

# PUBLIC PARTICIPATION IN HEALTH

Towards a clearer view

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Edited by Robert Maxwell and Nigel Weaver

## *Contributors*

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

King Edward's Hospital Fund for London

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# Public participation in health

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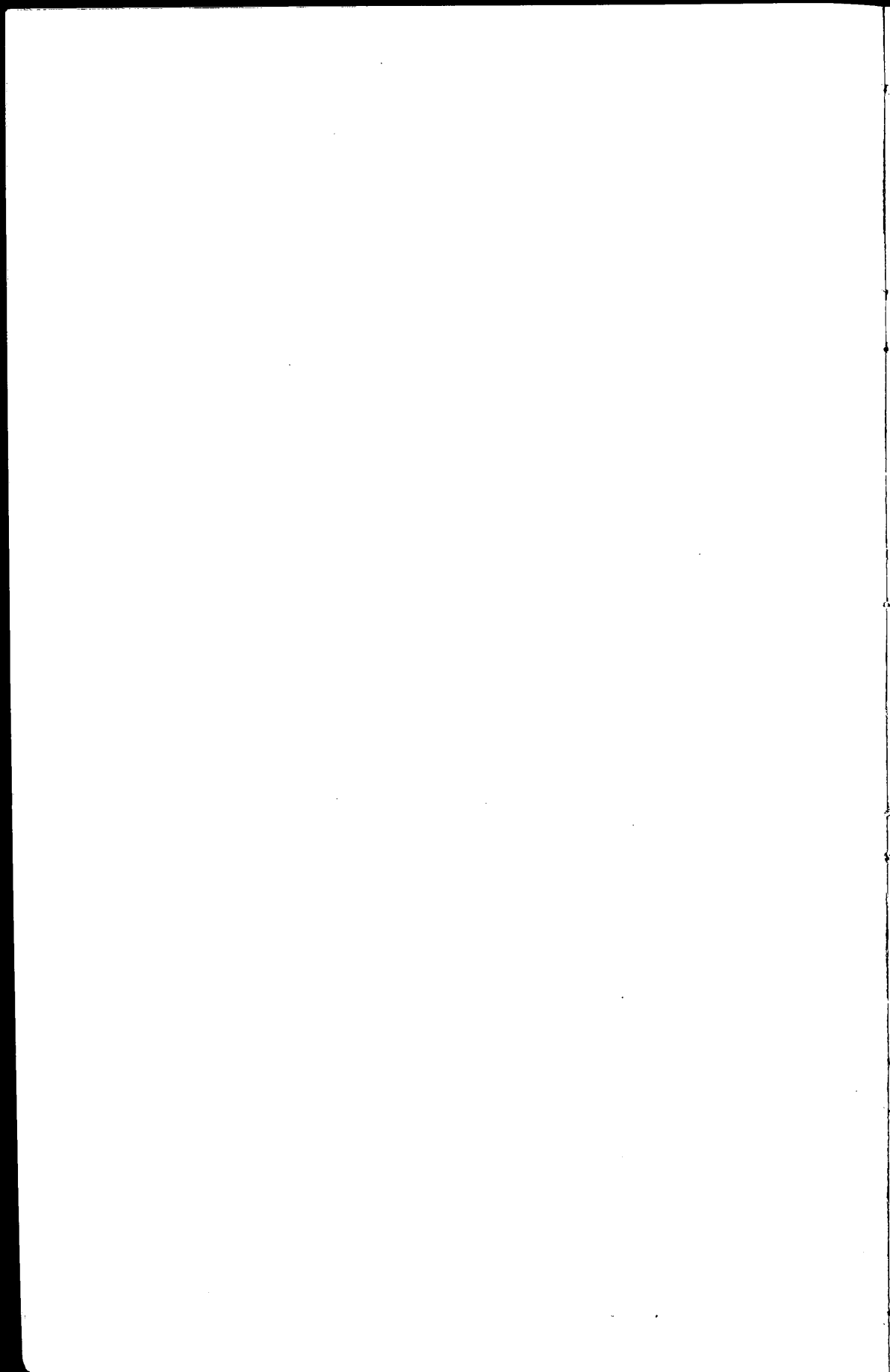
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Robert Maxwell is Secretary to the King Edward's Hospital Fund for London and author of *Health and Wealth*, 1981 and *Health Care : the Growing Dilemma*, 1974.

Nigel Weaver is District Administrator, Barnet Health Authority and co-author with David Owen and Bernadette Spain of *A Unified Health Service*, 1968.

Rudolf Klein is Professor of Social Policy at the University of Bath and author of *The Politics of the National Health Service*, 1983.

The Rt Hon Sir Patrick Nairne is Master, St Catherine's College, Oxford, and prior to that Permanent Secretary, Department of Health and Social Security 1975 – 1981.

Sir Douglas Black was formerly Professor of Medicine at Manchester University, Chief Scientist to the Department of Health 1973-77 and President of the Royal College of Physicians 1977-83.

Jo Wood is Research Fellow in the Primary Care Research Unit, University of Manchester.

John Bettinson is a solicitor and industrialist, and was Chairman of the Birmingham Area Health Authority (Teaching) 1974 – 1982 and Chairman of the National Association of Health Authorities 1976 – 1979.

Ruth Levitt from 1973 to 1981 was concerned with health policy and particularly community health councils. Author of *The Reorganised National Health Service*, 3rd edition, 1984 and *The People's Voice in the NHS*, 1980.

Stephen Hatch is a Senior Research Fellow at the Policy Studies Institute and author of various publications on voluntary organisations and social policy. He is co-editor of *Self-help and Health in Europe*, published recently by WHO.



## 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>

To say that individual and community participation should be 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> *Introduction*

iv *Full management participation by public representatives*

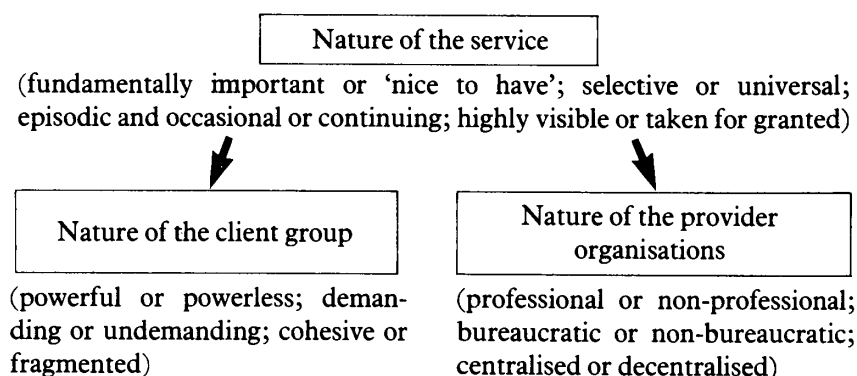
This, which has been called interactive participation<sup>4</sup>, comes closest to the rather straightforward concept from which we thought we had started. People should not be arbitrarily subjected to decisions made by others about matters that intimately affect their own lives, without the chance 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  
12 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

separate book.

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 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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# 1

## 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

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

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.

*The politics of participation*

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.

### Consumerism: a conceptual muddle

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

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>5</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

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 Consitution 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 decry 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).

*The politics of participation*

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>10</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-a-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

preceived 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

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



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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# 2

## Parliamentary control and accountability

SIR PATRICK NAIRNE

The National Health Service presents a paradox. Of all the public services it can have the greatest personal impact on members of the public – with some 7 million admissions to hospital, 15 million attendances in accident and emergency departments and at least 40 million outpatient attendances every year in the United Kingdom. But no public service thinks less about the public as such: to the NHS the public are patients. Here lies a significant difference – for both the service and the patient.

### The concept of public participation

For most people the concept of public participation in the National Health Service, if it means anything at all, means their personal experience as a patient or as a relative of a patient. For them, public participation is more likely to suggest, say, experience as a patient in a ward of a district general hospital than the concept of active involvement in the public scrutiny and discussion of the policies and management of the National Health Service. As for those working in the NHS, for most of them public participation is likely to mean nothing beyond contact from time to time with health authority members, or the activities of the local community health council.

In creating the NHS over 30 years ago, Aneurin Bevan had to take account of many interest groups: the public was the least of them. Throughout the history of the service the interests of the public have tended to be obscured by the commitment to the care of the patient. As many consumer surveys have shown, the standards of care have consistently secured a wide degree of public approval. So long as the service was continuing to receive each year a significant increase in real resources, the service was also spared a great deal of the criticism of management that the public inflicted on other parts of the public sector.

Not that people have been indifferent in the past to what was happening in the NHS. The experience, for example, of waiting in an antenatal clinic, of visiting an elderly patient in a psychiatric hospital, or of taking a minor injury to a casualty ward at the weekend, can underline the vulnerability of the public in what is for most people the only health service available. A patient can be quickly transformed into (so to speak) a member of the public if

something goes seriously wrong with his case; there has always been some provision for complaints (though the process can be tortuous). There has also been, over the years, fairly widespread frustration about delays in the improvement of services – for example, over the new hospital that never gets built – and that has led to some strong public pressures being applied to NHS resource policies and health service planning. But, in general, since the outset of the NHS, participation by the public has been limited – surprisingly so, given the ambitious conception of a comprehensive health service with free access at the point of need to all members of the British public.

### Parliament and political participation

Hence the importance of parliamentary control and public accountability, with which this chapter deals. If the NHS, as envisaged by some in the 1940s, had been based on the local authorities, public participation would have been principally provided through locally-elected representatives responsible for overseeing both the hospital and community health arrangements in their authority area. But that was not to be. Nor is it a realistic possibility in the foreseeable future. The fact is that the creation of a centrally-financed National Health Service, managed through subordinate health authorities which were accountable upwards rather than downwards, has always left ultimate responsibility in the hands of ministers and the department; they have been accountable to parliament, and the elected members of the House of Commons have provided vicariously for a large measure of public participation. Aneurin Bevan established a system of managerial delegation to the regional hospital boards and the hospital management committees as the only practical way of delivering health services; but it was also an essential feature of his policy that, if major NHS measures or financial issues had to be discussed, or if something was found to be gravely awry in the service, parliament must be the centre of questioning and debate. As he put it half-jokingly, 'when a bed-pan is dropped on a hospital floor, its noise should resound in the Palace of Westminster'.

Thus there is a second paradox. The NHS may embrace the patient while keeping the public at arm's length; but, compared with other public services, its operation and management are more closely exposed both to the oversight of ministers accountable to the House of Commons, and to the vigilance of Members of Parliament watchful of their constituency interests.

34 No wonder there is the regular anguished cry within the service

that the NHS should be 'taken out of politics'! The press highlighted a characteristic comment from a consultant radiotherapist at the Charing Cross Hospital in January 1980:

'The NHS has become less satisfying over the years. It is bedevilled by the vagaries of politicians. They don't spend enough money on it and, if they left the organisation to local people, there would be more for treating patients.'

It is easy to sympathise with that *cri de coeur*. The consultant was reflecting the painful impact of public expenditure cuts and the particular pressures to which teaching hospitals have been exposed in recent years – pressures which have generated a feeling that distant ministers can have no understanding of the severe difficulties created for some hospital unit by the strict application of cash limits. Those in the service have been no less critical of the impact of political objectives – finding it difficult to recognise that in a parliamentary democracy governments can be elected with party commitments about, say, the future of private medicine, to which the NHS must adapt as best it can.

But, if politics sometimes appear to be a disagreeable incubus, they are also an inescapable necessity for the NHS. The long-standing participation of parliament has been reinforced in the last ten years by an increase in public participation at the local level – notably, the establishment of community health councils and (at least in some places) closer links with local authorities than existed before 1974 – but this cannot, and should not, lead to any weakening in the role of the government and House of Commons. The local authority members of health authorities, important though they are, have often been criticised as the least effective members; and although many community health councils have succeeded in striking a successful balance between constructive involvement and objective criticism, others have so far tended to be little more than parochial pressure groups. The Royal Commission on the National Health Service, in its report of 1979, made no specific recommendation about more 'public participation'; but it did acknowledge the crucial functions of parliament and recommended the establishment of a Select Committee on the National Health Service which would assist in parliamentary control of the service and would enable 'Parliament to influence health policy and keep in touch with the work of the NHS in a more systematic way'.

Parliamentary control depends on a great deal more than the work of a single select committee. The government of the day – in effect the Secretary of State for Social Services and his ministerial colleagues – is accountable to parliament for all matters relating to

the NHS other than the clinical decisions within the service. Parliament votes the money required by the National Health Service budget, now running at a total of over £15 billion. The affairs of the NHS are exposed to the scrutiny of three committees of the House of Commons – the Committee of Public Accounts, the Select Committee on the Social Services, and the Select Committee on the Parliamentary Commissioner for Administration (who is also the Health Service Commissioner). Ministers regularly answer parliamentary questions on the floor of the House, and they reply to frequent adjournment debates on NHS issues. They, and also senior officials, are required to give evidence to the Social Services Committee. The Permanent Secretary of the Department is also required to give evidence to the Public Accounts Committee and to the select committee dealing with the annual reports of the Health Service Commissioner. For some years the department has had to respond to a rising number of parliamentary questions for written answer, and of letters from Members of Parliament.

Thus the waves of parliamentary probing and pressure break almost unceasingly on the shore of the Department at Alexander Fleming House. The committees of the House offer members their best opportunities for direct participation; and it is the public and the patient, as one and the same person, for whom Members of Parliament speak in overseeing the soundness and effectiveness of government policies, in scrutinising the management of financial and manpower resources in the NHS, and in enquiring into particular cases affecting individuals, units, or specific activities, where there are grounds for doing so.

But parliamentary participation, indispensable though it is, is heavy in bureaucratic cost, for the NHS as well as for the department. It creates, or leads to, a range of problems which need to be more clearly understood.

### Social Services Committee and government policy

First, there is a third paradox. The Conservative government which came into office in May 1979 has been committed from the start to a policy of greater devolution or delegation to the local level of the National Health Service. The government circular *Patients First*, published in December 1979, put it like this:

‘We are determined to see that as many decisions as possible are taken at the local level – in the hospital and in the community. We are determined to have more local health authorities, whose members will be encouraged to manage the

Service with the minimum of interference by any central authority, whether at region, or in central government departments. We ask that our proposals should be judged by whether they achieve these aims.'

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accountability*

The thrust of parliament, on the other hand, has been in an opposite direction. While the department was translating the government's approach into proposals for revising the structure and management arrangements of the service, the Social Services Committee published two reports which clearly pointed to a more centralist and, if necessary, interventionist role on the part of the department.

The first report (Second Report of Session 1979/80) related to perinatal mortality; it recommended among other things that the department 'should initiate further cost-benefit studies of effective interventions designed to reduce death and handicap of perinatal origin', and it suggested that the government should give some priority to resources for those interventions most likely to be of value, and that there should be a special financial allocation to the areas of social deprivation. The second report (Third Report of Session 1979/80), published only a few weeks later, dealt with public expenditure on the social services and amounted to a major indictment of what the committee represented as the department's failure to formulate coherent social policies in general, and to have 'a comprehensive information system' as a basis for judging the cost-effectiveness of 'different packages of care' and for 'effective monitoring and information-collection by the DHSS which might in future either affect its own investigatory role or limit the capacity of Parliament to hold Ministers to account'.

The government is thus confronted with the need to reconcile two important factors. On the one hand, there have been the pressures on Members of Parliament – in all three of the committees concerned – to participate more actively in NHS affairs by securing from ministers and the department a more effective degree of accountability and what might be called 'answerability'. On the other hand, it has been essential to the policy of the government that the health authorities at district level should exercise greater responsibility, that the department should stand further back from the service, and that this should contribute to the administrative and staff savings which the DHSS is required to make.

This tension between decentralisation and centralisation has continued throughout the term of the present government, and indeed is a persistent theme in the earlier history of the NHS. In

its more recent manifestations we have seen the contradiction between a series of detailed interventions, culminating in the 1983 manpower cuts and, on the other hand, the Secretary of State's welcome in October 1983 for the Report of the NHS Management Inquiry, headed by Mr Roy Griffiths. Depending how the report's recommendations are interpreted, they could imply a radical shift in the way the NHS is managed at the centre, with the Secretary of State delegating substantially more operational authority than in the past through the proposed NHS Management Board.

It is still too early to say whether a successful reconciliation between centralisation and decentralisation has been achieved, or is likely to be. Indeed, that question may never be open to a definitive answer. But the Government has sought to make its own position clearer. For example, in its reply (Cmnd Paper 8086) to the Social Services Committee's report on public expenditure, the second report already mentioned, the government said:

'The Government see their role as essentially strategic. They have responsibility for the level of funding of the National Health Service and Ministers have continued to give strategic guidance relating to national policies and priorities, broadly indicating ways in which they look for development in the Service and where economies should be sought. But if the government's policy of giving greater responsibility to the new District Health Authorities is to be effective, it is essential that those Authorities should have adequate flexibility in applying national guidelines in a way that takes proper account of local needs and circumstances. In the case of management costs specific limits have been set; in general, however, guidance will be less detailed and precise than in the past. The reply to the Committee's Second Report on perinatal mortality will indicate how the government see these principles being applied in a particular service.'

In its reply to the report on perinatal mortality the Government did make it clear that, concerned though they were to see improvements in measures to reduce prenatal and perinatal mortality, they would nevertheless regard it as running counter to the application of 'adequate flexibility' to the health authorities if there was to be some 'special financial allocation by the government to the areas of social deprivation'. The Secretary of State, while acknowledging that he was not satisfied with the existing information system or with all aspects of strategic policy



planning, was also cautious about committing himself or the department to any new administrative arrangements which might not be compatible with cutting down DHSS guidance and staffs and giving health authorities greater freedom to settle their own local priorities and plans, within a broad national framework. On the whole, that line has since been followed by the government in response to subsequent select committee reports – that it would be inappropriate for the Secretary of the State to intervene in detail in matters of local implementation.

Where does this leave the select committee? Select committees have a limited record of success over the last 30 years; but the new committees, more directly related to individual departments, have had a sharper impact on government departments. The hand of the backbencher – and his opportunity for participation – has been visibly strengthened. Backbenchers themselves are well aware of this and value the opportunity to question ministers and departments more closely than they can in the House itself, and to do so in a way that often cuts across party lines.

For the Social Services Committee, much may turn, in practice, on the relations which the Secretary of State is able to establish personally with the committee in the evidence he gives from year to year. There must never be too cosy a relationship between the department and the Social Services Committee; but the latter is inescapably dependent on the former for much of the information it needs, and the effectiveness of its participation – as the reports on perinatal mortality and on medical education demonstrated – depends on its facts being as accurate as possible and its recommendations taking a realistic account of resources. The committee will usually gain from sounding out informally the views of the department on areas or problems to be examined; but, if its participation is to be at least as much with the NHS as with the DHSS, its recent practice of taking evidence directly from those in the service must be right. It might also consider surveying areas of the service in a more systematic way than it has yet done. It is natural for a committee of MPs from all parties to wish to enquire instantly into any major matter of concern which has caught the political headlines; but, at the same time, the value of the select committee's work for the NHS would be enhanced if it could follow a carefully planned programme of enquiries over a period of several years. There are signs that the committee might move in that direction: for example, its decision to follow up (after a three-year interval) its work on perinatal mortality. Selecting the best topics for the committee's work will increasingly require very careful choice. For that purpose the committee, composed as it is of busy MPs with many other commitments,

may need more support than it can expect to get from its single clerk and perhaps two or three special advisers.

### Committee of Public Accounts and accountability in the NHS

The Committee of Public Accounts receives support on a much fuller scale from the staff of the Comptroller and Auditor General. That committee is able to be more active and systematic in its participation in the financial and managerial problems of the National Health Service. How effective does experience show that participation to be?

