



6 May 2022

The Hon Mark Butler MP
Shadow Minister for Health and Ageing
Via email: [REDACTED]

CC [REDACTED]

Dear Mr Butler

MAKING #100DAYS TO ACCESS FOR PATIENTS A REALITY – REQUEST FOR FURTHER REFINEMENTS OF PUBLIC COMMITMENTS TO DATE ON THE PBS

Better Access Australia (BAA) continues to welcome the Labor party's evolving commitments to restoring the equity of access to Medicare if elected on 21 May, and is seeking clarifying commitments to your public statements to date on:

1. Improving the affordability of the PBS
2. Ensuring the National Medicines Policy Review is conducted fairly and transparently
3. Recognising the importance of the Health Technology Assessment review and its importance to the medicines AND medical devices sectors

These requests are in addition to our unqualified support for your commitment to a national and expanded newborn screening program, which we are so excited to see come to fruition if you are elected. It will literally save tiny lives.

1. Improving the affordability of the PBS

Better Access Australia has publicly welcomed Labor's recognition of the increasing cost of living pressures and unaffordability of medicines, with its commitment to reduce the general PBS co-payment from \$42.50 to \$30 on 1 January 2023.

As you are aware BAA's election commitment requests the freezing of indexation until our economy is less volatile for working families, and support for a means-tested access to a \$20 co-payment to ensure those that can afford to pay, do, to make funds available for those that cannot.

Whilst this is important to us, our even greater concern is the inequality of access to the PBS co-payments and safety nets imposed on those accessing treatments for opioid dependence.

Neither the 2022-23 Budget's safety-net measure, nor Labor's commitment to reduced co-pays will help these 53,000 patients as the department continues to deprive them of the protections of the National Health Act. A removal of protections the Parliament considers a court would find unlawful.

Rather than redress this discrimination against those with a recognised disability under the Anti-Discrimination Act, the Minister commissioned a post-market review which is now in its 14th month.

Please, end the discrimination against a disease that is taking 3 lives everyday. These are some of the most stigmatised and judged people in our community. We have to make these policy commitments of cheaper co-pays and safety nets available to all patients, not just some.

BAA is asking for immediate inclusion of opioid dependence treatments in safety net calculations and PBS co-payment application

2. Ensuring a proper NMP Review

As you are aware BAA lobbied extensively over the past nine months to ensure patients were being given genuine access and consideration as part of the NMP review. The draft policy document raced out ahead of the election, contained no reflection of the community's expectation. Instead, it mostly reflected the department's priority of embedding process to limit access and that placed the government's budget ahead of patient need – always.

We welcomed Labor's support for the NMP review to be conducted transparently, and the Minister eventually halting the process following repeated concerns raised by the community.

The NMP must be recommenced with a fully independent Chair and committee based on the commitment to take into account the materials from the community, industry and clinicians so far to start a genuine consultative process.

The new Chair and committee must be able to work with a new Minister to rescope the terms of reference for the review and ensure it meets the longer-term strategic view Labor has always brought to Medicare and has brought to its policies in this election.

New membership should include a greater variety of consumers, including younger people, consistent with Labor's voice of youth commitment if elected.

We respect all appointments are a matter for an incoming Minister. That said, we would recommend [REDACTED]

[REDACTED]. A wealth of knowledge, with established links in the sector, but respected independence of thought.

3. HTA Review timing, membership and scope

BAA noted the department's announcement of the HTA review team membership after the election was called. We further note that Medicines Australia welcomed the appointments and their commitment to commencing this Review by 1 July 2022.

BAA does not believe a HTA review can be commenced until the NMP review has been delivered. Principles of cost of access, time to access (#100days from ARTG please!), the roles of public and private health and clinical trials must all be set in advance of any process review. The Why must dictate the How.

It is in this context we also formally express our concerns with the current Review Team membership. Reviews of this nature should be truly independent and have an alignment with objectives. We do not consider that almost any of the proposed appointments meet this objective.

Based on the program reviews undertaken by Department of Finance, or any best practice on program reviews, it is not appropriate for those delivering the program to be part of its review committee.

All these representatives work on the program on a daily basis and are remunerated by the department to deliver the PBAC and Life Saving Drugs Program (LSDP) processes as they currently stand. They have a wealth of knowledge to provide and are important stakeholders, but they cannot assure independence or innovative new thinking when they have been working within the system for decades.

We strongly support their provision of advice and input and materials, but not controlling the scope, content and recommendations of their own work.

Likewise, as per our previous public statements we do not support the appointment of Dr Boxall.

Whilst an extraordinary intellectual mind and economic thinker, he has always been transparent about his philosophies on public health programs. This was reaffirmed through his recommendations as part of the Coalition's 2013-14 Commission of Audit. He does not instil confidence that a public health lens will be applied to this review.

As you personally and Labor have identified, this review is not just about medicines it is about the broader health system and its increasing use of HTA.

Since HTA was introduced to the PBS in 1993, it has been gradually and at times haphazardly applied to many other areas of health access for patients: medical devices, MBS items, pathology, blood products, complex treatments in hospital.

What is decided in this review will impact the broader federally funded health system, and as such these areas of the community, of industry need to have full visibility and access to this review.

It is only that way we can ensure the medicines industry treads with a light foot mindful of where they are walking in the race to address their own priorities and problems.

As such, we would welcome consideration of the following HTA review appointments:

- [REDACTED] as chair of the review (incredibly experienced former secretary with economic background and strong development work in public policy)
- Two clinicians who are not part of the PBAC - for example [REDACTED] – experienced clinician in non-oncology sector and remote healthcare access worked on MBS reviews, [REDACTED] [REDACTED] (cancer specialists)
- Consumer representatives who are not long-term appointments in the system – [REDACTED] [REDACTED] (cancer patient), under 30s diabetes patient using both insulin and devices
- Device and hospital sector representatives
- Continued representation by Dawn Casey or other indigenous health representative
- Medicines industry representatives

We appreciate you are busy and inundated with requests and ideas in these final weeks of the election, but hope you will consider these requests and embed them as part of your implementation planning for these critical policies you have already committed to.

Medicare is an extraordinary legacy and commitment to the community, and its stewardship has never been more important.

Should you wish to discuss any of these matters, please do not hesitate to contact me directly on [REDACTED]

Yours sincerely,

Felicity McNeill ^{PSM}
Board Chair