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# Public participation in health

Towards a clearer view

EDITED BY Robert Maxwell and Nigel Weaver

CONTRIBUTORS

Rudolf Klein  
Sir Patrick Nairne  
Sir Douglas Black  
Jo Wood  
John Bettinson  
Ruth Levitt  
Stephen Hatch

SOUTH BIRMINGHAM  
COMMUNITY HEALTH COUNCIL  
933 BRISTOL ROAD  
SELLY OAK  
BIRMINGHAM B29 6ND  
TEL. 021-472 4089

KING EDWARD'S HOSPITAL FUND FOR LONDON

## Introduction

As editors, we set out to take a rounded view of public participation, without appreciating in advance anything like its full complexity. Our reasons for doing so still seem appropriate. The more sophisticated medical care becomes, the more important is it to emphasise that patients capable of choice should nearly always have the final say in their own treatment. The exceptions are ones where the individual concerned is incapable of exercising choice, or is a danger to others. But do patients actually choose?

The traditional relationship between one patient (or one family) and one doctor provides a less and less adequate model of the total situation in which communication and participation are needed. For any grave or lasting condition more than one physician is likely to be involved, along with members of other professions, particularly nursing. Thus the picture is complicated on the provider side, making communication with the patient substantially more difficult and frequently blurring the responsibility for decisions, despite the continuing value of the bond between individual patient and individual physician.

If the patient is not paying directly at the time of use, there is also a third party involved as paying agent, whether that is a private insurance company, a social security organisation or a government. This brings in another network for communication and, if public money is involved, for public participation and public accountability. In the National Health Service, the community health councils, the health authorities, central government and Parliament, are all mechanisms for this purpose. Just as patient choice should almost always be paramount in authorising any course of treatment, so public choice should be paramount in determining the ultimate uses of public resources, including the allocation of health authority budgets. The question then is what mechanisms will achieve this.

In arguing for the dominance of patient choice in treatment, and of public choice in resource allocation, we have no intention of disparaging the professional contribution at either level. Few patients can choose wisely without the advice of their physician. No public body can make sensible decisions without listening very carefully to professional opinions, formulated with an awareness of resource limits. Public participation does not deny the need for professional participation, although finding the right relationship and balance between the two is another matter.<sup>1</sup>

strong is not the same as saying that it is so in fact: nor that it is well informed, nor responsible. We undertook this book because we believed in the principle, and were not at all happy about the practice.

### Concepts and definitions

Among other things that we have had to learn is the fact that public participation is an elusive concept, meaning different things to different people. It can mean any or all of the following:\*

- i *Consumer protection*  
As with any goods or services the user of health services can expect a degree of protection against exploitation. Hence the importance of, among other things, professional standards, the licensing of medicines and of private sector providers, ethical committees governing research, and insistence upon informed consent.
- ii *Public consultation*  
People want their opinions and feeling to be taken into account. Most will accept that their views may not prevail, so long as they are satisfied that they have been listened to, and not lightly overridden. In some matters, such as the style of maternity care, many consumers may feel that *they* know best what is right for them, and that their views should cause patterns of care to be radically reshaped. From the viewpoint of the providers, it makes sense to listen to consumer views. Just as any service business in the private sector depends for its success on knowing what its customers and potential customers think, so also (as the recent Griffiths Inquiry argued<sup>8</sup>) ought the same to apply in the public sector, even if that makes the management task more difficult, within a fixed budget.
- iii *Openness of managerial decision-making*  
In a service that is so important to individual users, so sensitive and so large a user of public money, people can properly

\* This analytic framework is not based on any one study, but is indebted to several in a voluminous literature. For a bibliography on the subject see Barker's *Public Participation in Britain*.<sup>2</sup> Although this is predominantly British, it also includes some of the key American references. At that date, there was far more material on physical planning than on health, education and social welfare. More recently the balance has been partially redressed. See particularly (with the bibliographies included in them) Hadley and Hatch, *Social Welfare and the Failure of the State*;<sup>3</sup> Boaden and others, *Public Participation in Local Services*;<sup>4</sup> Richardson, *Participation*;<sup>5</sup> Bates, *Health Systems and Public Scrutiny: Australia, Britain and the United States*;<sup>6</sup> McEwan and others, *Participation in Health*.<sup>7</sup>

demand public openness concerning the manner in which management decisions are reached.<sup>9</sup>

#### iv *Full management participation by public representatives*

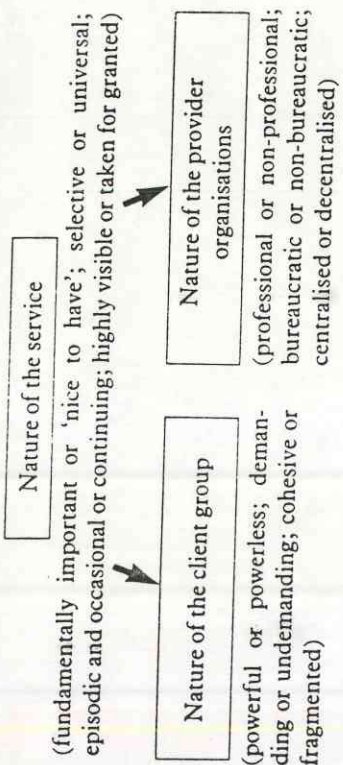
This, which has been called interactive participation<sup>4</sup>, comes closest to the rather straightforward concept from which we thought we had started. People should not be arbitrarily subjected to decisions made by others about matters that intimately affect their own lives, without the chance to shape those decisions. Communities should therefore share in the processes of health policy making and service provision. From the provider viewpoint, unpopular decisions can be defended only if the process by which they have been reached is seen to be legitimate. However, what is legitimate and effective opens up a whole further argument about the nature of democracy.<sup>10</sup> Democracy in national and local elections – at least in a relatively large country like the United Kingdom – by no means guarantees participation in the management of specific public services.

