



ME/CFS South Australia

Supporting South Australians with ME/CFS since 1987

medboardconsultation@ahpra.gov.au

Public consultation on clearer regulation of medical practitioners who provide complementary and unconventional medicine and emerging treatments.

1. Do you agree with the proposed term 'complementary and unconventional medicine and emerging treatments'? If not, what term should be used and how should it be defined?

The terms 'complementary medicine' and 'emerging treatments' are sufficient.

The term 'unconventional medicine' lacks specificity in that it is defined by what it is not, rather than what it is.

If conventional medicine is understood to be evidenced-based medicine then other approaches to practice are either emerging towards conventional practice or are complementary to conventional practice.

2. Do you agree with the proposed definition of complementary and unconventional medicine and emerging treatments – 'any assessment, diagnostic technique or procedure, diagnosis, practice,⁴ medicine, therapy or treatment that is not usually considered to be part of conventional medicine, whether used in addition to, or instead of, conventional medicine. This includes unconventional use of approved medical devices and therapies.' If not, how should it be defined?

The concept of 'not usually considered to be part of conventional medicine' is completely open to the interpretation of the reader. It does not state by whom it is considered to be that way or offer any standard against which the degree of conventionality can be measured.

It also disregards varied cultural understanding of what is usual, traditional or conventional.

It should be defined in consultation with those who have the expertise and who practice in these fields.

3. Do you agree with the nature and extent of the issues identified in relation to medical practitioners who provide 'complementary and unconventional medicine and emerging treatments'?

Regulated health professions

Where the MBA has identified regulated health professions as providing the complementary or alternative medicine, patients should have a reasonable expectation that their doctor will discuss these modalities and make a referral if appropriate, given that regulation exists.

Qualifications and expertise to assess the practice of complementary and emerging therapies

Where a medical practitioner holds qualifications or has recognised expertise in a field identified by the MBA as complementary or emerging, how does the MBA propose to oversee work where members of the oversight body do not hold that qualification or expertise? We propose that this is another reason why Option 2 is problematic, in trying to separate sound medical practice into 'conventional' and 'other'.

The term "generally accepted"

There is a problem with the use of the term "generally accepted". This does not indicate scientific evidence or lack thereof.

When the majority of patients who are affected accept something as accurately reflecting their experience, to whom does "generally accepted" apply? When two thirds of consumers report using complementary medicines, does that not indicate 'general acceptance' of complementary medicines?

General Practitioners providing treatment for complex conditions

The MBA has indicated a concern about general practitioners providing treatments for complex conditions.

For some complex conditions there is no identified specialty precisely because the condition is complex and thus does not fit into any conventional specialty. As one example, ME/CFS (Myalgic Encephalomyelitis) is a disabling, complex, chronic condition that affects up to 250,000 Australians. There is no identified specialty. Does this mean that a quarter of a million Australians should attempt to manage this serious and debilitating illness without medical care? Until all complex conditions are covered by a specialty, it is **harmful** to propose that general practitioners who have developed expertise should be discouraged from helping those patients.

Commercial innovation

The "blurred lines between research and commercial innovation" apply equally to conventional medicine, where evidence of commercial malpractice based on fudged or misleading research findings abounds. It is inappropriate to link this topic specifically to complementary and emerging therapies.

Treatments based on early research data

The issue of limiting access to treatments based on early research data is highly problematic for consumers whose condition does not attract adequate research funding. Often the only evidence is early or limited evidence and there is no foreseeable prospect of that changing. While research funding remains limited, many patients will have either **no treatment** at all or be confined to emerging treatments.

Tribunal decisions; Current regulation and guidance

The section on tribunal decisions is an indication that the current system is working. It is supportive of Option 1, as is the material on current regulation and guidance in Australia. Any systemic changes need to apply equally to **all** practice - conventional, complementary and emerging- in order to be effective in the protection of patients.

Confirming safety and efficacy

The lived experience of patients is a form of evidence which merits further investigation. Unless research funding is provided, safety and efficacy will remain unknown. Unknown does not mean unsafe or ineffective. Where there is insufficient evidence then this highlights the need for research funding.

For example, many of the issues in the public consultation paper have been illustrated by reference to Lyme-like illness. Until adequate research funding occurs, all people with Lyme and Lyme-like illnesses will be limited to receiving either emerging therapies, complementary medicine or no treatment at all.

It should be noted that evidence is limited because research funding has not been provided at an appropriate level.

4. Are there other concerns with the practice of 'complementary and unconventional medicine and emerging treatments' by medical practitioners that the Board has not identified?

