

PUBLIC EXPECTATIONS

From paternalism to partnership: Changing relationships in health and health services

This paper addresses the rising public expectations that are driving health debates in the UK. Marian Barnes documents the process of increased public involvement in decision-making in health policy and health care services that has been a feature of the last 20 years. She posits user or consumer involvement in health as a challenge to professional and expert authority, which will have further consequences for the organisation and administration of health care services if there is to be real 'partnership' between users and professionals in the future. Her paper reflects wider movements in public expectations, including use of the Internet amongst consumers of health care, that are likely to drive health expectations in the future.

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POLICY FUTURES FOR UK HEALTH

Edited by Charlotte Dargie

This paper is part of a series written for the Policy Futures for UK Health Project, which examines the future environment for UK health, with a time horizon of 2015. The full series is listed below.

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Technical Series

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From paternalism to partnership: Changing relationships in
health and health services

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Charlotte Dargie

FOREWORD

Since its inception the Nuffield Trust has identified individuals and subjects that would impact on health and health care policy in the United Kingdom, with notable examples being *Screening in Medical Care* [1], Archie Cochrane's *Effectiveness and Efficiency: Random Reflections on Health Services* [2], Thomas McKeown's *The Role of Medicine: Dream, Mirage or Nemesis?* [3], David Weatherall's *The New Genetics and Clinical Practice* [4] and Alain Enthoven's *Reflections on the Management of the National Health Service* [5].

In keeping with tradition and reflecting the more complex issues in health and health care policy today, the Nuffield Trust established a Policy and Evaluation Advisory Group (PEAG), supported by the appointment of a Nuffield Trust Fellow at the Judge Institute of Management Studies at the University of Cambridge, to provide a research and intelligence capability for the Trust.

The Policy Futures for UK Health Project stems from the work of PEAG. It involves examining the future environment for UK health, with a time horizon of 2015. The first environmental scan has resulted in a series of 10 technical papers, which cover the following areas¹:

1. The Global Context
2. The Physical Environment
3. Demography
4. Science and Technology
5. Economy and Finance
6. Social Trends
7. Organisation and Management
8. Workforce
9. Ethics
10. Public Expectations

Each paper in the series is a stand-alone piece, but has also been used by the project to derive an overview report, which focuses on policy assessment in the light of the environmental scan. Entitled 'Pathfinder Report', the overview report is published separately and will be subject to external consultation².

The Policy Futures for UK Health Project and the work of PEAG are ongoing. Further reports and publications will appear in subsequent years. The technical papers will also be revisited and different subjects will be tackled.

The strength of the technical series is in providing a context for analysing health and health care policy for the United Kingdom. Each author has produced an independent piece of work that analyses trends and issues in their subject area, focusing on 2015. The papers enable one to read across the issues, in order to provide a general analysis of health and health care policy, which is lacking in the highly specialised debates that dominate the health world today. They have formed the basis for consultation and discussion as part of the Policy Futures for UK Health Project.

Finally, the Trust is grateful to the members of the PEAG, to Professor Sandra Dawson and Pam Garside of the Judge Institute of Management Studies and to the authors of the 10 technical papers. A particular thanks due to Dr Charlotte Dargie, Nuffield Trust Fellow at the Judge Institute of Management Studies, the author of the Pathfinder report.

John Wyn Owen CB

July 1999

ENDNOTES

1. *Screening in Medical Care: Reviewing the Evidence* A collection of essays with a preface by Lord Cohen of Birkenhead (Oxford: Oxford University Press for the Nuffield Provincial Hospitals Trust, 1968).
2. AL Cochrane *Effectiveness and Efficiency: Random Reflections on Health Services* (London: Nuffield Provisional Hospitals Trust, 1971).
3. T McKeown *The Role of Medicine: Dream, Mirage or Nemesis?* (London: Nuffield Provisional Hospitals Trust, 1976).
4. D Weatherall *The New Genetics and Clinical Practice* (London: Nuffield Provisional Hospitals Trust, 1982).
5. AC Enthoven *Reflections on the Management of the National Health Service: An American Looks at Incentives to Efficiency in Health Services Management in the UK* (London: Nuffield Provincial Hospitals Trust, 1985).
6. S Williams, S Michie and S Pattani *Improving the Health of the NHS Workforce* (London: The Nuffield Trust, 1998).

Each of the papers in the series is available from the Nuffield Trust.

² C Dargie *Policy Futures for UK Health: Pathfinder* (London: The Nuffield Trust, 1999). The Pathfinder Report is for wide consultation and invited comment. You can email your comments to policyfutures@jims.cam.ac.uk. You can also send your comments to Dr Charlotte Dargie, Nuffield Fellow in Health Policy, The Judge Institute of Management Studies, Cambridge University, Cambridge, CB2 1AG. You can also find this Pathfinder Report along with other technical papers in the Policy Futures series at the Nuffield Trust website: <http://www.nuffieldtrust.org.uk>. Please respond with your comments by Friday 19 November 1999.

