1-1-2016

Involving patients in health technology funding decisions: Stakeholder perspectives on processes used in Australia

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Recommended Citation

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Abstract

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Disciplines

Education | Social and Behavioral Sciences

Involving patients in health technology funding decisions: stakeholder perspectives on processes used in Australia

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Abstract

Background Governments use a variety of processes to incorporate public perspectives into policymaking, but few studies have evaluated these processes from participants' point of view.

Objective The objective of this study was twofold: to understand the perspectives of selected stakeholders with regard to involvement processes used by Australian Advisory Committees to engage the public and patients; and to identify barriers and facilitators to participation.

Design Twelve semi-structured interviews were conducted with representatives of different stakeholder groups involved in health technology funding decisions in Australia. Data were collected and analysed using a theoretical framework created by Rowe and Frewer, but adapted to more fully acknowledge issues of power and influence.

Results Stakeholder groups disagreed as to what constitutes effective and inclusive patient involvement. Barriers reported by interviewees included poor communication, a lack of transparency, unworkable deadlines, and inadequate representativeness. Also described were problems associated with defining the task for patients and their advocates and with the timing of patient input in the decision-making process. Interviewees suggested that patient participation could be improved by increasing the number of patient organizations engaged in processes and including those organizations at different stages of decision making, especially earlier.

Conclusions The different evaluations made by stakeholder groups appear to be underpinned by contrasting conceptions of public involvement and its value, in line with Graham Martin's work which distinguishes between 'technocratic' and 'democratic' public

involvement. Understanding stakeholders' perspectives and the contrasting conceptions of public involvement could foster future agreement on which processes should be used to involve the public in decision making.

Introduction

Public-involvement processes satisfy a range of purposes: to ascertain public preferences about policy options; collect information from publics to inform decision making; and clarify the nature of particular policies.[1–3] The reason for engaging the public can impact on the type of public included, which engagement processes are used and the outcomes that follow.[2,4] Calls for public involvement in government decision making continue to be made,[5–11] and debate about which processes are most appropriate has yet to be resolved.[2,4,12–23] With regard to decision making about health technologies, although the socio-political nature of health technology is recognized,[23,24] patient organizations struggle to be meaningfully engaged in decisions that affect their members. A better understanding of current engagement processes, and insight into how these processes succeed or fail, would support development of effective public engagement in government decision making.

In Australia, for decision making related to public funding of new technologies, the federal Department of Health assembles Advisory Committees as a means of collecting information and interacting with stakeholders.[25] These Advisory Committees utilize health technology assessment (HTA) to evaluate information on new technologies and provide recommendations to the Minister for Health regarding whether or not these technologies should be publicly reimbursed. HTA, defined as the systematic evaluation of properties, effects and/or impacts of health-care technology, conducted by interdisciplinary groups using explicit analytical frameworks, may assess the direct, indirect, intended or unintended consequences of technologies.[26,27] The role of patients and the public in the evaluation of these health technologies has been widely investigated.[14–18]

Attempts have been made to create assessment tools to determine which processes are most appropriate for a given objective or context.[20,21] One widely used tool was devised by Rowe and Fewer. Based on a review of public-involvement processes, Rowe and Frewer's framework[20] provides two sets of criteria against which public-involvement processes can be evaluated (Table 1). These criteria include 'process standards', concerning the construction and implementation of the engagement with the public, and 'acceptance standards' that relate to the public acceptability of these processes. The framework is limited in its scope in that it does not engage with the socio-political context within which health technologies are placed. The objective of this study was twofold: to understand the perspectives of selected stakeholders with regard to processes used by Australian Advisory Committees to involve public, patients and patient organizations; and to identify barriers and facilitators to participation in these processes.

