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A Focus Group Study of Health Care Priority Setting at the Individual Patient, Program and Health System Levels

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TABLE OF CONTENTS

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ABSTRACT

Faced with an ageing population and newspaper warnings that escalating costs are leading to a health crisis, debate has intensified in Australia and elsewhere on the allocation of limited health resources. But whose values should inform decision-making in the health area, and should the influence of different groups vary with the level of decision-making? These questions were put to 54 members of the public and health professionals in eight focus groups. Unlike previous studies, participants were not asked if particular groups should be involved in decisions but rather through deliberation and discussion nominated their own potential decision makers. This delivered a clear message that participants saw a legitimate role for a broad range of stakeholders in priority-setting decisions. The results suggest that qualitative methods of investigation have the potential to improve the legitimacy and accountability of policy decisions by contributing to a better understanding of the values of the public and health professionals.

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1. Introduction

In Australia, and other countries, debate on the allocation of limited health resources has intensified in recent years, fuelled by newspaper headlines that declare a "massive health crisis is looming", and articles that warn readers that in the near future national GDP will be consumed by health spending (Wroe & Wood, 2005). While some medical advances can result in a net reduction in health costs (e.g. antibiotics), dire predictions of a looming health crisis are not without foundation. Indeed, it is predicted that in 2044-45, a quarter of Australians will be aged over 65 (Productivity Commission, 2005) with many requiring treatment for hypertension, arthritis, heart disease and other disabling conditions associated with aging (National Academy on an Aging Society, 1999). The same challenge confronts other developed countries.

Faced with this large ageing population, together with increasing health care costs, it is inevitable that health budgets in Australia, and elsewhere, will be subject to increasing pressure and allocating finite health resources will be more difficult and hotly contested. But who should resolve these problems? Is there a place for citizen involvement, or are decisions best left to others? How much of the decision-making should be left to professionals? This study examines who different players in the health area, including health professionals and members of the public, believe the decision makers should be.

2. Public Participation in Healthcare Decision-Making

While it is generally agreed that the need to ration health resources will increase as Australia's population ages and health costs grow, the extent to which the public should participate in setting priorities is an unresolved companion issue. In contrast to the limited discussion that has occurred in Australia, for more than two decades researchers and governments in Canada, Great Britain, New Zealand and Sweden have investigated and vigorously debated the benefits and shortcomings of public participation in health care decision-making (McKee & Figueras, 1996; Smith, 1996; Stronks, Strijbis, Wendte & Gunning-Schepers, 1997). Frankish, Kwan and colleagues identify three domains ('Theoretical', 'Practical' and 'Political') that provide a useful schema for describing a cross section of these points of view (Frankish, Kwan, Ratner, Higgins, & Larsen, 2002:1472-1473).

The first of these is concerned with 'theoretical' reasons. These are associated with empowerment and democratic arguments that assert citizens have a right to be involved in decisions regarding public institutions. Such participation is seen, among other things, as promoting social capital and supporting a sense of public ownership and responsibility for health systems (Frankish et al., 2002:1472; Abelson, Forest, Eyles, Smith, Martin, & Gauvin, 2003:239; Litva, Coast, Donovan, Eyles, Shepherd & Tacchi, et al., 2002:1825). Next, there are 'practical' reasons for public participation, which include beliefs that a citizenry can contribute a breadth of views and local knowledge that will lead to better decisions, greater efficiencies and enhanced

accountability in healthcare (Frankish et al., 2002:1473; Church, Saunders, Wanke & Pong, 2002:12). In the last of the Frankish, Kwan categories are 'political' motives, benign and otherwise, for seeking to involve the public in decision-making. Participation at this level may be used to assuage community concerns that health institutions are "unresponsive and unaccountable to citizens" (Church et al., 2002:12), or to gain public support for contentious health care decisions (Abelson et al., 2003).

Arguments against public participation can also be found in each of these domains but most are associated with 'practical' concerns. Sceptics such as Torgenson and Gosden warn that rationing decisions are "painful, complicated and difficult" and so conclude these are best left to experts (Torgenson & Gosden, 2000:1679). More moderately, Jordan, Dowswell, Harrison, Lilford and Mort (1998) point out that public deliberation is a challenging and resource-intensive exercise that few health professionals or the general public are trained to do well. Other arguments raise questions of accountability (i.e. should the public be accountable for decisions?); the degree to which the public can make informed decisions (i.e. is the public sufficiently knowledgeable?); representativeness (i.e. who should participate?); or focus on the potential for power imbalances among participants. Finally, there are those who ask "how will different public priorities, views and opinions be weighed against each other to effect positive change?" (Jordan, 1998:1670; Stronks et al., 1997).

