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Health Care Partnerships

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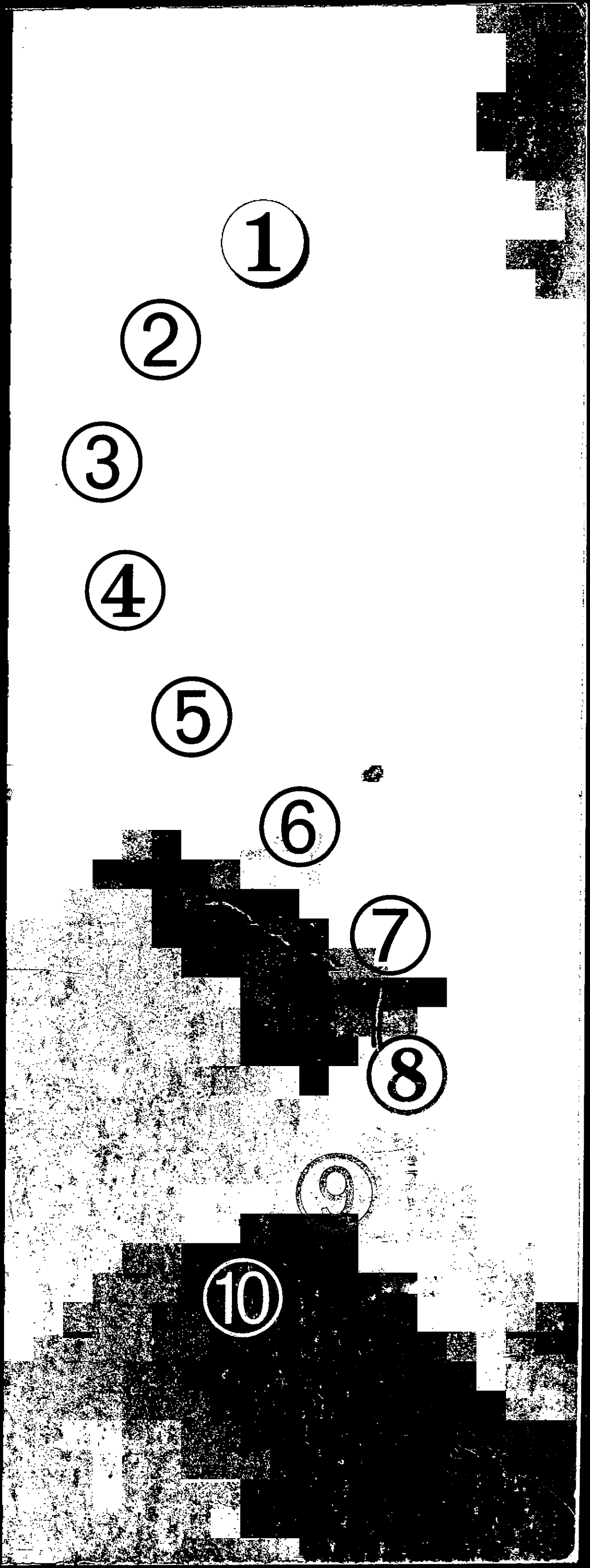

Promoting Patient Choice

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Health Care Partnerships

Debates and strategies for increasing patient involvement in health care and health services

Christine Farrell & Hilary Gilbert

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Contents

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Chapter 1

Introduction

The debates about patient rights, choices and responsibilities and the need to involve the public in health care decision-making have gained momentum in the past few years. The reasons for this ground swell are many and varied but the turning point, in recent history, was undoubtedly the reforms of the health service in 1989/1990. Based in part on market principles, these reforms introduced the concept of consumerism more explicitly into the provision of health care; and, using the purchaser/provider mechanism, set out to make health care providers more accountable to the public.

Subsequent policy initiatives such as *The Patient's Charter* (1991) and *Local Voices* (1992) and the publication of hospital league tables (1994) have encouraged patients and the public to become more actively involved in choices about their own health care and decisions about local service provision. Another, less public initiative strengthened the moves towards greater involvement in 1993 when the NHS Executive set up the Patient Empowerment Focus Group. This group has been actively involved in promoting alliances and policies to encourage more active partnerships between patients and doctors.

The King's Fund Development Centre has a long history of promoting patient and public involvement in health care. Through its own initiatives and its work with patient organisations, professional groups and the NHS, it has collected evidence, materials and insights into the processes by which greater user involvement can be achieved and services helped to become more responsive to people's needs. Most of the work of the King's Fund Development Centre has had a user focus, but the increased political and public interest in this perspective has given a boost to a particular set of projects grouped under the title 'Promoting Patient Choice'. This work began in 1991 when the Development Centre formed an alliance with the US Foundation for Shared Medical Decision-Making to promote a series of interactive videos. Used by patients in collaboration with their doctors, the information provided on the videos is based on the most up-to-date evidence and treatment choices. The videos include interviews with patients who have made different treatment decisions to suit their own circumstances and preferences.

This work has been extended in several directions and since 1995 has been guided by a strategy which includes research and evaluation; the development of new patient materials; and the promotion of the concepts of patient choice and shared medical decision-making.

Current work includes the following.

- Randomised controlled trials of interactive videos on benign prostatic hyperplasia (BPH) and benign uterine conditions (BUC) and hormone replacement therapy (HRT) in general practice in London and Oxford.

- A survey of consumer health information services which assessed the extent of public use of information services to obtain clinical information, and evaluated five development projects aimed at improving the effectiveness of the services providing it. (A report will be published in this series later in 1996.)

- The development of new patient materials covering a range of conditions and communication technologies:

  - a multi-media programme on incontinence with CD-i and leaflets;
  - an information package, including leaflets, a video and a CD-i for patients with colorectal cancer;
  - a video and leaflet outlining treatment options for inflammatory bowel disease;
  - a computer-assisted learning package for children who wet the bed;
  - an information pack with video for post-operative pain control;
  - a trial of the new US interactive video on HRT;
  - materials in four languages for Asian women with anxiety and depression;
  - a Department of Health-funded project to develop and evaluate a video and a leaflet to help women with menorrhagia choose the best treatment options.

Work has begun on the development of a database of people interested in patient information and on exploring the feasibility of making information available on the Internet.

In April 1995 the King's Fund's Clinical Change Programme, which leads these initiatives, was commissioned by the NHS Executive Patient Empowerment Focus Group to run a seminar to help identify the key elements of a strategy for patient empowerment in the NHS. Most of the material used in this publication was generated by that seminar. Recommendations were developed from this work and the wider King's Fund work. These recommendations are given at the end of Chapter 6.

The authors are aware that, in a field which is moving so rapidly, many new contributions have been made to the debate since the core work for this publication was done. However, the major challenges are still there to be tackled. Patients and users are still waiting to be treated as equal partners in their own health care. This publication reviews the issues and aims to inform managers, professionals, voluntary and public agencies about processes which they might use to achieve greater patient and public involvement in health care decisions.

Chapter 2

Defining terms and concepts

One of the few things on which all recent authors of texts about patient and public involvement agree is that there is no agreement on either the use or definition of relevant terms. This applies equally to the terms used for users of health services (patients, clients, consumers), and for the acts in which their participation is sought (consultation, involvement, engagement). In recent publications there is agreement about the need for clarity of terms, but all use different definitions and conventions, often using words interchangeably.

It is important at the outset to make a conceptual distinction between *individual* and *collective* involvement in health care. Individual involvement is about individual patients and their encounters with individual clinicians during episodes of illness or care. Collective involvement is about participation of *groups* or *communities* in health care planning and/or service delivery. There is a grey area in the middle where individuals may be participating in discussions about policies, planning and service delivery, and where groups may be involved in discussions about individual treatments, but theoretically, at least, it is essential to separate the two forms of involvement because they usually have different objectives.

The need for this distinction of the individual from the collective is recognised in the burgeoning literature on user involvement.

Barnes & Wistow (1992) identified two broad categories of purpose behind initiatives aimed at increasing what they term *user involvement:*

- those which seek to improve the quality of services by making them more sensitive or responsive to the needs and preferences of the individuals who use them;
- those which seek to extend the capacity of users to participate in decisions about the design, management and review of services.

There is general agreement that *empowerment* itself means different things to different people. As Saltman (1994) has pointed out, an NHS manager's definition may not be the same as a patient advocate's. Professionals may see empowerment as a matter of 'giving' – the granting of something which is in their gift to bestow or withhold. Users generally feel that it is more to do with playing an active part in their own care or community. Most of the current work which aims to shift the balance of power between individual patients and their clinicians and between local communities and health commissioners is looking for ways to encourage users and professionals to work together.

Power itself could be defined at length without adding much to a common understanding of the term. A standard working definition might be:

> *'The ability to effect control by the exercise of professional or other authority, natural or invested.'*

Harrison, Hunter *et al.* (1992) point out that the logical corollary of power is *dependence*; that the two are inversely related; and that the freedom from dependence – from powerful influences – is usually termed *autonomy*.

Empowerment seems to have no synonyms. It can be described as the act of conferring authority, ability or control. As a verb, to empower someone means to confer a particular power on a person who, by definition, previously lacked it. Described this way, the word dovetails neatly with the most commonly used term for the user of health services – a *patient*. A patient is one who suffers or is passive, and therefore lacks power or control. The term *patient empowerment* could therefore be seen to have a message of equalisation in its linguistic structure.

Thus, the term *patient empowerment* is used here to describe the process of redressing the balance of power in health care between the individual receiving care – the patient – and the health care professional in a provider setting.

