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Interpreting public input into priority-setting: the role of mediating institutions

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Abstract

Discussions about public participation in health priority-setting have tended to assume that the best type of information about public values is that in which the public 'speaks for itself'. However, wherever public input has been used in priority-setting, the way in which it is used is far from transparent. Those jurisdictions that have initiated priority-setting processes have been characterised by the substantial involvement of 'mediating bodies' i.e. bodies such as the Oregon Health Services Commission or the New Zealand National Health Committee, that take on the role of *interpreting* information about public values. The information that they interpret is usually presented in a highly ambiguous form and most definitely does not 'speak for itself'. In the priority-setting literature, however, little attention has been paid to the role of these bodies and the way in which they interpret and digest information about public values. This article argues that these bodies are essential, but that their decision-making processes are necessarily opaque and should not be judged according to the criterion of transparency. © 2002 Elsevier Science Ireland Ltd. All rights reserved.

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1. Introduction

As health policy debates about priority-setting have developed over the past 10 years, one point readily agreed upon by those involved is that any policy formulation contributing to the setting of health priorities requires the involvement of the

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public. There are a number of reasons for this. One is the high visibility of health issues on the public agenda. Any attempts to move towards more explicit rationing and priority-setting decisions will inevitably attract a great deal of scrutiny. Health policymakers in those countries that have pursued a priority-setting agenda have generally taken the attitude that public support will be easier to achieve if the public is involved in the process. Another reason is that the issue of health priority-setting has been generally recognised as one which cannot be worked through on technical grounds alone. Value questions are almost universally recognised to be in the forefront of priority-setting. With the identification of the need to involve the public, a number of jurisdictions, most notably the US state of Oregon and New Zealand, made the political and organisational commitment to embark on such a course.

I argue below that the key question for those who advocate public participation is not 'how should information about public values be collected?' as much as 'what should be done with it and who should do it?'. However, little sustained attention has been paid to what happens to information about public values once it has been gathered. There is an enormous amount of literature that purports to outline the principles that should govern the elicitation of public input and the methodologies that should be followed [1]. By and large, the emphasis in this literature has been on trying to devise 'best practice' in the elicitation of public participation from first principles. In contrast, this article argues that the most important clues for best practice may be derived from an analysis of existing practices.

An important feature of policy processes that have developed in relation to priority-setting is the formation and operation of what I will call 'mediating bodies' or 'mediating institutions'. These bodies, such as the Oregon Health Services Commission, or the National Health Committee in New Zealand have played a prominent role in policy processes. However, very little of the literature that is used to support the elicitation of public input has much, if anything, to say about the role of these mediating bodies. Indeed, if one were to take this literature at face value, there would be every reason to be suspicious and dismissive about the capacity of these bodies to play a constructive role in priority-setting processes. The main reason for this largely negative interpretation of mediating bodies is that most justifications for public participation are based on the (largely implicit) ideal that *information about public values should 'speak for itself'*. This assumption remains embedded in debates about how to involve the public even though policymakers recognise at a practical level that there are some rather intractable problems that confront any attempt to let publics speak for themselves.

However, mediating bodies typically find it necessary to *interpret* the public voice rather than allowing the public to speak for itself. From this evaluative standpoint the presence of mediating bodies indicates at best a significant watering down of the ideal, and at worst a corruption of it. In contrast, I wish to argue that these mediating, interpreting bodies are *essential* to the enhancement of priority-setting processes that aspire to rationality and legitimacy. In practice, no government could or should proceed without them. What is needed is a greater acknowledgement of the role and functions of mediating agencies and more attention paid to what enhances their capacity to make wise interpretations of the meaning of public input.

The article proceeds according to the following line of argument. Firstly, I outline the ways in which unmediated public input is regarded as the ideal by which the rationality and legitimacy of policymaking can be evaluated, and how this ideal underpins a negative interpretation of the involvement of mediating bodies. Secondly, I argue that mediating bodies have been a constant feature of actual priority-setting processes that have involved public input, drawing mainly on the development of processes in Oregon, New Zealand and the United Kingdom. Finally, I develop the argument that mediating bodies can *enhance* both the rationality and legitimacy of priority-setting processes provided that we are prepared to accept alternative ways of thinking about rationality and legitimacy.

2. The rationality and legitimacy of unmediated public input

Arguments for including the public in processes of health priority-setting tend to be based on particular interpretations of rationality and legitimacy.[1] Two particular ideals regarding the use of public involvement have been dominant throughout the 1990s. The first is a technocratic approach that aspires to the accurate measurement of public values and the appropriate integration of this information into decision-making formulas. The second is a participatory democratic approach that sees the translation of public discussion and deliberation into priority-setting decisions as ideal. These approaches appear to have little in common. However, despite their enormous differences on how to elicit public input, both technocratic and participatory democratic arguments share two assumptions. The first is that good policy processes are those that gather clear and unambiguous information from the public about what it wants and then faithfully converts this information into clear policy priorities. The second is that legitimate policy making requires minimal or strictly delimited involvement from politicians, organised interests and government officials.

2.1. Rational policy requires transparent information

Transparency has become a key criterion for evaluating the rationality of policy processes [2]. Essentially, the case for transparency is a case that states that any observer will be able to see how the information collected in the policy process was used to make the eventual decision. In essence, it is a requirement that the

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[1] In practice, the two types of argument for public participation are often difficult to distinguish from one another. Many theoretical approaches that support greater public participation suggest that the two criteria are symbiotically related. They argue that techniques of public participation that are designed to produce more rational decisions have the added benefit of ensuring that processes of priority-setting have greater legitimacy. Similarly, those concerned primarily with involving the public for legitimacy reasons often claim that the information gleaned from mechanisms such as citizens' juries can help decision-makers to make more rational decisions. More often, these arguments are framed as critiques of existing policy processes. For instance, Alan Williams criticises implicit approaches to priority-setting as irrational and *therefore* illegitimate [3].

rationality be as 'objective' as possible. As Alan Williams puts it in his debate with Rudolf Klein:

> One of the main obstacles to progress is the clash of cultures between analysts who see the need for clarity and openness, and politicians (including the professional wielders of power within the health care system) who rightly feel vulnerable when their muddled thinking and inadequate evidence base are exposed to external scrutiny [3].

