

Rethinking patient involvement in healthcare priority setting

Lars Sandman¹  | Bjorn Hofmann²  | Greg Bognar³ 

¹National Centre for Priorities in Health, Department of Health, Medicine and Caring Sciences, Linköping University, Sweden

²Department of Health Science, Norwegian University of Science and Technology (NTNU) at Gjøvik, Norway

³Department of Philosophy, Stockholm University, Sweden

Correspondence

Lars Sandman, National Centre for Priorities in Health, Department of Medical and Health Sciences, Linköping University, Sweden.

Email: lars.sandman@liu.se

Funding information

Forskningsrådet om Hälsa, Arbetsliv och Välfärd, Grant/Award Number: 2014-4024; Swedish Research Council, Grant/Award Number: 2014-4024; Linköping University

Abstract

With healthcare systems under pressure from scarcity of resources and ever-increasing demand for services, difficult priority setting choices need to be made. At the same time, increased attention to patient involvement in a wide range of settings has given rise to the idea that those who are eventually affected by priority setting decisions should have a say in those decisions. In this paper, we investigate arguments for the inclusion of patient representatives in priority setting bodies at the policy level. We find that the standard justifications for patient representation, such as to achieve patient-relevant decisions, empowerment of patients, securing legitimacy of decisions, and the analogy with democracy, all fall short of supporting patient representation in this context. We conclude by briefly outlining an alternative proposal for patient participation that involves patient consultants.

KEYWORDS

deliberative democracy, empowerment, legitimacy, patient involvement, priority setting, rationing

1 | INTRODUCTION AND AIMS

With healthcare systems under pressure from scarcity of resources and ever-increasing demand for services, difficult priority setting choices need to be made. At the same time, a clear trend towards more emphasis on person centered care and growing pressure for patient involvement in a wide range of settings have given rise to the idea that those who are eventually affected by priority setting decisions should have a say in those decisions.¹ Accordingly, there has been increasing support for patient involvement initiatives as well as more research on involving patients in priority setting processes.²

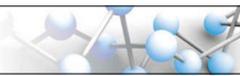
The issues raised by patient involvement in healthcare in general and patient involvement in this particular context are similar in some ways and different in others. In this article, we focus exclusively on patient involvement in priority setting. We argue that it is an unresolved question exactly why and how patient involvement should be part of priority setting and what role patients should have. As the contributors to a recent special issue of the *Journal of Health Organization and Management* emphasize:

With resource allocation, there are many built-in conflicts of interest: among different patient groups, as well as between citizens as consumers and citizens as tax-payers. If public participation is to be more than a slogan in relation to priority setting, then those responsible for the design of institutions and practices need to address the differences in the roles and responsibilities that different forms of public representation involves.³

¹Douglas, C. M., Wilcox, E., Burgess, M., & Lynd, L. D. (2015). Why orphan drug coverage reimbursement decision making needs patient and public involvement. *Health Policy*, 119, 588–596; Weale, A., Kieslich, K., Littlejohns, P., Tugendhaft, A., Tumilty, E., Weerasuriya, K., & Whitty, J. A. (2016). Introduction: Priority setting, equitable access and public involvement in healthcare. *Journal of Health Organization and Management*, 30, 736–750.

²Douglas, C. M., et al., op.cit., note 1; Kiesloch, K., Ahn, J., Badano, G., Chalkidou, K., Cubillos, L., Haugeen, R. C., ... & Wilson, J. (2016a). Public participation in decision making on the coverage of new antivirals for hepatitis C. *Journal of Health Organization and Management*, 30, 769–785; Parsons, S., Thomson, W., Cresswell, K., Starling, B., & McDonagh, J. E. (2017). What do young people with rheumatic disease believe to be important to research about their condition? A UK-wide study. *Pediatric Rheumatology Online J.*, 15, 53; Watson, V., Carnon, A., Ryan, M., & Cox, D. (2012). Involving the public in priority setting: a case study using discrete choice experiments. *Journal of Public Health*, 34, 253–260.

³Slutsky, J., Tumilty, E., Max, C., Lu, L., Tantivess, S., Haugeen, R. C., ... & Tugendhaft, A. (2016). Patterns of public participation: opportunity structures and mobilization from a cross-national perspective. *Journal of Health Organization and Management*, 30, 751–768, p. 763.



One way for patients to be involved is as *patient representatives* in a decision making body at the policy level, making choices or providing priority recommendations together with other members of the group. We find numerous examples around the world. In Sweden (where two of the authors work), patients have been routinely involved in such bodies in the last few years. In the UK, the National Institute for Health and Care Excellence (NICE) guidelines claim that ‘patients, service users, carers and the public can be involved directly in producing or promoting our guidance, quality standards and other products as formal members of our committees and working groups’.⁴ In many countries, patient involvement has gained significant traction in health technology assessment.⁵

Nonetheless, there remain unresolved issues. The point of priority setting is to allocate scarce resources between competing needs, with ‘winners’ and ‘losers’ in every decision as a result. In this context, patient representation seems to be inherently problematic, and its standard justifications might not even be appropriate.

Our aim in this article is to explore the role of patient representation in priority setting at the policy level. We proceed by juxtaposing standard justifications of the need to set priorities and common justifications of patient involvement. Finally, we also provide the tentative outline of an alternative conception.

