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?
Monica Ferrie
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
Genetic Support Network of Victoria
9
Are you making feedback on behalf or 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,1.4. 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)
3.2. Clinical Evaluation Methods
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
4.3. 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
5.2. Establishment of horizon scanning programs to address specific informational needs within HTA and the health system
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)
22
If you would like to expand on your answer above you can do so below:
Like the suggestions however it would be great if there could be a more proactive approach for consumers - such as push notifications to registered patient support groups or organisations like the GSNV who could then notify the relevant patient communities. Currently this is a time-consuming and not always comprehensive task to inform the community stakeholders. Responses could then be supported if required.
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
25
If you would like to expand on your answer above you can do so below -Publish plain language summaries
Plain language also needs to be easy english and include options for non-english speaking and neurodiversity
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:
Whilst the option implementation would make a significant positive difference, the role of the consumer and the support for consumers needs to be addressed.
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
This is very important and requires much greater analysis of how this would work and how it would impact. Critical that all stakeholders are part of the design.

32

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

This is critical and has to be recognised as such. The education and agreement of all stakeholders in how this evidence is weighted and how it is utilised must be transparent and reported on. Best practice models should also be developed to inform all those gathering consumer evidence

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:

The options do not fully address the implementation of decisions. This needs to be explicitly addressed to ensure that all jurisdictions are committed to HTA decisions that can be equitably implemented.

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

Neutral

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

There may be other types of baseline data which would be useful to have in a centralised data sharing system. This should be explored by all stakeholders collaboratively and available to all.

44

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

Again, this is terrific in principle but runs the risk of ensuring that the larger, better resourced voices are those that get heard and included. This must be an equitable process where there is support for being part of increasing consultation and work sharing opportunities.

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)

Implementation expectation including timeliness must be built into the HTA process. A decision that cannot be implemented is meaningless.

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:

It feels very PBAC focussed this section

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))

Positive

48.2

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

Positive

48.3

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

Neutral

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))

The unified national HTA pathway is preferred rather than piecemeal components however the options outlines under the LSDP will imporve current practice

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

This has to be the goal with very clear roles and responsibilities for all stakeholders. The logistics and details require much greater development but would eliminate confusion around pathways, remove decisions about what goes where and therefore save time.

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)

64

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

This section is unclear about the criteria that would be used for triaging which makes it difficult to comment. This would need to be totally transparent. It would also need to be monitored and reviewed to ensure that equity is being maintained.

65.1

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

Very positive

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

Don't know

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)

Don't know

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

65.5

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 3: Early Price negotiation

Don't know

65.6

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 4: Introducing an optional resolution step after HTA committee consideration but before advice is finalised

Don't know

65.7

If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Expanding resolution step to all relevant cost effectiveness submissions

Positive

65.8

If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Development of a disease specific common model (reference case) for disease areas with high active product development

Positive

65.9

If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Decouple the requirement for the TGA Delegate's overview to support PBAC advice

Don't know

74

If you would like to expand on your answer above you can do so below -Development of a disease specific common model (reference case) for disease areas with high active product development

This would seem to be a really productive use of resources and benefit sharing. It would be important to review for equity over time.

76

If you would like to expand on your answer above you can do so below -Case manager

There would be real value in formalising this role and making it transparent to all stakeholders.

86.1

If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Overarching principles for adopting methods in Australian HTA

Neutral

86.5

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

Very positive

89

If you would like to expand on your answer above you can do so below -Overarching principles for adopting methods in Australian HTA

Provides clarity for all stakeholders although should be jointly agreed formally.

93

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

This is really important to provide clarity and certainty about how value is understood and included as part of the HTA process. It is clear that currently different stakeholders have differing views on what this means which also translates into the evidence that is collected and provided. This would need to be a co-designed and developed framework.

94

Therapies that target biomarkers (e.g. tumour agnostic cancer therapies, therapies that target particular gene alterations)

This is a huge gap at the moment

121

Taking all Options within this section: 4.3. Understanding the performance of health technologies in practice into account.

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

Mostly address the issue(s)

122

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

I have stated mostly because although the options are good ones, they are not new and have been discussed before so of themselves they are clearly not totally the answer. There must be an appetite to implement and support all stakeholders. The exploration of why these important pieces have not already been in place must underpin the way forward.

123.1

If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Oversight " reforms to optimise access to and use of RWD in HTA

Very positive

123.2

If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Develop a strategic approach to increase confidence, awareness, and acceptance of cross-jurisdictional and cross-sectoral RWD access and use in HTA

Very positive

123.3

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

Very positive

123.4

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

Very positive

123.5

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

Very positive

123.6

If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Collection of utilisation and outcome data for provisionally listed health technologies

Very positive

140

Taking all Options within this section: 5.2. Establishment of horizon scanning programs to address specific informational needs within HTA and the health system into account.

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

Mostly address the issue(s)

141

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

Definitely need to include all stakeholders including patients/consumers and support organisations

142.1

If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Horizon scanning for advanced therapies (including high cost, HSTs funded through the NHRA) and other potentially disruptive technologies

Very positive

142.2

If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Horizon Scanning to meet priority areas (including addressing equity and HUCN)

Very positive

142.3

If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Horizon Scanning to help operational and capacity planning for HTA and health systems

Very positive

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:

It depends a bit on what is implemented. The options to improve the HTA process, including the engagement of consumers is great but without improved implementation pathways, we will again be waiting for services and therapies. Without support for consumers to be engaged, we will again be building into our system an inequity built on capacity.
The development of transparent measures for system improvement based on implemented outcomes I think is really important as is the transparent evaluation and reporting.

170

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

Thank you to the HTA reform team who have obviously been doing a power of work which is much appreciated and valued. I would also like to share my appreciation for the process, its been flexible and comprehensive. Now we cannot waste the investment, we must reform and implement!

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 format and content for plain language summaries and changes to the website must be co-designed with all stakeholders to optimise the changes.

212

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.

Whilst the option implementation would make a significant positive difference, the role of the consumer and the support for consumers needs to be addressed. All consumers/patient support groups would love to be gathering evidence, keeping data, measuring quality of life and impacts however the consumer landscape is not a level playing field. Well resourced organisations will be better equipped to influence, engage and involve themselves which already leads to inequity. There is a danger this gap widens if we do not undertake affirmative action for equal participation opportunity.

221

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.

We recognise that some of these options could potentially increase burden to stakeholders, support should therefore be built into the operations and practice for HTA.

222

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.

It is difficult to predict the impact on consumers or the patient groups based on the information we have. It does appear that many of these options would streamline and expediate the current processes.

232

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.

Important to again consider the role of consumers and how support could be provided to ensure equitable participation and engagement.
Many of these points reference the development of guidelines which is great but critical to include measures to evaluate that guidelines are being used, are of value to the process and outcomes and are reviewed as required.

236

Which of the proposed reform options do you think offers greatest scope to improve the HTA assessment process?

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

237

Why did you select that response above?

Option 2 seems to be the most efficient at coming to a resolution.

243

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.

All of these seem to be so self-evident and will require a sustainable and ongoing approach to be successfully implemented.

252

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.

Again, these seem so self-evident so ensuring an equitable and sustainable process that supports all stakeholders is critical.