It is worth thinking for a moment about how information about public values could meet these criteria of clarity and openness. In the above quote, Williams was speaking of information per se, not just information about public values. Nevertheless, he has been a crucial figure in developing a method of analysis designed to enhance such clarity and openness, namely cost-utility analysis. The public input component is contained within the quality of life dimension that constitutes one dimension of the QALY. Public involvement is required to define the utility of health interventions and utility is one of the two key criteria used to assess the rationality of resource allocation decisions. The logic of public input into the quality dimension is that it should be possible to state definitively how the public have evaluated particular health states against each other and that this information could then be used to provide comparative measures of utility. The transmission of information about public values, therefore, is transparent in the sense that it does not require further interpretation.

Those that advocate techniques of deliberative democracy raise the transparency criterion in a very different way. Their ideal policy process is one that achieves public consensus based on open debate and deliberation in which the best arguments carry the day [4]. The type of information used to produce such public consensus is very different from that which is preferred by technocrats. Democratic deliberation would take into account all sorts of views and information that would not be captured through the more technocratic QALY approach. Most deliberative models regard consensus as desirable and achievable. The ideal form of decision-making that is aspired to in these models is one in which communities openly debate issues and eventually reach agreement. Thus, the discursive process requires consideration of the widest possible range of community interests and concerns. These are to be sifted through a deliberative process in which the best arguments carry the day. Such processes "can help to make public decisions more rational because they require officials to defend their decisions using arguments and evidence rather than rhetoric" [5]. Ultimately, it is the community itself that decides on best arguments, and therefore the best decision.

One detailed elaboration of a deliberative approach is that developed by Ortwin Renn and his colleagues in their formulation of the 'citizens' panels' model [5]. According to this model "(t)he major task of the citizens is to evaluate options and generate or modify policies" [5]. While some proponents recognise the problems in achieving a view of the general will through deliberative processes, they tend to put

these difficulties down to the distortions created by existing power structures. Powerful interests, therefore, are the main reason why transparency of policy rationality is difficult to achieve in practice [6]. This body of ideas has been very influential in the development of innovative approaches to citizens' involvement, particularly the development of citizens' juries in the UK [7]. By somewhat different routes, both technocratic and deliberative methods envisage a decision-making process that could be judged as rational according to whether or not it has followed the identifiable directions given by the public.

2.2. Legitimate policy requires minimal involvement of politicians and public officials

These rationality arguments are closely tied to a particular view of policy legitimacy. In the dock, as indicated by Williams' comment above, are politicians, government officials and interest group leaders who have a tendency to make policy behind closed doors because their interests are threatened if policymaking is subject to scrutiny. Once again, this claim has a technocratic and participatory democratic version. The complaint of technocrats is that policymaking by public officials, interest groups and politicians lacks legitimacy because each of these actors has a propensity to ignore technical evidence if and when it suits their interests to do so [8].

A different type of distrust is that associated with the view that public policy making has been subject to a significant 'democratic deficit' [7]. Representative institutions are not capable of effectively translating the public will into policy as the whole structure of representative government creates a tier of actors whose interests often run counter to those of the public at large [6]. Deliberative democrats do acknowledge the role for public officials and intermediate bodies in facilitating democratic deliberation. However, this role should be limited to 'making suggestions about options and to providing testimony to the citizen panels' [5]. Clearly, the role of government agencies is to support the decision-making capacity of citizens' groups rather than the other way around. Such assumptions are also present in Arnstein's well-known ladder of citizen participation in which 'citizen control' is located at the top, above 'delegated power' and 'partnership' [1]. Similarly, those who favour a technocratic approach recognise the need to operate within an institutional framework. However, they tend to imagine the role of governmental institutions as analogous to transmission belts. While facilitation may be necessary in order to create frameworks for others (either technical experts or democratic communities) to work within, both perspectives implicitly regard the active intervention and interpretation of evidence by government agencies as something that should be kept to a minimum.

If we put all this together we have a particular view of the way in which information about public values should be included in the policy process. As far as possible, public input should speak for itself, that is to say, it should not require interpretation and mediation by other actors lest the real message from the public be diluted, distorted or ignored altogether. From either version of this broad

perspective, it is easy to conclude that public involvement as currently practised in relation to priority-setting issues falls well short of the ideal and could therefore be regarded as a waste of time. These ideals are rarely expressed in 'pure' form in the priority-setting debate. Nevertheless, they are significant because they underpin the prevailing negative image of political institutions and mechanisms.

3. Public participation and priority-setting processes

3.1. The experience of priority setting

Given nearly 10 years of experience one may well think that it is now possible to assess the impact of public participation on priority-setting policymaking processes. However, there is a fundamental difficulty in actually identifying the outcome of particular initiatives. There is a dearth of examples of attempts to construct explicit priority-setting frameworks that have involved public input. Oregon's prioritised list is by far the most well-known and it would dwarf any other identifiable example.