2 | SOME NOTES OF CLARIFICATION

To forestall misunderstanding, we would like to begin with a few preliminary remarks. Our analysis makes a set of assumptions. First, our discussion takes place in the context of a fully developed welfare system, characterized by universal coverage, an ideal of equitable access, and high levels of trust. The legitimacy of the health-care system at large is taken for granted. Following Weale et al., we

are assuming that deliberative, consensual processes in which patients could be effectively involved are available; they are largely seen as legitimate; and patients do not have to resort to ‘contestatory participation’ in the form of public protest and the like.⁶

Second, our discussion concerns priority setting at the level of policy. This includes decision making at the national, regional or local levels (including clinical decisions), but it does not include decision making concerning individual patients. The decisions can pertain to specific technologies (e.g., new, innovative, but expensive interventions) as well as general policies. In these decisions, there are usually competing and conflicting moral considerations that decision makers have to handle. Often, these considerations include the role that personal characteristics (e.g., having a disability or being responsible for one’s health need) can play in determining eligibility, access, or other forms of advantage. These decisions can have profound impacts on different patient groups. Hence our argument may have important practical implications.

Third, we note that patients can be involved in priority setting at the policy level in different ways. A distinction can be made between being involved through research and through participation.⁷ Here we will focus on patient participation in decision making bodies. Such participation can take the form of being a representative of patients or patient groups, but it can also involve playing the role of ‘consultant’ in patient issues. In the latter role, the representative is not supposed to represent patients, but rather help the decision making body understand and take into consideration aspects relevant to patients, create channels of communication, and the like. Most of this article focuses on patient representation, but it uses the patient consultant role as a contrast at the end.

Furthermore, we can distinguish between having a vote and (merely) having a voice.⁸ In having a vote, the patient representative has a formal impact over the decision, and may thereby also have some responsibility for it. In having a voice, the patient representative can take part in discussions, express opinions, share thoughts and perspectives, and thereby informally affect the decision—but she does not take part in the actual decision or have voting rights. This implies that the patient representative cannot tip the balance when the decision making body is divided on the decision that needs to be made. In practice, we find examples of patient representatives in both of these capacities.

Finally, we assume that patient representation does not entail legal responsibility for the decisions.

3 | PRIORITY SETTING

The fundamental reason for priority setting is the scarcity of health-care resources. Setting priorities is a way to distribute scarce

⁴NICE (2019). *Patient and public involvement policy*. Retrieved from <https://www.nice.org.uk/about/nice-communities/nice-and-the-public/public-involvement/public-involvement-programme/patient-public-involvement-policy>

⁵Oortwijn, W., Sampietro-Colom, L., & Habens, F. (2017). Developments in value frameworks to inform the allocation of healthcare resources. *International Journal of Technology Assessment in Healthcare*, 33, 323–329; Facey, K. M. (2017). Developing the mosaic of patient participation in HTA. In K. Facey, H. Ploug Hansed, & A. Single, *Patient involvement in health technology assessment* (pp. 51–65). Singapore: Springer Nature Ltd; Moreira, T. (2014). Understanding the role of patient organizations in health technology assessment. *Health Expectation*, 18(6), 3349–3357; Gagnon, M. P., Candas, B., Desmartis, M., Gagnon, J., La Roche, D., Rhainds, M., ... & Legare, F. (2014a). Involving patient in the early stages of health technology assessment (HTA): A study protocol. *BMC Health Services Research*, 14, 273; Gagnon, M. P., Desmartis, M., Gagnon, J., St-Pierre, M., Gauvin, F. P., Rhainds, M., ... & Legare, F. (2014b). Introducing the patient’s perspective in hospital health technology assessment (HTA): The views of HTA producers, hospital managers and patients. *Health Expectation*, 17, 888–900; Henshall, C., Schuller, T., & Mardhani-Bayne, L. (2012). Using health technology assessment to support optimal use of technologies in current practice: The challenge of ‘disinvestment’. *International Journal of Technology Assessment in Healthcare*, 28, 203–210; Danner, M., Hummel, J. M., Volz F., Van Manen, J. G., Wiegard, B., Dintios, C. M., ... & Ijzerman, M. J. (2011). Integrating patients’ views into health technology assessment: Analytic hierarchy process (AHP) as a method to elicit patient preferences. *International Journal of Technology Assessment in Healthcare*, 27, 369–375; Facey, K., Boivin, A., Gracia, J., Hansen, H. P., Lo Scalzo, A., Mossman, J., & Single, A. (2010). Patients’ perspectives in health technology assessment: A route to robust evidence and fair deliberation. *International Journal of Technology Assessment in Healthcare*, 26, 334–340.

⁶Weale et al., *op. cit.*, note 1.

⁷Facey, *op. cit.*, note 5.

⁸Kieslich, K., Bump, J. B., Norheim, O. F., Tantivess, S., & Littlejohns, P. (2016). Accounting for technical, ethical, and political factors in priority setting. *Health Systems & Reform*, 2, 51–60.

resources in a fair or just way that can be accepted as legitimate by all affected stakeholders.⁹ Regardless of how the priority setting process is implemented—what procedure or values are followed, whether it is done transparently, who has influence over the decisions—it is inevitable that some will gain, and some will lose. Priority setting inherently involves conflicts of interest. Some stakeholders will be advantaged and others disadvantaged by these decisions. The stakeholders are first and foremost patients, but also include healthcare professionals, industry, politicians, and the general public.