Research funding

The biggest single issue which has not been addressed is the lack of research funding for tests and therapies which patients have reported as helpful, but in which the funding bodies have shown little interest. The evidence base is limited because it exists only in lived experience. For patients, this becomes a significant issue when their condition is one for which research funding has been minimal. Evidence would emerge if funding were made available.

Training gap

The report overlooks the importance of training in medical schools and professional development to include, as high priority, pathways to treat those conditions that have only early research data.

Early adoption of best practice

Best practice takes a considerable time to become standard practice. The report does not discuss at which point newly evidenced best practice shifts from an emerging therapy to conventional practice. Early adopters have no reassurance that their practice will be respected. For example, Dr Barry Marshall whose work with *Helicobacter pylori* bacteria led to a treatment for stomach ulcers.

This situation is exacerbated by the time required to update clinical guidelines.

Personalised medicine

The public consultation paper has not identified the clinical issues that arise when an individualised approach is needed for a complex presentation that precludes conventional approaches.

Government innovation policy and emerging therapies

There is an inherent conflict between state governments focusing on innovation while the MBA is seeking to limit clinician use of emerging therapies.

In SA there is a new Commission on Excellence and Innovation in Health being established by Health SA. The vision is “best value healthcare through excellence and innovation”.
<https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/about+us/governance+reforms/commission+on+excellence+and+innovation+in+health>

There are similar bodies in Victoria, New South Wales and Queensland, for excellence and **innovation**.

In the public consultation paper, "practice" has been very widely defined, to include education, research, policy development and more. How is any therapy, no matter how effective, to transition from emerging or complementary into supported and best practice, if medical practitioners are not allowed to explore them as researchers and academics; and how are policy makers to promote emerging best practice?

5. Are safeguards needed for patients who seek ‘complementary and unconventional medicine and emerging treatments’?

Reporting of harms to an independent agency must be extended beyond drugs and medical devices. This applies equally to conventional medicine practised by registered medical professionals. This recently published paper addresses this issue of collecting harms data where no system exists.

https://journals.sagepub.com/doi/abs/10.1177/1359105319854532?journalCode=hpqa&fbclid=IwAR0JWuNzeo45MGAZ0ugtgdUThJ2gqY6EDQ4efv0EtIPHdmI0PIZMMOP4C_U

Where safeguards are required, then this should be done on a case by case basis, independent of whether or not it falls into conventional medicine.

6. Is there other evidence and data available that could help inform the Board’s proposals?

The MBA needs to seek evidence from the lived experience of patients and to understand the expectations of patients about their intended behaviour if Option 2 occurs. How many consumers will no longer discuss their actual health care practices with their doctor if they believe that doing so will bring sanctions and disrepute to their doctor? How many patients will no longer seek conventional medical care at all if they believe that it will not be undertaken in the context of their full healthcare, which includes “unconventional” care? How many consumers will be driven to undertake experiments with their own healthcare without any medical supervision?

This is not available evidence. It is missing evidence which makes Option 2 a potentially dangerous social experiment. To choose Option 2 is to do exactly what the MBA is claiming occurs when complementary or emerging therapies are used: to act without a sufficient evidence base.

7. Is the current regulation (i.e. the Board's Good medical practice) of medical practitioners who provide complementary and unconventional medicine and emerging treatments (option one) adequate to address the issues identified and protect patients?

The current regulation is adequate except for the prevention of harm from conventional medicine. Any changes must apply to **all** medical practice.

8. Would guidelines for medical practitioners, issued by the Medical Board (option two) address the issues identified in this area of medicine?

Any guidelines are inappropriate and incomplete if they do not apply to **all** medical practice. Addressing efficacy and harm are not the exclusive province of complementary medicine and emerging therapies.

9. The Board seeks feedback on the draft guidelines (option two) – are there elements of the draft guidelines that should be amended? Is there additional guidance that should be included?

Any elements and additional guidance that are required should be equally required for **all** medical practice.

10. Are there other options for addressing the concerns that the Board has not identified?

Option 3.

If Option 1 is not adequate to address safety and efficacy for complementary and emerging therapies, then it is equally insufficient for conventional medicine. Making a single new set of guidelines for **all** practice that is sufficient to support and protect patients should be considered.

11. Which option do you think best addresses the issues identified in relation to medical practitioners who provide complementary and unconventional medicine and emerging treatments?

- Option one – 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.
- Option 2 - Strengthen current guidance for medical practitioners who provide complementary and unconventional medicine and emerging treatments through practice-specific guidelines that clearly articulate the Board's expectations of all medical practitioners and supplement the Board's Good medical practice: A code of conduct for doctors in Australia.
- Other – please specify.

We support **Option 1**.