#### v *Heightened individual and communal responsibility and power*

Some people have argued strongly that our attitudes to health have become overmedicalised, and that the balance must be redressed by individuals and the community as a whole taking far more responsibility for their own welfare.<sup>11,12</sup> The boundary between this view and iv above is not precise, but there is some value in differentiating participation as partnership, from advocacy of much more radical shift in the balance of power. There are thus important arguments about the appropriate balance of power in participative decision-making, and about the breadth of the health field, as opposed to health services within their traditional, narrower definition.<sup>13</sup>

These five perspectives can be seen as an ascending order of public demands, of which consumer protection is the lower or minimum demand, and the others represent increasing bids for public accountability and participation. Not surprisingly, somewhat different reasoning underpins the case for each level of participation, depending not only on ideology, but also on more objective factors.<sup>14</sup> Boaden and others have argued<sup>4</sup> that the position of any local service on such a ladder of public participation depends on a range of variables, including the selectivity or universality of the service, its importance and sensitivity, its identification with a particular neighbourhood, and the nature of its clients and providers. Their approach is summarised and adapted in Figure 1, we hope without distortion, though in a simplified form.

FIGURE 1 Variables determining the degree of public participation



Source: Based on *Public Participation in Local Services*<sup>4</sup>

Because (among other things) health care is highly professional and most users are in a weak position to assert themselves at the time of use, it can be portrayed as the prototype of a service in which public participation is low, and is likely to remain so. That is a discouraging conclusion, as is the view that there are no public services at the upper end of the participation spectrum.<sup>4</sup>

Where, then, should health care fit in this spectrum? If change is needed, what types of change should they be and how can they be achieved? These are the questions that underlie the contributions to this book. The fact that, as Ann Richardson has noted recently<sup>5</sup>, it has become much less fashionable to discuss public participation in social policy than it was a decade ago is part of our justification for the task.

### Approach and outline

We picked contributors for their individual strengths and their different perspectives in order to achieve a three-dimensional view of the central issues. This was not a matter of copying the popular television formula of selecting people with polarised views for the sake of a good argument, or trial by verbal combat. On the contrary, we chose people who have a variety of relevant experience to bring to bear and a broad vision, seeking from the interchange among them to generate light not heat.

In Chapter 1 Professor Rudolf Klein examines the development of the National Health Service in terms of tensions and shifting balances between professional paternalism and public participation, and between national and local power. He also explores some of the differences between increased citizen participation and increased consumer responsiveness, for the two are not synonymous. As reflected in our earlier discussion of definitions,

an organisation can be highly responsive, yet wholly non-participative. The contrary is less likely but not impossible in a field like health, where the consumers of a service may be a small minority. To increase public participation involves both costs and risks. Nevertheless it can probably be done by lowering the costs of participating and increasing the benefits – for example, by providing information and support, by making each unit of management as local as possible, and by encouraging local diversity.

Sir Patrick Nairne, in Chapter 2, describes the arrangements for parliamentary control and accountability in the National Health Service. Thus, he deals primarily with what Ann Richardson has called 'indirect' participation, meaning the ways in which democracy influences policy, rather than with face to face contacts between consumers and providers. He perceives a series of paradoxes, starting with the proposition that despite its great public importance and sensitivity 'no public service thinks less about the public as such: to the NHS the public are patients'. He suggests no radical changes in the arrangements, and stresses instead the need for the main participants in parliament, the DHSS, the professions and the National Health Service, to understand better one another's role in terms of control and accountability. Paradoxes such as those perceived by Rudolf Klein are, in Sir Patrick's view, resolvable. Clear accountability to parliament need not stand in the way of a greater decentralisation of authority. As current experiences show, however, there is in the short term an almost irresistible temptation for government to tug on the reins of control and accountability so as to centralise decisions, whenever it judges that the political price of living with decentralisation is too high.

From a Permanent Secretary's perspective we turn, in Chapter 3, to what Sir Douglas Black modestly and correctly labels a medical view. He deals, first, with the individual consultation and then with broader questions of the professional role in public decisions at national, regional and local levels. The sequence is deliberately chosen. Important as the management of health services is – and few clinical physicians have invested more of their own effort in health services management, broadly defined, than Sir Douglas Black – getting the individual consultation right comes first for him. Both in the private consultation and in most management arenas, he emphasises that the physician is ultimately only an advisor. He participates in and strongly influences decisions, but in the end it is the patient (in individual treatment), or the public authority (in collective matters) who should decide.

Sir Douglas's clinical experience is as a hospital consultant. We

could have turned to a general practitioner to complement his chapter. Instead we asked Jo Wood to describe the relatively recent development of patient participation groups in general practice. She explains the varied range of activities undertaken by such groups, and draws attention to the common problems of maintaining long-term commitment (rather than gradually lapsing into apathy) and ensuring that the group is sufficiently representative of the practice. She thinks that patient participation in general practice is here to stay, though it may be a minority taste, and that the number of groups will rise slowly. This seems to be a specific example of the more general proposition advanced by Rudolf Klein in Chapter 1, that the degree of public participation can be increased by lowering the costs of participating and raising the benefits from doing so: the scale of patient groups in general practice is small, with the promise of direct personal benefit from any resulting improvement in service, and the effort involved from any one patient representative is not too daunting.

