THE UNIVERSITY OF
MELBOURNE

We thank you for your time spent taking this survey.
Your response has been recorded.

Below is a summary of your responses

Download PDF

**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 reviewthe 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

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.

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 access it on the project webpage before proceeding further.

● **YES I HAVE READ THE CONSULTATION DOCUMENT**

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

**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

○ 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.

1 Consumer engagement framework

2 Plain language communications

3 Stakeholder resources and training

Centralised and expanded consumer

4 support

5 Single digital consumer portal

6 Consumer identification and development

7 Consumer-informed horizon scanning

8 Facilitated collaboration with industry

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.

1. A framework which underpins the consumer involvement process in its entirety can ensure all committees and staff are aware of their responsibility to effectively involve consumers across the pathway. Given the impact of a framework, these processes need to be well thought out, supported and resourced, especially considering the number of proposed consumer touchpoints across the pathway. This framework should have practical and clear advice on how best to develop policy to support effective consumer involvement across the HTA pathway, with transparency of impacts on decision-making. 2.Providing plain language (PL) materials can be a challenge, however when done well is a great tool for informing consumers/the public and supporting relevant and informed input from consumers. We note PL summaries have been previously provided at the end of the HTA process. It will be a significant change to develop PL resources during the process, however this will support consumer understanding and allow for consumer contributions to better the decision-making process. To ensure the collection of broad perspectives and to capture the voices of people that the technology is most relevant to, the provision of PL summaries in various formats, such as infographics, videos, or community specific resources, may be required. This could require more resourcing, including a permanent team to support the consumer involvement process, and may take more time to develop than expected. PL communications are a worthwhile investment as they promote accessibility and inclusivity. 3.All stakeholders, including department staff and consumers, should be provided with training opportunities. However, all consumers, whether they have undertaken training opportunities or not, should be able to contribute to HTA processes. Involve Australia’s (https://lnkd.in/gt8_RUMX) research found that a pillar of good consumer involvement was training researchers and consumers. Training should receive ongoing support.

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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.

1 Consumer evidence in Australian clinical research
2 Consumer-initiated submissions to PBAC
3 Consumer evidence in PBAC submissions
4 Criteria for consumer hearings and stakeholder meetings
5 Consumer evidence in TGA applications
6 Consumer notifications about PBAC submissions
7 Consumer notifications about TGA applications
8 Consumer input feedback loop
9 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.

1. Consumers have requested that consumer involvement be mandated in all medical and health research. Including consumer voices in clinical research can ensure that research priority setting through to outcomes will be pertinent to the community they are trying to serve. This leads to more relevant research that can lead to improved health outcomes. Consumer involvement can also improve the quality of data collection and provide more complete evidence for an intervention. As consumers are the beneficiaries of this research, they have a right to be involved in the process as early as possible. Involve Australia found that consumers want to be involved at the beginning of research projects, to help set priorities and strategies (australiangenomics.org.au/projects/involve-australia-public-involvement-in-genomic-research/). This means that clinical research and clinical trials are informed upfront by consumer priorities. This leads to the next highest ranked recommendations, which are to accept consumer-initiated submissions to PBAC and to include more consumer evidence in PBAC submissions. 2. Establishing a pathway for consumer-initiated submissions to PBAC will provide consumers with a mechanism to not only engage in HTA processes, but to also shape submissions as equal partners and leaders. This will ensure that submissions are directly informed by lived experience to address unmet clinical needs and improve quality of life for patients. 3. Making the inclusion of consumer evidence a requirement in PBAC submissions will promote transparency in decision-making and help ensure that the voices and experiences of consumers are captured in submissions.

Characters remaining: 323

## Q14. How can we improve any of the proposed recommendations?

## Please describe your response below.

R2: As well as developing a single digital portal, Australian Government should identify groups affected by specific applications and notify them that they are coming through the pipeline and outline the timelines and different opportunities to contribute. For example, contacting relevant patient groups. These trusted networks could be leveraged to provide broad consumer input and could support consumers in providing input to HTA. R3: While the provision of plain language summaries is very useful, we note that writing in plain language does require skill. If applicants are providing their own lay summaries according to the given template, will these be reviewed and edited by someone with expertise in plain language prior to being made available online for the public? If the digital portal is not implemented consideration needs to be given to where these summaries will be held and how consumers will be made aware of their availability. R9: Involve Australia’s Community Involvement Guidelines for Genomic Research can be used as a tool for other researchers to engage consumers more effectively in the clinical research, pre-HTA phase. These guidelines also link to several other relevant, comprehensive resources that researchers will find useful. Many of the linked resources are not genomics-specific. R10 and R13: Criteria for consumer evidence assessment should be codesigned with consumers. Consumer evaluators are also recommended. Mechanisms for consumers to provide verbal evidence, particularly through hearings and stakeholder meetings, should be encouraged for those who prefer to provide verbal rather than written evidence. Consumers should be provided with the support they require to attend and contribute to these meetings. Minutes of these meetings should also be made publicly available. R18: Plain language summaries of submissions should also be linked to alongside status reports and thought should be given as to how consumers will be made aware of these.

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

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

We note that a digital portal is being made available for consumers - will a portal or repository be made available for department staff to provide resources on how best to involve consumers in the different stages of the process? Involve Australia's Guidelines for Community Involvement in Genomic Research which aims to provide researchers in Australia with practical information for involving community members effectively and meaningfully in research projects. Although these guidelines have a research focus, we believe that department staff may find them useful when involving consumers. Through the development of these guidelines and networking with other researchers, we found that researchers value a single repository for resources.

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

Please describe your response below.

We are supportive of all recommendations

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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.

1 Invest in systemic change

2 Address health equity and access needs

3 Commit to timely consumer-focused reform

Strengthen the use of consumer evidence and

4 Strengthen the use of consumer evidence and experience

5 Leverage existing and emerging strengths for consumer engagement

6 Partnership work for positive flow-on-effects

7 Facilitate beneficial communication between the medicines industry and consumers

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

Invest in systemic change: Consumer involvement in all health technology processes, including the early stages of health research, will have a significant impact on health priorities and outcomes for the general public. This involvement, however, will require significant resources and time to be carried out in a meaningful and inclusive manner. Relevant to the pre-HTA stage, Involve Australia's position is that consumer voices should be included at the beginning of research projects and we strongly advocate for consumer-led research. Through our work we identified that consumer involvement should not only fall to researchers - funders and institutes play a vital role in changing the landscape. Involve Australia are seeking to soon release recommendations for funders and institutes involved in medical research on how best to support consumer involvement which we hope will bring about change at the beginning of the research pathway (ie. consumer involvement in research). In relation to strengthening the use of consumer evidence and experience, it is important that HTA systems develop a transparent framework for including and weighting consumer evidence. This will assure consumers that taking the time to contribute and sharing their often-personal stories will have a worthwhile impact on HTA decisions.

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

## Please describe your response below.

R6: Identifying and maintaining engaged consumers can be challenging. Involve Australia's research shows that reaching out to the same consumers to assist repeatedly, can place a strain on their to ability to remain engaged in research projects. Having multiple people/groups can ensure consumer perspectives can still be sought even if one relied upon group/person is unable to be engaged. Employing multiple methods of involvement will also allow a broader range of community perspectives to be heard. Information that is being made available to the public should be provided in different formats such a written, infographic and video. This will allow broader input from communities as it is more accessible.

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## Q20. Do you have any further comments you would like to make about the

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

Please describe your response below.

Characters remaining: 2000

**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.

Australian Genomics

**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.

Drop files or click here to upload

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.

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.