

# Setting priorities for high-cost medications in public hospitals in Australia: should the public be involved?

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## Abstract

**Aim.** To explore healthcare decision makers' perceptions about public involvement in setting priorities for high-cost medications (HCMs) in public hospitals in Australia.

**Methods.** In-depth, semi-structured interviews were conducted with 24 decision-makers (executive directors of hospitals, area health service managers, directors of hospital pharmacy departments and senior medical doctors) in a Sydney Area Health Service. Interviews were digitally recorded, transcribed verbatim, thematically content analysed and coded.

**Results.** The majority of participants perceived that the 'rationing debate' needs to happen in Australia. The community at large should be encouraged to understand that healthcare resources are limited and choices need to be made. The perspectives of the public, according to participants, were considered diverse (tax payers, patients, consumers). Owing to the complexities of the healthcare system, their involvement of the public in decision-making regarding access to HCMs in public hospitals was considered limited. For participants, the role of the public was likely to be at the macro level, deciding how much they were prepared to spend on healthcare.

**Conclusion.** The role of the public in setting priorities for HCMs in public hospitals was perceived by these healthcare decision makers as limited. However since rationing is unavoidable, there should be an explicit debate about the principles and issues concerned.

**What is known about the topic?** Recognition of the importance of engaging the public in healthcare decision making is increasing. However, there is only limited understanding of the role of citizens in current priority setting mechanisms for allocating scarce resources to high-cost technologies such as medications at the public hospital level.

**What does this paper add?** This study describes how involving the public in setting priorities for HCMs can present specific challenges from the perspective of decision makers working in the public hospital system.

**What are the implications for practitioners?** In a time when public awareness is increasing about medical advances the challenge is to find ways of informing and involving the public in the debate about the distribution of healthcare resources. The results from this study will be useful for policy makers working on ways to improve the legitimacy of decisions at the institutional level.

**Additional keywords:** decision-making, priority setting.

## Introduction

Pharmaceutical expenditure in many countries has increased as a result of the introduction of new high-cost medications (HCMs).<sup>1</sup>

Given the ageing population, the rising expectations in healthcare and the fast development of these high-cost technologies, priority setting seems inevitable.<sup>2</sup> HCMs can be defined in several ways.

In New South Wales (NSW), HCMs for outpatient use, not funded by the Commonwealth Government, are defined as: 'those not listed for subsidy on the PBS Section 85 or 100<sup>A</sup> of the National Health Act, and which incur an acquisition cost equivalent to, or more than AU\$500 per week per medication per patient'.<sup>3</sup>

In Australia, access to medicines at the national level is facilitated via the Pharmaceutical Benefits Scheme (PBS). The Pharmaceutical Benefits Advisory Committee (PBAC) makes recommendations about which medications will be subsidised through the PBS, on the basis of assessment of comparative efficacy, safety and cost-effectiveness.<sup>4,5</sup> The PBAC is an independent statutory committee that provides recommendations to the Minister for Health and Ageing. This means that the Minister for Health and Ageing can decline to implement a positive recommendation (e.g. on budgetary grounds), but cannot decide to list a pharmaceutical product in the absence of a positive recommendation from PBAC.<sup>5</sup> However, under the Australian health system arrangements, public hospitals are not bound by the decisions of the PBAC and fund medicines out of their own drug budget. Furthermore medicines prescribed to public hospital inpatients are funded from within public hospital budgets and are not limited to those listed on the PBS.<sup>6</sup> Pharmaceuticals are assessed at the public hospital level by Drug and Therapeutics Committees (DTCs). DTCs make their own funding decisions within the hospital's limited budget.<sup>7</sup>

Although there is no defined budget constraint for the PBS, there are budget constraints in public hospitals. However, it is at the public hospital level where decisions are enacted – for inpatient medication use.<sup>8,9</sup> As described by Kaye *et al.* sometimes patients needing expensive medications (e.g. rejected by PBAC) are referred to public hospitals.<sup>10</sup> Decisions regarding drug funding for HCMs will inevitably involve values and judgements.

