



Julie Keys  
via email: [foi+request-12144-74a69e49@righttoknow.org.au](mailto:foi+request-12144-74a69e49@righttoknow.org.au)

Dear Julie

**FREEDOM OF INFORMATION REQUEST: No. 2024/25-002**  
**Request Consultation (section 24AB)**

I refer to your request made under the *Freedom of Information Act 1982* (Cth) (FOI Act) to the National Health and Medical Research Council (NHMRC) on 6 October 2024, which you clarified on 8, 19 and 27 October 2024. You also revised the scope of your request on 20 November 2024, which is seeking:

*Information relating to the NHMRC's actions/correspondence/ consultations to date regarding the development of safe and clinically appropriate guidelines for best practice management of ME/CFS.*

*The information I am seeking includes but is not limited to:*

- i. Advice provided to the NHMRC to date regarding the scope of the guidelines by Prof, Andrew Lloyd (Sydney Fatigue Clinic) , Prof. Paul Glasziou et*
- ii. Advice provided to government organisations such as the NDIA on the management of ME/CFS*
- iii. Any information relating to interim measures e.g. the adoption of the comprehensive UK NICE Guidelines and/or the IOM report- CDC website, Mayo Clinic, Batman Horne Clinic, Workwell Foundation etc...best practice management for ME/CFS.*
- iv. A copy of the procedural steps taken by the NHMRC to develop guidelines e.g. the Australian equivalent of the NICE research protocol.*

On 20 November 2024, you also noted that:

*I do not think that the scope is onerous as it appears that little work has been done towards updating these guidelines and I don't expect that there is a large volume of information.*

I am an officer authorised under subsection 23(1) of the FOI Act to make decisions in relation to FOI requests.

On 8 October 2024, you clarified the scope of your request by advising that it *relates to information on this topic that post dates the publication of the NHMRC's recommendation to update the guidelines in 2019 until current date.*

On 14 October 2024, NHMRC's FOI Unit sought your agreement via email to further clarify the scope of your request (in line with paragraph 3.72 of the [Guidelines issued by the Australian Information Commissioner under s93A of the Freedom of Information Act 1982](#)<sup>1</sup>). This email also provided some background and context about NHMRC's *clinical practice guidelines for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), long COVID and related conditions* (the

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<sup>1</sup> URL: <https://www.oaic.gov.au/freedom-of-information/freedom-of-information-guidance-for-government-agencies/foi-guidelines>

guidelines). You responded on 19 October 2024 and provided further clarification on the scope of your request. You also reiterated on 27 October 2024 that you are *only requesting information the post dates the 2019 NHMRC publication of their report on ME/CFS and not any earlier correspondence or information*.

On 14 November 2024, the FOI Unit sought your agreement via email to reduce the scope of your request. This was based on the large number of results that were identified in our search for potentially relevant documents. This email also provided further information on the outcome of our search, reducing the scope of your request, as well as the development of the guidelines.

On 20 November 2024, you agreed to reduce the scope and provided the details of your revised request. Although parts of your request have been refined, I note that your request remains broad in nature (e.g., advising that the information you are seeking *includes but is not limited to* the 4 points provided).

I am writing to advise that I intend to refuse access to the documents requested, for the reasons detailed below. However, before a final decision is made to do this, you have an opportunity to further reduce the scope of your request. This is called a 'request consultation process' as set out under section 24AB of the FOI Act. You have 14 days to respond to this letter in one of the ways set out under the 'request consultation process' heading below.

### **Power to refuse request**

Section 24 of the FOI Act provides that if NHMRC is satisfied that a practical refusal reason exists in relation to a request, NHMRC must undertake a consultation process with you. If, after that consultation process, NHMRC remains satisfied that the practical refusal reason still exists, NHMRC may refuse access to the documents subject to the request.

### **Practical refusal**

A practical refusal reason exists if either (or both) of the following applies:

- (a) the work involved in the processing of the request would substantially and unreasonably divert the resources of the agency from its other operations
- (b) the request does not satisfy the requirement in section 15(2)(b) of the FOI Act, which requires you to provide such information concerning the document you are seeking access to, to enable the agency to be able to identify it.

### **Reasons for practical refusal**

#### **The work involved in processing the request - section 24AA(1)(a) of the FOI Act**

I believe that the work involved in processing your request in its current form would substantially and unreasonably divert the resources of this agency from its other operations due to the broad scope of your revised request (dated 20 November 2024).

The FOI Act gives any person the right to request access to copies of documents held by an agency (s11(1)). In processing a request for documents, I must have regard to the resources required to perform the following activities (specified in s24AA(2) of the FOI Act):

- identifying, locating or collating documents within the filing system of the agency
- examining the documents
- deciding whether to grant, refuse or defer access
- consulting with other parties
- redacting exempt material from the documents
- making copies of documents
- notifying an interim or final decision to the applicant.

NHMRC conducted another search of its electronic files and email mailboxes within the agency, to find any documents that may be relevant to your revised request of 20 November 2024. The key search terms used were [**'Myalgic Encephalomyelitis/Chronic Fatigue Syndrome', 'ME/CFS', 'ME-CFS', 'MECFS', 'long COVID'**]. I note that these are general search terms that have been used due to the nature of your request. Although a date range was not specified in

your revised request, we assumed that it was only for information that post-dated the [2019 NHMRC publication of the ME/CFS report](#)<sup>2</sup> (i.e., after 30 April 2019), as you previously advised. We also assumed an end date of 20 November 2024, as this is the date you submitted your revised scope. Accordingly, the date range for the search was **1 May 2019–20 November 2024 (inclusive)**. We have tried to refine the search by excluding documents that do not fall within the scope of your request. This search has identified 199,553 documents which potentially fall within the scope of your request.