But to limit our analysis to clearly identifiable frameworks of explicit priority-setting would miss much that is important about both the processes of priority-setting and the use of public input. Most exercises in public input are steps in continuing processes that have no specific end-point or decision-point. Priority-setting processes, as the advocates for explicitness constantly remind us, take place whether or not decisions are explicit or not. If this point is taken seriously we need to widen the ambit of inquiry. As it turns out, this is not so difficult because the principles outlined in the earlier section can be applied regardless of the presence of a 'visible' priority-setting policy. Critics from these standpoints do not need to wait and see what the results are. The techniques and processes can be judged in terms of methodological and normative principles before any outcomes become apparent.

In looking at the experience of public involvement I make no attempt to exhaustively cover the range of exercises that have been undertaken. That would be far too complex a task, and in any case of dubious value. My main sources are examples and settings with which this audience should be familiar—those that have been most widely reported and dealt with in the literature. These include the Oregon exercises in the early 1990s, the public consultation exercises carried out by New Zealand's National Health Committee (formerly the Core Services Committee) and the numerous exercises in public involvement in the United Kingdom, most of which have taken place at the level of local health authorities. One restriction on the range of examples drawn upon in this discussion is that the views of the public are sought as new or additional information for the policy process. Practices of consultation that are primarily directed to informing the public or attempting to achieve consent for decisions already taken are beyond the scope of this discussion. Table 1 lists some examples of public involvement in priority-setting, particularly the more well known examples that have received significant coverage in the literature.

Table 1
Some examples of public involvement in priority-setting

Location	Exercise	Mechanism	Initiated by:	Did it lead to identifiable priority-setting decisions?	Reactions
Oregon	Construction of quality-of-well-being (QWB) scale	Telephone survey	Oregon Health Services Commission	Was used in the early stages of development of the Oregon Health Plan (1990)	Substantial criticism, use of telephone survey led to the federal rejection of Medicaid waiver request
Oregon	Identification of community values re health care	Open community meetings	Oregon Health Services Commission (carried out by Oregon Health Decisions)	Not directly, information was made available to the Health Services Commission	Some methodological criticism, particularly about representativeness of participants
New Zealand	Identification of broad health care priorities	Open community meetings	Core Services Committee	No, identified six broad priorities to inform policymakers (Best of Health 1), and four overarching priority-setting principles (Best of Health 2)	Fairly neutral generally—good feedback from those consulted
New Zealand	How much should social criteria determine prioritisation of access to surgery	Focus groups	National Health Committee	The use of social factors in scoring systems was limited to three criteria and 10% of booking system score	A very specific issue—some adverse reaction to overall booking system rather than this issue
United Kingdom	Specific service related questions (e.g. mental health, back pain management)	Citizens juries	Local health authorities (some with assistance of policy research organisations)	Generally, juries led to recommendations about future processes	Favourable responses from those involved

4. Rationality and the use of public input

4.1. 'Transparently rational' use of public input

In Table 1 there are few available examples of public input *directly* determining priority-setting decisions. Perhaps the closest approximation we can find is the attempted use of QALYs in the early stages of development of the Oregon Health Plan. Undoubtedly, Oregon policymakers wanted to produce information about public values and preferences in order to enhance the rationality of the framework. In the very early stages of the Oregon Health Plan's developments, the Oregon Health Services Commission hoped that the information derived from the quality of well-being survey would, along with cost, be the most significant driver of the prioritisation process [9]. However, one thing that became abundantly clear from a public meeting in May 1990 was that the cost-per-QALY mechanism would not be able to bear the weight of expectations on its own. As has been noted numerous times, the data were far too unreliable, there was far too much guesswork and the products of the analysis were highly counter-intuitive [10].[2]

If we take into account that at the time Oregon was going boldly where no jurisdiction had ever gone before, such difficult experience could be attributed to teething problems such as poor quality data [11]. However, I think the early Oregon experience draws attention to more fundamental problems with 'self-executing' analysis of information about public values, and, indeed, any sort of technocratically derived information. Put simply, these methods offer ample opportunity for opponents to attack and challenge the rationality of these processes. Allowing public input to speak for itself in this way implies that it is not necessary to check the results against 'common sense'. They therefore provide a 'sitting-duck' target that can be challenged on any number of grounds—philosophical, methodological or practical. All it needs for such arguments to be 'activated' is for opponents of the policy to be present. The transparency of methodology for deriving quality of well being measures gave the federal government the material to build a case against Oregon because they could claim that the methodology systematically discriminated against the disabled.[3]

This is the downside of transparency. All methodologies aimed at 'rationalising' public input are highly sensitive to particular assumptions and operational decisions [12]. Change the assumptions and operationalisations ever so slightly and you can end up with quite different 'objective' data. In a policy area as complex and volatile as health, it makes little sense to base decisions on processes that can be challenged and undermined so easily. The high sensitivity of the evaluations of quality of life to methodological decisions has been clearly demonstrated. It is almost certain that Oregon's plan would have been challenged on technical grounds even if the early version of the list had not been counterintuitive.

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[2] The draft version of the list presented to this meeting was regarded as highly counterintuitive OHSC members refer to this episode as the 'data-dump'. From this point, their approach changed substantially to a much greater emphasis on the collective judgement of the Commission.

[3] The basis for this argument, it should be pointed out, was flawed. Federal health officials failed to take into account that people without disabilities scale disabilities on the QWB index far lower than people with disabilities.

This has significant implications for policymakers aspiring to a technocratic version of transparent rationality. If the use of technical information in policy decision-making is to be transparent, the types of information used must be kept to a minimum and assumptions must be made as simple as possible. The more factors one attempts to include, the more scope there is for arbitrary judgements regarding how the different types of information should be weighed against each other. Technocratic approaches are caught in a bind. If they keep things simple, this simplicity is politically vulnerable because so many considerations have been excluded. But if they opt for approaches that try to capture complexity, the grounds for political challenge are multiplied and transparency is greatly reduced. The cost of transparency, therefore, is inevitably the complexity and richness of information. And with the inevitable simplification of issues that is required by transparency comes a high degree of vulnerability to charges of irrationality. If priority-setting policies have opponents (and they usually do) then aiming for transparency amounts to handing weapons to an opponent.

