongly disagree

26. What, if anything, do you think could be improved about this chapter? *(optional)*

Select all that apply

- Some content is missing
- Some content does not reflect my experience
- Some content could be simpler or clearer
- Some content could be more detailed

Do you have further comments? 250 words maximum *(optional)*

Use this free text box to tell us more about your responses above, for example about how you think the chapter could be changed or improved. Do not include any information in this space that could identify you or somebody else.)

Support for children and young people with ME/CFS

We have heard that children and young people with ME/CFS can struggle to get the right support to help them succeed in education and training and that they and their families may face safeguarding referrals to children’s social care departments.

This section of the plan sets out what arrangements should be in place to meet needs through adaptations or alternative education provision for children and young people who are not able to attend school. We aim to ensure that support for the education of children/young people with ME/CFS is effective and that social care involvement is appropriate and meets best practice standards.

27. To what extent do you agree or disagree with the contents of this chapter? (Select one option only)

- Strongly agree
- Agree
- Disagree

- Strongly disagree

28. What, if anything, do you think could be improved about this chapter? (optional)

Select all that apply

- Some content is missing
- Some content does not reflect my experience
- Some content could be simpler or clearer
- Some content could be more detailed

Do you have further comments? 250 words maximum (optional)

Use this free text box to tell us more about your responses above, for example about how you think the chapter could be changed or improved. Do not include any information in this space that could identify you or somebody else.)

Health Services for people with ME/CFS

We have heard that people with ME/CFS can struggle to get adequate investigation and correct diagnosis, appropriate management support, advice, supportive treatment and review. Existing services vary in what they can offer and their approach to ME/CFS. People with more severe forms of ME/CFS can struggle to access health services both for their ME/CFS and for other health concerns. Many ME/CFS services can find it difficult to recruit and retain appropriately trained staff.

We aim to make progress to make progress on raising awareness and understanding of how to support people with ME/CFS to access appropriate advice and support, diagnosis and specialist services where necessary, as well as general health services for health needs not related to ME/CFS.

29. To what extent do you agree or disagree with the contents of this chapter? (Select one option only)

- Strongly agree
- Agree
- Disagree
- Strongly disagree

30. What, if anything, do you think could be improved about this chapter? (optional)

Select all that apply

- Some content is missing
- Some content does not reflect my experience
- Some content could be simpler or clearer
- Some content could be more detailed

Do you have further comments? 250 words maximum (optional)

Use this free text box to tell us more about your responses above, for example about how you think the chapter could be changed or improved. Do not include any information in this space that could identify you or somebody else.)

Adult social care

We heard that that adults with ME/CFS and their unpaid carers can struggle to access informed and appropriate social care support. We aim to raise awareness of the support that adult social care services provide to eligible people and how to access it, including access to advocacy support and personalised care planning. We will support adult social care staff to have sufficient knowledge of ME/CFS to enable them to adopt a person-centred approach when assessing needs and supporting individuals.

31. To what extent do you agree or disagree with the contents of this chapter? (Select one option only)

- Strongly agree
- Agree
- Disagree
- Strongly disagree

32. What, if anything, do you think could be improved about this chapter? (optional)

Select all that apply

- Some content is missing
- Some content does not reflect my experience
- Some content could be simpler or clearer
- Some content could be more detailed

Do you have further comments? 250 words maximum (optional)

Use this free text box to tell us more about your responses above, for example about how you think the chapter could be changed or improved. Do not include any information in this space that could identify you or somebody else.)

Welfare support

We heard that children and adults with ME/CFS and their unpaid carers can struggle to access benefits and find the process difficult to navigate. In this section, the Department for Work and Pensions (DWP) set out its priorities for the future which includes improving the experience of the welfare system for people with disabilities and/or health conditions. DWP wants to make its services easier to access, their processes simpler and carry out improvements to increase people's trust in the system.

