

# Enhanced Consumer Engagement Co-Design Survey

March 2024



THE UNIVERSITY OF  
MELBOURNE

## Survey Questions

---

**Q10** The consultation document proposes 'System-wide' recommendations that intend to embed consumer evidence and experience across the end-to-end health technology pathway as a whole. See Section 1 (table 1) for an overview of 'system-wide' recommendations or refer to Section 2 for a more detailed description.

We are interested in the System-wide recommendations that are most important to you.

To respond, please rank the recommendations listed below in order of importance.

- \_\_\_1\_\_\_ Consumer engagement framework
  - \_\_\_2\_\_\_ Single digital consumer portal
  - \_\_\_3\_\_\_ Plain language communications
  - \_\_\_7\_\_\_ Stakeholder resources and training
  - \_\_\_4\_\_\_ Consumer-informed horizon scanning
  - \_\_\_5\_\_\_ Consumer identification and development
  - \_\_\_8\_\_\_ Facilitated collaboration with industry
  - \_\_\_6\_\_\_ Centralised and expanded consumer support
- 

**Q11** Thinking now about your **top three** 'System-wide' recommendations, what difference do you think they will make for enhancing consumer engagement in health technology assessments?

Please describe your response below.

It is critical there is a well-developed and accepted framework to direct how consumers should and will be involved in the HTA process. Without this being well-defined the other aspects are somewhat moot. To engage consumers in this process, consumers must be able to understand the process and know how they can contribute. Thus a simple access portal and plain language information are key to enabling this engagement. Supporting consumers to access the system is also important but the higher priority is making sure the system is fit for purpose first. Overall, these changes will enable high-quality consumer input and increase the chance of the HTA-process addressing the needs of consumers.

---



---

**Q12** The consultation document proposes recommendations described as 'Pre-HTA enhancements', 'HTA Process Enhancements', and 'Post HTA Enhancements'. See Section 1 (table 1) for an overview of these recommendations or refer to Section 2 for a more detailed description.

We are interested in which of these recommendations are most important to you.

To respond, please rank the recommendations listed below in order of importance.

- \_\_\_9\_\_\_ Consumer evidence in Australian clinical research
- \_\_\_1\_\_\_ Consumer evidence in TGA applications
- \_\_\_7\_\_\_ Consumer notifications about TGA applications
- \_\_\_6\_\_\_ Consumer-initiated submissions to PBAC
- \_\_\_2\_\_\_ Consumer evidence in PBAC submissions
- \_\_\_8\_\_\_ Consumer notifications about PBAC submissions
- \_\_\_5\_\_\_ Criteria for consumer hearings and stakeholder meetings
- \_\_\_4\_\_\_ Consumer input feedback loop
- \_\_\_3\_\_\_ Consumer input on implementation considerations following PBAC recommendations
- \_\_\_10\_\_\_ Pre-listing status reports
- \_\_\_11\_\_\_ Consumer pathway to post-market reviews

---

**Q13** Thinking now about your ranking for the **top three** recommendations above, what difference do you think they will make for enhancing consumer engagement in health technology assessments?

Please describe your response below.

\_\_\_ Currently this is little scope for consumer input into TGA applications. It is critical that this be changed as safety and efficacy considerations must be made in context of each disease and potential impact on consumers. For rapidly progressing degenerative diseases such as MND, treatment benefits need to be considered in the context of the average 27-month survival. A 3- or 6-month gain in survival is considerably more significant than it might be in a less rapidly progressing condition. It is not clear if this is currently well-considered.

Although there is currently some opportunity for consumer input into PBAC applications, this should be greatly enhanced, to ensure disease-specific context of the impact on consumers of a new treatment is considered appropriately.

As end-users of a therapy, consumers should be consulted on how it will be used/administered. This should also incorporate regional/location/resourcing specific concerns. Treatments should not only be available in specialist centers in capital cities – consideration needs to be given to true national access. If there are formal requirements for consumer input into TGA/PBAC applications then by default, notification processes will need to be established. If implemented, these changes will significantly increase the engagement of consumers in the HTA process and embed consumer engagement across the application process thereby ensuring the consumer voice is prominent.

**Q14** How can we improve any of the proposed recommendations?

Please describe your response below.

The recommendations, whilst lacking detail at this time, seem reasonable and comprehensive. A number of them could easily be combined, or some if implemented fully would render some of the other recommendations unnecessary

---

**Q15** Are there any recommendations that you think we should add?

If so, please describe your proposed recommendation and its purpose.

No current suggestions

---

**Q16** Are there any recommendations that you do not support or require further explanation?

Please describe your response below.

Further explanation would be desirable about the mechanisms involved for “Consumer-initiated submissions to PBAC”. There is potentially a risk that divergent views could lead to consumers approaching multiple industry partners and creating confusion or unnecessary competition or use of resources.

---

**Q17** The consultation document describes implementation considerations for the proposed recommendations. See Section 1 (table 2) for an overview of these considerations or refer to Section 2 for a more detailed description.

We are interested in the implementation considerations that are most important to you.

To respond, please rank the implementation considerations listed below in order of importance.

\_\_\_6\_\_\_ Leverage existing and emerging strengths for consumer engagement

\_\_\_2\_\_\_ Commit to timely consumer-focused reform

\_\_\_5\_\_\_ Partnership work for positive flow-on-effects

\_\_\_4\_\_\_ Address health equity and access needs

\_\_\_1\_\_\_ Invest in systemic change

\_\_\_3\_\_\_ Strengthen the use of consumer evidence and experience

\_\_\_7\_\_\_ Facilitate beneficial communication between the medicines industry and consumers

---

**Q18** Please describe why you selected your **#1 most important** implementation consideration.

---

Significant investment is needed to realise true consumer engagement in the complex HTA process. Tweaking of current processes or “bolt-ons” will not be sufficient – consumer engagement must be built-in from the ground-up and integral to all stages of HTA. This can only be done by a systemic approach.

---

**Q19** Are there any implementation considerations that you would like to change or add?

Please describe your response below.

These processes may take a while to implement. Should there be urgent fixes that can be applied in the near-term for situations such as rare disease and high unmet clinical need (HUCN) which are poorly served currently and where consumer input is more critical?

---

**Q20** Do you have any further comments you would like to make about the consultation document?

Please describe your response below.

---

No additional comments