From a completely different methodological starting point, citizens' juries are often advocated as the mechanism of choice of those that favour a deliberative democratic approach to letting the public 'speak for itself' [7]. But none of the citizens' jury processes evaluated by Lenaghan et al. [13], McIver [14] and Needham [15] could be described as letting the public 'speak for themselves'. All involved reporting back to the commissioning health authority that was required to respond. In any case, even when issues for deliberation were defined fairly tightly, they rarely produced results that might resemble specific priority setting decisions. For example, the jury in Buckinghamshire was set up to deliberate on the treatment of back pain in the local health authority. Its recommendations tended to concentrate more on future processes of decision-making rather than making clear substantive decisions to shift resources from one set of treatments to another [15].

In the absence of specific examples of 'self-executing' citizens juries for priority-setting, one could easily imagine the sorts of political problems a local health authority would face if it commissioned citizens' juries to come up with binding decisions. The jury's reasoning would be subject to considerable analysis, and there would also be numerous grounds for challenging the jury's rationality. Empowerment of citizens starts to take on rather different connotations when there is responsibility attached to power. What would happen when the jury's reasoning is questioned by experts and experienced interest groups—i.e. policy actors who have had a lot more time and experience available to them in formulating their arguments than members of the jury? McIver's evaluation of citizen juries reported that many jurors themselves voiced considerable doubts about whether or not the products of their deliberations should be binding [14].[4]

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[4] Although there are indications that some British local health authorities, such as Leicester, are moving towards a process in which the deliberations of citizens' juries become binding. It will be well worth watching how these processes develop over the next few years.

In summary, mechanisms such as cost-utility analysis and citizens juries cannot be expected to bear the weight of expectations that they can effectively translate public views, values and priorities directly into explicit priority-setting decisions. The 'direct' or 'unmediated' approach to the use of information about public values is beset by too many obstacles to warrant serious consideration even as a policy-making ideal. Indeed, it would be fair to say that most practitioners have come to exactly the same conclusion. The problem that confronts them once they have accepted this, however, is that the alternative way of using public input is still regarded as normatively suspect. The only way of 'rationalising' their pragmatism is to resort to arguments that 'theory is fine but it doesn't work in practice' [16].

4.2. 'Opaquely rational' use of public input

By far, the overwhelming majority of uses of public input into priority-setting decisions depart significantly from the ideals of transparent rationality and minimal influence from public officials. In virtually every case information gleaned from public input was commissioned by a particular government agency and, most importantly, was designed to be digested by that authority. As the Oregon Health Plan is probably the closest approximation to a clearly delineating process with an identifiable outcome, it is worth taking a closer look at the process of public input.

Oregon Health Decisions, a non-governmental consultancy based at Oregon Health Sciences University, was given the task of organising a series of community consultations on the topic of the proposed Oregon Health Plan. Members of the Oregon Health Services Commission have always emphasised that the prioritisation of conditions in the Oregon list took into account the public input garnered from the Oregon Health Decisions forums. Nevertheless, in the terms described above, this process was a long way short of being transparent. Many of the methodological questions posed by Mullen in her checklist simply cannot be asked [1]. There was no attempt to aggregate responses (either of individuals or groups), and no attempt to offer constrained choices. The OHD process simply listed important values and interpretations of them by noting the number of times they were mentioned at the town hall meetings. Nor could the process be characterised as neutral facilitation along the lines proposed by Renn et al. The meetings were clearly used as opportunities to evangelise to the public about the serious nature of the issue of inadequate health insurance coverage in Oregon and in the USA more generally.[5]

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[5] The script for facilitators was as follows (OHSC 1991: Appendix F)

Following introductions at the tables, the meeting facilitator says:
"We have a very important task this evening.. Before we get to work it is important to understand why we are here."

INTRODUCTION BY FACILITATOR
Of all the industrialized nations in the world, there are only two which do not provide healthcare to all their citizens: the United States and South Africa.
The United States is now facing a crisis in health care. The crisis is forcing a change in the way the federal

This raises the broader issue of agenda-setting. However open the OHD sponsored meetings were, the agenda (the consideration of how to make priority decisions *between* service categories) was established prior to the 1990 community meetings.

In addition, the public participation process was roundly criticised at the time because of the unrepresentative profile of the participants in community discussions [18,19]. Far from being a sample of the general public, most participants were involved themselves in the delivery of health care services. Finally, as Mita Giacomino has argued, the scheme of categorisation of health services went through several iterations such that it is not clear how the 17 broad categories that structured the eventual prioritised list of 1994 related to the categories that members of the general public discussed at the meetings in 1990 [20]. Despite all these alleged deficiencies, however, members of the Oregon Health Services Commission consistently refer to the importance of those community meetings as providing information on public values that they used as part of their deliberative processes [19].[6] Oregon Health Decisions continues to conduct public forums, the results of which are fed into the OHSC's processes [21].

The New Zealand Core Services Committee (later the National Health Committee) adopted a similar approach to the development of its mechanisms of gathering public input. None of its exercises in public engagement were designed to produce definitive, unambiguous information. All information required the active interpretation of the Committee [22]. Knowledge gained from these information-gathering exercises was channelled into the further development of processes rather than the production of explicit decision-making frameworks [23]. As with Oregon, none of this information took the form of the public 'speaking for itself'. The National Health Committee had considerable latitude for judgement in the way this information was used.[7]

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government, the states, and Americans view our health system.

