Australian Government
National Health and Medical Research Council

NHMRC

ME/CFS Scoping Survey

Analysis and report

October 2025

Content warning: This report discusses topics related to ME/CFS that include experiences of illness, healthcare challenges and distressing personal accounts. Some readers may find certain sections emotionally challenging. Reader discretion is advised.

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1. Background

In recognition of calls for better support for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and related conditions (i.e. Long COVID, postural orthostatic intolerance syndrome (POTS) and fibromyalgia), and NHMRC's legislated role in guideline development, in June 2024, the Hon. Minister Mark Butler announced $1.1 million in funding for NHMRC to develop clinical practice guidelines for ME/CFS and related conditions.

NHMRC has never issued or approved guidelines for ME/CFS and there are no current Australian clinical practice guidelines for ME/CFS. In 2019, the ME/CFS Advisory Committee's Report to NHMRC's CEO indicated that development of health advice for ME/CFS was one of three key priorities (See: 5.3.3 Strategic Focus 3: Develop health advice).

To ensure that the ME/CFS Clinical Practice Guidelines provide the most up-to-date, high-quality and evidence-based advice, the guidelines are being developed in accordance with NHMRC's Procedures and requirements for meeting NHMRC standards for clinical practice guidelines and the GRADE approach. The guidelines are expected to take approximately 3 years to complete, with the aim of having a draft guideline ready for public consultation in 2027.

1.1. Context

The goal of the ME/CFS Clinical Practice Guidelines is to provide advice on diagnosis, clinical management and models of care for patients living with a diagnosis and/or symptoms of ME/CFS. The guidelines will be based on up-to-date evidence that meets NHMRC's Standards for Guidelines. They will be aimed at primary care, with a focus on the interactions between patients and general practitioners, including referral pathways.

ME/CFS is a complex and debilitating condition, characterised by profound fatigue following exertion (not relieved by sleep or rest), unrefreshing sleep and cognitive impairment, with post-exertional malaise (PEM) suggested as a cardinal feature of the condition. Secondary symptoms may include gastrointestinal disorders, muscle and joint pain and immune impairments.

The global prevalence of ME/CFS is estimated to be 0.2% to 1% of the total population, suggesting approximately 48,000 to 250,000 people in Australia may be affected by the condition (noting that related conditions, such as Long COVID, are likely to further increase prevalence estimates).[1] A recent (2022) study found that ME/CFS prevalence reported in Australian primary care settings ranged between 20,140 and 22,050 people.[2] The study noted that these figures are likely an underestimate, mainly due to a lack of consistency across diagnostic criteria used in clinical practice and barriers to diagnosis experienced by patients.

The first step in guideline development is identifying the broad scope and end users of the guidelines. Clinical practice guidelines should answer the most clinically relevant questions and

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[1] Lim, EJ., Ahn, YC., Jang, ES. *et al.* Systematic review and meta-analysis of the prevalence of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). *J Transl Med* 18, 100 (2020). https://doi.org/10.1186/s12967-020-02269-0

[2] Orji, N., Campbell, J.A., Wills, K. *et al.* Prevalence of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) in Australian primary care patients: only part of the story? *BMC Public Health* 22, 1516 (2022). https://doi.org/10.1186/s12889-022-13929-9

should follow a systematic, transparent and robust process. Early stakeholder input is key to ensuring that guidelines are useful for the intended audience and most relevant to those they impact.

NHMRC is conducting a series of scoping activities to assist the ME/CFS Guideline Development Committee in prioritising key areas for inclusion in the Australian ME/CFS Clinical Practice Guidelines. The ME/CFS Scoping Survey forms part of these activities. The findings of this report will be considered by ME/CFS Guideline Development Committee when refining topics for inclusion in the guidelines.

1.2. Purpose and scope of the survey

The ME/CFS Stakeholder Survey was open from 21 February 2025 to 27 April 2025. The purpose of the survey was to gain insight into the perspectives of the ME/CFS community and stakeholders on priority topics and areas to be considered for inclusion in the Australian ME/CFS guidelines.