33. To what extent do you agree or disagree with the contents of this chapter? *(Select one option only)*

- Strongly agree
- Agree
- Disagree
- Strongly disagree

34. What, if anything, do you think could be improved about this chapter? *(optional)*

Select all that apply

- Some content is missing
- Some content does not reflect my experience
- Some content could be simpler or clearer

- Some content could be more detailed

Do you have further comments? 250 words maximum (optional)

Use this free text box to tell us more about your responses above, for example about how you think the chapter could be changed or improved. Do not include any information in this space that could identify you or somebody else.)

Employment

We heard that inclusive and flexible job opportunities (paid or unpaid) are limited for people with ME/CFS, recruitment processes are often not easily accessible and that access to informed and appropriate Human Resources (HR) support, including Occupational Health, varies in the workplace.

On 15 March 2023, the Department for Work and Pensions (DWP) published 'Transforming Support: The Health and Disability White Paper' which sets out its vision to help more disabled people and people with health conditions to start, stay

and succeed in work. The impact of this vision is described in the Employment section of the interim delivery plan.

35. To what extent do you agree or disagree with the contents of this chapter? (Select one option only)

- Strongly agree
- Agree
- Disagree
- Strongly disagree

36. What, if anything, do you think could be improved about this chapter? (optional)

Select all that apply

- Some content is missing
- Some content does not reflect my experience
- Some content could be simpler or clearer
- Some content could be more detailed

Do you have further comments? 250 words maximum (optional)

Use this free text box to tell us more about your responses above, for example about how you think the chapter could be changed or improved. Do not include any information in this space that could identify you or somebody else.)

Agreed Actions

37. To what extent do you agree or disagree with the actions for improving research? (Select one option only)

- Strongly agree
- Agree
- Disagree
- Strongly disagree

Do you have further comments? 250 words maximum. (optional)

Use this free text box to tell us more about your responses above, for example about how you think the actions could be improved or advice on how they could be implemented. Do not include any information in this space that could identify you or somebody else.

38. To what extent do you agree or disagree with the actions for improving attitudes and education? *(Select one option only)*

- Strongly agree
- Agree
- Disagree
- Strongly disagree

Do you have further comments? 250 words maximum. (optional)

Use this free text box to tell us more about your responses above, for example about how you think the actions could be improved or advice on how they could be implemented. Do not include any information in this space that could identify you or somebody else.

39. To what extent do you agree or disagree with the actions for improving awareness and understanding? *(Select one option only)*

- Strongly agree
- Agree
- Disagree
- Strongly disagree

Do you have further comments? 250 words maximum. (optional)

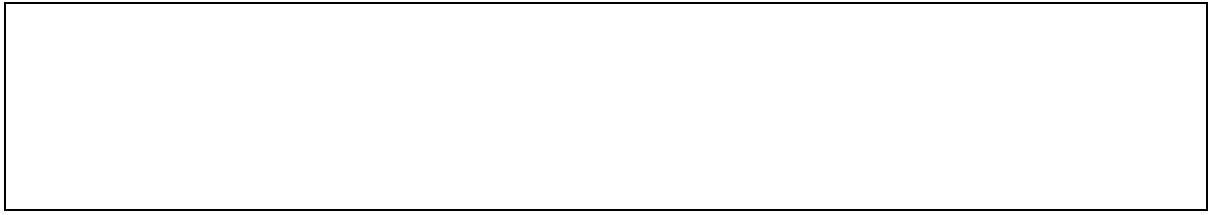
Use this free text box to tell us more about your responses above, for example about how you think the actions could be improved or advice on how they could be implemented. Do not include any information in this space that could identify you or somebody else.

40. To what extent do you agree or disagree with the actions to improve statutory support? (Select one option only)

- Strongly agree
- Agree
- Disagree
- Strongly disagree

Do you have further comments? 250 words maximum. (optional)

Use this free text box to tell us more about your responses above, for example about how you think the actions could be improved or advice on how they could be implemented. Do not include any information in this space that could identify you or somebody else.