A decision to prioritize a certain treatment for one group of patients comes at opportunity costs and displacement of care for other (often unidentified) patients. In principle, various efficiency measures in healthcare systems may reduce opportunity costs in order to finance new treatments or services. However, it rarely happens that before their introduction, the healthcare system is first made more efficient in order to release the necessary resources. Hence, there is usually an opportunity cost for some patients. The fact that the patients who have to bear the opportunity costs are normally unidentified or unidentifiable due to the complexity of healthcare systems may create the illusion that there are no such costs.

Now if the patients who bear the opportunity costs are unidentified or unidentifiable, then they cannot protest, mobilize, or press for their interests. Thus, it is normally impossible to provide proper representation for this group in the decision; they are neither represented nor considered stakeholders. Given the uncertainty, it is very difficult to identify any party that could represent both the winners and the losers and provide a balanced representation for all sides in the priority setting decision.

Consequently, a decision needs to be made as to whom the patient representative is supposed to represent—or at least the mandate of the patient representative has to be made clear.¹⁰ In our experience, patient representatives normally advocate for the patient group that is in need of the treatment to be decided upon, and they seldom acknowledge the patients who bear the opportunity costs from the decision. Thus, there seems to be a 'naivety of policy and practice'¹¹ in the belief that one or a handful of lay members on decision making panels can represent 'the collective voice of the people' or 'the public's view' in the round.¹²

It might be objected that over time things will even out—that is, over a sufficiently long period, all patient groups will be 'advocated for'. But this is an overly optimistic claim, unsupported by empirical

evidence and unlikely in light of the typical agenda of decision making bodies and patient representative selection processes. Priority setting normally focuses on new treatments, and the development of new treatments is unevenly distributed over patient groups (there are more new treatments for certain types of cancer than for Alzheimer's disease). Moreover, vulnerable groups that lack voice are rarely represented. It is therefore unrealistic to expect fair representation over time.

In other words, stakeholder pressure and competition cannot lead the way when it comes to priority setting. As it has been pointed out, 'some aspects of healthcare decisions, such as resource allocation, are not easily amenable to individual rights of choice, as it is necessary to maintain an overview to assure the just distribution of resources'.¹³

To satisfy the moral demands of fairness and legitimacy, it is unavoidable that priority setting processes go beyond the competition of stakeholder interests and are guided by a set of procedural or substantive values.¹⁴ In the literature there are different proposals for sets of procedural and substantive values to follow. One prevalent framework is 'Accountability for Reasonableness' (A4R), suggested by Daniels and Sabin.¹⁵ It includes the following procedural values: *transparency* about the grounds for decisions, *appeals to relevant criteria* acceptable to all, *procedures for revision*, and *enforcement* of decisions. In A4R, stakeholder participation or representation is not presented as a procedural value for a legitimate and fair process. It is argued that 'even in the absence of consumer participation, we believe, it is possible to achieve accountability for reasonableness and thus legitimacy'.¹⁶

More recent proposals of procedural values do, however, add stakeholder involvement. For instance, Dolan et al. list six procedural values: *voice* for those affected by the decision; *neutrality* by decision makers so that they do not act out of self-interest; *consistency* of applying decision making criteria and procedures over time; *accuracy*, by requiring decisions to be made on the basis of good evidence; and, finally, *reversibility* and *transparency*, which correspond to revision and transparency in the A4R framework.¹⁷

Similarly, Clark and Weale propose three procedural values: *transparency*, *accountability*, and *participation*.¹⁸ Transparency corresponds to its A4R equivalent. Accountability demands that decision makers

⁹Montgomery, J. (1996). Patients first: The role of rights. In K. Fulford, S. Ersser, & T. Hope (Eds.), *Essential practice in patient-centred care* (pp. 142–151). Oxford: Blackwell Science.

¹⁰Daniels, N. & Sabin, J. E. (2008). *Setting limits fairly: learning to share resources for health*. Oxford: Oxford university Press; Weale et al., op. cit., note 4; Wiseman, V., Mooney, G., Berry, G., & Tang, K.-C. (2003). Involving the general public in priority setting: experiences from Australia. *Social Science & Medicine*, 56, 1001–1012; Dolan, J. G. (2010). Multi-criteria clinical decision support. *The Patient: Patient-Centered Outcomes Research*, 3, 229–248; Cookson, R., & Dolan, P. (2000). Principles of justice in healthcare rationing. *Journal of Medical Ethics*, 26, 323–329.

¹¹Daniels and Sabin, op. cit., note 14; Daniels, N., & Sabin, J. E. (2008). Accountability for reasonableness: An update. *British Medical Journal*, 337, a1850.

¹²Daniels & Sabin, op. cit. note 14, p. 62.

¹³Dolan, P., Edlin, R., Tsuchiya, A., & Wailoo, A. (2007). It ain't what you do, it's the way that you do it: Characteristics of procedural justice and their importance in social decision making. *Journal of Economic Behavior & Organization*, 64, 157–170.