3. Does the Public Actually Want to Participate?

But to what degree does the public want to be involved in priority-setting in the health area? An underlying assumption in much of the literature on public participation has been that citizens have a legitimate role to play in setting health care priorities. As we have noted there are arguments for and against this view. Furthermore, according to Abelson et al., interest in involving the public in decision-making has generated a "fascination" with methods for facilitating participation (Abelson, 2003:239). Approaches have included leaflet response forms, surveys, polling, interviews, focus groups, citizen's juries, panels, forums, conferences, volunteer boards, the list goes on (Anderson & Florin, 2000; Bowie, Richardson & Sykes, 1995). However, there are few studies that have actually consulted the public on their role in priority-setting, and more broadly about who they feel should be involved in resource allocation decisions and priority-setting. The number of studies where these differing views can be tested is therefore correspondingly small. This section describes some of these studies.

Using a mail questionnaire Richardson, Charny and Hanmer-Lloyd (1992) asked members of the English public if they were in favour of greater public involvement in decision-making. A slim majority of respondents (58 %) indicated they agreed that "decisions should be left to doctors and other experts at the health authority", while a greater number (65 %) felt that "the public should have more say in decisions". The authors concluded that "[p]ublic support for the delegation of decision-making to professionals and the health authority cannot be assumed". However, as we shall see below, the effectiveness of using one-off surveys has been argued by some to be a less than ideal method (Dolan, Cookson & Ferguson, 1999).

In another British study using a questionnaire, Bowling (1996) surveyed 2005 members of the public asking, among other things, if participants thought that surveys of the public's opinions, like the one they were conducting, should be used in the planning of health services. Of respondents, 88% percent indicated they thought this should occur. Participants were also asked to select from

a list who they thought should be responsible for rationing health care. Three quarters of responders favoured doctors over "managers, health authorities, or the government". However, care is needed when interpreting these results. Firstly, it is not clear whether participants distinguished between budget level and patient level decisions when making these judgments (Nord, 1999:7-8). Furthermore, it is unclear if participants had an adequate understanding of healthcare decision-making when nominating who might be involved. Indeed Bowling's study revealed little about the beliefs, values, motivation or meanings (Ritchie 2004) that participants attached to healthcare decision making or the roles of decision makers.

In Canada, Abelson, Lomas, Eyles, Birch & Veenstra (1995) conducted a study that probed more deeply into the extent of public willingness to be involved in local health-care and social-service decision-making. The researchers drew upon selected random citizens, interested citizens, appointees to district health councils and experts in health care and social services. Rather than use a survey approach Abelson et al. (1995) sought to elicit informed views from these groups by using deliberative polling, a technique that combines random sampling with group deliberation of issues. This public participation process features lengthy deliberation, sometimes over several days, the weighing up of competing views and consideration of supporting materials. The objective of this method is to generate reasoned "decisions or recommendations to action" on a topic of interest (Abelson et al., 2003: 242). Of the 280 participants, nearly three quarters expressed a personal willingness to take on a role involving decision-making. Interestingly, substantially fewer (30%) felt their particular group would be suited to take responsibility for overall decision-making, while just over half (55%) indicated that their group should only have a consulting role. Of the four types of participants, randomly selected citizens were least willing to be responsible for overall decision-making, and only 17% indicated their group should be responsible for decisions. Abelson et al. concluded that "although the public is willing to be involved in planning and setting priorities, it may be willing to take on only a limited consultative role" (Abelson et al., 1995:411). This seemingly paradoxical position of rational members of the public not wishing the public's opinion to be taken into account, or to only fulfil a limited advisory role, has also been reported by Richardson in Australia (Richardson 2002). In a pilot study that examined, among other things, public participation in health resource allocation Richardson found that *"… respondents may mistrust the acumen and wisdom of their fellow citizens and have greater confidence in the decision procedures adopted by government".* This and other recent studies conducted in Australia are examined further in the next section of this paper.

Meanwhile, Dolan, Cookson and Ferguson (1999) took such research one step further and investigated the extent to which people change views about priority-setting in health as a result of discussion and deliberation. In this study, ten groups of 5-7 attended two focus groups a fortnight apart. Initially, participants indicated there should be less involvement of managers and government and greater participation from the public, doctors and nurses. However, as participants discussed and explored the complexity of the topic at hand they became more reticent about their role and the role of their views in determining priorities. Participants also became more "sympathetic to the part that health care managers play" (Dolan, Cookson & Ferguson, 1999:919). Noting these changes in attitudes and perceptions following deliberation, the authors suggest that methods "that do not allow respondents the time or opportunity to reflect on their responses" may be of limited value.

