

DECIDING HOW TO DECIDE: THE CASE OF HEALTH CARE RATIONING

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One of the challenges awaiting health care systems around the world is the containment of expenses in the face of exploding costs for new drugs and treatments. In most countries, the allocation of health care has not been politicized so far and the problem is still treated as a purely regulative one. However, there is increasing interest in the procedures used for priority-setting. The paper argues that while normative standards for their evaluation are desirable, more attention should be paid to institutional factors and their effects. I identify two demands on decision-making – discursiveness and coordinativeness – from which I derive four ideal-typical procedures. By way of international comparison, corresponding empirical cases are analysed. I conclude with considerations on whether efficient and publicly accepted decisions over the allocation of health care are possible and, if yes, by means of what type of procedures and in what forum(s) they can be taken.

INTRODUCTION

The public debates about the future of health care systems still widely assume that the distribution of health goods follows the principle of need alone: everyone gets what they need, neither more nor less. Remaining regulative challenges such as the appraisal of new pharmaceuticals and technologies are regarded as purely technocratic problems to be solved by experts. Ever increasing costs for new drugs, demographic change and decreasing employment rates, however, have in most countries long made cost containment policies necessary.

The failure of governments to effectively control expenses enhances the pressure for explicit priority-setting in health care and increases the probability of its politicization. The challenge of distributing health care fairly under conditions of limited resources draws attention to the dangers and shortcomings of purely technocratic decision making as well as to those of emotionalization and apparent irrationality. Rationing decisions always have both an information aspect and a distributive aspect. The information aspect is entailed in the fact that it matters a lot who receives which treatment when and where, which is why expert information is required to ensure an efficient and rational allocation of limited resources. The distributive aspect is entailed in the fact that efficiency calculations alone will not suffice to achieve a fair and acceptable allocation. Decisions necessarily entail a comparative evaluation of needs and deserts (what people need and what they deserve), which cannot be replaced by expert judgements but requires democratic legitimacy and procedures.

Under conditions of uncertainty and complexity, a plurality of fundamental values and clashing interests, it seems clear that no such thing as an 'objectively rational' allocation of goods can be determined. Accordingly, the focus has to shift to procedures and to the extent to which they do justice to the informative and distributive aspects of rationing decisions. The central questions this article pursues are thus the following: what criteria do we have to analyse and evaluate different procedures for the allocation of health care?

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What practical effects do different procedures and their institutional parameters have on decision making and distribution? How are we to select reasonable and acceptable procedures?

The paper proceeds in four steps. In the section that follows, I point out the inevitability of rationing in health care and discuss advantages and disadvantages of implicit and explicit rationing strategies. Next, I address the conflict between efficiency and democracy and indicate why purely expertocratic decisions are neither possible nor desirable. Necessary compromises between conflicting allocation principles are eventually contingent, thus procedures not principles should be at the centre of the debate. Norman Daniels and James E. Sabin have offered convincing criteria for the normative evaluation of priority-setting procedures in health care (Daniels and Sabin 2002). However, in particular where the European public health services and social insurance systems are to be analysed, more attention should be paid to institutional factors and their effects in order to better understand procedures. I go on to define ideal-types of forums by two properties, discursiveness and coordinativeness. For illustration, I then compare four empirical examples to these ideal-types and discuss procedures and decisions. The Conclusion seeks to define the possible and necessary role of different types of forums in decision-making processes, the conditions under which rationing can be effective and legitimate, and calls for a deliberate selection and design of procedures and institutions.

LIMITED RESOURCES AND THE ALLOCATION OF HEALTH CARE

Expenditures in the health sector are limited by the simple fact that no society can use its entire resources for health care and that expenses in one sector effect opportunity costs in others. With a limited budget, it becomes impossible to fulfil all medical needs or desires. The necessity of cost containment is partly a consequence of the success of medical research and technology, which increase the quality of life and survival rates for formerly untreatable conditions (Daniels and Sabin 2002, p. 2). Aaron and Schwarz (Aaron and Schwartz 1990) have persuasively rejected arguments (for example, Reagan 1990) that rationalization, that is, the (financially) more efficient use of resources, can suffice to control the costs incurred by medical progress and demographic changes. This necessitates rationing, or curtailing, of health care, which brings up questions about the justice and efficiency of its allocation.

A common and useful distinction in this context is that between implicit and explicit rationing strategies. Implicit rationing takes place through limited budgets for single sectors and thus effectively relocates decision making from the macro- to the meso- or micro-level, that is, to the single hospital or physician. Explicit rationing strategies, by contrast, specify criteria by which funding for services is either denied priority or refused. Three sets of criteria may be distinguished. The first are criteria concerning the recipient, such as age, gender or lifestyle. Secondly, there are criteria concerning the condition to be treated, that is, whether and under what circumstances it qualifies as a disease. Finally, there are criteria concerning the effectiveness and risks of technologies to be funded. In practice, so far, criteria mainly of the latter two types have been applied.

Arguments have been made both for implicit and for explicit rationing strategies. The general principle of subsidiarity and the possibility of individual scrutiny militate for implicit rationing. In addition to this, it has been argued that explicit rationing decisions and public debates over them might challenge and erode shared values, in particular the value of life (Calabresi and Bobbit 1978). Hospitals and practices at the meso-level,

however, are frequently overtaken by decisions on individual cases. In consequence, informal decision rules are set up which are neither transparent to patients, publicly justified nor democratically legitimated. Besides the necessity of public justification, there are strong arguments – general bindingness, transparency and confidence in expectations – in favour of explicit rationing strategies (Fleck 1992).