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ABBREVIATIONS

| | |
|-------|--|
| BSE | bovine spongiform encephalopathy |
| CHCs | community health councils |
| CPA | care programme approach |
| DHSS | Department for Health and Social Security |
| GP | general practitioner |
| HA | health authority |
| HAZ | Health Action Zone |
| IHSM | Institute of Health Service Management |
| IPPR | Institute for Public Policy Research |
| NHS | National Health Service |
| NHSE | National Health Service Executive |
| NHSME | National Health Service Management Executive |
| PCGs | primary care groups |
| UK | United Kingdom |
| US | United States |

SUMMARY

Main trends

- There has been a general shift away from blind trust in experts. Within the National Health Service (NHS) the attempt to introduce market mechanisms contributed to a loss in public confidence, even though the NHS has remained the most popular of all public services.
- Action to increase public involvement in decision-making has been taking place across the public sphere. Within the NHS this has been gathering pace since the early 1990s, although the establishment of community health councils (CHCs) in 1974 and the Griffiths Report of 1983 both (in different ways) gave expression to the need for the public interest to be represented to health professionals and decision makers.
- The consumerist ideology of the Thatcher and Major governments emphasised private choice as the means by which individual consumers could become 'empowered'. The election of a Labour government in 1997 marked the emergence of a new discourse of partnership, although the 'partnerships' between health professionals, patients, user and community groups are very unequal.
- Action amongst user, consumer and community organisations has developed to provide a challenge to professional and expert authority and such groups are increasingly playing a part in health decision-making at different levels.
- Widening access to information previously dependent on professional gatekeepers has enabled individuals and groups to pose questions to health professionals, rather than always being supplicants for information.

Policies

- A return to paternalism is not possible, but there is a need for substantial skill, attitudinal and organisational development within the NHS to support user and citizen involvement in decision-making.
- User and citizen perspectives highlight lack of co-ordination in service delivery and lack of fit between policy objectives. Increasing public participation is likely to challenge current administrative boundaries and existing parameters of policy-making.
- The rhetoric of partnership requires taking seriously the perspectives of those occupying comparatively powerless positions within such partnerships.
- Professional education and training will increasingly need to include social science and user perspectives in order to enable clinicians and others to develop a model of professionalism based on working with users and citizens, rather than on an assumption of the superiority of expert knowledge.
- Time and resources will need to be given to developing more effective models that enable users and citizens to engage in dialogue and deliberation about service and policy issues. There will be tensions

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deliberation about service and policy issues. There will be tensions between achieving these developments and meeting government-imposed service targets.

INTRODUCTION

This paper deals with the growing recognition that health care decision-making is not something that can be left entirely to the 'experts'. Health policy-making in the twenty-first century will not be solely a matter of bargaining between professional, bureaucratic and political interests, but will include both organised groups of health service users and the interests of citizens represented through increasingly diverse methods of gauging and developing public opinion. The delivery of health care will involve greater partnership between health care professionals and their 'patients', as well as the active engagement of patient representatives in service design, planning and monitoring. In this paper I will consider the origins of this shift in thinking about how policy should be formulated and services delivered at both individual and collective level. I will illustrate how this is taking place using examples drawn from different parts of the health care system, and suggest some of the dilemmas and possibilities for the future.

But first, the origins. An increase in the active participation of both citizens and recipients of public services is not restricted to the NHS. Action is being taken to open up decision-making and find new ways of including citizens in the planning and provision of public services across the public sector [1][2][3][4]. This reflects a renewed interest in the role of citizens in shaping the public sphere, as well as a loss of faith in the capacity of professionals alone to solve the most pressing problems facing public policy at the end of the twentieth century. Particular factors affecting the NHS include the following:

Loss of public confidence The attempt to introduce market mechanisms into the delivery of health care services led to a loss in public confidence that the NHS was continuing to embody its founding principles. Such principles have been the source of public confidence in both individual health care professionals and the service as a whole. Whilst local democratic accountability was always weak in the NHS (deliberately so in a service which emphasised its *national* character through a line of accountability going centrally through the Secretary of State to Parliament itself), public confidence was secured on the basis of the principle of equity on which the NHS was founded [5]. Social attitudes surveys have consistently shown a near unanimous level of support for the principle that it is the government's responsibility to provide health care for people who are sick. During the decade from 1983 to 1993 there was a steady increase in the proportion of the population considering that the government should choose to increase taxes and spend more on health services. At the same time a rising dissatisfaction with particular health services, in particular hospital services, suggested that there was a level of dissonance between public commitment to the values of the NHS and their direct experience of it [6] [7] [8]. One interpretation of this is that the foundation of public trust was undermined by the introduction of market values into the system.

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Technological advances Beck's analysis of 'the risk society' [9] highlights human culpability rather than natural disasters as the source of many of the risks faced within contemporary society. In particular, scientific 'progress' has created new dangers of which we are starting to become aware. Public concern about genetically engineered food is directly related to the fiasco around bovine spongiform encephalopathy (BSE). Advances in health technologies and in scientific knowledge are generating questions that cannot be resolved by reference to science or technology alone. The fact that it is now possible to conduct research on aborted fetuses, which holds out the possibility of developing cures for hereditary disease, raises profound ethical, moral and political issues needing public debate.

Involvement in change The NHS at the start of the twenty-first century has to meet very different health needs from the NHS of 1948. The pattern of services necessary to this end will of necessity be different from that which characterised the early NHS. Yet people feel comfortable with familiarity and the public needs to be involved at the outset in the direction of change if they are to feel confident about those changes.