Methods and rationale

We selected two Advisory Committees that provide advice to the Australian government on whether new technologies ought to be supported with public funding. Committee names, interviewee names and medical conditions and interventions mentioned are omitted to preserve the anonymity of interviewees. The Committees use three main processes to involve patients: online consultations; 'consumer representation' on the committee; and 'consumer impact' assessments, the latter being documents via which patients, carers and patient family

Table 1 Rowe and Frewer[20] criteria

Acceptance criteria (related to the effective construction and implementation of a procedure)	Representativeness – the public participants should comprise a broadly representative sample of the population of the affected public
	Independence – the participation process should be conducted in an independent, unbiased way
	Early involvement – the public should be involved as early as possible in the process, or as soon as value judgments become salient
	Influence – the output of the procedure should have a genuine impact on policy
	Transparency – the process should be transparent so that the public can see what is going on and how decisions are being made
Process criteria (related to the potential public acceptance of a procedure)	Resource accessibility – public participants should have access to the appropriate resources to enable them to successfully fulfil their brief
	Task definition – the nature and scope of the participation task should be clearly defined
	Structured decision making – the participation exercise should use/provide appropriate mechanisms for structuring and displaying the decision-making process
	Cost-effectiveness – the procedure should in some sense be cost-effective

members can provide in-depth information about a health condition.

We used a qualitative and iterative approach[28] to apply Rowe and Frewer's[20] theoretical framework to the collection and analysis of interviewees' evaluations of the processes. In response to our concerns about the limited scope of the Rowe and Frewer criteria, we adapted the framework using the critical

perspective offered in works by Foucault.[29–36] The Rowe and Frewer framework permits evaluation of patient and public engagement largely from the perspective of sponsors and organizers of the process, whereas Foucault's critical perspective permits evaluation of involvement processes from the perspective of less powerful or marginalized parties (e.g. patients and their advocates). The work of Rowe and Frewer and Foucault informed the project design, sampling method, data collection and analysis. The interview schedule was developed by two researchers (EL and JS), piloted with an Advisory Committee consumer representative, and iteratively adapted in response to emerging themes during data collection. Ten telephone and two face-to-face interviews were conducted by one author (EL) ranging from 17 to 74 min in duration (averaging 51 min) with interviewees drawn from across Australia.

In analysing the findings, we found that terms such as 'involve', 'engage', 'participate' and 'consult' can have different meanings depending on context and stakeholder group.[2,14,37] In this study, we use the term 'involvement', in the sense of 'to participate, or share the experience or effect (in a situation, activity, etc.)'.[38] In the health-care sector, there is also controversy about terms describing health technology end-users: as service users, health consumers, or patients and their carers.[39,40] This controversy stems from an ideological debate about the concepts of representative and deliberative democracy.[41] The term 'consumer' suggests that health-care provision entails a contract between two equally powerful parties, a notion that we would challenge. We use the term 'patient', to emphasize the potential imbalance in the power relationship between the parties. However, when interviewees have used the term 'consumer' in interviews, the original expression has been maintained.

Theoretical frameworks and critical perspective

Rowe and Frewer's framework was adapted using Foucauldian concepts.[29,30,32,33,35] For example, Foucault reflected on how power relations and strategies used by hegemonic

groups can influence understandings of what is socially acceptable, and how such understandings affect the ways in which social groups and individuals act in society. These insights informed our examination of how interviewees see their roles and those of other stakeholders and how contextual issues influence participation and non-participation. Foucault's ideas also helped us to identify some of the sources of problems reported by interviewees. Understanding these sources is important, as they stand to inform one's choice of solutions. Foucault argued that sweeping political and economic changes would be needed to resolve the conflicts specific to a capitalist society, while also maintaining that conflict cannot be avoided and is inherent to any society insofar as issues of power permeate and, indeed, partly constitute all social relations. This research project does not advocate for such sweeping change in the interests of achieving more agreement among stakeholders connected with health technology funding. In this regard, the solutions this project proposes are more aligned with the ideological underpinnings of Rowe and Frewer, who adopt a more pragmatic stance.

The findings reported here relate only to Rowe and Frewer's framework, which was used to examine the structure of the involvement processes according to interviewees' perspectives. The findings interpreted using a Foucauldian lens are reported elsewhere.[65] (see Appendix S1 - Theoretical frameworks, recruitment, data collection, and coding for further details on research design and methodology.)

Interviewee recruitment

A maximum variation (heterogeneity) purposive sampling strategy[28] was used to select key informants. This strategy was employed to capture themes that 'cut across a great deal of variation'.[28] Variation in actors and perspectives was accessed by selecting organizations with different characteristics (size, location) and participants with different roles in the processes.