While implicit rationing leaves the allocation of limited resources to market forces and the discretion of professionals, explicit rationing requires authoritative political decisions. In most health care systems, allocation decisions take place at different levels between the micro (patient-doctor) and the national level. Regional entities such as primary care trusts in the UK or county councils in Sweden, especially, often play a significant role. Typically, the higher the level at which they are taken, the more explicit and prone to politicization rationing decisions become. Politicization brings up questions about the rationality and justification of allocation principles, but also about how and by whom they are to be selected and applied. That is, explicit rationing enables the politicization of rationing decisions and raises questions about their rationality and legitimacy as well as the possible conflicts and trade-offs between these.

POLITICIZATION AND DE-POLITICIZATION OF RATIONING DECISIONS

Where health care is publicly funded or publicly sanctioned, explicit rationing decisions – and thus political decisions – must be generally binding. Collective decisions qualify as genuinely political by virtue of being contingent, meaning that they are neither predetermined by external forces nor clearly deducible from principles or evidence. Decisions are political because there exist alternatives over which citizens and politicians can, more or less autonomously, form preferences. Neither of the alternatives is unmistakably the ‘correct’ one, but, typically, several are viable and supported by good reasons.

There are two ways in which an issue may be politicized. The first is by demanding the replacement or regulation of decisions hitherto taken in the private sphere or on the market by generally binding law. The second is by pointing out the contingency, and thus the alternatives to, political decisions that are otherwise regarded as inevitable or without alternatives. The latter presupposes the former in that it takes for granted the necessity of a decision on the political level. For government and administration, a strategy to mitigate opposition consists in highlighting both the necessity of a generally binding decision and the lack of alternatives to their preferred option. Such de-politicization, it is suggested, allows for rational and efficient decisions by avoiding compromises and allowances. Opposition parties and groups excluded from power and influence can be expected to initiate politicization by pointing out alternatives, mobilizing veto power and exacting concessions for their benefit. The degree to which de-politicization is successfully countered in this way may be regarded as an indicator either for the distribution of power or for the prevalence of conflicts within a society.

What are the preconditions and consequences of politicization or de-politicization with regard to the allocation of health care? On the one hand, priority-setting definitely entails distributive conflicts. That is, certain groups of patients or potential patients are privileged over others and their claims and needs attended to with priority. Such distributive conflicts are to a large extent irreducible and cannot be solved in an expertocratic fashion. On the other hand, the matter is extremely complex and decisions apparently require a sound basis in expert information. According to Elster’s definition, health care is a heterogeneous

rather than homogenous good: it matters immensely who receives what, when and where (Elster 1995a, pp. 4–6). As allocation decisions immediately affect the welfare of citizens, poorly informed, ‘wrong’ decisions are likely to result in a public outcry. In the face of cut-backs of entitlements, the expectation of achieving optimal results with limited means grows. It seems that where a government curtails entitlements, it must increase productivity and cannot afford watered down, inefficient policies. Seemingly sub-optimal outcomes that fail to meet expectations might undermine the acceptance and legitimacy of decisions more profoundly than a lack of transparency and participation. Insofar as de-politicizing decisions increases welfare, it could thus not only be desirable under ethical aspects, but also preferred by a majority of the population.

One strategy to de-politicize decisions over health care has been to derive them from an overarching, and allegedly uncontroversial, principle of efficiency. The allocation of health care is efficient, health economists would say, where services optimally meet requirements and neither too much or too little, nor the wrong kind of care is provided in any place. Where resources are finite and some requirements cannot be met, efficiency can only plausibly be measured in terms of the absolute utility produced with a given budget. The problems of establishing such an interpersonally comparative measure for utility have long characterized utilitarian theorizing. Do we consider subjective wishes or objective needs? How do we determine or weigh either? In health care, though, objective needs seem to be easier to determine than in most other areas, and a respective calculus has been proposed and applied. For the assessment of medical technologies, the ‘Quality Adjusted Life Year’ (QALY) calculus registers only the costs of each life year in ‘improved quality’ that on average is gained by the treatment (Loomes and McKenzie 1989). The criterion by which care is allocated is hence the cost-benefit ratio of drugs and technologies. Who receives the benefit and whether a condition is particularly severe or even life-saving is irrelevant to the calculation. Decisions based on the purely utilitarian QALY-calculus have, although ‘efficient’, been regarded as unjust by the public. Consequently, they were politicized and, at least in the Oregon case in the United States discussed below, rejected.

In response to purely utilitarian principles, a calculus of most urgent need, or priority to the worst off, can be proposed as an alternative. Urgency of need could be measured for instance by estimating remaining life expectancy without treatment. Such a calculus would take the condition to be treated as criterion for allocation. Although, empirically, shifts from utility towards need were in many cases the result of a politicization of efficiency-maximizing rationing strategies, the unconditional preference for the neediest similarly qualifies as an attempt to artificially reduce complexity. In fact, de-politicization by means of the need principle seems to be particularly successful. It obscures the fact that available treatments for less serious conditions and benefits from prevention need to be forgone, so that in some cases, by the time treatment is provided, curing a condition may have become more difficult or even impossible. A third principle that plays a role in the allocation of health care is the principle of desert. It takes characteristics of the recipient – for example, lifestyle or family status – as criteria. Although an application of the desert principle that considers non-health related characteristics of the patient is mostly frowned upon, the principle surfaces in arguments about responsibility for health – such as the one that smokers should not be treated for lung cancer.

The bottom line is that a calculus of most urgent need privileges the critically ill, while a utilitarian calculus privileges the less severely ill and healthy members of a society. Desert criteria tend to privilege the more powerful and better off groups in a society, since they tend to be the ones who define what counts as individual responsibility.

Any necessary compromise between such principles is contingent in that it cannot be deduced from higher-ranking principles and requires a political decision. At the same time, the challenges lying in the combination and application of distributive principles under conditions of uncertainty provide strong incentives for de-politicization. Given the irreducibility of the underlying conflicts, however, the de-politicization of rationing decisions is likely to remain both frail and incomplete.

