Participation in health care priority-setting through the eyes of the participants

Douglas Martin1,2, Julia Abelson3, Peter Singer2,4
1Department of Health Policy, Management and Evaluation; 2Joint Centre for Bioethics, University of Toronto; 3Department of Clinical Epidemiology and Biostatistics, McMaster University; 4Department of Medicine, University of Toronto, Canada

Objectives: The literature on participation in priority-setting has three key gaps: it focuses on techniques for obtaining public input into priority-setting that are consultative mechanisms and do not involve the public directly in decision-making; it focuses primarily on the public’s role in priority-setting, not on all potential participants; and the range of roles that various participants play in a group making priority decisions has not been described. To begin addressing these gaps, we interviewed individuals who participated on two priority-setting committees to identify key insights from participants about participation.

Methods: A qualitative study consisting of interviews with decision-makers, including patients and members of the public.

Results: Members of the public can contribute directly to important aspects of priority-setting. The participants described six specific priority-setting roles: committee chair, administrator, medical specialist, medical generalist, public representative and patient representative. They also described the contributions of each role to priority-setting.

Conclusions: Using the insights from decision-makers, we have described lessons related to direct involvement of members of the public and patients in priority-setting, and have identified six roles and the contributions of each role.

Introduction

Health care priority-setting occurs at every level of policy-making in every health care system in the world. Unfortunately, our understanding of how priority-setting decisions are and should be made is still rudimentary, although evolving.1–4

A goal of priority-setting is justice, which involves priority-setting by legitimate authorities using fair processes. Daniels and Sabin have proposed ‘accountability for reasonableness’ as a framework for legitimate and fair priority-setting with four conditions (relevance, publicity, appeals and enforcement; see Box).5 The relevance condition requires that rationales for priority-setting decisions rest on ‘reasons and principles that fair-minded people can agree are relevant to deciding how to meet context-specific needs under resource constraints’.6 The relevance condition is particularly important since the reasons for priority-setting decisions are crucial and the people involved generate the reasons. In a previous paper we described the reasons for particular priority-setting decisions.7 In this paper we focus on the people.

Who to involve in priority-setting decision-making, and how, has been the focus of debate and empirical study in the participation and priority-setting literature over the last decade. While an extensive literature has developed in this area, its primary focus has been on public involvement in priority-setting, although some authors have also considered the public’s role in relation to others such as health care professionals. Much of this literature has emphasized experimenting with and evaluating different methods of incorporating public consultation into priority-setting decision-making. There is also a broader public participation literature that has similarly emphasized the public’s involvement in decision-making in a variety of other policy sectors such as the environment,8 science,9 biotechnology10 and local government.11 However, to our knowledge, no one has studied groups making priority-setting decisions to discern the roles of various participants who are directly involved. In particular, no one has asked participants about their participation in priority-setting decision-making.

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In this paper, we begin by reviewing literature on public and professional participation in health care priority-setting and describing three key gaps in this literature. We then describe the views of participants on two priority-setting committees regarding participation in priority-setting. Our goal is to identify, synthesize and discuss the key insights of priority-setting participants. Ultimately, these insights could be used to refine the relevance condition of ‘accountability for reasonableness’ and, thereby, to suggest ways to improve the legitimacy and fairness of priority-setting decisions in health care organizations.

The literature on public participation

Because clinicians, and to a lesser extent health economists, are perceived to dominate priority-setting, there is a large and growing literature concerning the role played by the public in these types of decision-making processes. Scholars have argued the need for public input to enhance the legitimacy of priority-setting decision-making.\(^{12-14}\) and governmental reports have advocated greater public input in health care priority-setting.\(^{15,16}\) A few authors have described conceptual frameworks for how this should be accomplished. Lomas described roles that members of the public may adopt – taxpayer, collective community decision-maker, or patient\(^{13}\) – and others argue that individuals must identify the ‘community’ perspective and place this ahead of the ‘individual’ perspective.\(^{17}\) Charles and DeMaio developed a conceptual framework for analysing public participation in various contexts that outlines three possible levels of public involvement: consultation (lowest level), partnership and dominant (highest level).\(^{12}\)

