

Response

2
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Yes, I consent to my identified submission being published

3
What is your name?
Giacomo Romagnoli

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), Industry association / Peak body, Other [please specify]

7.22
Please select the type of individual(s) or organisation(s) you represent. Please select all that apply. - Other [please specify] - Text
Consumer Peak Body

8.1
What is the name of your organisation? - My organisation is called: - Text
Consumers Health Forum of Australia

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, 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

16
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

17
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

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, 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?
Mostly address the issue(s)
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
Plain language summaries will be pivotal in ensuring consumers can be involved in HTA processes. Currently, the high level of technical and health literacy required to engage with HTA is a significant barrier for consumer and community involvement.

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
Re-designing the HTA webpage in a more consumer-friendly way will also help guide consumers through complex HTA processes, and reduce current barriers to consumer and community involvement. The new HTA webpage needs to be easier to find, and more accessible. The review should also consider whether the term Health Technology Assessment (HTA) should be reconsidered and changed to a different name that carries more meaning for 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)
29.1
If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Develop an engagement framework
Positive
29.2
If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Strengthen consumer evidence
Positive

31
If you would like to expand on your answer above you can do so below -Develop an engagement framework
Consumers will benefit enormously from an engagement framework that enshrines their participation within HTA processes, and that allows them to provide input into HTA processes. Legislated involvement of consumers will ensure that consumer voices become an integral part of the HTA process. Consumers Health Forum (CHF) considers these options all satisfactory and expansive in their effort to engage with consumers, and should all be adopted in the final framework. Of course, this is an ambitious plan and CHF hopes that adequate resources will be employed for its realisation. Inadequate funding will result in a half-baked reform riddled with unintended, negative consequences.

It is CHF's view that the framework for consumer engagement must be legislated and become an obligatory step of the HTA process. This will ensure that consumer feedback is received and considered on a consistent basis. If not legislated as a requirement, the engagement framework will fail to implement, and all benefits to consumers and the HTA process will be foregone.

32
If you would like to expand on your answer above you can do so below -Strengthen consumer evidence
CHF supports the use of real-world evidence, both qualitative and quantitative, including Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs). We support the development in co-design with consumers of the enabling systems, pathways, evaluation and research that will optimise access to this type of data. Additionally, CHF supports all other options in the "strengthen consumer evidence" section, and in particular the promotion of consumer input into clinical trials, and the inclusion of consumers in HTA committee meetings. We note that such evidence should include not only clinical outcomes, but also lifestyle outcomes (for example, a new treatment with identical clinical effects but taken as a monthly injection instead of a daily pill).

Consumers are concerned about privacy and data guardianship. Adequate resources must be in place to guarantee the establishment of strong systems of data safety and guardianship. This will ensure consumers feel safe in releasing information, increasing the quality and quantity of available data.

Measures should be in place to prevent consumer evidence to be used for financial gain. Consumers are happy to release data for altruistic purposes, but its use for financial profit is completely unacceptable. Legislators must not shy away from the challenge of ensuring that there are cases in place preventing this from happening.

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)
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
CHF welcomes and supports better involvement of First Nations peoples in HTA processes. News of the widening of the health disparities in Australia between Indigenous and non-Indigenous populations are alarming, and reveal the great need for ambitious health reform - HTA included. CHF supports the creation of a specific sub-set of the priority list which will be dedicated to areas of high unmet clinical need specifically for First Nations Peoples.

38
If you would like to expand on your answer above you can do so below -Dedicated resource for HTA submissions and education
CHF welcomes and supports the utilisation of resources to assist organisations representing First Nations peoples build the skillsets required to make HTA submissions.

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)
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
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
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)

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

CHF understands the potential benefit to consumers of central standardises data sharing, but is also aware of some of the risks involved. Consumers are concerned about privacy and data guardianship. When consumer-generated evidence is to be used more consistently, adequate resources must be put in place to guarantee the establishment of strong systems that protect and maintain such data. This will lead to a virtuous cycle in which consumers are confident releasing data, leading to a richer, more fit-for-purpose database. Measures should also be put in place to prevent consumer-generated data to be used for financial gain. Consumers are adamant that while they are happy to release data for altruistic purposes, its use for financial profit is completely unacceptable. Legislators must not shy away from the challenges of ensuring that there are clauses in place preventing this from happening

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

CHF support an increase of opportunities to provide input for state and territory governments, across the whole health technology lifecycle.

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)

CHF supports the reform towards a nationally cohesive approach to HTA. CHF also supports the establishment of timeframes for the accelerated processing of high-cost, highly specialised therapies, provided that it does not pose unacceptable safety risks to consumers. CHF also supports the establishment of horizon scanning to facilitate timely planning and preparation for adoption by jurisdictions.

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?

Don't know

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

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

Positive

61
If you would like to expand on your answer above you can do so below -Expanding role of PBAC

Consumers are generally amenable to the idea of unifying the HTA pathway for all technologies. A unified process will allow for better access to health technologies, and reduce the preventable deaths created by current barriers and inconsistencies. Despite this, consumers are also worried about the way such a process will be executed. Proper unification will require a very sizeable amount of funding and HTA structure augmentation. The risk of a half-baked unification process will ultimately borne by consumers, who will experience the loss of expertise of de-funded local HTA bodies. If this option is implemented, specialist bodies must be appropriately resourced to enable them to provide advice that is pertinent and up to date.

62
If you would like to expand on your answer above you can do so below -Unified HTA pathway for all health technologies with Commonwealth funding

Consumers are generally amenable to the idea of unifying the HTA pathway for all technologies. A unified process will allow for better access to health technologies, and reduce the preventable deaths created by current barriers and inconsistencies. Despite this, consumers are also worried about the way such a process will be executed. Proper unification will require a very sizeable amount of funding and HTA structure augmentation. The risk of a half-baked unification process will ultimately borne by consumers, who will experience the loss of expertise of de-funded local HTA bodies. If this option is implemented, specialist bodies must be appropriately resourced to enable them to provide advice that is pertinent and up to date.

63
Taking all Options within this section: 2.2. Proportionate appraisal pathways 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)

65.1
If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Triaging submissions

Neutral

65.2
If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Streamlined pathway for cost-minimisation submissions (therapies not claiming a significant improvement in health outcomes or reduction in toxicity)

Positive

65.3
If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Early resolution mechanisms for submissions of major new therapeutic advances in areas of HUCN:

Alternative option 1: Introducing an optional resolution step before HTA committee consideration

Don't know

65.4
If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Early resolution mechanisms for submissions of major new therapeutic advances in areas of HUCN:

Alternative option 2: Introducing an optional resolution step before HTA committee consideration, with additional post committee resolution

Don't know