Consumers Health Forum of Australia

Co-design of an Enhanced Consumer Engagement Process for health technology assessment

SUBMISSION: March 2024

Consumers Health Forum of Australia (2024)
Co-design of an Enhanced Consumer Engagement Process for health technology assessment. Canberra, Australia

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Consumers Health Forum of Australia is funded by the Australian Government as the peak healthcare consumer organisation under the Health Peak and Advisory Bodies Programme

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Introduction

Consumers Health Forum (CHF) is the national peak body representing the interests of Australian healthcare consumers and those interested in healthcare consumer affairs. CHF works to achieve safe, quality, and timely healthcare for all Australians, supported by accessible health information and systems. At the heart of CHF's policy agenda is consumer-centred care, which includes advocating for a consumer-centred Health Technology Assessment (HTA) process. CHF appreciates the opportunity to provide a submission to the "*Co-design of an Enhanced Consumer Engagement Process for health technology assessment"* consultation.

The overall health of Australians accessing the healthcare system relies heavily on the availability, safety and quality of health technologies approved by the TGA. Technologies are then subsidised by bodies such as the Pharmaceutical Benefits Scheme (PBS) and the Medicare Benefits Schedule (MBS) after recommendations by mechanisms such as the Pharmaceutical Benefits Advisory Committee (PBAC) and the Medical Services Advisory Committee (MSAC).

Consumers ultimately bear the cost of all health technologies through their taxes and out-of-pocket expenses. For this reason, consumers are major stakeholders in any HTA reform. While recognising that ambitious reform will always require broad-ranging consensus, the views of Australians as health consumers are the most significant group during this process.

On consultation paper language and survey methods

HTA language: The language of HTA is complex for many consumers, which restricts their ability to participate in HTA-related consultations. CHF would have liked to see the consultation paper use more plain language, as that would have made the consultation more accessible.

A more extensive Table of Key Terms could have helped, and any further documents should try to incorporate more such terms. For example, while having a very specific meaning in HTA processes, the term "Sponsor" is not included in the table of key terms. Later in the text, the term sponsor is used eight times, but a comprehensive definition of the term is not provided at any stage.

Survey methodology and question design:

CHF welcomes the use of surveys rather than just calling for written submissions. Surveys can be a helpful instrument in obtaining consumer views on policy matters.

However, the surveys must be crafted in a way that is accessible and acceptable to the intended audience.

CHF has found it challenging to work with ranking questions. Members of the CHF Safety and Quality Special Interest Group – a group of 42 consumers meeting monthly to discuss Safety and Quality matters – also expressed concerns with the survey instrument, as the question format would unavoidably require them to put some of the policies they consider very important at the bottom of a long list. The difficulty of ranking questions also compounds with the language barriers described above. CHF fears ranking questions might create many types of bias in the findings, such as anchoring bias and question-order bias. These biases could cause the options presented earlier in the survey - or the more straightforward ones – to be over-represented in the high rankings.

Ranking questions also present methodological challenges for organisations wanting to lodge a submission. The amount of data that organisations should collect to rank 11 different recommendations in order of importance and in a way that is truly representative of the wishes of consumers (in CHF's case on a national scale) is unachievable, especially in a short 4-week timeframe.

For these reasons, CHF has elected not to complete the survey questionnaire. CHF will instead provide policy recommendations with this document.

System-wide enhancements

Consumer Engagement Framework: Consumers will enormously benefit from an engagement framework that enshrines their participation within HTA processes. CHF calls for a legislated involvement of consumers, ensuring that consumer voices become an integral, obligatory component of HTA processes.

CHF strongly supports the options of embedding the role of consumers across key touchpoints across the whole health technology pathway. CHF also supports the proactive inclusion of First Nations communities and socially and culturally diverse/underrepresented groups. If implemented, these options will considerably improve consumer participation in HTA. CHF recommends these options all be adopted into the final framework.

If not legislated as a requirement, the engagement framework risks being implemented ineffectively, possibly jeopardising benefits to both consumer and HTA processes. CHF recognises this is an ambitious plan that will require a considerable augmentation of funds/resources.