Patients and citizens can make an important contribution to priority setting for new health technologies such as pharmaceuticals.<sup>11</sup> However, despite the increased interest in involving the public in priority setting for medications,<sup>12,13</sup> the role of the general public in priority setting for medications at the institutional (public hospital) level in Australia appears to be limited. A study by Johnson explored the community's and consumer participation in Australia in healthcare services.<sup>14</sup> Although this study focussed on consumers' input into health services, some of the findings are relevant to priority setting at the hospital level. Johnson showed that hospitals did not have strategies to involve consumer participation and lacked coordination of, and planning for, consumer and community feedback and participation. It also suggested that community and consumers seemed to have a passive role in decision-making in hospitals. Few effective community working groups have been developed and there is a lack of shared decision-making.<sup>14</sup> Furthermore Tan *et al.* reported that of 124 hospital Drug and Therapeutic Committees (DTCs) surveyed in Australia only nine had a consumer representative.<sup>7</sup>

Consumer participation in priority setting poses a direct challenge for decision-makers (DMs). On the one hand DMs face regular pressure to 'increase meaningful public engagement'.

Conversely in the absence of good guidance, decision-maker's efforts could be costly and produce unusable data.<sup>15</sup> As noted by Contandriopoulos, 'At a policy-making level, [existing] literature does not help in the elaboration of productive and realistic [public] participation policies'.<sup>16</sup> Some of the barriers to public involvement include: inadequate time for consultation; inadequate community infrastructure and knowledge; lack of resources and managerial skills.<sup>17,18</sup>

However, citizens can bring different knowledge to the decision-making process,<sup>19</sup> as the values and preferences of members of the general public differ from those of healthcare professionals.<sup>20–22</sup> The question can be asked: 'Is there is a place for citizen involvement in priority setting for HCMs at the public hospital level?' The aim of this research was to explore healthcare decision-maker's perceptions about public involvement in setting priorities for HCMs in public hospitals in Australia.

## Study methods

### Setting

In NSW, local health regions are responsible for delivering health services to the general population residing in their catchment area.<sup>23</sup> One of the main objectives for local Area decision-makers is to maximise health outcomes using available resources and within budget constraints. Access to public hospital-funded medications is determined locally by prescribers and Drug and Therapeutics Committees (DTCs). However, funding decisions regarding HCMs may also need to be taken at the hospital executive management level.

The study took place in an Area Health Service in Sydney, NSW. At the time of this study, the South East Sydney Area Health Service (SESAHS) was one of 10 state Area Health Services. There were nine public hospitals in the SESAHS which ranged in size, the largest of which had 560 beds. Some of Sydney's major tertiary referral and teaching complexes were included in SESAHS. Approximately 780 000 people (12% of the NSW population) lived in south-eastern Sydney (see [http://www.sesahs.health.nsw.gov.au/about\\_us/index.asp](http://www.sesahs.health.nsw.gov.au/about_us/index.asp), accessed 10 April 2011). On the first of January 2005, South East Health and Illawarra Health merged to form the South Eastern Sydney and Illawarra Area Health Service (SESIAHS).

For this study a purposive sample of decision-makers within the SESAHS were approached for inclusion in the study. These individuals included executive directors of hospitals, area health service managers, directors of hospital pharmacy departments and professors of medicine. Invited participants had already taken part in the 'Access and Equity for High Cost Medications in South East Area Health Service' forum on 11 March 2003. These decision-makers were involved in HCM funding decisions or in providing access to HCMs for patients in public hospitals within the AHS.

### Data collection and analysis

An interview schedule was used which listed topics to be discussed during the interviews. The schedule was a guide or prompt

<sup>A</sup>Section 100 medicines are used for certain chronic conditions, prescribed by specialists and dispensed through pharmacies associated with hospitals participating in the Section 100 HDS program. These medications are often expensive, and include ones for the treatment of cancer, HIV and organ transplantation. Administrative agreements are in place between the Commonwealth Government and the States and Territories to manage this program.

sheet to ensure the same topics were covered during the interviews. However, questions were not asked in a standard way and respondents were able to generate their own concerns. The interview guide allowed for relevant issues to be discussed and evolved as the study progressed to allow new emerging concepts to be included. Interviewees were reminded it was their thoughts and opinions as decision-makers that were sought.