The adapted theoretical framework was used to generate criteria for purposive sampling: we recruited both people who were knowledgeable about the public-involvement processes being studied (Rowe and Frewer) and people who could be considered to have marginalized voices, that is particular patient organizations unable to participate in the involvement processes (Foucault).

The interviewees were members of Advisory Committees, specifically chairs and consumer representatives; representatives of patient organizations who had either participated in the Committee's involvement processes or might have been expected to participate but did not (see Table 2). Advisory Committee members were recruited via email and/or telephone. During interview, these participants were asked which interventions had received public comments, and this information was used to identify health areas from which to recruit patient organizations.

Seventeen individuals were contacted: five declined or were unable to be further contacted, and one organization opted to include two interviewees. Twelve interviews were conducted with 13 interviewees (five males and eight females; aged 20–70 years). Despite considerable efforts, it was not possible to recruit two small patient organizations that had participated in the involvement processes. Interviewees repeatedly mentioned 'umbrella patient organizations' as relevant stakeholders. Umbrella patient organizations are institutions that represent various patient groups, rather than a specific condition or disease; can act at the national or state level; and usually identify themselves as health consumer 'peak bodies'. Two organizations of this type, one small and one large, were added to the sampling framework. Acronyms used to describe the interviewees are shown in Table 2.

Data analysis

The interviews were transcribed verbatim and checked twice for accuracy by one author (EL). Two interviews were separately coded by two authors (EL and JS); codes were compared for affinity and minor changes made. The criteria from Rowe and Frewer's framework (see

Table 2 Purposive sampling criteria

Type of institution	Type of interviewee	Number	Initials in article	Additional criteria
Advisory Committee	Past or current chair	2	C1	
			C2	
Advisory Committee	Past or current consumer representative	2	CR1	
			CR2	
Umbrella patient organization	CEO/Manager	2	U1	Small umbrella organization
			U2	Large umbrella organization
Large participating patient organization	CEO/Manager/ Representative	2	P1	Taken part in one of the processes
			P2	Large organization
Large non-participating patient organization	CEO/Manager/ Representative	3	P3	Not taken part in one of the processes
			P4[1]	Large organization
			P5[1]	
Small non-participating patient organization	CEO/Manager/ Representative	2	P6	Not taken part in one of the processes
			P7	Small organization
Total interviewees		13		

Small organizations had <15 employees and large organizations over 15 employees).[64] This criterion is used by Fair Work Commission (it also considers an institution's financial resources). Membership size was also taken into consideration.
[1]P4 and P5 were from the same organization and interviewed together.

Table 1) served to provide 14 initial codes that were used in the data analysis, and the interviews were iteratively coded using NVivo 10, QSR International Pty Ltda, Doncaster, Victoria, Australia. Some codes were collapsed, particularly when interviewees identified them as interconnected rather than distinct issues. For instance, a lack of transparency (code: transparency) was linked by various interviewees to a lack of information (code: resource accessibility-information) or to a lack of communication from Advisory Committees (code: resource accessibility-communication). These codes have been presented in the study together under the subheading of 'The involvement process'. The subheadings 'Patients' contributions' and 'Representativeness' similarly group multiple codes: representativeness, influence on final outcome, structured decision making, and task definition (see Appendix S1 - Theoretical frameworks, recruitment, data collection, and coding for the complete list of codes and details on the coding process). In this way, the subheadings below do not correspond to the full set of codes but rather to overarching themes.

This study presents issues that can be construed as involvement barriers or facilitators depending on the type of participant. For instance, the role of consumer representatives on Advisory Committees and the use of umbrella patient organizations can be seen as facilitators by Advisory Committee chairs and umbrella patient organizations, but as barriers by patient organizations.

Findings

Decisions made at the Advisory Committee level are part of broader decision-making structures within the Australian Department of Health. Some patient organization representatives make no distinction between Advisory Committees, other areas of the Department and the Health Minister. By contrast, Advisory Committee members and the umbrella patient organizations mostly understand the different levels of decision making.

