

Response
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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?
Lily Grigsby-Duffy
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
8.1
What is the name of your organisation? - My organisation is called: - Text
Lung Foundation 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, 4.2. Approaches to incentivise development of products that address antimicrobial resistance (AMR), 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
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
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
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
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
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

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)

This should be considered a high priority to prevent people waiting for access to approved therapies.

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)

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

Don't know

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

61

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

more information is needed to fully comment on this.

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

Lung Foundation Australia supports this option and considers it a high priority.

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?

Mostly address the issue(s)

65.1

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)

Very positive

67

If you would like to expand on your answer above you can do so below -Triaging submissions

more detailed needed to understand the full implications of this.

77

Taking all Options within this section: 3.1. Determination of the Population, Intervention, Comparator, Outcome into account.

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

Mostly address the issue(s)

79.1

If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Increased early stakeholder input

Very positive

79.2

If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Increased transparency for stakeholders

Very positive

79.3

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

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?

Mostly address the issue(s)

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

Very positive

86.2

If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Methods for the assessment of nonrandomised and observational evidence

Very positive

86.3

If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Methods for the assessment of surrogate endpoints

Very positive

86.4

If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Generate a curated list of methodologies that are preferred by decision-makers, in collaboration with evaluation groups and sponsors.

Very positive

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

86.6

If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Therapies that target biomarkers (e.g. tumour agnostic cancer therapies, therapies that target particular gene alterations)

Very positive

86.7

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

Very positive

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)

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

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:

Lung Foundation Australia strongly supports horizon scanning. We note that consumer engagement/involvement in this process is not fully developed. We advocate for consumer engagement being incorporated into the horizon scanning process. For horizon scanning to work, and work effectively and efficiently, it must: be forward facing and future proof with a minimum of five years to decrease lag time to clinical application and approval as it presently is impacting too many Australians; be enhanced to ensure that Australians are provided with timely access to new drugs and novel medical technologies, including for rare diseases; and, include Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs) as the absence of these across the continuum limits the quality of care and value of health services being delivered.

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?

Very confident

168

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

We commend the Committee on the options outlined in the Options paper and are supportive of the goal of improving equitable and timely access for patients. In particular, we were pleased to see option 1 (Transparency, communication, and stakeholder involvement in HTA), horizon scanning, and therapies that target biomarkers, and support these being implemented. For all options, we would like to reiterate the need to engage with consumers and consumer organisations and to adequately resource and support this consumer engagement/co-design. We would also like to express the importance of including KPIs and timelines. We note that important KPIs and timeframes are missing from the options paper and recommend aligning KPIs to the National Medicines Policy.

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.

Lung Foundation Australia strongly supports the principle of unbiased plain language summaries and webpage improvements as a high priority. We believe this will go a long way to improving stakeholder engagement. We note that there needs to be a commitment to resourcing to achieve this. Consumers should be consulted on the development of the dashboard, HTA website improvements, and plain language summaries.

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.

We strongly support strengthening consumer evidence. We understand that the clinical evidence is not always reflective of the patient experience. We note that consumer evidence should be considered in the earliest stages of the HTA process, before the PBAC application. LFA places a strong focus on meaningful participation with consumers, carers, and clinicians through our committees, advocacy education, support, and research work. This is an important priority and requires adequate resourcing and support for consumers and consumer organisations to meaningfully strengthen consumer evidence. The consumer portal and engagement framework should be co-designed with consumers and consumer organisations.

213

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.

Establishing a First Nations Advisory Group should be considered a high priority. Adequate resourcing is needed.

214

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.

Lung Foundation support this option and consider it an important priority.

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 support timely and equitable access to medicines. LFA strongly emphasises that there should be no reason for an Australian to be denied access to life-saving treatments while the company and Government negotiates on price. As such we note that the negotiation period should be no greater than 6 months from TGA approval to being listed on the PBS, in line with the German and UK models which places a legislative requirement not exceeding 180 days from approval to prescribing. We note that important KPIs and timeframes are missing from the options paper and recommend aligning KPIs to the National Medicines Policy.

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.
We support timely and equitable access to medicines. LFA strongly emphasises that there should be no reason for an Australian to be denied access to life-saving treatments while the company and Government negotiates on price. As such we note that the negotiation period should be no greater than 6 months from TGA approval to being listed on the PBS, in line with the German and UK models which places a legislative requirement not exceeding 180 days from approval to prescribing. We note that important KPIs and timeframes are missing from the options paper and recommend aligning KPIs to the National Medicines Policy.

231

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.
Lung Foundation Australia strongly supports increased early stakeholder input, increased transparency for stakeholders, and updated guidance.

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.
We strongly support therapies that target biomarkers as a priority option.

236

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

Alternative option 3: Early Price negotiation