Every commentator on the current scene has their own label for the people for whom empowerment is being sought. This is an area where judgements seem often to be based more on tradition and preference than any clearly defined understanding; and use of alternative terminology often leads to misunderstanding among those with differing perspectives. It is important to keep the debate open enough to accommodate many viewpoints and to celebrate the validity of each one. Recognising the value of people's experience of health care is, after all, at the heart of this debate. However, rational differences do underlie the use of different terms, and it is worth examining how they work.

Patient, consumer or user

In this publication, the use of 'patient' as the preferred term for individuals undergoing health care is an acknowledgement of the passivity which traditional structures impose on people in that setting. Some people would prefer a definition which emphasises the patient's potential for active participation rather than imposed passivity. The use of *patient*, however, serves as a reminder of the context of individual care in provider settings.

Whether people viewed collectively are termed 'consumers', 'clients' or 'users' (few commentators yet refer to 'customers' in the NHS) depends on the role in which they are cast by the systems in which they operate. Some authors (e.g. Saltman) observe a distinction between a *commercial/economic* approach, in which consumers exercise individual choice in a market-driven system and a *political* model in which users are given a real voice in a system which tries to ensure that their participation is integrated into all processes.

The NHS reforms, by introducing market principles into the NHS, have to some extent introduced the notion of health care 'consumers'. The extension of consumer choice to the patient is at the heart of major policy initiatives such as *The Patient's Charter* (DoH, 1991) and the publication of league tables (DoH, 1994) of hospital performance. It is also central to *Local Voices* (DoH, 1992). In 1994, Brian Mawhinney told a purchasing conference: 'We must get away from the notion that health services can be designed for the community by "experts" who define people's needs but ignore their wishes'. People, he implied, should be allowed to choose for themselves what is right for them.

Consumer choice is a tenuous mechanism for delivering patient empowerment in the system as it currently operates. The only field in which most patients can exercise choice and influence the market is in choosing their GP. Even this is only possible in urban areas with more than one accessible practice. Thereafter, choice is delegated to the GP if a fundholder, and removed still further, to a distant commissioning agency, if the GP is not a fundholder.

Saltman points out that: 'The extensive paraphernalia with which managers have begun to address the patient as a "consumer" ... reflects a fundamentally different understanding of the role of the patient than does the direct decision-making about appropriate providers made by the patient as "user".' He comments that many current management initiatives – customer care training for staff, patient satisfaction surveys – are not designed to empower patients, as many purport to do, but rather to increase the market share of their organisation. The aim is to appeal to potential purchasers – those with the real choice and the resources to effect it.

Saltman notes the following distinction, in highlighting the difference between the commercial/economic (i.e. market-driven) approach and what he defines as a political approach: 'The patient as consumer remains the compliant *object* of the service delivery system, in contrast to the patient as decision-making user, who thereby becomes the *subject* of the service system' (emphasis added). It may be argued that the transition of patient from passive object to active subject of care is at the heart of patient empowerment.

Other commentators (e.g. Donahue & McGuire, 1995) point out that by emphasising individual choice and consequent responsibility for choices made, market-led health care systems may result in accountability for poor health being laid directly at the door of the individual. These viewpoints will be considered in more detail below.

Whether the view of the patient as consumer contributes positively to the furthering of patient empowerment is a matter for debate. Barnes & Wistow (1992), among others, have argued that consumer choice tends to mould demand to the products being marketed and to interpret need in terms of what is available, rather than develop service around user-defined needs.

If *Working for Patients* (DoH, 1989) set out to create a consumerist model for the NHS, *Caring for People* (DoH, 1989) established a more participative approach. It set out to enable people to 'achieve maximum independence and control over their own lives'. It does so by creating a framework for active participation by users and carers in the assessment process for individuals, and in the design of care plans, bringing users closer to the deployment of resources – at least in principle – than any but the patients of fundholding GPs. Furthermore, it establishes mechanisms for collective involvement by putting in place a statutory requirement to consult on community care planning. While mechanisms for involving users and carers in developing service specifications and monitoring delivery may vary in their effectiveness, the principle of user involvement enshrined in the legislation is an important one. Equally, the emphasis on local relevance and user input in the development of community care charters (DoH, 1994) is very different from the approach adopted by *The Patient's Charter*.

It is perhaps unsurprising then that, while initiatives in NHS secondary care are biased towards surveys of satisfaction with existing services, the recent literature abounds with examples of attempts to develop client-led or user-led services in social services or community care settings. The terminology follows suit: this approach is most frequently characterised by use of the term *user* or – more often in social services examples – *client*.

The many perspectives from which people may approach services – for example, as citizens funding the service, voluntary or involuntary users, carers or potential users – have been dealt with in detail by Barnes & Wistow and Saltman, among others.

Collective involvement

The process of discovering what people, collectively or individually, think about services has given rise to an additional crop of terms, often used synonymously and with little precision. Discussions of different definitions of *involvement*, *consultation*, *empowerment* and *participation* have appeared in Hamilton-Gurney (1993), Barnes & Wistow (1992), Saltman (1995), Rifkin *et al.* (1988), and Richardson (1983). There is little agreement on appropriate usage – indeed some are contradictory.

Hamilton-Gurney suggests that *involvement*, *consultation* and *participation* represent a hierarchy of increasing commitment to an active user voice in either collective or individual decision-making. *Involvement* is seen as a loose, umbrella term for any area where consumers are brought into the decision-making process at any level. *Consultation* demonstrates a more explicit intention on the part of the consulting body to obtain user views, albeit with no stated commitment to act on the results. *Participation* is defined as a more active process, drawing on a wider definition of the term as 'partnership', indicative of a more dynamic function. He comments that if, as Rifkin *et al.* (1988) have suggested, 'participation is to be characterised by activity, choice, and the possibility of choice having an effect, then participation may approach empowerment'.

Richardson (1983) defines *participation* in terms of involvement in the democratic process – the extent to which, either as individuals or as members of a social structure which supports a publicly funded service, people are able to influence the course of decision- or policy-making. However, this use does not enable a distinction to be drawn between activity involving people who are currently using services and the wider interest of those potential users who also fund it. In this publication *participation* is used to describe the highest level of activity undertaken by people currently using services. Bringing the wider community into the question of democratic interest has been characterised by Sullivan (1994) as *public engagement*. Using this term allows the distinction between current users and the wider community of taxpayers and potential users.

In the end, the many-sided nature of patient empowerment and user participation is such that no one definition will cover all angles to everyone's satisfaction. Selecting terminology on rational grounds should at least serve to clarify the basic concepts involved in the current debates.

Some movement towards consensus about the meaning of the term *patient empowerment* was achieved during the King's Fund workshop in April 1995. Discussion of the term produced a definition to which all participants felt they could subscribe:

> '*A process (or processes) of giving people the knowledge and skills to make it possible for them to become active partners, with professionals, in making informed decisions and choices about their own treatment and care; and of enabling communities to exert informed influence on NHS service planning, development and delivery.*'

There were two important riders to this definition:

1. Not everyone wishes to be involved in this way and the process must recognise this.

2. Not everyone starts from the same place and the process should take account of different needs.

It is interesting to note, however, that not long after this definition was found to be acceptable, the NHS Patient Empowerment Focus Group changed its name to the Patient Partnership Steering Group.

Chapter 3

Patients and the NHS: the current situation

The NHS reforms have given providers in primary and secondary care the responsibility for managing the treatment and care of individuals and the environment in which care takes place. It falls to providers to ensure that their services meet the needs and expectations of patients. What practical changes can providers make to the way services are delivered which will give greater control to users? What can be done to give patients a real sense of confidence in their ability to act autonomously? There is a wealth of evidence that the NHS plays fast and loose with the time, dignity and autonomy of some of the people who use it. The case studies in the Health Service Commissioner's Report illustrate only a fraction of the daily distress caused to patients and their families, adrift in a system designed for its own convenience, not theirs. How are NHS providers trying to change the systems which disempower people receiving care and prevent local communities from taking part in discussions about local service provision?

The policy context

The Patient's Charter is arguably the most important mechanism for patient empowerment to emerge from the reformed NHS. However, its value is far from being universally accepted. Arguments against it tend to focus on the lack of consultation on the standards it established, especially in its original version. This criticism is heard not only from patients' organisations but just as loudly from providers, whose practical difficulties the *Charter* does not consider. Provider participants at a *Patient's Charter* seminar (Birmingham Health Services Management Unit, 1993) were keen to point out that the combination of a high political profile, and public expectations raised far in advance of providers' capacity to deliver improvements, had created an arena for widespread dissatisfaction. The more flexible, bottom-up approach of the primary care version (DoH, 1993) and the approach taken to local community care charter development (DoH, 1994) suggest that note has been taken of earlier criticism.

But despite its problems *The Patient's Charter* has led to improvements in some aspects of quality, particularly in the so-called 'hard standards' – the quantifiable performance measures now published annually as a league table of hospital performance. Published figures and visits from the Audit Commission have sharpened many minds and have overcome even the acute difficulties entailed in meeting and monitoring *Charter* standards.

Implementation of the 'soft' standards has been subject to much less pressure. In a culture dominated by performance targets, the difficulty of quantifying progress in these areas has tended to undermine them: investment of time and effort has been concentrated on areas where success can be readily demonstrated. 'Soft' standards have consequently been less systematically implemented, despite a range of attempts to provide guidance and basic performance measures (e.g. Andrews & McIntosh, 1992; Gilbert, 1994). This is not to say that they have been neglected. *Charter News*, the NHS Executive's regular bulletin, is filled with initiatives such as redesigned hospital gowns and better food for patients from minority ethnic communities. Often starting with the slimmest pump-priming monies, these projects are, more often than not, led by staff working close to the patient (frequently nursing staff or therapists) and based on patient involvement.

