

Enhanced Consumer Engagement Co-Design Survey

March 2024



THE UNIVERSITY OF
MELBOURNE

Enhanced Consumer Engagement Co-design Survey

Important information – please read

About the Survey

This survey gathers feedback about a consultation document presenting the proposed recommendations of the Co-design Working Group (CWG) for the Enhanced Consumer Engagement Process in health technology assessment (HTA).

The proposed recommendations in the document are a work in progress and not yet finalised. The CWG are seeking input from consumers and other stakeholders to inform further development of the proposed recommendations. The final recommendations will be prepared and submitted in a report to the Minister for Health and Aged Care. The survey is open to any individual or organisational representative (aged 18 years and over) interested in providing feedback to support this co-design project.

The survey opens on 1 March 2024 and closes on 2 April 2024 at midnight (AEDT).

Please visit this [webpage](#) to access the consultation document and review the recommendations before responding to the survey.

What will the survey ask?

Questions 1 to 9 ask about:

- whether you are an individual consumer, carer, health professional or other representative from the medicines industry, government, or the research sector.
- the state or territory where you or your organisation are located and whether your location is considered urban, rural or remote.
- general information about your background including: gender identity, Aboriginal identity, whether you were born in Australia or overseas, the language you mainly speak at home, your level of education, and whether you identify as someone with a disability or long-term health condition.

These questions are required as they help us gain a sense of the background and perspectives of people participating in the survey. You may respond with 'prefer not to say' to any of these questions.

Questions 10 to 20 ask your opinion about the proposed recommendations and implementation considerations in the consultation document. These questions are not required and you may provide as much or as little information as you like.

Can I provide a written submission instead?

You have the option to upload a written submission at the end of the survey instead of, or in addition to, answering questions directly in the survey itself. You will still be required to answer questions 1 to 9 to provide information about your general background. After this, you may answer questions 10 to 20 or skip them using the forward button until you reach a prompt to upload a submission if you choose to do so.

Is the survey confidential?

The survey asks you to provide general information about your background as a survey respondent but does not ask you to provide your name or contact information. If you are providing feedback on behalf of an organisation and would like the organisation to be acknowledged as a contributor to the consultation, you have the option to provide this information in the survey, but you are not required to do so and may respond

anonymously. If you write any personally identifying information about yourself or other individuals in the survey, this information will be removed before analysis to protect privacy.

How long will the survey take?

Depending on the length of your answers it may take about 20 to 30 minutes to complete. If you elect to add a written submission with the survey, the response time may vary depending on the amount of information you choose to submit.

What will happen to information I provide in the survey?

The results of the survey will be processed by the University of Melbourne researchers contracted by the Department of Health and Aged Care to facilitate the co-design project. The survey results will be collated and reported back to the Department of Health and Aged Care and the CWG to support ongoing co-design work. High-level, de-identified findings from the survey will be summarised in project communiques available on the [project webpage](#).

Do I have to take part in the survey?

No. Participation is voluntary. If you start the survey, you can choose to stop at any time, without any reason by closing your Internet browser before completing the survey. After you complete the survey, you cannot withdraw as the information you provide will be processed with all other survey responses and will not be identifiable.

Can I receive a copy of my responses?

At the end of the survey a PDF of your responses will be available for you to download and keep for your records.

Can I start the survey and return to it later?

Yes. Your answers will be saved every time you click the forward button in the survey. If you do not click the forward button the answers you provided in that section will not be saved.

To return to the survey, re-open the survey link in the same browser (e.g., Google Chrome, Microsoft Edge) on the computer or mobile device where you started the survey. Your survey should open where you left it after clicking the forward button.

If you have any problems, contact mary.stathopoulos@unimelb.edu.au

Please note that when the survey closes on 2 April 2024 you will not be able to complete it. For this reason, we recommend completing the survey early to ensure that your responses are included in the analysis.

How are the survey results stored?

The raw survey data is password protected and only accessible to the University of Melbourne researchers working on the co-design project. The survey is stored in Qualtrics survey software securely managed by the University of Melbourne. Qualtrics provides a [security statement](#) that ensures all data storage adheres to industry standards.

All reasonable steps will be taken to ensure that the information provided is accurate and complete and that it is protected from misuse, loss, unauthorised access, or disclosure. The information will be retained only for

as long as required and only for the purpose it was collected and then destroyed in accordance with the [University's retention and disposal authority](#).

Please refer to the University's [General Privacy Statement](#) or [other privacy statements](#) for general information about how we process and protect personal information, including:

- our lawful basis for processing personal information
- collection, use and disclosure of personal information
- accuracy, security and storage of personal information
- retention and disposal of personal information
- your individual rights
- applicable privacy laws.

Who do I contact for more information?

Contact HTAconsumerengagement@health.gov.au for general enquiries about the project.

Contact Mary Stathopoulos at mary.stathopoulos@unimelb.edu.au for questions about the survey.