¹⁴Clark, S., & Weale, A. (2012). Social values in health priority setting: a conceptual framework. *Journal of Health Organization and Management*, 26, 293–316.

⁹Slutsky et al., op. cit., note 3; Daniels, N., & Sabin, J. (1997). Limits to healthcare: Fair procedures, democratic deliberation, and the legitimacy problem for insurers. *Philosophy & Public Affairs*, 26, 303–350; Bognar, G., & Hirose, I. (2014). *The ethics of healthcare rationing: an introduction*. London: Routledge; Gibson, J. L., Martin, D. K., & Singer, P. A. (2004). Setting priorities in healthcare organizations: Criteria, processes, and parameters of success. *BMC Health Services Research*, 4, 25.

¹⁰Rosenberg-Yunger, Z. R. S., & Bayuomi, A. M. (2017). Evaluation criteria of patient and public involvement in resource allocation decisions: A literature review and qualitative study. *International Journal of Technology Assessment in Healthcare*, 33, 270–278.

¹¹Russel, J. (2017). *The rationality of rationing: A rhetorical policy analysis of deliberations about resource allocation in the NHS*. Oxford University Research Archive.

¹²Martin, G. P. (2009). Whose health, whose care, whose say? Some comments on public involvement in new NHS commissioning arrangements. *Critical Public Health*, 19, 123–132.



take responsibility for their decisions and explain them to the public. Participation requires that every affected stakeholder—first and foremost patients—is allowed to take part in the decision making process.

Once the values of ‘voice’ and ‘participation’ are interpreted in terms of patient representation, a number of potential conflicts arise. As a representative, it would be odd to expect a participant to remain neutral, since she is there to represent a specific set of interests in the process. The relevance condition, requiring only relevant reasons to be taken into account, may also lead to conflict.¹⁹ That is because what counts as relevant is often a contested issue. Furthermore, accountability may be too demanding for patient representatives: they should not be expected to be able to defend and explain complex and controversial priority setting decisions. In general, procedural values like appeals to relevant criteria, accuracy, or consistency, seem to leave little room for including specific stakeholder perspectives.

Can these conflicts be resolved by introducing some set of substantive values to priority setting procedures? Of course, some substantive values are already used in priority setting: for instance, clinical effectiveness, patient need, different equity criteria, cost-effectiveness, or solidarity.²⁰ However, decision making is not an automated process. It requires the balancing of different values and principles against each other to reach final decisions.²¹ Substantive values are generally open to interpretation, reasonable people may disagree on their relevance in a given application, and different trade-offs between them can be justified from an ethical point of view. As a result, participants in decision making bodies have the opportunity to influence choices in their preferred direction.

To be sure, all members of a decision making body bring their values to the table. There is always the risk that they will fail to meet the requirements of neutrality, relevance, accuracy, or consistency. Priority setting bodies are made up of medical or other kinds of health experts who all have their own professional or academic interests and perspectives that might equally bias their input and influence decisions.²² Moreover, those interests and perspectives are often less transparent than those of patient representatives, who after all might represent specific groups with publicly known interests and perspectives. The interests and perspectives of experts might be much less apparent. Consequently, the danger of biased decisions due to the influence of these interests and perspectives should not be ignored—neither for patient representatives nor for professionals.

Let us, however, set these considerations aside for the moment. Despite its problems, patient representation might still, all things considered, be justified and desirable. We now turn to standard justifications of involving patients in priority setting decisions.

4 | PATIENT REPRESENTATION

The most common justifications for involving patients in priority setting at the policy level include the following: patient involvement helps achieve patient-relevant decisions; it empowers patients; it secures the legitimacy of decisions; and it is required by democratic ideals. We are going to analyse these justifications with two questions in mind: (1) To what extent do they support patient representation in priority decisions? (2) Can patients be represented in ways that correspond to these justifications?

4.1 | Relevance

The goal of healthcare is to benefit patients by protecting their health, maintaining and improving their quality of life—including extending their lives—as well as preserving their autonomy and dignity. Taking patients' benefit into account is essential when priority setting decisions are made. In particular, patient benefit must be considered when different values are interpreted and weighed in order to reach priority decisions. It is often argued that this process must inevitably include input from the perspective of patients. This is especially true for assessing the impact of a treatment on quality of life, its risks for patients, and the degree of need for the treatment. Effectiveness, risk, and patient need cannot be assessed without taking into account patient perspectives, and any decision that does not include them risks missing the mark and wasting resources on treatments that are not relevant for patients.

A crucial assumption behind this justification is that one size does not fit all: even patients that share the same diagnosis and prognosis have considerable heterogeneity due to individual circumstances, experiences, preferences and values.²³ In order to interpret and adapt priority setting criteria for the relevant patient population, decision makers have to take heterogeneity and diversity into consideration. But inviting a single patient representative (or a few representatives) into a decision making body is not a guarantee of getting the necessary input. On the contrary, there is a risk of bias towards the specific diagnosis or situation of the patient representative. The representative's perspective is based on their own experience, even if they are trying to provide input that is as balanced as possible. In general, this is a problem for all the parties involved in the decision making process, but due to the fact that they are supposed to supply the relevant patient perspective, patient representatives may end up with greater credibility and thereby a stronger voice.