In addition to *The Patient's Charter*, the reforms have generated a number of mechanisms designed to improve quality and, to some extent as a by-product, patient satisfaction. A whole quality industry has grown up in the health service, with the ostensible aim of improving service for patients as well as potential purchasers. There is an encouraging amount of work in progress to improve the quality of services to patients (the NHS Executive's *A to Z of Quality* (1993) illustrates only a small sample). Quality standards in contracts are proving a qualified agent of change, particularly in the hands of GP fundholders. This process increases in potency where there has been consultation with patients about what the standards should be. However, the fact that quality plays second fiddle to activity measures is a powerful rider. The best-intentioned purchasers can invest only small change in the pursuit of quality for its own sake, and without that investment many providers are unable to implement even the most obviously needed improvements in process or access. While quality is, in theory, free (Crosby, 1979), many providers find themselves so hampered by traditional poor practice that they cannot release staff time and energy to solve their problems. Staff and patients continue to suffer, and resources which improved quality would release, remain entangled in wasteful processes.

The NHS reforms were characterised by the widespread use of quality systems such as BS5750 and ISO9000 and a proliferation of home-grown quality strategies. Quality management has an entire literature of its own which falls outside the scope of this discussion. Øvretveit's (1992) introduction to quality methods provides a useful contemporary overview of principles and practical issues. Although often beset by management jargon and having little credibility with many clinicians, these strategic approaches at least represent a move towards the systematic consideration of patients' interests where they are seen to coincide with the interests of the organisation. Saltman's (1994) analysis suggests that altruism in managers is a rare attribute! Quality initiatives tend to remain localised and low-key, the preserve of small bands of enthusiasts; while activity on the one hand, and clinical freedom on the other, retain their pre-eminence at the top of the organisational hierarchy. Quality needs to come of age; there needs to be recognition, underpinned with investment, that improving quality of service to patients is of primary significance to the success of organisations. So far, the NHS has acquired the language of quality, but efficiency targets and short-term performance goals mean that effective action and genuine commitment rarely keep pace with the rhetoric.

Clinical services

Both *The Patient's Charter* and local quality systems confine themselves almost exclusively to non-clinical aspects of care, and we consider those aspects in more detail below. However, if quality policies are to be serious tools for effecting patient empowerment, they will have to pay much greater attention to the patient's view of clinical aspects of care. The reforms have chosen to reinforce the accepted argument in favour of professionally dominated audit activity. *Working for Patients*, in determining the future shape of medical audit, states that: 'The quality of medical work can only be reviewed by a doctor's peers' (DoH, 1989). However, this view is increasingly losing ground in the face of challenges by vocal and articulate user organisations. Recognition of the validity of patients' involvement in both assessing quality of treatment and demanding clinical effectiveness is gaining currency. Dunning & Needham (1994) bring together a number of arguments supporting the need for user participation in areas from which non-professionals have traditionally been excluded.

Involvement in research

Until recently the only area in which non-professionals had any scope for influencing research was as lay members of Research Ethics Committees. Established in the mid-seventies as a response to public concern about rapid advances in medicine and clinical trials, they have generally been appointed on an *ad hoc* basis to provide flexibility and local appropriateness. However, lack of national guidance on their operation has led to widely differing practice and patchy lay membership, and left them open to criticism: 'suffering from too many flaws, lacking sanctions, operating behind closed doors and often failing to follow guidelines' (Neuberger, 1992). New guidance was issued in 1991 (DoH, 1991) providing for at least two lay members, one of whom should be appointed chair or vice-chair. It has been argued (Brotchie & Wann, 1992) that if lay members are to make a full and valued contribution, they need training in committee skills and research protocols, as well as support networks such as those provided by CHC membership.

There is evidence (Stiller, 1994) that cancer patients who take part in clinical trials have better outcomes, measured in terms of survival rates, than those who do not. Despite this evidence, less than 5 per cent of cancer patients who are asked agree to take part in trials. Why is this, and how can people be encouraged to participate in trials which may positively influence their prospect of survival? One factor may be the language and format in which trials are explained to patients. Patients are liable to drop out of studies when they experience side-effects of treatment and other disadvantages which were inadequately explained to them. The methods researchers use to obtain informed consent are coming under increasing scrutiny (Maslin, 1992).

The language in which some researchers have seen fit to explain trial details to patients would at times be laughable if its consequences were not so important. The following quote, reproduced in full for its stunning effect, is from a publication designed to help researchers write more clearly (Consumers for Ethics in Research, 1994):

> *'After commencement of oral administration, the patient's progress will be assessed and he or she will frequently be investigated to verify the occurrence of adverse reactions at ambulatory monitoring sessions to suit his or her convenience while lengthier interval monitoring will be accepted if he or she has not previously displayed any tendency to be predisposed to toxicity ... Those who are unable to adhere to the regime as a consequence of malfunctioning or adverse effects or who feel unable to continue to support the objectives of the protocol before the trial is accomplished may terminate their participation and shall be assured that despite declining to continue to participate their routine clinical treatment will be in no way affected and that they shall not be interrogated about their motives'.*

One method of promoting involvement is to design trials around patients' own treatment preferences. Brewin & Bradley (1989) suggest that the patient's own preference or disinclination for a treatment may well bias the results of a trial in which the patient is asked to play an active role in complying with treatment. They suggest fitting patients to treatments by asking them to choose the one that they feel suits them best, thus giving the patients optimal motivation in complying with the treatment. A study in Sheffield (Knight, Boulton *et al.*, 1984) of self-management methods for people with diabetes focused on patients' preferences and the reasons for their choice. The researchers were then able to make recommendations for better patient education to help patients decide which treatment would be best for them.

The most radical attempts to empower patients in the context of research have been generated by patients themselves. The seeds of this development were sown initially in 1990 when results of research into complementary therapies at the Bristol Cancer Help Centre were challenged by breast cancer patients, angered by the minimal attention paid to ethical aspects of their involvement (Goodare & Smith, 1995). More recent work has gone one step further, by involving patients in the design of trials themselves. Building on the core principle of developing patients' role in research (Thornton, 1994), the Consumers Advisory Group for Clinical Trials (CAG-CT) has been established, working with clinicians and researchers in involving patients in trial design and patient information. A current study at the Royal Marsden Hospital is working with the CAG-CT to identify issues of importance to menopausal women with breast cancer receiving HRT. The trial can then be designed to take account of factors women themselves perceive as relevant, including the careful design of information and consent forms. Early experience from another study at Mount Vernon Hospital suggests that, in addition to increasing compliance and satisfaction, time and money may be saved in the long term if patients are consulted earlier rather than later in the design of research proposals (Bradburn, Maher *et al.*, 1995).

Failure to design trials which patients perceive as relevant to their needs is not the only way in which the research agenda may bypass patients' needs. Often, the results of research indicate that one treatment is more effective than another: the use of one would secure better outcomes for patients who received it. Haines & Jones (1994) point to the role which better-informed patients could play in asking for evidence-based medicine of proven effectiveness. They cite the Interactive Video Shared Decision-Making Programs as an example of evidence-based patient information. There is growing interest in the development of similar materials. Six projects currently funded by the King's Fund Development Centre are designing other means of providing effectiveness information to patients in order to promote shared decision-making. The Centre for Reviews and Dissemination at York has collaborated with midwives to produce a series of evidence-based information leaflets for expectant mothers. An increasing number of Consumer Health Information Services are responding to requests for information about the effectiveness of drugs and other treatments (Gann & Buckland, 1994). Many other examples could be quoted which illustrate the growing recognition that research is a legitimate area for patient involvement.

Providers who are serious about patient involvement have a range of models for encouraging patient-centred research in their establishments. However, efforts to do so are apt to be hampered by distrust. Any development in this field which is not generated by professionals tends to be seen as unwarranted trespassing on hallowed ground. Haines & Jones note the lack of common approach and beliefs between researchers and practitioners. This is multiplied in relations between practitioners and those – especially managers – perceived as challenging traditional practice. Nowhere is this discomfiture felt more than in the field of audit.

Audit and outcomes

Recent Department of Health guidance (DoH, 1994) requires providers to 'develop mechanisms to ensure successful patient/carer input to clinical audit processes.' The policy framework for involvement is therefore in place. However, practice in this instance tends to lag behind policy. Kelson (1995) notes that many doctors serving on audit groups and committees are still hostile to the involvement of lay people.

Lack of guidance on appropriate areas for lay involvement is apparent from the start of the audit cycle. Rigge (1994) comments that patients have little say in what should be audited and are rarely asked to participate in studies of the quality of clinical care they receive. She asks whether lay members should not be appointed to Audit Committees with a similar remit to their counterparts on Research Ethics Committees to approve the subjects of proposed clinical audit studies. Lay people involved in audit certainly face similar problems to those identified by Rigge (1994) and Brotchie & Wann (1992) in respect of Research Ethics Committee members: hostility, marginalisation, lack of support and training.

Rigge suggests that there should equally be a role for the patient at the end of the audit cycle. Noting the considerable resources committed to audit activity, she asks whether, in the interest of public accountability and in the spirit of *The Patient's Charter*, the results of studies should not be published by Audit Committees – or at least made publicly available. Kelson's (1995) review also points out that no guidance has been given about when or whether users should be involved in discussions about results from the audit process.

Joule (1992) makes it clear that the user has a legitimate role in every stage of the audit cycle: selecting the study topic, setting criteria and standards, monitoring, disseminating findings and implementing change. Her recommendations have earned the support of the Department of Health's Clinical Outcomes Group. Nonetheless, this is an area where it is hard to find successful examples of good practice.