There are over 37 million uninsured Americans and insurance rates are growing an average of 20% a year—twice the rate of inflation. Several states have started advancing proposals for universal access to health care. Oregon is at the forefront of those efforts.

You have been asked to attend this community meeting tonight aloong with hundreds of other Oregonians in 49 similar meetings around the state to participate in developing Oregon's plan for universal access to health care. Your time, your involvement, your willingness to come to this meeting is critical to the success of Oregon's plan. We thank you.

For the next 15 minutes, I will give an overview of the health crisis in Oregon and then focus in on our responsibility at this meeting. After that we will have 10 minutes for questions and answers. Please hold your questions until the slide show is over.

[6] Leichter quotes an example given by one of the commissioners in which the Commissioners let community preference for preventive services influence the ranking of these services more than the doubts of physicians as to their effectiveness ([19], p. 1961). A more recent example of a similar dynamic involves the ranking of services associated with physician-assisted suicide. Commissioners claimed that community sentiment overruled Commissioners' preferences (interview with Darren Coffman, July 12, 2000).

[7] Coast [23] notes that there were changes in titles of some of the priorities, even though the Committee reports that these priorities were simply confirmed.

New Zealand's clinical guidelines groups developed within this broader NHC approach and their approach to citizen input is based upon a similar logic. However, this time the device of community consultation and deliberation is facilitated through the involvement of trained and informed community representatives on the guidelines groups themselves [22]. One example of public input contributing to an identifiable decision is the decision to limit the use of social criteria in determining access to coronary artery bypass graft surgery [24,22]. The Committee's conclusion that 'lifestyle' and behavioural issues should not be included in the priority scoring system was based on its interpretation of the views of members of the public that were ascertained through focus groups [22].

The use of citizens' juries in the UK as a mechanism for public involvement points to a similar way of dealing with knowledge about public values and decision-making processes. As with the Oregon process, the pattern that emerges from the use of the citizens' jury process is that they are used to provide public input that is *interpreted* by another party, be it the health authority, the local NHS trust or some other actor. All the jury processes evaluated by McIver produced outputs in the form of *recommendations* to local health authorities. For example, juries in the Kensington, Chelsea and Westminster authority recommended "the need for constant liaison between all the agencies involved in caring for people with mental health problems" [14]. Decision-makers have ample scope to do what they will with the recommendations arrived at by the jury. In each of the juries, the local health authority took the recommendations seriously [14]. But McIver then notes that, as far as the health authorities were concerned, the most significant benefits of the jury process were the capacity to find out whether proposed services stood up to public questioning and debate [14]. In contrast, the capacity of the juries to bring new information to the decision-making process "did not appear to be a major criterion of success for the health authorities concerned" [14]. Most of the discussion in the literature on citizens' juries in health priorities concentrates on whether or not the public is "willing and able to contribute" to health decision-making [13]. Once again, the process of transformation of public input into substantive decisions is highly opaque. But it seems this situation is regarded as preferable by both the health authorities that commissioned the juries, and the juries themselves [13,14].

4.3. Opaque rationality and mediating bodies

Mediating bodies such as the Oregon HSC, New Zealand NHC and British local health authorities are the most important features of the institutional landscape of priority-setting and appear to have a pivotal role to play in making priority-setting processes more rational.[8] However, important objections have been raised about the seemingly arbitrary nature of the judgements made by such bodies. Given that mediating bodies such as Oregon's HSC or New Zealand's NHC have taken such

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[8] An important recent development is the dissemination of the 'priorities forum' model originated by the Oxfordshire Health Authority [25]. Such forums could take on similar roles within health authorities as the HSC and NHC take on at the provincial or national level.

a central role in interpreting public input, what can be said about the rationality of their interpretations? In particular, in what ways do members of these bodies regard their deliberations as rational?

One possible argument is that there is a rationality that emerges from processes of 'pluralistic bargaining' [23,26]. Through discussion, negotiation and compromise, different stakeholders agree on particular policy decisions or frameworks, without necessarily agreeing on the reasons and values behind such decisions [27]. According to this view, these mediating bodies could operate as mechanisms of corporatist interest representation. However, this account of the function of mediating bodies misses something crucial. While the Oregon HSC and New Zealand's NHC may have been selected according to considerations of 'balance' in mind, they are not intended to be vehicles of interest representation. Indeed, participants in these bodies emphasise that formal interest representation is more likely to be an obstacle to good policy-making on this issue.[9] It would not be accurate, therefore, to characterise the workings of these bodies in terms of negotiation and bargaining from set positions. Rather, the rationality is something that emerges from an initial commitment to the group. It is a 'group rationality' of people that develop a like mind as a consequence of their discussions and deliberations.[10]

One could easily view this as self-serving justification. Nevertheless, I think such an articulation of the rationality of mediating bodies is of greater significance and therefore should not be dismissed out of hand. I would argue that it is only agencies of this type that enable the 'digestion' of complex sources of information and knowledge. If information relevant to priority-setting is inherently multi-faceted and not reducible to transparent algorithms then a more organic rather than mechanical approach is called for. This digestion of complex information—making some sense of disparate information—is a highly demanding activity. It is not easily amenable to systematisation. It primarily requires *judgement*—rather than the systematic application of rules and principles. The OHSC is quite clear about this. The original draft of the Oregon Health Plan list states that the list is a 'combination of ranked categorisation and Commission judgement'.[11] Under this heading, the report elaborates further:

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[9] Interview with Wendy Edgar of the NHC in New Zealand (7 February, 2000), interview with Barney Speight, former administrator of the Office for Oregon Health Plan Policy (17 July, 2000).