John Bettinson had been a health authority chairman, prior to the 1982 reorganisation, and has also served as an early Chairman of the National Association of Health Authorities. In Chapter 5 he weighs his experience of the role of chairman and members. The conclusions are not reassuring. Most members have found their role elusive and somewhat unsatisfactory, though since 1982 the smaller health authorities at district level have offered a greater chance of understanding what the NHS is doing, and of making a useful contribution as members – perhaps another example of Klein's proposition that participation can be increased by improving the perceived ratio of benefits to costs. Chairmen do not, on the whole, suffer from the same frustration as other members, though they have some of their own. For them too there is role uncertainty, but in a rather different form. There is no lack of demands for their attention and involvement. The difficulty for them, in face of endless diversions, is to help their authority decide where, in broad terms, it should be heading, and to mobilise the efforts of all concerned (including themselves) to move in that direction. John Bettinson has no radical new approaches nor panaceas to offer, but much sound common sense, with a few provocative twists for good measure.

Ruth Levitt and Stephen Hatch, in Chapters 6 and 7, take a more radical view of the whole topic of public participation. Ruth Levitt argues that health policy requires fundamental rethinking and broadening. We have come to equate health with health services, whereas environmental conditions, social inequalities and personal behaviour all make more impact on health than does

medical treatment. Within health services, we have been overimpressed by medical science, high technology and acute care, compared with less glamorous activities. We have to take more responsibility for our own health, and break out of the cul-de-sac represented by an overmedicalised view. Yet, paradoxically, the majority of the general public is more than happy to leave things as they are, with physicians in the role of skilled and trusted garage mechanics, who repair damage whenever necessary. The dialogue that is needed, therefore, is less about participation in the management of health services conventionally defined, than about changing people's perceptions of health.

This analysis provides a good precursor to Stephen Hatch's chapter about the voluntary sector. Approached from this standpoint, the voluntary movement is not a marginal adjunct to mainline statutory services, but central to the issues of personal responsibility and self-help. Hatch distinguishes three principal types of voluntary organisation: *the service providers and assistants*, like the Red Cross, the St John's Ambulance Service, the Women's Royal Voluntary Service, the Samaritans and hospital Leagues of Friends; *the self-help groups* like Mencap and thousands of other condition-specific associations; and finally *the community health movement*, based on neighbourhood projects. The common feature of all three types is that through them the lay public moves from a passive to an active stance, learning more about health, influencing patterns of service provision, and selectively taking the initiative. The whole complex self-help movement may seem at first sight a separate topic from public participation in the governance of health services, but Ruth Levitt and Stephen Hatch are, we think, correct in arguing that it is not. Apart from anything else, a more aware and articulate public is bound to be more demanding about standards and choices in the statutory services. Hatch sees an especially important role for community health councils in this connection. Because they are at the interface between the National Health Service and the public, they can promote lay involvement in self-care and mutual aid, besides their more obvious role of representing consumer views. The two functions ought, he argues, to be interdependent and inseparable in a pluralistic and participatory system of health care.

Inevitably there are some aspects of participation that we have omitted which different editors would have included. For example, we have left on one side the whole question of worker participation, including the arguments for professional and trade union representations in management and on health authorities. This seems to us to be a sufficiently different topic to warrant a

In the final chapter we seek to draw the threads together. It would be impertinent as well as tedious to attempt a comprehensive synthesis of the different views. Since our purpose was, with the help of the contributors, to take a three-dimensional view of the complex terrain, it would be a pity to try to turn the results back into a two-dimensional representation. Instead we return to the questions posed earlier in this introduction. Where should health care fit into the conceptual spectrum of degrees and types of public participation? If change is needed, what types of changes should they be and how can they be achieved? Our answers are our own, rather than in any sense representative or collective. They are neither authoritative nor precise. Getting things exactly right – whatever that may mean – is less possible, and even perhaps less useful, than diagnosing where change is needed and suggesting broad lines of movement. That is what we have tried to do.

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# I The politics of participation

RUDOLF KLEIN

## Introduction: from paternalism to participation?

At the heart of the debate about participation, and about the relationship between the providers and consumers of health care, there lies a profound contradiction. This is that while the National Health Service was set up in order to democratise access to health care, it is also a monument to the values of enlightened paternalism. If the overriding policy aim in designing the NHS was to make sure that everyone should have equal access to the wonders of medical science, the institutional means reflected the belief that this could only be brought about by creating more scope for professional expertise and bureaucratic rationality.<sup>1</sup>

Indeed this flowed ineluctably from the underlying philosophy of the founders of the NHS: to create a health service where the only criterion of access would be need, and where people with equal need would have the same opportunities of receiving equal care irrespective of their financial resources or their geographical location. For who but the professional experts – that is, the medical profession – could define and identify need? And who but the bureaucratic rationalisers could ensure that health care resources were distributed equitably?

Moreover, the philosophy that shaped the NHS had a further ingredient. This was faith in the ability of medical science to deliver the goods. Improving the people's health was seen, essentially, as the problem of creating a framework in which medical science could continue to advance and yield its benefits to the whole population. Only provide a rational framework in which it could operate to the limits of its potentials, so it was assumed, and everything else would follow. If the 1948 model institutionalised the 'voice of the expert' – the medical profession – this reflected not just the trade union power of the doctors but a wider social consensus about their crucial role as social engineers.