The College of Health's system of Consumer Audit (College of Health, 1994) is designed to complement scientific clinical audit using a range of qualitative methods. It obtains the views of patients and other service users, as well as those potential users who have been unable to obtain services. This system has also recently been endorsed by the Department of Health and distributed widely. Consumer Audit records subjective areas which are important to patients, but often ignored by professionally led audit studies. Growing use of the system has revealed that 'those best placed to inform about access, process and outcome – some of the key elements of clinical audit – are patients themselves'.

Audit has traditionally been approached from the standpoint of natural science, in which only those factors empirically measurable are held to be worth considering. This has meant that the subjective elements of patients' experience of ill health and treatment have routinely been excluded from studies of outcome. Examples where patients have been actively involved in defining outcome measures for clinical audit are hard to find. Routine attempts to obtain patients' views of care have tended to concentrate on process measures: on what Pound *et al.* (1994) characterise as 'the hotel aspects of health care or the personal qualities of staff'. The patients in Pound *et al.*'s study were in fact more concerned with the outcome of treatment, in terms of physical recovery, than peripheral aspects of care.

However, despite the slow pace of change, the definition of outcome has expanded in the last decade to include patients' assessment of their own health and their evaluation of the care and services they receive (Ross Davies, 1994). The integration of patients into clinical audit is made easier by the development of multi-dimensional health status profiles. These instruments are designed to assess patients' own response in different dimensions to the outcome of care. Ross Davies offers a model of health status which accords with the instruments she cites (EuroQOL and SF-36); it could be extended to others such as the Nottingham Health Profile and Functional Limitations Profile. But we might ask whether even the advance that these measures represents is sufficient to ensure patient involvement in this field. Ross Davies points out that (despite widespread statements of commitment to continual quality improvement) most organisations still concentrate on one-off measurement or piecemeal monitoring of outcomes. These are far easier to accomplish than systematic and routine audit cycles, which ensure that outcomes are managed: that is, that clinical and administrative processes are systematically improved so as to produce outcomes that patients identify as desirable.

Organisational issues

The aim of user involvement is to enable patients to feel 'confident, competent and in control' (Liddle 1991) and for communities and groups to exert influence on services. In practice, the way in which many aspects of care and treatment are provided clearly detracts from this aim. Areas where improvements are required can be found throughout the health care system. Patients, patients' representatives and the staff who work with them are often well aware of what is needed and all too aware of the operational obstacles. Shortfalls in service delivery are well documented in the complaints files of trusts and FHSAs: the Health Service Commissioner's Reports record only the most striking examples of non-clinical mishandling of patients.

Patient's Charter rights and standards illustrate at least some of the areas in which improvement is needed if patients are to feel confident as they travel through the complexities of the system. Local charters and those specific to different user groups (e.g. NAWCH, 1988; Cancerlink, 1994) give an additional catalogue of areas both general and specific where people feel their rights in need of safeguard. The particular needs of patients from minority ethnic groups are amply documented (e.g. Hopkins & Bahl, 1993; Henley, 1991), but less successfully addressed (Chan, 1994; Smaje, 1995).

People with a sensory or physical impairment and those with mental distress or learning disabilities approach the NHS from a position of dispossession greater than many others. Their rights to a service which treats their needs with respect requires even more careful consideration (Begum & Fletcher, 1995). Advocacy schemes and Patients' Councils are an important step to finding out what users need by listening directly to them.

Even if progress is slow at times, *The Patient's Charter* has brought about improvements. GPs seem as keen as hospitals and community services to demonstrate commitment to greater responsiveness, whether by improved waiting rooms, appointment systems or patient participation groups. The NHS Executive's *A to Z of Quality* and *Charter News* have already been mentioned: both illustrate examples of more responsive service delivery which represent only the tip of the iceberg of national effort. Weekly publications such as the *Health Service Journal*, *Nursing Times* and *Community Care* regularly feature reports from successful initiatives, as do some peer-reviewed journals (e.g. *Quality in Health Care*, *British Medical Journal*). It is clear that many of these have worked because their methods were appropriate to their local situation. What works in one area with one set of constraints will not necessarily be applicable elsewhere, but there is a wealth of experience which providers can use in their own localities.

Strict observance of *Charter* rights and standards is one way for providers to reorganise their service for patients' benefit. Another has been successfully demonstrated by many Nursing Development Units (Copperman & Morrison, 1995). A third more radical – and controversial – solution is offered by recent moves to restructure the care process along patient-focused care principles. An increasing number of hospitals are pursuing this experiment at different levels – from a single discipline to multi-directorate change. The projects aim to redesign services around the patient's convenience, bringing formerly centralised functions like pathology and medical records down to ward level. They also rest on the use of clinical practice guidelines (McNicol *et al.*, 1993) documented by a single multi-disciplinary record to which the patient has access: a far cry from the frustrations of gaining access to traditional notes.

Patient satisfaction surveys are now in widespread use. They vary greatly in value and effectiveness, and only the minority are scientifically designed. Results can thus be highly questionable (Thompson, 1989); however, the best examples provide useful snapshots of user experience and helpful indications of necessary improvements. The same can be said of focus group methods. Almost every health authority now seems to be using this technique as a method of consultation but there are indications that it is not used as rigorously as it should be; and there are few evaluations of its effectiveness. Health panels and citizens' juries are increasingly seen as ways of involving communities in health care planning and prioritisation but their use and evaluation are at an early stage (Stewart, 1996).

Although not all quality improvement initiatives set out to promote patient empowerment, it could be argued that any measure which reforms process, and thereby smoothes the user's passage through the system, will improve both their experience and their confidence in the care-giving team. But if that confidence breaks down or something goes wrong, do we empower patients to complain without fear?

Complaints

It is a fundamental right of patients – especially in a system which views them as consumers – to make a complaint without fear of retribution. However, few would argue that NHS complaints procedures defend the rights of patients. The traditional system which was reformed with effect from April 1996 seemed often not to serve anybody's interests. Professionals saw themselves as subject to arbitrary attack from increasing numbers of demanding patients. Patients soon realised that the system was stacked against them in principle and in practice, offering no redress even when a complaint was upheld.

The Association of Community Health Councils of England and Wales (ACHCEW) has been demanding reform of the complaints procedure since 1989. CHC staff are in a unique position to observe the damage done to both sides of a dispute under the traditional system, although the balance of grievance has generally rested with the patient. This is especially so in primary care, where formal complaints have been subject to a quasi-legal service committee hearing. These committees were designed to find out whether the professional had breached his or her terms of service, not to address the grievances of the complainant. Inaccessible procedures and rigidly operated time limits have meant that a would-be complainant might lose the opportunity to complain before discovering how to do it. Complainants have had no statutory right to CHC representation at hearings, although the style and format could be formidable and daunting to a lay person. In practice CHC staff are still the only people likely to provide informed patient representation, although they are not formally trained for this role. Practitioners were generally represented by trained secretaries to local professional committees. If a case went to appeal (which could take many months), the untrained CHC representative, or even the patient, faced a solicitor or even a barrister. The complainant had no guaranteed access to legal aid for professional representation. In only a minority of cases was the practitioner found in breach of his or her terms of service. Belated knowledge that a small sum might have been withheld from the doctor's remuneration was scant consolation to the complainant.

Former hospital procedures were always less rigidly enacted and generally less formal. However, they could be frustratingly inconclusive. Unlike primary care systems, they did not exist to discipline doctors. Complainants could still be left with unsatisfactory answers and little redress. Even if a clinical complaint progressed to independent professional review, the complainant had no right to know the outcome. Before the introduction of the new complaints procedure in April 1996, the Health Service Commissioner was only empowered to investigate procedural issues, not matters of clinical judgement. The reforms were long overdue.

However, it seems that complaints are at last being taken seriously as a vehicle for listening to patients' needs. First, *The Patient's Charter* right to swift investigation and a prompt reply from the chief executive has raised the profile of complaints handling. Most providers now have 'suggestions and complaints' leaflets available. Many have altered their approach to complaints handling, with a greater emphasis on informal discussion and conciliation. Many hospitals are now appointing patient's representatives, giving a point of personal contact and support to unhappy patients. While lacking the formal independence of a CHC representative, they have the great advantage of instant access. Patients' representatives who acquire credibility in their workplace can be powerful advocates and change agents. Of course, a higher profile generates more complaints, and this aspect of patient empowerment needs to be recognised. Providers are justifiably wary of introducing good practice while purchasers still publish league tables of complaints performance which favour low scores.

The reformed complaints system has generally been welcomed as a step forward, although note should be taken of ACHCEW's concerns that review panels might screen out serious complaints, and that the CHC function might be set up for redundancy in the reformed system. It is important that the role of CHCs as independent advocates for complainants is recognised and supported. In the field of complaints as elsewhere, CHCs have done more than any other body to bring about patient empowerment.

Chapter 4

Individual patient involvement

Patient involvement at an individual level is about enabling people to move towards more active participation in their own care and treatment. The following sections look at the issues which need to be addressed in order to make this happen.

External influences on doctor-patient relationships

Policy

The current policy framework is geared towards strengthening the concept of the patient as consumer: one who exercises choice and thereby drives the market. Some commentators have challenged this analysis. Blaxter (1993), summarising the comments of several other researchers, argues that in a market model a consumer must have:

- adequate information and a practical range of alternatives;
- competence to make rational choices;
- the opportunity to exercise choice;
- readiness to make quality comparisons;
- protection by legal rights and possibility of redress.

Numerous criteria are identified which distinguish the individual user of health services from the true consumer. These include the limitation of choice (e.g. by geographical differences in access to services); the powerless position of the patient at the time when choice is most necessary; the gap in knowledge between patient and service provider; and uncertainty about what constitutes the best 'product choice' in many situations.