I have applied an estimated review time of 2 minutes per document to confirm whether the document is in scope of your request, identify any duplicates, examine whether any [exemptions](#)<sup>3</sup> and/or [conditional exemptions](#)<sup>4</sup> apply under the FOI Act and record the reasons for applying any exemption/s. This would result in a process time for this FOI request of 6,652 hours, or the equivalent of around 887 days of work.

Further time may be required for NHMRC to perform any relevant redactions and create/secure the PDF document. In addition, NHMRC has not yet assessed if it would be required to consult with third parties affected by the potential release of the documents. These activities would add considerably to the above estimate of time required to meet the request in its current form.

In determining an unreasonable diversion of resources, I have taken into account the number of hours which would be required to process your FOI request and the staffing and resources of NHMRC; a small agency of just over 200 staff, of which only a small team of officers have specialist knowledge on the relevant subject matter. In my view, undertaking your request as it stands would divert resources and adversely affect the ability of the team to perform their other functions properly. My responsibilities require me to be mindful of these matters when considering your request.

### Request consultation process

I invite you to submit a further revised request with a reduced scope to enable it to proceed. By focussing your request on information that you are more interested in, NHMRC may be able to pinpoint the documents more quickly and avoid using excessive resources to process documents that you are less interested in.

For example, you may wish to remove the more general parts of your request from the scope, which contribute to the large number of search results, i.e.:

- *Information relating to the NHMRC's actions/correspondence/ consultations to date regarding the development of safe and clinically appropriate guidelines for best practice management of ME/CFS.*
- *The information I am seeking includes but is not limited to...*
- *Any information relating to interim measures e.g. the adoption of the comprehensive UK NICE Guidelines and/or the IOM report- CDC website, Mayo Clinic, Batman Horne Clinic, Workwell Foundation etc...best practice management for ME/CFS.*

In addition, you may wish to focus on some of the more specific points of your request, for example:

- Advice provided to the NHMRC to date regarding the scope of the guidelines by Prof. Andrew Lloyd (Sydney Fatigue Clinic) and Prof. Paul Glasziou.
- Advice provided to the government organisation NDIA on the management of ME/CFS

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<sup>2</sup> URL: <https://www.nhmrc.gov.au/about-us/publications/mecfs-advisory-committee-report-nhmrc-chief-executive-officer>

<sup>3</sup> URL: <https://www.oaic.gov.au/freedom-of-information/freedom-of-information-guidance-for-government-agencies/foi-guidelines/part-5-exemptions>

<sup>4</sup> URL: <https://www.oaic.gov.au/freedom-of-information/freedom-of-information-guidance-for-government-agencies/foi-guidelines/part-6-conditional-exemptions>

- A copy of the procedural steps taken by the NHMRC to develop guidelines, e.g. the Australian equivalent of the NICE research protocol.

Please note that NHMRC has published extensive information on its website about [developing guidelines](#)<sup>5</sup>, which will provide you with information that helps to address point iv of your request. The development of the ME/CFS guidelines will essentially follow the steps laid out in the [guideline development process diagram](#)<sup>6</sup>, even though that was technically produced to illustrate the process for public health guidelines. You may also be interested in the [2016 NHMRC Standards for Guidelines](#)<sup>7</sup> (which align Australia's standards for guidelines with international best practice), as well as the [Guidelines for Guidelines Handbook](#)<sup>8</sup> and [Procedures and requirements for meeting the 2011 NHMRC standard for clinical practice guidelines](#).<sup>9</sup>

As stated above, the consultation period runs for 14 days and starts on the day after you receive this notice. In this time, you must do one of the following, in writing:

1. make a further revised request – that is, make a request with a reduced scope
2. withdraw your request
3. advise that you do not wish to change your current request.

During this period, you are welcome to seek assistance from NHMRC's FOI Unit to revise your request. If you revise your request in a way that adequately addresses the practical refusal grounds outlined above, we will recommence processing it.

If you do not do one of the 3 things listed above during the consultation period, your request will be taken to have been withdrawn.

### Timeframe for processing your request

Your request was received by NHMRC via email on 6 October 2024. The statutory timeframe for processing a request is 30 days, starting from the day after the day on which your application was received. On 27 October 2024, you agreed to extend the processing period by 30 days, under s15AA of the FOI Act. Accordingly, the due date for a decision on your request is 5 December 2024. However, once this letter is sent to you, the period stops until you respond with your advice on how the access request will proceed as per the 3 options outlined above, or the 14-day response period concludes (whichever is shortest).

### Contact

If you have any queries or would like to discuss your request, please contact me via NHMRC's FOI Unit by email at [foi@nhmrc.gov.au](mailto:foi@nhmrc.gov.au) or by phone on (02) 6217 9000.

Yours sincerely

*signed electronically*

Alan Singh  
Executive Director  
Research Quality and Advice

26 November 2024

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<sup>5</sup> URL: <https://www.nhmrc.gov.au/research-policy/guideline-development>

<sup>6</sup> URL: <https://www.nhmrc.gov.au/health-advice/public-health/nutrition/how-nhmrc-develops-public-health-guidelines>

<sup>7</sup> URL: <https://www.nhmrc.gov.au/guidelinesforguidelines/standards>

<sup>8</sup> URL: <https://www.nhmrc.gov.au/guidelinesforguidelines>

<sup>9</sup> URL: <https://www.nhmrc.gov.au/about-us/publications/meeting-2011-nhmrc-standard-clinical-practice-guidelines>