Patients' contributions

Opinions about the relevance of the information provided by patient organizations differed across Advisory Committee members. One Advisory Committee chair (C2) explained that the type of information that the Advisory Committee examines has to be grounded in

research evidence and cannot include informal or anecdotal information; that is, C2 considered that the input provided by patient representatives does not change the Committee's final funding advice. By contrast, another Advisory Committee chair (C1) believed that consumer representatives and patient organizations present data that contribute to the 'value construct' of a decision because it can reflect patients' preferences and societal values. Advisory Committee consumer representative CR1 concurred with C1 and added that consumer representatives can have great influence at the decision-making table.

Advisory Committee consumer representatives (CR1 and CR2) described being able to fully participate in Advisory Committee meetings in the same manner as the other members; however, they believed that the evidence presented by patient organizations should carry more weight, because of the value of the in-depth information about particular conditions that those organizations could provide. This view was shared by some patient organization representatives.

Advisory Committee members saw consumer representatives as both providers of in-depth information about a condition and providers of a citizen perspective, namely one with no specific or vested interest in the decision. Patient organization representatives who were not part of an umbrella patient organization saw consumer representatives as providers of information about particular conditions and as illegitimate if they were not active in patient organizations or grass-roots groups. The small number of consumer representatives on the Advisory Committee board was also seen as problematic by some patient organizations. One participant described how the consumer representative selection process might be considered a tokenistic way of involving patients in the decision-making process.

> We actually have the view that any committee or group that calls for a consumer representative and requiring that person to be an individual consumer is just making of tokenism [sic] and

that person has limitations generally in what they can offer up to the committee. (P4)

In this respect, consumer representation can be seen as a barrier to meaningful participation. One Advisory Committee consumer representative (CR1) and interviewees from patient organizations (P1 and P2) suggested that having only one or two consumer representatives on an advisory committee was a shortcoming. They were doubtful that such limited participation would make a difference, arguing that patient representatives' comments can be dismissed when not congruent with the views of other Advisory Committee members.

Some Advisory Committee members defended the current involvement processes, arguing that the influence of information provided by patient organizations is dependent on how other types of data are weighted in the decision. In particular, these interviewees indicated that if the financial and clinical data are not conclusive in favour of a particular decision, then the evidence provided by patient organizations may have more impact.

The involvement processes

Advisory Committee chair (C1) contended that the online consultation allows any person with Internet access to provide information for consideration at the decision-making meeting. Consumer representatives, however, expressed doubt in relation to the usefulness of the information received via the website. These interviewees highlighted that the online consultation forms can be difficult to understand and therefore act as barriers to participation.

> I think there's got to be a way to ask people those questions in a way that is meaningful to them. Because having read the comments over time, people sometimes find it hard to work out exactly what they're being asked in terms of the benefits… People can't fit their comments into the question (…). There's a character limit for each question and sometimes that really just makes it difficult for people to actually provide

the input that they want to provide (…). It stops the flow of information for some people. (CR1)

Some interviewees believed that online consultation processes serve to exclude some types of patients and organizations, as they require people to be computer savvy, to have access to the Internet, and to be able to fill out online forms.

Patient organization representatives criticized other aspects of the involvement processes, asserting that the processes are complex and improperly publicized, with difficult-to-understand language and no explanation as to whether or how the outcomes would be incorporated into decision making.

Both Advisory Committee consumer representatives (CR1 and CR2) argued for the introduction of education programmes to instruct patients and patient organizations about the processes employed by Advisory Committees, in particular the type of information useful to the Committees and the impact of confidentiality issues in limiting the background information that committees can share. C1, CR1 and CR2 explained that confidentiality agreements restrict how far in advance the meeting agenda can be publicized and prevent the dissemination of information provided by other stakeholders (e.g. drug and device manufacturers) and feedback on how evidence is weighted in the final decision. Advisory Committee chairs (C1 and C2) clarified that some of the decision-making parameters are not publicized to preserve flexibility for government in making funding decisions, as they weight some issues differently depending on the context. Consumer representatives felt that confidentiality agreements impeded their ability to interact with patient organizations and thereby fulfil their role adequately. A lack of transparency was also considered a problem by all patient organization representatives, who (except for umbrella organization representatives) were unfamiliar with the broader decision-making structure within which the Advisory Committees act. According to the interviewees, patient organizations are not informed whether the input they provide is used in the decision-making process.