Given this approach, it was not surprising that the design of the NHS – as it emerged in 1948 – put the emphasis on expertise and centralisation. The option of a locally controlled health service was explicitly rejected. Central control was essential, Bevan argued, in order to ensure the rational and equitable distribution of resources. If the aim was to universalise the best, as he optimistically put it, then it followed that there would have to be

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Given this approach, it was not surprising that the design of the NHS – as it emerged in 1948 – put the emphasis on expertise and centralisation. The option of a locally controlled health service was explicitly rejected. Central control was essential, Bevan argued, in order to ensure the rational and equitable distribution of resources. If the aim was to universalise the best, as he optimistically put it, then it followed that there would have to be

national standards. In turn, national standards implied a national service.

Despite the changes brought about by the next three and a half decades, this remains – in essence – the public philosophy of the NHS. The 1974 reorganisation represented an attempt to bring the organisational reality of the NHS nearer to its original aspirations: it marked the triumph of the faith in expertise and bureaucratic rationality. The 1982 reorganisation represented, in turn, a shift in the opposite direction: a rhetorical retreat, at any rate, from centralisation and bureaucratic rationality (though not from the belief in the technical expertise of the medical profession). The recent Griffiths proposals imply a shift of a different kind – from professional paternalism to managerial dominance. However, despite this latest change of emphasis, it would be difficult to argue that the underlying ideology of the NHS has changed – as yet.

If this point is accepted, then it follows that the debate about participation raises fundamental issues about the nature of the NHS. In part at least, it reflects the decay of the 1948 consensus: disillusionment with some of the underlying beliefs that shaped the NHS. No longer is the professional expert's monopoly of need-definition and identification accepted uncritically. No longer does the authority of bureaucratic rationalisers go unchallenged. No longer do we believe in the infinite capacity of medical science to deliver miracles. No longer do we assume that the policy aims of the NHS can be defined in exclusively technical terms.

The debate about participation is therefore a debate about the role of politics – defined as competition between different interest groups to decide who gets what – in the NHS. To see the organisation and delivery of health care in terms of the rational development of expert-defined policy aims is, by implication, to argue for the insulation of the health care arena from politics. From this perspective politics is at best an irrelevance, at worst a damaging interference with rational planning. Conversely, to question the role of the professional expert and the bureaucrat – to suggest that they may be defining, in all good faith, the public interest in terms of their own special interests – is to argue also for the introduction of politics into the paternalistic Eden of the NHS. From this perspective, participation is all about bringing politics into the health care arena and, consequently, about changing the balance of power by challenging the decision-making monopoly of the providers. Essentially the assumption is that the logic of democratising access to health care is also to democratise access to the decisions about the organisation and

distribution of health care<sup>2</sup>: that is, those decisions which actually determine *what* people have access to, *how* and by whom their needs are defined and the *way* in which they are met.

Moreover, reinforcing the case for participation is the fact of scarcity. Given that the NHS – like all other health care systems<sup>3</sup> – inevitably and inescapably has to ration scarce resources, then clearly the issue of who determines the criteria of making such judgments becomes central. Once again, we have become aware that this is not just a matter of applying the right techniques: such tools of analysis as cost benefit studies and health status indicators can certainly help us to clarify the options, but they do not tell us what we should be doing. If it is accepted that the criteria for rationing – like the criteria for defining needs – are essentially contested notions, then the issue of power becomes central: that is, the question of who has a voice in the process of deciding on the criteria being used in policy making and implementation. While the assumption that the aims of health care policy can be shaped by a technical consensus leads to the acceptance of paternalism, the growing realisation that the aims of health care policy involve weighing up competing (and sometimes conflicting) claims to scarce resources leads to the demand for participation.

The point can be simply illustrated. If it is generally accepted that decisions about who gets what (for example, who gets renal dialysis or a heart transplant) involve only technical criteria, then there will probably also be agreement that decisions should be left to the experts: that is, doctors. But once we acknowledge that such decisions may also involve judgments about ethics, or about the economic value to society of different lives, then it is no longer self-evident that they can be left to the experts. Indeed, there may well be no expertise when it comes to determining what weight should be attached to different, and perhaps conflicting, criteria: technocracy has to yield to a debate about the desirable or tolerable trade-offs between competing social values. And the question of who is entitled to participate in such a debate becomes crucial. In what follows, this chapter will seek to provide a political analysis of participation: to examine the NHS as a political system. In doing so, the assumption will be that – whatever one's view of the desirability or otherwise of participation – it is important to be clear about the scope for changing the existing distribution of power within the health care arena and the feasibility of different policy options. The aim of the exercise is therefore not to provide a cook-book recipe for more participation but to analyse the trade-offs involved and the implications of different options.



simplest way of transferring power to the individual consumer is to make him or her the paymaster of the health care providers. (A policy option which is certainly feasible if we are prepared to make heroic assumptions about the willingness of governments to redistribute incomes sufficiently drastically to give all individual consumers the necessary purchasing power).

As we all know, however, the health care market is a peculiar one. In particular, it is characterised by an imbalance of knowledge between consumers and providers. The consumer does not necessarily know best (though he or she may do so more often than is assumed by the professionals). Similarly, mistakes – once made – may often be irreversible. A defective car can be returned to the garage; a defective operation poses rather more difficult and perhaps permanent problems.

So we come back to the central tension within the NHS. The whole justification for its existence lies in the rejection of the market principle as inappropriate for the organisation of health care. It is this which, in a sense, gives moral legitimacy to the paternalism of the providers: if the NHS does not exist to meet professionally determined needs, as distinct from consumer demands, why have it in the first place? Yet, at the same time, there is pressure to accommodate within the system the kind of consumer demands that would be appropriate in a market system but which go against the grain of the NHS's own ethos.