Nevertheless, a series of active initiatives to promote consumer rights has been implemented in recent years. *The Patient's Charter* is the most forthright in assigning rights to patients and their families. NHS patients now have rights to many things. To quote the *Charter:*

> *'You [the patient] have a right*
>
> - *to receive health care on the basis of your clinical need, not on your ability to pay, your lifestyle or any other factor;*
> - *to be registered with a GP and to be able to change your GP easily and quickly if you want to;*
> - *to get emergency medical treatment at any time;*

- *to be referred to a consultant acceptable to you, when your GP thinks it is necessary, and to be referred for a second opinion, if you and your GP agree this is desirable;*

- *to choose whether or not you want to take part in medical research or medical student training;*

- *to have any proposed treatment, including any risks involved in that treatment and any alternatives, clearly explained to you before you decide whether to agree to it;*

- *to have access to your health records [...];*

- *to have any complaint about NHS services (whoever provides them) investigated and to get a quick, full written reply from the relevant chief executive;*

- *to receive detailed information on local health services. This includes information on the standards of service you can expect, waiting times, and on local GP services.'*

Some of the practical obstacles to patients exercising their rights as consumers have already been considered. Some commentators (e.g. Saltman, 1994 and Winkler, 1987) have seen consumer rights as specious in the absence of resources directly linked to the exercise of consumer choice. Others (e.g. Donahue & McGuire, 1995) have gone further. Behind the concept of the individual consumer exercising choice, they see a tendency to attribute responsibility to the individual for choices made. This extends to blaming individuals who are perceived to have made the wrong choices, irrespective of the complex social circumstances which may have influenced them. This applies particularly to lifestyle choices, where factors contributing to poor health are often seen as avoidable – as in the case of smokers who contract lung cancer or coronary heart disease. This approach has already had an observable impact on access to care: the Manchester man denied cardiac surgery due to his inability – or refusal – to give up smoking was one prominently publicised example. It might reasonably be asked how meaningful his *Charter* right was to 'receive health care on the basis of clinical need'. Certainly, in advance of any legal test of the standing of *Charter* rights, it is perhaps premature to assign them too great a significance as agents of change. However, they do imply a greater readiness to view medical practice in terms of patients' rights, and consequently represent, along with new management practices, what Teff (1994) describes as a 'pronounced threat to the dominant tradition'.

Law

To what extent does the law recognise patient's rights within the doctor-patient relationship, with or without the safeguard of *The Patient's Charter*? Lord Scarman has noted that: 'The law so far as it concerns the doctor-patient relationship has been, at any rate within the United Kingdom, static for a number of years, indeed for a number of generations'. (Byrne, 1987). Teff notes that the tradition of benevolent paternalism is supported by the courts, and that, in matters of civil liability, British courts are still broadly willing to let doctors set their own standards.

However, despite widespread challenge to the traditional basis of the doctor-patient relationship, there seems to be little evidence of legal principles adapting to accommodate changing social expectations. Teff (1994) observes that there is growing criticism, notably though not exclusively from outside the medical profession, that the patient's voice is insufficiently heard and that the legal system fails to recognise patients' rights. While warning against a confrontational assertion of rights likely to damage individual doctor-patient relationships, Teff notes the need for a shift away from the paternalistic model, based on a medically defined concept of patients' welfare, to a 'therapeutic alliance' which places greater emphasis on patients' rights. He argues that the most obvious scope in law for this change lies in the field of negligence, with especial regard for decision-making and consent.

Currently, liability for negligence is more a mechanism for regulating doctors' conduct than addressing patients' rights. Doctors are required to 'have skill appropriate to their work and exercise due care in undertaking it'; the implicit aim of their work, endorsed by the law, being to promote patients' welfare. The criterion of due care is articulated in the *Bolam* principle (Lord Scarman, 1957):

> '*A doctor is not negligent if he acts in accordance with practice accepted at the time as proper by a responsible body of medical opinion, even though other doctors adopt a different practice ... The law imposes a duty of care, but the standard of care is a matter of medical judgement*'.

Teff argues that a more appropriate test of negligence would be: 'failure to attain a standard of care which is reasonable in the circumstances', and that this should entail consideration of the circumstances of the individual patient.

This argument is particularly pertinent to patients' rights in the field of consent (on which there is an entire body of literature outside the scope of this discussion). According to Brooke & Barton (1994), English law is unlikely to apply any particularly rigorous test of a patient's capacity to understand what he or she was being told before deciding whether the patient in fact gave consent. According to the *Sidaway* judgment (1985): 'The decision about what degree of disclosure of risks is best calculated to assist a particular patient to make a rational choice as to whether or not to undergo a particular treatment must primarily be a matter of clinical judgement'.

Hence, the ruling in the case of *Gold* vs *Haringey Health Authority* (1988). The plaintiff had become pregnant with a fourth child after undergoing a sterilisation operation. She complained she had not been warned of the failure rates of such operations. The Court of Appeal ruled that at the time of the operation there was a substantial body of responsible doctors who would not have warned her about the failure rates. Her claim for damages for negligence therefore failed.

Teff comments that, even in those systems which accept a doctrine of informed consent (i.e. 'consent based on disclosure by the doctor of such information as would be deemed material by a reasonable person in the patient's position'), subjective considerations of importance to the patient may be given insufficient attention by the Courts. He argues for a negligence framework based on a model of 'collaborative autonomy' in the doctor-patient relationship: an analysis 'conducive to the maximisation of patients' welfare at the same time as affording due respect for patients' rights'.

It might be added that the obtaining of material compensation, as well as satisfaction in principle, is tied to the exercise of these judgments. Inability to prove negligence may leave patients with overwhelming physical and financial hardships. The Association of Community Health Councils for England and Wales (ACHCEW) has noted the 'serious difficulties and dangers' patients face in pursuing negligence claims through the courts, whether to obtain financial compensation for medical accidents or an admission of guilt. In their submission to the Wilson Complaints Review Committee (1994), ACHCEW proposed that the Government establish a formal review, 'to focus on the whole area of compensation in relation to health care'.

Some optimism has been expressed (Evans, 1994) that the emphasis of future legislation may shift the balance in favour of protecting the rights of patients as well as other consumers. Nonetheless it would seem that, while the law continues to endorse the traditional model of the doctor-patient relationship, prospects for change from this quarter are slight. There is real scope for action here.

The dynamics of doctor-patient relationships

The traditional model of the doctor-patient relationship upheld by the courts is one of benevolent paternalism. With the invested power of the professional, the doctor decides unilaterally, in the interests of the patient's welfare, what treatment should be provided and presumes how much the patient wants or needs to know (Teff, 1994). It is by virtue of their role as initiates, custodians of information inaccessible to others, that doctors can exercise this power. The principle of beneficence on which the doctor-patient relationship is based relies on doctors themselves to define what may or may not do good. Failure to involve patients in their treatment has almost been considered a virtue – a protection of patients from concerns they might find distressing or needlessly worrying. Yet many patients do want to be involved in decisions about their care and may positively benefit from this involvement. The following factors have been identified as those which may be used to change the traditional doctor–patient relationship balance in favour of a more active patient role.

Information and communication

Information is power, and there is ample evidence that people do want information about their condition(s) and treatment. There is evidence that they may feel better if they are given more information and feel more in control. It has also been found that some people wish to take an active part in making decisions about their care, and that they may even feel better (or at least less unwell) if they do.

The desire for information is apparently independent of social or other factors. Vertinsky *et al.* (1974) found that, while no single factor could predict whether a patient would take an active or passive role in their relationship with their doctor, patients do wish to receive information from doctors. Another American study (Kaplan, Greenfield & Ware, 1989) found that, however they chose to measure health (clinically, behaviourally or subjectively), there was a strong link between better doctor-patient communication and better health. The strongest indicators for improved health were: a greater sense of patient control in the consultation, more information provided by the doctor, and more feelings – even negative ones – displayed during the consultation. Perhaps a greater degree of honesty in the relationship, expressed through a greater willingness to share doubt or conflict, makes the relationship less unequal and more satisfactory to the patient.

The same group of researchers (Greenfield & Kaplan, 1985) found that patients who were coached to interpret and understand their own medical records proved twice as effective in obtaining information from their doctors than a control group receiving standard information. This reinforces the importance of another piece of research (Street, 1991) which found that doctors respond to patients' requests for information more than they volunteer it. The amount of information patients receive depends a lot on their own communication style; however, doctors can encourage patients to be more questioning by adopting an open and 'partnership-building' manner. These findings place a considerable onus on the doctor to revise the traditional approach to communication with patients. Perhaps the most significant research in this context is reported by Brody *at al.* (1989), who found that patients who perceive themselves to have taken an active part in their consultation report better alleviation of symptoms and more improvements in their general state of health, than patients who see themselves as passive.

The message from this important body of work is clear: the doctor's own manner contributes to the amount of information requested and given. The provision of information, and an active patient role in the consultation may be linked to better outcomes. This is a powerful argument for improving both communication and information in order to redress the traditional balance of power between doctors and patients.

Decision-making

Good information and communication between doctor and patient are not the only determinants of how treatment decisions are made. In the present context, another key factor is the extent to which the patient is prepared or permitted to act autonomously in the consultation. Woodcock & Francis (1992) put forward a model of decision-making styles which articulates the range of possibilities from the doctor's perspective. Starting from the traditional, prescriptive end of the decision-making spectrum, it moves from *deciding & telling*, *deciding & selling* and *deciding & consulting*, through *proposing & consulting*, *consulting & deciding*, *consulting & steering* to *defining & delegating* at the non-directive, patient empowerment end.