The survey collected information on:

1. Questions 'about you'
    - Demographics, including location, sex, gender, Indigenous status, and language spoken at home
    - Respondents' relationship to ME/CFS and related conditions (i.e. lived experience, carer, clinician, researcher, etc.)
    - Duration and management of ME/CFS for individuals with lived experience
    - Types of support used by individuals living with ME/CFS
    - Current guidance used by healthcare professionals
    - Preferred formats for the guideline
    - Useful tools to accompany the guidelines
    - Details from researchers on research type and funding sources
2. Questions 'about the guidelines'
    - Priority topics for inclusion in the guidelines
    - Priority health outcomes critical for the evidence reviews.

The results of the ME/CFS Stakeholder Survey will be used to assist the ME/CFS Guideline Development Committee as part of their deliberations when deciding on key areas for inclusion in the guidelines.

2. Methods

2.1. Survey design and distribution

The survey was targeted at primary care clinicians (i.e. GPs) and healthcare professionals that work with people with ME/CFS or related conditions (i.e. Long COVID, POTS and fibromyalgia), individuals with ME/CFS and their carers.

Survey questions were drafted by NHMRC and reviewed by the ME/CFS Steering Committee at their February 2025 meeting, who provided initial feedback and further refinements to questions (see Appendix A). The survey was open for 9 weeks from 21 February to 27 April 2025 and accessed via Citizen Space, an online community engagement platform.

The survey was open to the public and distributed to stakeholders via email, NHMRC's Tracker and social media platforms and was accessible through NHMRC's ME/CFS webpage via a weblink. All stakeholders were invited to participate, including individuals, peak bodies, medical colleges and health professionals. The survey was intended to seek responses from ME/CFS-treating clinicians as primary users of the guidelines and, in addition, stakeholders with lived experience as secondary users of the guidelines.

Responses to the survey were anonymous. Any personal information collected as part of the survey was stored and used in accordance with NHMRC's obligations under the *Privacy Act 1988*, and in accordance with the NHMRC Privacy Policy.

2.2. Survey response analysis

Survey questions were designed to include a mix of multiple-choice questions and open-text comments. A mixed methods approach was employed in the analysis. Multiple-choice responses were analysed using percentages, and thematic analysis was conducted for free-text responses.

Percentages were calculated based on the number of respondents that provided the same answer to a multiple-choice question (*e.g. X out of XXX (X%) respondents selected PEM as a critical outcome*).

The thematic analysis allowed patterns and themes to emerge from the data. The NHMRC Project Team began by reading responses to get a general sense of repeating patterns. Responses were then extracted and compiled into a coding spreadsheet and assigned codes based on patterns, relationships and general narrative.

Themes emerged iteratively, beginning with broad categories such as 'diagnosis', 'management', 'models of care' and 'education and training', as well as a number of sub-themes. Most responses repeated general narrative and were subsequently coded to multiple themes where appropriate. Some of the survey questions were interpreted differently than what was originally intended and where this occurred, the response was assigned to a relevant theme. Where possible, thematic responses were also quantified and expressed as a percentage (e.g. *XXX out of XXX (X%) respondents stated PEM as an important diagnostic criteria*).

3. Results

3.1. Characteristics of respondents

In total, 1087 responses to the survey were received from individuals, organisations and healthcare professionals. Approximately 99% (1077 out of 1087) of respondents were individuals with ME/CFS or a family member or carer of someone with ME/CFS, and less than 1% (10 out of 1087) of responses were from stakeholder organisations.

Approximately 81% of respondents identified as female and there was an almost even split between those living in a capital city (48%) and those who did not (51%). Less than 1% of respondents identified as Aboriginal or Torres Strait Islander, and 12% of respondents spoke a language other than English at home. Age-related data were not collected.