Moreover, there is a further reason why the consumer model fits rather badly into the specific context of the NHS. In the economic market place, a consumer seeking the best buy for himself or herself is not damaging the interests of anyone else. The language of equity is irrelevant. In the case of the NHS, however, it is central. What may be the best buy for the individual may not necessarily be the best buy for the community collectively: maximising the health of the community as a whole may actually involve giving individuals less than the optimum possible treatment, and possibly even denying them treatment (as, for instance, in the case of renal dialysis).

Nor is there a necessary or logical link between consumerism and participation seen as involvement in the decision-making processes. After all, the management of a firm which finds that the consumers of its products are dissatisfied does not invite them into the board room. Instead, it is likely to carry out some market research and adapt its products to meet consumer preferences. In the case of the NHS, too, management has this option. Indeed, the Griffiths report<sup>3</sup> takes the view that good management requires a sensitivity to consumer views. 'Businessmen have a keen sense of how well they are looking after their customers', it points out and

Participation is about politics: the involvement of citizens in the process of making decisions on issues of public policy. The point is obvious enough, yet all too often forgotten in the debate about participation. For when we examine the arguments for more participation, we frequently find these being put in terms of giving more power to the consumer. Yet the difference between citizens and consumers is all important.

In the first place, the consumers of health care are only a minority of those affected at any one time by the policies and practices of the NHS. As a citizen, I may have an interest in the NHS even though I am not a consumer. My interest may be that of a contingent user: someone who wants to be sure that there will be the appropriate facilities should I ever want to use them. Or my interest may be that of a taxpayer: someone who wants to make sure that my money is not being wasted.

From this it follows that participation by citizens and participation by consumers do not necessarily point in the same direction. As a citizen I may well wish to minimise the investment in a particular form of health care, while as a consumer I may want to maximise it. In short, we have to be clear whether we are concerned about strengthening the responsiveness and accountability of the NHS to a wider body of citizens, or of strengthening consumers as an interest group *within* the NHS. Both may be legitimate aims of policy, but they are not the same or necessarily congruent.

In the second place, the language of consumerism is that of the economic market place rather than that of the political market place. Consumerism (despite its rather paradoxical adoption by the Left) is about the individual getting his money's worth, as any issue of *Which?* demonstrates. The consumer movement in health care makes much the same sort of demands as the consumer movement in other markets. It generates demands for more information about the goods being sold, for minimum standards, against poor quality, and so on. It is all about creating more scope for informed choice; for allowing the consumer to satisfy his or her demands. It concentrates attention on the individual consumer's experience of health care; in particular, the relationship with providers discussed in Sir Douglas Black's chapter.

Indeed the logic of consumerism is a market-based health care system, as the Institute of Economic Affairs quite rightly argues.<sup>4</sup> If our priority is to ensure a health care system organised around the principle of responding to individual consumer demands, then clearly there is no better machinery than the market. The

argues for a similar approach in the NHS. Thus it should be the responsibility of NHS management, the report suggests, to 'ascertain how well the service is being delivered at local level by obtaining the experience and perceptions of patients and the community' using a variety of methods, including market research.

The trouble is that while a business firm which ignores consumer preferences long enough will eventually go bankrupt, there is no equivalent sanction in the case of the NHS. For the NHS, losing customers is a bonus: exit by patients (whether into self-care or the private sector) simply relieves the burden on the organisation.<sup>6</sup> The incentives to change organisational routines and practices, in response to information about patient preferences, are weak. Thus, for example, the survey of hospital patients carried out on behalf of the Royal Commission on the NHS<sup>7</sup> showed that 43 per cent of those interviewed were aggrieved about being woken up too early. This entirely predictable finding illustrates the difficulties of overcoming organisational resistance to changes designed to meet consumer preferences. The organisational bias favours maintaining those routines and practices perceived to be desirable by the producers.

If we adopt a consumerist perspective, therefore, the problem becomes one of devising ways of making the NHS more *responsive*: of introducing incentives to the managers and producers not only to seek information about patient preferences but to act on the signals received. But, once again, it is worth stressing the limitations imposed on such an approach by the very nature of the NHS. Given that the NHS is an instrument for rationing scarce resources equitably, there may be good reasons for refusing to respond to patient preferences if meeting these reduces the overall capacity of the service to meet the needs of the community as a whole. The real difficulty is to know when this argument is being invoked because of organisational self-interest or conservatism, and when it is a genuine reason for refusing to meet consumer preferences.

Further, there is the problem that consumer preferences tend to be shaped by what is available. Overall, the evidence of successive surveys over the decades – confirmed by the Royal Commission survey – is that most people are satisfied with the services they receive. This somewhat passive acceptance of the status quo may be changing, perhaps influenced by the increasing coverage of health care issues by the media. Certainly there is evidence that the better educated and the younger consumers tend to be more critical. But, in general, the paradox of the NHS would seem to be that it is the producers who are more aware of

what could be done – the gap between existing provision and the potential scope for improving scope and quality – than the consumers.

Lastly, it is worth noting that consumer preferences – where they are expressed – tend to be biased in a particular direction: that is, towards the acute services. If we assume that the use of the private sector measures consumer dissatisfaction with the NHS (at least for those consumers who can afford to opt out), then it is clear that the repressed demand is largely for better facilities for elective surgery for people of working age (as well as for choice of timing and of consultant). In short, there would appear to be a clash between the paternalistic values that have shaped policy making in the NHS – as reflected in the priority given to the elderly and other vulnerable groups – and consumer preferences. To reject paternalism, while embracing consumerism, might therefore have profound implications for the distribution of the NHS's resources.

