

Emerge Australia Submission

Medicare Benefits Schedule Review Advisory Committee Draft Report: Post Implementation Review of Telehealth MBS items

25 October 2023

Summary

On the grounds of safety, the MBS Review Advisory Committee (MRAC) has recommended the removal of initial non-GP telehealth consults from the MBS. The requirement for initial GP consults to be face-to-face remains, as does the requirement for a face-to-face appointment each 12 months (“12 month rule”). For people who are bedbound or housebound, such as those with ME/CFS and the growing number of people with Long COVID, this is potentially harmful. A group of these patients experience orthostatic intolerance and post-exertional malaise so attending medical appointments in person makes them sicker or they simply do not seek medical care.

It takes an average of five years to be diagnosed with ME/CFS, often requiring multiple initial non-GP consultations in the format of telehealth. There is no diagnostic test but an accurate diagnosis can be made by a doctor using accepted diagnostic criteria based on patient self-reported symptoms and exclusion of other conditions via standard laboratory tests.

If the *Disability Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* (September 2023) recommendation to introduce a Disability Rights Act is accepted, the right for people with disability, such as those with ME/CFS, to equitably access and receive quality health services appropriately adapted or specifically designed to meet their needs will be enshrined in law. This aligns with Principle One of MRAC’s proposed revised telehealth principles which states that “*telehealth items should be patient-focused and based on patient need, as determined by the clinician and the patient”.*

Emerge Australia therefore calls for

- A “vulnerable population” exemption to be included in “*Recommendation 9 For initial consultations, make non-GP specialist MBS items available only face-to-face, with subsequent consultations available through telephone or video at the clinician’s discretion*” and to broaden Recommendation 9 to include the exemption for **initial GP consultations** where:
 - inequality of service is widely acknowledged
 - lack of telehealth access would be highly detrimental for the patient; AND
- The “12 month rule” for face-to-face consultation in the previous 12 months to be modified so as not to specify the format (thereby permitting face-to-face or telehealth).

Anne Wilson
CEO

Background

Emerge Australia (EA) is the national patient body representing 250,000 Australians with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and increasingly people with Long COVID (cases estimated between 189,627 and 1,278,764) with between 5% and 25% being unable to work. 50% of Long COVID patients meet the diagnostic criteria for ME/CFS. A proportion of these will likely suffer debilitating illness for years¹.

ME/CFS, in most cases, is a post-infection disease which can cause a wide range of severity and functional impairment, leaving approximately 25% of patients homebound or bedbound. The most severely ill patients may need total care. Yet patients with severe or very severe ME/CFS struggle to receive appropriate medical care because they cannot travel to medical practices and doctors lack accurate information about the nature of the disease and how to diagnose and manage it. As a result, many people with ME/CFS are often not diagnosed or are misdiagnosed.²

Why telehealth matters to people with ME/CFS and Long COVID

- Some people experiencing severe or very severe ME/CFS are too sick to travel to the doctor and time sitting in waiting rooms makes them feel more ill for hours, days or weeks afterwards, the worsening of symptoms following physical or mental exertion).
- Many patients experience orthostatic intolerance (difficulty being upright, dizziness, sweating, nausea or other symptoms when standing that are reduced when lying down).
- Access to specialised care in regional areas is usually out of reach and limited to those who have the means and the ability to travel considerable distances.
- The nature of ME/CFS means that seeking a diagnosis and medical appointments take up an enormous amount of time and effort for the patient and also their carer. When a lot of detailed feedback needs to be given to the doctor, and a lot of complex information is provided to the patient, it can be too much for just one person to manage. The patient gets so much more if their carer can join in the appointment, particularly for patients whose symptoms include brain fog, memory problems and fatigue. Telehealth enables carers to participate, regardless of where they are (eg at work) when the appointment occurs. It also reduces the carer's financial cost of travel and parking, as well as missed work time ([Associate Professor Karyn Galvin, University of Melbourne, 2022](#))
- An online survey of 419 people to understand how ME/CFS patients and their carers experienced telehealth services found that introduction of Medicare rebates had improved access to health services for 82% of respondents and reduced the risk of experiencing the disabling effects of post-exertional malaise³.

Telehealth reduces these difficulties and the emotional strain, offering rural and remote patients, as well as those who find attending appointments exacerbates their symptoms, greater access to care.

¹ Estimating the Current Scale and Impact of Long COVID in Australia. Angeles, M. Hensher, M. Menzies Institute for Medical Research, Deakin Health Economics and Institute for Health Transformation. November 2022

² Montoya, J.G.; Dowell, T.G.; Mooney, A.E.; Dimmock, M.E.; Chu, L. Caring for the Patient with Severe or Very Severe Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Healthcare* 2021, 9, 1331. <https://doi.org/10.3390/healthcare9101331>

³ Emerge Australia. 'Telehealth campaign'. Available at: <https://www.emerge.org.au/telehealth-campaign> (accessed 20 January 2022).

For these reasons, Emerge Australia raises its concern for

- the MBS Review Advisory Committee's proposed change to cease 'initial' non-GP specialist consultations by telehealth; and
- retention of the "12 month rule", requiring patients to have a face-to-face appointment in the previous 12 months.
- retention of the requirement for an initial GP consult as face-to-face

Emerge Australia notes that the MBS Review Advisory Committee's review of telehealth items acknowledges that:

"Telehealth could improve access for some patients, such as those with disability who are largely housebound, by providing access to an increased frequency of consultations and more timely access".