3.2. Questions ‘about you’

3.2.1. Respondents’ relationship to ME/CFS and related conditions

Respondents were asked to describe their relationship to ME/CFS and related conditions (see Appendix A: Q10). In total, 1077 out of 1087 people (99%) answered this question. There were two parts to this question. In the first part, respondents were asked to select one option that best describes their relationship with ME/CFS: person with lived experience (899; 83%), healthcare professional (40; 4%), researcher (10; 1%) or other (128; 12%). However, the second part of this question allowed a free-text response to describe how people best identified themselves, with some respondents indicating that they had more than one relationship to ME/CFS. This gave a total of 915 respondents having lived experience of ME/CFS, 62 identifying as a healthcare professional and 14 people being researchers. In addition, 61 people were parents/carers of people living with ME/CFS and 9 had friends/relatives with the condition. Regarding other conditions, 35 said that they had Long COVID, 13 had POTS and 3 had fibromyalgia; some of these respondents had more than one condition. Three people reported that they had similar conditions but did not identify what those conditions were.

Respondents were also asked if they had experience with other related conditions (see Appendix A: Q12). This was a free-text response, and many respondents listed multiple conditions. To analyse results, a physical word count was used to determine the number of respondents that mentioned each condition. Of the conditions that will be covered by the guidelines, 356 people listed POTS, 226 mentioned fibromyalgia and 161 people said that they had Long COVID.

The survey also asked healthcare professionals to describe their role by choosing one of a predetermined list of options (Appendix A: Q13). For this question, 41 people responded, with 29 choosing allied health professional, 8 choosing medical specialist, 1 choosing GP and 1 choosing nurse. Eight people chose ‘other’.

3.2.2. Duration and management of ME/CFS for individuals with lived experience

Respondents were asked to indicate how long they had had ME/CFS (see Appendix A: Q11). Of the 836 people who responded to this question (77% of survey respondents), 322 reported that they had had ME/CFS for less than 5 years, 168 said that they had ME/CFS for 5–10 years and 346 people said it was more than 10 years. In the latter group, some respondents noted that they had had the condition for 20, 30, or 40 or more years.

3.2.3. Types of support used by individuals living with ME/CFS

Respondents were also asked if a medical practitioner was helping them manage their symptoms (see Appendix A: Q11). Of the 950 respondents who answered this question, more than half indicated that they see a medical practitioner for symptom management.

Respondents were then asked what support they were using to manage their symptoms. Results from the 958 respondents are presented in Table 1, noting that respondents could tick more than one option.

Table 1. Types of support received by people with ME/CFS

Type of support	Total	Percent
GP	654	60%
Medical specialists	420	30%
Allied health	364	33%
Friends	304	28%
Peer support group	261	24%
Support group	260	24%
Complementary medicine practitioners	206	19%
NGO	61	6%
No support	97	9%
Other^	265	24%
Not answered	129	12%

^Of the 265 people who selected ‘other’, 59 mentioned family as a source of support.

3.2.4. Current guidance documents used

Respondents were asked about the types of guidance documents that they used (see Appendix A: Q14). In total, 35 responses were received, including 33 from healthcare professionals. Existing guidelines (e.g. NICE and ICC), research articles and websites of consumer organisations were the most frequently mentioned.

3.2.5. Preferred formats for the guideline

Respondents were asked to indicate the preferred format of the new guidelines, noting that respondents could tick more than one option (see Appendix A: Q15). In total, 42 respondents answered this question, including 39 healthcare professionals, with results shown in Table 2.

Table 2. Preferred format of ME/CFS guidelines

Option	Total
PDF	32
Webpages	30
Print copies	10
Phone app	9
MAGICapp website (https://app.magicapp.org/#/guidelines)	6
Other	0
Not Answered	1045

3.2.6. Tools to accompany the guidelines

Respondents were asked to identify useful tools that could accompany the guidelines (see Appendix A: Q16). Results of the 44 responses (including 40 from healthcare professionals) received are outlined at Table 3, noting that respondents could tick more than one option.

