

NHMRC ME/CFS Advisory Committee report to the CEO – making submissions

Daunted by the process for responding to the NHMRC Draft Report?

ME/CFS SA has pulled together some information to assist with your submission process, including **what** you might say and **how** to submit.

Contents:

Submission Guidelines from NHMRC
Tips for submissions
Ideas about what to say
The registration process
Setting up your submission and preparing it for editing
Saving, returning and submitting
Options for anonymity
Trouble shooting

Submission Guidelines from NHMRC

The report is available at: https://consultations.nhmrc.gov.au/public_consultations/mecfs-2019a

Closing date for submissions is 11.29pm (AEDT) **18th February 2019**.

The NHMRC committee will only consider submissions that address the five prescribed consultation questions. These are:

- **Question 1(a):** How well does the report present the difficulties faced by ME/CFS patients in receiving medical care?
- **Question 1(b):** How well does the report present the challenges facing clinicians in providing care, when there is lack of clarity on diagnostic and management tools and minimal professional education about the condition?
- **Question 2(a):** The research and clinical guidance recommendations accurately address the specific needs of ME/CFS community.
- **Question 2(b):** The research and clinical guidance recommendations provide an accurate representation of the current gaps in research.
- **Question 2(c):** The research recommendations inform the CEO of the most effective and strategic research options currently available.

Up to 300 words is allowed for answering each question. You can save your work and return to the submission process. There is no automatic save function, so please remember to save your answers regularly.

Submissions will **not** be considered if they are:

- detailed personal history or narratives
- personal medical information/records
- opinion pieces/blogs/newspaper articles
- personal opinions regarding the Advisory Committee membership
- research proposals or requests for funding of specific projects
- specific recommendations for clinical care

Tips for submissions

It is just as important to indicate those aspects of the report that you support, as well as those you wish to see amended.

It may help the NHMRC if you are able to indicate which section of the report you are talking about when you make a comment. But the most important thing is simply to let them know what is important to you.

Ideas about what to say

Many people have expressed confusion about how to begin developing a submission. In particular, there has been concern about how to determine what sort of material to include under which of the five given questions.

- ME/CFS SA has created a document to identify the types of information that could be included under each question.
- For people who would like to focus their submission on PEM, there are additional notes in a separate document, with quotes and reference material.

To obtain a copy of one or both documents, please email secretary@sacfs.sa.asn

Also, #MEAction Network Australia (MEANA) have produced a document based on member discussions, with some of the main concerns of patients described under each question. Many thanks to MEANA for this.

The MEANA document is available here: <https://bit.ly/2G7gIQU>

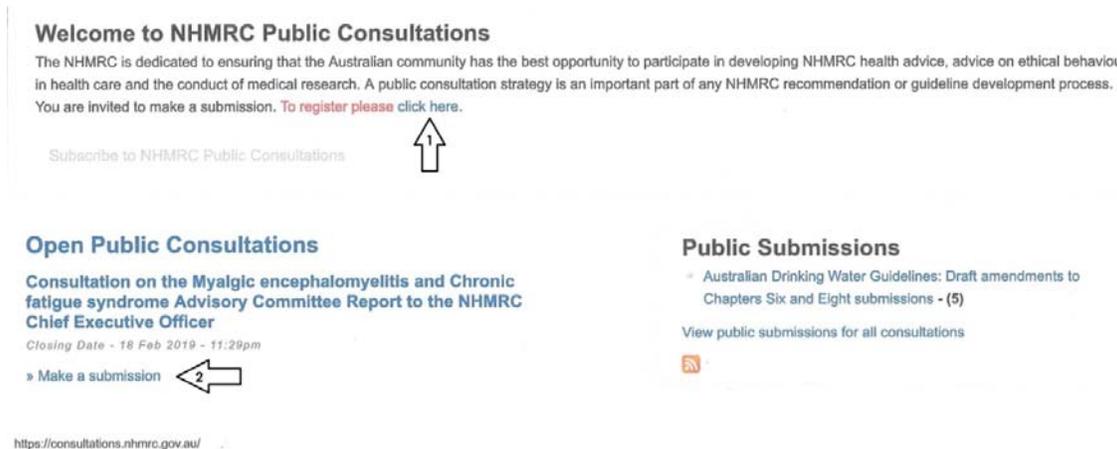
Please remember to use your own words in your submission as identical responses will be disregarded.

The registration process

To register for submitting a response, go to <https://consultations.nhmrc.gov.au>

Registration requires an email address, name and address. After registration, an email will be sent to you to confirm registration. The email will contain a link where you create your own password. You need to respond to this email within a stated time limit.