Tackling inequalities In spite of the innovations and progress in health care that have taken place since the founding of the NHS, health inequalities have widened as society itself has become more unequal in terms of income differentials and opportunities [10]. Successful action to reduce inequalities and to promote health can only be taken with the active participation of the communities and individuals that have been excluded from the benefits available to more affluent members of society.

New information Information about health, illness and treatment options is more widely available than ever before. Developments in information technology make it easier for lay people to access research that was formerly accessible only to those undergoing professional education and training. Professional closure is no longer absolute in terms of access to the information on which professional authority is built. At the same time, health user groups and social movements are generating their own sources of information, which sometimes provide alternative perspectives from those offered by health professionals. One example of this is the website developed by the 'Strategies for Living' programme undertaken by mental health service users and supported by the Mental Health Foundation [11].

Environmental links Other social trends point to increased public awareness of health issues - for example, an increasing awareness of environmental issues and some evidence that people are prepared to alter their behaviour in response to such concerns [7] can be considered to link into concerns about the relationship between food production and health, as well as broader awareness of the relationship between environmental conditions, lifestyles and health. It has been suggested that social policy needs to incorporate environmental

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policy and that sustainable development is necessary not only in the interests of the physical environment but also of public health [12].

Healthy trends Health and fitness have become big business. Sports clubs, gyms and health spas have proliferated and sports clothes are high fashion. Unhealthy behaviour, such as smoking, is becoming socially unacceptable. Whilst changes in smoking behaviour are unevenly distributed across social class and gender, the overall trend is down [6][13], reflecting both a greater awareness of the health consequences as well as peer group pressure.

OFFICIAL POLICY AND 'BOTTOM UP' ACTION

In this context, 'user involvement' and 'public participation' have become official policy, both in opening up decision-making about health services, and in delivering policy objectives relating to health improvement. Key policy developments are summarised below:

- 1974 Community Health Councils were established to represent the public interest.
- 1983 The Griffiths Report [14] encouraged market research and consumer satisfaction surveys.
- 1990 The NHS and Community Care Act introduced the internal market, to enhance choice. It also required local authorities to consult over community care plans, and encouraged user involvement in the assessment process.
- 1992 The NHS Management Executive published *Local Voices* [15], which encouraged health authorities to seek public views on health needs and priorities. The summary of examples of action being taken to this end indicated that research-based methods for obtaining the views of local people were more in evidence than initiatives that involved public participation in decision-making processes, or initiatives that used community development approaches to enable the development of capacity to engage in decision-making.
- 1992 The Patient's Charter introduced new procedural rights and defined the first nine Charter standards. Three new rights were introduced in the first version of the Patient's Charter: 'To be given detailed information on local health services, including quality standards and maximum waiting times; To be guaranteed admission for treatment by a specific date no later than two years from the day when your consultant places you on a waiting list; and To have any complaint about NHS services - whoever provides them - investigated and to receive a full and prompt written reply from the chief executive or general manager' [16 pi0-11]
- 1994 League tables were published for the first time to enable comparison of performance on Charter standards.

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- 1994 The Clinical Outcomes Group (chaired by the Chief Medical and Nursing Officers as an advisory group to the Department of Health) established a patient sub-group to identify the extent to which patients were involved in clinical audit and ways for promoting such involvement [17].
- 1996 The NHS Executive 'patient partnership' [18] strategy was launched to support the medium-term priority of giving a greater voice to users in their own care and in the development of policies and standards.

The overall approach advocated by the strategy was that 'patient partnership' should be integral to the way the NHS pursues all its objectives. Thus, post 1996 we can identify ways in which patient or public participation is included in other policy developments:

- 1996 The Standing Advisory Group on Consumer Involvement in the NHS Research and Development Programme was established.
- 1997 'The new NHS: Modern, dependable' [19] was published in December 1997, setting out the parameters of government policy for the NHS. One of the principles underlying the proposals was that of rebuilding public confidence in the NHS. The report indicated some ways in which it was intended that this should be achieved. For example, all NHS trusts would be required to conduct their board meetings in public; a series of national service frameworks would be developed with representatives of users and of carers as well as professionals; the new primary care groups (PCGs) would be expected to have clear arrangements for public involvement. Subsequent detailed guidance documents have provided more indication of how these objectives are to be achieved. For example, PCGs are required to have a lay representative on the board.
- 1997 Health Authorities, in partnership with other public, voluntary and private bodies, were invited to seek health action zone (HAZ) status [20]. The objectives of HAZs include: 'empowering people and giving them the tools to take greater responsibility for their own health'; 'building on existing strengths in the local community to achieve a sustainable capacity'; 'enlisting public support for change and involvement in the work of the HAZ, developing strategy and appropriate structures for involving the public on a continuing basis in partnerships for improving health and for monitoring services, so ensuring sustainability' [20].