Here there is a further paradox. The Public Accounts Committee focusses its criticism on expenditure and activities of a service nearly one million strong, but until now it has placed only one man in the witness box – the accounting officer.

The responsibilities of the accounting officer for the NHS vote have fallen on the Permanent Secretary of the DHSS. The impact upon him is substantial. His programme of work has to reflect, in large part, an annual cycle which starts with what are technically known as 'reference sheets' sent by the Director of Audit on behalf of the Comptroller and Auditor General (C and AG), and stemming from the inquiries of the C and AG's auditors into the affairs of the NHS. These reference sheets arrive during the course of the summer, containing detailed evidence and specific questions relating to ways in which it would appear that public money is being wasted or at least not spent to best advantage; and the character of the DHSS's replies will probably determine whether the C and AG will include any issue covered by the reference sheet in his report to the Public Accounts Committee (PAC) as a basis for oral evidence to that committee by the accounting officer. The C and AG's report rarely puts less than three major NHS topics each year in front of the PAC; and three topics are likely to require the accounting officer to face at least two sessions of oral evidence, each lasting up to two hours. In consultation with NHS officers, he has to ensure that he understands fully, and can convincingly explain, the management issues criticised; that he can reassure the committee that, where things have gone wrong, the department and the NHS between them will get them right for the future; and that he is able, not only to defend the NHS where defence is justified, but also to present to the committee those relevant features of the service where the performance is good and where value for money is obtained.

40      Some notable issues have been put to the committee by the

Comptroller and Auditor General in recent years – for example, excessive delays, deficiencies and costs in hospital building (witness the Royal Liverpool Hospital); the failure of the service to establish a more effective and economical system of procurement and storage of supplies (witness the Salmon Report and the activities of the Supply Council); the control of prescribing costs in the service (witness the rise in real terms of drug costs and the sensitive topic of profit levels in the pharmaceutical industry); and the costs of NHS reorganisation (witness the cost of early retirement). The views of the Public Accounts Committee were vigorously expressed by Mr Edward Du Cann, the chairman of the committee until May 1979, when speaking in the House of Commons in January 1978 on the report of the Committee of Public Accounts:

‘If ever there was an instance of a case where it is necessary to see that the Nation obtains value for money, surely it is the National Health Service. There is the very greatest need for much to be done.’

With a service the size of the NHS, growing in complexity every year and with clinical freedom for the doctor at its centre, it would be surprising if there were not always activities of management open to challenge by the C and AG. The managerial efficiency of the service has greatly improved over the years; but, if the active participation of the PAC is to be matched by more effective accountability to it, it would be an advantage to have more than a single accounting officer responsible to the PAC. This would also be consistent with the policy of greater devolution from the department to the NHS. A step in that direction would be to identify the Chairman of the NHS Management Board as accounting officer for the NHS vote as proposed by the Griffiths Inquiry. A further step would be to extend the practice of having health authority chairmen and chief officers appearing before the PAC, albeit with the accounting officer.

The PAC itself has considered fairly recently whether present arrangements for accountability are as effective as they might be. One member of the committee, in 1976, queried whether it was sensible to expect the accounting officer to be personally concerned with the kind of detailed managerial failures sometimes reported to the committee by the Comptroller and Auditor General, arguing that the chairman of a large company in the private sector would never be expected to know about, let alone answer for, some of the managerial deficiencies about which the

accounting officer has been grilled by the PAC. But the committee did not accept his views. Nor did the health departments, the Treasury and the Civil Service Department in their evidence on the matter to the committee in 1977. Having examined alternative possibilities, they concluded that there was at that time no practical alternative to the responsibility of accounting officer remaining personal to the Permanent Secretary of the DHSS.

The issue was raised again in the report of 1979 by the Royal Commission on the National Health Service. The Royal Commission was critical of the scope of the accountability falling to the Permanent Secretary as accounting officer, and it sought a solution through a redefinition of the roles of the Secretary of State and the department. Its words were these:

'It seems to us that the fact that the Secretary of State and his chief official are answerable for the NHS in detail distorts the relationship between the DHSS and Health Authorities. It encourages central involvement in matters which would be better left to the Authorities. In consequence no clear line is drawn where the Department's involvement ends.'

The commission's solution – the recommendation that accountability which at present falls to the DHSS should be transferred to the regional health authorities – was rejected by the government as inconsistent with the accountability to parliament which the Secretary of State must continue to accept.

It will be interesting to see whether the Griffiths proposal is more acceptable, and what difference it will make in practice. A change of accounting officer for the NHS vote (as proposed by Griffiths) would undoubtedly lighten the Permanent Secretary's burden. But that might mean no more than the substitution of one individual for another. Certainly parliament has in recent years shown itself more vigorous rather than less, in exacting detailed accountability from ministers and senior civil servants. The result is a similar problem to the tension in the relationship between the Social Services Committee and the department – a conflict between, on the one hand, parliament's wish to make its participation more effective through an adequate degree of central control by the DHSS over managerial efficiency in the NHS and, on the other hand, the government's policy of promoting a more efficient service through less, rather than more, central guidance and intervention.

42 The then Secretary of State restated the government's policy in the foreword of a DHSS document of 1981, *Care in Action*. All

health authorities were expected to have regard to national policies and priorities, but the principal thrust of government policy was that the new district health authorities should stand firmly on their own managerial feet. The Secretary of State wrote:

'We want to give you (the district health authorities) as much freedom as possible to decide how to pursue these policies and priorities in all your own localities. Local initiatives, local decisions, and local responsibility are what we want to encourage.'

Later in the same year the Public Accounts Committee, after taking evidence from the health departments, published a report (17th Report from the Committee of Public Accounts – session 1980-81) which acknowledged the government's policy towards the NHS, criticised in certain important respects the present largely devolved system of control in England, and emphasised the importance which the committee continued to attach to the service's formal accountability upwards through the DHSS to parliament. Having noted the plans of the government for introducing the new district health authorities from April 1982, the committee put its own views firmly on the record:

'From the standpoint of financial control and accountability, we trust that these arrangements will work out as planned. We accept a degree of informal accountability to the Community Health Councils should provide a useful local input to the District Authorities about the quality of the health care they provide, but we emphasise the importance nonetheless of the formal accountability upwards through the DHSS to Parliament, as the representative of the tax-payers who provide virtually the whole of the resources used by the Health Authorities.

'However, the arrangements will be satisfactory in practice only if accountability upwards is accompanied by a flow of information about the activities of the District which will enable the Regions, and in turn the DHSS, to monitor performance effectively and to take necessary action to remedy any serious deficiencies, or inefficiency, which may develop.'

The Secretary of State for Social Services responded to the report of the Public Accounts Committee in a written reply to a parliamentary question from Mr Edward Du Cann on 22 January 1982. This important statement by the government aimed to resolve the degree of conflict that existed between government's

approach and the PAC recommendations by a fuller and clearer restatement of the policy core of the 1973/74 reorganisation – ‘devolution downwards, accountability upwards’. It provided a succinct definition of the extent of responsibility and accountability at different levels of the NHS in order (to quote the words at the end of the parliamentary answer) to ensure that through the new arrangements ‘the Health Service obtains the maximum amount of direct patient care and the greatest value for money from the resources which the government has made available to the NHS.’

The most important feature of the arrangements thus outlined was the strength of the role now defined for the regions. Ministers of both political parties have blown hot and cold (or rather cold and then hot) about the scope of regional health authority (RHA) responsibilities, and the section of *Patients First* devoted to ‘the region’ reflected the concern of the Conservative government in 1979/80 to eliminate, if possible, what the then Secretary of State called ‘the suction pump effect’ of too active an oversight at regional level. The views of parliament have significantly helped to qualify what had been said earlier about the need for regional health authorities – along with the department – to ‘stand back’ from the activities of the service at the local level.

It remains to be seen how the arrangements will work out in the longer term. The involvement of the DHSS and the RHAs together in a more regular and thorough system for reviewing the plans and the performance of health authorities is a substantial extra commitment for ministers and senior officials; its success depends on careful and discriminating preparation, and on the amount of time the Secretary of State personally is ready to devote to it. It cannot fail to tighten the grip which RHA chairmen and regional officers wish to exercise over the district health authorities; and it is therefore important for the department (or the NHS Management Board) to see as one element in the annual reviews an opportunity to probe the way in which the regions are positively promoting, as they should be, the maximum degree of discretion and responsibility on the part of the district health authorities.

The January 1982 statement of policy suggested that the extent of direct participation in the affairs of the NHS by the department was unlikely to be much less. But perhaps the degree of participation of the health authorities in the business of parliament – the PAC as well as the select committee – might be more? The PAC’s concern about the new Royal Liverpool Hospital led it to set a new precedent by taking some evidence from the accounting officer and representatives of the health authority in

Liverpool itself. In 1981 another precedent was set when the committee took evidence from two regional health authority chairmen, again in the company of the accounting officer, on the broad question of financial control and accountability in the NHS. Both those occasions were experimental; and joint evidence between NHS representatives and the accounting officer created some anxieties, even though the PAC treated the former more as 'friends of the court' than as witnesses for the defence. It was a potential source of difficulty that the health authorities had no equivalent to the Permanent Secretary and accounting officer, since a part-time chairman cannot be expected to carry a similar degree of responsibility. Neither the administrator nor the treasurer could be held accountable as officers in the same way as the Permanent Secretary of the department. But that difficulty might be removed by the recent proposals to strengthen general management at all levels in the service. If the impact of parliamentary participation in NHS affairs is to be as fruitful as possible, there will be advantage for the PAC in complementing the carefully prepared advocacy of the accounting officer with the more direct questioning – perhaps on a selective or sample basis – of health authorities and their representatives.

#### Select committee and Health Service Commissioner

A greater degree of direct involvement is already to be found in the work of the select committee dealing with the reports of the Health Service Commissioner – the third parliamentary committee concerned with the NHS.

The participation of the Health Service Commissioner in the operation of the NHS does not raise the same issues as those presented by the activities of the Social Services Committee and the PAC. The Health Service Commissioner is answerable to a select committee, and he himself is in a broadly similar relationship to that committee as the Comptroller and Auditor General is towards the PAC. But DHSS ministers have not been invited to appear before the committee; and the Permanent Secretary of the department, though required to give evidence each year, is not directly accountable for the specific administrative failures in the service which have led to complaints to the Health Service Commissioner. Evidence is taken direct from the local health authorities on the cases criticised by the commissioner – and that has a salutary effect on the areas concerned.

It is still early days for the Health Service Commissioner; the first holder took up office in October 1973 and it took a little while for a pattern of work to develop, and a pattern of reporting

to the select committee. The total number of complaints put to him by members of the public has been smaller than might have been expected; and a good many of them have been rejected each year – notably those concerned solely with clinical matters – because they were outside the commissioner's proper jurisdiction. Meanwhile the department and the NHS have usefully clarified the normal arrangements for complaints within the service; and, after protracted negotiations with the medical profession, a modest new procedure – a step in the right direction, which does not involve the Health Service Commissioner, but provides access to independent 'second opinions' – has been introduced for handling clinical complaints.

It is difficult, therefore, to have a clear and balanced perspective of the current arrangements for dealing with individual complaints. What can be said is that this important element in public participation has a much larger place in the operations of the service than at any time in the past. The topics considered by the select committee in recent years – for example, the handling of waiting lists, administrative procedures relating to mental patients, waiting times in antenatal clinics and in accident and emergency departments, and procedures following sudden death in hospital – have stemmed from serious individual complaints; and the strictures of Parliament as well as of the commissioner have benefited the service.

But there is still the question: could the NHS public and patient secure greater benefit from the commissioner's role? When the Permanent Secretary has been questioned on the criticisms made, he has usually been able to assure the select committee that relevant guidance to health authorities, sometimes in abundance, already exists. But that is not enough. If the lessons of the commissioner's reports are to be fully learnt, the most telling method is likely to be to give the maximum publicity within the NHS about the mishandled cases and about what went wrong. The regular reports by the commissioner are full enough; and the 'epitomes' of selected cases, first introduced in June 1983, are bound to be more widely read than the full texts of completed cases. But are even these a sufficiently effective form of communication? They are not as forceful as, for example, the annual reports of the Medical Defence Union. It would be a difficult, and possibly fruitless, exercise to review in any formal manner the measures taken to promulgate the commissioner's reports, but it may well be timely to try and assess, in a more selective and informal way, the local reaction and response to his criticisms and how the lessons learned in one district can be more widely recognised and applied. Unless the commissioner's words



have the widest possible impact, the full harvest cannot be reaped from his participation in the service.

*Parliamentary  
control and  
accountability*

## Conclusions

Given that most people do not usually think about the NHS at all, the recent improvement in the arrangements for complaints is particularly important. Here at least is a wider system of protection, if not participation, supposing that the public is ready to use it. But many patients or ex-patients are not ready. There is a psychological factor at work.

In his book, *Medicine and Politics: 1975 and After*, Mr Enoch Powell vividly described the position of the hospital patients:

'Traditionally, the hospital patient has been lucky and glad to be looked after, whether an out-patient, casualty, or in-patient. The historical origins of the hospitals are either charity, religious or secular, or the Poor Law authorities. These origins are still detectable in the attitude of hospital staffs to their patients: anyone who questions this can verify it for himself unless he is exceptionally fortunate, by simply taking a seat for an hour or two on the benches in an out-patient or reception department. The patient and the patient's relatives are face to face not with the doctors and individuals but with the panoply of an institution, physical, corporate and social. All the romance, wonder and terror of modern medical science is associated with the hospital and its deep recesses: the hospital has prestige and inspires awe. For good measure, the hospital patient is often for one reason or another helpless.'

And none tend to be more helpless than those who have most need of medical care or advice – the poorer and more elderly members of the community. The middle classes are the most active participants in the service; it is they who provide most of the members of health authorities or community health councils. As individual patients they can be expected to cope with the panoply of the NHS 'institution', and to minimise the failures of communication which so often cause the cases that reach the commissioner's reports. They are ready to stand up, if necessary, to the doctors, nurses, and other professional workers who have an inescapably dominant position in the service. But they are a minority of the public; and they are a minority more concerned with the scope and quality of local health services than with their equally important managerial efficiency.

Hence the great importance of parliament's role – and of its

impact on ministers and the DHSS. The adversarial relationship between the department and the committees of parliament is the natural product of democratic system in which ministers have to answer for, or at least explain, anything done in the NHS, outside clinical decisions, which may be challenged by parliament or the press; the accounting officer has to defend, or at least explain, any expenditure which may be criticised by the Comptroller and Auditor General, and may become the subject of investigation by the Public Accounts Committee; and the policies and plans of the health authorities have to reflect national objectives, and the priorities which government attaches to them, as well as local requirements and pressures.

The character of that relationship – by which parliament principally participates in the NHS – has been subject to shifts of emphasis, but it has not changed significantly since the service was established over 30 years ago. It is unlikely to do so unless there should be radical constitutional and administrative changes, which appear wholly unrealistic at present – for example, some form of regional government with elected authorities responsible for health as for other local services, together with the replacement of the existing system of central financing by arrangements for local taxation and funding. Even the Griffiths proposals, although radical in a managerial sense, in no way change the fundamental basis of accountability through parliament to the nation.

In short, a key element of public participation must continue for the foreseeable future to be the active participation of parliament and its committees as we know it at present.

Is there then scope for improving parliamentary participation in the interests of the NHS and the public? This chapter has sought to show that paradoxes and problems exist, and that the tensions and difficulties they create are likely to remain. It has also suggested that the service and the public would gain from developing further a more direct relationship between health authorities and parliament. But, given the complexity of the service and its major role in the public sector, what matters most is that there should be a wider and clearer understanding of the importance to the public and the NHS of effective and satisfactory relationships between parliament, ministers, the department, and health authorities. It is less a question of what needs to be done than of what needs to be understood.

There needs, first, to be better understanding within the NHS itself. Most of those working – and frequently over-working – in the service, will never be directly concerned with the participation of government and parliament. The remoteness of the

department contributes to the resistance to departmental circulars and notices; the gulf between the parliamentary committees and the hospital ward is a factor in generating the plea that the NHS should be taken out of politics. And yet, during the present period of strain in the NHS – caused particularly by public expenditure constraints, industrial troubles, and changes in attitudes – there is a greater need for all staffs to understand the political framework within which the service has to operate, and that the service cannot be isolated from the economic and social pressures of the country.

It will help to meet that need if the Social Services Committee and the Public Accounts Committee develop further the practice of taking evidence direct from health authorities, thus fostering a keener sense of accountability at the level where it matters most. That will also contribute to a smoother working relationship between the health authorities, particularly the regional health authorities, and the department. And it will assist the health authorities, in their use of the planning system, to present their local policies and plans with the maximum realism to the community health councils and the wider public.

Secondly, it will be for ministers and the department to consolidate a fuller understanding of the essential interdependence of the DHSS and the NHS by keeping the organisation of the service stable after too many years of change and turbulence. There is no alternative to a policy of maintaining the best possible balance between, on the one hand, the centralising factors of a regular response to the parliamentary committees, the provision of essential departmental guidance, and the general oversight of national policies and priorities, and, on the other, the decentralising thrust required to devolve responsibility for local policies and day-to-day management in a way that will leave district health authorities standing more on their own feet than the health authorities that they replaced. There is no more difficult balance to be found within the public sector, and its maintenance will depend on an understanding partnership between the department and the service. The Secretary of State's parliamentary answers on accountability have established the letter of the guidelines for the future. Their spirit must be fostered by developing further the closer personal contacts of recent years between officials of the DHSS and officers of the NHS.

Thirdly, as to parliament and its committees, their crucial role as the elected representatives of the public will not be as beneficial as it might be unless the House of Commons appreciates fully the character and the constraints of the NHS, and the delicate balance of its relationship with the department. Members of

Parliament have not always displayed this degree of understanding; and without it their important critical fire may be misdirected.

The Comptroller and Auditor General sets up the targets for the Public Accounts Committee, but the Social Services Committee can be much more hit or miss in its choice of topics. And yet, just as the inquiries of the PAC strengthen the managerial hand of the accounting officer and the NHS, so also could the Social Services Committee reinforce the more difficult policies which ministers have been seeking to implement – relating, to take a major example, to the policy of gradually shifting more resources to the long-stay services of the mentally ill and mentally handicapped – and which the health authorities themselves do not always find it easy to follow. Too adversarial an approach may put the department too much on the defensive and so limit the constructive opportunities open to parliament.

Finally, for both the patient and the public, there needs to be an understanding of the crucial value of an efficient parliamentary role in compensating for their own limited role in participation. The arrangements for parliamentary control and NHS accountability are better than in the past; but further improvement must be fostered by a wider public understanding of the way in which parliament, ministers, civil servants, and health authorities have to work together for the good of the service and its patients. The NHS operates in a political environment, and the House of Commons is at the centre of that. Sir Ian Gilmour, in his book *The Body Politic*, was reflecting his own experience when he wrote:

‘The House of Commons does not govern, could not govern, and is not intended to govern. But it controls government, it restrains government, it influences government, and if its leading members control the House, so does the House control those leading members. “The centre of gravity of the State”, Lord John Russell remarked, “has been placed in the House of Commons.” And there, despite all the changes of the last 150 years, it has remained.’

# 3

## A medical view

SIR DOUGLAS BLACK

I would like to begin by underlining that this is *a* medical view, not *the* medical view, which would defy formulation, in view of the characteristic way in which doctors differ. Nor of course is it a College of Physicians or British Medical Association view, but simply a personal essay on an interesting topic. A further important reservation is that my own experience has lain almost entirely in hospital practice, so that I am in no position to comment on the merits of patient groups in general practice from any expert standpoint. I know that some of my colleagues in family practice are enthusiastic about their value; I suspect that others are not.