Hence, it may be argued that patient research and broad patient consultation are more appropriate avenues of getting information on patient perspectives, and they may better serve the aim of achieving patient-relevant decisions. Consequently, the justification

¹⁹Lauridsen, S., & Lippert-Rasmussen, K. (2009). Legitimate allocation of public healthcare: Beyond accountability for reasonableness. *Public Health Ethics, 2*, 59–69.

²⁰Clark and Weale, op. cit., note 18.

²¹Cookson and Dolan, op. cit., note 14; Bogner and Hirose, op. cit., note 9.

²²Hofmann, B. (2018). Fake facts and alternative truths in medical research. *BMC Medical Ethics, 19*(1), 4.

²³Sandman, L., Bond, K., & Hofmann, B. (2017). Exploring ethical rationales. In K. Facey, H. Ploug Hansed, & A. Single (Eds.), *Patient involvement in health technology assessment* (pp. 17–29). Singapore: Springer Nature Ltd.

of achieving patient-relevant decisions does not, in itself, support patient representation in decision making bodies. It can even be viewed as an argument against patient representation, due to the risk of overly narrow and even biased input.

4.2 | Empowerment

Another justification for patient involvement is that it is a prerequisite of patient empowerment.²⁴ There is no single, universally accepted definition of empowerment. However, generally speaking we can say that empowering people is about increasing their control over their lives through supporting or strengthening their self-confidence, self-esteem, self-efficacy, capacity for autonomy, knowledge, or freedom by removing obstacles or providing options.²⁵

Being on the 'inside' of a decision making process provides knowledge about priority setting in general and about the details of specific decisions. It provides insight into the way discussions take place, experience with negotiation, and knowledge about which arguments are likely to be persuasive or able to tip the balance. Familiarity with priority setting processes can help representatives in their effort to make patient-centered narratives more important in framing decisions.²⁶ For representatives, this in turn can result in increased self-confidence, self-esteem, self-efficacy, and so on—in short, some degree of power over decisions in priority setting.

Thus, patient representation in priority setting decisions can have an empowering effect—directly for the patient representatives themselves, and indirectly for the patient populations they represent. However, the effect is likely to be local and unlikely to make any tangible difference on a larger scale. At such scales, any empowerment derived from patient participation is going to be dispersed. But even if this worry is set aside, another remains. Effective empowerment presupposes a well-defined patient population. The patient population the representative is most closely associated with is likely to become more empowered than more distant populations. The idea that all patient populations can be empowered by participation through a single patient representative is far-fetched.

If empowerment is a good thing for patients, it must be a good thing for all patients. Other things being equal, it is better if more patients are empowered than if fewer patients are. But if empowering some patients results in disempowering other patients, then it is less clear that it is an unmitigated good. In other words, when a patient representative for a specific patient population is part of a decision making body, the representative and the group they represent might enjoy opportunities for empowerment that others do

not have. They might be able to influence decisions in ways others cannot. Other patient populations may become less empowered with little chance of influencing the outcome of the decision making process.

A better way to empower patients in priority setting may be to have transparent decision making processes with ample time for feedback and dialogue with any and all patient groups that want to contribute to the process. Perhaps this would be less empowering than direct participation through representatives, but at the same time it may result in a broader, fairer kind of empowerment.

In conclusion, empowerment through patient representation is at risk of coming at the cost of disempowerment for other patient populations that are not represented or whose perspectives are not shared by the patient representatives. This is an inherent problem for any argument for patient representation that appeals to empowerment.

4.3 | Legitimacy

A central justification for involving stakeholders in general—and patients in particular—in decisions on priority setting is to achieve legitimacy.²⁷ Legitimacy is commonly thought to include three different conditions: legality, justifiability, and participation. Legitimate decisions must be based on stable rules and laws; the rules and laws must have adequate moral justification; and stakeholders must have had an opportunity to voice their concerns and provide input to the decision making process. Whether a decision is considered legitimate affects whether stakeholders protest or accept them, whether they try to overturn or undermine them: 'those who come out of a decision less well than others may feel better able to accept it if they have at least had their voice heard'.²⁸

Thus, legitimacy can be viewed as a combination of theoretical and empirical factors. With respect to legality and justifiability, legitimacy is a matter of theoretical, normative requirements. These requirements provide a necessary condition. But legitimacy is also a matter of empirical factors, having to do with the extent people actually find decisions or decision making processes legitimate, regardless of whether the decisions in fact satisfy the theoretical requirements.

In the present context, this means that legitimate priority setting decisions must not only be based on sound theoretical considerations, but they must also be actually accepted by people, including patients. It is often suggested that the best way to ensure empirical legitimacy or acceptance is to involve patients in these decisions. But it is not obvious why patient involvement should be necessary for legitimacy. Part of the problem is that the empirical relation between participation and acceptance is less than clear:

²⁴Facey, *op. cit.*, note 5.

²⁵Tengland, P.-A. (2008). Empowerment: A conceptual discussion. *Health Care Analysis*, 16, 77–96.

²⁶Russell, *op. cit.*, note 11.

²⁷Daniels and Sabin, *op. cit.*, note 14.