Some interviewees deemed the current involvement processes unsuitable for collecting appropriate and extensive input from patients. In particular, they recommended that Advisory Committees contact a broader range of patient organizations; use focus groups or round table discussions; and develop a standing network of patients and patient organizations that could be pre-briefed about specific issues. Some Advisory Committee members agreed that more innovative processes to involve patients in decision making should be used, but they did not agree on which method would be the most appropriate.

Representativeness

Consumer representatives and umbrella organization representatives (CR1, CR2, U1 and U2) saw umbrella patient organizations as mediators between the Advisory Committees and other patient organizations. Their role included interpreting technical documents and presenting them in lay terms to other organizations, and collating responses and reporting back to the Advisory Committee. According to interviewees, umbrella patient organizations can select and train consumer representatives and thereby may facilitate the participation of a wider range of patient organizations. Nevertheless, some patient organization representatives saw the Advisory Committees' preference for umbrella patient organizations as an obstacle to the inclusion of a broader spectrum of stakeholders in consultation processes. In particular, involvement processes that demand specialist knowledge make the processes less accessible to small patient organizations. One patient organization representative elaborated on this:

At the moment, DoHA [the Australian Department of Health and Ageing] has an incredibly narrow group of stakeholders – that's our perception anyway – that it would see as being relevant in submitting comments on various issues (…). I think DoHA probably talks to the

[name removed to preserve anonymity] and, by doing that, they think: 'Right. We ticked the box'. We've spoken with consumers and I guess our view is that speaking to one organisation with a very general remit probably isn't reaching consumers on particular or specific subjects.(P4)

P1, P2, P4 and P5 all said that they were unable to present evidence related to a diversity of patients because of the narrow view of what was considered appropriate by the Advisory Committees. There was a perceived requirement for single consensus-view responses which did not incorporate the range of experiences and opinions across patient groups. Nonetheless, Advisory Committee members maintained that they required clear-cut answers to assist them in reaching a decision. To obtain such answers, Advisory Committees adopted the following strategies: interacting with one umbrella patient organization which collated a range of patient views; connecting with patient organizations ostensibly representing the views of patients at the national level; and selecting consumer representatives to attend decision-making meetings.

Discussion

The rise of the patient advocacy movement in recent years[42,43] has increased pressure on governments to include patients in decision-making processes, with a range of processes being implemented to meet the changing health landscape. The change in the nature of patients from passive recipients of services to active partners in their own disease management[42,43] has produced a class of patients capable and motivated to engage in funding decisions that impact on their own treatment. However, it is clear from our findings that there remains a gulf between the current processes and the processes that many patient organizations believe would allow patients to be true active partners in decision making regarding the affordability of their own treatment.

In analysing current processes of patient and public involvement in Australia, we found that Rowe and Frewer's framework[20] goes only so far in considering the relevance of contextual issues, their impact on involvement processes, and issues of patient partnership in decision making. Including a critical perspective indebted to Foucault[29,30,32,33,35] made it possible for us to identify different problems, including how these issues stemmed from the different views that interviewees had about the involvement processes and decision-making methods more broadly, for example what counts as evidence, how relationships between stakeholders outside the involvement processes can affect the outcomes, and why particular groups do not participate.

The interviewees in our research identified a range of barriers and facilitators with respect to patient and public involvement in health technology decision making, many of which have been described in evaluations of HTA processes in other jurisdictions.[17,44–47] In particular, a systematic review of patient perspectives in HTA identified the lack of transparency and information about processes described by our interviewees.[48] Similarly, difficulty in identifying who should represent patient and public perspectives in decision making has also been raised as an important issue in HTA and other health research areas.[49,50]

Patient representatives asserted that involvement processes are tokenistic and created by the government merely to satisfy the public demand for participation. For example, including participants within a framework where the parameters of the engagement are set by the hegemonic class may be as problematic as excluding patients and public.* Some interviewees were particularly concerned that including different types of participants in involvement processes may not be sufficient to adequately represent the target population.[51] They questioned the legitimacy of umbrella organizations and of some patient ('consumer') representatives in representing the wide range of patients and patient organizations with some interest in the process. The differences in what diverse patient organizations considered 'representative' can be explained by the nature of some organiza-