Table 3. Tools to accompany the guidelines

Option	Total
Summary of recommendations	37
Factsheets	34
Evidence summaries	32
Plain language summary	29
Shared decision-making tools	23
Evidence maps (graphic representation of evidence)	21
Clinical algorithms	19
Instructional videos	14
Decision aids	12
Other	1
Not Answered	1043

3.2.7. Details from researchers on research type and funding sources

Of the 14 people who identified as researchers, 11 answered the question about their type of research and funding sources (Appendix A: Q17). Research topics included occupational therapy, autonomic dysfunction, molecular and cell biology, immunological disturbances, gut health and exercise physiology. Funding sources included government, universities, philanthropic organisations and private companies.

3.3. Questions ‘about the guidelines’

3.3.1. Priority topics for inclusion in the guidelines

Respondents were asked to list the top three topics they would like to see addressed in the Australian ME/CFS Clinical Practice Guidelines (see Appendix A: Q20). Responses allowed for up to three free-text fields to be completed. No prompting or example answers were provided. In total, 1049 respondents (97%) answered these questions. Some respondents provided multiple topics within one free text field; however, each topic was counted once per respondent to reduce duplication and overinflating results (e.g. if someone mentioned the same topic twice, that topic was only counted once).

The top three topics described by respondents included:

1. **Managing energy levels**
    a. PEM should be included in diagnostic criteria
    b. importance of pacing
    c. exclusion of graded exercise therapy (mentioned 751 times across sub-themes).
2. **Re-categorisation** and **acknowledgement of ME/CFS** from a disease of the nervous system to a biological and physical disease to remove stigma that the condition is 'not real' (mentioned 432 times).
3. **Non-health related supports/outcomes** including financial supports (e.g. NDIS, Medicare, housing, etc) and broader social determinants of health (mentioned 174 times).

Other topics included diagnosis, education and training of healthcare providers, models of care and the ME/CFS severity spectrum.

Table 4 provides an overview of responses and general sentiment from respondents.

