

## Postprint

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### **Moving beyond the rhetoric of consumer input in health technology assessment deliberations.**

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## **Moving beyond the rhetoric of patient input in health technology assessment deliberations**

### **Abstract**

At a health system level the importance of patient and public input into healthcare decision-making is well recognised. Patient and public involvement not only provides a mechanism to legitimise decisions but also contributes to improved translation of these decisions into practice, ultimately leading to better patient outcomes. Recent reviews in the health technology assessment space have identified the need for, and increased use of, patient input through systematic methodologies. Yet what does this mean in practical terms? This paper outlines both short and longer-term options for strengthening patient input into health technology assessment deliberations. This is particularly important given the planned reforms in this area and the commitment to public consultation as part of the reform process.

### **Introduction**

Health technology assessment (HTA) is the process by which information about the medical, economic, social and ethical issues related to the use of a health service or technology is analysed and summarised to assist policy makers in making decisions about the adoption or reimbursement of these technologies (1). In Australia, the Pharmaceutical Benefits Advisory Committee (PBAC) and the Medical Services Advisory Committee (MSAC) are the two main committees that provide such ministerial advice – with a remit centered on clinical and economic evidence. In the HTA process patients or consumers are recognised as stakeholders, with policy makers including this perspective by appointing consumer group representatives on decision-making committees. However as expectations have increased regarding access to new and expensive technologies, so too have the expectations of patients to be able to contribute to the decision-making process beyond this ‘consumer’ and medical and economic focus. In recent years there has been a move to broaden and increase patient input through opening agenda items to public submissions at different stages of the assessment process, elicitation of patient and carer stories, and, more recently the use of consumer

hearings as part of the PBAC process, where, for particular submissions, consumer groups or patients are given the opportunity to be heard directly by the PBAC about harms, benefits and costs.

### **Issues in the current approach**

While the PBAC hearings aim to give a voice to the rising number of people submitting responses to agenda items, the first tranche of these hearings highlighted systemic issues with the process (2). Namely there is a significant gulf between patients' and consumers' expectations of the HTA process, and what decision-makers want to know from these groups. There remains a tension between the remit of these Committees and patients' expectations of the process. It would also appear that patient input processes in Australia are poorly understood and, for at least some consumer groups, the capacity to engage in, and influence, the process is lacking (3). This may partially be explained by the focus of reform in Australian HTA; driven by deregulation and decreasing administrative burden rather than patient-centeredness. For this to occur, social and ethical issues need to be formally addressed within the HTA process. There also needs to be greater recognition of the value patients can add, and that supporting this, does not necessarily have to result in a more lengthy or complex process, or only rely on consumer representation.

### **Other approaches to patient input**

Representation aside, another approach to incorporating patient input is to consider data on the patient perspective as part of the review of evidence. This evidence may centre on qualitative information such as the experience of living with a health condition or more quantitative information on risk-benefit considerations and quantitative assessment of preferences. While there has been a substantial increase in primary research, including stated preference studies, and other approaches such as qualitative evidence synthesis, few HTA scientific reports have included a systematic assessment of this type of patient literature (4). Australia, often considered as a leader in HTA methodology has done little to advance the inclusion of such research, nor followed other HTA organisations leading on patient participation in improving information about, and transparency of, HTA-decision making to support patient input. One of the barriers seems to be resources (5), where funding for such reforms has been lacking despite the need .

### **Moving forward in the short term**

Substantial improvements however could be made with comparative ease and relatively low cost. This would involve strengthening existing systems to focus on issues of health literacy, capacity and transparency.

Such mechanisms include:

- A dedicated website for patients, carers and the general public outlining the Australian HTA processes. Such a website could contain:
  - Accessible information on the evidence to be reviewed , where opportunities exist for input, the purpose of this input and clarity as to what decision-makers want to know from patients
  - Agreed HTA patient and input templates and accompanying guidance,
- Capacity building for patients and consumer groups, including training - supported by a coordinator within the HTA system to guide and manage input
- Acknowledgement of input and feedback on the usefulness of this input in decision-making
- Inclusion of published literature on patients values and preferences as part of the evidence assessment

The above suggestions are drawn from patients, consumer groups, sponsor submissions (6) as well as other HTA organisations that systematically review and evaluate public engagement practices. While the suggestions may appear self-evident, they demonstrate that without genuine commitment to patient-centeredness in HTA, such ideas remain unattainable and continued advocacy is necessary in this area.

### **Longer-term considerations**

Longer-term considerations are more complex. The 2015 report on Efficiency in Health (5) highlighted the duplication and fragmentation of the Australian HTA system and flagged that many of the elements in the Australian HTA system needed structural and conceptual reform. For patient input, questions may include what a systematic approach for patient and consumer input would look like across the processes. What

issues should be considered? Would it include quantitative methods such as multi-criteria decision analysis to guide transparent decision-making or more deliberative approaches? Other issues may be how registries, such as the National Joint Replacement Registry could be used to provide real-world evidence on technologies or how patients can be better informed about evidence on treatment options. These debates can only occur when there is a strong foundation acknowledging the role and importance of the patient voice in shared decision making, of which input into health technology assessment processes is one important part.

## **Conclusion**

Considering the breadth of services considered by the technology assessment committees, as well as the scale of the Pharmaceutical Benefits Scheme and Medicare Services Schedule budgets, direction is needed as to how and when patients are considered in funding decisions, as well as the extent of that input. Clear guidelines are needed enunciating the approach for such input across the Australian HTA system.

Fundamental to this will be the provision of resources and support to ensure the patients and consumers are informed, educated and can participate meaningfully in these processes. Without a commitment to address some of these issues, the situation for patients and consumers will be unchanged, and a system that reflects the patient view will remain an aspiration rather than a potential reality.

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