More recently Litva et al (2002) conducted another study in the UK. Like the study by Abelson and colleagues (1995), this research sought to test the degree of support for public involvement in health care decision-making - but this time at different levels within the system; i.e. at the health system level, the program level and at the individual patient level. Participants were drawn

from the general public as well as from health and non-health related organizations. Results from focus groups and interviews showed most support for public participation at the system level, less support at the program level and least support at the individual patient level. Confirming the findings of Abelson et al. (1995) it emerged that, although there was strong support for public consultation at the system level, it was felt they should not be responsible for actual decision-making. Participants took the view that while the public possessed important "lay knowledge" that could inform and improve decision-making, ultimately health professionals should be responsible for decisions (Litva et al., 2002:1831, 1834). Participants also noted that emotional responses to issues could potentially compromise public involvement in decision-making.

4.   Recent Work in Australia

There have been some, although few studies in Australia exploring the public's desire to participate in decision-making in the health area. In Sydney, Wiseman, Mooney, Berry & Tang (2004) surveyed the general population regarding whether their preferences should be used to inform resource allocation and, like the work of Litva et al. (2002), explicitly distinguished between different levels of priority-setting in health care. Participants were asked, in a questionnaire, whether their preferences should play a role in allocating resources between medical procedures, between health care programmes, and between different population groups. To aid understanding, respondents (373 citizens attending two medical clinics in central Sydney) were given examples of priority-setting at each level. The authors report that the public overwhelmingly wanted their preferences to inform priority-setting decisions in health care, particularly for programmes and at a system level. The majority of respondents (97%) also felt priority-setting decisions should be informed by the preferences of more than one group (Wiseman et al., 2003:1005).

Partly in contrast to these findings, as noted earlier, another Australian study by Richardson (2002) obtained survey results suggesting that citizens may sometimes want to "abdicate" responsibility for health care decisions, preferring governments to make such decisions. In this study, participants supported the overriding of public opinion by government "if the government believes the public is being short sighted". Reflecting on this, Richardson comments that the degree of public support for citizen involvement in decision-making appears to be more complex that is usually assumed, and is potentially influenced by context (Richardson, 2002:673). It should be noted, however, that believing that the government is justified in overriding public opinion if such opinion is short-sighted, is not inconsistent with believing that the public should have input into priority-setting decisions, and that such input should be taken seriously.

5.   Method

As Wiseman et al. (2003) note an issue that emerges for studies inquiring into whether the public should have a say in health care decision-making is that "being in favour of public participation is rather like being against sin; it is hard to find disagreement". Indeed, several studies appear to have only sought to confirm rather than explore this assumption, employing closed methods and largely leading questions that in the absence of important contextual information or discussion were unlikely to produce contrary responses or illuminate the meanings underpinning responses. On the other hand, as we have seen, some studies have shown that when participants are given

the opportunity to reflect and deliberate on decision-making their support for public involvement becomes increasingly circumspect and qualified.

In this exploratory study we have also sought to examine public preferences (and those of other groups) when participants are given the opportunity to deliberate on matters. Our interest was to see how different groups would respond if there was no predetermined notion that the public should be involved in health care decisions. Consequently, it was decided that this particular study would amalgamate various approaches outlined earlier to address an open question of the form: "Who should decide how health priorities are set in Australia?" To fully explore this key question, the methodological approach aimed to create a "permissive, flexible environment" (Hurworth, 1996:49) to afford participants the greatest opportunity to raise and discuss issues with minimal agenda-setting by the researchers. Unlike some previous studies, we sought to include participants from a wide range of stake-holder groups (see Table 1), including the general public (both patients and non-patients) and health professionals (including clinicians and administrators).

The study took place in Victoria, Australia, and involved modified focus groups with the general public (four groups), health professionals and state government health bureaucrats (four groups). Focus groups were chosen as this method is ideal for studies that are seeking to explore and understand attitudes and behaviours (Hurworth, 1996). Overall, 54 people participated in a total of eight focus groups, with each group comprising between four and eleven people (see Table 1). Informed consent was obtained from all participants and the study was approved by the Monash University Human Research Ethics Committee. On average, sessions ran for 1.5-2 hours. Initially, each interview began with a question that asked participants to nominate who should make decisions about how public health resources are utilised, and the advantages and disadvantages of each individual or group that had been nominated. This was followed by the presentation of scenarios at patient, program and system levels, with participants then asked to suggest who they felt should make the decisions at each level.

In more detail, the interviews followed the focus group theory espoused by Krueger and Morgan (1998) where interviews start with one open question followed by a few transition questions and end with a key question. In this case each focus group opened with "Can you name one group that should be involved in making decisions about how the health dollar should be spent?" From the wide-ranging responses, interviewers were then able to progress naturally to transition questions about making choices in various hypothetical scenarios. In brief, the scenarios presented were:

- Patient level: Who should decide which of two patients should receive a heart transplant if both patients cannot be treated?