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- 1998 *In the Public Interest* [21], a report of work commissioned by the National Health Service Executive (NHSE), the Institute of Health Service Management and the NHS Confederation, was published. This set out proposals for the development of a strategy for user and public participation in the context of the new policy agenda introduced following the election of the Labour government. It proposed four models through which user and public participation should be secured:
- the direct involvement of users in individual decision-making and, collectively, in service design and evaluation
 - accessing the informed views of citizens through mechanisms such as citizens' juries and other methods that enable deliberation amongst citizens
 - community development to enable marginalised groups to define their own health needs and to engage in creating solutions to those needs
 - greater user and public involvement in the local scrutiny of health policy and services as a means of calling officials to account.
- 1998 The Standing Advisory Group on Consumer Involvement in the NHS Research and Development Programme held a conference and published a report: 'Research: What's in it for me?' [22].
- 1998 The NHS Research and Development Policy Research Programme invited proposals for research on the theme Health in Partnership intended to inform the further development of the Patient Partnership Strategy.
- 1999 The College of Health was funded by the Department of Health to create a training and support scheme to enable lay representatives to become more effective participants in health care decision-making.
- 1999 Relaunch of the Patient Partnership Strategy.

This summary of official policy developments demonstrates not only the gathering pace of action to support the development of public participation, but also a shift in the nature of thinking about the appropriate balance between producer and user power within the NHS. During the years of the Conservative government the emphasis was on mechanisms intended to curb the power of professionals and bureaucrats through the crafting of more informed and assertive consumers. But whilst 'choice' was elevated to the position of a core value in terms of access to services, there was substantial discomfort at the implication that health care was simply another commodity to be bought and sold in the market place and for which consumers might shop around for the best deal. Critiques of choice as the mechanism through which health consumers could become empowered in relation to health professionals were based not only on the United States (US) evidence of increased costs and litigation arising from an assertive consumerism, but also on the fact that

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rational choice theory cannot deal adequately with the reality of doctor-patient relationships in conditions of uncertainty, risk and asymmetric power [23][24][25][26][27].

The election of the Labour government in 1997 marked a shift in discourse from that of consumerism to that of partnership. Rather than relying on mechanisms such as charters and complaints systems, service users and citizens (or their representatives) are increasingly being invited to take part in deliberations about policy development, service delivery and evaluation. Both individuals and communities are being expected to take greater responsibility for their own health and for delivering the government's twin objectives of overall health improvement and a reduction in health inequalities. There is a growing recognition that community development is not something that should be viewed as a threat to right-thinking health professionals, but as central to the achievement of official policy. Whether such shifts in thinking represent a fundamental change in the balance of power or influence over decision-making is something I consider below.

Alongside changes within official discourse concerning the relationship between health services with those who are recipients of health services and the public in whose interest the NHS was established, it is also important to consider action that has been developing amongst user groups, community organisations and in the context of more traditional voluntary organisations to ensure that, both individually and collectively, the voices of service users are heard.

Action within the sphere of civil society is, by nature, diverse. It is possible to identify different types of organisations or groups which are acting to give voice to the experiences of those who use health services:

Groups based on shared identities These include, for example, women's groups, disabled people's organisations and groups based around cultural or ethnic identity. The defining characteristic of groups in this category is that control of decision-making is with those who share the relevant identity. Thus, disabled people's organisations may include non-disabled people as supporters, employees, allies or associate members, but such members do not have voting rights. In some instances local groups are part of wider network organisations such as the British Council of Disabled People and the UK Advocacy Network (mental health advocacy groups).

Groups based on specific diseases, conditions or interests This would include many 'traditional' voluntary organisations: Scope, Arthritis Care and Age Concern, for example. The Long-Term Medical Conditions Alliance has brought together many such groups to work for greater participation of people with 'long-term conditions' in both individual and collective decision-making. Whilst such groups include members who have the 'condition' - e.g. cerebral palsy and arthritis - or who come within the relevant 'category' - e.g. older people - decision-making is not necessarily controlled by those people.

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Community organisations based on localities Here 'place' is the key factor in defining membership, although locally based community groups may also share other identities. For example, in localities where a particular minority ethnic group is concentrated, both ethnicity and locality are often the bases for organisation.

Organisations established to represent the interest of patients generally In different ways, the Patients' Association, the College of Health and Consumer Congress act in the interests of patients across the board.

The position of community health councils (CHCs) is somewhat ambiguous within this categorisation. Some would regard CHCs as examples of 'bottom-up' opportunities for public participation in health decision-making, whilst others point to their statutory position within the NHS to suggest that they should be included as examples of 'top-down' initiatives. As statutory bodies, CHCs have a status and rights not available to other groups and organisations. Nevertheless, most CHCs are keen to assert their independence from health authorities and health service providers. The future of CHCs has been the subject of considerable debate during the latter part of the 1990s [28]. It is recognised that the conditions in which they now operate are very different from the 1970s when they were first established and that, if they are to survive and develop, their role and composition needs to be clarified and, perhaps, redefined.

The diversity of groups engaged in representing the voices of users and citizens to health decision makers is reflected in the varying ways in which the officials with whom they come into contact understand the nature of their activities and objectives [29]. They are often referred to as 'pressure groups', considered to be self-interested and thus unrepresentative of the 'authentic' voice of local people. This is one reason for interest in the development of methods to hear from a cross section of citizens who might otherwise not become involved through mechanisms such as citizens juries [30][31].

