

Response

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Yes, I consent to my identified submission being published

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What is your name?
Meredith Cummins

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
NeuroEndocrine Cancer Australia

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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,2. Health technology funding and assessment pathways,3. Methods for HTA for Australian government subsidy (technical methods),4. Health technology funding and purchasing approaches and managing uncertainty,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,1.3. First Nations people involvement and consideration in HTA,1.4. State and territory government collaboration in HTA

15
Please select the topics within the chapter(s) you would like to provide feedback on. 2. Health technology funding and assessment pathways
2.1. Streamlining and aligning HTA pathways and advisory committees,2.2. Proportionate appraisal pathways

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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)
3.1. Determination of the Population, Intervention, Comparator, Outcome,3.2. Clinical Evaluation Methods,3.3. Economic evaluation

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Please select the topics within the chapter(s) you would like to provide feedback on. 4. Health Technology funding and purchasing mechanisms and decisions
4.1. Approaches to funding or purchasing new health technologies,4.3. Understanding the performance of health technologies in practice

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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,5.2. Establishment of horizon scanning programs to address specific informational needs within HTA and the health system,5.3. Consideration of environmental impacts in the HTA,5.4. Mechanisms for continuous review and improvement,5.5. Capacity and capability of the HTA system,5.6. Strengthen international partnerships and work-sharing

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:
Option 1 has some workable points however it remains a convoluted process which is not ultimately timely.Option 2 again has some workable points but in point 2 what factors were identified in the determination of future submissions or not, to ensure complete transparency regarding the decision.
Option 3 price should not be a decider - we need to make sure that patients can receive the most appropriate treatments - what price is a life?
Option 4 is too limiting and negative.

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

25
If you would like to expand on your answer above you can do so below -Publish plain language summaries
Transparency and clear communication are essential to keep all stakeholders aware and notified.

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
The HTA webpage needs to be user friendly which is easy to navigate, provides consumer updates and is up to date, provides summaries of sponsors submissions, easy to provide input by general community / consumers.

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?
Mostly address the issue(s)

28
If you would like to expand on your answer above you can do so below:
Remunerated comprehensive consumer input into clinical trials development and objectives, plus consumer involvement from PICO scoping and involvement in comparator selection.

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

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

31
If you would like to expand on your answer above you can do so below -Develop an engagement framework
The engagement framework must involve patients and clinicians from the outset with established KPIs to measure success and consumer access to

32
If you would like to expand on your answer above you can do so below -Strengthen consumer evidence
Points 1. a-e Must be fully implemented
Ensure real world evidence applied as early as possible in the process
Require clear criteria including PROMS/PREMS and equity in health measures.

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?
Address some but not most of the issue(s)

34
If you would like to expand on your answer above you can do so below:
All parties must be culturally aware and work and work to ensure that we are meeting and collaborating the needs of First Nation People. Without this consideration the involvement in HTA of First Nations People will not occur or be accepted.

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

37
If you would like to expand on your answer above you can do so below -First Nations peoples partnership in decision making
This is not an option, it must occur.

38
If you would like to expand on your answer above you can do so below -Dedicated resource for HTA submissions and education
This is not an option, it must occur. There needs to be consultation with First Nations People to decipher what the dedicated resources are, and will the resources be operational.

39
Taking all Options within this section: 1.4. State and territory government collaboration 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)

40
If you would like to expand on your answer above you can do so below:
Unified systems of collaboration to reduce gaps and meet the needs of all nationally.
Data sharing across States and Federally needs to be transparent and easily accessible and understood by and for all stakeholders.

41.1
If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Development of central standardised data sharing system for utilisation and outcome data
Very positive

41.2
If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Increase opportunities for consultation and work sharing

Very positive

41.3
If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Health technologies that are jointly funded by the Commonwealth and state and territory governments (such as high cost, Highly Specialised Therapies (HSTs) delivered to public hospital inpatients)

Very positive

43
If you would like to expand on your answer above you can do so below -Development of central standardised data sharing system for utilisation and outcome data

Essential.

44
If you would like to expand on your answer above you can do so below -Increase opportunities for consultation and work sharing

Essential.

45
If you would like to expand on your answer above you can do so below -Health technologies that are jointly funded by the Commonwealth and state and territory governments (such as high cost, Highly Specialised Therapies (HSTs) delivered to public hospital inpatients)

Essential.

46
Taking all Options within this section: 2.1. Streamlining and aligning HTA pathways and advisory committees into account.

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

Mostly address the issue(s)

47
If you would like to expand on your answer above you can do so below:

A unified approach is essential

We request a simplified (single entry) HTA gateway which reflects a consistent HTA approach nationally.

48.1
If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Pathway for drugs for ultra-rare diseases (Life Saving Drugs Program (LSDP))

Very positive

48.2
If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Vaccine pathway

Very positive

48.3
If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Expanding role of PBAC

Very positive

48.4
If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Unified HTA pathway for all health technologies with Commonwealth funding

Very positive

50
Pathway for drugs for ultra-rare diseases (Life Saving Drugs Program (LSDP))

Point 2.1.1- what is the eligibility criteria when considering value for money, what price is a life?

It is essential that point 2.1.2 is enacted for reducing double handling and delays.