There are several empirical studies of public participation in priority-setting.\(^{18-20}\) Mullen provided an overview of various strategies used to involve members of the public in priority-setting, including: mass approaches, such as telephone hotlines and large-scale surveys; targeted approaches, such as focus groups; proxy approaches, such as interviewing ‘key’ people (e.g., teachers, family physicians); and attempts to achieve ‘informed’ involvement, such as ‘citizens’ juries’.\(^{21}\) These approaches focus on the consultation end of the consultation-to-domination spectrum, and the literature does not explore how information from the public is used by decision-makers. In addition, Mullen reviewed the multitude of methods used for eliciting public input, such as voting, ranking, scaling, simple trade-off and willingness to pay. These methods have limited public input to those parameters prespecified by the research instrument.

Members of the public have sometimes been reluctant to support public participation in health care priority-setting. Lay decision-makers often feel unqualified or are unwilling to participate fully in health care priority-setting exercises, preferring to participate in a consultative role by providing their input to a decision-making process rather than to take the responsibility for making the final decisions.\(^{13,22-24}\) In the USA, efforts to increase lay participation have been hampered by insufficient clarity regarding expectations, roles and the representativeness of lay participants.\(^{25}\) On the other hand, some regions are trying to make public participation work,\(^{26,27}\) but the quality of these efforts has been questioned.\(^{28,29}\)

The literature on professional participation

The issue of participation by professionals in priority-setting is usually presented in connection with micro-level priority-setting by physicians at the bedside. At this level, two conflicting views have emerged: the position that ‘physicians are required to do everything that they believe may benefit each patient without regard to costs or other societal considerations’;\(^{30}\) and the view that ‘the physician’s obligations to the patient can no longer be a single-minded, unequivocal commitment but rather must . . . be weighed against the legitimate competing claims of other patients, of payers, of society as a whole, and sometimes even of the physician himself’.\(^{31}\)

Sabin has written that this debate and the perceived conflict between the important values of fidelity and stewardship is moot because an ethical clinician should embrace both.\(^{32}\) He then reframes this debate by arguing that meso-level (or institutional) priority-setting cannot be legitimate without the support and participation of clinicians. Sabin reasons that clinicians’ experience in health care institutions, which are the context of conflicts between the needs of patients and the good of society, can give them a unique perspective important to institutional priority-setting. Professional participation and the role of provider expertise have also been viewed by the public as essential to priority-setting decision-making processes.\(^{19}\)

Gaps in the literature on participation

The literature on participation in priority-setting has three key gaps. First, techniques for obtaining public input into priority-setting, such as surveys or citizens’ juries, are consultative mechanisms and do not involve the public directly in decision-making. Second, the literature is focused primarily on the public’s role in priority-setting, not on all potential participants. Third,
although there are a few studies of priority-setting decision-making, we are unaware of any descriptions of the full range of roles various participants play in groups making priority-setting decisions. To begin addressing these gaps, we interviewed individuals who participated in two priority-setting committees to identify and describe key insights from participants about participation.

Methods

We conducted a qualitative study involving interviews with participants of two committees while they were actively engaged in priority-setting for new technologies in cancer and cardiac care for the province of Ontario, Canada (population 11 million) between May 1997 and May 2000. The two committees were: the Cancer Care Ontario Policy Advisory Committee (CCOPAC) for the New Drug Funding Program and the Cardiac Care Network of Ontario Expert Panel (CCNOEP) on Intracoronary Stents and Abciximab (a glycoprotein IIb/IIIa inhibitor).

The CCOPAC’s mandate was to decide which new chemotherapy drugs should be funded by the New Drug Funding Program provided by the Ontario Ministry of Health. In Ontario, chemotherapy drugs such as those under consideration by CCOPAC are available only through public funding via either the New Drug Funding Program or hospital budgets. CCNOEP’s mandate was to develop a multi-year plan for stent volumes and use of Abciximab. The Ontario Ministry of Health provides funding envelopes to hospital cardiac care programs in the province based on the decisions of CCNOEP. In other words, both these committees made funding recommendations that were followed by the Ontario Ministry of Health, which provides the funds. These two committees were de facto priority-setting decision-makers, not merely advisors.