- Program level: Who should decide between a heart health program and a breast care program when there is not enough funding for both?

- System level: Who should decide about what treatments should be covered by Medicare in the context of resource shortages?

These levels are more closely aligned with those articulated by Litva et al. (2002) than those used by Wiseman et al. (2003), as it was felt that participants would find it easier to grasp the differences between the levels. The above scenarios, filled out with further details, were projected onto a screen using a computer and data projector, so that the participants could engage more

easily in discussion without having to remember the details of a scenario. Each focus group progressively honed in on making a final choice of "who should decide" for each scenario. A final question asked participants to reflect on the extent to which they had changed their mind regarding their choice of decision-maker(s) over the discussion period.

Groups were moderated by "complementary moderators" (Kruger 1994) consisting of a senior member of the research team with particular expertise in the facilitation of focus groups, a second moderator with extensive knowledge of health care decision making was also present to answer participant questions or provide additional information to assist deliberations. The eight focus groups were tape-recorded with all tapes transcribed in full. Transcripts were then coded, beginning with a basic set of codes established through an extensive review of the literature. Codes were maintained, adapted, added to or collapsed following further close readings of the text. Next, all major ideas for each group were displayed under thematic headings on matrices of the type proposed by Miles and Huberman (1994). These displays, in combination with verbatim quotes from the transcripts, are a particularly rigorous way of dealing with such qualitative data. Major themes illustrating commonalities and differences between groups regarding the question of who should decide how priorities are set, at each of the three levels of priority-setting, are presented below.

6. Results

6.1 Who Decides – Patient Level Decisions

As might be expected, there was strong support across all groups for involving doctors in patient level decisions. Indeed, some participants in the general public focus groups immediately nominated doctors as they were felt to be "the only ones qualified to make the decision" (FG 2). However, when discussion moved beyond medical issues to squarely addressing the ethical issue of allocating limited resources between patients, doctors then emerged as just one group among a range of health professionals, health researchers and members of the community who were identified as having an important role to play in priority-setting at this level. This suggests that while participants acknowledged that doctors have vital medical expertise, there was scepticism regarding the idea of doctors as "ethical experts" (Singer, 1988).

Participants in all focus groups were strongly drawn to the notion that priority-setting should be determined by more than one person or profession, and proposed a variety of ways that this might occur. Some participants felt decisions could be shared within a multidisciplinary medical team, noting this would involve not only doctors but nurses, allied health workers, social workers and others (FG 7). Several respondents added that decision-making by medical teams should include consultations with health economists and ethicists so as to consider "the value of someone's life, their contribution and value that they leave to the community" (FG 2, FG3, FG 6, FG 7). A number of participants also explored the idea that medical teams might consult patients and family (FG 2), although this was just as frequently rejected as unfair and burdensome for those in already emotionally charged situations.

Meanwhile, other participants, in seven of the eight groups, took a different approach, suggesting that priority-setting between individual patients would be best determined by decision-making bodies using predetermined 'criteria', 'protocols' and 'guidelines' established through group processes. Reasons given for taking decisions beyond the hospital ward were to ensure decisions were unbiased (FG 7), took into account a range of viewpoints (FG 8) and relieved medical teams of the "burden" of priority-setting (FG 6). Two of the four groups composed of

members of the general public gave suggestions of who might be included in such decision-making bodies: "the big wigs…hospital board members" (FG 4); "everybody but the finance people" (FG 2); "the ethics committee and groups like that" (FG 2); "a broad spectrum of independent people" (FG 4).

A third citizen group explored the idea of collective responsible for priority-setting decisions further. Members of this focus group felt that a decision-making body should have a balance of health practitioners including doctors, allied health workers and community health workers together with community members including consumer representatives and people from different socio-economic and cultural backgrounds (FG 1). According to one group member, when forming this assemblage the aim would be to "get an ideal mix of representatives of the community as well as a broad spectrum of the health and community service professionals" (FG 1). However, this configuration led some group members to question if such a collective would be capable of timely decisions, with several suggesting that a decision-making body would consequently "need to make choices about how things were decided in the future" (FG 1) – a form of pre-commitment which harks back to the idea of 'protocols' and 'guidelines'.