However, it is important to distinguish self-organisation amongst user and community groups from, for example, the self-interested lobbying carried out by the pharmaceutical industry. Many groups have developed amongst people who have been marginalised and excluded from decision-making about their own lives, never mind from decision-making about issues of public policy. For organisations such as People First, a national umbrella group of people with learning difficulties, groups of people with mental health problems (e.g., at a national level, MINDLINK, the UK Advocacy Network and Survivors Speak Out) and for disabled people's organisations, collective organisation has been necessary to an articulation of experiences of exclusion and to a developing confidence to reclaim the right to define their experiences in their own way [1][32][33][34]. Such organisations can also support people to become more informed about health services and to develop their capacities to make judgements about the quality of services.

Campbell and Oliver [35] describe the link between the development of a disability consciousness and action within the disability movement in language which is reminiscent of that developed within the women's movement. Both feminism and the social model of disability are theories developed from the experiential knowledge of those occupying particular social positions. Such theorisation of experiential knowledge has been used, amongst other ways, to challenge clinical perspectives on the health and treatment needs of women and of disabled people [3 6] [3 7] [3 8] [3 9].

Whether or not experiential knowledge is theorised in the way that it has been within feminism and the disability movement, health professionals and policy makers more generally are recognising that effective interventions require a dialogue between the abstract knowledge of professionals and the particular, situated knowledge of those who use services or are on the receiving end of policy interventions. Rather than leaving the 'choice' of treatment up to the individual patient, the notion of 'shared decision-making' is being advanced as the means to achieving a higher quality of care and more effective outcomes, as well as rebuilding trust between clinicians and patients [27] [40]. This is the case in situations as diverse as health promotion initiatives with families living in poverty [41], treatment for women with early stage breast cancer [27] and the provision of support for frail older people and their carers [42]. Recognition of the legitimacy and usefulness of experiential knowledge has been helped considerably by the collective organisation of groups representing those interests and supporting individuals in articulating and expressing their views and experiences.

'Self-management' of health and health care is based on sharing knowledge and encouraging users to take control. For example, Arthritis Care is organising and delivering arthritis self-management programmes in a variety of settings. This programme of work is being evaluated [43][44] and is indicating positive results in terms of reduced pain, improved psychological well-being and a reduction in visits to general practitioners (GPs). There is also an indication of benefits associated with being with others with similar experiences and being able to share such experiences.

A further 'bottom-up' impetus to more dialogic forms of decision-making within health services has come from increasing lay access to information previously only accessible to professionals and academics. Control of access to information has been one of the main ways in which professional groups have achieved closure. Dependency on professionals as gatekeepers to information has been a characteristic of encounters with medical professionals. And even if clinicians and other health care professionals have been prepared to share information, they have not always been very good at it. Communication skills are not automatically part of the repertoire of either GPs or specialist clinicians. But things have started to change. Access to information through the Internet cannot be controlled. Those who can access a networked computer can access a wide range of information from professional

sources as well as that generated by user organisations, which are increasingly using information technology as a means of building international networks. This was one characteristic of the challenge to health care decision makers from David Bowen, father of 'Child B' [45]. New skills and new systems are necessary to respond to such challenges.

WHAT DO THE PUBLIC WANT?

The above discussion of the origin and nature of public participation indicates something of the diversity of objectives and action involved. It is not possible within the scope of this paper to provide a comprehensive analysis of the outcomes of public participation across the range of health services, nor indeed to describe the full range of activity that is taking place. For more detailed discussion of activity within the NHS to engage the public and patients as active participants in decision-making, Barnes [46] and Lupton *et al.* [47] provide analytical accounts, whilst resource packs have also been published to assist those developing practical initiatives in public participation [48][49][50]. Research exploring the clinician-patient relationship has identified issues affecting user involvement in the decision-making process at this one-to-one level [27][40][51]. The significance of factors such as asymmetric power relations, the emotional content of many of the decisions involved and the necessity of trust as a basis for effective decision-making in conditions of uncertainty, as well as the likelihood that decision makers will include others in addition to patients and clinicians, all point to the difficulty of reaching highly generalisable conclusions about patients' expectations in relation to involvement at this level.

Here the intention is to provide examples of different types of initiatives within different parts of the health services in order to indicate the type of change outcome that might be expected to flow from increased user and public participation in health service decision-making.

Health care purchasing and commissioning

The Long-Term Medical Conditions Alliance, with support from the Department of Health, the NHS Executive and the King's Fund undertook a project published as *Patients Influencing Purchasers* [52]. Many of the recommendations deriving from this work concerned ways in which health authorities could support the involvement of patients in purchasing decision-making. However, what became clear during the course of this project was that, even amongst those with long-term conditions who become 'expert' users of health services, few understand the split between purchasers and providers and what this means for them. For those who are frequent and regular users of health services, the immediate issues of concern relate to service provision rather than more strategic purchasing or commissioning issues. However, from this study and others, there is a strong sense that those directly using services should make an input to the process of contract monitoring - without the perspective of direct users of services, any assessment of the quality of services can only be partial.

The London Primary Care Health Forum [53] reviewed a range of community-based health needs assessments that sought to engage local people in this process. One conclusion from this review was that rapid appraisal methods tend to produce similar results regardless of the location in which they are carried out. The authors of the review suggest that this is because such methods are designed to examine health in its wider sense rather than health services specifically. From the perspective of this current analysis, and in a policy context in which public health issues are being given greater priority than for many years previously, this finding may be viewed as a positive indication of public perceptions and priorities. Others [54] have demonstrated the way in which rapid appraisals used to determine community perspectives on health needs have revealed the discrepancy between professional and community perceptions of priorities.