Søren Holm uses a model of two phases to describe a learning process that has taken place in the rationing debate (Holm 2000). The first phase, Holm argues, was characterized by the search for an 'objectively' rational and just method of priority-setting. Allocation decisions taken on the basis of the correct principle would escape politicization by virtue of being *ipso facto* legitimate. According to Holm, the debate in most countries has now reached a second phase. This abandons the search for simple solutions and acknowledges the complexity of the matter and contingency of decisions. Decisions have come to be regarded as gaining legitimacy through the use of the correct procedure rather than the choice of the correct principle (see also Goold 1996).

The recognition of the fact that political decision making cannot be replaced by the automatized application of a specific calculus brings demands for transparency, accountability and democratic legitimacy into play. Norman Daniels and James E. Sabin have developed a concept of 'accountability for reasonableness' consisting of four conditions which rationing decisions should meet in order to qualify as legitimate (Daniels and Sabin 2002, p. 45). The 'publicity condition' requires that decision and rationales for them must be publicly available, that is, in the terminology applied above, that they must be explicit. The 'relevance condition' specifies the kind of reasons that may play a role in rationales – they must appeal to evidence and principles that are accepted as relevant by 'fair-minded people'. The 'revision and appeals condition' requires that there must be opportunities for revision of policies and decisions in light of new evidence and arguments. Finally, the 'regulative condition' demands a regulation of procedures that ensures that the other three conditions are met.

Daniels and Sabin's approach provides a convincing and useful standard for the comparison and evaluation of procedures, and it has been extremely influential in the literature on rationing. However, Daniels and Sabin focus mainly on health maintenance organizations (HMOs) in the US which are at liberty to set up forums to meet their requirements. In European public health services and social insurance systems, the situation is somewhat different. Here, forums and procedures have to build upon pre-existing institutional structures and political cultures, and they have to involve different sets of stakeholders. Moreover, demands for democratic input-legitimacy and parliamentary accountability are of different significance in public than in private systems.

Institutional variables, such as the composition of a forum, its decision rules, tasks and responsibilities, are likely to affect interaction in the forum and its decisions. Even if these decisions do meet Daniels and Sabin's conditions of accountability for reasonableness, it makes sense to assume that different types of forums will produce different distributive results. In this sense, the choice of a procedure and forum for rationing decisions inevitably has distributive consequences. While for any procedure, it seems important to ensure that normative conditions of accountability for reasonableness are met, the selection of forums charged with decisions and their institutional properties should also be a deliberate one. In the section that follows, I propose a possible framework for the comparison and analysis of different types of forums that could be charged with rationing decisions.

DISCOURSE AND COORDINATION

With regard to the output of forums charged with rationing decisions, two major demands are apparent both at the empirical (what citizens expect) and at the analytical level (what their function within the larger societal system is). One demand directed at the political system in general is that it provide explicit, generally binding, decisions of complex matters within a reasonable timeframe. The other is for these decisions to be the 'correct' ones in whatever sense: based on available evidence, morally right, maximizing collective welfare. However, there is an apparent conflict between these goals, since a system that guarantees timely and explicit decisions on any matter cannot at the same time guarantee thorough assessment of the matter and 'correctness' of the decision. Although the assumption that a single objectively rational calculus exists to allocate health care has been pointed out as illusory, the expectation that the decision-making process provide satisfactory reasons for decisions remains intact both empirically and normatively – this is what Daniels and Sabin's concept of accountability for reasonableness makes clear.

At least two institutional properties can be identified that promote the give-and-take of reasons in argumentation. The publicity of a procedure forces participants to justify their positions and decision under reference to generalizable, 'public' reasons (compare Elster 1995b). What is required is not necessarily mass media attention. Even where a forum is in principle accessible to a wider public, incentives for bargaining and appeals to non-generalizable, 'private' reasons are stifled. In-depth justification of positions and their premises, however, is only warranted in a situation of dialogical interaction, where hearers can challenge and reject a speaker's assertions. As the realization of dialogical interaction becomes more difficult with the size of a forum, a conflict between dialogue and publicity may certainly arise (compare Elster 1995b, p. 252), albeit not necessarily. I therefore define forums in which interaction is both public and dialogical as discursive ones.

Justification is essential, but any explicit, generally binding decision, in addition, necessitates the coordination of different positions and reasons for action. The larger the coalition required for a decision, the higher is the necessary amount of coordination. Advocates of deliberative models of politics assume that coordination may be achieved through discursive interaction. If reaching understanding is the 'inherent telos of human speech' (Habermas 1984, p. 287), any kind of linguistic interaction contributes to the coordination of action plans – even if the quality of results depends on properties of the discourse. Under conditions of incomplete information on the one hand and time pressure on the other hand, however, communication alone is unlikely to suffice for coordination. Rather, additional incentives or forces to coordinate action plans and preferences seem to be required. These always necessitate compromises of different kinds. Thus, the coordinative quality of an institutionalized forum depends mainly on factors other than its discursiveness. In particular, coordinative qualities can be induced by an externally exacted decision rule or by internal aspirations to reach an agreement. The definition of the conflict (as conflict over facts, values or interests), the definition of actor roles (expert, citizen, representative or interest group), as well as the tasks and responsibilities of a forum, seem to be essential for such aspirations. The coordinativeness of forums will thus be defined by the presence of incentives or sanctions for the coordination of action plans through compromises, which are constituted primarily by decision rules and aspirations of the actors involved.