Table 4. Topics described by respondents

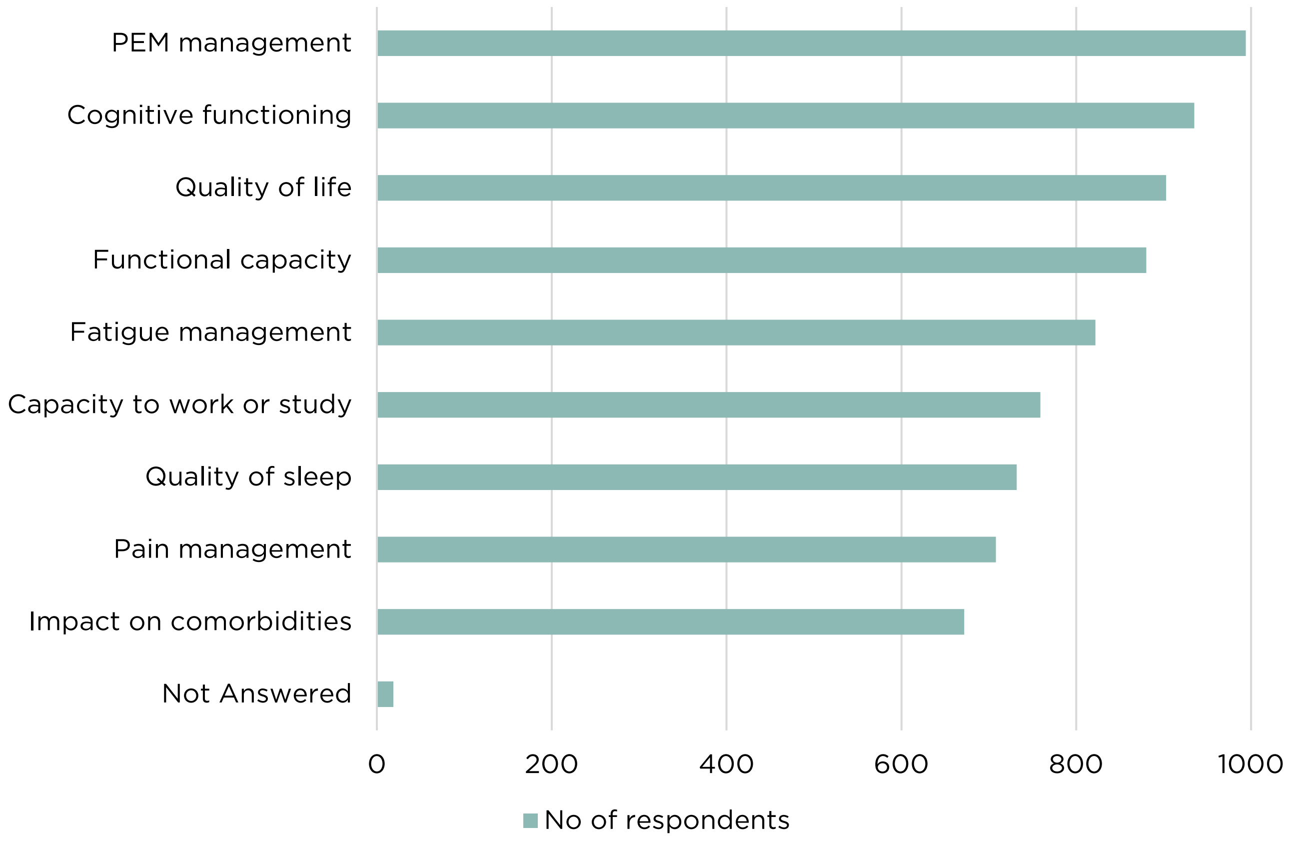
Theme	Key issue/ subtheme	Number of responses
Managing energy levels TOTAL = 751 responses	*Post-exertional malaise* — Respondents strongly supported inclusion of PEM as a key feature of ME/CFS and noted that PEM should be a key symptom of the diagnostic criteria to be used in the ME/CFS guidelines.	264 responses
	Graded exercise therapy — Respondents strongly opposed graded exercise therapy (GET) and were keen to see it excluded from ME/CFS guidelines.	283 responses
	Pacing — Pacing was described as the most efficient way of managing energy levels.	204 responses
Categorisation and acknowledgement of ME/FS TOTAL = 432 responses	*ME/CFS is not a psychological condition* — Respondents were strongly opposed to the suggestion that ME/CFS is a psychological condition and stated that for this reason, CBT is not a suitable treatment. However, mental health support can still be important for managing the impact of ME/CFS on a person's life.	258 responses
	Acknowledge that ME/CFS is real — Respondents felt that healthcare professionals need to acknowledge that ME/CFS is a real, multisystemic physical condition and move away from outdated perspectives that it is of psychological origin.	174 responses

Theme	Key issue/ subtheme	Number of responses
Non-health related support TOTAL= 174 responses	Respondents indicated that additional supports (outside of medical care) are needed for ME/CFS patients (e.g. NDIS and other financial/social supports), noting that significant barriers are experienced by those with already limited energy when navigating social support services and compounded by being unable to go to school or work.	174 responses
Diagnosis TOTAL = 141 responses	Respondents mentioned the need for specific diagnostic criteria, processes and tools. Respondents mentioned the importance of getting an early diagnosis for ME/CFS, so that patients can start getting support to manage their symptoms. Some respondents suggested using existing diagnostic criteria, such as the International Consensus Criteria (12 responses) and those from the NICE guideline (7 responses).	141 responses
Education and training of healthcare professionals TOTAL= 128 responses	Respondents commented about the need for healthcare professionals (particularly primary care clinicians) to have a more in-depth understanding of ME/CFS and how best to manage the condition.	128 responses
Models of care TOTAL = 85 responses	Respondents mentioned that various models of care should be included in the guidelines, including: • multi-disciplinary teams (49 responses) • allied health practitioners (15 responses) • specialist referrals (13 responses) • specialist centres (8 responses).	
Severity TOTAL = 51 responses	Respondents indicated that the guidelines should include information about/acknowledgement of the severity spectrum of ME/CFS, noting that having clear descriptions of what constitutes severe and very severe ME/CFS would be helpful.	51 responses