Thirty-seven people were invited to participate. Four considered they were not appropriate and recommended other participants. Twenty-four people expressed interest in being interviewed. Twenty-five semi-structured interviews were conducted. One participant refused to be recorded and another participant was interviewed twice to clarify previous answers.

In-depth, semi-structured interviews were conducted between August 2003 and April 2004. All interviews were conducted by the same researcher (GG). Interviews were transcribed verbatim by transcriberonline. Preliminary data analysis was conducted after each interview. This allowed identification of issues that required further exploration in the interviews that followed.<sup>24</sup> Continuous analysis of collected data was performed.

After preliminary analysis was performed, segments (paragraph, sentences) were coded and labelled. Coded segments were then compared for differences and similarities of events and ideas. This process was repeated until all comments were assigned to categories (constant comparison).<sup>25,26</sup> As per the grounded theory approach, analyses of the data were done through a set of relevant and specific questions: What is being described here? Who are the actors involved? How do they characterise the situation? What is its meaning to them?<sup>25</sup> QSR NVivo Version 2.0 (QSR International, Australia) was used as a data management tool.

### *Ethics*

This study was approved by the University of Sydney and St Vincent's Hospital Human Research Ethics Committees, and was endorsed by the CEO of the South Eastern Sydney Area Health Service. Written consent was obtained from all study participants. All interviews were anonymised. All data were kept confidential.

### **Results**

The interviews drew out a broad range of themes related to setting priorities for HCMs and the role of the public in these sorts of decisions. To allow the reader to judge the veracity of the interpretation, quotations were used to illustrate the themes presented. The quotations selected are intended to be illustrative of the major themes (Box 1).

#### *Implicit rationing*

Interviewees were asked about the role of the public when it comes to setting priorities for HCMs in public hospitals. Perceptions differ according to the participants' roles but also went beyond the public hospital (meso) level of decision-making. For those in hospital and Area Health Service managerial positions, choices about how to allocate scarce resources are made every-day. 'Rationing' may occur without this being done in an explicit way:

You pretend that you don't have to make those decisions in terms of rationing services but we do, we have to make

#### **Box 1. Major themes**

##### **Predetermined interview topics**

Perceptions about the role of the public and priority setting for HCMs in public hospitals

##### **Major themes emerging from the data**

Implicit rationing

Need to increase public awareness

Who represents the public?

Media discourse

those decisions every day and we do make them every day but it would just be a lot better if we actually made them in a more consistent way. [Interview #14]

At the end of the day, the resources that the community had given us for health are capped and therefore decisions about rationing are real and happen all the time but nobody talks about it and there is very poor community understanding of this major dilemma and very little debate about it. People seem to understand that rationing [occurs] but when you start then bringing [it] into the equation, like should we be rationing who gets a renal dialysis or who gets a high-cost medication, that debate hasn't been had yet. [Interview #18]

#### *Public awareness*

The majority of participants perceived that the 'rationing debate' needs to happen in Australia and the community at large needs to understand that healthcare resources are limited and choices need to be made. However, public involvement, according to participants, should be at a Government (macro) level:

At the societal level we have to decide how far we are going to go and at the moment all of these decisions are being made in closets, you know, within camera . . . you have to know what is going on, it is not a matter of the drug committee it is a matter of community for everybody and it is not openly debated and it really needs to be openly debated. [Interview #6]

I think where the public needs to be involved . . . if we work towards having a system whereby we say this is how much we are spending and this is the priorities. If we are going to introduce this we have got to knock something off and what we should do over the next few years is start to have this discussion publicly over and over and have people say what they think. [Interview #14]

Until we have a community debate about what are we prepared to spend on health? How much tax are we prepared to pay? Are we prepared to continue with the situation where 50% of healthcare expense is in the last 6 months of life? Are we prepared to spend the sorts of money we are on the \$2 million-a-year-person? [Interview #21]

#### *Who represents the public?*

Different views were identified regarding the role of the 'community', consumer, and the general public (these terms were used interchangeably). Participants commented about

public involvement in different ways. Most considered that the general public should be aware that if they want access to HCMs they may need to pay more taxes.