Dowswell *et al.* [55] surveyed health authorities to find out the extent to which they were involving the public in decision-making about priorities. Results indicated that, from the perspective of health service officials, there is no necessary link between public involvement and public influence over decision-making. Different attempts to involve people in decision-making about priorities for resource allocation have come up with different outcomes in terms of the extent to which citizens *want* or feel they *ought* to be involved in this area of decision-making. Some studies [56] suggest that people find it very hard to determine priorities and are resistant to the notion that explicit rationing should happen at all. Others [57] suggest people are willing to engage in debate about such issues.

In the Cambridge and Huntingdon Health Authority, prompted by the experience of controversy concerning the 'Child B' case, a citizens' jury was held specifically to address the question: 'Do you think there should be a National Council for Priority Setting in the NHS?' [30]. During the course of the jury, citizens were asked what values they would use if they were the chief executive of a health authority having to make decisions about priorities for health care in the area. This led to the following list of criteria, in no particular priority order:

- severity of disease
- quality of life
- effectiveness
- whether we can afford it
- how many will benefit
- clinical judgement
- view of the individual
- need
- progress
- best for general public
- fairness
- local flexibility

Whilst these criteria are in themselves subject to considerable dispute and differences in interpretation, it was noted that they are not substantially different in content from those already adopted by the Health Authority.

The general conclusion that can be drawn from experience in the context of public involvement in health care commissioning is that people do want to be involved in determining the needs on which such decisions should be based and will identify some different priorities from professionals based in a holistic, rather than clinical, perspective on health need. Given the opportunity to reflect and deliberate, local people will define criteria on which prioritisation decisions should be based, but think that the actual decisions should be left to those with formal responsibilities rather than taken directly by the public. Deliberative methods also enable citizens to become more informed about issues affecting decision-making, to develop skills in questioning expert knowledge, and in debating amongst themselves [58][59] But there is also a strong sense that assessing the quality of services, and thus whether providers have met their obligations within purchasing or commissioning contracts, should involve obtaining feedback from those with direct experience of using the services concerned.

Users as experts: the example of mental health

People who experience long-term health problems are likely to be more highly motivated than short-term or occasional users of health services to take an active part in service decision-making. There is thus more experience of long-term users playing a continuing role in health care decision-making. In this section I take the example of mental health in order to illustrate the type of issues which are prioritised by users who are able to have their say about services.

Finding a voice and being able to express that voice to service providers can be very difficult for people experiencing mental health problems. This is one reason why collective organisation on the part of service users is important [60] [61] [62]. The development of mental health user groups has grown substantially since the mid 1980s and initiatives to engage with service users are now widespread.

The voices of mental health service users can be experienced as threatening by professional service providers. When users have had the opportunity to express their views they have often been very critical of the service they have received and those messages can be difficult to hear [63] [64]. Whilst many health and social care professionals find this challenging, many users find it hard to express their views to those who have considerable power over them. There is also still substantial public fear and stigma associated with mental illness, although opportunities for informed public debate can lead to a questioning of such stereotypes [30]. The extent to which users' perspectives are able to exert significant influence has been tested by Frank Dobson's declaration that the issue of non-compliance with community treatment is not

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Health Act. There is widespread opposition to compulsory community treatment amongst service users (and amongst many mental health professionals). Dobson's announcement led to the resignation of user representatives from the group developing national service frameworks for mental health services.

Whilst many people who live with mental health problems accept that there are times when admission to hospital is necessary [65], the reality for many is that the experience of being in hospital is one of isolation, powerlessness and fear. Poor, overcrowded physical environments provide little opportunity for healing [66]. Indeed, for some - particularly women - it can be an unsafe environment [67] [68]. Thus improvements to hospital services have been a key focus for user councils and advocacy organisations [63]. Few mental health user groups are campaigning for complete abolition of hospital or other types of residentially based mental health services, but they are seeking to ensure that the quality of such services can offer genuine asylum and specialist help over which users have control, and which acknowledges and respects their individual needs. This implies developing relationships with clinicians that are both therapeutic and accountable.

It also reflects attempts to reclaim the positive meaning of the term 'asylum' from the pejorative ways in which it has been applied to 'madhouses'. Wallcraft [69] notes the range of practical meanings the term can have, including the possibility of self-referral to an acute unit on the understanding that there will be no forced treatment and that personal preferences will be respected. Users have also argued for the creation of crisis houses away from the hospital setting, run by professional staff but with substantial user input, as well as less formal safe houses provided by friends and by other service users.

But mental health service users give priority to the development of appropriate forms of support that will enable them to live their lives as they wish in the community.

The development of the care programme approach (CPA) and the introduction of community care assessments were both intended to ensure services were designed around the needs of individuals and that users were able to play a more active part in determining how services would be provided. Beeforth *et al.* [70] conducted an evaluation based on users' views of case management in four health districts. The key positive themes emerging from this study were:

- what people valued most was their relationship with their case manager
- people felt they were listened to and allowed to make choices
- practical help with housing and benefits was valued
- case managers were seen to help people make better use of their time
- case managers were also able to help with sorting out family relationships.