From the titles of this book, and of its individual chapters, it seems a fair inference that the burden of the discourse will relate to organised public participation in the running of the health service, and of the institutions and practices which it comprises; and I will express a view on these matters. However, the concern of the great majority of doctors is not with these grand matters, but with individual participation in a clinical context. This is not an aspect which is likely to be much, if at all, considered in other chapters; but a medical view on public participation is likely to be considerably conditioned by an assessment of the likely effects of public participation on the doctor's primary responsibility, that of providing a high standard of clinical care. I feel justified in devoting a considerable part of my own contribution to a description of the consultation between patient and doctor, sometimes rather tendentiously referred to as 'the clinical encounter'.

### The individual consultation

With the obvious exceptions of pre-employment, insurance and other screening examinations, and of immunisation procedures, the majority of contacts between patient and doctor are initiated by patients, because they are concerned about their state of health. They may be suffering from some well-defined illness – and such illnesses do apparently exist; or they may simply be worried, a state which is just as real as illness, though even harder to define precisely. Neither 'illness' nor 'worry' is an abstract Platonic idea; but this does not deprive the concepts of a certain

crude pragmatic value. The 'labelling' of diseases or of mental states is sometimes stigmatised as a medical conspiracy. In my innocent eyes, it looks more like a kind of shorthand, which in the main facilitates communication between doctor and patient, and also between doctors and others entitled to possess a summary description of the state of affairs. Like every other convenience, it can be abused; but that language has pitfalls is not a sufficient argument for doing away with it.

I sincerely admire the good family doctor who knows his patients and, partly with the aid of that knowledge, can define a clinical problem in an astonishingly short space of time, and take appropriate action. I also admire, and to some extent envy, my colleagues on the other side of the Atlantic who can devote a couple of hours to seeing a single patient for the first time. But to speak of what I know, I shall try to describe what is likely to happen when a patient is seen for the first time in a general medical clinic. If the physician has some particular interest, and most of us do, one or two patients may be referred from other hospitals, or from another department of the same hospital; but the great majority of patients will be referred by their family doctors. Although there are grave problems in inner city areas, we are in general fortunate in this country in having retained a comprehensive primary care service; and the good general practitioner is selective in referring patients to a hospital clinic. The system by which the physician or surgeon only sees patients referred to him by a colleague is sometimes criticised as denying freedom of access to a specialist opinion; but I have always upheld it, since it can be a fearful thing to fall into the hands of the wrong specialist.

But to return to the patient, certainly if it is his first visit to the hospital, and quite possibly if it is not, he will be very conscious of being in unfamiliar territory. Some hospitals employ a receptionist, but in any case the clerical staff who book patients in have a duty to be at least courteous and, if possible, friendly. The ultimate responsibility for putting 'the patient at his ease' remains with the doctor; I hope it is not too fanciful to say that he is the host, and the patient is the guest, with all that that implies. When the patient is comfortably seated, the physician should begin by trying to elicit the nature of the problem, while avoiding the phrase 'What is wrong with you?', with its obvious retort. 'What do you feel is wrong?', or 'What seems to be the trouble?' are possible openings; or, having read the referral letter, one can say 'Your doctor tells me ---'. I think it is good practice to start with the presenting complaint or complaints, encouraging the patient

52 to describe his symptoms in detail, and asking specific questions

when necessary. Patients of course vary in intellectual and auditory acuity, and in their mood; but time spent in the particular form of reconnaissance known as history-taking is seldom wasted.

*A medical  
view*

When the full story of what the patient feels wrong has been elicited, general enquiries are then made about systems of the body other than that which appears to be affected (if you don't ask about the bowels, you will be considered 'a careless doctor'). A social, occupational and family history are taken, and the patient is then asked to undress to a reasonable degree, and examined on a couch. During the examination, the opportunity to add to the history should be given to the patient – things which he/she has overlooked or been too shy to mention may come out at this stage.

When the patient has dressed, and is sitting down again, he should be given a preliminary assessment of your view of his condition. He should be told whether any tests are required, and what they will involve; and whether he should be admitted to hospital, either then or at a later date, and if possible given some indication of what 'a later date' may mean. Except in urgent circumstances, treatment is not prescribed; advice on treatment is given in the letter to the family doctor. If a reasonable conclusion can be reached on the basis of history and examination, the letter to the doctor can be sent without delay; if investigations are needed, the doctor should be sent an interim note, giving a clinical opinion, and stating what tests have been asked for.

The process which I have outlined takes on average about 30 minutes. Where the problem is straightforward, and already largely defined, it may take as little as 15 minutes; at other times, it may take an hour or more.

I have described the process at some length, partly to indicate the various ways in which it is possible to encourage a fruitful participation between patient and doctor – a friendly reception, at least the appearance of leisure, repeated opportunity to repair omissions, and an explanation at the end of the consultation of your view of the case, and what remains to be done further. If, as can happen, your view of the case differs from that of the family doctor, you must keep in mind that you are seeing the patient in one episode of illness, whereas his family doctor will be seeing the patient and his relatives throughout life. Your disagreement, if any, should be expressed to the doctor, and not to the patient. An investigative journalist would no doubt describe this as 'a cover-up'; to me it represents good manners and common sense.

If the patient has to be admitted, or if urgent treatment is needed, the necessity for these steps has to be clearly explained to

the patient, and if possible to an accompanying relative. When patients are admitted, their notes go with them; so it is important to keep a note of the doctor's name and address, and write to him during or after the clinic; the first intimation of admission to hospital should not be the discharge note. If the patient is given treatment to take at home, the verbal explanation should be supplemented by details in writing.

Evil communications corrupt not only good manners; they can also corrupt good medicine, or at least render it nugatory. If the doctor does not understand the patient, he may get an entirely wrong concept of the problem. If the patient does not understand the doctor, he can scarcely be expected to comply with the treatment. Communication between doctors also has its problems. The best general account of medical communication is to be found in Charles Fletcher's Rock Carling Lecture.<sup>1</sup> There is considerable public concern about the minority of doctors who fail to communicate with their patients – 'he told me nothing'. Even worse, a bad doctor may refuse to answer the most reasonable questions; though I can understand the reluctance of a busy man to respond at length to a series of interrogations. At the other extreme, there is the view that a doctor must tell the whole truth in all circumstances whether asked to or not. My own view is that there is no formula for communication which will fit all the delicate interactions between doctor and patient; even when the patient asks 'to know the truth' in circumstances of severe illness, there is still an element of judgement in deciding what it is good for him to know. In short, my attitude is one of pragmatic paternalism; I realise that this is open to a variety of criticisms.

Understanding between doctor and patient lies at the very basis of medical practice. I have tried to describe the ways of fostering it in the branch of practice of which I have had most experience. Other branches of practice will vary in detail, but the opportunity to increase understanding is present in all of them, and a part of good medicine is to grasp it.

### Difficulties at the individual level

The most obvious difficulty, and one which is in no way peculiar to medicine, but runs through individual contacts in all walks of life, is a simple failure of rapport between the two parties. In the particular relationship which we are considering, the doctor is likely to be in good health, and the patient to be poorly; so *prima facie* there is a greater obligation on the doctor to smooth the relationship so far as possible. In this, his professionalism, for which he is sometimes criticised, may in fact be helpful. He must



at all costs retain his sympathy for his patients, but as a professional he must retain an element of detachment, which should help him to avoid heated encounters, which are seldom helpful. Nevertheless, doctors are human, and it is not surprising that they get on better with some patients than with others. We live in a stratified society, and there may be truth in the allegation that doctors find it easier to get on with patients with whom they share common social attitudes. It is, however, a misconception that all doctors are socially hidebound; and to a greater extent than in any profession, they do meet all social classes in their training and in their work. Entrants to medical school are drawn from a wider range of social class than is commonly believed. I was admissions tutor at Manchester University Medical School for some years, and we certainly did not discriminate on any class basis among educationally qualified candidates. A medical career gives the opportunity to meet all sorts and conditions of men and women; and I am not aware of any selection procedure which would enable us to avoid students who cannot profit from the experience, to shed any social bias which they may have had on entry. Quite rightly in my view, good manners at an interview will not prevent their entry, if they are otherwise qualified; while good manners are not a substitute for good medicine, yet when conjoined with it they increase the likelihood that doctors will be acceptable to their patients. I reject the inverted snobbery which claims that a doctor should be uncouth in his manner, just as I reject the inverted elitism which looks askance at educational achievement.

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With the possible exception of pressure of work and time, I can see no excuse for the doctor who is unsympathetic, uncommunicative, and even rude and intolerant with his patients. Without condoning it, it is perhaps faintly to the credit of doctors that they are more often rude to their colleagues than to patients – at least their colleagues can, and do, answer back. On the other hand, for patients I am prepared to make all manner of excuses. Some of them, of course, are mentally disturbed, and it can be very trying; but allowance must be made for their condition. Others may express a hidden worry by abruptness of manner, or frank truculence; difficult though it is to be calm and understanding in these circumstances, the effort has to be made to lower the temperature, otherwise we will be quite unable to help. All of us get cross at times, and also sad at some of life's inequities; but we must still struggle towards what Sir William Osler regarded as the supreme medical virtue – equanimity – not heartlessness or complacency, but the ability to keep a cool head in difficult circumstances. People vary very much in their ability to do this; 55

professional training is a help towards it, but it is largely a matter of innate good fortune, and the example of good teachers.

I have felt it necessary to indulge in this extended lay sermon, not with any implication that I have invariably practised what I now preach, but to indicate the delicacy and importance of the doctor-patient relationship, and to suggest that one factor in judging the value of public intervention in health care should be a judgment as to whether it makes the care of patients better or worse, easier or more difficult.

A few years ago, at the invitation of my predecessor as President of the Royal College of Physicians, Sir Cyril Clarke, I had the honour of delivering the Harveian Oration.<sup>2</sup> Under the cryptic title *Cui Bono?*, loosely and rather ungrammatically translatable as 'Who is it for?', I developed the thesis that the prime aim of medicine is not to help organised society; not to improve the human race; not to preserve life at all costs; and not to advance scientific knowledge. These are all important objectives; but, for me, they all come behind our central task, which is to help patients. Of course, by 'medicine' I do not mean just doctors, but as Sir Theodore Fox expressed it, the 'greater medical profession' that is, all those who work in the health services.<sup>3</sup> So the simple, possibly over-simple, answer to the question 'Who is it for?' is 'Patients'. This answer implies giving a greater priority to the care of patients than to either preventive measures for the healthy, or the provision of good living standards and working conditions for health service staff. I recognise that these two things are important, but I rate them as less so than the care of those who are in directly demonstrable need, and who have positively sought our aid. It is from this background that I view the benefits and the costs of public participation in the health service.

#### Public participation in health affairs

I have chosen the rather vague term 'health affairs' to emphasise that the promotion of health involves far more than the provision of effective primary and hospital care for those afflicted by illness. Within the medical sphere, we have specific methods, such as preventive inoculation, for forestalling the onset of illness; and a medical contribution to health education, and to environmental control. However, traditional medical measures by themselves cannot ensure acceptable levels of health in our entire population. The declared aim of the World Health Organization of 'health for all by the year 2000' cannot be achieved by medical means alone,

in services and in research. It will demand not merely the massive transfer of resources recommended in the Brandt report; but also an enlightened programme of health education, of practical nutrition, of agricultural development, and of participation by the whole population in avoiding known health hazards. Even in our own comparatively fortunate country, inequalities in health between the social classes have proved resistant to our efforts to universalise health care.<sup>4</sup> I do not accept the contention in the third 1980 Reith Lecture by Ian Kennedy<sup>5</sup> that 'the National Health Service has failed us'. It has certainly not fulfilled the Beveridge expectation that after a few difficult years the backlog of illness would have been overcome; but this was never a realistic forecast. What has happened is that there is now an improved standard of medical care throughout the country, and the population as a whole is living longer, but at the cost of a greater burden of the troubles which accompany old age. If we are to overcome the remaining burden of illness, with its unfair incidence on our poorer citizens, we need a wider strategy of social and economic measures, as well as improved provision of, and access to, both preventive and curative health services. Public participation could find its most effective expression in a determination to shoulder the undoubted burden of making things better for the most deprived of our fellow citizens, a cause to which they too have a contribution to make, by adopting a healthier lifestyle. But we cannot escape our own responsibility by 'blaming the victim'; we need to provide acceptable standards of conditions at work and at home, the two places where the seeds of illness are sown.

Public participation can be exercised at various levels – national, departmental, regional, district, and even individual. At each level, it brings both opportunities and dangers.

*National level* The ultimate corporate responsibility for the health of the nation lies with the legislature and the executive – parliament and government. They determine the share of the gross national product which is to be allocated to the social services, and within that to the health service – a smaller share than in some other countries, but still a very considerable sum. They also have ultimate control of the terms and conditions of service of health service workers, including doctors; of supplementary charges for medicines and appliances; and of the balance between public and private provision of health services. The suggestion has at times been made that the National Health Service should be managed by a public corporation, and not directly by government; but the sums of money involved are so

vast that no government is likely to relinquish financial control. Although I believe that democracy is the only long-term safeguard against the worst political evils, it does have some short-term disadvantages. For example, the reasonable and relatively stable balance between public and private provision of health care which prevailed in the sixties, and was commented on by the Royal Commission<sup>6</sup> as late as 1979, has been subjected to violent swings, first by the determined phasing out by the Labour administration of the convenience of private practice in the NHS hospitals; and latterly by the encouragement given to the private sector by the Conservative administration. Both of these initiatives seem to me to be unwise incursions of political attitudes into the provision of health services. The first, because it increased the unproductive travel time of a considerable number of consultants, and divided their loyalty to their main hospital; the second, because it must lessen commitment to the National Health Service, which is the source of care to the great majority of our people. From my own background as a medical teacher, I regret the tendency of both these measures to diminish the contacts between full-time and part-time medical staff, both of whom have a vital part to play in teaching, research and clinical work.

Although they also operate at more local levels, two other influences are important at the national level – the media and pressure groups. The media include the press, radio and television. This is a rapidly changing scene, in which television now occupies the predominant place as the source of popular information, which was formerly held by the daily press. It is easy to underestimate the continuing significance of radio, which is listened to by many people for a considerable part of the day. All the media are aware of the great public interest in health matters; and on the whole their response to it is balanced, given that no one is taken in by the obviously fictional presentations of life in hospitals. I have on the whole been impressed by the responsible attitude of journalists in all the media, and especially of those who are specifically ‘medical’ and ‘science’ correspondents. It is, of course, true that relations between ‘the media’ and ‘the medical establishment’ are sometimes less than perfect. The plodding processes of routine medical care, such as I have tried to describe in the first part of the chapter, are dull stuff compared with ‘cures’ from eating grass or consulting the witch of Endor; and these last have greater media appeal. On the whole, however, the gap in understanding between doctors and journalists has been narrowing, and it is now respectable for a doctor to be named on a programme, so long as he is not making particular claims to advance his own practice. The relationship will never be free of

problems, and particular incidents can lead to setbacks. The notorious BBC Panorama programme on 'brain death' led directly to a falling-off in the numbers of kidneys available for transplantation; it also exposed the lack of perspective of the 'current affairs' outlook, by contrast with science programmes. The need for acceptable criteria of 'brain death' stems not from transplantation, but from the desire to save relatives from the agony of watching for many days a 'life' being prolonged by artificial means when the brain has been irretrievably damaged. The form taken by the programme gave quite unjustified prominence to the electroencephalogram, which is at the very most a marginal criterion of viability.

Pressure groups related to ill-health and other forms of social deprivation abound, and they reflect both a praiseworthy concern with suffering, and the honourable history of voluntary effort in this country. There can be little doubt that the good which they do outweighs any possible harm. They do, however, at times appear to display the defects which go with their undoubted qualities. To give a specific example, legitimate concern with mental impairment following whooping cough immunisation had, as an unintended sequel, a falling-off in the take-up of other forms of immunisation. Concentration even on a legitimate objective, such as compensation for the putative victims of a public health measure, may prejudice a broader perspective. Pressure-group activity is perhaps particularly hazardous in the area of research, where excessive preoccupation with a particular disease can divert scarce funding from the broader and more fundamental aspects from which really major advances are likely to come.

*Departmental level* The health departments in the United Kingdom comprise the Department of Health and Social Security, the Scottish Home and Health Department, the Health and Social Work Department of the Welsh Office and the Department of Health and Social Services in Northern Ireland. It seems to me at least possible that the three smaller health departments not only have a more manageable task, but are also more flexible in their response to public participation; but I cannot speak from direct knowledge. The DHSS is in a very different situation for a number of reasons. It has responsibility for a population ten times larger even than that of Scotland; it is adjacent to Whitehall, and at least liable to be dominated by it; and it has the overwhelming responsibility, in financial terms, for the massive spending on social security, beside which even that on health and personal social services is small. Nevertheless, it tries hard. There is an

influential organisation for dealing with the press, and the media in general. There is a massive network of consultative machinery with the various professions, and informal discussions with pressure groups who to some extent represent currents of popular opinion. Through the ministers and Permanent Secretaries, it is in very direct contact with central government. The image of remoteness, often ascribed to it both by the media and by concerned individuals, is at least not self-sought.

*Regional level* A few years ago, an important working party, in which the chairmen of regional health authorities were strongly represented, was set up to advise on the transfer of certain responsibilities from the department to the regions.<sup>7</sup> Not too surprisingly in view of the membership of the working party, they were enthusiastic about this; and there was a considerable transfer of funding and responsibility to the regions. From one point of view, this has not been an unmixed blessing; for example, it has lessened the resources which the department is able to set aside for special developments related to medical and other advances. However, by transferring some responsibilities to bodies which include members of the public, and whose meetings are normally open to the press and public, it has extended the area of possible public participation in health matters. This opportunity may not yet have been fully exploited.

*District level* Many of the decisions which most directly affect the provision of health care are taken at this level; and this I believe to be right, for local knowledge and local interest are essential components of making good decisions. Moreover, it is at this level that there first appears, in the shape of community health councils, a formal machinery for the expression of 'informed public opinion'.

The composition of the district health authorities (DHAs) is clearly of great importance. As a firm believer in the principle that the health service should be truly national, I would risk acquiring an 'anti-democratic' label by declaring my firm conviction that the membership of DHAs should not simply be a reflection of the prevailing hue of local government. In the past, some local authorities ran good health services; others did not. Our political institutions seem to be going through a phase of quite notable instability; and I believe that the balance of advantage lies in keeping politics out of health service management at local level, impossible though it may be to do so at national level. Over the years, I have been impressed by the devoted service given, usually on a voluntary basis, by members

of health service authorities, who were prepared to work for the good of the service. I believe this valuable tradition should be maintained.

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Community health councils are a comparatively recent innovation, and it may be too early to judge their long-term effect on the service. Some of these, I believe the majority, have done excellent work, and have been of real service to patients, both by advocating improvements in services, and by informing patients of how best to use them. A minority of CHCs have, in my view, displayed undue political or sociological bias, have resisted the closure of hospitals which were not giving a good service, and have added rancour to complaints, not all of which have been justified. On balance, however, I believe that the experiment will justify itself.

*Voluntary participation* I have already touched on the splendid tradition of voluntary service which we have inherited from the Victorian era, in relation to service in health authorities. It may be vain nostalgia, but I regret the disappearance in 1974 of the old hospital management committees, and indeed of the boards of governors of the teaching hospitals, which brought together citizens who could take legitimate pride in 'their' hospital or hospital group. However, many opportunities for voluntary service remain, in leagues of friends, in voluntary transport, and in other ways. Voluntary service has the peculiar grace of blessing both him (more usually her) who gives, and him who takes. A rare and welcome piece of common ground among the political parties is their advocacy of, and support for, voluntary effort; and I trust that this reflects not only a desire to save public money, but some appreciation of the intrinsic value of voluntary work.

