

June 2019 - Submission for the Medical Board of Australia's Consultation

Guidelines for registered practitioners – complementary and unconventional medicine and emerging treatments

Thank you for the opportunity to provide feedback on the Medical Board of Australia's (MBA's) proposed "*Guidelines for registered medical practitioners - Complementary and unconventional medicine and emerging treatments*".

Recommendation

Emerge Australia supports **Option 1**: Retain the status quo of providing general guidance about the Board's expectations of medical practitioners who provide complementary and unconventional medicine and emerging treatments via the Board's approved code of conduct.

We believe that the proposed guidelines have been insufficiently justified and will likely result in unintended consequences for patients' ability to access care, and we therefore recommend that the Board retain the existing guidelines.

About Emerge Australia

Established in 1980, Emerge Australia provides hope and help for people with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). We work to ensure that those living with ME/CFS have access to the support, education and advocacy that empowers them to make their lives more liveable.

What is ME/CFS?

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a complex, chronic health condition which affects as many as 250,000 Australians. ME/CFS affects many body systems, including the neurological, cardiac, gastrointestinal, endocrine and immune systems. The central feature of ME/CFS is post-exertional malaise (PEM), which is the exacerbation of all of the symptoms experienced by ME/CFS patients following exertion. An estimated 25% of people living with ME/CFS are housebound or bedbound.

Emerge Australia's reasons for supporting Option 1

1. The need for these guidelines has been insufficiently justified.

- a. **The existing Medical Board of Australia (MBA) guidelines, '*Good medical practice: a code of conduct for doctors in Australia*', are adequate.**

The existing guidelines cover all of the issues raised in the discussion paper. The discussion paper also provides examples of complaints which have been upheld against doctors practising complementary and unconventional medicine and emerging treatments (CUMET), suggesting that these guidelines are in fact providing sufficient protection for the public.

b. The issues raised in the discussion paper and the proposed guidelines are not unique to complementary and unconventional medicine and emerging treatments (CUMET).

The areas of concern about, and examples of complaints upheld against, doctors practising CUMET raised in the discussion document are not unique to these practitioners. Whilst we acknowledge that there are doctors practising CUMET in unsafe or unethical ways, this is also true of doctors practising conventional medicine.

The assumption of the proposed guidelines is that doctors practising CUMET pose a higher level of risk for patients than those practising conventional medicine, but this is not always the case.

c. The proposed guidelines erroneously assume that conventional medicine is safer than CUMET for patients because it is evidence-based.

The practice of medicine evolves with scientific knowledge and understanding. However, there is a delay between scientific advances and changes in clinical practice, during which time conventional medicine is operating on outdated evidence. This delay is considerable, estimated to be as long as 17 years.¹

For example, conventional medicine currently treats ME/CFS with graded exercise therapy (GET) and cognitive behaviour therapy (CBT). These treatments are based on a now discredited model of ME/CFS, which casts the primary pathology as deconditioning and activity avoidance. These treatments have been adopted by conventional medicine based on research evidence. However, that evidence has now been questioned²³ which, coupled with consistent patient reports of harm from these treatments and biomedical evidence highlighting issues with energy production in ME/CFS, has led to the US Centers for Disease Control and Prevention (CDC) to no longer recommend these treatments for ME/CFS.

¹ Morris, Z. S., Wooding, S., & Grant, J. (2011). The answer is 17 years, what is the question: understanding time lags in translational research. *Journal of the Royal Society of Medicine*, 104(12), 510-520.

² Vink, M., & Vink-Niese, A. (2018). Graded exercise therapy for myalgic encephalomyelitis/chronic fatigue syndrome is not effective and unsafe. Re-analysis of a Cochrane review. *Health psychology open*, 5(2), 2055102918805187.

³ Vink, M., & Vink-Niese, A. (2019). Cognitive behavioural therapy for myalgic encephalomyelitis/chronic fatigue syndrome is not effective. Re-analysis of a Cochrane review. *Health Psychology Open*, 6(1), 2055102919840614.