3.3.2. Priority health outcomes for the evidence reviews.

Respondents were asked to indicate the health outcomes they considered as most important to include as part of the de novo systematic reviews for the ME/CFS guidelines (see Appendix A: Q21). A list of 9 multiple choice options were provided (see Figure 1) as well as one free text field to raise any additional outcomes not listed.

Figure 1. **Health outcomes considered most important by respondents**



In total, 435 responses were included in the free text. However, of the responses, many were related to the 9 health outcomes already listed and topics considered important for the guideline (e.g. GET), rather than actual health outcomes.

Of the responses that did suggest additional health outcomes, the most common ones were (number of respondents in brackets):

- orthostatic intolerance (49)
- sensory sensitivities (46)
- gastrointestinal issues (44)
- dysautonomia/autonomic nervous system issues (42)
- immune system (27).

3.3.3. Other comments

The final survey question asked respondents to raise any other issues they felt were important to address in the guideline (see Appendix A: Q22). Most responses repeated answers to topics and health outcomes from earlier questions and so were not re-analysed.

The following are general sentiments raised by respondents throughout the survey and illustrate the complexity and deeply impactful realities facing ME/CFS patients.

General sentiment of responses
Many individuals living with ME/CFS report feeling profoundly unsupported and isolated. There is a strong sense of being left to navigate the condition alone, often while experiencing cognitive impairments such as brain fog. Unlike other illnesses that receive structured support and clearer outcomes, ME/CFS is perceived as lacking both recognition and assistance, contributing to feelings of invisibility and loneliness.
There is a call for clinical guidelines to acknowledge the historical context of harm and misinformation surrounding ME/CFS, with emphasis on correcting past misconceptions and ensuring that healthcare professionals become more aware of the condition and appropriate management strategies.
The impact of ME/CFS on personal relationships and daily life was described as devastating. The condition affects every aspect of a person's life, leading to the loss of social connections, career opportunities, and hobbies, while often being met with disbelief by others. This contributes to emotional distress and in some cases, suicidal ideation.
Healthcare interactions are frequently described as traumatic, with many individuals experiencing dismissal and a lack of appropriate support. These experiences often exacerbate the condition and lead to further isolation and adverse outcomes.

4. Discussion

The ME/CFS Scoping Survey has provided key insights into the lived experiences, clinical challenges and systemic barriers faced by individuals with ME/CFS and related conditions. The overwhelming response from individuals, particularly those with lived experience, highlights the importance of producing a guideline that considers the complexity experienced by patients and provides the most up-to-date evidence base available to manage the condition.

Respondents consistently emphasised the need for biomedical recognition of ME/CFS, with PEM identified as a key symptom requiring careful management. The strong opposition to GET and the preference for pacing strategies was generally expected, noting that these concerns have been raised both nationally and internationally between clinicians, patients and researchers, with some 'for' and some 'against' GET as a form of management/treatment for ME/CFS.

The survey also highlighted the importance of acknowledging ME/CFS as a legitimate, multisystemic condition. Many respondents expressed frustration with the historical framing of ME/CFS as a psychological condition, noting that such perceptions have led to misdiagnosis, inappropriate treatment and emotional distress. This sentiment was particularly strong among those who had experienced dismissal or disbelief when seeking support for the condition.

Beyond clinical management, respondents drew attention to the broader social determinants of health that impact individuals with ME/CFS. Financial insecurity, difficulty accessing services such as the NDIS, and the inability to work or study were recurring themes. These too were generally expected and have also been raised elsewhere as key barriers for patients accessing care.