## Conclusion

Both in the clinical consultation, and in advising on health and on the provision of services, the doctor cannot but be aware that he has undergone a long professional training, following which he has acquired important and relevant experience. The temptation then arises to confuse the status of an advisory expert with that of an autonomous decision-maker; at least in the individual consultation, this temptation may be increased by an obvious wish on the part of some patients to transfer the responsibility for decision to the doctor. On the other hand, in his more public responsibilities, the authoritarian stance assumed by some doctors is increasingly being challenged by sociologists, by lawyers and the media. In my view, the temptation to be authoritarian is one to be

resisted so far as possible.

In the individual consultation, there should be a true partnership between doctor and patient, with the doctor offering expert advice, but leaving the patient with the ultimate decision, after full discussion, whether to accept it. This partnership is threatened if the doctor exercises unreasonable authority, or if the patient is too submissive or too demanding. The relationship between doctor and patient is intimate and confidential, leaving a very limited role for third parties, except where the patient is prevented by mental or physical disability from playing his proper part.

In the public sphere, doctors can have an executive role in areas such as communicable diseases and the public health. But for the most part, they are more effective as sources of expert advice, leaving the ultimate decisions on the provision of services and on the allocation of resources to politicians and public servants. Decisions on matters of health are complex, emotional and liable to be swayed by political considerations or by the advocacy of pressure groups, whether medical or lay. For the best utilitarian solution, an element of detachment is necessary, difficult though it may be to achieve. In the longer term, a doctor who remains conscious of his advisory status may have more influence than one who aggrandises the medical component of a complex decision.

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## Patient participation in general practice

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Patient participation in general practice means different things to different people. In the broadest sense, it can refer to any means by which the public can affect the way general practitioner services function. These can include individual decisions about health and health care, direct interactions between individual doctors and patients, the activities of consumer bodies such as community health councils, the machinery for handling complaints and parliamentary debate. Recently, however, there has been a tendency for the phrase to become identified with the activities of patient groups which have been established in some health centres and general practices.

These groups are part of a grassroots, professional movement. The first groups were started by three doctors, quite independently of each other, in different parts of England and Wales in the early 1970s. Nearly all of the subsequent groups have also been formed by doctors. From the beginning, the groups have taken many different forms and have had different aims and activities. But, the idea common to them all is that a group of patients – representative as far as possible of all the patients registered with a practice – should meet together regularly with the doctors and other practice staff in the interests of improving communication and the services. A National Association of Patient Participation Groups was formed in 1978 from seven groups. Their numbers have now grown to about 50, and groups exist in all types of neighbourhood – in inner city areas, middle-class suburbs and rural areas.

In the last few years, the activities of patient groups in general practice have attracted a considerable amount of public and professional interest and a keen debate has ensued about their potential merits. At national level, support for these groups has come from many quarters. The Royal Commission on the National Health Service welcomed the groups as a way in which health professionals and patients could meet informally and work together to improve services.<sup>1</sup> The Royal College of General Practitioners gave its blessing to the groups by publishing a collection of essays on the subject<sup>2</sup>, and a working party set up by the Gulbenkian/Guardian Community Challenge Conference in 1981 called for patients to be given the statutory right to start groups in general practice.<sup>3</sup> By signing the Declaration of

Alma-Ata, which was issued at the end of a WHO/UNICEF conference in 1978, the government committed itself to developing strategies for primary health care which

'requires and promotes maximum community and individual self-reliance and participation in the planning, organisation, operation and control of primary health care, making fullest use of local, national and other available resources: and to this end develops through appropriate education the ability of communities to participate.'<sup>4</sup>

Abroad, the Committee of Ministers of the Council of Europe has recognised the desirability of patient associations at local as well as at other levels and recommended that they should be encouraged and stimulated.<sup>5</sup>

At grassroots level, the small number of patient groups – an average of one in every 120 practices – suggests that either the groups are difficult to start or keep going, or that the public and the profession at large remain to be convinced of their merits. Some argue that sufficient opportunities for patient participation in general practice already exist and that to seek to extend them would be a pitiful waste of professional time and resources. Others accept that greater patient participation is desirable in principle, but are sceptical whether patient groups are, or can be, an effective way of achieving this goal. Cynics suspect that patient groups are a cruel hoax – the result of a conspiracy to maintain and increase professional dominance.

This chapter aims to contribute to a clearer view of the potential and problems of patient groups and the prospects for an expansion in their numbers.

### The potential of the groups

Patient groups in general practice provide opportunities for stimulating three kinds of public participation: participation in self-care, participation in the care of others, and participation in the running of the NHS. In his chapter, Stephen Hatch refers to the first two kinds of participation as the 'largely informal involvement of everybody in health' and to the third kind as the 'formal arrangements for taking into account the views of patients and the public in making decisions about the NHS'. In practice, many groups are active in promoting more than one of the three kinds of participation, but not always simultaneously. The way the groups attempt to promote different kinds of participation also varies enormously.

### *a. Participation in self-care*

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In the field of health education, patient groups are active on three broad fronts: organising programmes of lectures and discussions, producing educational materials such as booklets, videotapes and films, and setting up self-help groups. Groups for people who want to slim, get fit, and give up smoking, and groups for the mentally ill and handicapped are examples of some self-help groups that have been started.

The impressive number of educational activities the groups have organised and the number of people they have involved are tangible measures of their success. Some groups, for example, have organised over 100 meetings with audiences of 30 to 100. But, it is difficult to pin down who benefits from these activities. One study in Aberdare by the Welsh Consumer Council<sup>6</sup> showed that lectures were attended mainly by members of the middle-class and those who were better informed. But the experience of other groups with different kinds of programmes may be different.

It is also difficult to pin down the impact of patient groups' activities in terms of increasing knowledge and understanding about health and illness and stimulating desirable changes in health care practices. Do they, for example, reduce the number of consultations for minor self-limiting conditions? Do they increase the number of requests for cervical smears, screening for hypertension and routine immunisation, particularly in those socioeconomic groups which are most in need and least inclined to make such requests? One small study carried out in an inner city health centre in Birmingham suggests that they can have an impact. Following a talk on the menopause, a comparison of the consultation rates of the women who did and did not attend showed that those who came to the talk consulted their doctor less frequently.<sup>7</sup>

Few problems to do with the educational activities of patient groups have been identified. But, a study of the Aberdare group by the Welsh Consumer Council showed that disagreement between patients and doctors may arise over the proper scope of a health education programme. In addition, while many of the educational activities are underpinned by a belief that increased public knowledge about health and health care will lead to better doctor-patient relations, and to greater public satisfaction with the health service, it should be recognised that it will not necessarily do so. It could also lead to more informed criticism.

With the re-ordering of work priorities within general practice in favour of prevention, the prospects for continuing professional

support for the educational activities of patient groups appear favourable. This emerges from the report from the Royal College of General Practitioners on Health and Prevention in Primary Care.<sup>8</sup> Having identified disease prevention and health promotion as 'the most important growth area in the foreseeable future' the report goes on to emphasise that this will entail radical changes in the traditional active doctor-passive patient relationship and to suggest that patient groups may have an important contribution to make to this process.

*b. Participation in the care of others*

Many groups stimulate participation in the care of others in the community by providing opportunities for voluntary action. To coordinate voluntary work, some groups have appointed voluntary service coordinators who take calls for crisis and long-term help from practice staff and pass them on to a panel of volunteers. Some of these coordinators are unpaid, while others are paid by funds from district health authorities and sources such as joint financing, job creation schemes and MIND.

There are three major ways in which volunteers complement and supplement the care provided by health professionals. First, they link people with the services they need by providing transport to take them to the surgery, or their prescriptions to the chemists, and to collect and deliver medicines. Second, they link people to the services they need by providing information about patients' rights and entitlements to statutory services and by advising them about whom they should turn to with this or that problem. Third, they help to create and reinforce informal care networks in the community on which health and social services depend by organising lunch clubs for the elderly, young mothers' groups, baby-sitting services and so on.

The number of volunteers and the number of people patient groups help are two tangible signs of their success in encouraging cooperation between health professionals and the public. But evidence is lacking to dispel the lurking suspicion that the schemes only work in areas which have little need for them – where social networks are already strong and statutory provision is high.

There are no reports that the activities of patient groups in this sphere cause problems. On the contrary, health professionals say they very much appreciate what volunteers do to help solve problems. With cuts in health and social services, continued professional support for voluntary work by patient groups seems assured.

*c. Participation in the running of the NHS*

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participation  
in general  
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Rudolf Klein puts forward three propositions in his chapters which suggest that encouraging public participation in the health service should be easiest at health centre or practice level – the lowest unit of the service. At this level, the costs of public participation are relatively low and the potential benefits of participation relatively high. In general practice, the scope for local diversity – which results from general practitioners' independent contractor status – and the promise of direct and immediate benefits to the individuals concerned, provide powerful incentives to participate.

Up to now, however, the opportunities for the public to have any say in the running of general practitioner services have been distinctly limited. There has been no forum for a dialogue at practice level, and community health councils have found it difficult to influence this branch of the service. They have not had the right to enter doctors' surgeries without their permission and many have been excluded from family practitioner committees. The mechanisms for handling complaints against general practitioners have also been criticised as being inadequate. In this context, patient groups are an important innovation creating a new communication channel between health professionals and the public and new opportunities for a dialogue about matters of organisation and practice (for example, appointments systems, home visits, prescribing of antibiotics, tape-recording of consultations for teaching and research).

But simply creating a new communication channel does not guarantee that there will be useful exchange of views or that health professionals will use the information they obtain to make the services more accessible and acceptable. Health professionals have a greater stake in practice decisions than the public and are better placed to control discussion. The public may also be unable or unwilling to challenge health professionals' views. Patients and health professionals who have been involved in patient groups claim that the opportunity for discussion, in itself, helps to improve practice-community relations and to increase mutual trust and understanding. Patients also say that they gain new insight into the workings of the practice – a prerequisite for making a useful contribution – and professionals that they gain a better understanding of public opinion. So, the groups do provide opportunities for mutual learning. It is difficult to say, however, how far the claimed benefits of discussion spread to the majority of patients who have shown no active interest in the groups.

It is also difficult to say how much influence discussions with

patients have had on health professionals' policies and practices. Where health professionals are sincerely concerned to provide patient-oriented services, the groups can apparently have a significant impact. In one practice, following patient representations, a woman doctor joined the practice. In other practices, changes requested by patients have been made in appointments systems, reception arrangements and practice facilities. If the groups are aware of the influence they can exercise, and if health professionals are genuinely responsive to patients' views, it would seem of little consequence that decision-making power continues to reside within the ambit of the practice.

The most common problem that the groups encounter in seeking to represent general opinion within the practice is apathy, and this is discussed later on. Professional fears that the formation of a patient group will lead to 'the practice being taken over by an unholy mixture of the most frequent practice attenders, the unhappily married escaping from home and a task force of Militant Tendency'<sup>9</sup> are quite unfounded. Patients who are sufficiently interested to attend meetings say they are seeking collaboration not confrontation and reject the idea that they are interested in 'patient power'. The more likely problem is that patient groups will become institutionalised and degenerate into mutual admiration societies. To avoid this happening, a frequent influx of new members – although it may be difficult to achieve – would seem desirable.

Most groups discourage open discussion of individual complaints and grievances about the services and have developed special procedures to deal with them. Such procedures should enable health professionals and patients to sort out problems without delay or fuss. In practice, the procedures are rarely used – some groups report one complaint a year, others three or four. This may be because there are no problems, or because the procedures act as a safety valve, or because the procedures are in some way unsatisfactory.

In some patient groups, discussion extends from matters which are the responsibility of the practice to matters which are the responsibility of other bodies – for example the district health authority and the local authority. Where this happens, patient groups occasionally lobby those bodies for changes in provision. Acting in this way, some groups have been successful in keeping open hospital beds or ambulance stations and in reducing waiting times for chiropody.

## Common problems

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Two common problems that the groups have faced are apathy and difficulty ensuring that the membership of the group is adequately reflective of opinion within the practice. These problems worry both advocates and critics of the groups. The critics argue that apathy is proof that ample opportunities for public involvement already exist and that if the public choose not to avail themselves of them, then they should not be compelled to do so. This is a seductive argument which requires an answer.

It is true that there is no sign that the public are consumed with a desire to participate in general practice. But apathy partly stems from the fact that patient groups have had difficulty in making their existence widely known. They lack the resources needed for good publicity and their efforts have been constrained by guidelines, issued by the BMA's Central Ethical Committee in 1979, indicating what kind of 'advertising' by the groups doctors should not tolerate. Apathy also partly derives from a belief among patients that their views will not carry weight with health professionals and from lack of expertise or self-confidence to make their influence felt. In either case, decisions not to participate may result not from lack of interest but from lack of ability to participate effectively. So, one rejoinder to critics who believe that apathy is a good reason for doing nothing is that their case only stands if efforts have been made to eliminate the causes of inaction – to stimulate interest and to provide a suitable organisational framework for people to express their views.

Whatever the underlying reason, it needs to be recognised that there is no quick and easy way to overcome apathy. As Ruth Levitt said, speaking of the experience of community health councils:

'it is a slow and steady working at this problem that will probably provide the answer. . . it is not possible to just "switch on" public involvement; you have got to work very steadily at it.'<sup>10</sup>

Despite the problems, some groups have succeeded in getting themselves known largely as a result of their health education programmes and community care activities.

Apathy is linked with the problem of ensuring that the groups adequately reflect opinion within the practice. Although arrangements for taking account of patients vary from group to group, broadly speaking there are two different approaches. On the one hand, there are what Peter Pritchard<sup>11</sup> calls 'open' groups,

formed from open meetings, which any member of the practice may attend. These subdivide into informal groups without any set membership and formal groups with committees elected annually. On the other hand, there are 'nominated' groups which are formed from nominees of other community groups such as old people's clubs, youth clubs, parish councils, women's institutes, single parent groups and tenants' associations. This model tends to be favoured where patients have been reluctant to come forward.

Whichever model is used, some critics argue that the groups only increase the opportunity for middle-class activists and the most frequent attenders to have a say in the running of services. In reply to this view, three points can be made. First, although the usual tendency for the middle-class and middle-aged to predominate is evident in some groups, there is a good deal of variety in the membership. Second, as Stephen Hatch points out, a bias in the groups towards the frequent attenders – the elderly, the chronically ill and handicapped – may be no bad thing insofar as it may act as a corrective to the bias in the health service towards curative medicine. Third, so long as the groups recognise their shortcomings in this respect, they can provide some of the resources for tapping a wider range of opinion. For example, some groups help to conduct surveys to find out more about patients' health problems and views, and others chat to patients in the waiting room.

### Future prospects

Patient groups are a new phenomenon but are unlikely to be an ephemeral one. In the late 1970s, the development of patient groups was associated with a re-ordering of work priorities within general practice in favour of prevention, a shift towards larger practice units and more readily identifiable practice areas, and increased demands for the medical profession to be more accountable to the public. These trends are likely to continue and to lead to a wider recognition of the potential benefits to be derived from patient groups.

But there is no guarantee that the broad acceptance of the desirability of patient participation in principle by the profession or the public will be accompanied by more than a few attempts to form patient groups. The groups are unlikely to emerge spontaneously in response to public demand and, for many health professionals, the perceived costs of starting a patient group will outweigh the potential long-term benefits. The diffusion of the groups will, therefore, partly depend on finding ways of reducing



the costs involved in starting a group. The publication of a new guide on starting up a patient participation group in general practice is one practical step in this direction.<sup>11</sup> The provision of financial and community work support are other possible steps that family practitioner committees and district health authorities could take.

While such steps could have an important influence, the complex and diffuse nature of patient groups needs to be recognised as a major obstacle to a rapid rise in their numbers. Perhaps quite deliberately the processes and boundaries of patient participation have been left undrawn. Clearer guidelines from the National Association of Patient Participation Groups, setting out what the groups are meant to do and why doctors have set them up, would help to reduce the uncertainty that exists about their role and to accelerate their diffusion.

The crucial question is what the role of patient groups should be. The present activities of the groups suggest a wide range of possibilities for development. For example, each group could attempt to maintain a balance between encouraging greater participation in health, in community care and the health service, or they could give priority to encouraging participation in one or two of these fields.

Whatever role patient groups choose to play, some cynics will argue that doctors stand to benefit more than patients. In the past, doctors have introduced other innovations such as practice receptionists and appointments systems saying they will be in the patients' interest. Years later, commentators question whether patients have gained as much from these innovations as doctors. Many patients and doctors who have been involved in the patient groups claim they both benefit. But they will not automatically do so. The need for evaluation, when the groups have had time to have an impact, is obvious.

## Conclusion

Patient groups are a recent innovation in general practice with considerable potential for benefiting the public and health professionals. They provide many new opportunities for the public to become more involved in their own health, the care of others and the operation of the health service. They also enable health professionals to give a higher priority to prevention and to redefine their relationships with the public.

Apathy is a common problem faced by patient groups and is linked to difficulties in ensuring that the groups adequately reflect general opinion within a practice. But despite considerable

problems, and as a result of their health education and community care activities, patient groups are succeeding in making themselves known and arousing interest.

The prospects for a slow expansion in the number of patient groups are favourable. Clearer guidelines setting out what the groups are meant to do and practical guidance on how to set them up from the National Association of Patient Participation Groups, combined with financial support from family practitioner committees and district health authorities, would help to accelerate their diffusion.

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# 5

## Health authority membership and chairmanship

JOHN BETTINSON

The management of the National Health Service, like the service that it now provides, has come a long way since 1948. The fierce competition for increasingly scarce resources, and the pull between the demands of primary and secondary care, were then things of the future. Clinicians and other staff, long accustomed to making do, could contain without great difficulty the claims then made upon them by a largely undemanding public. With a new and generous paymaster in the form of the NHS there was so much that could be done.

The days of voluntary support were over, but it was natural that for every hospital or group of hospitals there should continue to be a management committee of public worthies, drawn predominantly from 'the establishment'. Among them were captains of industry, members of the professions, men and women from largely middle-class families, imbued with a sense of public duty that probably did not extend to active involvement in politics but entailed giving their intelligence, and above all their time, to the development of a service for the community. One may doubt whether they were, in fact, any more effective than their present day (and perhaps rather different) counterparts, and to what extent they materially influenced the direction in which the service went and the improvement in its quality, but there is every indication that they, and those who worked under them, were at least satisfied with their role. There seems to be little evidence, however, that their role was ever defined or critically examined.

Thirty years ago many of the major institutions of this country were run by gifted and motivated amateurs – a system that seemed to work very well then, but is it appropriate in the 1980s? The Kogan report, published in 1978 by the Royal Commission on the National Health Service (Research Paper No 1), disclosed that there was widespread scepticism on the part of both members and officers about the reality of the member's role. It was suggested by officers that the majority of members had neither the time nor capacity to understand and apply the planning system. Members felt remote from it and that they were only 'rubber stamping' the proposals of others. 'Only the Chairman was well enough placed to make an impact on the decision making

of officers.' The general feeling was that members' influence on the service was not very significant.

It has been argued that this growing sense of frustration has been aggravated by the greatly reduced real growth in NHS resources over the last six years, yet it could equally be claimed that the challenge – the need for ingenuity and greater efficiency – has been all the greater and that this should have stimulated authorities. There has, for example, been scope in the developing field of joint finance, but in many parts of the country it is sadly clear that neither members nor officers have applied themselves to it with much imagination.