The potential for user involvement in the process of assessment has been taken further in Avon where users and professionals have jointly developed an

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approach intended to support users in conducting their own self-assessments before discussing their needs with care managers [71]. Elsewhere (e.g. Nottingham), advocacy groups have negotiated the provision of advocacy support to users at the key points when assessments are being undertaken and reviewed.

The Centre for Mental Health Services Development at King's College, University of London, developed an approach to the strategic planning of mental health services based on stakeholder conferences [72]. As a result, they were able to set out user-defined parameters of a mental health service. Such a service would be rooted in an understanding of their culture or background and would provide help with the following:

- emotional problems
- getting through a crisis
- finding somewhere to live
- having a full life during the day
- making and keeping friendships
- getting a reasonable income
- finding someone to speak on their behalf if necessary
- getting and holding down a job
- linking with others of the same race/culture and/or gender
- learning new skills.

This reflects earlier work by Ritchie *et al.* [73] and emphasises the significance of help with the ordinary activities of life, rather than that of specialist mental health services.

Rogers *et al.* [65] reported a majority of users having a more positive response to the help received from their GP than from their psychiatrist. However, some were concerned about their GP's lack of specialist mental health expertise. One particular criticism of GPs is that they are too ready to prescribe medication and spend too little time talking to their patients. Users are also concerned that a reduction in hospital based services should not mean a reduction in services such as counselling and psychotherapy. Bailey [74] explored users' views of primary care services and developed criteria to be used in assessing the quality of mental health services in primary care. These include criteria relating to information provision, to the availability of shared care programmes with community mental health teams, and access to specialist counselling services.

This brief discussion illustrates the potential for the direct involvement of users to inform service design as well as an individual care programme. A common theme in this and evidence from public involvement in needs assessment is the holistic concept of 'health' being applied and the emphasis on 'non-health service' sources of support alongside more specialist interventions.

FUTURE DIRECTIONS: BARRIERS, BENEFITS AND POSSIBILITIES

Whilst voices are still to be heard within the NHS extolling the virtues of paternalism, it is unlikely that the trend towards more pluralistic models of decision-making will be reversed. Whilst there is considerable uncertainty about how best to include users in decision-making about their own care and treatment, about how to engage users collectively in service planning and evaluation, and how to ensure that citizens generally can have their say in shaping services and policy, it is now official policy that this should happen. Indeed, in the context of 'trailblazing' initiatives such as HAZs, demonstrating how communities will be involved in developing and implementing plans is a prerequisite for achieving special project status.

In the late 1990s the predominant discourse is a more co-operative one than that which emerged during the Thatcher years. Tudor Hart [26] suggests that the way forward requires a return to the founding principles of the NHS together with another missing from the original vision: the principle that professionals should be accountable to their patients as their intelligent partners. The aim should not be to rely on complaint and litigation after poor practice has been exposed (as for example, in the case of paediatric surgeons in Bristol), but for an expectation of direct accountability to patients, based in a reciprocal process of information and knowledge sharing, to be integral to the clinician/patient relationship. The continuing presence of user groups and other bodies outside the NHS providing challenges to professionalised and exclusive modes of decision-making, together with a growing commitment amongst some NHS workers that the interests of both the service and the citizens it serves will best be met by working together, rather than in opposition, will continue to provide an impetus for change.

The benefits of public participation were identified by the authors of *In the Public Interest* [21] as follows:

THE BENEFITS TO THE NHS

- Restoration of public confidence
- Improved outcomes for individual patients
- More appropriate use of health services
- Potential for greater cost effectiveness
- Contribution to problem resolution
- Sharing responsibilities for health care with the public

BENEFITS TO PEOPLE

- Better outcomes of treatment and care
- An enhanced sense of self-esteem and capacity to control their own lives
- More accessible, sensitive and responsive health services
- Improved health
- A greater sense of ownership of the NHS

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BENEFITS TO PUBLIC HEALTH

- Reduction in health inequalities
- Improved health
- Greater understanding of the links between health and the circumstances in which people live their lives
- More healthy environmental, social and economic policies

BENEFITS TO COMMUNITIES AND TO SOCIETY AS A WHOLE

- Improved social cohesion
- A healthier democracy - reducing the democratic deficit
- A health service better able to meet the needs of citizens
- More attention to the cross-cutting policy issues and closer co-operation between agencies with a role to play in health improvement

This wide-ranging summary of potential benefits reflects the variety of purposes for which public and direct user participation in the NHS needs to be developed and hence the wide ranging strategy necessary to realise the promise. But the report also identifies the factors that stand in the way of progress:

- the perception of health professionals
- the 'myth of perfectibility'
- lack of clarity about what is being asked of people
- lack of ownership
- lack of skills
- the need to resource communities and build capacity
- barriers between agencies.

The concept of 'partnership' has become ubiquitous in public policy-making. It is a concept which implies joint responsibilities made explicit in examples such as the forward to 'Our healthier nation':

This Green Paper sets out proposals for concerted action by the Government as a whole in partnership with local organisations, to improve people's living conditions and health. It recognises that there are limits to what Government can do and spells out what the individual can do, if the Government do their bit. That's why we are proposing a 'contract for health'. [75 p3]

Many of those engaged in user groups seeking to influence health and other public services do not feel they are equal partners in such ventures. The power of health professionals and large public bureaucracies is considerably greater than that of, for example, mental health user groups. The commitment of such groups to work with the health service will depend on the seriousness with which their different perspectives are taken. We are beyond the point at which user groups will be satisfied by the offer of choices over the 'paint and wallpaper' aspects of health services.