From the patient's perspective, Vertinsky *et al.* (1974) identify three types of relationship: *activity/passivity*, *guidance/co-operation* and *mutual participation*. They found that, while the patients in this study were happy to some extent for doctors to make medical decisions for them, many wished to participate in the decision-making process. Different research teams have produced varied findings as to the proportion of patients who wish to take an active part, and their reasons for doing so. Ende *et al.* (1989) found that while patients do want information, there is a general preference for letting doctors decide, with age and severity of illness being key predictors of a more passive approach. Other studies (e.g. Strull *et al.*, 1984 and Fallowfield *et al.*, 1994) have also concluded that the desire for information may be stronger than the desire for autonomy and that patients should also have the right to decline to participate in decision-making. In the context of the doctor–patient relationship we need to ensure that the many people who would choose to participate actively are given the opportunity to do so and those who do not are not obliged to be more active than they wish.

Treatment choices

The recent movement towards evidence-based practice suggests that treatment choices should be based on published evidence about the likely outcome of different options. Current research indicates that this does not happen often. Hammond (1995) indicates that doctors may rely more heavily on their own experience or that of colleagues, tradition, practice laid down by their medical school and other subjectively evaluated criteria, than on the evidence of outcomes supplied by research.

A review of literature on variations in hospital admission rates by Sanders, Coulter & McPherson (1989) highlights the commonly observable variability between patterns of disease in different communities, the treatments which are prescribed to remedy them and the outcomes of those treatments. This variability led John Wennberg, an influential US epidemiologist, to coin the phrase 'geography is destiny'. For many patients, what happens to them depends more on locally accepted practice than rigorous clinical evidence.

Blaxter (1990) has pointed out that: '... health is a subjective state, and individuals have information about their symptoms and feeling states which only they can give'. Many doctors do now recognise the value and validity of patients' subjective experience, and seek to accommodate it in clinical decision-making. Kassirer (1994) notes the importance of individualising decisions, especially when they involve choices between possible outcomes that may be viewed differently by different patients. In such cases, he says, we should identify patients' preferences scrupulously. This is particularly the case in areas where clinical practice guidelines are gaining currency, both (notably in the USA) in pursuit of defensive medicine, and more generally in pursuit of improved outcomes. There is a concern that standardised practice, in offering better outcomes to the many, might reduce choice for those whose individual preferences do not conform to a professionally defined norm. The forward-thinking doctor will help patients assess the degree of risk entailed in any procedure, standardised or otherwise, so as to arrive at a decision which feels right to both.

There is an increasing body of work in this country and elsewhere devoted to finding means of presenting information to patients about the risks and benefits of different treatment options available to them. In some cases the materials used confine themselves to giving basic information about condition and treatment, and resort to generalities to explain possible risks. A survey by the King's Fund Development Centre (Hyatt, 1994) found only a tiny proportion of patient literature which was evidence-based and updatable, unbiased and readily accessible.

Hard data alone may not be enough to enable patients to deal with the implications of different choices for their own circumstances. The way in which data are presented may influence patients' views to a considerable extent. McNeil *et al.* (1982) found that the way in which outcomes were framed affected the expressed preferences of both patient and control groups: the attractiveness of one treatment over another was greater when information given consisted of life-expectancy data (i.e. the average number of years patients live after the treatment) rather than cumulative probability data (i.e. the probability of survival or death at one, three and five years after the treatment). Treatments whose outcomes were expressed in terms of probability of living were preferred to those expressed as probability of dying. O'Meara *et al.* (1994) found that patients who had suffered a deep vein thrombosis were unwilling to accept even the very small short-term risk of intracranial haemorrhage and death associated with experts' preferred treatment. They note that: 'A high risk of a swollen painful leg did not seem nearly as frightening as even a small risk of a haemorrhagic stroke'. Equally, McNeil *et al.* (1978) found that many lung cancer patients were not prepared to gamble with the risk of operative mortality entailed in surgery even though the long-term survival rates were better than for radiotherapy (which lacks the short-term risk).

The problem is that such findings may run counter to the doctor's inclination to offer those treatments which offer the greatest life-expectancy (O'Brien, 1986). O'Brien comments that: 'The distribution of risks and the patient's attitude toward such risks is not in general a consideration. Yet to ignore patient preferences on risk might be to include people in treatment gambles that they may prefer to avoid'.

Increasing attention is being paid to the development of materials which will facilitate genuinely shared decision-making, and hence promote patient empowerment by paying attention to precisely these issues. Perhaps the most developed example of such materials is the series of Interactive Video Shared Decision-Making Programs produced in the USA (Kasper, Mulley & Wennberg, 1992). The programmes grew out of Wennberg's work, referred to earlier. Each programme addresses a particular condition, and presents personalised information to the patient about the risks and benefits of different treatment options for a person of their age and symptom severity. Outcomes data are derived from large, systematic outcomes studies, and risks are framed in different ways to avoid bias.

In addition to hard data, patients see interviews with previous patients who have lived through the decision they themselves are facing. Watching different people's subjective reactions to their decision and its results helps patients understand their options in the context of their own life. Having watched the basic information, patients viewing the videos can choose whether to learn more about different aspects of the treatments available. Then they decide what to do on the basis of their own lifestyle and preferences, whether autonomously, with their doctor, or leaving the decision to their doctor. The systems encompass many of the factors already identified as contributing to patient empowerment: access to as much evidence-based information as the patient wishes; consideration of subjective factors as well as hard data; unbiased presentation of risk; and as major or minor a part as the patient chooses in making the final decision. While it is important to note that not every condition, treatment or patient is suitable for this type of treatment, the US Shared Decision-Making Programs provide an excellent model for genuinely involving patients in their treatment care.

Advances in information technology are already opening an impressive range of new avenues for presenting sophisticated information to patients. Our ability to use new technologies to inform patients and the public is just starting to gather pace. It will be important to encourage the development of systems which seek to involve as well as inform.

Professional attitudes

It is likely that if users of health services were asked *en masse* what single change would do most to improve their experience of clinical care, the answer would be a change in professional attitudes. At a recent meeting of the Long-Term Medical Conditions Alliance (AGM, 1995) members of support and self-help groups with long experience of using the NHS identified doctors' manner and attitude as the most important priority for change. Seventeen out of 28 identified points which referred to the way doctors relate to patients. Training in communication and listening skills was highlighted as the most urgently needed development. This view is reinforced by a glance at the complaints-handling records of any hospital, FHSA or CHC, where a substantial number of all complaints received have at least one component relating to the manner and attitude of staff. In response to a complaint about a junior doctor's insensitive handling of bad news, a senior surgeon once commented that: 'a doctor who can't communicate with his patients shouldn't be in practice'. Yet doctors, more frequently than other caring professionals, stand accused of failing to inform, support or listen to their patients – of failing to respect them as human beings. The reasons for this include tradition and the nature of medical education and training.

Medical training has traditionally had the effect of marking out doctors as a privileged elite. Only recently has it been acknowledged by the GMC (1993) that medical training must take account of the change in doctor-patient relationships brought about by a more questioning and expectant public, and that there is 'a clear duty on the doctor to be able and willing to communicate effectively'. We can expect that tomorrow's doctors, according to GMC guidelines, will be trained 'to demonstrate attitudes essential to the practice of medicine, including respect for patients and colleagues that encompasses, without prejudice, diversity of background and opportunity, language, culture and way of life ...'

There is still no effective way of taking action against the minority whose training failed to instil these basic principles. Even demonstrably poor manner and attitude still do not give grounds for a formal complaint against a GP; terms of service do not include behaviour acceptable to patients. And despite the holding by trusts of consultants' contracts, complaints against individuals rarely result in disciplinary action.

Williamson (1992) gives thoughtful treatment to the subject of respect for patients in clinical settings, noting the imbalance which may arise between a professional's concentration on the task of treating disease (the *work-object*) and the whole and vulnerable person who lives with and manages the disease (the *person-subject*). She also notes the vulnerability of professionals themselves in constant contact with physical and mental pain – especially in an age where the old concept of 'professional detachment' is at least ostensibly discredited. Patients' experience would sometimes suggest that detachment is still thriving. Can it be breached in the interests of greater patient autonomy?

Professional bodies may hold the key, at least in part. The GMC may need to take a more flexible approach to the range of faults comprising serious professional misconduct as a result of the new complaints procedures. This development should also mean that manner and attitude of GPs will be treated more seriously. Acknowledgement of the value of patients as individuals should be at the heart of all professional care-giving.

Medical school curricula could lay heavier emphasis on interpersonal skills training – the one skill identified by patients as needed across all disciplines. The value of subjective experience should be given serious consideration alongside quantitative data-collection. People could be asked to speak to doctors in training about their own experience of treatment, health and illness. The Nottingham Self-Help Team's regular input to medical school sessions is a good illustration. This could extend to in-service training: for example, GPs in St Helens and Knowsley have been enrolled by their commissioning authority in their local British Diabetic Association as part of continuing medical education.

A good deal can be done to create the culture change needed before consultations in clinical settings are seen by both parties as genuine meetings of experts. We might hope with Williamson (1992) that: 'Interests can be brought closer: good feeling, intelligence and justice can do it'.

Chapter 5

Public involvement in health care decisions

The policy framework

There is clear policy guidance from *Local Voices* (1992), and to some extent from *The Patient's Charter* (1991), about the need for purchasers and commissioners to involve themselves both with users of services and the wider public. They are charged with taking account of local people's views, 'to help establish priorities, develop service specifications and monitor services ... Their aim should be to involve local people throughout the purchasing cycle: a combination of information-giving, dialogue, consultation and participation in decision-making and feedback, rather than a one-off consultation exercise'.