Part of the members' role is believed to be the encouragement or – put more strongly – the inspiration of their officers. The former will say that they find this task difficult to perform without more detailed information and a greater involvement than they are usually vouchsafed. They will often complain that officers seem intent only on finding reasons why things cannot be done. Officers for their part will claim that, with a few exceptions, members are not, when put to the test, prepared to get sufficiently involved. They cannot devote the time to reading up the subject and yet, on a largely superficial appraisal, expect their views to be respected and accepted. As usual, there is some truth on both sides.

Perhaps the greatest deterrent to initiative and imagination in the course of an authority's deliberations is the 'set piece' approach to paperwork. If recommendations come to a meeting that do not commend themselves, the only solution is their reference back to officers, and a regurgitation some weeks later. I still remember the evening when my authority attempted to beat the system. Certain resource allocations had not found favour and, to the officers' horror, members there and then produced their calculators and proceeded to project a whole set of alternative proposals. A dominant factor will of course be the nature and extent of the matters put before an authority by its officers, either of their own volition or by request. This is for the judgement not only of officers but of chairmen. It is usually relatively straightforward to determine what matters need to be put before members, but it is not so easy to strike a proper balance between members' desire for full information and the suppression of unnecessary detail. The humorous legendary plea not to be confused with the facts is sometimes taken so seriously in the NHS that none are given – on the grounds that members should not become involved in matters of day-to-day management, or that they would not understand the detail.

A chairman's preliminary criticism of the paperwork that his\* officers propose to put before a meeting can be valuable, but as he grows more expert himself he finds that he may overestimate the capacity of his members – certainly of his average member. He also needs to beware of becoming so involved in the preparation of his officers' papers that they must necessarily reflect his own views. There will surely be times when he has reservations about what is being recommended but, having expressed those to his officers, he would be most unwise to prevent those recommendations going forward to the authority. A corollary is that, after other members have had an opportunity to indicate their views of the report, he should be free to express to the authority as a whole his personal opinion.

The chairman of a health authority – as a layman, working part-time and, for some years now, paid – is in a somewhat curious class of his own. He is only quasi-executive in character, providing a balance or link between the executive management and the wholly non-executive health authority membership. It does not seem to be envisaged that he should also undertake the role of management team chairman, although the distinction is a fine one and much will depend upon personal style and character. There will be some management teams which accept, and are strengthened by, such an involvement on the part of the authority chairman. But the practice can also have the effect of opening up a rift between the chairman and the other members. He may be seen by them as just another officer whose authority they may have to accept but whose lead, if it is seen as less than objective, they will increasingly distrust. It is not easy for a chairman to keep in the middle ground. He must maintain a constant, preferably daily, contact with his officers and all that is going on, yet he must be able to stand back and at times advance a critical or opposing view. On such occasions, he may need to look for support from his members; he will get it, one hopes, on the strength of his case not the force of his character. It is in the interest of any good chairman to develop the skills and independence of his members, not to create a caucus of 'yes men'. There is no more dispiriting task than presiding over a passive and uncritical committee. The mute acceptance of recommendations put before such a meeting should give both officers and chairman cause for concern not congratulation – attractive though it may seem to have 'got the business through'.

The chairman, unlike any other member of an authority, is appointed directly by the Secretary of State and as such is

\* Here and elsewhere I use 'his' as a shorthand for 'his or her'; similarly with 'he', 'him'.

expected to explain and secure the adoption of government policy in his area of responsibility. Yet this should not be a political appointment in the sense that his personal political views (if any) must necessarily coincide with those of his appointor. On the great majority of health issues, political differences may not be crucial at the level of the authority, but in certain circumstances a chairman's loyalty can be strained to breaking point and resignation would then seem to be the only course open. This could arise not only if a difference emerges between Secretary of State and chairman, but just as easily if a majority of authority members challenges their chairman on a matter of government policy. He is chairman of the authority not chairman of his members, and they have no say in his appointment, but in the absence of mutual confidence his position would be untenable (as illustrated by the difficulties in Brent in 1983). In the final analysis, the decisions of a health authority are those of its members and the chairman is one of them.

Fortunately, where there is a strongly held view in health authorities generally that is at variance with the expressed policies of the government of the day, the National Association of Health Authorities is available as an appropriate instrument publically to express political views and exert pressures on behalf of the NHS. No individual chairman or health authority can undertake that role.

In the absence of a chief executive – an absence which, it seems, is about to be filled under the Griffiths proposals – the chairman of a health authority may find himself having to hold the balance among the chief officers of the various disciplines. This was a responsibility peculiar to chairmanships in the NHS since no other organisation has, to the same degree, this multidisciplinary approach to management. Officers in turn have to ensure that they distinguish between their individual responsibilities as managers in their own disciplines and their role as members of management teams. A chairman must recognise this distinction and ensure that in addition to working with his management team as an entity, he relates without preference to each team member. Almost inevitably the administrator, as general coordinator of the team and secretary to the authority, will tend to have more frequent contact with the chairman. Nevertheless, equality of access on the one hand, and on the other direct reference from the chairman to the appropriate discipline, must be preserved. In an evenly balanced team, non-specialist responsibilities should be shared between team officers, not left exclusively to the administrator. The fact that no one discipline or officer can predominate, emphasises the importance of the

chairman's position both within his authority and to the outside world. While some of this will undoubtedly change post-Griffiths, the chairman will share with any chief executive a general management function of fusing the parts of the enterprise into a single corporate whole, internally and externally. He may at times be seen as only a figurehead, but that role is vital and no one, least of all the chairman himself, should underestimate the extent of his authority and capacity for influence. He must above all exercise leadership.

No nationalised industry, let alone any commercial or industrial enterprise in the private sector, operates with a management structure approaching that of the NHS. Yet at its core the service is not so very different from such organisations. It is a business and a very big one. It is there to provide the best and widest range of services for its customers that they as electors and taxpayers are seen to want, and which their representative government determines they can afford. The measure of its success, unlike that of its industrial counterparts, cannot be gauged by the profit it achieves each year for its shareholders, but it is required to give the electorate value for money, and in so doing to demonstrate its efficiency. The private sector has been fighting for some time now to survive the constraints and pressures imposed by economic circumstances. The public sector, of which the NHS is a substantial part, is having to do the same. The job required of the district health authorities in the 1980s is therefore immense. Their members need to be very clear about the task, their role and their powers.

The 1982 reorganisation was designed to improve the effectiveness of management, primarily by creating a greater number of smaller health authorities with smaller memberships. This should help members to get to know their colleagues better and to gain a greater corporate sense than characterised many of the area health authorities of the 1970s. They were daunting bodies to join and at times difficult to chair. In the absence of firm chairmanship they could on occasion get out of hand and deliver a perverse decision. A large body should theoretically gather strength from its size – helpful surely when difficult decisions have to be taken – but too often the reverse occurs, individuals leaving it to 'the others' to determine what must be done. Of one such area health authority it was alleged that when difficult decisions were to be taken, members stayed away from the meetings.

It is easy to make out the case for authorities that are smaller and more local. For example, the officers can relate more effectively to a smaller number of members, particularly when they are concerned with a reasonably compact community. Any

group which works closely together quickly learns to which of its number to turn for particular wisdom – and when to discount the advocacy of a special interest. But small size can also bring with it some limitation of the available skills, and a greater risk of domination by a strong minority. There will also be the temptation, familiar to the hospital management committees pre-1974, for members to involve themselves in the minutiae of the day-to-day operation and to become, however unwillingly, the recipients of persistent staff lobbying. The allocation to members of particular responsibilities or areas of interest – whether it be by function, unit, speciality or whatever – is two edged. It helps to develop knowledge and experience, but it can also narrow the mind and create a 'constituency' approach. It is no part of a member's role to fight for a corner. Moreover it can engender the dangerous assumption in the mind of a member, and perhaps those of his colleagues, that on a particular subject he knows it all – and rather better than the professional. Probably the happiest compromise is a system of allocation that is periodically reviewed, so that a member moves on and gradually builds up a valuable jigsaw of experience in a number of fields.

At the time of the 1974 reorganisation, Circular HRC(73)24 furnished a formidable blueprint for ideal members who needed to be '... interested in health services, able to identify themselves with the area concerned and collaborate with the local authorities in providing services; to have an unbiased and critical approach to problem solving so that the right questions are asked when plans and policies are reviewed; to possess common sense and good judgement; to be able to provide leadership to officers without attempting to do the work that officers are employed to do; to be able to work well in a group ...'

The so called 'Grey Book' on management structures, produced in 1972, clearly envisaged a board of directors' role for health authorities in which, apart from a general accountability upwards to the Secretary of State, each authority would largely determine its own policies and objectives, and would monitor the performance of its officers and, where appropriate, of its subordinate authorities. But experience does not indicate that the majority of area health authorities ever fully accepted that role – if they were ever qualified for it. Perhaps they were not given the time to grow into it. But how many district health authorities are functioning in this strategic way? What is clear is that the available people with proven management talent (or the time, capacity and inclination to acquire it) are not many in number. This is not so surprising. How many younger men and women in industry, commerce or the professions today are able to give the



necessary time to the NHS without risking their career prospects and even their present employment? One of the top priorities in management in the NHS, as indeed in business generally, is the effective control and deployment of finance. The service is now rather better served than it was a few years ago in the financial discipline, but there is still very considerable scope for improvement in cost effectiveness. Yet there are relatively few accountants or finance men to be found among authority members. Despite the receipt of an honorarium, the same problems must affect the availability of suitable candidates for chairmanship – which is a pivotal role in the working of any health authority, calling for managerial ability and, preferably, a working knowledge of the service before taking up office. Nor is there an effective training programme for chairmen once recruited. Officers will be able to do something to cover or correct their chairman's ignorance of the service, but they cannot make good a lack of management experience without usurping his authority. Moreover a chairman will all too often find that he has to make an off-the-cuff public comment, or pronounce on some vital and sensitive issue, without his officers being there to guide him.

An NHS manager's counterpart in the private sector would be horrified by the limelight in which so much of the business of the service has nowadays to be conducted. It has come as a considerable shock to many members of health authorities when their less happily expressed or considered contributions to a debate are publicised and ridiculed. Such occurrences usually stem from nothing more serious than ignorance of the service and, in view of its size and complexity, may be excused in any but the experienced. Much preparatory work can be done in private session, where ignorance can be corrected and knowledge can be acquired relatively painlessly. Care must nevertheless be taken to ensure that the road by which an authority reached a decision is clear, and that the decision itself is taken in public meeting. It is a particular strength of the NHS, in contrast with many other public bodies, that so much information is made available to anyone seeking it with good cause, and that its work is accorded so much publicity by the press and by the activities of CHCs. This openness is probably a more effective discipline upon an authority than any hierarchical control.

The duty to consult on a very considerable scale before reaching decisions is an onerous requirement in the NHS, and one that has perhaps been overdone. Dissatisfied parties tend to demand so much time to respond, and such frequent reconsultation when decisions are not to their liking, that the procedure has fallen into disrepute. Too often an urgent decision has been

unduly delayed. Pressure groups appear to have coined an eleventh commandment 'Thou shalt consult and continue consulting until thou shalt agree with us'. Allegedly, representative expressions of public opinion, whether by CHCs, special interest groups or the media, must be treated with caution by managers. Those seeking to employ the powers of publicity to court public sympathy will inevitably be drawn into highlighting those issues and features most likely to attract the eye and stir the emotion – not necessarily the factors or criteria by which situations should be judged and decisions reached. Management in turn is then tempted to react so as to be seen to be doing something. Yet such action (for example setting up formal enquiries or creating working parties) may often be unnecessary, possibly harmful and certainly costly. The price paid for democracy is all too often delay.

Community health councils continue to press for greater involvement in the work of health authorities, including membership of working parties, planning teams and project groups. They may also seek access to members' private sessions. Yet they are not members, and it is important that the distinction of roles is clear. They have no responsibility for the provision of the service. It was at one time being suggested that they could undertake the role of communicators for NHS management – for example in the field of health education. This is surely wrong in principle. In no sense should they be the mouthpiece of the health authorities, which must speak for themselves. The task of the CHCs is to criticise, preferably on a constructive basis, the services that are, or ought to be, being provided. They, more than health authority members, need to be representative of all sections of the community and of all age groups. Personal experience of being on the receiving end of the service will be particularly valuable to them. In general CHC members may have more time available to them than health authority members personally to examine areas of the service in detail, and for frequent visiting. Visiting by members of the authority is nevertheless important, not only for their own education, but so that their concern is manifest, and they themselves are known.

The other demands upon members of health authorities should never be underestimated. In addition to the long process of building up a working knowledge of the service and participating in meetings of the authority, they are called upon regularly to undertake many day-to-day 'last resort' management tasks, such as conducting disciplinary appeals and undertaking the interviewing and appointment of senior staff. While in a multidisciplinary organisation the latter is probably essential, one may question the

need for so great a participation in appellate work. Neither in the private sector, nor elsewhere in the public sector, is the need for such complex internal procedures so evident. Could not much more of this work be left to the specialised public agencies such as the Industrial Tribunals – whose ultimate involvement is in many cases unavoidable?

There is, however, no doubt that many members undertake such tasks with a greater enthusiasm than any other part of their work, which suggests that it is an aspect of their role that they can identify with clarity and which gives them a sense of satisfaction. This sense of satisfaction is vital to all those employed in the work of the NHS, from the top to the bottom, if morale is to be high. The welfare of staff and their encouragement are features of the management task too often overlooked.

Little time or opportunity is given for member training (or the training of chairmen) either locally or nationally. Moreover until the National Association of Health Authorities, and, in its time, *The Health Supplement*, began publishing material directed towards the lay management of the NHS, there was little available of a self-help character. It is, of course, arguable that a little knowledge is worse than none at all, yet neither chairman nor members can set themselves up as more than generalists. They must nevertheless be prepared and able to challenge the experts at least on general principles. They must be thinking people and know what questions to ask. They need to deploy their own imaginations and fire those of the executive managers who, after a good many years in a service not remarkable for its encouragement of those who administer it, may be inclined to take a sceptical or even cynical view of fresh ideas. Considerable resistance to any change other than by way of incremental growth is all too customary in the NHS. A health authority's hardest task is to determine what is reasonable and practicable. What on analysis may prove to be self-interest can too easily be defended as being essential for the welfare of the patient, or be withdrawn behind the protective barrier of clinical freedom. The assumed interest of the public in all matters relating to health services will generally be fuelled by the media, so that even dubious minority viewpoints can secure considerable supportive publicity. NHS managers can perhaps be forgiven for feeling that they are seldom believed, while clinicians are invariably reckoned to be right.

Successive governments must accept some responsibility for this undermining of managerial authority. It is temptingly popular to stigmatise those who administer the service as faceless, ineffectual and expensive bureaucrats, but their capacity for effective action is correspondingly diminished. Such criticism

inevitably weakens the authorities for which they work.

To what extent has management been able to influence the direction and rate of progress of the service – as compared for example with the influence of the clinicians, or of the national bodies that represent them and other workers in the NHS? To what extent does government genuinely believe that health authorities can and should be undertaking a full management role, when it has decided that the employment contracts of consultants are not to be held by the authorities for whom they work, and that the contracts of the general practitioners shall be administered by totally separate statutory bodies?

There are those who still find it difficult to distinguish the roles of CHCs and health authorities. The number of CHC members who transferred over to health authorities in 1982 perhaps underlines this. The membership of both can be said to be broadly representative of the community to be served, the health authority in addition having representatives of the health care professions and one or two people with broad management experience. The health authority may appear to be charged primarily with a consultative or audit role, so that officers have periodically to justify their actions: a supervisory body with a 'watchdog' responsibility to shout when things seem to be going wrong, and to provide a respectable local buffer between a demanding public and a parsimonious government. One trusts that such a cynical view underrates the role of a health authority. It is certainly contrary to the stated objectives of the 1982 reorganisation. The extent to which the role develops as envisaged in 1982 will depend not only upon ministerial support, but also upon the will and commitment of health authority members to fight for it. The NHS has had such a commitment and contribution without reservation from authority chairmen for some years now, but their services are recognised by the payment of remuneration. Is there any real justification for not extending that principle to members, in order to attract a high calibre of men and women for what, done properly, is a demanding task – and not a particularly popular one? It may be argued that such payments could attract applications from individuals with the wrong motives and with less than obvious merits. Provided, however, that their remuneration is set at a sensible, not over-generous level, and the system of selection and appointment is a good one, the advantages would far outweigh any disadvantage. Why, for example, should the process of identifying authority members be so much less searching than that applied to the appointment of full time officers? One would also like to think that we could monitor the performance of chairmen and members

– and officers for that matter – more actively than we do. Sadly, changes in appointment appear to occur on party political grounds, or for change's sake, rather than for reasons of performance.

*Health  
authority  
membership  
and  
chairmanship*

If a case was ever well made out for small, effective, non-executive management boards, it was surely the record of the Commissioners appointed by the Secretary of State in 1978 to assume temporary responsibility for the then Lambeth, Lewisham and Southwark Area Health Authority. There was a political song and dance about the legality of that action, but the Commissioners worked well, at least for their limited period of office. The relationship with their officers was good, and their actions were endorsed rather than challenged by the AHA, after it was reinstated. The Commissioners presumably worked with the authority's team of officers very nearly to the model of a mixed board of full time executive officers and part-time non-executive members put forward in 1980 by the late Brian Watkin, as editor of the Health and Social Service Journal. It was perhaps a pity that this suggestion was received by the service with such incredulity and disdain.

One of the features of NHS management that it is difficult to justify is the national insistence upon rigid, uniform structures that give little scope for variation or experiment. There were some who, with so much at stake, would have dearly liked to conduct management experiments in various parts of the country. Perhaps that opportunity has come again, if the government decides to allow substantial local flexibility in the timing and method by which health authorities implement the Griffiths proposals on general management.

There seems little doubt that since 1974 lay chairmen and professional officers have come closer together, but one suspects that the same cannot be said for members. For them the gap, with both chairmen and officers, may have widened. Chief officers achieve their positions of responsibility on the basis of their experience and ability. They may see themselves as the experts, and their task as being not merely to carry out the authority's plans and decisions, but also to guide their authority towards making the 'right' decisions. While entirely understandable, such an approach is likely to be viewed with suspicion and a sense of impotence by members. How can they challenge proposals put forward by the experts? In this respect officers may not have helped by deliberately excluding members from participation in working groups. 'Handholding', it is sometimes forgotten, is a two way process. The absence of any substratum to the public meetings of authorities – committees being regarded for some

years after the 1974 reorganisation as 'prohibited' – contributed to the arrival on the authority's agenda of proposals in the development of which members had no part. In such circumstances members are likely to take the offensive. The officers for their part will then be on the defensive, having no assurance, such as that enjoyed by their local authority colleagues in the party political arena, that there is within the membership a majority group committed to the policy being advanced. There may also be differences of view as to the form and detail in which proposals should be presented by officers. Sometimes it is a fine point whether a proposal should be the subject of a clear recommendation, whether options should be rehearsed, or whether the matter should be left entirely to the authority. One thing is certain, if an authority is minded to reject and refer back proposals put to it by its officers, members must be prepared to indicate the criteria by which they believe that acceptable alternative proposals can be identified. This surely is where every health authority can and must come into its own. If difficult decisions have to be taken, involving (as they sometimes will) choices that seem uniformly unattractive, it is the responsibility of the authority to take them and the duty of all its members to participate in doing so.