[10] A number of people involved in the Oregon HSC remarked in interviews that similar interpretations of the evidence before them (including evidence collected from public participation processes) would have been offered by any informed and reasonable observers. This is an intriguing claim. The HSC's room for interpretation has been very wide, particularly during the process of 'hand-adjustment' between 1991 and 1993. Such a claim is impossible to prove either way. But such claims are highly significant in that members of these bodies clearly believe that the process of interpretation is robust and even 'objective'.

[11] This was at a point in the process in which the cost-utility analysis was still included.

The Commission used professional judgements and their interpretation of the community values to re-rank items on the draft list… The Commissioners used a ''reasonableness'' test when they adjusted the objectively ranked health services. The ''reasonableness'' standard was applied by evaluating the public health impact, cost of medical treatment, incidence of condition, effectiveness of treatment, social costs, and cost of non-treatment to determine a new ranking [17].[12]

Because the Commission actively employs its judgement it is not that necessary for the information collected to be objectively interpretable through a transparent rationality.

Those who support a more technocratic approach are uncomfortable with the role of judgement. For instance, Alan Maynard says in relation to Oregon: '(u)unfortunately because of the injection of judgement and opinion about reasonableness it is not clear how the ranking was reached' [28]. Similarly, Caitlin Halligan has lamented that the OHSC's criteria for reasonableness was somewhat ad hoc [18]. Halligan is highly critical of the role of the Oregon HSC on the grounds that it substituted a process that was vague and highly dependent on the Commissioners' subjective judgement for one that elicited a clear view of public priorities (i.e. the QWB measures in cost-utility analysis). Referring to the hand-adjusted decision to rank preventive services and treatments for pregnant women and children above treatment of illnesses in advanced stages, she argues:

It justified this decision with vague references to community values rather than with any ''scientific'' evidence as to why prevention and treatment of women and children should trump other types of care. … Only subjective preferences for one type of care over another, then, can explain OHSC's choice [18].

In my view, though, the very thing that Halligan sees as problematic—i.e. the fact that Commission decisions do not stand up to the scrutiny of applying consistent, logical principles—may not, in itself, be objectionable. Good judgement need not be reducible to clear principles. Given the complexity of information and the vast potential for conflict between different principles of evaluation, the requirement for logical consistency is far too demanding and the results are likely to disappoint. A good example of this would be the 'hand-adjusted' shift in the ranking of tuberculosis. The OHSC's allocation of conditions to seventeen categories originally placed tuberculosis in the fifth-ranked category—chronic fatal conditions. Without hand-adjustment, this would mean that tuberculosis would probably have been ranked somewhere between 200 and 300 on the list [17]. Yet the commission hand-adjusted tuberculosis to number 2 in the 1991 draft list, presumably on the basis that the condition had a particular characteristic—conta-

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[12] Appendix G, p. 15.

giousness—that was not shared with most other chronic, fatal conditions such as end-stage renal failure. This decision is defensible, without necessarily being transparent. The 17 category process used as the basis of the list may have been useful for the ranking of most, but not all, of the conditions.

Because of this, the OHSC and other bodies like it need not be too concerned with demonstrating that their judgements are objective. The real value of such bodies is that they actually have the *capacity* to make judgements. The purpose here is not necessarily to defend the substance of OHSC's decisions, or those of any other mediating body. Rather, some type of 'unsystematic' rationality is probably the only practical way of dealing with the type of informational complexity that characterises priority-setting.

This is not to say that such bodies should not be obliged to explain their decisions. Certainly, *reasons* for decisions should be articulated publicly. However, in my view the articulation of reasons hardly amounts to 'transparent' rationality, nor should it be expected to. A transparent form of reasoning would be objective in the sense that any actor, given the same information and considerations, would come to the same decision. Judgement, by its very nature, cannot be transparent in this way, a point well understood by those who study legal processes.

5. Legitimacy and mediated public input (trust)

Advocates of more deliberative processes would no doubt agree that 'digestion' of complex information, including information about public values, is preferable to a more mechanistic approach to the interpretation of public input. Nevertheless, deliberative democrats would have grave reservations about the legitimacy of these mediating bodies because experts dominate such bodies. It would be far better, they would argue, that the public itself does the deliberating. Expertise represents relations of power and structures of domination, and even the development of 'expert deliberators' is something to be avoided lest new structures of domination be created [6].

Expert domination of the Oregon Health Services Committee is mandated by the Oregon legislature. The Senate Bill stipulates that:

… five members shall be physicians licensed to practice … who have clinical expertise in the general areas of obstetrics, perinatal, pediatrics, adult medicine, geriatrics or public health. One of the physicians shall be a Doctor of Osteopathy. Other members shall include a public health nurse, a social services worker and four consumers of health care [17].

Commissioners are selected on the basis of their expertise and experience in the health sector. However, they are not selected as 'representatives' of identifiable interest groups. Participants in the New Zealand NHC also regard their legitimacy as based on their aggregated experience in the health sector and the capacity of

members to suspend their particular professional allegiances and perspectives.[13] More recently, the composition of 'priorities forums' in British local authorities shows similar composition.[14]

The common denominator in all these mediated approaches is that the citizens are being asked to *trust* the judgement of these bodies that mediate the public's input because they have experience of judgement. Trust, or at least trust in political institutions, tends to be underestimated as a possible source of legitimation. A useful definition of trust is that offered by Aniel Mishra:

> Trust is one party's willingness to be vulnerable to another based on the belief that the latter party is competent, open, concerned and reliable ([29], p. 265).