Crossing the two institutional factors of discursiveness and coordinativeness yields a matrix in which four types of forums are defined by these two properties (see Landwehr

TABLE 1 *Ideal-types of forums*

	Non-coordinative	Coordinative
Discursive	Expert discussion	Citizen deliberation
Non-discursive	Parliamentary debate	Distributive bargaining

2009, Ch. 3). I have assigned familiar types of forums to each of the four fields, which, however, are to be understood as ideal-types rather than categories (see table 1). The function of ideal-types in this context is not so much to organize empirical data, but to serve as theoretically derived reference points for the analysis of concrete forums. At the same time, I believe that somewhat similar regulative models affect the choice and design of procedures and institutions by political actors.

Forums of expert discussion are discursive in that they are – at least in their underlying logic – public and dialogical. They are characterized by a quest for truth in which reasons have to pass a test for generalizability and assertions can spontaneously be challenged. However, the competition of arguments in expert discussions is characterized by antagonistic dynamics of interaction. Members of an ideal-typical expert forum compete for esteem and want to win their point, but have little to gain from coordination, since they should not have material interests in the matter they are discussing. While consensus can in principle be achieved about purely factual matters (such as the effectiveness of a new drug), disagreements about social and moral matters tend to be to some extent irreducible. In these cases, the lack of coordinative incentives in expert discussions is likely to lead to indecision in the respective forums. Their potential therefore rather lies in the information of decisions and argumentative assessment of viable and justifiable options for action. In sum, expert discussion is ideal-typically most successful where a clear goal (for example, cost-benefit-analysis) has been defined, but scarcely likely to reduce the plurality of different social and moral positions on an issue.

Citizen deliberation in the comprehensive and inclusive sense is typically attributed to the Ancient Greek city democracies. In modern times, consensus conferences and citizen juries represent attempts to institutionalize respective forums. The logic of argumentation in these forums should be both public and dialogical. They are characterized by the quest for joint values and a common good, the ideal-type goal being to find a consensus on which of several justifiable options participants choose as citizens for their community. Despite its discursive and coordinative qualities and potential for the evaluation of different options, forums for citizen deliberation are notoriously difficult to institutionalize. In particular, easy exit options for participants can undermine coordination, and a lack of information and specialization can curb the quality of arguments. Nonetheless, forums of citizen deliberation may be expected to provide offers for a reduction of complexity and plurality.

Forums of distributive bargaining, while necessarily dialogical, take place behind closed doors, where private, non-generalizable reasons can dominate public and generalizable ones. Decisions require consensus, and the focus on interests makes compromises not only possible, but necessary from the point of view of actors. In combination, strong coordinative incentives and a lack of discursive properties in bargaining forums are likely to result in explicit, albeit inadequately justified, decisions, possibly at the expense of third parties. The potential of distributive bargaining nonetheless lies in a maximization of the total utility of participants (but only participants) and in increasing the efficiency of implementation. In this sense, it may serve to integrate a plurality of different stakeholder interests.

The forum of a parliamentary debate is a non-discursive one because, although public, interaction is better characterized as a sequential monologue than as a dialogue. It is also non-coordinative, since the coalition required for a decision already exists. Speakers seek to vindicate their position rather than assess and evaluate options. Obviously, this ideal-type is institutionalized to a greater extent in parliamentary and majoritarian systems than in presidential and consociational ones. Insofar as a lack of dialogical properties precludes in-depth justification and the antagonistic logics of interaction obstruct coordination, decisions in the parliamentary forum presuppose information and preparation in forums of the other three types. The generally binding decision will ideal-typically set an end to a decision-making process. The forum of the parliamentary debate, then, serves to publicly justify this act of arbitration and to reflect the plurality of different positions.

Looking at the way in which decisions over the list of services to be covered by national health services or social insurance systems are taken, international comparison reveals a heterogeneous picture. Most commonly, expert forums have been charged with this task, a solution that often has its origin in a time when the approval of new services was still regarded as a purely regulative matter. The challenges of health care rationing, however, have induced several countries to experiment with alternatives, for example, participatory or parliamentary forums and procedures.

For purposes of exploration and illustration, I will now discuss four examples of different forums and procedures and use the ideal-types defined above as reference points for their comparison. The analysis shows that neither of the examples is a perfect institutionalization of the respective ideal-type. Instead, they either combine properties of different types or only function in collaboration with other forums. These deviations from the ideal-types often seem to occur subsequently and to be a result of the practical shortcomings of ideal-typical forums. While ideal-types such as the ones defined here often serve as models where new procedures are established, the subsequent reforms of respective forums indicate that a single type may not be sufficient to achieve explicit, well-justified and acceptable allocation decisions.

SETTING PRIORITIES: FOUR EXAMPLES OF DECISION-MAKING PROCEDURES

Expert discussion: The National Institute of Clinical Excellence (NICE), UK

The National Institute of Clinical Excellence (NICE) was set up in 1999 as an expert commission, with the task of evaluating new and existing technologies to be funded by the National Health Service (NHS). The NHS charter requires that any person living in Britain is entitled to medical care and that no medically necessary and useful services may be denied to patients. Given its comparatively tight budget, though, the NHS has a long tradition of implicit rationing that surfaces in waiting lists, shortages of hospital beds and overloaded medical staff. Most allocation decisions are in fact taken by local primary care trusts, which leads to regional inequalities and intransparency. NICE was intended to improve transparency, participation and quality control and to provide explicit guidance to local trusts. Formally, trusts are still free not to follow NICE recommendations. However, the positive case (funding drugs NICE has not recommended) is usually prevented by cash shortages, while the negative case (not funding recommended drugs) is likely to result in public protests.

Within NICE, the 'technology appraisal committee' is of particular relevance in the present context. Authorized by the Department of Health, it evaluates drugs and technologies. Working with three independent chambers, the committee commissions

universities or research institutes with a report before it assesses a specific treatment. Besides academic experts, practicing nurses and physicians, patient representatives and representatives of the pharmaceutical industry are members in the committee's chambers. The committee aims at consensual decisions; however, the chairman can call a simple majority vote if consensus cannot be reached.