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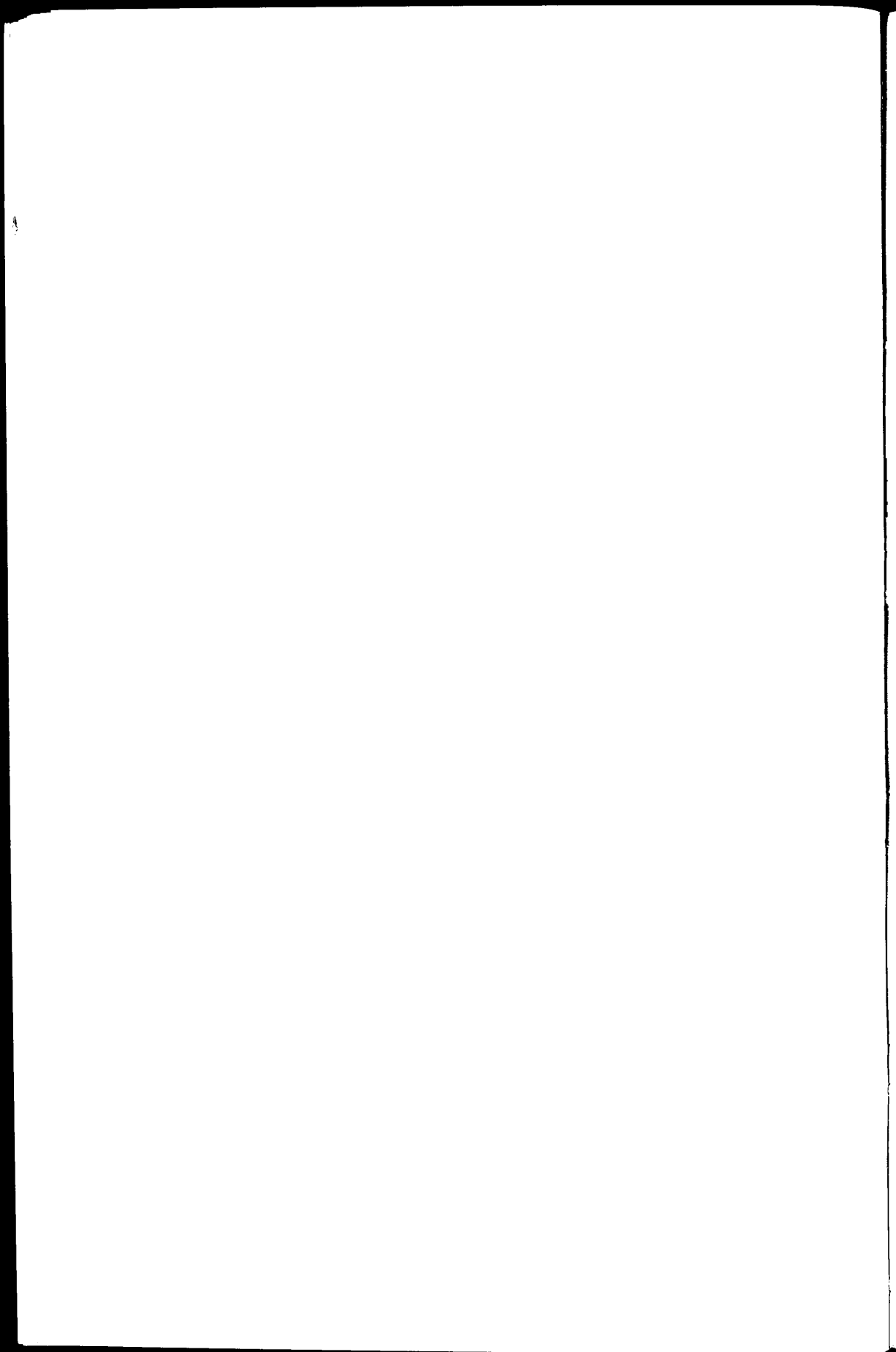
Nineteen eighty-four seems likely to mark another milestone in the evolution of the management of the National Health Service, with a reassertion of the importance of general management. That will change a number of things, but it will not alter the fact that, in a major public service, the executive must always be accountable to a representative authority. It would be quite wrong for managers (or the professions) to decide how best to use limited public resources on their own, without public oversight.

We therefore can never do without representative authorities so long as there is a National Health Service – nor should we want to do so. In principle, the role of the health authorities is clear enough, with the accent on strategic direction and control, and on maximising the responsiveness of services within resource limits.

The difficulties lie in practice rather than principle. Generations of health authority members have found their role elusive and frustrating. In part that is because functioning at the strategic level does not come easily to most people: it requires breadth of view, a sense of long-term purpose, a determination to delegate, at times a willingness to take unpleasant decisions. Since we need members to do these things, we must be prepared to put more care than in the past into their recruitment, their training, and their support.

Officers have a key role here, in serving their members, without trying to manipulate their decisions. So also do chairmen. In general, chairmen have not suffered from the same frustrations as other members, for their role is more concrete and their impact much more obvious (both to others and to themselves). Chairmen have the opportunity to make worthwhile contributions to patients, to staff and to the community. It is up to them to remember that they are *only* chairmen. Under them they have an executive. Around them they have a membership. Above and beyond both there is always the public interest which they exist to represent and serve.

*Health  
authority  
membership  
and  
chairmanship*





# 6

## Health or health services: professional and public choices

RUTH LEVITT

The reason for having a chapter about the medical profession written by a non-physician in a book dealing with public participation may not at first be obvious. But it will be suggested here that the dominating influence of the medical profession has fuelled public confusion between health and health services; and that the confusion has prevented a sufficiently objective review being made of the choice for public attention – health or health services.

The key position doctors have historically held in health service provision has resulted in the profession's values being very widely accepted and supported. The values in themselves are worthwhile, and they are necessary for any humane and decent system for coping with the consequences of suffering and disability. But since the profession is centred on values and perceptions which tell only part of the story about the distinctions between health and health services, the public too has come to perceive only part of that story. It might be different if the medical profession had not come to play such an important part in the arrangements for health care – yet although they represent only 7 per cent of the National Health Service workforce, they are responsible for initiating most of its £15 billion annual expenditure, and they play a key part in management too.

The confusion, in this country, between health and health services is deep-seated, and reinforced by the existence of the National Health Service. Though the aims of the NHS embrace health and health services, prevention as well as treatment, by far the greatest amount of activity and investment is directed at treatment of ill health. The same can be said of the Department of Health and Social Security – almost all its efforts are concentrated on treatment and care. Most people think the DHSS and NHS are synonymous with health policy, not just with the treatment of ill health – a very different thing. Is this just playing with words or are issues of substance involved?

A look at the curriculum for medical students illustrates quite clearly what skills and perspective doctors are required to acquire.

# Undergraduate Medical Curriculum

<i>First and second years</i>	Ophthalmology
Anatomy	ENT
Physiology	Paediatrics
Biochemistry	Casualty
Growth, development, genetics	Orthopaedics
Psychology, sociology	Special surgery
Statistical method	Radiology
Human biology, ecology	Geriatrics
<i>Third year</i>	Neurology
Medicine	Obstetrics and
Surgery	gynaecology
Pathology	Post mortem
Bacteriology	Pathology
Pharmacology	Chemical Pathology
Anaesthetics	Bacteriology
Microbiology	Applied anatomy
<i>Fourth and fifth years</i>	Psychiatry
Dermatology	Forensic medicine
Cardiology	Social medicine

NB: Individual medical schools vary the precise order of the courses they offer. The above subjects are the essential and usual ones to be taught to all medical students.

Source: *Which Degree?*, 1981

The Royal Commission on the National Health Service investigated medical education and concluded that the medical student should be far better prepared than he or she is at present for team working with other disciplines because '... there are few things more important for the NHS than that its health professionals should work well together'.<sup>1</sup> The Royal Commission thought medical education should be relevant to the major health problems of the day, including geriatric illness, mental illness, disability and handicap and '... the potentially preventable diseases and injuries which result from an unhealthy life-style'.<sup>2</sup> There should, said the Commission, be more emphasis on community care and the importance of continuity of care in medical studies. The Commission noted that the universities had been slow to develop academic departments for fields which have become priorities for health care – geriatrics, community medicine and rehabilitation are examples.

Another point that the Commission drew attention to was the selection of students to study medicine. The evidence indicates

that most medical students are selected from science forms of secondary schools and from the wealthier socioeconomic classes. A slight increase in the already high proportion of final year medical students with fathers from social classes I and II has been observed between 1966 and 1975.<sup>3</sup> Most medical students enter university straight from school on the basis of increasingly high academic requirements. The Royal Commission recommended experiments to modify these trends, including admission of mature students and more account being taken of relevant experience other than traditional academic performance. Further, on postgraduate medical education, the Commission noted that specialist education had had less influence on the undergraduate medical curriculum in reducing some of its specialist vocational content than should have been the case.

The evidently scientific, clinical, curative basis of medical education has enabled a health service to flourish which is similarly devoted to scientific excellence, clinical intervention and the priority of acute over long-term care services. In reviewing these trends, a number of observations about the medical profession and its influence over public expectations and standards have been made. The 1980 Reith Lectures, entitled *The Unmasking of Medicine*, were devoted to this theme.<sup>4</sup> In the lectures, Ian Kennedy analysed the concepts of 'illness', 'health' and 'disease' to argue that medicine has become distant and out of touch with people because these basic concepts have had their meaning distorted by doctors' particular interpretations of them. Medicine, he argued, has taken a wrong path with the result that it is thought of as being scientific, dispensing cures, concentrating on specific diseases; it presents doctors as problem solvers who must intervene, and there is a strong focus on hospitals. The balance needs to be redressed between high technology and care, integrating primary and community care, developing promotion of health and prevention of accidents and ill health. The means for achieving this are commitment to action, to education, to controlling hazards and caring more for children's health. Finally, Kennedy argues that existing mechanisms are inadequate to set standards, measure performance and provide remedies or sanctions. Professional self-audit is unreliable and community health councils and complaints procedures are inadequate. He thinks litigation is worthwhile in some cases, but that its role is limited. A new system of supervision and sanction is needed, and that system must be one that gives the ultimate power to set standards to consumers.

Kennedy was by no means the first observer to express such thoughts. Many years before, Ivan Illich had written about the

health-denying effects of medicine and its organisation, as well as the phenomenon of doctor-induced disease.<sup>5</sup> Thomas McKeown presented a less provocative but no less powerful critique in his book *The Role of Medicine*.<sup>6</sup> This demonstrated that scientific medicine's contributions to reductions in mortality from infectious diseases had been very limited; and that the three most significant health-promoting phenomena were improved sanitation and clean water supply, improved nutritional standards and voluntary restriction of family size through birth control. McKeown called for the medical profession's values to shift towards the priorities of epidemiology and prevention.

Further insights into the role of medicine were provided by Archie Cochrane in his celebrated Rock Carling Lecture for 1971.<sup>7</sup> He identified sources of bias in interpretation of medical intervention in disease which underestimated the true effects of natural recuperation, the powers of suggestion and the placebo effect, and the differential effects of memory in the recall of events. He proposed that randomised controlled trials should be used to test the outcomes of treatments, diagnoses and preventive measures as a practical step forward.

Collin Dollery, another doctor, has studied Illich, McKeown and Cochrane critically<sup>8</sup> and concluded that modern medicine's achievements are indeed modest when compared with what they might have been. He claims, though, that the benefits from improvements in drug therapy and surgical methods should not be overlooked, and that the value to patients of the reassurance that doctors provide is an important consideration. His conclusions seem rather bland (though in themselves they are far from it) when put alongside the writings of those academic theorists who have investigated the phenomenon of professional dominance. Vicente Navarro has argued that in the distribution of power in society the economic base is crucial and the ruling ideology is maintained through the control of institutions. From his analysis of the class hierarchy in the medical care system he perceives that medicine is supportive to capitalism because it obscures the true causes of ill health. These, he says, are the social and environmental consequences of the capitalist mode of production. In other words, the state legitimises and maintains the medical model of illness through its involvement in medical education and health care provision.<sup>9</sup>

Navarro's particular version of Marxist analysis has been taken further by Lesley Doyal<sup>10</sup> who has characterised the NHS as part of the post war settlement between labour and capital, and who has argued that the prevalence of certain diseases in third world countries – for example, tuberculosis in Africa – can be linked to

imperialist policies (since TB was unknown there before the colonial presence). But other theorists take different perspectives, arguing for instance as Alford does<sup>11</sup> that policy is the outcome of interactions between three sets of structural interests: dominant, repressed and challenging. Events can then, he argues, be understood in terms of which interests dominate. In his analysis of health care politics the doctors (he calls them professional monopolisers) are dominant, the bureaucrats (corporate rationalisers) are repressed, and the local people represent the challenging interests.

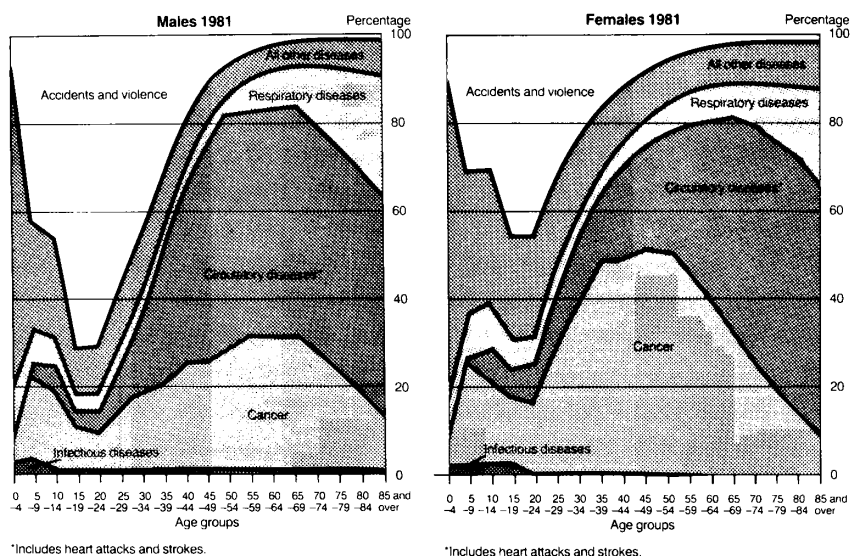
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Whatever one's preference for different approaches and languages of analysis, the general message is clear: there is more than meets the eye in the activities of the medical profession. Though one may not be persuaded to go as far as George Bernard Shaw – who wrote that 'All professions are conspiracies against the laity'<sup>12</sup> – it seems reasonable to conclude that the way power and responsibility for health are, in practice, distributed is influenced by doctors' attitudes and actions – and that this is a matter of interest and some concern.

Unfortunately, the phrase 'doctor-bashing' has been coined and applied indiscriminately so that those who genuinely seek to understand the facts are always in danger of being put together with those who only want to brandish insults. The truth is that although some of the comment about medical actions and attitudes may be ill conceived or unfair, an underlying need nevertheless persists to clarify in what ways and to what extent the medical profession should act if the best interests of society as a whole are to be protected. Though many doctors would say that this is a matter for their profession alone, it is thought by others to be a matter which the public legitimately needs to take an interest in, and so should be encouraged to formulate views.

It has been argued here that the dominant position of the medical profession has confused the public about the distinctions between health itself and health services, and academic and medical opinions have been cited to support this. But other evidence can show how clinical services have grown and developed to treat ill health while, at the same time, preventable causes of premature death and illness continue largely unchecked by preventive action. For example, the facts about the major causes of death in men and women at different ages (see Figure 2 on page 92) show: that most deaths in young people are caused by accidents and violence; cancers account for over 40 per cent of female deaths between 30-60 years, and over 20 per cent of male deaths between 35-75 years; circulatory diseases, including heart attacks and strokes, account for as much as 50 per cent of all

Figure 2 Selected causes of death by sex and age, 1981: United Kingdom



\*Includes heart attacks and strokes.

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Source: Ramprakash, Deo. Social trends no 14: a publication of the Government Statistical Service, London, HMSO, 1984. Chart 7.3.

deaths in middle-aged men and elderly women; respiratory diseases are a relatively small but still significant cause of death, particularly in elderly people; and infectious diseases are not a major cause of death.

This indicates that the major causes of premature death are mainly associated with environmental hazards and risks that are potentially preventable – though not necessarily by clinical medicine or conventional medical research. Accidents and violence are, by definition, preventable, particularly if living and working arrangements are suitably designed and properly used. So too are premature deaths and ill health associated with smoking. If car seat belts are always worn, drunken driving is severely punished, vehicle speed limits are enforced, drivers' training and licensing are made more stringent, pedestrian safety is improved – road accidents involving death and serious injury can be dramatically reduced. The 1970s saw 750 000 people – about the population of Leeds – killed or seriously injured by road accidents.<sup>13</sup>

For other known environmental hazards doctors will also agree that more lives can be saved from premature end, and can be enjoyed in better health, through measures quite outside medicine's scope: nutrition, housing, education, exercise, satisfying work, are some of the key ones. The potential for effective

prevention is indeed great, and little of it depends on traditional clinical medical knowledge and methods. The figures on sickness and injury benefit claims bear this out too. In 1978/9, 371 million days of ill health were claimed for<sup>13</sup>, and the top four causes of incapacity in men were: respiratory diseases, accidents/poisonings/violence, musculoskeletal disorders and infectious diseases; in women they were: respiratory diseases, infectious diseases, symptoms/ill defined conditions, and accidents/poisonings/violence.<sup>14</sup> Many if not all of these are preventable conditions, which require individuals and society to act in health-promoting ways, independently of doctors, to reduce the toll of discomfort and disease.

The seminal report, *Inequalities in Health* (the Black report)<sup>15</sup>, has conclusively demonstrated that health is not the preserve of the medical profession nor is it correlated with the availability of health services. The report's analysis of data revealing a social class gradient in so many of the measures of health and illness proves that the existence of health services does not guarantee health nor equal access to services for people who have become ill. Despite all the considerable achievements of the National Health Service in distributing general practitioner services and specialist hospital treatment facilities around the country, social class differences of a profound extent persist and have even deepened (see tables 1 and 2).

The Black report concluded that improvements in these trends must be made and that the single most important vehicle for this is the reduction of child poverty. Quite clearly this is a task which the health services in general and doctors in particular can only contribute a modest amount towards – responsibility rests far

Table 1 Mortality of men by social class, 1911-1971: England and Wales<sup>1</sup>

Period covered	Social class				
	I	II	III	IV	V
1910-12 <sup>2</sup>	88	94	96	93	142
1921-23 <sup>2</sup>	82	94	95	101	125
1930-32 <sup>3</sup>	90	94	97	102	111
1949-53 <sup>3</sup>	98	86	101	94	118
1959-63 <sup>3</sup>	76	81	100	103	143
1970-72 <sup>3</sup>	77	81	104	114	137

<sup>1</sup> Data usually cover men aged 15 or 20 to 64 or 65, and are as published, taking no account of classificatory and other changes.

<sup>2</sup> CMFs (comparative mortality figures).

<sup>3</sup> SMRs (standardized mortality ratios).

Source: Great Britain, Office of Population Censuses and Surveys. Occupational mortality. The Registrar General's decennial supplement for England and Wales. 1970-72. London, HMSO, 1978. Table 8.1.

Table 2 Chronic sickness by socio-economic group, age and sex, 1979 and 1980: Great Britain. Rates per thousand

	Males aged					Females aged				
	0-15	16-44	45-64	65 or over	All ages	0-15	16-44	45-64	65 or over	All ages
People reporting limiting long-standing illness										
Professional	50	76	198	260	111	36	98	169	348	111
Employers and managers	51	84	176	358	131	31	98	199	362	136
Intermediate and junior non-manual	67	82	279	372	157	50	95	236	326	169
Skilled manual and own account non-professional	65	111	278	442	175	45	124	255	474	170
Semi-skilled manual and personal service	65	141	310	390	196	49	124	308	484	234
Unskilled manual	61	144	377	392	233	47	136	293	468	282
All persons	62	109	267	397	168	44	112	252	455	185

Source: Ramprakash, Deo. ed. Social trends No 12: a publication of the Government Statistical Service. London HMSO, 1981. Table 7.8.



more widely in services and policies of many different agencies both within and outside government.