Such a definition fits well with the distinction commonly made in studies of democratic representation between 'delegate' and 'trustee' representation ([30], ch. 5). Delegates are required to do what their constituency wants (i.e. translate constituency preferences into action) and are judged according to whether or not they have done so. It is assumed that the preferences of the particular constituency can be distinguished from the preferences of the whole. Trustees, on the other hand, are asked to put constituency concerns at a distance and make decisions on behalf of the whole. Trustees are evaluated on their performance, and the criteria used are likely to be those that make up Mishra's definition above. Trust, therefore, provides a different underpinning of legitimacy to that which is provided by mechanisms of representation.

When evaluating mediating bodies such as the Oregon Health Services Commission or the New Zealand NHC there are a number of possible grounds for withholding such trust, or at the very least taking a sceptical attitude to requests for such trust. Halligan's basis for scepticism is that such bodies may be no more than mouthpieces of professionals and clinicians. She does not place much store in the fact that only 5 of the 11 OHSC commissioners are clinicians (unless one regards community and mental health nurses as clinicians). Without doubt, she would be even less impressed with the New Zealand guidelines processes that are clearly dominated by clinicians, with the public view only present via the trained consumer representative. Such mediated and opaque approaches could be argued to be against the spirit of public involvement in that they provide a device for 'taming' public input.

Is it possible to argue that these mediating bodies can legitimately claim the right to interpret public input? A relatively straightforward response is that these bodies have been mandated to take on such a task by the elected authorities. Oregon Commissioners typically identify the clause in the original Senate Bill that authorised the prioritisation process that requires the HSC to act in accordance with

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[13] Interview with Wendy Edgar (7 February, 2000).
[14] Although these are also likely to include 'ethical experts' [25].

public values. It is difficult to imagine how they might do so without being given discretion for interpretation. As with other processes grounded in legislation, the legislature is there to oversee the activities of the HSC and it is through this route that the public could challenge the deliberations of the Commission. The New Zealand National Health Committee can also point to its legislative mandate that also requires this body to gauge public input.[15]

The deliberative democracy perspective somewhat misconstrues the activity of experts. Clinicians and other service providers do not rely so much on scientific or technocratic expertise as much as ethical experience [31]. Theirs is the experience of making difficult decisions in contexts in which ethical judgements may conflict and information is ambiguous. This is exactly the type of background that is desirable for involvement in priority-setting policy processes. Furthermore, instead of a divergence of political interests between professionals and the public on priority-setting, their common interests seem to be more important [32]. Advocates of direct public involvement typically offer general arguments why professional expertise should not be trusted [33]. However, in the case of priority-setting, the public may well be saying that it is necessary for trust to be placed in clinicians and service providers [34]. The trick in enhancing the legitimacy of priority-setting decisions lies in supporting the development and maintenance of trust rather than in undermining it through hyper-democratic questioning of all expertise.

It is impossible to legislate for trust, so while formal mechanisms may be important in setting the frameworks for policymaking they cannot, by themselves, guarantee the legitimacy of bodies that take on the role of mediating the public voice. One of the keys to trust, ironically, is the depoliticisation of such bodies. In Oregon, such depoliticisation was achieved through a separation of responsibilities—political operatives handled the stakeholder issues and more or less successfully ensured that the HSC's deliberations did not become a site for broader debates about the Health Plan itself. In New Zealand, the CSC/NHC depoliticised itself, distancing itself ever so carefully from the highly partisan agenda under which it was created, a strategy that (perhaps ironically) secured its long term survival.

Nevertheless, to what extent have these bodies managed to generate trust? Probably the key condition for trust in the process is public and stakeholder acceptance of the policy substance that is produced by the process. Broader public judgements of the legitimacy of priority-setting processes may ultimately be dependent upon public acceptance of the substance of priority-setting decisions where they are identifiable. If the public is supportive of outcomes, there is less chance that the process will be questioned. But if outcomes are problematic, processes will be subject to much more scrutiny.

Once again, dynamics in Oregon illustrate this point rather well. I would argue, in agreement with Jacobs, Marmor and Oberlander, that broad public acceptance of the legitimacy of Oregon's priority-setting process in the late 1990s—and the

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[15] The situation is less clear with bodies such as guidelines groups or priorities forums within British local health authorities as the authority for these processes tends to originate from professional bodies rather than from the political executive or legislature.

role of the Health Services Commission within that process—is certainly dependent upon public acceptance of the substance of the plan [35]. Public acceptance of the substance of the plan has been predicated firstly on good political management—keeping all the important stakeholders on board—and secondly on the fact that the plan significantly expanded access to health services, a luxury not available in other jurisdictions that embarked on explicit priority-setting. Still, what is intriguing about the Oregon experience is that there are so many possible grounds for criticising both the rationality and legitimacy of the processes that underpin the Oregon Health Plan. The fact that these criticisms have had little impact within the state is primarily attributable to good stakeholder management [35]. This wider top-level political protection allowed the Health Services Commission to operate in a less politicised and contested environment.

The reverse image of this point is that mediating bodies may have difficulty gaining or maintaining public trust if they are seen to make identifiable decisions that adversely affect some groups or individuals. A key test of legitimacy is the degree to which policy 'losers' accept the process by which they lost. This is inherently difficult in priority-setting because, unlike other policy areas, the identity of losers is clear once decisions have been made, but is almost impossible to specify in advance.[16] By way of contrast, most participants in elections in western democracies agree on the rules (the process) by which winners and losers are decided. Participants know they are potential losers, and therefore take an interest in the rules that define the electoral process. Without this possibility of potential losers agreeing to the process in advance, the legitimacy of mediating bodies is inherently fragile.

