

Response**2**

The Department may, at its discretion, publish part or all of the information provided in your submission on the Department's website or in related documents. If information from your submission is published, the Department may identify you and/or your organisation as the author of the submission. All personal contact details will be removed prior to publishing.

Yes, I consent to my identified submission being published

3**What is your name?**

Karen Trapani

7

Please select the type of individual(s) or organisation(s) you represent. Please select all that apply. - Selected Choice

Patient or consumer (or representative organisation)

8.1

What is the name of your organisation? - My organisation is called: - Text

PRIMCAT Consumer Panel (Independent Consumer Panel)

9

Are you making feedback on behalf of your organisation?

Your organisation

13

Please select which chapter/s you would like to provide feedback on. You may provide feedback on as many or few chapters as you wish.

1. Transparency, communication, and stakeholder involvement in HTA, 5. Futureproofing Australia's systems and processes

14

Please select the topics within the chapter(s) you would like to provide feedback on. 1. Transparency, communication and stakeholder involvement in HTA

1.1. Transparency and communication of HTA pathways, processes and decisions, 1.2. Consumer, clinician and other stakeholder engagement and consideration in HTA

18

Please select the topics within the chapter(s) you would like to provide feedback on. 5. Futureproofing our systems and processes

5.1. Proactively addressing areas of unmet clinical need and gaps in the PBS

21

Taking all Options within this section: 1.1. Transparency, communication and stakeholder involvement in HTA into account.

Overall, to what extent could the options (if implemented) address the issues that relate to them?

Address some but not most of the issue(s)

22

If you would like to expand on your answer above you can do so below:

The proposed options address only a subset of the identified issues, with a strong focus on the outward sharing of information. The document refers to stakeholders as a homogenous group however different stakeholders have different requirements. We represent consumers and assert that the proposed options in this section do not achieve the level of reform that is required. We need to consider authentic consumer engagement in the operation of the HTA process, not just the way in which HTA process information is shared.

There is a power imbalance in the operation of the HTA process with the consumer voice largely missing. Stakeholder involvement needs significant reform, this must go further than how information is shared and putting a consumer representative or two on committees.

Much broader and more transparent processes for incorporating the consumer voice and clarity about the role of the consumer voice in decision making is needed.

Specifically, the following issues do not appear to be addressed by the proposed options:

'cIt is not explicit in advisory committee guidelines and public summaries how evidence that does not form part of the clinical or economic evaluation is factored into decision-making.

'cThere is limited description of what influence patient and consumer information submitted as part of the consideration of health technologies has on decision-making or what information is most useful to advisory committees.

23.1

If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Publish plain language summaries

Positive

23.2

If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Improvements to the HTA webpage including development of a dashboard

Positive

27

Taking all Options within this section: 1.2. Consumer, clinician and other stakeholder engagement and consideration in HTA into account.

Overall, to what extent could the options (if implemented) address the issues that relate to them?

Address some but not most of the issue(s)

28

If you would like to expand on your answer above you can do so below:

The options proposed don't address "how submissions from consumers are used and what impact they have on the outcome of the application" or that "there is no feedback directly to patient organisations about their submission and that submissions from consumers were not published".

Whilst we welcome the proposed options, little information is provided about how they will be implemented and how consumers will have the opportunity to participate in this process.

We note that despite the "development of an engagement framework" being an option that is currently under review through this consultation process, the Department has initiated the "Co-design of Enhanced Consumer Engagement Process", with a working group in place and first meeting held 16 November 2023, prior to the publication of the HTA Review options report. Information published 5 Feb 2024 suggests that two further meetings and a public consultation are planned by this group.

There could be a significant mismatch between these two processes, and it could potentially demonstrate a lack of understanding or maybe even commitment to the consumer engagement process.

Consumers engaged in HTA Review consultation 1 do not appear to have received notice of the Expression of interest for consumer participation in this co-design exercise, raising questions about how all consumers have the same opportunities to authentically participate and provide feedback on process reform.

29.1

If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Develop an engagement framework

Don't know

29.2

If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Strengthen consumer evidence

Don't know

31

If you would like to expand on your answer above you can do so below -Develop an engagement framework

It is difficult to comment on whether the development of an engagement framework will be positive or negative without more information on how the engagement framework will be established and what its features will be.

32

If you would like to expand on your answer above you can do so below -Strengthen consumer evidence

It is difficult to comment on whether strengthening consumer evidence will be positive or negative without more information on how this will be established and how such evidence would be used in the HTA process.

131

Taking all Options within this section: 5.1. Proactively addressing areas of unmet clinical need and gaps in the PBS into account.

Overall, to what extent could the options (if implemented) address the issues that relate to them?

Mostly address the issue(s)

132

If you would like to expand on your answer above you can do so below:

We are very supportive of a more proactive approach to identifying unmet needs and potential therapies that may address them, as well as processes that provide a path for such therapies to be made available to Australian patients.

133.1

If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Development of a priority list

Very positive

133.2

If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Identifying therapies to meet priority list (horizon scanning)

Very positive

133.3

If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Early assessment and prioritisation of potentially promising therapies

Very positive

133.4

If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Proactive submission invitation and incentivisation

Very positive

133.5

If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Early PICO scoping

Very positive

135

If you would like to expand on your answer above you can do so below -Development of a priority list

It will be important to ensure that the process of developing the priorities is transparent and that consumer voice is present here. The process must not be subject to power imbalance where industry or well funded consumer groups dominate the priorities established.

167

In summary, considering all the draft reform options together:

How confident are you that the reform options (if implemented) will make health technology assessments better overall?

Somewhat confident

168

If you would like to expand on your answer above you can do so below:

Many of the proposed options will make HTA better overall, however the options do not go far enough to establish the type of reform that is required. The options are tinkering at the edges of the process. Our main concern is the authentic engagement of consumers in the process and there is a lack of clarity on how the consumer voice will actually influence HTA decision making.

Further, we have been very disappointed in the execution of Consultation 2 process. The Consultation was not run at the advertised time.

Despite participating in a review of the HTA Review terms of reference, participating in Consultation 1 and registering for updates on Consultation 2, we received no proactive notice of the Consultation 2. We had limited time to digest a 174 page report prior to the online consultation sessions. We applied for and attended the online consultation in good faith, despite no agenda for this consultation being provided until 6.22pm on the evening prior to the consultation.

This gives the impression that the consultation process is rushed and tokenistic and raises questions about the quality of consultation and the impact of feedback provided.

We would recommend that consultation should be carried out with different stakeholder groups independently to ensure that all voices are heard.

We would prefer that the HTA Review process be run with adequate time to propose significant reform and authentically engage stakeholders for their feedback.

211

Do you have further comments or concerns to add specific to this topic that should be considered? For example, here you can detail any unintended consequences or overlooked considerations if applicable.

The proposed options do not address the engagement of consumer stakeholders in the HTA process. Consumers require more input than they currently have. There is currently a power imbalance amongst stakeholders with industry having a very strong voice and consumers having very little input into the HTA process.

Further there is a power imbalance across consumer representation with different consumer groups having more influence (through access to budget and access to other stakeholders). This creates a competitive landscape where many consumer voices are not heard.

We are disappointed to see the options that are presented in the context of the reform that is needed.