These are important aims, and a wealth of initiatives has been set up to respond to them. However, *Local Voices* cannot be seen as sufficient in itself to secure public participation because those who govern its implementation are neither explicitly nor implicitly accountable to the public for the decisions they make. Unpopular or inept decisions may go unchallenged for want of a mechanism for removing the decision-makers. Davis & Daly (1995) have asked: 'If we do not like what is being done, can we remove those responsible? The answer to that question is no'.

What impact can the public have on decisions made on its behalf by commissioning authorities? At the heart of this question is the issue of accountability. Who bears ultimate responsibility for decisions made, and how are they held to account? Much discussion was generated in 1995 by the case of a young Cambridge leukaemia patient. 'Child B' was denied a second round of costly and painful treatment, ostensibly on the grounds that the suffering entailed could not be justified by the minimal chance of benefit. The health authority held that their limited resources could be used more effectively to treat other patients. The Court of Appeal upheld the authority's right to deploy its resources at its own discretion. Public opinion was unconvinced that cost had not dictated the authority's decision, and it seemed unwilling to revise its judgement of management insensitivity – even though private care could buy Jaymee Bowen only a few months' extra life.

This case highlighted the need for central policy clarification. Calling for a parliamentary debate in its leading article following the case, the *Health Service Journal* commented: ' ... purchasing managers will ponder how difficult rationing makes their working lives. It calls into question the fundamental legitimacy of their very organisations; what scope have their local populations for influencing and challenging their decisions?'

Should public opinion influence rationing decisions? Hoffenberg (1992) warns that, while determining priorities is a legitimate arena for public involvement, rationing – as in the Cambridge decision – is not. He defines rationing as 'the deliberate withholding of certain services due to costs or lack of facilities or staff', and designates it 'a policy decision, one that is taken by the Government or a health authority, not the public'. Hoffenberg argues that if services are to be withdrawn, it must, in the interest of equity, be *en bloc*. Service reduction will then be explicit so that, whether or not they agree with it, doctors and the public know what to expect. Wise authorities will take note of the public's expressed priorities before deciding what to cut. The alternative – reducing the amount of care available within a given service – leaves doctors shouldering the burden of deciding which patients not to treat, and the public not knowing what level of service any individual can expect. Practising medicine on this basis, Hoffenberg notes, puts doctors into 'an extraordinarily difficult position'. However, it has the political advantage of leaving rationing in the murky realm of clinical judgement. How can decision-making be made more accountable to the public?

The problem of democratic accountability in the new NHS, noted by Harrison *et al.* (1992) is one result of the removal of local authority representation from health authorities. They point out that:

> *' ... the new DHA is supposed to champion the people's needs, but lacks any representative element that might legitimise its role in speaking for those needs. On the contrary, DHAs are in danger of being merely "ivory tower" contracting bodies governed by a small group of managers and non-executive members, many of whom have come into the NHS from business backgrounds'*.

Public concern about accountability has been even more widely expressed in respect of the actions and appointment systems of trust boards, fuelled by media campaigns against a faceless 'quangocracy'.

Harrison *et al.* comment that a proposal by the Opposition for 'more broadly based public authorities with the return of local authority representation' would give more explicit attention to the nature of public accountability of health authorities. (Although they also note as a caveat that elected status would not guarantee local authority non-executive members any greater weight than their unelected counterparts, since the decision-making process remains dominated by professional and managerial interests.) They offer tentative support to the devolution of some functions to an elected regional body which could become 'a force within the NHS which could offer a source of legitimate authority alternative to that of the medical professional'.

The need for greater direct public accountability is underlined not only by dramatic individual cases but more importantly by public policy, as it affects whole sections of the population. Whitehead (1992) draws attention to the fact that changes in funding formulae, in which the public have no say at all, have in some cases 'channelled more resources back to the south-east of England and away from the north ... Some deprived districts, particularly in inner cities, with high mortality and morbidity are net losers of resources ...' Whitehead also raises the case of non-acute nursing care for elderly people, arguing that equity of access has been damaged by piecemeal local decision-making. She asks: 'When was the policy debated and the decisions made that health authorities would reduce their responsibility for funding long-term non-acute health care for elderly people?', and comments that the removal of entitlement and access to NHS services for vulnerable groups should cause disquiet in many circles.

Widespread public concern at community care provision for elderly and mentally distressed people and public anger at recent rulings that NHS provision is no longer guaranteed 'from the cradle to the grave' reinforce the importance of developing an effective policy framework in this area. Until this happens, implementation of *Local Voices* will lack the rigour provided by public accountability.

Achieving participation

Apart from the policy imperatives to involve 'local voices', what practical considerations must commissioners bear in mind if they wish to integrate public and user participation into their planning? Drawing general lessons is not easy, because approaching the issue strategically is a relatively new discipline. There is a whole library of publications outlining effective ways of involving users in discrete projects, research and consultation exercises. The following represent a small sample: Jones, Leneman & Maclean (1987); Thompson/NCVO (1991); DoH (1992); Barnes & Wistow (1992); Sykes *et al.* (1992); NAHAT (1992); McIver (1992); Deakin & Willis, eds (1992); DoH (1993); Bowling (1993); Hendessi (1994); Hogg (1994); Hamilton-Gurney (1994). Harding & Upton (1991 and 1994) have catalogued hundreds of user involvement initiatives in social care in a two-volume bibliography. All these studies illustrate different methods, give case studies and recommend best practice. However, there are very few evaluations of attempts to address participation strategically and little guidance for commissioners wishing to do so.

The essential purpose of public participation is to inform purchasing, both by identifying needs and priorities and by monitoring the effectiveness of services purchased. The aim is to arrive at what Øvretveit (1995) characterises as 'justifiable commissioning' – commissioning as a service to the public. Purchasers as service organisations have to decide which services they will and will not purchase. They need to 'seek guidance about prioritising decisions in a way which upholds its [the purchasing authority's] purpose in the eyes of the public as a service to them'.

Øvretveit and others (e.g. Sullivan, 1994; Lupton & Taylor, 1995) stress that the first need for commissioners is to be clear about their purpose in involving the public in prioritising. He notes that the purpose may include: 'educating and informing [e.g. about effectiveness and outcome], getting a representative view of priorities and "posteriorities" ... giving an account of decisions made on the public's behalf and allowing appeals and challenges'. That authorities are following this guidance in practice seems to be borne out by one recent study (Lupton & Taylor, 1995), which records a range of different objectives among commissioners: 'to inform the public about health issues and concerns; to establish accountability to, and credibility with, local communities; and to seek feedback on current services and future needs'.

According to Lupton & Taylor, the outcome and focus of public participation activity tends to depend on which part of the organisation has initiated it. They comment that: 'If public health takes the lead, it is likely to concentrate on work with local communities in the identification of health needs and priorities ... Where the lead role is with quality assurance, the focus is more likely to be on work with direct service users and the development of feedback and monitoring mechanisms'. Communications and public relations initiatives centred on the media and one-off public meetings are identified as a third area.

The different disciplines and commissioners involved share certain conditions which Lupton & Taylor identify as central to effective development of public participation. They are:

- where there is senior management involvement, and where identified senior managers have a clear responsibility for working at the strategic level to ensure its effective integration into commissioning;

- where there is access to staff with sufficient skills and confidence to undertake public involvement activity and to develop credibility with outside organisations;

- where there is a positive organisational culture for public involvement and effective mechanisms for making good use of the knowledge of specialist staff and ensuring the messages from consumers and the public are fed into the organisation.

Lupton & Taylor note that the best-intentioned commissioners may be hampered by various factors. They identify particular difficulties when 'the organisation, driven ... by national requirements, requires instant action and clearly identifiable outcomes. This tends ... to skew their work towards the superficial and short-term, so missing opportunities for the development of more substantial and ongoing forms of public involvement'. Other issues may be given priority, 'with constant organisational change playing a part in the disruption of good, but less urgent, intentions on public involvement'. Like quality, participation can fall prey to short-termism. These are salutary early lessons for commissioners who are serious about involving the public strategically.

Public engagement

The reforms changed the role of DHAs from bodies which managed the provision of services to authorities which assess the health needs of their population and purchase care to meet those needs. Øvretveit (1995) suggests that the three key functions of commissioners for health gain: assessment of population health status and need; evaluation of effectiveness of treatment and cost-effectiveness of services; and 'social value prioritising'. The experience quoted above suggests that the areas most amenable to tackling through public engagement are the functions associated with public health: that is, needs assessment and prioritisation. The development of a health strategy which incorporates public participation in these elements is the first essential.

Needs assessment will not be discussed in detail here. In addition to epidemiological information and data on the uptake and use of services, though, it should incorporate the views of local stakeholders: GPs, providers and local people.

As well as assessing needs, purchasing authorities have to decide how best to deploy limited resources to meet them. They need to do this in such a way that their population may reasonably see them as 'champions of the people'. As commissioners, DHAs can now take decisions which depend less on the management of local providers than was so in the past. Ham (1993) notes both the freedom and the obligation DHAs now have to listen to other factors, such as the voice of local people.

Ham also notes the difficulty authorities have in prioritising services, especially where judgements have to be made about the relative value of quite different services, with no real basis for comparison: for example, health promotion, shorter waits for surgery and care for people with learning difficulty. The authorities in his study made more progress by analysing priorities within individual service areas rather than across services (see below).