### The political market

So far the argument has identified two rather different reasons for worrying about the political context of policy-making in the NHS. The first, discussed in the introductory section of this chapter, puts the emphasis on wider participation in policy-making: the challenge is to the paternalistic assumption that needs can only be defined by professional experts. The second, discussed in the preceding section, puts the emphasis on making the NHS more responsive: the challenge is to the organisational assumption that the perceptions of the providers must inevitably censor consumer preferences.

Both points raise questions about the nature of the political market in the health care arena. This section therefore addresses itself to analysing this market. If we want to encourage greater participation and involvement by citizens in the formation and implementation of policy – if we want to see decisions being taken not exclusively by experts but as the outcome of a wider debate – what are the problems and options?

But before discussing issues specific to the health care arena, it is important to note the central irony of the whole debate about participation. While the advocacy of more participation tends to be made in the name of anti-elitism, participation itself tends to be something of an elite activity. In other words, we cannot start with the assumption that there is a dammed-up demand for greater participation, only waiting for the institutional changes needed to open the floodgates of public involvement.

Thus a survey carried out on behalf of the Commission on the Constitution in the early 1970s found only a 'fairly low level of interest and involvement in political and community affairs'.<sup>8</sup> Moreover, those rated as 'very involved' – because they were active in political or community affairs, as distinct from being passive members of such organisations as trade-unions or local voluntary associations – tended to speak with an upper-class accent. While 44 per cent of professionals and managers came into the 'very involved' category, only 10 per cent of unskilled workers did so (while the figure for skilled workers was 21 per cent). Interestingly, too, the survey showed an age bias: involvement tends to rise with age until people are in their 40s, declining thereafter. Not surprisingly, involvement is also linked to education: while 48 per cent of those who had gone on to higher education were rated as 'very involved', only 19 per cent of those who had left school before 15 came into this category. And much the same pattern emerged when the survey examined people's knowledge of how the public services are run: again, social class and education turned out to be important factors.

At first sight this evidence would seem to be at odds with the much cited phenomenon of a boom in a wide variety of action groups: ranging from tenants' associations to self-help voluntary groups. But, in fact, a rapid growth in such groups is perfectly compatible with public involvement remaining very much a minority interest: if we assume 100 members per group (a fairly generous assumption probably) then even the birth of 1000 new groups does not amount to a large proportion of the population. And, indeed, the 1977 General Household Survey confirmed the findings of the earlier investigation: it found that only about 10 per cent of the adult population participated in social and voluntary work.\*

All this is not to deny the extent of the commitment to participation in public affairs in Britain. In my own view, 10 per cent is an impressively high figure. It is to suggest, however, two cautioning conclusions – both with important implications for policy (and not just in the health care arena). The first is that we should not take the willingness to participate for granted: that we should examine carefully both the enabling conditions and the barriers which either encourage or discourage people from participating. The second is that we should avoid the easy rhetoric which opposes participation to elitism: the case for widening participation, it is tempting to argue, is simply that it offers opportunities for new elites to involve themselves in the

policy process: to create more competition among elites (which may, in itself, be a very desirable objective – but should not be confused with populist rhetoric).

To elaborate the first point, participation involves – self-evidently – both costs and benefits. It requires time, knowledge, social skills and self-confidence: an investment of effort, in short. Conversely, participation can bring rewards. Some of these may be psychic: an intrinsic sense of satisfaction at doing one's social duty or of asserting one's rights as a citizen. Others may be more directly material. The incentive to participate is obviously greater if, as a result, one increases one's chances of getting some specific return: a motorway rerouted, a local hospital kept open, and so on.

Following on from this point, it is not surprising that, as we have already noted, the participating population is in no sense an accurate mirror of the community as a whole. It is a biased sample – because the resources required to make the most of any opportunities to participate are not equally distributed in the population at large. The less educated, less articulate and less confident are likely to lose out. Indeed it is tempting to suggest that there is an inverse law of participation – that those with the greatest need to push their own interests have the least capacity to do so effectively. Conversely, it would seem to follow that extending the opportunities to participate would favour precisely those who already have the most resources, whether social and economic.

However, this is to assume that the costs and benefits of participation are set in concrete for all time. In fact, of course, if the objective of public policy is to encourage participation, it is possible to create conditions which lower the costs and increase the benefits. Specifically, three propositions would seem to flow from the arguments put so far.

#### *Proposition 1*

The costs of participation can be lowered by diffusing free information and providing organisational support. Thus it is possible to make it easier for people to participate (particularly the least knowledgeable) by deliberately setting out to provide them with information. Equally, it is possible to lower the organisational costs of participation by providing support, for example, from community workers.

#### *Proposition 2*

The greater the scope for local diversity, the greater also are the incentives to participate. In other words, the benefits yielded by participation can be increased by accepting the right

for local communities to be different: that is, to make their own decisions about the level and pattern of services.

#### Proposition 3

The smaller the size of the political universe, the lower will be the costs and the higher will be the benefits of participation. To the extent that the universe is small, so information is more accessible and the organisational effort involved is lower. Conversely, the benefits will be more direct and immediate to the individuals concerned.

Each of these can now be translated into the specific context of the NHS. If the aim is to encourage participation, then clearly there has to be a greater willingness to provide free information. Similarly, from this perspective the role of community health councils can be seen – in part at least – as being to lower the organisational costs of participation: they provide a ready-made (and free) machinery which can be used by citizens to express their views.

Again, greater participation would seem to imply accepting greater local diversity in the NHS. For why should people take an interest in their local NHS services if these are determined exclusively by national decisions about the level and pattern of provision? So here we come to a trade-off between the conditions required to encourage participation and other aims of policy, such as the achievement of national priorities and geographical equity. For example, we might well wish to encourage participation by giving communities the right to levy extra rates in order to keep local hospitals open. But this might well mean that richer communities would have more by way of health care provision than poorer parts of the country, so defeating one of the objectives which the NHS was set up to bring about.