Use of language in ME/CFS

This part of the survey should only be completed by respondents with personal experience of living with ME/CFS.

The supporting information to the plan aims to give an insight into the way that some people (for example, family members, friends and professionals) can use language in ways that frustrate or upset people who have ME/CFS. This personal experience was gathered by people with personal experience who took part in the development process for the plan on ME/CFS. This part of the survey asks you to tell us if this reflects your experience as a person with ME/CFS (past or present) and what you feel would be more appropriate language for others to use, when speaking to someone who has ME/CFS.

Chronic fatigue as a symptom of ME/CFS

41. Have these or similar comments been made to you? (optional)

“Just go to bed earlier.”

“I’d love it if I could stay in bed all day.”

“You’re just lazy.”

“Yeah, I’m very tired too.”

“Sounds like a normal life (as a parent)”

Yes

No

42. What do you suggest would be more appropriate language to use? Maximum 30 words (optional)

Recovery from ME/CFS

43. Have these or similar comments been made to you? (optional)

“You’ve just got to get more active.”

“I don’t see why she doesn’t recover.”

“My Mum’s friend had that and she recovered.”

“You’ll be fine.”

“You should aim for full recovery.”

“We can get you back to normal with some time and effort.”

Yes

No

44. What do you suggest would be more appropriate language to use? Maximum 30 words (optional)

Misconceptions that ME/CFS is a mental health condition, or how you think can impact your symptoms

45. Have these or similar comments been made to you? (optional)

“Everyone’s been struggling since the pandemic.”

“Are you sure it’s not health anxiety?”

“Maybe you should ask your doctor to put up your dose of antidepressants.”

“If you thought differently, you would get better.”

“You need to make more of an effort.”

“It helps to have a positive attitude.”

Yes

No

46. What do you suggest would be more appropriate language to use? Maximum 30 words (optional)

The lack of medical tests to prove someone has ME/CFS

47. Have these or similar comments been made to you? (optional)

The test results came back normal so...

“you need to be referred to another specialist.”

“I can’t find anything wrong with you.”

“you are lying.”

“maybe you are depressed about something.”

“good news – the tests say there is nothing wrong with you.”

“you can’t really be sick because one of these tests would show something.”

Yes

No

48. What do you suggest would be more appropriate language to use? Maximum 30 words (optional)

There are no obvious signs that someone has ME/CFS

49. Have these or similar comments been made to you? (optional)

“You look normal”.

“Is it as bad as you say it is?”

“You don’t need the wheelchair because I saw you walk last week.”

“Of course you can walk, you don’t have a broken leg or anything.”

Yes

No

50. What do you suggest would be more appropriate language to use? Maximum 30 words (optional)

Using pacing to manage energy

51. Have these or similar comments been made to you? (optional)

“How can you go for lunch with someone, but you can’t go to work for 8 hours?”

“You shouldn’t be going on holiday if you can’t work full time.”

“You went for a walk yesterday – you don’t need that aid.”

“The equipment needs to be returned to us the day after the test.”

Yes

No

52. What do you suggest would be more appropriate language to use? Maximum 30 words (optional)

Post-exertional malaise is hard to explain/understand

53. Has this or a similar comment been made to you? (optional)

“You did nothing yesterday, why are you still in bed?”

Yes

No

54. What do you suggest would be more appropriate language to use? Maximum 30 words (optional)

Before you submit your response

We have a few questions we would like to ask you to help us improve future consultations.

How satisfied are you with the consultation process? (optional)

- Very satisfied
- Satisfied
- Dissatisfied
- Very dissatisfied

How did you hear about the consultation? (optional)

- Social media
- Received an email
- Word of mouth (family, friend or colleague)
- Direct communication from third sector organisation or regulatory organisation
- Broadcast news (online or print)
- GOV.UK or other government website
- Newspaper (online or print)
- Website (non-government)
- Trade magazine
- Other (*please specify*)

Do you think we could improve this process? (optional)

Thank you for completing this survey.

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