In the screenshot below, we have added an upward-pointing arrow (1) for the **link to register**, after which you can use the sideways-pointing arrow (2) for the link to **set up a submission**.



Setting up your submission and preparing it for editing

Your submission will have five parts:

1. Disclaimer (see pic above)
2. Personal Details
3. This submission reflects the view of
4. Specific questions
5. Finalise submission

On the each page of the submission site is a navigation list on the left-hand side, with those five parts. Click on each heading to complete the required details.

At the bottom left hand corner of each page are the options to Save and Preview. Saving takes you to a page showing your details. Bookmark this page, and use the 'Edit' link to continue your submission.

Consultation on draft report to the NHMRC CEO for 'Myalgic Encephalomyelitis / Chronic Fatigue Syndrome' submission

Submission on the Myalgic encephalomyelitis and Chronic fatigue syndrome Advisory Committee Report to the NHMRC CEO Consultation on draft report to the NHMRC CEO for 'Myalgic Encephalomyelitis / Chronic Fatigue Syndrome' submission has been updated.

[View](#) [Edit](#)

Submission Closure Date: 18 Feb 2019 - 11:29pm

Disclaimer

Permission to publish on the NHMRC website:
Yes, NHMRC may publish my submission on the NHMRC website

Agreement:
I agree

Personal Details

This submission reflects the views of

Views:
An individual

Individual Background:
Student - undergraduate

Saving, returning and submitting

There is no auto-save function for your submission drafts. You will need to 'save' each time before you leave the page.

At the bottom left hand corner of the NHMRC submission page are the options to Save and Preview. Saving takes you to a page showing your details. You can bookmark this page, and use the **'Edit'** link to continue your submission.

The submission pages will automatically log you out if you leave them unattended too long. Remember to save your work each time you take a break and to keep a record of your login details, so that you can log back in easily if you get timed out.

When you are happy with your saved submission, remember to hit the 'Submit' button!

Consultation on draft report to the NHMRC CEO for 'Myalgic Encephalomyelitis / Chronic Fatigue Syndrome' submission

View

Edit

Please note that there is no auto-save function. You must regularly save your submission as you go through each of the steps of this consultation. Refer to the [Submission Guidelines](#) for further information.

| | |
|--|--|
| Disclaimer | My submission is complete: * <input checked="" type="radio"/> Not complete, save this submission so it can be updated later <input type="radio"/> Complete, this submission is complete and is ready for NHMRC consideration By selecting "yes" you agree that your submission has been finalised and ready for review. Submissions that remain incomplete when the consultation closes will not be reviewed by NHMRC. |
| Personal Details | |
| This submission reflects the views of | |
| Specific Questions | |
| Finalise submission | |

Save

Preview

Options for anonymity

1. The submission process allows for publishing, not publishing, or redaction of parts of your submission. This occurs through the form in the screenshot below.

Permission to publish on the NHMRC website: *

- Yes, NHMRC may publish my submission on the NHMRC website
- No, I do not consent to my submission being published on the NHMRC website
- My submission contains some information which I do not want published on the NHMRC website. I have clearly marked the information I'd like redacted before NHMRC may publish my submission.

*Note: Any submission made to the NHMRC may be subject to the requirements of the Commonwealth Freedom of Information Act 1982. NHMRC retains the right to determine which submissions it will publish. All personal information should be removed from your submission if permission to publish has been granted. Submissions may not be made public if personal information is included in the submission

Agreement: *

- I agree

I am aware that if I agree to release information from my submission, it will be widely available, e.g. it may be placed on NHMRC's website and made available in hard copy. I am also aware that the information may be further referenced in later publications. I consent to NHMRC contacting me in regards to this submission for clarification purposes. You should be aware that any submission made to the NHMRC may be subject to the requirements of the Commonwealth Freedom of Information Act 1982. By checking this box you agree to the above conditions and agree that you have read and understood the "Submission Guidelines" page.

2. If you want to have your **submission appear publicly, but without your name attached**, you need to fill in an offline form and clearly document what specific personal details you do not want published. This form then needs to be emailed to: ME_CFS@nhmrc.gov.au by the close of public consultation on 18 February 2019. NHMRC staff can then manually input the submission information (without the personal information) into the public consultation portal so that the comments are captured in the system.
The form can be accessed here: <https://bit.ly/2DUwbMz>

Trouble shooting

If you have difficulty with anything technical on the NHMRC website, please email ME_CFS@nhmrc.gov.au for assistance.