However, the Australian “Chronic Fatigue Syndrome Clinical Practice Guidelines” have not been updated since 2002, and these treatments are still recommended here in Australia, including by the RACGP. We consider that these conventional medicine treatments, not CUMET, currently pose a greater risk to ME/CFS patients.

d. These guidelines have attempted to cover too many areas of clinical practice without sufficient justification.

The proposed guidelines are too wide reaching. They have grouped together high risk clinical practices (such as stem cell therapy) with lower risk practices (such as offlabel prescribing or intravenous vitamins), and widely accepted complementary treatments with some evidence base (such as Traditional Chinese Medicine and acupuncture), with less accepted practices (such as Reiki or energy therapies). In doing so, the guidelines have assumed that these practices all pose the same level of risk for patients and have applied the same level of regulation for all, which is inappropriate and unjustified.

For all of the above reasons, we believe that any changes to the regulation of doctors should apply to all doctors, not just a subset of practitioners. However, the need for such additional regulation has not been sufficiently justified.

2. The proposed guidelines are likely to have unintended consequences which will impact the ability of patients to access appropriate care.

a. The proposed guidelines penalise those at the forefront of medicine.

Emerge Australia supports evidence-based medicine, but is also aware that medicine is an ever-evolving field. Whilst there are no ME/CFS treatments with adequate evidence, there are expert ME/CFS doctors who provide treatment based on both biomedical research and years (sometimes decades) of clinical experience working with the illness. The work of these practitioners is at the forefront of medicine, and often leads to clinical trials for treatments for which there is some practice-based evidence of efficacy.

The existing MBA guidelines require that doctors provide ‘treatment options based on the best available information’, which these expert practitioners do. However, the proposed guidelines penalise such practitioners, adding additional burden to their practice, and placing their practice in a separate, higher risk, category to conventional medicine. These guidelines will therefore also likely discourage practitioners from becoming specialists in ME/CFS, an illness for which conventional medicine has little to offer. Discouraging practitioners from joining the field is of significant concern to both Emerge Australia and the ME/CFS patient community.

- b. The proposed guidelines will likely discourage doctors from practising CUMET, resulting in reduced patient choice, increased cost of healthcare and increased risk of harm.**

Whilst Emerge Australia advocates for evidence-based treatments, we also respect patients' right to choose the treatments which work best for them. We recognise that many patients choose complementary medicine. The MBA is seeking to better regulate certain medical practices by increasing the regulation of an already well-regulated profession. We believe that it is better for patients to access CUMET from a trained and qualified doctor, than from a health practitioner within a less well-regulated profession. These new guidelines also penalise the many doctors who practise CUMET safely and ethically, creating a two-tier system within medicine, which is unjustified and which will likely discourage innovation and learning.

We are concerned that the effect of these guidelines will be to discourage doctors from practising CUMET. This will not reduce the number of patients who seek these treatments, but will likely make them more difficult to regulate. This would likely have three unintended consequences:

- Reduced patient choice as fewer doctors offer these treatments.
- Increased risk of harm to patients, as they seek these treatments from less well-regulated practitioners rather than doctors.
- Increased cost of healthcare for patients, as those doctors practising CUMET increase their fees to cover the burden of the increased regulation and, with fewer doctors offering these treatments, patients are more likely to be forced to source them outside the Medicare system.

- c. These new guidelines will disproportionately impact patients with illnesses like ME/CFS, for which there are few or no evidence-based treatments.**

Conventional medicine currently has little to offer ME/CFS patients as there are no evidence-based treatments. However, there are a range of treatments which are often prescribed by doctors with knowledge of ME/CFS, and from which patients report benefit. Many of these treatments would be covered by the proposed guidelines, as they are offlabel, compounded, unconventional (eg: prescribed without noted deficiencies), or complementary treatments. We are concerned that these guidelines could have the unintended consequence of making access to these much-needed and beneficial treatments either more difficult or inaccessible, if fewer doctors will prescribe them, or more expensive if the doctors who do prescribe them increase their fees.

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