CHF believes that there is benefit in understanding how the commercial and clinical processes and perspectives of the HTA process interact. As such, CHF sees roles for clinical and commercial input. In some cases – however - this approach will create a

real or perceived conflict of interest. For this reason, CHF calls for this legislation to actively seek balance in HTA consumer consultation processes. This can be done in a number of ways, such as by ensuring that among selected consumers there is a quota that has no previous experience in the pharmaceutical and medical field. Legislation should clearly define the length of each consumer's appointment, and roles should rotate regularly.

This will ensure a more diverse range of consumer views, reducing the risk of any selection bias developing within the legislated consultation body. If equipped with dedicated funding, an independent consumer peak body such as CHF is well placed to educate and train new consumers to provide valuable input into complex HTA processes.

Single digital consumer portal: Re-designing the HTA webpage in a more consumer-friendly way will help guide consumers through complex HTA processes and reduce the current barrier to consumer and community involvement.

The new HTA webpage needs to be easier to find and more accessible. Accessibility can take many different forms. While we have earlier called for plain language approaches, it should be noted that accessibility requires additional design considerations. The HTA webpage must cater to Australia's multicultural community by providing content in multiple languages and options for various accessibility needs - physical and cognitive.

Plain language communications: Plain language summaries will be pivotal in ensuring consumers can be involved in HTA processes. The high technical and health literacy level required to engage with HTA is a significant barrier to consumer and community involvement. Care must be taken to ensure the plain language summaries provide helpful, accurate, pertinent information. Adequate resourcing must be in place to guarantee their timely update. CHF recommends that plain language communications maintain a Flesch reading ease score between 80 and 60 and a Flesch Kincaid grade of up to 8.

Stakeholder resources and training: CHF supports establishing a central unit that offers training and resources to the government, industry, and consumers. This central repository of knowledge needs to be developed in collaboration with consumer peak bodies and patient groups to ensure that the content presented is up-to-date, accessible, and evaluated to ensure it is helpful to consumers. The expertise of health consumer peak bodies in developing and creating such content cannot be understated.

Consumer-informed horizon scanning: CHF would welcome establishing a horizon scanning body that embeds consumer input. The HTA Review options mention that horizon scanning should be "open to the use of patient and clinician partnerships". CHF argues that a more substantial commitment is necessary to ensure consumers are involved in horizon scanning design and implementation.

Consumer Identification and development: CHF supports the Department in identifying consumers with in-depth, specific expertise about a particular technology. However, CHF would like to caution against a process by which the Department single-handedly identifies and trains consumers to provide advice. CHF strongly advocates for a collaborative process by which consumers are nominated, vetted, and trained with oversight from health consumer peak bodies. Such an approach will likely increase trust in the independence of health consumer input into HTA processes.

If equipped with adequate funding, an independent, national consumer peak body such as CHF can educate and train new consumers to provide valuable input into complex HTA processes.

As mentioned earlier in this submission, the Department must actively seek balance in HTA consumer consultation processes. This can be done by ensuring that among selected consumers there is a quota that has no previous experience in the pharmaceutical and medical field. Legislation should clearly define the length of each consumer's appointment, and roles should rotate regularly.

This will ensure a more diverse range of consumer views, reducing the risk of any selection bias developing within the legislated body of consultation.

Centralised and expanded consumer support: CHF supports the expansion of support mechanisms available to consumers to facilitate their engagement with the health technology pathway and HTA processes. However, the consultation paper does not mention what such expansion would entail. As such, it is hard for CHF to provide additional comments on this topic.

Pre-HTA enhancements

Consumer evidence in Australian clinical research: CHF supports using real-world evidence, both qualitative and quantitative, including Patient Reported Outcome Measures (PROMs) and Patient Reported Experience measures (PREMs). We support the development in co-design with consumers of the enabling systems, pathways, evaluation, and research that will optimise access to this type of data.