Lastly, if small size encourages participation and *vice versa*, then we might well have to revise our ideas about what are the appropriate administrative units for the NHS. The definition of democracy as direct participation in decision-making was born in the circumstances of the Greek city states and the Swiss cantons. And it may be that the population of a general practice is the largest compatible with this kind of definition: anything larger would certainly not have been recognised by Aristotle or Rousseau as a suitable setting for participatory democracy. So the kind of experiments discussed in the chapter by Jo Wood may offer a model with only limited applications. Certainly even the post-1982 districts – with populations of up to half a million – would seem to be much too large administrative units for encouraging participation. Again there would appear to be a

trade-off between creating what are efficient and effective units of administration and the demands of participation. If we were to give overriding priority to the latter, we might well end up with designing a NHS of local cottage hospitals: the ideal constituency for participation (to judge by the enthusiasm with which citizens mobilise to defend these much-cherished institutions).

All this suggests that while, in theory, it is perfectly possible to create a different kind of political market within the NHS, there is a price to be paid. Participation cannot be seen as icing on the cake: something extraneous to the structure and organisation of the NHS. It represents, rather, an entirely different approach, involving at least some sacrifice of other valued aims. Moreover, it presents a number of other problems as well: the subject of the next section.

### Professionals and citizens

So far the case for participation has been examined on the assumption that greater citizen involvement is desirable in its own right. And, indeed, this may well be so: there is a long tradition of political theory which argues for more participation as a way of educating the citizen to his full capacities. But, as we suggested at the start of this chapter, the case for greater participation in the NHS is usually argued in somewhat different terms: as a means towards changing the balance of power within the NHS and opening up the debate about policy aims and instruments. In other words, the concern is about *effective* participation – not just about token involvement by the citizen.

Once we adopt this focus, we immediately come up against the imbalance between producer and citizen interests<sup>6</sup>: an imbalance of both knowledge and organisational resources. By definition, NHS producers know more about the health service than citizens, have a permanent stake in defending their own interests and are organised in trade unions and professional bodies. In contrast, citizens have only a contingent interest in the NHS, as already argued, and lack both the information and organisational resources of the producers. While the producers are a concentrated interest group, the citizens are a diffuse interest group. They may well have incentives to mobilise on particular occasions and for specific causes, but they have little reason to take the kind of long-term interest which is so crucial in a service where policy making is inevitably incremental, building on past history, and where there is a complex interdependence between decisions taken at different times, in different circumstances and at different levels of the administrative hierarchy. Moreover,

decisions in the NHS tend to be the outcome of complex bargains between different groups of producers: untying the package may be both difficult and counter-productive.

It is therefore not surprising, perhaps, that successive studies of local policy making in the NHS have all come to the conclusion that the influence of lay authority members tends to be ineffective and marginal.\* Much the same conclusion flows from such inquiries as the Normansfield report<sup>12</sup>, which seem to indicate that lay members are also ineffective when it comes to looking after the interests of consumers. (Although in this particular instance the members of the relevant AHA were fully alerted to the conditions at Normansfield by the CHC). This would indeed seem to follow from the imbalance in knowledge as between service providers and citizens.

Once again, however, it is important to ask whether such an asymmetry is inevitable, or whether it would be possible to create institutional devices designed to change the balance. If we see citizen participation not necessarily as direct involvement by individuals in decision-making, but more broadly as widening the interests represented in the running of the NHS, what can be done to make the representation of such interests more effective?

One obvious option would be to move towards directly elected health authorities. The argument for doing so would appear to be twofold. First, election would give the authority members a legitimacy which at present they do not have: it would strengthen their authority *vis-à-vis* the NHS providers. Second, and more central to the present discussion, election would give authority members a direct incentive to be responsive to the wishes of the local community: there would be a direct channel for the articulation of local interests and preferences. If the aim of policy is to democratise access to decision-making then, surely, there could be no better way of doing so than by having elected authorities.

The theory is neat but practice might be rather less so. Indeed there would seem to be reason for considerable scepticism as to whether elected authorities would be more effective – in terms of widening the debate about policies and ensuring responsiveness – than the present ones. In the case of existing local authorities, we have got considerable evidence which suggests that elections are decided not by performance but by national swings of opinion. Similarly, the problems faced by local police authorities in controlling their experts would seem to indicate that the mere fact of election does little to ensure an effective lay voice in what are

perceived to be 'professional' issues. Lastly, there is little evidence that local authorities are regarded by citizens as more responsive than the NHS. On the contrary, the survey conducted for the Commission on the Constitution – cited earlier – suggested that the public rate the NHS more highly than local authorities in this respect: 59 per cent of those interviewed thought that the NHS would be good at dealing with complaints from members of the public, as against 49 per cent who thought the same about the local council office. Moreover, it may be significant that many of the demands for greater citizen participation have come precisely in those areas and services controlled by local authorities: town planning, education and housing.

There is a further problem about the direct election option. Can we be really sure that the local citizens would participate in the elections? Once more, the available evidence suggests cause for scepticism. If we look at the experience of New Zealand<sup>13</sup> where health authorities were directly elected, there would appear to be a risk of massive apathy. Nor is this surprising. For we come back to the central dilemma, discussed earlier, of how to reconcile incentives to citizens to participate with the central aim of the NHS, which is to maintain national standards. If there is little scope for deviating from national standards, there is little incentive for citizens to participate in elections or anything else. If there is a lot of scope, then it is difficult to see the point of having a national health service – as distinct from a conglomerate of local health authorities.