The discursiveness of the NICE expert forum is high. Discussions are at least partially public, so that references to private interests and bargaining are prevented. Reports and decisions are published promptly in both an expert and lay version and justified extensively. In case of negative votes, patients can make use of an appeals procedure and explicitly challenge the reasons named for a decision. Decisions thus also satisfy Daniels and Sabin's conditions of publicity and revision.

With regard to the criterion of coordination, by contrast, NICE deviates from the ideal-type forum of expert discussion. The available option of a majority vote increases incentives for coordination, since all members have to bear the decision. Moreover, the fact that the committees are staffed not only with experts, but also with interest groups and patient representatives, increases the relevance of interests compared to medical and economic controversies, something which in turn makes compromises easier. This deviation from the ideal-type expert forum has enabled the high productivity of NICE, which has produced up to 40 appraisals per year. Apparently, lower decision costs and higher coordinative pressures yield an increased willingness to compromise, which is also reflected in its decisions. So far, drugs and treatments have rarely been categorically denied funding, and only for specific indications or groups of patients. For example, in the case of the controversial treatment of multiple sclerosis with the drug interferon beta, NICE has decided that only patients with a certain type of the disease should be offered the drug and only under certain conditions, namely that they had at least two major relapses and that the disease had yet not progressed too far (NICE 2004a, p. 67).

With regard to Daniels and Sabin's criterion of relevance, which demands that the reasons for decisions should be such that all fair-minded people could accept them, and with regard to the thorough assessment of reasons, NICE has been sharply criticized. An evaluation of NICE by the WHO is critical that ethical and social aspects which affect decisions are, in contrast to economic and medical ones, not sufficiently articulated (Devlin *et al.* 2003). Others argue that under pressures from patient representatives and the pharmaceutical industry, NICE passes too many positive votes on new drugs, which leads to aggravated forms of implicit rationing elsewhere (Cookson *et al.* 2001). Another point that has led to disapproval is the fact that NICE guidance is predominantly based on utilitarian cost-benefit assessment in the form of QALYs (Harris 2005). Although NICE does not aim to produce a ranking of services, the WHO report comes to the conclusion that it applies an implicit threshold of £30,000 per QALY (Devlin *et al.* 2003). The application of QALYs is also acknowledged and defended by its chairman, Michael Rawlins (Rawlins and Dillon 2005).

Partly in response to such criticism, NICE set up a 'Citizens' Council' in 2002 (see Davies *et al.* 2005; Rawlins 2005). The council is modelled on American citizen juries and meets twice a year. Its lay members are supposed to be representative of the population at large and are appointed for three years; doctors, nurses and interest group representatives are banned from taking part. NICE chairman Rawlins argues that the council provides NICE with 'social value judgments', which an expert body is not as qualified to make, and which receive due consideration in NICE guidelines (Rawlins 2005, p. 473). However, the Citizens' Council's reports do not deal with the appraisal of single treatments, but

address more general topics such as clinical need or age (NICE 2003, 2004b). Moreover, it is unclear whether the citizens' recommendations have any real impact on decisions. Mike Stone of the Patients' Association has argued that the council is merely a 'tokenistic body', 'a tiger without teeth' (quoted in Gulland 2002, p. 406).

NICE itself deals primarily with the assessment of new pharmaceuticals and is less concerned with distributive decisions. Comparative evaluations for the justification of priority setting and 'tragic choices' do not take place. It thus focuses on scientific and clinical evidence as reasons to guide decisions and neglects other relevant reasons – violating Daniels and Sabin's relevance condition. This could also be the reason why delegation of allocation decisions to NICE has failed to effectively de-politicize rationing in the UK. Given the centralized system and the limited budget of the NHS, health care has always been more politicized in the UK than elsewhere, and the establishment of NICE can be regarded as an attempt to diffuse accountability. The debate about the breast cancer drug Herceptin shows, however, that a national expert forum is a likely target for protest whenever a drug is not made available for patients. In this case, public protests were directed at NICE although it did not have a say in the matter since the drug had not yet been licensed. Genuine distributive decisions would probably bring NICE to the limits of both its coordinative capabilities and democratic legitimacy. The majority decision of an expert body is hardly likely to meet with public acceptance, and an expert consensus becomes less likely in such cases.

Citizen deliberation: The Oregon Health Plan, Oregon, US

Worldwide, there have been different kinds of attempts to get citizens involved in health policy decisions (see Jorgensen 1995; Lenaghan 1999). Parliamentary and expert commissions have held public hearings in several countries, including New Zealand, The Netherlands, Sweden and Norway (Ham 1997; Calltorp 1999). The majority of procedures, however, were concerned with implementation and funding of single measures. The focus was either on the handling of risk (such as severe side-effects) or on the improvement of service provision (prevention, attendance and information). The only well documented example for extensive citizen participation in decisions over priority setting of public health care providers is the Oregon Health Plan, which was passed in 1991/2 and implemented in the following years (see Fleck 1994; Sipes-Metzler 1994; Daniels 1996; Rothgang *et al.* 2004).

In the late 1980s, the US state of Oregon had set itself the goal to extend the state-funded Medicaid-program to all its poor and uninsured citizens. The measure was to be funded by deleting less essential and less effective services from the Medicaid list. The Oregon Health Services Commission (OHSC), established for this purpose, could draw on a strong participatory culture when it decided to call 47 community meetings, in which over 1000 citizens participated (Sipes-Metzler 1994; Jacobs *et al.* 1999). From citizen statements, the commission derived 13 health-related values which it grouped into the three categories 'value to society', 'value to individuals at risk' and 'essential to basic health care' (Rothgang *et al.* 2004, pp. 209–10). However, a central goal of the commission was to use cost-benefit analysis to arrive at a ranking of condition-treatment pairs. In 1990, the commission published a preliminary ranking on the basis of the QUALY-calculus, which was vehemently criticized by the public and many experts (Rothgang *et al.* 2004, p. 211). Subsequently, the commission published a new ranking, in 1991, which was based on its members' assessment of condition-treatment pairs according to the categories derived from the citizen meetings and listed 'essential' and 'very important'

services as well as ones only 'valuable to certain individuals' (Oberlander *et al.* 2001, pp. 1584–5).