We invited all members of both committees to participate. Of 26 committee members, 21 were interviewed, including two public representatives and two patient representatives. Two were contacted but refused to be interviewed because they resigned from the committee due to scheduling conflicts; three did not respond to our invitations.

The interviews were semi-structured; the interviewer asked open-ended questions, pursued emerging themes, and sought clarification. Participants were asked to describe their role on the committee and evaluate their contributions. Interviews were audiotaped, transcribed and analysed.

The interview transcripts were read and committee members’ views regarding participation in priority-setting were identified. These units of text were underlined and descriptive notes were written in the margins of the transcripts, a process referred to as coding. Coded units were labelled as particular roles (e.g. administrator, public representative, etc.). Labelled units were then compared within and between interviews. Finally, descriptions of the roles and their contribution were developed using the participants’ own words. In order to enhance the generalizability of this study’s findings, roles that were committee-specific (e.g. pharmacist) were excluded and only roles common to both committees were included.

This study was approved by the Committee on Use of Human Subjects of the University of Toronto. All participants provided consent for the interview. All identifying information about participants and treatments has been removed.

Results

Direct participation in priority-setting

From the interviews we gleaned two general considerations about direct participation in health care priority-setting: consistency of membership over an extended period of time contributes to consistency in decision-making; and inclusion of a critical mass of individuals in certain roles can facilitate their contribution.

Consistency of membership

The priority-setting process of these two committees involved approximately 12 meetings over nearly 24 months during which a series of priority-setting decisions were made. The participants commented that meeting repeatedly over a long period of time permitted them to understand and appreciate each other’s perspectives and contributed to a collegiality that facilitated decision-making. Neither of the committees made a priority-setting decision until after at least the fourth meeting.

I was concerned that [participants] would become very focused on their area of interest and exclude other [areas] because they weren’t interested in that. But . . . everybody did take the broad perspective and I found that very good. And, having a very inclusive committee the way we did, when we came to decisions I think it was reassuring that many parties had participated and been involved.

In addition, as each decision was made, it was compared with previous decisions in an effort to achieve consistency. For these two reasons, the participants felt that it was important for committee membership to be consistent over time.

Critical mass

One committee had only one patient member, and the other committee had four community and patient representatives. Some of the participants felt that the lack of ‘collegial’ support may have inhibited the participation of the lone patient representative on the one committee, whereas the critical mass of individuals on the other committee facilitated the participation of the four patient and community representatives. In particular, two of the patient representatives stated that a critical mass of individuals in those roles can help level potential power differences between themselves and the
professionals on the committee, helping them to feel less intimidated. For example:

(I)’t’s very hard for me to have the confidence to question what they were doing. You try to some extent but, if there was a matter of conflict it would be very easy for me to defer to their expertise ..., I think if there were two of us that might have helped ... So one doesn’t feel quite so overwhelmed by the rest of the panel.

Identifying the roles

The participants in this study described six specific roles that were important in priority-setting: committee chair; administrator; medical specialist; medical generalist; public representative; and patient representative. Participants noted that an individual may fill more than one role: for example, a single individual may be both an administrator and a medical specialist.

All the participants commented that each of the committee members contributed significantly to the group’s decision-making – that is, no role was considered superfluous. However, maintaining a balance between the contributions of different members was sometimes difficult.

It’s a pretty balanced committee. I mean, radicals and conservatives, and community members, and administrators and I think they’ve been fair. We’ve been challenged by some of the members of the committee if we seemed to be making decisions on the basis of different criteria, and I don’t think we realized that we were doing it. But I think we’ve been consistent and fair.

One participant put it succinctly:

(Y)ou don’t want the person who has the most expertise to shut up. And yet, you don’t want the committee to be overinfluenced by, quote, an expert.

Many of the participants stated explicitly that the contribution of multiple perspectives, including a balance between public representatives and professionals, was a key element of a fair priority-setting process.