However, we note that whilst consideration was given to the improved accessibility that telehealth offers some patient cohorts, concerns for safety overrode the need for accessibility, leading to the proposed recommendation 9:

*"**Recommendation 9:** For initial consultations, make non-GP specialist MBS items available only face-to-face, with subsequent consultations available through telephone or video at the clinician's discretion".*

MRAC's concerns were:

1. Concerns for safety – missed opportunities for early diagnosis which can have tragic outcomes, including delayed diagnosis and intervention
2. Even if telehealth has potential to increase patients' access, there were perceived risks of both lower quality of care and lower value services
3. Difficulty to diagnose via telehealth as the information requirements for diagnosis increase – for example, additional information from pathology or imaging tests.
4. When hands on clinical assessment is necessary for diagnosis, especially for a new diagnosis, telehealth was unlikely to be suitable and a face-to-face consultation was highly preferred.

These concerns, however, do not apply to patients with ME/CFS as it takes an average of five years to be diagnosed with ME/CFS as medical practitioners often do not understand or accept the condition. It is therefore potentially more injurious not to enable people with, or suspected, ME/CFS to first access a non-GP medical specialist via telehealth consult.

Disability Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability - Disability Rights Act

The recently released *Disability Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability's* (DRC) final report (September 2023) provides a useful framework for assessing the changes proposed for MBS Telehealth Items from the perspective of people experiencing disability⁴. Recommendation 4.1 proposes the establishment of a Disability Rights Act (DRA) which will enable Australia to fulfil its international obligations to promote the human rights of people with disability. If adopted, it will require that people experiencing disability are able to access services in a format that supports their impairment:

“The right to equitably access and receive quality health services appropriately adapted or specifically designed to meet the needs of the person with disability”.

This means that to address difficulties accessing healthcare, people with disabilities such as ME/CFS will have a right to access healthcare via telehealth .

Further, a duty under the proposed DRA is Recommendation 4.10 which will make it unlawful for a ‘public authority’ [such as the MRAC] to act in a way that is incompatible with a right in the DRA and fail to give proper consideration to a right where relevant to the decision being made.

Whilst the DRC’s recommendations are yet to be considered by the Commonwealth, we view MRAC’s recommendation to cease ‘initial’ non-GP specialist consultations by telehealth, retention of the “12 month rule” and requirement for face-to-face initial GP consults act as environmental barriers in accessing medical care for the most unwell and vulnerable people with ME/CFS, Long COVID and other similarly disabling conditions. Emerge Australia therefore advocates for the need for people experiencing disability, such as with ME/CFS and Long COVID, to be able to access telehealth for all initial GP and initial non-GP specialist consultations.

12 Month Rule

Emerge Australia raises concern over retention of the “12 month rule”, requiring patients to have a face-to-face appointment in the previous 12 months. People with mental health issues are exempt from this rule on the basis of ensuring access to care. We believe an exemption to this rule should apply to people with ME/CFS and Long COVID, particularly those who are housebound. We also believe that MRAC’s rationale for this exemption also applies to people with ME/CFS and Long COVID and other disabling conditions.

“Specifically, telehealth could improve access for some patients, such as those with disability who are largely housebound, by providing access to an increased frequency of consultations and more timely access. “

MRAC considered it important that patients with complex conditions are not relegated to telehealth-only consultations, as this could result in inferior care in the longer term. People with ME/CFS and Long COVID can often only access healthcare via telehealth. We believe an ongoing clinical relationship can be maintained via telehealth and that the option for face-to-face appointments should be based on clinical need rather than a rule. Without this, housebound/bedbound patients are faced with either paying full fee for a telehealth appointment (which often they can’t afford) or exacerbating their condition by attending a face-to-face appointment.

⁴ “Disability” results from interactions between people with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others. United Nations Convention on the Rights of Persons with Disabilities (CRPD)

We note that MRAC considered the case for exemptions to established clinical relationship criteria and suggested two criteria that could be used to help identify vulnerable populations:

- where inequality of service is widely acknowledged
- where lack of access would be highly detrimental for the patient.

The MRAC noted the lack of general support for disease/condition-specific MBS telehealth items from the Royal Australian College of General Practitioners and the Australian Medical Association. However, the MRAC considered that condition-specific telehealth items may improve access for some populations where access is a barrier to obtaining high-quality health care. Offering telehealth items specific to ME/CFS and Long COVID accords with the proposed revised MBS Telehealth Principle 1, that MBS funded telehealth

“Should be patient-focused and based on patient need, as determined by the clinician and the patient”

In the case of ME/CFS and Long COVID, if the patient’s need is to not exert themselves and the issue can be assessed via telehealth, then provision for this should be made.

Emerge Australia therefore calls for:

- A “vulnerable population” exemption to be included in *“Recommendation 9 For initial consultations, make non-GP specialist MBS items available only face-to-face, with subsequent consultations available through telephone or video at the clinician’s discretion”* and to broaden Recommendation 9 to include the exemption for **initial GP consultations** where:
 - inequality of service is widely acknowledged
 - lack of telehealth access would be highly detrimental for the patient; **AND**
- The “12 month rule” for face-to-face consultation in the previous 12 months to be modified so as not to specify the format (thereby permitting face-to-face or telehealth).

Notes:

Emerge Australia supports the US National Academy of Medicine (NAM) symptoms criteria required for a diagnosis of ME/CFS using substantial reduction in the ability to engage in pre-illness activity. This must have persisted for six months or more, and be accompanied by profound fatigue that isn’t substantially improved with rest