The idea that a consultative group could be used for developing protocols governing future patient-level decisions was particularly popular among participants in the focus groups held with health professionals and bureaucrats. Health bureaucrats (FG 8) proposed that establishing "sets of rules" would need to have input from doctors, nurses, allied health professionals, ethicists, policy makers and representatives of consumer groups. Summing up the thoughts of many in this group, one participant explained, "It would be a group that develops a process which then produces a codification…so that you have a set of criteria against which you can make these decisions and you are not dumping it on individuals" (FG 8). Another group member suggested that the "Oregon experience" (a reference to the inclusion of citizens in priority setting in Orgeon (Ham, 1998)) might provide a useful model for gaining broad community and professional input when establishing protocols (FG 8).

While also advocating the use of criteria or a "pre-existing formula" (FG 5), General Practitioners (GPs) described a number of different ways this might occur. Members of one GP group suggested that sets of rules could be established by an "expert panel" consisting of health experts and "experts from society (including) an expert consumer, an expert ethicist and an expert health economist" (FG 5). Participants in the second GP focus group described an elaborate process of development and ratification of protocols involving many groups including medical teams, hospital committees and government. Acknowledging that the decisions involve ethical judgements, and are not purely technical, citizens were again nominated as important participants in this process, with one GP observing: "these days most public organization need to have some sort of community input in decision-making otherwise it's very hard to justify decisions." (FG 6)

6.2   Who Decides – Program Level Decisions

In their Australian study Wiseman and colleagues reported that a majority of citizen survey participants were in favour of public involvement in decisions at the program level (Wiseman, 2005: 132). This was not so clearly evident in the present study. By contrast, a much stronger theme that emerged across all focus groups was the desire to ensure that priority-setting decisions between programs were made by, or informed by, a range of parties with a legitimate interest in health system performance, including health professionals, patients, and members of the public. That is, consultative and/or collaborative approaches were often advocated as the way to achieve the preferred balance between using resources cost effectively and fairly.

In three of the four focus groups held with citizens there was little or no mention of directly involving the general public in decisions regarding programs. Rather, participants in these groups suggested that health economists (FG 3, FG 2), epidemiologists (FG 2, FG 3, FG 4), and health practitioners (FG 2, FG 3) would posses the expertise required to nominate programs that provide "the most benefit to society" (FG 3). Health economists and epidemiologists were specifically chosen by participants as they were thought to be "dispassionate" (FG 3), not driven by "vested interests" (FG 3), and as possessing "statistics and all the information" (FG 4) needed for selecting between programs. Several participants nominated health care professionals, explaining that this group could contribute their local knowledge of client needs and/or specialist understandings of health conditions (FG2, FG3). This involves a clear recognition that some groups have expert knowledge that is indispensable for informed decision making in the health area (e.g. "statistics and all that information"), but also that such decisions have an unavoidable ethical component that requires different ways of thinking and answers to different criteria (e.g. decisions have to be "dispassionate" and not driven by "vested interests").

Government and politicians were also put forward by participants from two citizen focus groups. Two members of these groups believed that priority-setting among programs should be determined by politicians as these decisions would ultimately reflect public opinion and the public's wishes (FG 4). Two other participants also identified politicians as legitimate decision-makers, but qualified this by adding that priority-setting choices by politicians would need to be informed by consultations with health economists (FG 4) and/or health professionals (FG 3). A member of a different focus group was less than convinced that politicians should be involved in program priority-setting at all, warning that "the problem with the politicians is that they might make a decision that is not objective or unselfish!" (FG 2). Self-interest was a concern for others as well, with suggestions that care would be needed to ensure that strong lobby groups did not sway the course of decisions (FG 3, FG 6, FG 8). One participant went so far as to recommend that the public should be kept out of program level decisions for this reason, explaining:

> In terms of the public being involved … you can see how groups will be more vocal than others and some groups are going to be marginalised. The minorities are going to be marginalised and so on. So I think there is a political danger in getting the public involved in these sorts of decisions. (FG 2)

A fourth focus group of citizens was much more disposed to involving the public in priority-setting at the program level. Members of this group emphasized the need to balance the perspectives of professionals with those of patients and local communities when making such decisions. The following provides a brief composite picture of the suggestions made by this group:

> (there should be) a collaborative community consultation process with users, carers, chronically ill and experts such as health practitioners … and social workers and people like that … because that group represents the community.… I think the health economists would be able to give a statistical picture of where the greatest needs are but the lived experiences of the people within these groups would be very valuable….(FG 1)

Meanwhile, this time more closely reflecting the findings of Wiseman (2005), participants in all four focus groups comprising health practitioners and health bureaucrats, nominated the public as being among those that should be involved in decisions at the program level. GPs proposed that "regional boards", "honorarium groups" or "panels of eminent expert decisions-makers" would be ideal for program priority-setting (FG 5, FG 6). With slight variations GPs recommended that the

composition of these decision-making bodies should include community, medical, allied health and government representatives. GP participants also commented that to be truly effective representative boards or panels would need to be bipartisan, independent and "around after the next election" (FG 5). Four GP participants proposed that these decision-making bodies could base priority-setting decisions on presentations made by different consumer, lobby and expert groups (FG 5, FG 6).