With regard to both discursiveness and coordinativeness, the community meetings held in the context of the Oregon Health Plan score high. The meetings were completely public and apparently experienced as dialogical by participants. Since the number of participants in the 47 single forums varied between seven and 132 (Rothgang *et al.* 2004, p. 209), it may be expected that dialogical qualities were easier to maintain in the smaller rounds. On the whole, however, there seem to have been few complaints about unequal participation or domineering organizational staff. A problem concerning the participants' self-definition as citizens consisted in their lack of (statistical) representativeness for the community as a whole. Participants were mainly members of the middle and upper class, a high percentage working in the medical sector. These people were not affected as patients by decisions over the Medicaid program: 'the plan could not avoid the appearance of "haves" setting priorities for "have-nots"' (Daniels and Sabin 2002, p. 152). It was less about what is important '*for us* as citizens and members of this community' than about what we deem important for '*the others*' – the poor and uninsured (Daniels and Sabin 2002, p. 152; original italics). The lack of representativeness thus exceeded the typical problems of lopsided self-selection which we find in all participatory procedures, since a majority of participants was not directly affected by the decisions they sought to inform.

The main problem with the Oregon procedure, however, has to do with the way the citizens' attitudes and preferences were coordinated. In fact, there were few pressures or aspirations for coordination at all, since the results of the single meetings were aggregated by the OHSC. This constitutes a deviation from the ideal-type of citizen deliberation. Of course, it is partly due to the fact that citizens lack the expertise to assess single treatments. At the same time, it can also be seen to indicate that Oregon's health leaders used citizen participation mainly strategically in order to gain support for reforms (Jacobs *et al.* 1999, p. 172). The eventual ranking is to a large extent based on highly subjective evaluations of OHSC members that could hardly be described as transparent (Jacobs *et al.* 1999, p. 169; Rothgang *et al.* 2004, p. 211), something which violates Daniels and Sabin's conditions of publicity and relevance.

With regard to the impact of citizen deliberation on rationing decisions, two points are remarkable. First, citizen participation seems to favour a prioritization of urgent need over cost-effectiveness. For example, the high priority Oregon has attached to palliative care is apparently a consequence of the public hearings. However, the fact that the explicit decision over the ranking of different services remained in the hands of experts indicates that citizen deliberation by itself will fail to produce explicit allocation recommendations (Lomas 1997, p. 106). The second interesting point is that participatory procedures, with a limited capability to produce explicit recommendations or even binding decisions, can at the same time serve to remove a topic from the political agenda. Although Oregon managed to significantly increase Medicaid coverage, this was mainly financed by general revenues and cost containment through managed care rather than explicit rationing (Ham 1998; Jacobs *et al.* 1999). Although there have been several follow-up meetings and hearings, the rationing topic appears to be less politicized today than in the early 1990s. To conclude, forums for citizen deliberation like the one in Oregon empirically seem to necessitate extensive expert involvement, while their potential contribution to explicit rationing decisions remains unclear.

Distributive bargaining: The Federal Joint Committee, Germany

In the late 1970s, German health policy made the first moves from service expansion to cost containment. Since then, the Joint Committee, where health insurers and doctors negotiate services to be covered, has gained in importance. In the German social insurance sector, committees of doctors, hospitals and insurers are part of a system of corporatist self-regulation. Institutions and their competences are sanctioned by federal law, so that actors negotiate in the shadow of hierarchy. Wherever they are charged with specific tasks, they are independent and their decisions are binding. This is a notable difference when compared with NICE in the UK, which issues only recommendations.

In Germany, the move from expenditure-oriented revenue policy in health care towards revenue-oriented expenditure policy was accompanied by an instrumentalization of the Joint Committee for the regulation of distributive conflicts (Döhler and Manow-Borgwaldt 1992, p. 584). In return for its commissioning for cost containment policy, the committee was given far-reaching instruments for its implementation (Urban 2001, p. 10). The Federal Joint Committee (FJC), set up in 2004, merges several existing committees and covers inpatient and outpatient medical and dental care. It issues legally binding decisions and thus possesses remarkably far-reaching competences for the allocation of health care.

The latest major health care reform, however, has also considerably restructured decision-making procedures in FJC. The committee has moved from a near ideal-typical distributive bargaining forum towards an institutionalization of expert discussion. Its discursive quality especially was substantially strengthened by the 2004 reform. The participation of patient representatives, albeit only with consultative influence and without voting rights, improves the publicity of meetings. The fact that each of the separate panels is chaired by three experts not only increases pressures for justification but at the same time reduces decision costs. Whereas previously, each party at the bargaining table (insurers vs. doctors or hospitals) effectively held veto powers, majority decisions are now possible. In case of a confrontation of interests, it is the experts who dispose of the deciding vote. Since a minimal winning coalition requires either expert support or compromises with the opposite side, coordinative incentives nonetheless remain strong. Moreover, an 'Institute for Quality and Efficiency in Health Care' was established to provide the Joint Committee with reports on specific technologies. Forums in the Joint Committee consider publicly available cost-effectiveness assessments of this expert forum as a basis for decisions.