²⁸Clark and Weale, *op. cit.*, note 18, p. 301.



We understand very little about the conditions under which representative, or authentic, participation generates legitimacy and under which it will be regarded as insufficient.²⁹

But even if participation (in some form) is considered a necessary condition of legitimacy, it does not follow that *patient representation* in priority decisions, in particular, is a necessary condition of legitimacy. Other forms of participation may be more appropriate.

Once we consider the relationship between patient representation and patients' acceptance of decisions as legitimate, we recognize that patient representation is not a necessary condition of patient acceptance. It goes without saying that decisions are often accepted and found legitimate even if no patient representatives took part in them, and decisions that involved patient representatives may not be accepted by affected patient groups (or the broader public). As already pointed out, acceptance has a complex relationship to legitimacy.

Moreover, decisions that are accepted might be illegitimate on theoretical grounds (for not following the criteria of legality and justifiability), and decisions that are legitimate on theoretical criteria might not be accepted by the affected patient group (even if they are accepted by the larger patient or stakeholder community). Hence, the relationships between patient representation, acceptance and legitimacy are contingent and dependent on a number of empirical factors. Perhaps one of these factors is the perceived ability to influence decisions: that is, the emphasis on 'having a voice' can create expectations of being able to influence decisions in directions that are favourable to the patient groups that are represented.

These expectations, in turn, can affect empirical legitimacy. The ability to influence decisions is compatible with overall legitimacy only if it is not in contradiction with the procedural and substantial values that provide the basis of theoretical justifiability. This puts constraints on the ability to influence decisions. On the one hand, if patient representatives can influence decisions in ways that conflict with substantial or procedural values, there is obviously a legitimacy problem. On the other hand, if their ability to influence decisions is limited, and they are considered incapable of making a difference (or at least this is believed by the patients whom they represent), then the expectations of these patients are frustrated, leading to its own legitimacy problem. Patient representatives might then be seen as providing merely token representation.

We will argue that giving patients a role as patient consultants rather than patient representatives can fulfil the requirement of participation without giving rise to the misconception that legitimacy involves having decision making power. We explain this proposal in the last section. But first we look at a final justification.

²⁹Hunter, D. J., Kieslich, K., Littlejohns, P., Staniszevska, S., Tumilty, E., Weale, A., & Williams, I. (2016). Public involvement in health priority setting: Future challenges for policy, research and society. *Journal of Health Organization and Management*, 30, 796–808, p. 797.

4.4 | Democracy

Despite these problems, it can still be argued that being represented in decisions affecting you is simply what democracy requires. In the words of a participant in a study on public participation in priority setting: 'because that is the whole point of having a democracy'.³⁰

One could argue that in a representative democracy, where elected politicians set the general rules for the distribution of resources in healthcare, the democratic ideal is already fulfilled. However, first, many decisions are decentralized to lower levels even in publicly financed and democratically governed healthcare systems. Second, it has been observed that elected politicians might be biased in making such decisions for two reasons: majority voting favours the average citizen or key populations (rather than what is considered a fair distribution) and some interest groups are better able to organize themselves to exert pressure on politics, which is problematic from the perspective of fairness.³¹

To remedy these shortcomings, more deliberative approaches to democracy have been proposed.³² In political theory, there are different models of deliberative democracy, but they all share the idea that democracy is more than just self-interested competition governed by bargaining and aggregative mechanisms. They all emphasize the idea that deliberation or reasoning among stakeholders focusing on the public or common good should be essential to political decisions.³³ In addition, deliberation should be guided by procedural requirements like communicative competence, reciprocity, inclusiveness and willingness to be persuaded by argument, rejecting the influence of power relationships or strategic behaviour on the outcome.³⁴

One difference between models of deliberative democracy, however, is whether they consider the deliberative procedure constitutive for arriving at a 'correct' decision, or whether they postulate some more 'objective standards'.³⁵ Since, in line with much of the discussion on priority setting in healthcare, we have argued that there are substantive ethical values that should guide priority setting, we assume some version of deliberative democracy that includes such standards.

³⁰Dolan et al., op. cit., note 17, p. 165.

³¹Lauridsen and Lippert-Rasmussen, op. cit., note 19; Goodard, M., Hauck, K., & Smith, P. C. (2006). Priority setting in health: A political economy perspective. *Health Economics, Policy and Law*, 1, 79–90.

³²Bohman, J., & Rehg, W. (Eds.) (1997). *Deliberative democracy: Essays on reason and politics*. Cambridge, MA: MIT Press. Habermas, J. (1984). *The theory of communicative action*, Boston: Beacon Press; Habermas, J. (1975). *Legitimation crisis*. Cambridge, MA: Beacon; Cohen, J. (1989). Deliberation and democratic legitimacy. In Goodin, R., & Pettit, P. (Eds.), *Contemporary political philosophy: An anthology*. (pp. 143–155). Oxford: Blackwell; Gutmann, A., & Thompson, D. (1996). *Democracy and disagreement*. Cambridge, MA: Belknap Press of Harvard University Press; Dryzek, J. (2000). *Deliberative democracy and beyond: Liberals, critics, contestations*. Oxford: Oxford University Press.