Describing the contributions of each role

Each of the participants viewed themselves as contributing to specific aspects of priority-setting in which they felt competent. Consequently, it is tempting to develop stereotypes of each participant to simplify the message about roles in participation; however, the stereotypes would be inaccurate. Each participant contributed to the decision-making of the committee in many ways.

In the following six subsections, we will describe the six specific participant roles and the contributions each made to the group’s decision-making, as described by the participants, using verbatim quotes from the participants to augment the description.

Committee chair

The chair’s task, from meeting to meeting, is to manage the flow of information, ensuring that everyone understands the information being discussed and has an opportunity to participate.

Part of my job is to make sure that the discussion is going on as level a playing field as it can. In other words, making sure that everybody around the table at least understands a reasonable amount about what the content of the discussion is – the specialists can drift off ... (I)’t’s sometimes important for me to bat people back a little bit and ensure that the statements made ... are rephrased in terms that everyone understands, and also, but probably more importantly, that they’re phrasing in the same kind of terminology that was used when we discussed the previous [decision].

In addition, the chair participates in selecting members, managing the setting of agendas and the structure of committee meetings, but with openness to the input of all members.

The chair specifically contributes to creating and maintaining the fairness of the priority-setting process.

Administrators

Different administrators contribute in different ways. Some serve as a liaison between the priority-setting committee and treatment centres and clinicians. They provide information to the committee, including budgetary information, about the operation of the program in which priorities are being set. Other administrators are involved in developing the goals and strategies of the program and, therefore, the priority-setting committee. One administrator-participant commented on both aspects:

My role would be to bring information about the operation of the [program] to the committee, and receive advice from the committee about the operation of the [program], because I am responsible for administering the [program] on a day to day basis, and interacting with the participating hospitals ... You do calculations based on the information that you have, you do projections, you prepare proposals ... These administrators may or may not participate in priority-setting discussions.

I wanted to be part of the committee but just a little bit removed, and certainly not the chair, so that the committee could advise me ... There are times that I do hold back a little, from the point of view of my comments. I don’t necessarily have to take their advice, although I’d be out of my mind if I didn’t.

The administrators specifically contribute to analysing budgetary information and establishing overall goals and strategies for the program in which priorities are being set.

Medical specialists

The medical specialists have experience caring for patients and, in particular, dealing with the treatments
and conditions under consideration. They have a primary concern for the welfare of these patients.

Even when the chances of benefit are relatively small, we would prefer to treat, offer the patient the potential of having benefit. Because, when you do that, every once in a while you get a dramatic result. And if you take the other philosophy, you have the certain outcome. People always do badly if you don’t treat them.

The medical specialists have a primary interest in seeing that resources are made available for effective treatments.

If you are a [clinician] carrying out a procedure on a patient, you’re going to do the absolute best for that patient with regard to the use of the tools, without really being concerned, I think, about how much money it’s costing to do that particular procedure.

The medical specialists contribute to discussions of conditions, treatments and their benefits to patients.

**Medical generalist**

The medical generalist may or may not have experience with the treatments and conditions being considered.

[I have] the perspective of somebody who has patients who have the procedure done to them, but I don’t have any vested interest in doing the procedure per se, so I’m unbiased in that regard . . . So I’m able to, I suppose, participate, ask questions, comment from the perspective of somebody who’s just interested in having the right things done and have absolutely no personal interest in what the outcome is.

The medical generalist can serve the committee by contributing to the analysis of evidence for new treatments and comparing it to their knowledge and experience with standard therapies.

I have a pretty broad knowledge of research data because of what I do in life when I’m not here . . . My biggest advantage is that, although I’m not a specialist in any one of the diseases – for every particular category we discuss there’s usually somebody on the committee who has a deeper knowledge than anybody else – I have a medium knowledge of most things.

The medical generalist contributes to the understanding of evidence and alternatives.

**Community representative**

The community representative’s role is to promote community interests, in particular priority-setting decisions that relate to ensuring a fair process.

As a community representative, I see myself as there to represent community values in the meeting, particularly to speak to patient and family concerns, but also I tend to focus on structural issues, on making sure that the process is one that I think is appropriate in a democratic context. I’m obviously not competent to judge the technical issues involved. I attempt to understand them in order to understand the reasoning, but I can’t really cast much light on any of that. I want to make sure that the process has been a reasonable one.