Another illustration of the confusion between health and health services can be perceived in considering what the results of G W Brown's work on depression imply for action by the medical profession and others. Brown's exemplary longitudinal studies of the incidence of depression in women living in various London areas has proved quite conclusively that their depression is caused by social factors.<sup>16</sup> Life events and circumstances, housing conditions, income, social and leisure activities – these are some of the determining factors. Depression is a condition which general practitioners regularly and increasingly see in their patients in one or other form, and often they prescribe drugs to deal with the symptoms. Yet one doctor has observed: 'Recognition of the fact that depression, anxiety and other mental symptoms are aggravated by social conditions creates an ethical problem for the medical profession. Is it right to prescribe drugs to damp down such symptoms when the tension which causes them might be able to bring about social changes which would deal with the underlying social problems?'<sup>17</sup>

In any debate about the health services and participation the views of consumers are a vital component, and their voice is increasingly heard through statutory and other means. The picture of their satisfaction with the services is clearly revealed in a survey published in *The Guardian* on 21 December 1981 (see pages 96 and 97).

Of those questioned, 71 per cent thought the NHS represents value for money to the taxpayer; 91 per cent said the treatment they got from their general practitioner was good or very good; and 92 per cent said the treatment they had from NHS hospitals was good or very good. High marks indeed, and eloquent support for the theme of this chapter – that the high priority and recognition given to health services (rather than to health itself) is a consequence of the public's willingness to enable medical professional values to dominate the health and health care scene.

Data about the complaints patients and their families make concerning NHS treatment and services uphold this too. The total number of recorded complaints is tiny compared with the number of individuals receiving attention each year. The cases investigated by the Health Services Commissioner rarely involve more than breakdowns in communication between different parts of the services and inadequate explanations of policies and procedures to patients and their families. Distressing and avoidable though these incidents are, the general impression of the health services' standing with the public is that they are

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Would you say the National Health Service represents value for money to the taxpayer?

	Total	ABC1	C2	DE	Con	Lab	SD/L	18-34	35-64	65+
Base	755	287	241	227	148	183	258	262	354	139
Yes	71	72	71	70	74	73	69	71	71	73
No	21	20	24	20	20	22	24	21	23	18
Don't know	8	8	5	9	6	4	7	8	7	9

Would you say the treatment you got from your Health Service GP was on the whole very good? Fairly good? Not very good? Or not at all good?

	Total	ABC1	C2	DE	Con	Lab	SD/L	18-34	35-64	65+
Base	573	225	178	170	115	136	197	207	260	106
Very good	58	59	57	57	63	54	54	47	59	76
Fairly good	33	33	35	31	31	34	37	43	30	22
Not very good	7	6	6	9	5	9	7	7	9	1
Not at all good	2	1	2	3	1	3	2	3	2	1

Would you say the treatment you got from the National Health Service hospital was, on the whole, very good? Fairly good? Not very good? Or not at all good?

	Total	ABC1	C2	DE	Con	Lab	SD/L	18-34	35-64	65+
Base	254	96	75	83	50	71	83	96	110	48
Very good	67	69	67	64	72	75	59	53	70	85
Fairly good	25	23	25	27	22	18	27	34	23	10
Not very good	7	5	8	7	4	7	11	10	5	2
Not at all good	2	3	—	2	2	—	4	2	2	2

widely appreciated and valued – there is little specific call for radical change. Pressure groups that have arisen to further the interests of particular patients play a significant part in improving the standards of care for their particular constituency, and these groups are generally tolerated and welcomed by the professional service providers.

Reasonable criticisms of the NHS's performance – for failing to deal adequately with regional inequalities, social class inequalities and the different standards provided for acute and long-term users – do not provoke a widespread outcry or pressure for change. Governments have been stating policies for many years which admit the need to improve services for the mentally ill, the mentally handicapped, the physically disabled, the elderly, but not against a backcloth of general popular interest, nor in the face of a real degree of censure at the disappointing record of implementation these policies have produced.

What stronger evidence can there be that on the whole public and medical attitudes about health and health services coincide? The voices calling for greater public participation, for greater emphasis on prevention of ill health, and for the eradication of social class health differences are mainly non-medical, and mainly well-informed about epidemiological data and the measurable impact of health services on health itself. Clinical judgment, the legitimate technical preserve of doctors, has been redefined over time as the boundaries between health and disease have been pushed back. The public has cooperated in allowing doctors to be involved in and responsible for many areas of policy and decision where they are poorly trained and frequently inexperienced, as Ian Kennedy has described.<sup>4</sup> Clinical judgment is probably impossible to define satisfactorily, yet it rests at the base of doctors' involvement with health policy as well as their individual work with patients.

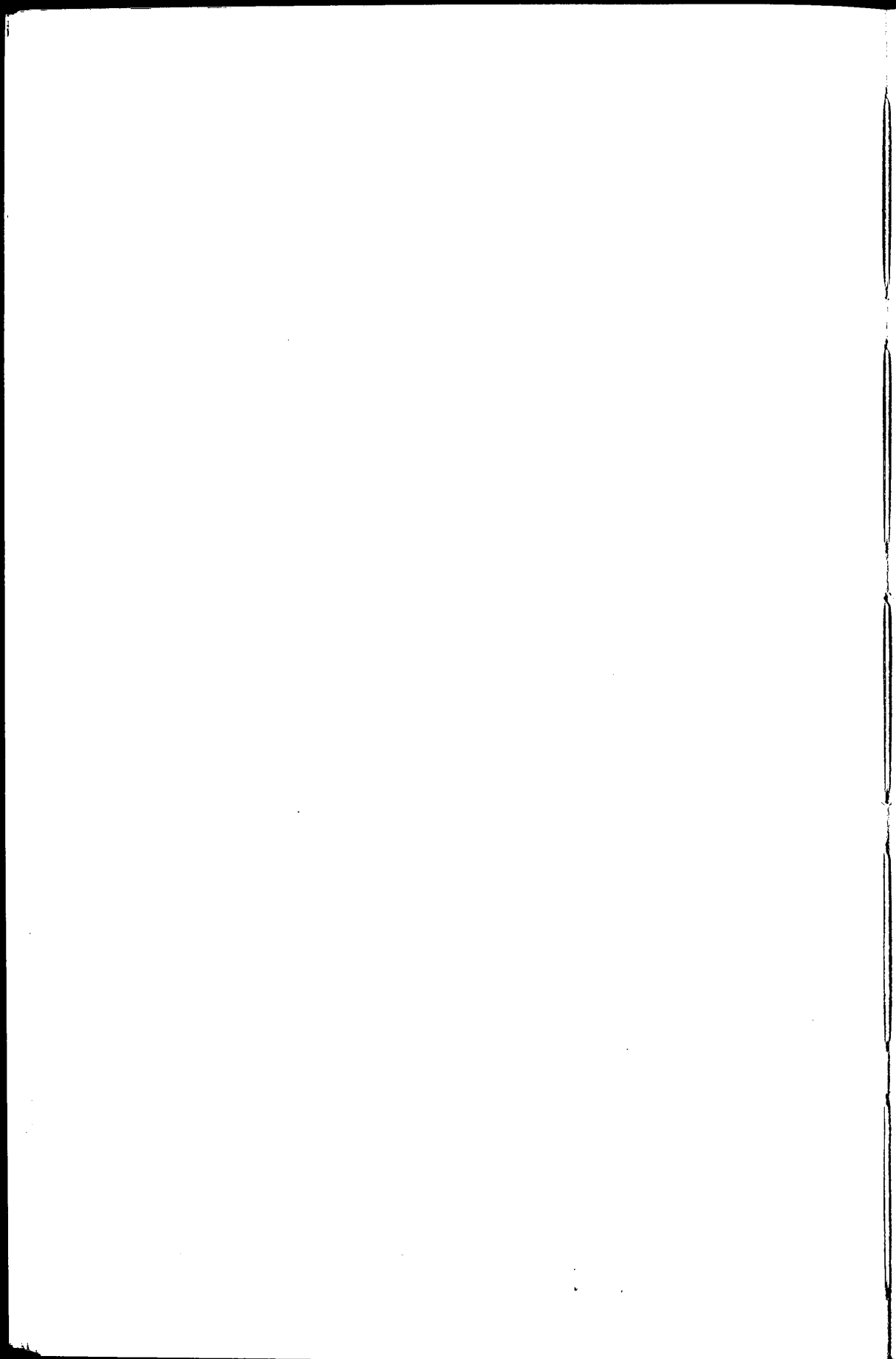
Leaders of the medical profession tend to regard lay interest in clinical judgment as illegitimate, and efforts to widen the Health Service Commissioner's powers to investigate some matters involving the exercise of clinical judgment failed completely, even though a body as eminent as the Royal Commission on the National Health Service supported it. So whatever the territory labelled 'clinical judgment' contains, it is fiercely defended, and seems to overlap with much if not all of the territory marked 'health services'. Health services are, rightly or wrongly, the firm province of the medical profession and there are no signs that this will change substantially, or that the public as a whole wishes it to change. But health itself is not owned by the medical profession, nor is it exclusively or even closely connected with doctors. It

links with a whole range of forces and factors to do with other aspects of life. Health and the pursuit of it offer the public a less simple subject for participation than the health services do, but one which is no less worthwhile.

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# 7

## Participation in health

STEPHEN HATCH

It is paradoxical that participation in the National Health Service should be discussed with minimal reference to participation in health care and health promotion. Like many other discussions of participation in state-run services, the contributions to this book are primarily concerned with formal arrangements for taking account of the views of patients and the public in making decisions about the NHS. Only a few lay people become involved in these processes. Yet in another sense, all of us are taking part much of the time in our own health care and that of our families and associates. Thus, tacitly, health tends to be equated with the health services, whereas in reality the interactions between patients and organised medicine are only the tip of an iceberg of health-relevant behaviour. The argument of this chapter is first that participation in the health service should not be considered in isolation from the everyday, largely informal involvement of everybody in health; and second that progress in health depends in no small measure on getting the right alignment between these two kinds of participation.

### Medicine and health

Although the aims of the NHS embrace health and health services – prevention as well as treatment – the service has been dominated by, and largely identified with, curative medicine. This dominance has both reflected and supported the very powerful position of professionals relative to consumers. Yet, despite impressive and glamorous advances in the techniques for medical intervention in disease processes, the major gains in health during the past two centuries have come from better sanitation and nutrition and other essentially preventive measures.

Another consideration crucial for any appraisal of the relationship between medicine and health is the growth of costs. In recent decades, expenditure on medical services has in most countries absorbed a growing proportion of the national income. Much of this increase is attributable to the expansion of expensive, high technology, hospital-based services. Had a high rate of economic growth continued, some curbs on the rate of expansion would have been inescapable; but with reduced or

negative growth it has become even more essential to look for lower cost alternatives and to question the necessity for continuing development on the pattern of the 1960s and 1970s.

In response to this situation it has become conventional to argue for more emphasis on prevention. Some forms of prevention have few implications for the role of the patient or consumer of health services. Maintaining the quality of the water supply in developed countries is essentially a technical matter, and screening and inoculation simply require the lay person to turn up at the right place at the right time. However, many preventive activities call for a much more active role on the part of lay people than does curative medicine. The latter requires the patient to be essentially passive and dependent: the problem, if there is one for professionals seeking to cure people, is that of non-compliance on the part of the patient. In contrast, much prevention depends on modifying lifestyles and behaviour – that is, on choices made by well people. Smoking is the clearest illustration, and diet, wearing seat-belts and regular exercise are other obvious examples. Preventive activity of this kind calls essentially for abstinence and self-discipline and this, no doubt, is why its popularity is limited. Consequently there are advantages in thinking more positively in terms of health promotion. The keep-fit class and the self-help group may have more appeal for many people than injunctions to abstain, and these represent even more active forms of lay involvement.

Another way of putting the same point is to say that just as better sanitation and nutrition made the main contribution to improvements in health in the past, so changes in behaviour may offer the best hope of progress in the future. But prevention is not just a private matter or even a matter of self-help on a group basis. It also calls for statutory action. Thus, the limitation of cigarette advertising, measures to prevent accidents, and the control of food additives and environmental pollution, all require political decisions which are unlikely to be made in the absence of an articulate public opinion. Hence, prevention requires the active support of the citizen in public as well as in private.

So far, the alternatives for medicine and health have been presented in terms of the priorities accorded to prevention and cure: care of the sick, particularly the chronic sick or handicapped, has been ignored. Yet the management of chronic conditions and handicaps, as of minor ailments, requires a large measure of self-care and support from kin and others in the community. It is well known that the number of prescribed medicines taken is exceeded by the number of patent medicines for which no prescription is given. In similar vein, Wadsworth and his



colleagues<sup>1</sup> showed that the number of ailments about which people sought medical advice was only a fraction of all the indisposition that they reported. No doubt the more serious were the ones they sought advice about, but the main point is that there is a huge amount of minor ill-health that is never brought to the attention of medical professionals. Further, a large part of the care provided for the sick and handicapped in the community comes from kin, not professionals. Indeed parents, spouses and children are the main carers for such people. Much of this care in the community might be described as social care rather than medical care, but there is no clear dividing line between the two kinds of care. Parker<sup>2</sup> has used the term 'tending' to embrace activities carried out by nurses and home helps as well as close kin. Thus even in caring and coping, where the professionals are sometimes thought to reign supreme, the transactions between professionals and patients represent only a fraction of all the health-relevant activities that take place.

There are limits to the range of topics that can be covered in a chapter such as this. However, any discussion of the implications of changing priorities in medicine and health for the role of lay people would be incomplete without some reference to recent research on the effect of social factors on morbidity and mortality. The work of Brown and Harris on the *Social Origins of Depression*<sup>3</sup> represents a major contribution to knowledge in this field. They surveyed a sample of women in Camberwell, and in analysing their data sought to show what factors determined whether women who had experienced a severe problem or crisis became seriously depressed. They found that four factors – whether they had a confiding relationship with a male partner, whether they were in employment, whether they had lost their mother in early life and whether they had three or more children under 14 at home – served to distinguish between those who did, and those who did not, become depressed. This study is remarkable for the way it identifies a causal chain, combining both provoking events and vulnerability factors, which manages to explain why women become depressed.

There is another study which also deserves to be cited in this context by Berkman and Syme.<sup>4</sup> This examined mortality from all causes in a large longitudinal survey of the population aged 30 to 70 in Alameda County, California: its concern was the impact on mortality of social ties and networks, as measured by marriage, contacts with close friends and relatives, church membership and formal and informal group associations. The findings are striking: in each age and sex group, mortality among the most isolated was approximately double that among the least isolated. Unlike

Brown and Harris, Berkman and Syme established correlations rather than a causal chain, but the evidence for the connection between social support and health is highly suggestive.

This kind of evidence does not point directly towards a number of specific preventive measures capable of quick implementation. Nevertheless, it does underline the far reaching connections between social behaviour and health, and the mistake of equating policies for health with services for the ill.

### Bridging public and private worlds

In discussing the future of voluntary organisations, the Wolfenden report<sup>5</sup> distinguished four sources or sectors of welfare provision: the statutory, the commercial, the voluntary and the informal. The relative roles of the statutory and commercial sectors are the subject of much debate. Not so relations between the statutory and the other two sectors. Voluntary and informal activity is large in volume, but it is not represented in financial or bureaucratic transactions, and therefore goes largely unrecorded and unmeasured. Partly for this reason its significance is not recognised.

This is not the place for an extensive analysis of health behaviour, but any discussion of participation in health must take into account the bridges that do, or might, exist between the private world of the individual and the public world of the statutory services. Many voluntary organisations act as bridges of this kind. Peter Berger<sup>6</sup> has coined the term 'mediating structures' to denote organisations that serve this function. Recently, Levin and Idler<sup>7</sup> have explored this concept in the context of health care in America. A brief review of voluntary action in the health field in Britain may therefore serve to establish an appropriately broad frame of reference for the present discussion.

### The organisations of lay people

The voluntary sector provides a channel for three kinds of lay involvement that deserve attention here – voluntary service, self-help and neighbourhood projects. These do not cover the whole span of activities carried on by voluntary organisations in the health field, omitting such things as raising money for research, and services that rely on paid staff, like providing day care for addicts. Before the establishment of the National Health Service a large proportion of all medical care was provided under the auspices of voluntary organisations. With the creation of the NHS, the voluntary sector lost many of its functions; but during

the 1960s and 1970s, in health as in other fields, voluntary organisations have been rapidly developing new functions, as vehicles for public involvement in a situation where the state is the main provider of professional services. It is in this context that voluntary organisations will be discussed here.

Familiar forms of voluntary action in the health field are the Red Cross and hospital leagues of friends. The former, along with the St John's Ambulance Service, provides a first aid service and extensive training in first aid; while the WRVS, hospital friends and other similar volunteers raise money, run trolley services, drive people to and from hospital and socialise with isolated patients. There are now some hundreds of hospital voluntary service coordinators, who between them mobilise tens of thousands of helpers. A more recent development is the deployment of volunteers in the context of primary health care. The most well-known and developed example of volunteers working in association with general practitioners is the Glaven District Caring Scheme in North Norfolk. Under the leadership of Dr Allibone, there is now a small army of volunteers (with a number of retired nurses in key roles), who provide an extensive support system for the elderly and handicapped of the area. The Glaven Scheme seeks to supplement and complement the care provided by professionals. This is one of the aims of the patients' groups described in Jo Wood's contribution to this book. But in addition, and to varying degrees, these groups are also active in prevention, health education and representing the views of patients.

Less closely linked to the statutory services are various volunteer-run counselling services. The best known of these is The Samaritans, which provides a 24-hour service from over 150 branches that between them cover the whole country. A recent development has been the establishment of a few more local and specialised services, such as rape crisis centres and gay switchboards.

Unambiguously in the sphere of mutual aid rather than philanthropy, are the thousands of self-help groups that have sprung up during the past two decades in this and other countries.<sup>8</sup> There are now groups, usually linked in a national network of some kind, for most handicaps and chronic conditions or diseases, from Friedrich's Ataxia to Depressives Associated. Self-help groups vary greatly in their structures, aims, methods and outlooks. The Royal Society for Mentally Handicapped Children and Adults, more colloquially known as Mencap, is one of the most firmly established federations of self-help groups and will serve as an illustration of self-help. As well as a national

headquarters and regional offices it has over 400 local branches, which are where the self-help takes place. These are the subject of a study carried out by the Policy Studies Institute, from which most of the following information is taken.<sup>9</sup>

The number of branches has continued to grow steadily since the formation of the society in 1947. They vary greatly in membership, with a top figure of over 500 and an average of over 100, and in the activities they carry out. Commonly they organise such services as a youth club for children, holidays, play groups and short-stay hostels. But the main reasons for which parents join are to gain information about services and facilities, to meet others in a similar situation, to gain emotional support and to obtain social activities for the children. In addition, many of the local societies are active in seeking better statutory provision.

About half of all parents of the mentally handicapped belong<sup>10</sup>, and a small proportion of the members are not parents but interested professionals or well-wishers. Certainly the most active members put in much more than they get out by way of help for their children. Thus local societies are animated by altruism or philanthropy, as well as by self-help.

A problem commonly faced by the local societies is the apathy of their members. Part of this seems to stem from the fact that not all parents face the same problems: in particular, parents with grown-up children are in a very different position from parents who have just learned that their infant is handicapped. Often it is difficult for one branch to cater adequately for both sets of needs, or more specifically for the younger parents to find a place for themselves in a branch dominated by the long-serving parents of grown-up children.