³³Estlund, D. (1997). Beyond fairness of deliberation: the epistemic dimension of democratic authority. In Bohman, J., & Rehg, W. (Eds.), *Deliberative democracy: Essays on reason and politics* (pp. 173–204). Cambridge, MA: MIT Press.

³⁴Goodin, R. (2000). Democratic deliberation within. *Philosophy & Public Affairs*, 29, 81–109; Parkinson J. (2003). Legitimacy problems in deliberative democracy. *Political Studies*, 51, 180–196. Dryzek, J. (2001). Legitimacy and economy in deliberative democracy. *Political Theory*, 29, 651–669.

³⁵Parkinson, op. cit., note 36.

Now, it has been noted that a problem with deliberative democracy is that it does not scale: that is, beyond a certain number of participants, meaningful deliberation becomes impossible.³⁶ As a solution to this problem, we suppose that it is sufficient if affected stakeholders are *represented* in the deliberation.³⁷

Parkinson proposes a number of requirements for such representation to be an acceptable replacement of full inclusiveness:³⁸

1. Representation should be context-specific, that is, depend on the concrete decision to be made.
2. Affected stakeholders should decide when it is important to be represented in a decision—that is, deliberation should be open.
3. If deliberation is to result in decisions (and not only recommendations) representatives should be elected, rather than simply selected.
4. Representation should not be proportional to stakeholder group size when decisions are made. Instead, it should be equal—all affected groups should be represented, regardless of size.
5. Representatives should act in a dual role: as *trustees*, it should be possible for them to be affected by arguments and change their minds; as *delegates*, they should provide input from the represented group.

To what extent does patient representation live up to these requirements?

Normally, one or a few patient representatives are recruited as formal and standing members for a longer mandate period on priority setting boards. This is done by allowing a patient organization or a cluster of patient organizations to appoint one or a few representatives or by the board asking members of patient organizations to become part of it. The representatives are supposed to take part in decisions, often covering a wide range of different diagnoses and conditions. There are several challenges with this related to Parkinson's requirements:

1. Patient representation is not context-specific.
2. Patients that are not represented by the current representatives are not allowed to change or influence representation when they are affected by a decision.
3. Patient representatives are often selected rather than elected.
4. Patient representation is not equal representation, that is, patient groups bearing the opportunity cost of a decision are normally not represented. Moreover, small patient groups or severely ill patients are less likely to be represented.

Requirements (1)–(4) are thus all problematic. In practice, allowing patient representation to change frequently according to requirements (1) and (2) would be unattainable—especially if representatives are to be elected when deliberation should result in decisions (3).

Regarding equal representation, requirement (4): representing small patient groups, or patient groups in which patients are too ill to take part, is not impossible. What is impossible, however, is to represent *future* patients—that is, potentially any member of the general population. Additionally, as already pointed out, the complexity of healthcare systems makes it very difficult to represent patient groups which potentially bear the opportunity cost of decisions.

In conclusion, even on the most favourable interpretation, justifying patient representation on the basis of deliberative democracy does not succeed. In practice, patient representation in this manner is likely to be impossible, and any attempt to implement it risks being biased towards some stakeholders at the expense of others.

5 | FROM PATIENT REPRESENTATIVE TO PATIENT CONSULTANT?

We have argued that the moral demands of priority setting pose problems for patient representation. The standard justifications for patient representation, such as to achieve patient-relevant decisions, empowerment of patients, securing legitimacy of decisions, and the analogy to democracy, all fall short when it comes to patient representation in priority setting. We are left with the question: how to promote patient participation in ways that do not conflict with the moral demands of priority setting, yet leave a meaningful role for patients?

We have already indicated that involving patient consultants could be a way forward. In this section, we briefly explore this idea.

It is common to include medical consultants in priority setting decisions; it has also become more common to include ethics consultants. These consultants do not necessarily have decision making power. Their involvement is based on the specific competence they bring to the decision making process. Their role includes raising awareness of overlooked issues, challenging assumptions, highlighting the connections of a decision to other issues in science or ethics. A patient consultant could fulfil a similar role by raising awareness, challenging assumptions about patients, acting as a liaison to patient groups, collecting or providing data on patient issues, and so on. Just like a medical consultant that does not represent all medical specialties, a patient consultant does not represent all patients or patient groups.

As we have emphasized above, it is important to recognize the diversity of patients with respect to their preferences, values, experiences, needs, and prospects. There is a need, therefore, for qualitative or quantitative patient research, as well as broad and open patient consultations.³⁹ The idea is not entirely new: there are already some examples of policy consultation initiatives or programmes related to priority setting. For instance, NICE uses a consultation process when making changes to its technology appraisal.⁴⁰

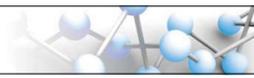
³⁶Facey, *op. cit.*, note 5.

³⁷NICE 2019. *Consultation on proposed changes to the technology appraisals programme*. <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/technology-appraisal-guidance/consultation-proposed-changes-to-the-ta-programme>

³⁸Facey, *op. cit.*, note 5.

³⁹Parkinson, *op. cit.*, note 36.

⁴⁰Mansbridge, J. (1999). Everyday talk in the deliberative system. In S. Macedo (Ed.), *Deliberative politics: Essays on 'democracy and disagreement'* (pp. 211–239). New York: Oxford University Press.