But while the legitimacy of mediating bodies may be fragile, it is infinitely stronger than the legitimacy of unmediated approaches. The 'direct' approaches of allowing the public to 'speak for itself' are justified on the basis that the raw public has a more legitimate role in determining policy than mediating bodies. Yet, as soon as these arguments take a concrete form of a particular methodology (citizens juries, cost-utility analysis) they become vulnerable to attack on grounds of representativeness, authorisation and the definition of the public itself—the very same sort of criteria used to attack mediated or representative methods.[17] Once again, it is important to emphasise the significance of trust as the basis of mediating bodies' legitimacy. If trust can be regarded as an alternative basis of legitimacy to representativeness (remember that these bodies do not see themselves as representing constituencies), then these bodies can defend their legitimacy in terms of their collective capacity to judge rather than their individual command of expert knowledge.

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[16] To use the British Child B example [36], the father of Jaymee Bowen was readily identifiable as someone who has 'lost' as the result of the priority-setting decision. However, it would have been almost impossible for the health authority to identify Mr Bowen as a 'potential loser' when it was formulating its priority-setting criteria. Therefore it is difficult for them to claim that Mr Bowen consented to the process. See also the New Zealand cases referred to by Feek et al. [37].

[17] See Lomas [38] and Mullen and Spurgeon [1] for the best discussions of different ways of identifying 'the public'.

I am not necessarily arguing across the board for trust-based legitimacy. Instead, I think that it is well worth exploring their usefulness simply in relation to health priority setting. Regarding priority-setting, there is little likelihood of mediating bodies being given a 'blank cheque' of trust. Any trust placed in them, or absence of distrust of them, is a product of the decisions they make (and perhaps even those that they do not make). Ultimately, this fragile basis of legitimacy means that mediating bodies rarely produce tough priority-setting decisions. I do not believe that there have been any identifiable examples in which public dissatisfaction with the substance of the decision is allayed by acceptance of the process underpinning it. As such, where mediating bodies have explicitly taken aboard public input, they have tended to do so in order to justify inclusion of services rather than exclusion, serving to soften rather than harden priority-setting.[18] Whether or not one regards this softness as desirable, this type of policymaking is preferable to and more realistic than approaches based on the hope or expectation that the public will 'speak for itself' *and* make tough, explicit priority-setting decisions. While there is evidence that getting the issue of priority-setting onto the public agenda has the effect of encouraging greater willingness for citizens to accept the inevitability of rationing [39], this does not yet translate into a capacity to make difficult choices directly. For those who are frustrated with the role of bodies such as New Zealand's NHC or Oregon's HSC it would be more honest to advocate an approach to priority-setting that minimised public involvement than to hope that tighter methodologies of public involvement would produce explicit priority-setting decisions.

6. Conclusion

Input on public values is commissioned by governmental agencies and it is received in forms that require active interpretation. Little if any information about public preferences speaks for itself. Yet if we look at literature that is prescriptive about public input, little if any attention is paid to the question of interpretation. Rather, the involvement of mediating bodies is regarded more as a possible impediment to more rational and legitimate priority-setting processes. Public involvement is an indispensable element of decision-making processes of resource allocation in health. Exercises in public involvement provide some of the raw material for policymakers. But information that is raw and that has to be swallowed whole (i.e. undigested by mediating bodies) will probably be regurgitated by the policy process.

Some form of opaque rationality is therefore essential. The institutions that support it require attention. But do opaque processes lead to more rational and more legitimate decisions? We would expect that mediated interpretation of public input might be subject to criticism as to its rationality and legitimacy if it

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[18] For Oregon, see [6] above.

consistently led to 'tough' decisions. Opponents of priority-setting would have ample grounds for challenging the process and the 'right' of these bodies to interpret what the public was saying. However, reviewing the experience of priority-setting over the past 10 years, we see little of this. That is because opaque interpretation of public input generally doesn't produce tough decisions. Accordingly, these bodies are more subject to a different type of criticism from those who push for explicit priority-setting frameworks—that they are not tough enough. Consequently, priority-setting processes that emphasise the role of mediating bodies are seen as lacking rationality and legitimacy because they lack toughness.

The biggest mistake of those that aspire to transparent rationality and minimal institutional involvement is that they imagine a world in which arguments about the rationality and legitimacy of policy will, ultimately, be resolved. They imagine that there are policy processes and decisions that can universally be recognised as rational and legitimate, and that it is appropriate for policymakers to aspire to this as a goal. My argument is that it is far better to assume that there will always be debate and argument about the rationality and legitimacy of policy processes—and this is particularly the case in relation to priority-setting. By their very nature mediating bodies are capable of actively participating in policy debate, defending their interpretation of public values, in ways that would not be possible if we expected the public to speak for itself. Only mediating bodies have the capacity to explain their reasoning.

For committed advocates of explicit priority-setting, mediating bodies may be unsatisfactorily soft, but surely this is better than policy that is self-defeating. I suspect, though, that the greatest significance of mediating bodies lies in the fact that they are able to learn from experience. Opaque mechanisms for digesting public input are far better equipped to deal with the rapidly shifting contingencies of policymaking arenas than transparent mechanisms that attempt to create spaces for the public to speak for itself. They are capable of building institutional memory—a feature of policy that is generally ignored by advocates of greater transparency.

The broad thrust of this argument supports Rudolf Klein's contention that 'institutions matter more than information' [3]. This doesn't mean that there is no point to trying to develop better methodologies for eliciting public input. Methodological improvement is admirable as long as it is not accompanied by the belief that methodological sophistication can solve fundamental political problems. The production of information is a crucial support for the application of judgement. The chief concern of policymakers, however, should be to concentrate on the structures and institutions through which information is interpreted. If these are robust then getting the methodology absolutely right becomes less of a pressing concern. Ultimately, policymaking is more art than science [40–42], so the priority of institutional design should be the creation and maintenance of bodies that are able to develop a sufficient degree of talent and proficiency of judgement.

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