Taken as a whole, members of the health bureaucrats focus group found little reason to nominate new or different decision-makers to those they had previously identified for priority-setting among patients. However, one group member held a contrary view, arguing that it was the role of public servants to canvas and present an array of opinions to politicians who would then make final decisions (FG 8). Disagreements aside, a key concern for this group, and for all the non-general public focus groups, was again to ensure that priority-setting was based on evidence gathered by researchers (FG 8, FG 7), health economists (FG 5, FG 6, FG 8, FG 7) and epidemiologists (FG 5), to guarantee the selection of programs did not neglect "better quality of life and long term health dollar impact" (FG 6).

Finally, participants in the focus group conducted with allied health professionals also recommended that a wide range of players be consulted to determine areas of greatest need and programs that would be "efficient and effective" (FG 7). Among their suggestions were: medical experts; health economists; policy makers; and consumer groups. One participant suggested that government policy makers could conduct focus groups with members of the general public so as to ascertain: "what the public feel … (because) … the best decision economically may not be what the public want … it has to fit in with public expectations as well" (FG 7).

6.3 Who Decides – Health System Level Decisions

In Australia, certain health care services are provided without charge or are subsidized under a Commonwealth-funded health insurance scheme known as "Medicare". Among other things, this scheme provides free services for patients in public hospitals and covers 85% of a schedule fee for consultations with General Practitioners and a range of medical specialists (Biggs, 2003). Similarly, a national Pharmaceutical Benefits Scheme (PBS) subsidizes a wide variety of medicines to ensure these are affordable for most Australians. However, some services such as dentistry, physiotherapy and home nursing are not covered by Medicare. Furthermore, not all medicines are subsidised by the Pharmaceutical Benefits Scheme and patients pay the full price of those drugs which cost less than the mandated co-payment.

When asked to nominate who should be involved in decisions regarding what should and should not be covered by Medicare and the PBS, the GP participants and health bureaucrats largely reiterated the suggestions they had given for program level decision-makers. For example, one group of GPs restated their preference for a panel composed of eminent medical, allied health and community representatives that would base decisions on representations made by a broad range of groups (FG 5). However, there was some disagreement within this group on whether such a panel should actually make decisions. One participant suggested the panel should play only an advisory or policy formulation role at this level, with decision-making left to the health minister and health bureaucracy. But this view was not popular with others, with one person saying that Medicare should not be "a political football" and another declaring, "that is too much power resting with one person…. Having more people involved is good…. It has to be an independent group with the power of the Minister diluted into that group" (FG 5).

The importance of ensuring Medicare priority-setting was not dominated by politics, and remained independent of government, was also discussed by the second group of GPs. Five members of this group felt that a decision-making panel composed of experts (such as those noted above) would need to be autonomous and could be set up as an "independent commission" or styled on "the judicial system" or "the Reserve Bank" (FG 6). This theme of power and influence was also prevalent in the group comprising health bureaucrats, although their focus was on possible power imbalances that could occur within a group responsible for health system priority-setting. While once again proposing a representative group of decision-makers (as outlined for patient level priority-setting), participants were mindful of the power held by some professions. Summing up the thoughts of others in this group one participant explained: "one of the issues about Medicare is that the strongest voice is that of doctors and health economists ... hence we have no dental cover" (FG 8). Several group members proposed that a "weighting system" might be used to resolve this problem:

> If we acknowledge that clinicians have the most power in this situation then maybe their voice should be weighted less. And some of the other groups at the table who haven't previously had a strong voice could be weighted more. So then clinicians will have less capacity to influence (outcomes).

With some humour, participants in the focus group with allied health workers confessed "we don't really know" who should set priorities for Medicare (FG 7). Preceding this admission, members of this group discussed the idea of a community representative group made up of an assortment of health professionals, social workers, consumers and the general public (with a spectrum of ages represented). However, they also noted an important countervailing influence to the advocacy of wide community involvement in priority-setting. Several participants felt that decision-making could be difficult with such a diverse group. Others commented on the difficulty of catering for diverse community needs, "things are so different in every different community. If you look at the needs of Melbourne, each community is different and each community could tell you what their needs are." This led some participants to conclude that it would be important to consult "policy makers, economists and researchers", or as one person remarked "people who understand numbers and can analyse data", to learn the benefits and consequences of including or excluding items from Medicare. This last point was also made in all of the non-general public focus groups.