While the survey was intended to capture clinician perspectives, the majority of responses came from individuals with ME/CFS. This imbalance suggests that additional targeted consultation, particularly with general practitioners, may be warranted given their role as primary users of the guidelines.

4.1. Limitations

The open distribution of the survey via social media and advocacy networks likely contributed to the high proportion of responses from individuals with lived experience. The survey was also shared to two Australian medical colleges; however, the small response from this cohort suggests that this was not the most efficient way to obtain clinician perspectives.

Although respondents were not encouraged to submit more than one response, there was no way to prevent this from occurring. NHMRC used Citizen Space to host the survey. Citizen Space is software designed for use by government organisations and does not generally apply restrictions to IP addresses. This is for a few reasons: placing a restriction on people responding (e.g. those from the same IP address) would mean that only one response would be accepted from places like a public library, an office block or a home, when multiple individuals may need to respond from that address. Given this, there is a risk that some responses were duplicates. However, during the analysis, duplicate answers were identified (where longer, identical phrases were used) and in all cases the respondent had listed different identities for their response (e.g. individual with ME/CFS and a carer of someone with ME/CFS) so they were sharing two different perspectives, which is a legitimate reason for responding twice.

While the survey included some questions about related conditions (i.e. Long COVID, POTS, and fibromyalgia) these were not the primary focus of the survey and representation from these groups was limited, with less than 20% of survey respondents identifying as having Long COVID or other conditions. Whilst this is considered a limitation of the survey, the main focus of the new guidelines is ME/CFS and therefore the responses collected in this survey generally reflect the relevant patient cohort.

Appendix A: Survey questions

Scoping survey for Clinical Practice Guidelines for myalgic encephalomyelitis / chronic fatigue syndrome

Privacy Disclaimer

1. Privacy Collection Notice

The content of your submission will be used solely by the National Health and Medical Research Council (NHMRC) to consider your comments for the development of clinical practice guidelines for ME/CFS. The personal information that you include in your submission is being collected to understand the needs and priorities of the guidelines' audience. Any personal information collected via this website will be stored and used in accordance with NHMRC's obligations under the *Privacy Act 1988*, and in accordance with the NHMRC Privacy Policy.

☐ I have read the security warning/disclaimer in the Privacy Collection Notice and accept the risks and conditions outlined. *(Required)*

About you

2. What is your interest in completing this survey?

For instance, do you have, know of or care for someone with ME/CFS? Have you previously had ME/CFS or related conditions? Do you treat people living with ME/CFS? Do you research ME/CFS or related conditions?

3. Are you responding as an individual or on behalf of an organisation?

(Required)

Please select only one item

☐ An individual (proceed to question 4)
☐ An organisation (skip to question 18)

For individuals

Why are we asking these questions

As part of the guideline development process, NHMRC is interested in the views of people from different geographical regions, people of all sexes and genders, Indigenous Australians and people from culturally and linguistically diverse backgrounds.

4. What state or territory do you live in?

State

Please select only one item

☐ Australian Capital Territory
☐ New South Wales
☐ Northern Territory
☐ Queensland
☐ South Australia
☐ Tasmania
☐ Victoria
☐ Western Australia
☐ Other (e.g. international location)

5. Do you live outside of the capital city in your state?

Please select only one item

☐ Yes
☐ No

6. What is your sex?

Please select only one item

☐ Male
☐ Female
☐ Other
☐ Prefer not to answer

7. What is your gender?

Please select only one item

☐ Man
☐ Woman
☐ Non-binary
☐ I use a different term
☐ Prefer not to answer

8. Do you identify as Aboriginal and/or Torres Strait Islander?

Please select only one item

☐ Yes, Aboriginal
☐ Yes, Torres Strait Islander
☐ Yes, Aboriginal and Torres Strait Islander
☐ No
☐ Prefer not to answer

9. Do you speak a language other than English at home?

Please select only one item

☐ No, English only
☐ Yes, one or more other languages

10. Which of the following best describes you?

Multiple perspectives

We recognise that some people might identify within multiple categories. If this applies to you please select the category you are most interested in providing information for. You can also select 'Other' to provide further information on your experience with ME/CFS.