Despite these institutional changes, the fact that a forum that was originally set up for bargaining purposes was charged with allocation decisions is in itself remarkable, since its lack of legitimacy and justificatory faculties is so obvious. The apprehension of insufficiently justified decisions at the expense of third parties seems less warranted after the most recent reforms. A decision to deny funding for a new type of insulin (GBA 2007), known to be effective but extremely expensive, indicates that cost-benefit assessments will play a role, even if less prominently than in NICE or in the first Oregon ranking. With regard to scientific judgements, Daniels and Sabin's relevance condition thus seems to be met, although it remains less clear how ethical and social reasons are considered in decisions.

In addition, the FJC's lack of transparency is problematic: the main committee is open only to a limited number of registered guests. In addition, no appeals procedure exists, so that decisions are only revised in the light of new evidence, not to correct ethical and social misjudgements. At the same time, the FJC seems to be, of the institutions

discussed here, the most successful one in terms of producing explicit and binding allocation decisions. This is in part enabled by the fact that the involvement of major veto players reduces potential opposition and facilitates implementation. In sum, decisions thus meet the condition of publicity (of decisions, although not of decision-making), but have shortcomings where the relevance and revision conditions are concerned.

However, recent conflicts between the Federal Joint Committee and the German Ministry of Health indicate a notable development. In 2005, the minister revoked a committee decision to limit funding for parenteral nutrition. The FJC insisted on its legislative capacities and took steps to justify the ruling to a wider public, naming acceptable (and not purely scientific), but also social reasons for it: for example, patients in nursing homes are often fed parenterally only because attendants want to save time (GBA 2005). Interestingly, the minister typically objects to negative decisions and thus contributes to the politicization of rationing decisions, which the delegation was seemingly intended to prevent.

Parliamentary debate: Sweden

In Sweden, too, growing demands and escalating drug costs increased pressures for priority-setting in the allocation of health care (Carlsson 2004). In accordance with Swedish tradition, a parliamentary commission was set up and charged with the development of a priority plan (see Ham 1997; Calltorp 1999). The commission consisted of seven members of parliament, in proportion with the larger parliamentary parties, and nine experts without voting powers. In 1995, the commission presented a consensual report that was discussed in parliament (Swedish Parliamentary Priorities Commission 1995). In 1996, the government turned the report (with minor changes) into a bill that was adopted by the plenum. A year later, a delegation was set up to ensure that the general principles stated in the report were to be turned into an obligatory basis for concrete allocation decisions. However, the Swedish health care system is highly decentralized (see Ham and Brommels 1994), so that, effectively, rationing decisions continue to be taken by county councils at the local level (Carlsson 2004, p. 52).

While the forum charged with priority setting in Sweden was not the parliamentary plenum itself, but a commission, it still allows us to see how the logics of the parliamentary debate affect decisions. It is a particularly relevant case, moreover, in that the Priorities Commission was equipped with a kind of democratic legitimacy which the other three forums considered here lack. To begin with, it is remarkable that the formulation of a consensual report was achieved in a time of hitherto unprecedented polarization of Swedish politics. The appointment of members in accordance with the parliamentary parties' size effectively transferred certain parliamentary logics into the forum. It was also clear from the beginning that the report was to be discussed and had to be adopted by the plenum.

With regard to the commission forum, discursiveness may be estimated as high. The number of participants was, compared with a plenary debate, low, which eases dialogical interaction. At the same time, expert involvement and public hearings kept justificatory pressures high and prevented moves towards bargaining. While the preparation of the decision in the commission to some extent countervailed the antagonistic logic of party competition (possibly helped by the high standing of consensus in Swedish culture), the commission's coordinative capabilities were not as strong as they seem. The report limits itself to an enumeration of comparatively abstract principles, which are to be converted into concrete decisions only by other bodies.

It thus seems that the commission's consensus on prioritization principles was only possible at the price of factoring out controversial issues. The report attaches priority to urgent needs over cost-effectiveness and highlights the principles of equality and non-discrimination. The far more explosive evaluation of specific treatments, however, takes place at a lower level, in the county councils, and therefore more implicitly. On the whole, the majoritarian logic of the parliamentary debate seems to have prevented coordination in the Priorities Commission as well. The likely reason for this is that in spite of general agreement on the necessity of priority-setting, any concrete cut-back would be met by a sufficient majority to prevent it. While the report itself does fulfil Daniels and Sabin's condition of relevance by being based on good scientific and ethical reasons, the way concrete rationing decisions are taken in Sweden cannot guarantee publicity and revision – it fails at their 'regulation condition' (Daniels and Sabin 2002, pp. 60–1).

In Sweden, the parliamentary decision thus constituted the beginning rather than the conclusion of a process. Although the commission's report sets little more than a frame for concrete allocation decisions in county councils, at least some of these have made considerable efforts to render decisions more explicit and to involve not only experts, but also citizens. In addition, a second commission was set up to succeed the Priorities Commission and is to guarantee central control and evaluation and to ensure that concrete decisions are guided by the report's framework. Nevertheless, while the commission's hearings and report drew attention to the rationing challenge and were accompanied by a comparatively broad public debate, the subsequent delegation to the local level mostly resulted in a de-politicization of the topic.

The empirical analysis of these four different institutional approaches to the rationing challenge has confirmed the probable deficiencies of the respective ideal-types that were established at the analytical level:

- forums of expert discussion tend to focus on scientific rather than ethical reasons;
- citizens in deliberative forums lack information to assess single technologies;
- distributive bargaining forums do not provide adequate justification for decisions, which therefore lack legitimacy;
- antagonistic logics in parliamentary debate prevent the coordination that would be required for explicit decisions.

The above explains why none of the cases analysed here is a perfect institutionalization of an ideal-type of forum. Instead, different types of forums or features of them are combined in decision-making procedures. At least two of the forums are clearly hybrids (the FJC in Germany and the Swedish Priorities Commission), and in all four cases, decision making takes or took place in more than one forum or at more than one level: in the UK and Sweden, responsibility for concrete rationing decisions partly remains at the meso-level of primary care trusts and county councils.