Meanwhile, most general public participants also concluded that health system priority-setting should incorporate a "voice larger than some man in a suit in Canberra (Australia's Capital City)" (FG 1). One focus group of citizens clearly wanted decisions to include a "collaborative process" involving the voice of health system users while taking into account "what is best for most" (FG 3). Other citizen groups were able to more fully articulate who they felt should be involved in priority-setting. One group proposed that a panel could be established "between users and the politicians" that would be responsible for "talking about what users want" (FG 2). The composition of this panel was to include health system users, doctors, other health professionals, health economists and ethicists. While one participant suggested this group should be responsible for decisions, others envisaged the panel as having an advisory role but stressed that government would "have to listen to that body" (FG 2).

Three participants in another group of citizens were also willing to have decisions made by government but again insisted on "iron clad mechanisms" to ensure decisions involved consultations with health system users, the community and health experts (FG 1). Two other participants did not reject this suggestion but were wary of entrusting priority-setting to politicians, noting that governments habitually change policy decisions between elections. Some participants

in the fourth group of citizens also wished to locate decision-making with government but offered other suggestions as well. Two group members indicated that the commonwealth government should make priority-setting decisions as "they were elected to make those decisions" but also noted that "governments fall on Medicare … so in the end the public makes the decision through voting" (FG 4). One participant felt that a separate body should be formed with elected members including "medical professionals, economists and community groups" but acknowledged this would be difficult to achieve. Two other participants also felt that "groups are a good idea for making these decisions" but cautioned that a collaborative body would need "a good chairperson to keep them on track and contend with the internal fighting and parochial views" (FG 4).

Lastly, it is interesting to note that although participants clearly valued the expertise and experience that doctors could bring to health-system level decision-making, some participants were nevertheless concerned about the power this group could wield over decision-making processes. The following exchange between four participants from a general public focus group provides an insight into the issues some participants associated with including doctors in priority-setting:

> *You have to consult everybody. You can't just focus on a certain group.*
>
> *I agree with that because doctors in the past haven't sent people to physiotherapists or chiropractors because they want to make the money.*
>
> *… I think it has been the medical doctors that have dominated those choices at the expense of the more preventative type services that are at the bottom of the list.*
>
> *Doctors have a lot of power really, whereas users have very little power. So I think that it is important for users to say which services they want to use.*

Whether this is true of the medical profession is debatable, but perceptions are important, and this view was expressed in several focus groups. The exchange also indicates what was evident throughout the focus groups – that the practical problem of deciding who should be involved in setting priorities is not a purely technical problem. Rather, there was a general recognition that the problem is unavoidably an ethical one, the solution to which needs to be sensitive to a range of legitimate views.

7. Discussion

There was a clear recognition, in all focus groups, that choosing between patients is not just a medical or economic decision. For example, although there was strong support for involving doctors in allocation decisions at most levels, there was also discussion of how to include nurses, allied health workers, social workers, patients and families in the decision making process. There was also a recognition of the emotional burden that prioritising decisions can place on individuals, and exploration of a range of means of lessening this – e.g. by the use of predetermined 'criteria' or 'protocols' established through group processes or by an 'expert panel'.

At the program and system levels decisions are more abstract, but the theme of collective decision making continued. Interestingly, health practitioners and health bureaucrats were sometimes more enthusiastic about public involvement than members of the public, thus lending some support to the "abdication hypothesis" described by Richardson (2002). At the system level

the preference for a collaborative approach for some was motivated by a concern that Medicare and PBS priority-setting should not be dominated by politicians and health bureaucrats.

One of the novel features of this study was the open-ended nature of the inquiry. Participants were not asked "Should the public be involved in priority-setting?" or "Should physicians be gatekeepers of medical resources?" Rather, the focus was on the more general question: "Who should make the decisions (at the different levels)?" This allowed participants to nominate and explore a wide range of possible answers without implicit directives from the researchers. This resulted in both a wide range of potential groups being nominated, and a wide range of decision-making procedures being explored.

Results of the focus group and interview study conducted by Litva et al. (2002) showed most support for public participation at the system level, less support at the program level and least support at the individual patient level. This stratification of responses was not so evident in the present study. Rather, the open-ended nature of the enquiry, which did not focus on public participation specifically, allowed most participants to arrive at a solution that they preferred at all levels – namely, some form of collaborative decision making incorporating a range of views, often including the public. We suspect that support for public participation per se does not differ as greatly between levels as some studies would suggest (e.g. Litva et al. 2002), but that the amount of influence the public should have may differ, and/or the nature of their involvement (e.g. informing, consultation, partnership, sole decision-maker). This is a question for future research.

