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Consumer voice and experience must be part of the Government's decision-making when funding innovative medical technologies

- 'Consumers' are people who have lived experience of a health issue. They might receive health care or advice, or otherwise use health care services. They include patients, their friends, families and carers. Consumers can also be people who represent the views and interests of a consumer organisation, a community or a wider constituency.¹
- The consumer voice is an integral part of the decision-making process as consumers have experience-based knowledge gained from living with a health condition and using innovative medical technologies.
- The Strategic Agreement between Medicines Australia and the Australian Government commits to the first Independent Health Technology Assessment (HTA) Review in 30 years, which is an important opportunity to introduce bold reform to address the Australian patient access gap.
- The Strategic Agreement also commits to co-designing a new *Enhanced Consumer Engagement Process* to elevate patient and consumer voice in access to medicines.

Possible policy solutions

1. **Formulate a robust and formal framework for consumer engagement in HTA for input from consumers.** Consumer participation is provided late in the decision process and participation rate remains low, despite existing platforms for consumer input (Figure 1). Greater consumer engagement before, during and after the HTA process will lead to improved decision-making.
2. **Provide additional resources to support consumer engagement in HTA.** These should explain in plain language the role of each committee and their processes, give clear

¹ Kelson M, Akl EA, Bastian H, Cluzeau F, Curtis JR, Guyatt G, Montori VM, Oliver S, Schünemann HJ, Integrating values and consumer involvement in guidelines with the patient at the center: article 8 in Integrating and coordinating efforts in COPD guideline development. An official ATS/ERS workshop report, Proc Am Thorac Soc. December 2012; 9(5):262-8. <https://pubmed.ncbi.nlm.nih.gov/23256169/>

guidelines on consumer involvement opportunities, and provide comprehensive links to tools and advocacy groups.

3. **Provide greater clarity on how consumer input informs decisions by HTA agencies.** This may help to demonstrate the value of consumer input and improve participation.
4. **Strengthen opportunities for direct consumer engagement by reviewing current restrictions around contact between sponsors and consumers.**

Elevating the consumer voice in access decisions

Consumer involvement helps to describe patient experiences and their perspectives on new medical technologies. For example, patients may place value on their experience and quality of life, which may benefit from improved pain control or more independence in activities of daily living. Early and continuous consumer involvement in HTA is required to empower consumers for meaningful input into decision-making.

The Australian HTA Policy Framework includes a principle to conduct “structured consultation with interested parties, including consumers,” implemented by the Pharmaceutical Benefits Advisory Committee (PBAC) and Medical Services Advisory Committee (MSAC). The Enhanced Consumer Engagement Process aims to capture consumer and patient perspectives earlier in HTA processes to allow enough time for consumer representatives to gather feedback and influence outcomes.

Figure 1: Existing platforms for capturing consumer input into PBAC decision making^{2,3}



Consumer Submission

- Any consumer may comment on medicines on an upcoming PBAC agenda
- Allows for 6-8 weeks for consumers’ input to be lodged
- PBAC consumer representative review and collates for the PBAC agenda



Consumer Hearing

- Consumers have opportunity for direct communications with the PBAC regarding medicines that seek PBS listing
- Participation is by invitation only, mainly between patient groups and PBAC representatives
- Take place only when deemed necessary by PBAC



Stakeholder Meetings

- Convened where a submission for a medicine that treats a serious, disabling or life-threatening condition, has not been recommended or deferred
- Patient group representatives and PBAC consumer representatives are invited to provide input

² Australian Government Department of Health, The Pharmaceutical Benefits Scheme – 6.7. Consumer input, Australian Government, 2022 <https://www.pbs.gov.au/pbs/industry/listing/procedure-guidance/6-consideration-submissions/6-7-consumer-input>

³ Australian Government Department of Health, The Pharmaceutical Benefits Scheme – 6.10 Stakeholder meetings, Australian Government, 2022 <https://www.pbs.gov.au/info/industry/listing/procedure-guidance/6-consideration-submissions/6-10-stakeholder-meetings>

NOTE: This Discussion Paper is not a final position paper. It has been developed as a conversation starter and to support discussion and feedback.

Recent initiatives such as the Consumer Evidence and Engagement Unit within the Department of Health⁴ and related pilot programs focus on supporting broader consumer participation strategies and better transparency and understanding of HTA decision making processes. While this is promising, further efforts are required. For example, new methodologies for including patient impact have been developed, such as measures of social return on investment, and there should be consultation to ensure new approaches are considered in improving consumer engagement.

International Example: The Scottish Medicines Consortium (SMC)^{5,6} has established a comprehensive patient engagement framework that includes:

SMC Patient Group Partner system. Currently 166 patient groups (both small local support groups and large national voluntary organisations) register with the SMC to contribute to treatment reviews. These groups are responsible for gathering contributions from individual patients and caregivers. Detailed guidelines for submissions are provided through official websites.

SMC Public Involvement Network (PIN). The PIN Advisory Group is made up of patient and caregiver groups, SMC public partners and other key SMC and Healthcare Improvement Scotland representatives. These stakeholders use their knowledge, experience and direct contact with patients, caregivers and the general public to ensure that their views are captured, and used to inform SMC processes. The PIN Advisory Group provides:

Forum/training to enable patient and caregiver groups to engage effectively with the SMC in developing and shaping public involvement in HTA
Advice to the SMC on strengthening relationships with patient groups and ensuring effective integration to inform SMC decision making processes for new medicines.

Feedback

Do you have any thoughts on the policy ideas in these papers? We'd love to hear your feedback! Please let us know at this email address: HTA-Reform@medicinesaustralia.com.au.

⁴ Australian Government Department of Health – HTA Consumer Evidence and Engagement Unit (HTA CCC secretariat), Australian Government, 2022 <https://www.health.gov.au/contacts/hta-consumer-evidence-and-engagement-unit-hta-ccc-secretariat>

⁵ Scottish Medicines Consortium, Patient group partners, Scotland UK, 2022 <https://www.scottishmedicines.org.uk/about-us/public-involvement/patient-group-partners/>

⁶ Scottish Medicines Consortium, Public Involvement Network Advisory Group, Scotland UK, 2022 <https://www.scottishmedicines.org.uk/about-us/public-involvement/public-involvement-network-advisory-group/>