Community representatives often do not have a robust knowledge of the technical or scientific issues being discussed and their contributions in this area are limited.

I have less of a role to play than some of the other members of the committee, certainly than some of the other community members who have more of a technical background than I have . . . I can’t remember a single occasion when there was a choice to be made between [A or B] and I had a point of view that was useful . . . [My role is to] make sure that access to new and emergent [treatments] be on an equitable basis throughout the community.

The community representatives contribute to considerations of fair process and equitable access to treatments.

**Patient representatives**

The patient representative’s role is to comment on the needs of patients and the impact of particular treatments from the point of view of prospective patients. For example, research evidence usually involves statistical measures of a treatment’s benefit or side-effects and may not completely describe the treatment’s impact on actual patients; the patient representative can provide that description.

Hopefully I’m able to express that patient’s desires, fears, and wishes, to the extent that I can put myself in his or her shoes. And I’m not trying to do it as a mass of all the patients. I’m trying to do it as: I’m one, and each patient is one . . . When you occasionally get the question around the table: what does a few months’ survival mean? I can say what it means because I know some people who’ve been given their death sentences and have far surpassed them. And I know what each day means to them. And, in some specific cases, what kind of toxicity they’re willing to endure for it, what kind of uncertainty, what kind of confusion.

The patient representatives contribute to an understanding of patients’ needs and the impact of treatment on patients.

**Discussion**

**Contribution to knowledge: addressing the three gaps in the literature**

These findings help to address three key gaps in the literature on participation in priority-setting.

First, techniques for including the public in priority-setting, such as surveys and citizens’ juries, typically involve the public in a consultative role and not directly in decision-making. The committees we studied demonstrate that it is feasible to involve members of the public directly in institutional priority-setting committees. To our knowledge, this has not been studied. Similarly, our findings illustrate how administrators, medical specialists, medical generalists and patient representatives in priority-setting committees can also be directly involved.
Techniques that do not involve individuals directly in priority decisions suffer from the same limitation as other ‘simple solutions’ such as cost-effectiveness analysis: they provide information but are not embedded in a fair priority-setting process. Consequently, they may enhance the perception of legitimacy in priority-setting without actually improving legitimacy itself. Individuals playing different roles on a committee can contribute directly to an institution’s priority-setting process. We also learned two important lessons about direct involvement of these individuals in priority-setting committees, both of which are supported by prior research: committee membership may need to be maintained over time in order to enhance decision-making consistency, and a critical mass of these representatives may be necessary to facilitate their contributions.

Second, the literature is focused primarily on public participation in priority-setting. Our findings show that members of the public can contribute to important aspects of priority-setting, thus improving the legitimacy and fairness of priority-setting. Some of the literature on public involvement in priority-setting suggests that lay decision-makers often feel unqualified or are unwilling to participate in health care priority-setting: members of the public have been described as ‘reluctant rationers’. This may be because members of the public and patients have been asked to contribute to evaluations of benefit, evidence, cost-effectiveness and other factors that are very often outside their individual areas of expertise. However, in this paper we have described contributions that members of the public and patients can make to priority-setting, and can feel comfortable making, such as discussions of fair process, access and equity, and the impact of treatments on patients. Focusing on these contributions may ease the trepidation some may feel towards participating in health care priority-setting, particularly those who feel unqualified to evaluate complicated medical or economic evidence. Our findings also support Sabin’s arguments that medical professionals and others can and should make an important contribution to priority-setting decision-making. The participants in this study described six specific roles that were important contributors to priority-setting: committee chair; administrator; medical specialist; medical generalist; public representative; and patient representative.