In many of the focus groups participants explored the difficulties confronting different decision makers, both from a personal and social perspective. For example, there was a recognition of the potentially high emotional cost placed on members of the public involved in decision making at the individual patient level. Alternatively, politicians were seen to have short-term interests not always in line with socially responsible, long-term health care planning ("the problem with the politicians is that they might make a decision that is not objective or unselfish!"). There was also a concern about medical dominance, and that patient support groups, and other lobby groups, could exercise an undue influence if safeguards are not in place. These dangers are exacerbated by assigning authority to one group, which no doubt explains the observed preference for collaborative decision making in many of the focus groups.

When participants raised the possibility of using 'criteria', 'protocols' and 'guidelines' to assist priority-setting, they were prompted to say more about how this might work in practice, as well as what advantages and limitations might apply. The results suggest that the procedure by which priority-setting decisions are made is important to people. Indeed, it was via procedural checks and balances that some participants saw some of the more important goals of priority-setting (in a public system) being achieved: e.g. decisions have to be "dispassionate" and not driven by "vested interests". Whether these procedural factors are seen as valuable because they will lead to the best (i.e. most efficient and equitable) outcomes, or safeguard against takeover or safeguard against omission, or because there is intrinsic value in public participation per se, is another question for future research (Wailoo & Anand, 2005). But it seems reasonable to conclude that if policy makers seek legitimacy for their decisions they must give serious consideration to matters of procedural justice, and not focus exclusively on outcomes and their distribution.

Related to this, there was discussion at all levels about the appropriate role of the decision maker(s). Participants may agree, for example, that members of the public should have input into funding decisions at the program level, but they may disagree about whether this role should be

one of "dictator" (the public as sole decision maker), "voter" (the public influences the final decision along with other stakeholders), or "consultant" (the public has input into the decision making process but not the final decision) (See: Arrow, Sen & Suzumura, 2002). For example, at the system level there was disagreement about whether an expert panel (composed of eminent medical, allied health and community representatives) should actually make decisions, or should play only an advisory or policy formulation role, with decision-making left to the health minister and health bureaucracy. In general, there was very little support for any individual or group having the "dictator" role ("that is too much power resting with one person"), and instead widespread backing for processes involving shared decision making. Moreover, support for citizens and other groups having a "consultative" role was accompanied by an insistence that "iron clad mechanisms" be in place to ensure that decision makers actually listen to those bodies.

It was clear that participants in the present study saw a legitimate role for a broad range of stakeholders in priority-setting decisions. This was a significant theme to emerge across all focus groups. Allocating health resources across competing interventions and programs, in the context of resource limitations, raises difficult ethical issues. There has always been controversy about such issues, both among professionals and the public, and there is little prospect of disagreement being eliminated. This is not surprising, since every individual brings to his or her deliberations on ethical issues a unique mixture of sympathies, commitments, aversions, and so on, based upon personal experience. In implicit recognition of this, our participants advocated consulting a range of stakeholders, and shrank from the idea of leaving such decisions to a small number of individuals, or a small (homogeneous) group, who might have a particular viewpoint. There was, by contrast, significant emphasis on ensuring wide-ranging input into priority-setting decisions, incorporating a diversity of opinion.

8.   Conclusion

One noticeable feature to emerge from these focus groups was the sophistication of the views expressed, not only by the professionals, who might be expected to have thought about the issues, but also by members of the public. No previous focus group study on this topic has brought to the surface quite the same range of views regarding who should be involved in setting priorities in the health area. Several lessons can be drawn from this. First, the general public, as well as professionals, may be prepared to entertain a much wider range of solutions to the practical problems of who should be involved in priority-setting, and what mechanisms should be used, than has previously been supposed. Second, allowing open-ended discussions of ethical issues in a supportive environment allows participants to explore alternatives they may not have thought about, to think about their values more deeply, and to engage in public reasoning in justification of their views. Third, following on from the previous point, the results of the study suggest there is need for further research, particularly qualitative, to improve the legitimacy and accountability of policy decisions and to improve methods of values clarification.

Our hope is that the findings of this study will contribute to a better understanding of the values of the public, health professionals and health bureaucrats regarding the problem of priority-setting in the health area, and that this will lead to a more informed debate about these complex issues. It is also hoped the study will encourage others to continue to explore more qualitative and deliberative techniques for exploring community and professional values in this area.

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Table 1: Composition of the Focus Groups

Group	Category	Number of Participants	Characteristics
FG 1	General Public	7	Postgraduate students and researchers
FG 2		8	Primary and secondary school teachers and administrators
FG 3		4	Breast cancer survivors
FG 4		7	Tradesmen and building maintenance workers
FG 5	Health Professionals/ Administrators	6	City-based general practitioners
FG 6		4	Rural-based general practitioners
FG 7		11	Hospital-based allied health professionals
FG 8		7	State government health bureaucrats