For further information about how the University manages personal information, and for details of how to make an enquiry, lodge a complaint, or to contact the University's Privacy and Data Protection Officer, please refer to our [Privacy webpage](#), view the [University's Privacy Policy](#) or contact privacy-officer@unimelb.edu.au

Survey Questions

Before proceeding with the survey, please acknowledge below that you have read the consultation document and are prepared to respond to the survey.

If you have not yet read the consultation document, please visit the [project webpage](#) before proceeding further.

YES I HAVE READ THE CONSULTATION DOCUMENT

Start of Block: Captcha Verification

Please verify that you are human by ticking the box below.

End of Block: Captcha Verification

Consent

By participating in this survey, I acknowledge that:

- I am over the age of 18 years.
- My consent to participate is entirely voluntary.
- I understand my rights as described in the privacy collection notice.

Do you consent to participating in this survey?

Please select one item.

- I CONSENT
- I DO NOT CONSENT (this response will close the survey)
-

Q1 Please indicate the group that *best represents* you or your organisation.

- Individual patient or carer
- Member of a health consumer or patient organisation
- Member of the public with an interest in medicines or medical services
- Clinical or health professional
- Pharmaceutical sector
- Government sector
- Consultancy
- Medical technology sector
- Academic/researcher
- Prefer not to say
- Other (please state below)
-

Q2 In which state or territory are you (if responding as an individual consumer or carer), or the organisation you represent located?

If your organisation has nation-wide coverage (i.e., most states/territories) please select that option.

- Nation-wide
 - New South Wales
 - Victoria
 - Queensland
 - Tasmania
 - South Australia
 - Western Australia
 - Australian Capital Territory
 - Northern Territory
 - External Territories
 - Prefer not to say
-

Q3 How would you generally describe your location?

- Urban
 - Rural
 - Remote
 - Not applicable (e.g., Nation-wide)
 - Prefer not to say
-

Q4 How do you describe your gender?

- Man or male
 - Woman or female
 - Non-binary
 - Prefer not to say
 - I use a different term (please state below)
-

Q5 Do you identify as an Aboriginal or Torres Strait Islander?

- No
 - Yes, Aboriginal
 - Yes, Torres Strait Islander
 - Yes, both Aboriginal and Torres Strait Islander
 - Prefer not to say
-

Q6 Were you born in Australia or overseas?

- Australia
 - Overseas
 - Prefer not to say
-

Q7 Which language do you mainly speak at home?

- English
 - Mandarin
 - Cantonese
 - Vietnamese
 - Italian
 - Greek
 - Arabic
 - Punjabi
 - Hindi
 - Spanish
 - Prefer not to say
 - Other (please state below)
-

Q8 What best describes your level of education?

- Primary education
 - Secondary education
 - Post-secondary Certificate or Diploma
 - Bachelor Degree
 - Postgraduate Degree
 - Graduate Certificate or Diploma
 - Prefer not to say
-

Q9 Do you identify as a person with a disability or other long-term health condition?

- Yes
 - No
 - Prefer not to say
-

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.

- _____ Consumer engagement framework
 - _____ Single digital consumer portal
 - _____ Plain language communications
 - _____ Stakeholder resources and training
 - _____ Consumer-informed horizon scanning
 - _____ Consumer identification and development
 - _____ Facilitated collaboration with industry
 - _____ 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.

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.

- _____ Consumer evidence in Australian clinical research
- _____ Consumer evidence in TGA applications
- _____ Consumer notifications about TGA applications
- _____ Consumer-initiated submissions to PBAC
- _____ Consumer evidence in PBAC submissions
- _____ Consumer notifications about PBAC submissions
- _____ Criteria for consumer hearings and stakeholder meetings
- _____ Consumer input feedback loop
- _____ Consumer input on implementation considerations following PBAC recommendations
- _____ Pre-listing status reports
- _____ 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.

Q14 How can we improve any of the proposed recommendations?

Please describe your response below.

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

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

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

Please describe your response below.

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.

_____ Leverage existing and emerging strengths for consumer engagement

_____ Commit to timely consumer-focused reform

_____ Partnership work for positive flow-on-effects

_____ Address health equity and access needs

_____ Invest in systemic change

_____ Strengthen the use of consumer evidence and experience

_____ Facilitate beneficial communication between the medicines industry and consumers

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

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

Please describe your response below.

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

Please describe your response below.

Optional Acknowledgement

If you or your organisation would like your contribution to the consultation acknowledged, you have the option of providing your name or organisation's name below. This is optional and not required.

Optional Submission Upload

If you want to upload a submission instead of, or in addition to, responding to the questions in this survey, you may do so here. This is optional and not required.

Submit survey

You are now about to submit the survey by clicking the forward button at the bottom of this page.

Click the back button now if you would like to edit your previous responses before completing the survey.

After submitting the survey, a PDF of your responses will be available to download on the next page.

The information you provided in this survey will be recorded and analysed together with all other survey responses.

The results will support further work by the Co-design Working Group for the Enhanced Consumer Engagement Process.

Please visit this [webpage](#) for future updates about this co-design project.

Thank you for your input.

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