

Response ID ANON-8S4X-7A6Q-P

Submitted to Framework for consumer engagement in HTA
Submitted on 2026-05-13 10:07:12

General information

1 What is your name?

Details:

Louise Healy

2 What is your email address?

General:

louise.healy@rarevoices.org.au

3 Which organisation do you represent (if applicable)?

Which organisation do you represent (if applicable)?:

Rare Voices Australia

4 Which of the following best describes you or your organisation?

Consumer organisation representative

If you selected 'health professional', 'industry' or 'other', please provide details.:

5 How did you find out about this survey? (Select all that apply)

Consumer webinar, HTA Engage newsletter, Patient or consumer organisation

Please provide details.:

Survey questions

6 How clear do you find the framework?

Very clear

If anything was unclear, please tell us what could be improved.:

The Framework is clear, well-structured, and easy to follow. It presents information in an accessible way that supports understanding across a broad range of stakeholders.

7 Do you think the framework includes the key elements needed to support consumer engagement in HTA in Australia?

No

If your answer is 'no' or 'not sure', please tell us what you think is missing.:

While the Framework includes many important elements to support consumer engagement, it does not address the fundamental purpose of that engagement. This was articulated in the Enhance HTA report as “to ensure consumer evidence and input will be integral in the delivery of a HTA system that aligns with our National Medicines Policy” (p.4)¹. As a result, the Framework is not fully aligned with the scope of the Enhance HTA Report, which was recognised by Minister Butler as a companion to the HTA Policy and Methods Review and was informed by consumer representatives and consultation with consumers.

To strengthen its effectiveness and alignment, the Framework should explicitly address:

- The purpose of consumer engagement as outlined in the Enhance HTA report
- How it is intended to be used by HTA stakeholders
- When it should be applied across the HTA process
- Who is accountable for ensuring its consistent implementation

Including a dedicated section outlining these elements would significantly enhance the Framework's clarity, usability, and impact.

8 Do you think the proposed actions are practical ways to strengthen consumer engagement in HTA?

Not sure

If your answer is 'no' or 'not sure', please tell us why.:

The Framework would benefit from a broader focus that moves beyond “consumer engagement” to explicitly recognise consumer evidence, knowledge, and lived experience as critical inputs into HTA decision-making.

Positioning consumers as contributors of evidence—rather than participants in engagement processes—would strengthen the intent and impact of the Framework and actions within the Framework.

9 Is there anything important about consumer engagement that you think the framework is missing?

Survey:

The Framework does not address several key recommendations from the Enhance HTA Report, including:

Recommendation 7: Further development of processes to enable consumer-identified items for HTA committee consideration

Recommendation 10: Ensuring consumer engagement is informed by consumer-focused horizon scanning processes

Addressing these gaps is essential to ensure the HTA system can adequately identify and prioritise technologies for populations with high unmet clinical need, particularly where there may be systemic barriers to access or limited commercial incentives. Consumer evidence is essential in these cases to ensure health technology systems can address systemic gaps for rare disease populations where there is a high degree of uncertainty and inequity.

Additionally, the Framework should provide clearer direction on:

- How and when it should be applied
- Who is responsible for ensuring accountability and implementation

10 Is there anything else you would like to share to improve the framework?

Survey:

The language used throughout the Framework would benefit from revision to more fully recognise consumers as experts with valuable knowledge and lived experience that strengthens HTA decision-making.

Specifically:

- Replace general references to “consumer engagement” with terms such as consumer knowledge, preferences, experiences, and evidence to emphasise purposeful and outcomes-driven involvement
- Avoid language or imagery that may unintentionally diminish the perceived rigour of consumer contributions

For example, the use of the word “heart” and associated symbols may suggest an emotive rather than evidence-based contribution, which risks undermining the framework’s intent. A more neutral tone would better respect the critical, evidence-informed and robust contribution of consumers within HTA processes.

Reference: Enhance HTA: An Enhanced Consumer Engagement Process in Australian Health Technology Assessment – A report of recommendations 2024.

(<https://www.health.gov.au/resources/publications/enhance-hta-an-enhanced-consumer-engagement-process-in-australian-health-technology-assessment-a-report>)

Privacy Policy

11 By providing your personal information to us, you consent to the department collecting your name, email address and your organisation, where relevant.

I consent to the department collecting my name, email address and organisation.