(Required)

Please select only one item

☐ Person with lived experience of ME/CFS (proceed to question 11)
☐ Health professional (skip to question 13)
☐ Researcher (skip to question 17)
☐ Other

Please provide further details if you selected 'other'

For people with lived experience of ME/CFS

Why are we asking these questions

NHMRC wants to understand the different support and management strategies people are using in Australia.

11. If you currently have ME/CFS

How long have you had it for?

Is a medical practitioner helping you manage your symptoms?

What support are you using to help manage your symptoms?

Please select all that apply

☐ Support group
☐ GP
☐ Allied health
☐ Medical specialists
☐ Friends
☐ NGO
☐ Peer support group
☐ Complementary medicine practitioners
☐ No support
☐ Other

If you selected 'Other' please describe additional supports

12. Do you have experience with other related conditions?

Please describe any other conditions

For health professionals

13. If you manage people with ME/CFS

Please select only one item

☐ Are you a general practitioner
☐ Are you an allied health professional
☐ Are you a medical specialist
☐ Are you a nurse
☐ Other

14. What guidance documents do you refer to currently?

Please describe reference materials or provide links

15. What format would you prefer the guideline be delivered in?

Please select all that apply

☐ PDF
☐ Webpages
☐ MAGICapp website (https://app.magicapp.org/#/guidelines)
☐ Phone app
☐ Print copies
☐ Other

Other

☐

16. What additional tools would be useful to accompany the guideline?

Please select all that apply

☐ Summary of recommendations
☐ Plain language summary
☐ Evidence summaries
☐ Evidence maps (graphic representation of evidence)
☐ Instructional videos
☐ Factsheets
☐ Clinical algorithms
☐ Shared decision making tools
☐ Decision aids
☐ Other

If you selected 'Other' please describe the tools you would like to use

For researchers

17. If you research ME/CFS

Why we are asking this question

NHMRC is interested in this information to understand what sort of research activity is underway in Australia.

What type of research are you involved with? Who provides funding for your research?

For organisations

18. Please identify the best term to describe the organisation

Please select only one item

☐ Aboriginal medical service
☐ Advocacy group
☐ Allied Health professional organisation
☐ Commercial company
☐ Condition group
☐ Consumer organisation
☐ Educational or training institution
☐ Government department or agency – Commonwealth
☐ Government department – State / Territory
☐ Health service
☐ Hospital – private
☐ Hospital – public
☐ Industry representative
☐ Medical College or professional organisation
☐ Non-government organisation
☐ Nursing and/or Midwifery professional organisation
☐ Pharmaceutical company
☐ Primary care organisation
☐ Research institute / organisation
☐ University
☐ Other

If you chose other, please provide a term that describes your organisation

19. What is the name of your organisation?

(Required)

About the guidelines

20. What are the three most important topics that you would like to see in an Australian clinical practice guideline for ME/CFS and related conditions?

One

Two

Three

21. In a guideline development process, health outcomes (or symptoms) are identified and prioritised before searching for evidence. What health outcomes would you consider important to review the evidence for?

Please select all that apply

☐ Post-exertional malaise (PEM) management
☐ Fatigue management
☐ Quality of sleep
☐ Pain management
☐ Cognitive functioning e.g. brain fog
☐ Capacity to work or study
☐ Functional capacity e.g. independence in everyday activities
☐ Quality of life e.g. physical, psychological and social wellbeing
☐ Impact on comorbidities

Please describe other health outcomes not mentioned above

22. Are there any other issues you feel are important to address in the guideline?

Please describe

23. Permission to Publish

(Required)

Please select only one item

☐ Yes, NHMRC may include my de-identified responses in public summaries of comments received.

☐ No, I do not consent to my individual, de-identified, responses being published.