The nature of the dilemma involved is reflected in the curious twists and turns of successive Conservative Secretaries of State since 1979. The aim of the 1982 reorganisation of the NHS, as expressed by Mr Patrick Jenkin, was precisely to devolve responsibility to the districts: implicit in much of the Ministerial rhetoric was a vision of the NHS as a loose federation of local health services.<sup>14</sup> But no sooner had Mr Jenkins left office than his successor, Mr Norman Fowler, changed the emphasis. In response to criticisms from the Parliamentary Public Accounts and Social Services Committees, the new Secretary of State introduced an elaborate system of annual reviews designed to make sure that local health authorities are following national priorities and national policies. The logic of a national service, financed out of central funds, runs counter to the logic of decentralisation – which is to accept and tolerate local decisions about priorities and policies.

So if we are really serious about devolving decision-making, and encouraging local participation, we have to face up to some very hard questions about the limits of tolerable diversity. Would

\* See for example, *Coping with Uncertainty*.<sup>11</sup>

we be really happy if an elected health authority were to decide, in response to local community demands, to put all its money into improving the acute services at the expense of the provision for, say, the mentally handicapped or the elderly demented?

The question is not merely rhetorical. For, to return to our earlier discussion about the differential ability and desire of different groups in the community to participate, there would seem to be good reason to expect a bias towards the acute services in response to local demands. If there is an imbalance as between providers and citizens, there is also an imbalance among citizens. The most vulnerable groups are precisely those least likely to participate in any political market, and least able to assert their own interests. The example of the mentally handicapped is self-evident. But the same point applies, if with less force, in the case of the elderly. In this respect, the NHS's much-criticised bias in its budget towards acute services would seem to mirror accurately the bias of power not just within the medical profession but within the community. It is also worth noting that those social groups identified as most deprived in terms of health care by the Black report<sup>15</sup>, among other similar studies, are precisely the same groups who, as noted earlier, are least likely to participate: notably, the unskilled and poorly educated.

The constitution of community health councils is instructive in this respect.<sup>16</sup> It represents a deliberate attempt to rig the political market in favour of those with the least resources for participation. By ensuring the presence of members representing pressure groups for the mentally ill and handicapped, among others, the constitution of CHCs gives a voice to those citizens least able to participate in political processes: that is, the most vulnerable. Similarly, at the national level, successive governments have deliberately sought to encourage such pressure groups as MIND, in an attempt to load the dice in favour of the weakest – that is, those who carry least weight in the political market. For it would seem that just as we are not prepared to leave the provision of health care to the free play of the economic market place, so we are not prepared to leave it to the free play of the political market place. Paternalism, it would seem, creeps in by the back door even when it has been thrown out by the front-door in favour of participation.

So the argument of this chapter has come full circle. To the extent that the NHS embodies a vision of what society ought to be like – that it represents an attempt not just to provide services but also to embody a particular set of values<sup>17</sup> – so it may be that a certain degree of paternalism may be inevitable. Certainly, as the analysis of this chapter has tried to demonstrate, giving priority to

the value of participation may mean embodied in the structure and policies for preserving the status quo but for the nature of the trade-offs being faced.

Moreover, in conclusion, a final in NHS is, in a sense, an instrument machine for redistributing resources sections of the population. But so particularly fragile in an era of equal allocation of resources becomes a zero-sum to the vulnerable means giving less to. There is indeed evidence that altruism when redistributing resources can not the dividends of growth.<sup>18</sup> In such circumstances the insulation of the health care arena from NHS's best protection against what might be the climate.

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## 2

### Parliamentary control and a SIR PATRICK NAIRNE

The National Health Service presents a service it can have the greatest personal experience the public – with some 7 million a million attendances in accident and emergency at least 40 million outpatient attendances in the Kingdom. But no public service thinks such: to the NHS the public are patients – a difference – for both the service and the

#### The concept of public participation

For most people the concept of public participation in the National Health Service, if it means anything to them, public participation is more a personal experience as a patient or as a doctor. In a ward of a district general hospital the concept of active involvement in the discussion of the policies and management of the National Health Service. As for those working in the public participation is likely to mean a change from time to time with health authority or the local community health council.

In creating the NHS over 30 years ago we have taken account of many interest groups: the patient, the doctor, the public. Throughout the history of the service the public have tended to be obscured by the interests of the patient. As many consumer standards of care have consistently sought public approval. So long as the service has provided each year a significant increase in real resources it has also spared a great deal of the criticism and public indignation inflicted on other parts of the public service.

Not that people have been indifferent to what is happening in the NHS. The experience of visiting an antenatal clinic, of visiting an elderly patient in hospital, or of taking a minor injury to a hospital on a weekend, can underline the vulnerability of most people the only health service available to them quickly transformed into (so to speak) a

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the value of participation may mean sacrificing other values  
embodied in the structure and policies of the NHS: a reason not  
for preserving the status quo but for being quite clear about the  
nature of the trade-offs being faced.

Moreover, in conclusion, a final irony must be noted. The  
NHS is, in a sense, an instrument of collective altruism: a  
machine for redistributing resources to the most vulnerable  
sections of the population. But such collective altruism is  
particularly fragile in an era of economic crisis, when the  
allocation of resources becomes a zero-sum game and giving more  
to the vulnerable means giving less to the rest of the population.  
There is indeed evidence that altruism declines in hard times,  
when redistributing resources can no longer be financed out of  
the dividends of growth.<sup>18</sup> In such circumstances paternalism –  
the insulation of the health care arena from politics – could be the  
NHS's best protection against what might otherwise be a hostile  
climate.

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