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*Thanks to anonymous reviewer.

tions,[43] whereby some organizations are able to develop criticisms from an 'insider' perspective, whereas others have an 'outsider' view of the involvement processes. Our research, like previous work,[42] demonstrates that the wide range of patient organizations in Australia, acting at local, state and national levels, do not form a homogenous group and they do not always work collaboratively; at times patient organizations can oppose one another on particular policy questions. In particular, it is clear that different grass-roots patient organizations can provide different information and may hold different views and priorities to those held by the more institutionalized and organized umbrella patient organizations. Developing different processes to make use of the evidence that different organizations can provide may help to solve some of the problems identified by interviewees.

Patient representatives indicated that the difficulties they encountered representing their stakeholder group related to lack of transparency of the process (due to confidentiality constraints), inadequate publicity about the involvement processes, lack of feedback about whether and how patient inputs were integrated into decision making, and inadequate access to relevant data that would enable them to take part meaningfully. Advisory Committee members and consumer representatives, on the other hand, indicated that they would have liked to provide more information and to interact more freely with patients and patient organizations but were bound by confidentiality agreements that they could not breach, particularly in protection of intellectual property. Bulfone *et al.*[52] support the call for greater transparency in cases where data are 'submitted to support a request for public subsidy' (p. S32) and argue that all 'evaluations of these data conducted by government agencies should also be made available' (p. S32). Bulfone *et al.*[52] reason that health professionals will be more likely to comply with restrictions placed on a technology if they understand the reasons behind the decision and the same could also be said about patient organizations, that is they

may be less likely to contest a decision if the underpinning reasons for a decision are made clear.

Our interviewees identified issues that concerned not only the structure of the involvement process but also its political context. Contandriopoulos[53] suggests that the political context also impacts on stakeholders' views as to who has legitimate claims and who can be delegated the role of representing those affected in decision-making processes. Views differed across the different participants in our research on what counts as evidence and whether information from patients is considered useful in decision making. This resonates with the work of Stronks *et al.*[54] and Hunter,[55] who demonstrated that patients, the general public and insurers, on the one side, and health professionals, on the other, can have differing opinions about how to prioritize health services due to their different values and political views. Similarly, understandings of 'evidence' held by disease-specific patient organizations were often quite different to those held by Advisory Committee members or even umbrella patient organizations.

Advisory Committee members' views on the need to involve patients in health policy decision making aligned with Gidden's[56] *third way* concept, whereby government, civil society organizations and the private sector work together to find solutions to public problems. Our Advisory Committee members tended to see the involvement processes as fostering collaboration between stakeholders, with the objective of providing better advice to government. By contrast, patient organization representatives believed that they had the *right* to be involved in policy development and decision making.[57–59]

Martin[60] explains the tension between what he calls 'democratic' and 'technocratic' rationales for public-involvement processes, and these two concepts are useful in understanding the different perspectives presented by interviewees. An involvement process based on a democratic motivation would try to include a wide range of people who would represent diverse groups within

the general population, while a technocratic process would seek out people who can provide in-depth information about particular issues. The Organisation for Economic Co-operation and Development handbook[11] designed to assist governments in implementing and evaluating involvement processes is an example of a technocratic (or instrumental) conception of public-involvement processes. By contrast, the World Health Organization has reinforced the need to include patients in policy decisions in at least two well-known publications, the Declaration of Alma Alta[61] and the Ottawa Charter for Health Promotion,[62] both of which demonstrate the more democratic goal of including in decision making those people who will be affected by the decision.

The use of consumer representation is one of the involvement processes used by Advisory Committees to include patients' perspectives. Consumer representatives, umbrella patient organization representatives and Advisory Committee chairs tended to see consumer representatives as useful because they can present views and issues not raised by other Committee members ('lay knowledge'). This conforms to a technocratic conception of involvement processes, where the information provided is valued because of its usefulness. On the other hand, some patient organization representatives believed that various factors impacted on the influence of a consumer representative on decision making. These factors included the selection process, how consumer representatives can exercise their role, and how Committee meetings are managed. Such concerns pertain to what Martin[60] called the democratic aspects of involvement processes.