It's a challenge to get people [from] the general population to realise that drugs, that equity, that access to drugs is going to cost a lot more money in the future and that if people expect to have access to those drugs probably more money needs to be diverted to help for drugs funding. I think the population in general doesn't realise that and the challenge will be to get more of the health dollar available for drugs and to get the money spent effectively. [Interview #5]

Some participants considered it was difficult to identify who represented the public. The general public, according to some participants, could focus on individual good and be biased towards their own need instead of adopting a societal perspective:

But who represents the public? Often consumer activists are as typical as a kick boxer I don't know. [Interview #1]

But the public looks through their own eyes at what is my problem, and I am not getting access to a drug that is going to save my life, and I don't have the money to pay for it, therefore I am disadvantaged [compared] to somebody who does have the money to pay for it and can get help. [Interview #16]

#### *Knowledge as a barrier*

Participants also considered that Australia's healthcare system is complex and the general public might have difficulty understanding it. Some also suggested the general public would need to be educated regarding priority setting.

I think the health system is very complex . . . and the reality is different to the policies. And every hospital situation is different. [Interview #13]

The State or the Commonwealth Government needs to start looking at an education program for the general populace that you can't necessarily have everything and there just isn't infinite money and all that sort of thing. [Interview #20]

I think what consumers need to do is understand the extent of the problem and understand the decisions that have to be made and be prepared to accept the decisions that are made for them or on their behalf. [Interview #6]

#### *Media discourse*

Participants were concerned about the role of the media and the sort of information the general public gets about access to HCMs. Some participants considered that the message sent by the media is not always right and tends to focus on cases where access to HCMs is denied.

I think the media, the messages the media give the public is different from the reality and the reality is different to the policies as well. And every hospital situation is different. [Interview #13]

Because all they get is the opposite view, what the public gets is poor Mrs so and so who has got three children and she

is dying of whatever, and the PBS does not approve the drug that she needs to keep her alive on the PBS. Everyone goes, how terrible, that is awful, she should have the drug and our heart knows that she should have the drug but you have to think well you know the reason they haven't put it on is that the evidence isn't strong enough and you have got to have a basis for subsidising something. [Interview #20]

. . . suddenly it becomes a big media story and then of course you get all that pressure and politicians and the thing is do we want this to go away and the way you do that is to address that issue. [Interview #24]

### **Discussion**

Decision-makers perceived that even though rationing is happening in Australia, it is not openly discussed. There has been limited debate, and there has not been public acknowledgement for the need for prioritisation.<sup>27–30</sup> Holm noted that if priorities need to be set in a country with a public healthcare system (such as the Australian system), there needs to be a public debate.<sup>31</sup>

In this study, some participants considered it was important to educate members of the general public about the need to set priorities and the importance of having an open debate. Some commentators have also voiced the importance of making priority setting explicit. New described that since rationing is unavoidable, there should be an explicit debate about the principles and issues concerned.<sup>32</sup> Williams stated that there should be a 'systematic effort to bring home to the citizen taxpayers the nature of the dilemmas that have to be faced, the options available and their likely consequences'.<sup>33</sup> Ham considered that in a time when public awareness is increasing about medical advances the challenge is to find ways of informing and involving the public in the debate about the distribution of healthcare resources.<sup>34</sup>