Most self-help groups and organisations are of more recent origin than Mencap. Among the newer organisations, the proportion of potential members who belong is often much lower, local groups are usually smaller, and the element of sharing among fellow sufferers possibly stronger. Like Mencap, they usually overlap the borderlines between health and social problems and form an important supplement and complement to the welfare state. They are important in promoting change in public attitudes and in statutory provision; and, in addition, the mutual sharing and support provide a kind of help which could come from no other source, and is particularly important among people whose problem is one that carries a social stigma.

An essential feature of self-help groups is their base in specific, usually quite thinly distributed, problems and situations. There are other health questions that affect many people in any given locality. The problems of maternity and old age are obvious

examples: so too are environmental matters such as housing and pollution, and the policies and practices of the local health services. Collective action at neighbourhood level directed towards health questions is a phenomenon even more recent than self-help groups. Much of what there is has arisen in the context of attempts to respond to the problems of inner city areas, particularly in London and Glasgow, and has taken the form of health-oriented community development and community action. In London there is now a Community Health Resource which aims to make individuals and groups involved in health issues aware of each other's work and to enable them to keep more closely in touch. Based at the Community Work Service of the London Voluntary Service Council, the network finds concrete expression in the form of a bulletin, the second issue of which listed over 80 local projects interested in health issues.

One of the best known of the London projects is the Waterloo Health Project which started in 1977.<sup>11</sup> Its objectives are to encourage people to take a more active interest in their own health, to enable people to gain more understanding of the meaning of health and sickness, to help people to be more informed about health care provision and the treatment they receive, to effect changes in the delivery of health care, and to effect changes in society to prevent ill health. The project is associated with a federation of local community groups and is managed by a committee consisting mostly of local people. The activities undertaken include establishing a regular relaxation and exercise class, mainly for elderly people; introducing a health element into the activities of local pensioners groups; starting a women's group on a local housing estate which discusses health among other topics; promoting a group specifically concerned with women's health issues; and running a small-scale advice service.

The tendency for people to be interested in health questions only when they are ill themselves, and then only in their own specific problem, makes it difficult to generate a lot of interest in health at local or neighbourhood level. Nevertheless, activities like those of the Waterloo Project are burgeoning, stimulated in part by cuts in the health service.

What is the significance of these various forms of voluntary action? The numbers involved in them run into hundreds of thousands and exceed those who take part in formal participation procedures. On the other hand, those who participate in voluntary action are often only a very small proportion of the target population with which the organisations are potentially concerned. As with other voluntary organisations, the existence

and survival of groups is likely to reflect the presence of a few particularly committed or inspirational leaders rather than the incidence of needs. One consequence is that participation through voluntary organisations is unlikely to be impartial between different demands on the health service. However, the people who come together in groups with a continuous existence are likely to be those with long-standing, chronic problems. Some chronic problems may prevent those suffering from them from taking part in collective action but, as in the case of mental handicap, those responsible for looking after the sufferers can and do form their own organisations. Thus, any bias from participation through voluntary organisations is likely to be in favour of care for the chronically sick or handicapped. It may, therefore, correct biases in favour of curative and acute medicine that stem from interests within the medical profession, or from the desire of the public to give money to equip hospitals with the latest technology.

Of course patients acting for themselves can mean a lot of different things. These include excursions into fringe and alternative medicines, not all of which may be beneficial; and the mainspring of some activities is suspicion of, and grievances against, professionals. However, one can reasonably argue that some of the ranker growths might flourish less well if there was more encouragement from within the health service for appropriate forms of lay involvement. Indeed, the extent and character of lay involvement are very susceptible to professional and statutory influences. Thus, the DHSS gives grants to some organisations to enable them to operate on a national basis. These include the National Association for Patient Groups and some of the more recently established self-help groups, like the National Eczema Society. Some health authorities have funded voluntary initiatives at a local level, and have thereby made possible some of the inner city neighbourhood projects and also, for example, the Self-help Groups Project in Nottingham. But it is not just a matter of funding. Support from medical professionals is often of great importance in initiating and sustaining voluntary organisations of the kind discussed here: indeed, the patients' groups in general practice are all the product of initiatives by general practitioners. This is not to say that voluntary organisations have no existence of their own. But at present there is more of the organ grinder's monkey than the genie in the bottle about most efforts to promote lay involvement.

On the positive side, such involvement offers a source of care and support that is complementary to the work of the health professions, an encouragement of preventive behaviour and

greater competence in self-care, and a strategy for creating an informed constituency for the health services. For more than a decade the personal social services have been actively seeking to strengthen the lay or community dimension in their work. In practical terms this has meant making grants to voluntary organisations, the appointment of community workers and voluntary service coordinators with special responsibilities in this field, and efforts (firmly endorsed by the Barclay Report on social work<sup>12</sup>) to introduce a community orientation in the role of social workers generally. Despite the present government's support for voluntary action, much less movement of an equivalent kind has occurred in the health service, apart from the widespread development of rather marginal roles for volunteers in hospitals. Significantly, within the DHSS there is no one with a remit for self-help and self-care. Yet current reappraisals of health and medicine point firmly towards an enhanced lay role, and the groundswell is there in terms of public interest. Hence it cannot be long before this subject is given a higher place on the agenda.

The question will then arise as to the relationship between participation through voluntary organisations and formal arrangements for the representation of consumer interests. In services run by local government the legitimate representatives of consumer interests are the elected councillors, who in practice combine both representative and managerial functions. But there is a tension between councillors and voluntary organisations which act as pressure groups on behalf of consumers, and similarly a tension between the party-dominated institutions of representative democracy and more direct forms of participation and involvement. This sometimes leads elected councillors to be suspicious of all forms of direct participation. Alternatively, they may seek to separate participation in service giving and self-help from participation that seeks to influence decision-making. The latter is a line that is difficult to maintain in practice, and one that tends to inhibit the development of a lively voluntary sector.

In the absence of local political control, the health service is free from this particular tension; it is also free from the tension inherent in the role of elected representatives in local government between representation and management. Community health councils have become the voice of the local consumer, and some have also embarked on health-oriented community development. Whatever the limitations of what CHCs have achieved up to now, they represent what could be the first step in recognising the right of consumers to come together to express their views and take initiatives of their own; and they provide scope for developing different forms of lay involvement in conjunction with each other.

In other words, at least as far as the health service is concerned, the combination of representation with direct forms of participation may have more to offer than the combination of representation and management found in local government.

### **In conclusion**

At this stage readers may be inclined to say 'so what?'. What useful pointers does this review of social factors and voluntary action offer for professional staff of the health service? Practical men usually seek to narrow down the issues with which they have to deal until they can identify specific objectives that can be pursued with a reasonable chance of success. They may not find this chapter very helpful, for it has sought to broaden out and redefine the issues at stake. But there is a powerful justification for such an approach. We are at a time of reappraisal in health and medicine, a reappraisal brought on by the escalating cost of medicine and by sceptical analyses of some of the confidently claimed achievements and prerogatives of medical science. Similar problems face other professionally staffed bureaucratic systems that have grown so fast during recent decades. In all of them the questioning of governing assumptions may be the beginning of wisdom.

Nevertheless, it is possible to identify a number of propositions which, if explored and developed further, would serve to map out an alternative strategy for health care, a strategy that would involve a different balance between curative medicine on the one hand and prevention, care and health promotion on the other. Most generally what this chapter has sought to establish is the plural character of health care. Participation, therefore, is not just a matter of finding expression for consumer interests in the running of statutory services. More fundamentally it is about the role of a huge variety of voluntary and informal activities, and of the relationship between statutory services and this diffuse non-statutory world. Hence the case for recognising this pluralism and seeking deliberately to enhance the lay role in the development of health policy and practice.

Possible elements of such a pluralist strategy can be specified as follows. First, the huge area of self-care is one which medicine has tried to limit. But it will never disappear. The right approach is to seek to support and strengthen it. Second, self-help groups and volunteer initiatives constitute a major resource and a means of influencing health behaviour. Hence they deserve encouragement from the health services and from professionals, rather than indifference or suspicion. Third, and more generally, it is



necessary to aim at the deliberate interweaving of lay and professional roles, and statutory and voluntary action. Fourth, the encouragement of a more active lay role, while it promises to augment the resources devoted to health, the awareness of health issues and the support for health programmes, also means that patients will be more articulate and more concerned to make their own choices. Fifth, for this reason, the representation of consumer interests and direct involvement in health care cannot be separated from each other. Sixth, this conjunction should be recognised in any formal arrangements for public participation. Community health councils are strategically placed at the interface between the health service and the public. Mainly they have sought to represent consumer views, but some have also tried to promote lay involvement in self-care and mutual aid. Their proper role is a dual one, however difficult it may be to balance the two elements of it. The same is true of other arrangements for participation, even if the individual participant has to make an inevitably gradual transition from exclusive preoccupation with a narrow field, to concern for a broader set of health issues.

None of what has been said removes the necessity for strategic decisions about resource allocation and standards of provision. These can only be sanctioned through the conventional political processes. But the arguments advanced here do suggest that national politics writ small are not an appropriate model for public involvement at the local level. Rather the CHC offers a more suggestive model, if not the only possible one, for orchestrating the various elements in a pluralistic, decentralised and participatory pattern of health care.

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# 8

## Envoi

We do not intend, in this final chapter, to summarise the rest of the book, nor to reconcile discrepancies and contradictions. Instead we return to the questions posed in the introduction and, taking account of what we have learned from the other contributors, attempt some answers, for which we alone are responsible.

### What degree of participation is appropriate?

There can be no single correct definition of where health care should stand in the conceptual spectrum of participation described in the introduction, ranging from consumer protection at the low end of the spectrum, to community action of a radical kind at the high end. Broadly, the less technical the aspect of health care under consideration, and the less dependent the individual concerned, the more dominant should the consumer be. Thus, in preventive activities and self-help, it should be the individual and the community who set the pace. Even here, however, there is a professional role in making the relevant facts known (in relation to tobacco and alcohol, for example) and in influencing the behaviour of people and of governments. There is a professional duty to inform public opinion and change behaviour when health is at stake, as the great public health movement of a century ago demonstrated, and as issues like drinking, smoking, accidents and environmental hazards demonstrate today.

At the other end of the spectrum, the surgical team is wholly responsible for what happens in the operating theatre, but within guidelines agreed by the patient, the family and (in a public institution) the health authority concerned. Thus, Rudolf Klein observes, there is inevitably tension and interplay in the health sector between professional paternalism on the one hand and consumerism on the other. Neither of these two elements should ever be wholly absent. Health care always has professional dimensions and yet, at the end of the day, it is the patient who has to live with the results, and who should, with relatively few exceptions, have the ultimate right to decide.

Trust is a crucial component in the relationship between patient and provider. The more technical the procedure and the more dependent the patient, the more is he or she at the mercy of

the professionals. To some degree, however, the individual always has to trust in the competence and integrity of the physicians, nurses and others engaged in his or her care. They, for their part, are entitled to ask for individual and public trust. In return, this trust must not be betrayed, and mechanisms must be in place to ensure that it is not. While the mechanisms may be professional, they will require periodic revision and must be under public scrutiny and governance.

What is the role of management in all this? In part, it is to see fair play between the professionals and the consumer. Returning to the analysis of participation in the introduction, management must ensure that consumers are protected from professional or commercial exploitation, and that they and the broader public are consulted about the range, form and manner of service delivery. Managers in a professional service have a special responsibility to hold the balance between the proper interests of providers and consumers.

In addition, managers have a further responsibility to the patient and the public on their own behalf and on behalf of their health authority and the Secretary of State. After all, the tension described by Rudolf Klein is not only between professional paternalism and the consumer, but also between each of them and bureaucratic rationalism. The attempt to manage services rationally within the available resources frequently conflicts with what consumers want.

At an absolute minimum, this management responsibility includes integrity, frankness about the substance of management decisions, and openness about the way in which decisions are reached. In a service like the NHS, managers are public servants and act legitimately only if they act as agents for the individual and the community.

### Is change needed?

The answer is an unambiguous yes. One does not have to travel the whole journey with Ian Kennedy, let alone Ivan Illich, to be convinced that public participation is not as effective as it ought to be. To take a few examples from the heterogeneous range of activities within health care:

#### *The experiences of patients*

Sample the experience of waiting in a busy outpatient department, or of negotiating an appointment in most general practices, and you recognise how little direct impact consumer opinion has in the NHS. Or read the Ombudsman's reports on

his investigations, and note the frequency with which lack of communication between patient (or family) and doctor (or team) is the nub of the problem; or, at a later stage in these same complaints, the poor administrative handling of many complaints. The fact that most people are very undemanding, or that staff are often overstretched, or that some of the same criticisms can be made in most other health systems around the world, is not a sufficient reason for complacency. One of the points emphasised by Roy Griffiths and his colleagues in their recent NHS Management Inquiry is the lack of evidence about how well the NHS is meeting the needs and expectations of the people it serves. The National Health Service has many virtues, but sensitivity to consumer reactions is not, on the whole, among them. *Envoi*

#### *Prevention and self-help*

As Ruth Levitt points out, most people are only too happy to take a passive view of their own health, turning from time to time to physicians and others for running repairs. This is a false view of health and must change if we have any common sense individually and collectively. That is why, for example, the World Health Organization's definition of primary health care is far broader than our conventional definition, and includes within it self-help and community participation as essential ingredients.

#### *Health authority membership*

Many members – perhaps most – have found their role as unclear and at times as frustrating as John Bettinson describes. Yet decisions about priorities within a fixed budget cannot properly lie with the professionals. There has to be a mechanism by which those who are in some sense trustees for the community decide these things. The scale of resources to be allocated to end-stage renal failure versus bone marrow transplants, or psychiatric care or care of mentally handicapped people, are not intrinsically questions for expert calculation or professional judgment, but for human choice. We simply cannot afford to be without a sound mechanism for making such grave public decisions, nor for overseeing more generally the effectiveness of a vital public service.

#### *National policy for health*

In Britain certainly, but not in Britain alone, health policy is currently more contentious politically than for a generation. It is also more subject to sudden changes in financial allocation in

line with adjustments in government economic policy. As a result there is a high level of uncertainty, and a very short time horizon. Somehow we and other countries must develop and pursue a more coherent long-term strategy in health care. There needs to be some counterweight, on the public behalf, to short-term expedience and to abrupt changes of direction based on doctrinaire politics: a sort of policy keel is required as a complement to constant tacking in changeable political winds.

In all these ways, and others, the need for more effective public participation is urgent.

### How could public participation be increased?

The better one knows a complex field like that of health care, the more one distrusts instant solutions. Against the background of this book, describing the heterogeneity of the problems, it would be foolish to expect the effectiveness of public participation in health care to be suddenly transformed by any single step or set of steps. Rather, one needs to test a range of actions that seem appropriate to the specifics of each different problem, and be prepared to learn from experience and try again. So, linking back to the needs described in the previous situation:

#### *The experiences of patients*

Complaints systems, necessary though they are, are a totally insufficient means of sampling consumer opinion. More use should be made of properly-designed surveys of the opinions of current users of services, past users and (in some cases) those close to them, particularly their families. Among other things, consumer opinion would be likely to underline Sir Douglas Black's points about the importance to the patient of courtesy, thoughtfulness and clarity of communication. In addition to the sampling of patients' views, every district health authority should try continually to sharpen its understanding of the community that it serves – including those from outside its catchment area who use its services. While the concept of a district profile is orthodox enough, it is quite another matter to invest substantial continuing effort – including sampling – in analysis of demography, epidemiology and public opinion. This, surely, is a field in which CHCs and authorities should be glad to work together: they have complementary skills and each needs the information.

### *Prevention and self-help*

Nationally, the British Government has a good historical record of unobtrusive help to pressure groups in the fields of health, handicap and social welfare, even though such groups may at times prove uncomfortable critics. Sadly there are some recent signs of official tolerance wearing thin, for example in relation to campaigns by the Health Education Council and others to change society's attitudes to tobacco and alcohol. Even government tolerance is not enough, however, for some important preventive actions require legislation (a tightening of the laws on drinking and driving, for example) or alterations in tax policy (for example, on alcohol pricing). At the local level, also, the encouragement of prevention and self-help has not been sufficiently sustained nor sufficiently imaginative. A new, local public health movement is required, and public opinion seems more ready for it than the health authorities or the professions (witness the increasing media interest in health matters and the recent formation of a public College of Health by Michael Young, that doyen of the consumer movement). Stephen Hatch suggests, at the end of his chapter, that CHCs have a key role to play in all this. Certainly the fundamental basis of any action must be spontaneous, not imposed, but there is much that can be done by way of encouragement and support – perhaps particularly in the poorest neighbourhoods and among those who are least able to mould events to their liking.

### *Health authority membership*

It should be easier, as John Bettinson says, to develop a purposeful, constructive and satisfying role for the members of the present district health authorities than for their predecessors on the larger area health authorities. But it will not just happen by itself, and it is vital that it should happen, so that the district health authorities truly govern: not as pawns of central government, nor puppets manipulated by their officers. Decisions about the best use of scarce resources at the local level must lie with the DHAs, as must public oversight of levels of service. Recruitment and selection of members; their preparation and continuing development; their individual assignments on the authority's behalf; the way in which proposals are prepared for the authority as a whole – all these can contribute to give substance to public governance through the health authorities.

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*National policy for health*

There is no lack of actors on the national scene with some measure of public responsibility for health services and health policy. The Secretary of State for Social Services is only the most obvious among several, including central government (because the Secretary of State is not a free agent, nor is he responsible for anything approaching the whole health policy field), parliament and its select committees, the Department of Health and – following the Griffiths report – supervisory and executive boards for the National Health Service. Yet the process of peaceful revolution through the ballot box, crucial as it is, does not guarantee public participation. Sir Patrick Nairne argues that what is needed is a clearer understanding among the actors of their respective roles. In addition, we see the need for better information, a longer time horizon and a more rounded view of health policy. It is absurd that there is often no source of reliable data on which to base the policy debate. Allowing for inflation, has public expenditure on the NHS gone up in real terms, or has it not? What have been the relative rates of growth and reduction analysed by area of the country and by programme? To what extent are changes in manpower in the different occupational groups explained by changes in hours worked? What is happening to relativities in pay, within the NHS, between the NHS and the private sector, or between health and other sectors of the economy? Is there, or is there not, a measure of unemployment in the health professions? What, above all, is happening to the quality and effectiveness of health care? These are important questions in which there is (through the media) a high level of public interest. Even if the Department of Health has some of the answers, it cannot be unbiased about the interpretation of the data, nor does it know much about some of the most important questions, such as the quality and effectiveness of care. The recently published *Health Care UK 1984* is therefore welcome as a first attempt at an annual independent audit of the data available. Perhaps something like an independent institute of health policy analysis is needed, to raise the quality of public participation, at the national level, in the making of health policy.

Central government policy in relation to health has recently concentrated on the pursuit of greater marginal efficiency within the National Health Service and the encouragement of private sector alternatives. To plead for more effective public participation is not necessarily in conflict with either of those two



approaches, but it is much less fashionable than it might have been a decade ago. Perhaps that is a good reason for this book, since no combination of health services is going to be satisfactory for long which does not explicitly recognise and promote the importance of participation by the individual, the local community and national organisations in matters of health.

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## PUBLIC PARTICIPATION IN HEALTH

A plea today for more effective public participation in health is much less fashionable than it might have been a decade ago, now that government policy is concentrating on the pursuit of greater marginal efficiency in the NHS and the encouragement of private sector alternatives. The editors argue, however, that no combination of health services is going to be satisfactory which does not explicitly recognise and promote the importance of participation by the individual, the local community and national organisations in matters of health.

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