Martin[60] argues that these different conceptions are not mutually exclusive when it comes to governments' organizing public-involvement processes, for there is both a need for in-depth information and a need to include a representative portion of the population holding diverse points of view. In examining the UK Government's approach to public and patient involvement as an example, Martin[60] observes that the policy needs of governments blur the boundaries between gaining input from people who are rep-

resentative of diverse segments of the population (democratic) and gathering information from 'lay experts' (technocratic). Precisely the same blurring was evident in our findings about Australian Government approaches. Patient organization representatives were more concerned to take part in involvement processes that are 'democratic', namely those that include a wider array of stakeholders, and this underpinned one of their main criticisms of current involvement processes – that they consult too narrow a band of stakeholders. By contrast, Advisory Committee chairs demonstrated a greater concern for the 'technocratic' aspects of involvement processes, for example in seeing that the information they receive does not always fit with evidence-based methodologies. Finally, consumer representatives and umbrella organization representatives tended to identify problems that can be linked to *both* democratic and technocratic elements of the involvement processes.

Strategies have been put forward to facilitate patient involvement, such as collecting patient and public experiences and views through alternative means such as weblogs and discussion forums;[63] mentoring, training and induction processes.[46] The use of outcomes-focussed processes[46] and inviting particular stakeholders to take part[46] also resonate with our interviewees' suggestions for change. Barnes *et al.*[51] argue that structural elements of involvement processes could influence participation and non-participation due to the different assumptions that participants and organizers of involvement processes have on who should take part. Similarly, patient organization representatives indicated that the processes used by the Advisory Committees act to exclude some patients and organizations because of the complex language used in documents and difficulties engaging in the online consultation. These issues could be addressed in a restructured process.

Conclusions

The debate about which processes are the most appropriate to incorporate patients' perspec-

tives into health-care policy decisions is on-going. According to our interviewees, Australia's current involvement processes for health technology funding decisions have both drawbacks and virtues. By considering Martin's[60] distinction between technocratic and democratic involvement processes, and by analysing interview data using Rowe and Frewer's framework[20] and Foucault's insights,[29,30,32,33,35] we were able to observe how different types of interviewees understood the involvement processes differently. Advisory Committee chairs demonstrated a technocratic conception of involvement, whereby involvement functions as a source of information that is instrumental to a good funding decision. For Advisory Committee chairs, procedural aspects have to be improved but there are no fundamental problems with the current involvement processes. Advisory Committee consumer representatives concurred with this view but also believed that there could be more ways to include patients' views in decision making, for example by expanding the role of consumer representatives and by having government interact with more patient organizations. In contrast, most patient organization representatives agreed that the current involvement processes are not sufficient to characterize what they consider to be meaningful participation. This is partly because they demonstrated a more democratic conception of involvement. However, patient organization representatives were a heterogeneous group and presented positions that varied more than the other types of stakeholders.

Contrasting conceptions of the basic value and aim of involvement processes seem to underpin different stakeholder views on what acts to impede or facilitate public and patient involvement in health policy decision making. Understanding this can assist in the development of a process that is acceptable to all. Revising existing processes in Australia may go some way towards addressing the problems identified here. However, as many of our interviewees have indicated, such an approach, in an era of active and involved patients, remains a comparatively superficial, mere 'band aid' fix. Government may find it useful to address aspects of both democratic and technocratic theory by improving the existing approaches and engaging more closely with grass-roots patient organizations to build a more flexible and inclusive platform for patient and public engagement.

Strengths and limitations

Despite considerable efforts, we were unable to recruit two small patient organizations that had participated in the involvement processes being studied. It was also not possible to recruit organizations from every state in Australia. However, the project was able to capture a diversity of views from organizations working in remote, rural and urban areas, and from organizations ranging from the very small (with meagre budgets) through to the large (with numerous funding sources).

Acknowledgements

Sources of funding/independence of researchers/conflict of interest

Ethics approval

Ethical approval for this research project was obtained from the Human Research Ethics Committee at the University of Adelaide (Project no. H-2012-167).

Supporting Information

Additional Supporting Information may be found in the online version of this article:

Appendix S1. Theoretical frameworks, recruitment, data collection, and coding.

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