Additionally, CHF supports all other options in the “strengthen consumer evidence” section, particularly promoting consumer input into clinical trials and including consumers in HTA committee meetings. We note that such evidence should include clinical outcomes and lifestyle ones. For example, a new treatment with similar clinical effects but as a monthly injection vs a current treatment of a daily oral pill may constitute a significant lifestyle/treatment adherence improvement for consumers.

However, consumers are concerned about privacy and data guardianship. If consumer-generated evidence is to be used on a more consistent basis, adequate resources must be in place to guarantee the establishment of solid systems of data

safety and guardianship. This will ensure consumers feel safe when releasing information, increasing the quality and quantity of available PREM and PROM data.

Measures should also be implemented to prevent consumer-generated data from being used for financial gain. Consumers are adamant that while they are happy to release data for altruistic purposes, its use for financial profit is largely unacceptable. Legislators must not shy away from the challenges of ensuring that there are clauses in place that prevent perverse or unwelcome outcomes through data sharing.

Consumer evidence in TGA applications: CHF supports the explicit and systematic use of consumer evidence during committee deliberations, as it is through consumer evidence that consumers can demonstrate broader benefits, cost efficiencies, and unintended financial impacts of technologies. This allows the HTA process to elevate itself from a "dollars and cents" view of health and provide recommendations that consider broader economic and social impacts. CHF supports the development of a checklist to assist decision-makers in integrating equity considerations. There also must be sufficient funding to update the checklist to ensure this list remains current.

Consumer notifications about TGA applications: CHF acknowledges the mention in the options of informing consumers with brief lay explanations. These explanations must not be too short and should provide a comprehensive overview of the different methodologies. There needs to be appropriate resourcing to ensure that the list is maintained and updated, and that the information is available in several priority languages.

HTA process enhancements

Consumer-initiated submissions to PBAC: CHF supports the creation of a formal pathway for consumers to initiate a submission to PBAC or other HTA committees. CHF understands that many potentially helpful and lifesaving technologies are currently not available due to a perceived lack of commercial incentives by sponsors. CHF supports the establishment of a formal pathway that will allow for increased collaboration between industry and consumers, facilitating collaboration and making it possible for consumers to initiate submissions to PBAC.

Consumer evidence in PBAC submissions: CHF strongly supports consumers being consulted for PICO scoping, which informs PBAC submissions. Consumer input must be enshrined as a standard in submissions. Consumers must also receive information on how their input was factored into the PBAC decision-making process.

Consumer notifications about PBAC submissions: CHF supports systematic, automated notifications of new submissions, parallel applications, and submissions made through alternate pathways. This would reduce consumers' time and effort to check agendas for relevant items.

Criteria for consumer hearings and stakeholder meetings: CHF supports the Consumer Working Group (CWG) recommendation for further developing clear and transparent guidance about the criteria used to call a consumer hearing or stakeholder meeting. CHF supports the recommendation that consumer hearings and stakeholder meetings are accessible and inclusive and allow consumers to provide their input via video, audio, and written formats.

Consumer input feedback loop: As previously mentioned, CHF supports the recommendation that consumers must receive information on how their input was factored into the PBAC decision-making process. This must happen in plain language so consumers can take any feedback on board for future reference.

Consumer input on implementation considerations following PBAC recommendations: CHF supports the establishment of an additional consumer consultation "checkpoint" following PBAC recommendations. At this phase, consumers can inform the Department of real-world implementation considerations for a particular technology.

This must be an additional step. This option may be insufficient if implemented in isolation and without prior opportunities for consumers to provide input before PBAC recommendation. Consumer voices must be heard before any significant PBAC recommendation to ensure they can inform the decision-making process.

Post-HTA enhancements

Pre-listing status reports: CHF will always support the enhancement of sufficient and timely information provided to consumers and supports the CWG recommendation that pre-listing status reports be published using plain language communications to describe the timeline for negotiations and reasons for any delay.

Consumer pathway to post-market reviews: CHF supports the CWG recommendation of establishing a path for consumers to initiate a post-market review about consumers' experiences and usage of health technology.