Third, we are unaware of any descriptions of the way in which members of the public, or others involved in priority-setting, contribute to decision-making. Our findings show, not only that all the roles we described can contribute directly to priority-setting, but also that the contribution of individual roles may be determined by the specific aspects under consideration in regard to the decision of the moment. Other conceptual frameworks of public participation have made important contributions in their depictions of different levels and domains of participation as well as different types of potential participants. They have fallen short, however, in describing the specific contributions members of the public can make, and obviously do not describe the specific contributions that other participants can make to specific aspects of priority-setting decision-making. The participants in our study described in detail the contributions made by each of the six roles:

- A committee chair helps ensure that the committee adheres to fair procedures.
- Administrators contribute to discussions of costs and goals and strategies.
- Medical specialists contribute to discussions of disease conditions and treatment benefits.
- Medical generalists contribute to discussions of evidence and alternatives.
- Public representatives contribute to discussions of fair process, access and equity.
- Patient representatives contribute discussions of patients’ needs and the impact of treatments on patients.

This is supported by research that has identified involvement at the treatment level of decision-making as a desired role for the public.

**Contribution to practice: how could this information be used?**

Since there is no societal consensus about what makes priority-setting decisions ‘correct’, a key goal is fair process. The relevance condition of ‘accountability for reasonableness’ encourages institutions to involve ‘fair-minded’ people to enhance the fairness of the priority-setting process. Our findings provide evidence for recommendations regarding who these ‘fair-minded’ people can be, and how they can contribute. These are not normative recommendations – further work to establish connections between our empirical description and a normative framework, such as ‘accountability for reasonableness’ is necessary – but recommendations based on our observations. To operationalize our findings, institutions could begin with these four steps:

1. Establish a priority-setting committee with individuals who can serve in each of the six roles described in this paper: committee chair; administrator; medical specialist; medical generalist; public representative; and patient representative. Add others to fill roles that are important and relevant to the specific decision-making context (e.g. if the context is pharmaceutical benefit management, add a pharmacist).
2. Keep the committee membership together for a significant period of time. This will help the committee to develop trust, collegiality and decision-making consistency.
3. Ensure that a critical mass of people serve in each role, especially patients and public. This can help establish a power balance, thereby facilitating the participation of all members.
4. Encourage the committee members to contribute to all aspects of priority-setting, but especially and extensively to those aspects for which they are particularly well situated, as we have described.
However, to achieve legitimacy and fairness in priority-setting, health care institutions must go beyond ‘simple solutions’ (e.g. get ‘fair-minded’ people around a table) to establish a legitimate and fair priority-setting process that meets all four of the ‘accountability for reasonableness’ conditions (publicity, relevance, appeals, enforcement).

Limitations

There are four limitations to our study. First, we may not have identified all the roles that can enhance the legitimacy and fairness of priority-setting. Therefore, our description should be considered a beginning rather than a conclusion. Second, we have described what is, not what should be. Further work to establish connections between our empirically based description and a normatively based framework, such as ‘accountability for reasonableness’ is necessary. Third, our findings may not be fully generalizable to priority-setting in other contexts. However, priority-setting presents essentially the same problems in all contexts. For example, the Chief Executive Officers of a hospital, regional health authority, or managed care organization must all decide what they will and will not fund. Fourth, we did not study whether participation as described here improves the quality of decision-making. However, to address that question one requires a goal against which to measure decisions; currently there is no consensus about priority-setting outcomes. On the other hand, legitimacy and fairness, operationalized through ‘accountability for reasonableness’, is a key goal, and these committees did try at least to enhance the legitimacy and fairness of their priority-setting by including the participants we described.

Conclusions

This paper has described participation in health care priority-setting through the eyes of participants on two priority-setting committees. The description includes lessons related to direct involvement of members of the public and patients in priority-setting, six roles (committee chair, administrator, medical specialist, medical generalist, public representative and patient representative) and the contributions of each role. This description helps to refine and expand the relevance condition of ‘accountability for reasonableness’.

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References

18. Richardson A. Determining priorities for purchasers: the public response to rationing within the NHS. Journal of Management in Medicine 1997; 11: 222–229
26. Field S, Giles A. Rationing health care: patients have strong input into purchasing decisions in Droitwich. BMJ 1996; 313: 557–558
28. Singer MA. Public participation in setting health-care priorities: should it be done and can it be done? Annals Royal College of Physicians and Surgeons of Canada 1994; 27: 275–278