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The Department of Health's Patient Partnership Strategy advocates 'patient partnership' as something that is intrinsic to the achievement of the broad spectrum of NHS objectives. 'In the public interest' suggests what that means in the context of the range of challenges facing the NHS in response to new policy initiatives of the Labour government elected in 1997:

- the development of PCGs
- the development of clinical governance
- action to improve health and reduce health inequalities
- the responsibility of the NHS to work in partnership with other organisations
- the need to develop more effective accountability to citizens.

Nevertheless, there will have to be substantial organisational and skills development, together with a preparedness to change attitudes, if health professionals are to develop effective partnerships with those who use their services and to become more accountable to citizens in general. Such developments are not cost free (at least in the short term) and sit uneasily alongside a priority of reducing hospital waiting lists.

It is unlikely that public expectations that health service decision-making should be open to public scrutiny will decline. The media attention given to health service issues is one reason for that. Whilst it is always likely to be a minority of citizens who opt to play an active part in citizens' juries, citizens' panels or other means of securing the active engagement of citizens in deliberation about public policy, those who do become involved value the experience and have expectations that such experiences will have consequences: both in terms of policy outcomes and some opportunity for continued dialogue. The challenge for public officials within the NHS is to develop appropriate strategies to engage the public in ways that deliver benefits both for the service and for the citizens who become involved, as a way of rebuilding a more reciprocal trust between citizens and the state in relation to health services. Whilst resource-intensive models such as citizens' juries will play some role in this, such mechanisms are likely to be used only occasionally in order to access value choices to guide strategic decision-making. When the decisions to be made concern specific service or policy developments, these will best be taken in consultation with those directly affected by the outcome: people living within a particular locality, or groups of users of particular services. In both cases, public expectations will be that there will be co-ordinated action across the public bodies involved: consultation fatigue and disenchantment set in when, for example, the health authority and social services department seek to consult separately about developments which cut across service boundaries. Recruiting one lay member to sit on the board of a PCG will be ineffective without means of securing broader and deeper participation in the range of activities undertaken by PCGs, and without mechanisms through which lay members can act as representatives of broader constituencies. This proposal is indicative of an official acceptance that decision-making bodies should include public involvement, but also of the

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which cut across service boundaries. Recruiting one lay member to sit on the board of a PCG will be ineffective without means of securing broader and deeper participation in the range of activities undertaken by PCGs, and without mechanisms through which lay members can act as representatives of broader constituencies. This proposal is indicative of an official acceptance that decision-making bodies should include public involvement, but also of the distance to be travelled before effective means of securing this can be achieved.

Professional education is increasingly encompassing multidisciplinary perspectives and, in limited areas, is including a user perspective. User involvement in both setting the research agenda and in carrying out health services research will start to shift the knowledge base underpinning the practice of health professionals, but it will have to battle with the 'neutral science' assumptions driving the evidence-based practice agenda. By 2015 we can expect to see health professionals in positions of power whose education has had a broader base in the social as well as clinical sciences. Some will also have experienced 'patients' in the role of educators rather than interesting case studies.

This is not just an issue of health services and health care decision-making. If the government is serious in its commitment to the reduction of health inequalities, the available evidence suggests that this can only be achieved by working with those at the wrong end of such inequalities. Health *is* a priority for communities who recognise only too well the limitation of the health service alone in achieving health improvements. But if the energies of community groups are to be harnessed to contribute to the delivery of policies for health improvement then they must feel they have some control over the process of agenda setting. Early experience of HAZs suggests that community and voluntary groups have been consulted after the main agenda has been set, not least because of the centrally imposed timescale within which health authorities had to deliver their plans. One of the key lessons to be learned from experiences of public and user involvement is that this cannot be rushed. If partnership with users and community groups is to form a key plank of the decision-making process within the NHS, this will have substantial implications for the pace of decision-making and the extent to which this can be imposed by the centre.

The current policy environment demonstrates a real tension between increasing centralisation (for example in the development of national service frameworks) and emphasis on the need for local solutions to local problems (as in the case of HAZs). How this is resolved will affect and be affected by public expectations regarding equality of access to health services, as well as by the extent to which public involvement in decision-making can make a real difference to health services.

At the start of the new millennium, the paternalistic structure of the welfare state designed in the 1940s is no longer sustainable. The implications for the

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education and training of those who work in the health service is profound. Recognising lay knowledge as having an equal part to play in health care decision-making with expert knowledge presents fundamental challenges to health care professionals. The holistic perspectives of those for whom poor health is only one part of their experience challenge the administrative boundaries that separate health care from social care, and which enable policies for health improvement to be undermined by policies that do little to reduce material inequality. The way in which both the research agenda and the educational curriculum develops will be as crucial to future developments as the political will to equalise the partnerships the government protests it seeks. If users and citizens play an increasing part in the decision-making process, by 2015 the boundaries of the health service and the parameters of health policy making may look very different from the NHS of 1948.

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