

Response

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Yes, I consent to my identified submission being published

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What is your name?
Rozalina Sarkezians

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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
I'm on the advocacy working group of Australian Patient Advocacy Alliance

9
Are you making feedback on behalf of your organisation?
Yourself

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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, 3. Methods for HTA for Australian government subsidy (technical methods)

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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, 1.3. First Nations people involvement and consideration in HTA

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Please select the topics within the chapter(s) you would like to provide feedback on. 3. Methods for HTA for Australian government subsidy (technical methods)
3.2. Clinical Evaluation Methods

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:
30% of Australia's population was born overseas, and over 20% speak a language other than English at home. However, awareness regarding the lived experiences of culturally and linguistically diverse (CALD) patients remains low. AIHW statistics indicate that CALD consumers face a greater risk of poor health outcomes.

To achieve the objectives 1 and 2 set out in the HTA Review ToR, it is unclear the extent of feedback and input collected from CALD communities to understand their lived experiences and how this impacts the two objectives.

As a first-generation Australian, my journey as a refugee has shaped my commitment to health equity. My passion in amplifying the voices of CALD patients is fuelled by my role as the caregiver for my father diagnosed with metastatic prostate cancer. Reflecting on my two-decade career in the healthcare industry, I have witnessed a positive shift with the increasing inclusion of patient voices in healthcare meetings and policy discussions. However, a profound gap persists in representing the lived experiences of CALD consumers.

Engaging CALD consumers, their carers and families in design, research and evaluation activities will support more equitable and person-centred results. In the case of my 78 year old father, the importance of family and carer involvement in these activities would be essential.

The listed 1.1 options do not currently indicate how they will meet the needs of the CALD consumers especially relating to language barriers.

23.1
If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Publish plain language summaries
Neutral

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
Neutral

25
If you would like to expand on your answer above you can do so below -Publish plain language summaries
How they will meet the needs of the CALD consumers especially relating to language barriers?

26
If you would like to expand on your answer above you can do so below -Improvements to the HTA webpage including development of a dashboard
How they will meet the needs of the CALD consumers especially relating to language barriers?

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:
In the options listed in 1.2, it is unclear which CALD stakeholders will be engaged in the development of the engagement framework. Also it's unclear how patient advocacy organisations will be funded and resourced to engage and develop the necessary engagement tools relevant to the needs of CALD consumers, their carers and families.

In relation to the goal of strengthening consumer evidence collection and utilisation, how will this be accommodated for CALD communities? Who/which organisation(s) will represent CALD consumers in the HTA committee meetings?

The 'Conversations for Change report: improving consumer engagement in Health Technology Assessment' (July 2023) suggested the need to 'broaden engagement to facilitate further inclusion of 'culturally and linguistically diverse (CALD) communities'' and for patient organisations to build their confidence and capacity to 'broaden capacity to include diversity' of patient voices including CALD consumers.

Awareness needs to also be built for clinicians and medical societies to also share the voice of CALD patients. For example, my father sees his medical oncologist every 3 months making the clinician an integral part of amplifying the unique needs and challenges facing him and many other CALD patients.

Additionally, submissions from consumers, clinicians and patient advocacy groups should be shared in an online repository that is easily searchable and accessible by all stakeholders.

29.1
If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Develop an engagement framework
Neutral

29.2
If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Strengthen consumer evidence
Neutral

31
If you would like to expand on your answer above you can do so below -Develop an engagement framework
According to a recent analysis of CALD consumer engagement frameworks in Australia 'There is limited discussion of what culturally sensitive services look like and what resources are needed to enhance CALD consumer engagement in high level decision making. Meaningful engagement is considered to occur when both consumers and service providers have the necessary skills, knowledge and resources to support ongoing, reciprocal interaction. Recognising this meaningfulness, most engagement frameworks in this analysis proposed capacity building and training of consumers and organisational staff, dedicated time and physical and financial resources as essential elements to enhance opportunities for meaningful engagement.'

-Reference: Chauhan et al. How do health services engage culturally and linguistically diverse consumers? An analysis of consumer engagement frameworks in Australia. Health Expect. 2021 Oct;24(5):1747-1762

33
Taking all Options within this section: 1.3. First Nations people involvement and consideration in HTA into account.

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

34
If you would like to expand on your answer above you can do so below:
Similar provisions need to be implemented in representing CALD consumers remembering that 30% of Australia's population was born overseas, and over 20% speak a language other than English at home - a significant % of the population.

35.1
If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - First Nations peoples partnership in decision making
Very positive

35.2
If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Dedicated resource for HTA submissions and education
Very positive

84
Taking all Options within this section: 3.2. Clinical Evaluation Methods into account.

Overall, to what extent could the options (if implemented) address the issues that relate to them?
Don't know

86.5
If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Develop an explicit qualitative value framework
Positive

93
If you would like to expand on your answer above you can do so below -Develop an explicit qualitative value framework
The development of the framework requires input from CALD consumers.

The PSD needs to clearly communicate the consideration of the value elements and the weighting applied to them in making the final decision.

The PSD needs to meet the language barriers of CALD consumers, or at the very least engage family and carers especially for older consumer like my father where the information can be explained to him.

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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?

Don't know

170

Finally, do you have any further comments about the draft Options Paper or consultation you would like to make before submitting your feedback?

The communication regarding the HTA Review including the research papers and communiquees need to be distributed to stakeholders in a more timely manner.

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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.

Factors that will limit the impact of option 1.1 Transparency and communication of HTA pathways, processes and decisions for the CALD population include:

'cEnglish language proficiency and access to professional interpreters

'cLack of/limited knowledge of the healthcare system

'cHealth literacy, including cultural perspectives on illness, attitudes to preventive health care and familiarity with the health care system

'cIsolation and absence of social and family support networks

'cCultural stigma and shame around health issues including disability, sexually transmitted diseases (such as HIV), tuberculosis, mental illness,

'cPrevious unfavourable or negative experiences with a health system, overseas or after migration to Australia including racism and discrimination

'cPast and ongoing experience of psychological trauma e.g. in the case of refugees