Taking Daniels and Sabin's conditions of 'acceptability for reasonableness' (Daniels and Sabin 2002) as a standard for the acceptability of the decisions produced by the different procedures, each of the four obviously has its shortcomings. Only NICE has an appeals procedure that fulfills the revision condition, which is essential for decisions in a democratic polity. The relevance condition, meant to ensure that all relevant reasons are adequately considered in decisions, is problematic in all four cases, and publicity of decision making and decisions remains insufficient. An interesting result concerning the democratic legitimacy of decisions is that the link commonly drawn between delegation to expert bodies and de-politicization of an issue (see, for example, Pettit 2003) does

not seem to hold: the effect of the participatory and democratic procedures in Oregon and Sweden was less rather than more politicization, while forums with strong expert involvement in the UK and Germany seem to enhance politicization.

CONCLUSION

Arguing that the focus in the rationing debate has rightly shifted from principles to procedures and finding that publicly administered health care systems use a variety of different ones to deal with the rationing challenge, this paper has proposed four ideal-types of forums that could be charged with decisions and has analysed corresponding cases. In light of the results of the empirical analysis, the question remains open: what does a forum that ensures explicit and effective decisions and fulfills requirements of legitimacy and acceptability look like and how should it be institutionalized?

I come to the conclusion that to ensure both efficient and effective procedures and acceptable decisions, it is both functionally and normatively desirable to involve different types of forums in rationing decisions. A promising approach would be to combine more or less ideal-typical forums with their respective weaknesses and potentials according to a cyclical model of policy formulation, in which information, evaluation, distribution and decision all have their place.

In a publicly administered system, explicit decisions at the political macro level are clearly desirable. Only where identifiable actors can be held accountable for decisions which apply to all members of the community in the same way, can the fulfillment of conditions of accountability for reasonableness be achieved. However, given time and budget constraints which macro-level allocation decisions will never entirely remove, doctors, hospitals and regional entities will still have to face hard choices. While the transferral of authority to the macro level relieves them of certain responsibilities, the experience and information of micro- and meso-level actors remains highly valuable for explicit decisions – decisions in which they should therefore be involved together with experts, citizens and elected representatives.

More specifically, a national or, in case of the European Union, even supra-national expert body could produce conscientious cost-benefit analyses that take into account relevant available information. These analyses provide an important basis for rationing decisions and would with high probability spark politicization of the topic. Once politicized, the topic needs to be addressed by a wider public of citizens. Forums could be public hearings, consensus conferences or standing citizen forums (like the NICE citizen's council), but the role of the general public and the mass media should not be forgotten here. A necessary function of the public is to weigh efficiency against other distributive principles and to correct rankings based alone on cost-benefit calculations.

Explicit decisions that aggregate expert information and the results of public and participatory debates might best be taken in stakeholder forums that, besides deliberation, allow for negotiation or even bargaining as modes of interaction. Membership in such forums should not be defined by political veto power (as it is in the German GBA), but through the way different groups are affected by decisions. Besides representatives of patients, doctors and hospitals, people who know about the specific needs of less articulate groups, such as disadvantaged children, homeless people or people with dementia, should have a say in respective decisions. At the same time, elected representatives – parliament or government – must remain accountable for the distribution of health care. The various

actors and forums thus prepare and take decisions in the 'shadow of the state' (Scharpf 1997, pp. 204–5).

Depending on the specific question, different procedures and kinds of rationing can be effective and legitimate. Where the funding of new drugs and technologies (for example new cancer therapies, IVF) is concerned, explicit macro-level decisions are appropriate and will require a high degree of expert information. For such decisions to be regarded as legitimate, it is essential that they meet criteria of transparency and relevance of reasons and that experts are seen as disinterested and neutral. Where the allocation of scarce resources at the meso and micro level is concerned (for example, placement on waiting lists for operations), implicit rationing by professionals must follow explicit principles determined at the macro level with the involvement of citizens and stakeholders. Here, it is particularly important that criteria of publicity and regulation are met, that accountability is clear, and that citizens and stakeholders know how they can influence decisions. On the whole, however, rationing decisions can only ever be effective and legitimate where it is clear that they can and will be revised in light of new evidence and arguments and where appropriate appeals procedures exist. This is the sense in which the model of policy formulation I argue for is cyclical: the evaluation of output and outcome of a decision-making process constitutes the input and basis for a new one.

With regard to the possibility of decisions that take the full complexity of the rationing challenge into account, this combinatory model yields a more optimistic outlook than the consideration of the potential of any of the forums by itself. The idea is less to make a single forum as deliberative and legitimate as possible, but to involve different forums, actors and modes of interaction in a deliberative system (compare Mansbridge 2006). Decisions would qualify as democratic insofar as the accountability of parliament and government is kept intact, transparency is guaranteed, and different forms of participation are permitted. At the same time, they could fulfil demands for information, assessment and justification insofar as different modes of interaction are allowed for, without one offsetting the effect of the others (compare Goodin 2005).

Finally, while the allocation of health care should from a normative point of view be guided by rational reasons, the choice of procedures, the resulting decisions and their factual acceptance are influenced by less rational factors as well. Whether a specific combination of forums and actors will work depends not on intelligent institutional design alone but also on the context in which it takes place. Procedures are established within a pre-existing institutional system and political culture, and attitudes about health, disease and care vary across the world. A procedure that is regarded as legitimate in one country may not be seen so in another, and a decision that is acceptable in one place may not be so in another. Nonetheless, institutional properties of procedures should be chosen deliberately and decisions should be assessed according to normative standards of acceptability.

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