A patient consultant could be responsible for both identifying relevant research (if not already available to decision makers) and for organizing consultations. This way, the consultant can act as a 'liaison officer' between decision making bodies and patients, facilitating communication between them. Having experience of working with patient issues, the consultant should have both contact routes and established contacts to a large number of patient organizations and patient communities.

These broad and open consultations could include both patient education and discussions of concrete decisions. Participation in consultations may provide patients and patient organizations with a better understanding of the healthcare system, its guiding values and principles, the process of making treatment prioritization and reimbursement decisions, and serve as a forum to influence decisions by providing input. Thus, consultations can result in empowering patients and capacity building in patient organizations.

Are patient consultations and other activities a patient consultant might undertake sufficient to achieve legitimacy? Our proposal allows for voice and participation, and may do so more equitably than having patient representatives on decision making boards. If the voices of patients in consultations are seen to be taken into account in decision making, then, even if they do not ultimately change the decision, the decisions are more likely to have public support. Part of the role of a patient consultant should be to make sure that views expressed in consultations and other avenues are documented and considered by decision makers. This could be made more transparent by explicitly stating in decisions how they have been taken into account.

Would this proposal fulfil the requirements of representation in deliberative democracy? Parkinson applies the requirements to public consultation, and concludes that, if organized properly, it can meet the requirements. Patient consultations are likely to fulfil the requirements as well. They might be viewed as part of a larger 'deliberative system', provided that the results of consultations are brought into the actual decision making process.

Our discussion of the proposal is preliminary and too brief to justify the implementation of patient consultants. Nevertheless, we hope to have shown that the proposal may address some of the challenges that we have identified for patient representation. More work needs to be done. It might, for example, be objected that our focus on patient representation is too narrow. Would not our arguments about patient representation apply to other participants in priority setting decisions? Why focus only on patients, and not on medical experts, bureaucrats, or health economists? In response, we contend that patient representation raises unique issues. To see this, we can distinguish between participants who are tasked with moral deliberation and those who are tasked with providing input to the deliberation. In so far as medical experts or bureaucrats are there to carry out moral deliberation, they are morally responsible for the decisions, which may not be so for patient representatives. Patient representatives (or their constituents) may also have a more direct stake in decisions. (Of course, these roles are context-dependent, so that other participants may have a direct stake in certain circumstances. In those cases, their

role should be adjusted accordingly.) The crucial thing is to keep the two roles separate.

6 | CONCLUSION

We have taken the growing support and demand for 'patient involvement' in priority setting decisions as our point of departure. We have found that the moral demands of priority setting pose problems for patient representation. In particular, its standard justifications, such as to achieve patient-relevant decisions, empowerment of patients, securing legitimacy of decisions, and the analogy to democracy, all fall short. Taking these shortcomings into account, we have initiated an investigation into whether patient consultants could be a viable alternative.

ACKNOWLEDGEMENTS

Lars Sandman and Greg Bognar have received financial support from the Swedish Research Council and from the Swedish Research Council for Health, Working Life and Welfare which is gratefully acknowledged (2014-4024). The manuscript has benefited from comments at a seminar at the Centre for Medical Humanities at Linköping University.

ORCID

Lars Sandman  <https://orcid.org/0000-0003-0987-7653>

Bjorn Hofmann  <https://orcid.org/0000-0001-6709-4265>

Greg Bognar  <https://orcid.org/0000-0001-5606-3201>

AUTHOR BIOGRAPHIES

Lars Sandman is Professor of Healthcare Ethics and Director of the National Centre for Priorities in Health at Linköping University, Sweden. He is also involved in different decision making bodies within the Swedish healthcare system. His research focuses on the ethics of healthcare priority setting, ethical analysis of new health technologies and shared decision making.

Bjørn Hofmann is a Norwegian scholar in philosophy of medicine and bioethics with a special interest in the relationship between epistemology and ethics. He is affiliated to the Department of Health Science at the Norwegian University of Science and Technology (NTNU) at Gjøvik and the Centre for Medical Ethics at the University of Oslo in Norway. Hofmann's main professional interests are: philosophy of medicine (concepts of health, disease, diagnostics, autonomy, enhancement, and futility), philosophy of the health sciences (causation, rationality, biases, overdiagnosis, validity, and evidence), ethics of biotechnologies (human enhancement, prenatal testing, reproductive technologies, biobanks, and organ transplantation), ethics in health technology assessment (HTA), clinical ethics and priority setting, research ethics.



Greg Bognar is Senior Lecturer in Practical Philosophy at Stockholm University, Senior Researcher at the Stockholm Centre for Healthcare Ethics (CHE), and Honorary Fellow at La Trobe University (Melbourne). He is co-author of the book *The ethics of health care rationing: An introduction* (Routledge, 2014). In the 2019–2020 academic year, he is Laurance S. Rockefeller Visiting Faculty Fellow at the Center for Human Values at Princeton University.

How to cite this article: Sandman L, Hofmann B, Bognar G. Rethinking patient involvement in healthcare priority setting. *Bioethics*. 2020;34:403–411. <https://doi.org/10.1111/bioe.12730>