The perspectives of the public, according to participants, were considered diverse (tax payers, patients, consumers). Due to the complexities of the healthcare system their involvement in decision-making regarding access to HCMs in public hospitals was considered limited. For participants, the role of the public was likely to be at the National level, deciding how much they were prepared to spend on healthcare. In contrast, a survey of the general public by Gallego *et al.* found that 38% of respondents did want to be involved in decisions regarding access to HCMs at the public hospital level.<sup>35</sup>

Most participants considered that the general public should be aware that if they want access to HCMs they may need to pay more taxes. Participants also considered that members of the general public might not be willing to pay more taxes to fund access to HCMs. McKie *et al.* found that members of the general public are sceptical regarding the ability or willingness of the government to use additional tax receipts to programs and services that focus on health rather than welfare.<sup>36</sup>

Participants also commented on the role the media has in shaping the views of members of the general public regarding access to HCMs. Concerns arose regarding the words the media uses to describe access to a HCM, especially when someone is 'denied' access to a medication. At the time of this study, cited examples included access to trastuzumab (treatment of breast cancer) and imatinib (treatment of chronic myeloid leukaemia) in



Australia<sup>37,38</sup> and interferon  $\beta$ -1b (treatment of Multiple Sclerosis) in the UK.<sup>39</sup> These cases, as noted by Daniels, attract public sympathy and show the great difficulty members of the public have with accepting limits.<sup>40</sup> Marley considered that 'on emotional grounds, the public rejects the idea that any treatment, however expensive and unproven, should be denied'.<sup>41</sup> However, the media discourse and how it influences views of members of the general public regarding access to HCMs, were beyond the scope of this study.

It has been suggested that community consultation in Australia is possible and might even produce surprising results.<sup>42</sup> Given limited healthcare resources, a community-wide consensus could be used to decide how best to employ these resources.<sup>22</sup> However, the best way to engage consumers in priority setting for medicines in Australia still remains to be determined. In Canada, patients and the public have been involved in the Citizens' Council Ontario Public Drug Program.<sup>13</sup> Citizens' Councils have also been used in England and Wales by the National Institute for Health and Clinical Excellence to shape its general social value principles that inform the broader decision-making process.<sup>12</sup> In Western Australia, citizen's juries have been trialled as a way to introduce greater democracy into decision-making priority setting in healthcare.<sup>22</sup> One of the conclusions drawn by Mooney is that citizen's juries are capable of dealing with complex concepts such as 'equity' and can provide meaningful advice on issues regarding healthcare resource allocation.<sup>22</sup>

Furthermore, a study conducted in Australia by McKie *et al.* found that when addressing the ethical issue of allocating limited resources between patients (such as the case with HCMs) the general public identified members of the community as having an important role in these sorts of decisions. Participants in this study considered that these decisions should be shared within a multidisciplinary team.<sup>43</sup>

This study shows that decision-makers faced with real resource allocation decisions at the local (public hospital) level considered public engagement important and necessary, but ultimately hard to operationalise. The call is for accountability, openness and a well-informed citizenry. These stakeholders consider that, more importantly, it is time to challenge the public's notion of 'free' access to healthcare in Australia. As described by Williams there needs to be a 'systematic effort to bring home the dilemmas that have to be faced'.<sup>33</sup> It is time consider consultative and collaborative approaches to achieve balance.

## Conclusion

Participants considered there should be a public debate to raise awareness about the fact that healthcare resources are scarce and that choices need to be made. Such a debate would explore just how much people are prepared to spend on high-cost medicines as opposed to other areas of healthcare, or non-healthcare costs. This study also raised questions regarding the role of members of the public in the decision-making process about healthcare resources at the institutional (public hospital) level with respondents suggesting a role at a macro rather than a micro level would be most appropriate.

It is also important to note that although health systems and solutions may be very different, the issue is relevant to other jurisdictions.<sup>44</sup>

## Competing interests

None declared.

## Acknowledgements

We express our gratitude to the participants for their time. This study was partially supported by the Society of Hospital Pharmacists of Australia (SHPA) through the DBL Development Fund (DBL 0314).

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Manuscript received 16 February 2009, accepted 25 August 2010