Absence of information to guide priority-setting (especially about clinical effectiveness and cost-effectiveness) was seen as a problem everywhere. Health authorities recognised that 'priority setting cannot be reduced to a technical or scientific exercise' (a judgement borne out by the very divergent rankings given to different services by lay and professional stakeholders in the City and Hackney study (Bowling, 1993)). Since prioritisation means making judgements on the basis of incomplete information, the exercise becomes more defensible if it is publicly debated. Ham comments: 'Given that there are no right answers in the priority-setting debate, an important justification for the decisions that are made is that they have been arrived at as a result of due process'. Øvretveit (1995) notes the need to establish rights, for example to a fair hearing, explanation and appeal, for groups which lose out in the process.

The range of methods that qualify as 'due process' in public involvement research is discussed in many of the publications listed earlier. They include surveys, focus groups, tapping into existing networks, community and voluntary groups, rapid appraisal techniques, health panels and citizens' juries. Whatever methods are chosen, it is clear that many pitfalls await those managing them and those involved.

Ham suggests that, 'given the complexity of some of the choices that have to be made, it may be that an investment in informing and educating the public about the issues involved is needed before citizens are asked to list priorities in rank order'. It is certainly important to frame questions with due care: Bowling found in City and Hackney that public response varied considerably according to the way in which questions were phrased.

Pollock & Pfeffer (1993) argue for greater consideration of ethical issues in social and market research. They comment that:

> *'Investigators experience no pressure to consider whether the public understands the different interests which drive these various undertakings and the purposes to which the findings might be applied. This is because, in contrast to the rigorous criteria set out for medical research, funders of social and market research have no established tradition of ethics by which to judge protocols.'*

Putting the case for a code of ethics in this area, Pollock & Pfeffer point out that local communities are not subject to any protection from informed consent guidelines. They often know very little about the purpose of the research, and are often not given enough information about the subject to make decisions. However, the results of research may be used by commissioners to justify purchasing decisions undreamt of by the community and which might deprive the community of services it values.

This point underlines the importance of giving information to people taking part in research, and clarifying the remit of the study. This is the first in a series of useful guidelines proposed by Sullivan (1994) under the heading: 'Who ought to be doing what to engage the public?'

Noting the cynicism that results from false expectations, Sullivan instructs commissioners to be 'honest with the public about what is being asked of it and what people can expect to influence. This includes ensuring that people understand the timescale involved – that is, whether they are being asked to influence short- or long-term changes'. The public must be clear about what processes are being used, who they are talking to and what issues they are being asked to debate.

Sullivan suggests that within this structure of debate, commissioners should adopt the role of an independent 'honest broker'. Commissioners can ensure the public voice is heard in debates previously dominated by providers and professionals. In listening to people, however, they have a responsibility to ensure that the public's views are responded to. Response may take a number of forms where practical changes in services are made according to expressed needs or wants. It may equally involve 'explaining to people why things cannot change in the way they would like'.

The 'honest broker' role may also be effectively fulfilled by CHCs, whose independence is an important assurance to communities, especially where consultation is a preliminary to service cuts. Many commentators have stressed the importance of proper resourcing for CHCs, which are often chronically under-resourced for their multiple functions in this field.

Sullivan's guidelines conclude with another key factor: 'sensitivity to the norms, values and cultures of different communities; and an understanding of where and how to approach different members of each community'. Perhaps the most powerful advice comes from people in the community themselves. Here are two whose views were sought in a needs assessment exercise in Derby (Harrison & Ward, 1994):

> *'We have a succession of people round to find out what's happening, but nothing actually happens. Is it worth telling them? Are we going to get something practical?'*
>
> *'Professionals must make sure that they start from the fact that the service belongs to service users. The NHS must start from that'.*

User participation

The practical issues which commissioners must address if they wish to create opportunities for fruitful public engagement apply equally when bringing people currently using services into the picture. Commissioners should ensure that the services they purchase on behalf of their populations meet the standards laid down in the contracts they let. How can users contribute to this process?

People currently receiving a service can judge its quality more competently than the wider public, whose interest lies more in its availability. Their experience of the service – especially if they are long-term users – gives them authority to highlight both shortcomings in service delivery and gaps in service provision. Health-related self-help groups, CHCs and organisations such as the Patients' Association and the Long-Term Medical Conditions Alliance have led calls for users to participate on both fronts.

At local level, self-help group members (who are often more empowered, by the giving and receiving of mutual support, than individual patients) are a rich source of guidance for commissioners prepared to listen. Whether purchasers tap into existing groups and networks, convene new consultative panels or try different approaches, the views of users are a valuable resource both in setting service standards and monitoring delivery.

One important prerequisite of successful participation has been identified by many commentators, especially those who have analysed involvement in social care. Many exercises consist of what Sullivan has called 'reactive consultation' – that is, asking user groups to respond to a predetermined and largely fixed agenda. 'Proactive consultation', on the other hand, allows users to make their own points about how a service should look, and permits a much wider influence on service planning and delivery.

Building proactive consultation into strategic planning is a key step to ensuring a genuine 'voice' for service users. It enables commissioners to set justifiable service standards for providers with the authority of the community and to demand improvement if standards are not met.

A further arena for user participation has been identified by Ham (1993) and Lupton & Taylor (1995). Both note the difficulty commissioners have had in making resource allocation decisions between different services. However, all the authorities in their studies made better progress with reallocating resources within services than across them. Ham suggests that one way to improve the effectiveness of purchasing is the development of guidelines to identify those patients most likely to benefit from particular interventions. The participation of users in such an activity, carefully handled, might achieve some of the positive benefits identified by Brewin & Bradley (1989) for patients who participate selectively in research trials.

The different methods open to commissioners and providers who wish to involve users have been extensively discussed in many of the publications referred to. Most methods recommended as suitable for engaging the public can also be used to involve smaller groups of service users or community groups. McIver (1991), among others, deals in detail with appropriate methods, and highlights the importance of approaching different user groups according to their specific needs. She directs researchers to a series of questions to be tackled before any exercise is undertaken:

> *'How much understanding does the user group have of health service culture?*
>
> *Is the user group homogeneous, or does it consist of a number of different levels of understanding?*
>
> *Are the views of all types of user in the target group of interest, or only some?*
>
> *Are there community groups ... or similar sources of help to enable you to get information from the service users concerned?*
>
> *What information already exists about experiences and views of those service users you are interested in?'*

The need for cultural sensitivity in reaching out to small groups of users is vital to securing successful participation, whether by groups of users or the wider public.

Many people have trodden the path of involving users. Commissioners who are serious about effective participation, and who wish their providers to be serious too, can benefit by learning from past experience.

From the literature and from the work of the King's Fund Development Centre, it has been possible to identify three main areas where changes are required before good-quality user participation can be achieved. These are:

- structural systems
- professional attitudes
- resources.

Structural systems

Structural barriers are created by policies and operational systems and need to be tackled in a number of different ways. Since health authorities, purchasers and providers are not directly accountable through elected representatives, local strategies and policies need to require the inclusion of service users and local representatives of patient or voluntary organisations, in planning, review and audit cycles at all levels of management. A more democratic and open system within the limits of an accountable NHS is essential. Greater openness could be achieved through a number of mechanisms, including more public criteria for the selection of lay non-executive members of trust boards; lay membership of review bodies, audit and monitoring systems and commissioning processes which involve local people. Existing mechanisms to encourage public involvement such as consultation and complaints procedures should be made more effective. Chief executives and managers should meet local people at least annually, and complaints procedures and policies should be more widely publicised with contact names and telephone numbers. Advocacy services should be established at all service levels and the recently published Code of Openness actively promoted.

Formal and informal mechanisms which have been effective in encouraging and enabling people to become more involved in the planning and delivering of local health services include: CHCs, locality forums, equal opportunities policies and user representation on service committees.

Professional attitudes

The attitudes of managers and health professionals can be seen as a major barrier to greater public involvement. The main mechanism for changing these attitudes is, in the long term, education and training. A culture and tradition in management of respect for the public's views and a preparedness to work in partnership and share information need to be developed. Other public services have been able to develop partnership cultures. In education, for example, teachers work with parent governors to develop strategies and policies which make local schools more accessible and education more relevant to pupils' needs. Parents are encouraged to help with activities and to become active partners in their children's education. Hospital and community trusts and general practices could (and sometimes do) incorporate these principles into their organisations. Recommendations to influence professional education and training courses include:

- the introduction of the principles of public involvement into professional education and training;
- the development of training for professionals to work with users;
- the development of training for lay people to work with professionals.

Resources

Resource factors are sometimes identified as a barrier and as an incentive to make the NHS more responsive to public involvement. Resources for more and better information on clinical research and outcomes data; resources for training to enhance and develop professional and lay communication skills; and resources to pay the costs of lay involvement and training.

Chapter 6

Conclusions

Patient and public involvement are complex and difficult issues. It is inevitable that people will disagree about the rights of patients; the extent to which they should be involved in their own care; and whether and how the public should be involved in the construction and delivery of health care services. Current policy initiatives recognise the importance of involving patients and their representatives so that when changes are introduced they are more likely to have the support of the people to whom they are directed. The principle behind all forms of empowerment is that the people for whom services are provided should have the opportunity to participate in their formulation and delivery.

The Patient Partnership Steering Group of the NHS Executive accepted most of the recommendations from the seminar organised by the King's Fund in April 1995, which form part of the list below. Since then it has continued to work with voluntary organisations and the health care professions to implement a strategy aimed at helping patients and clinicians view each other as partners in care.

Evidence is beginning to emerge (Stewart 1995 and 1996) that some health authorities are taking the issue of public involvement seriously. The health panels pioneered in Somerset, the citizens' jury pilot studies in Cambridge and Huntingdon and Kensington and Chelsea, and the many focus group initiatives involving local people around the country are recent examples. There is mounting evidence too that information on treatment outcomes is more frequently sought by individuals (Buckland & Gann 1994) and produced by hospitals, GPs, voluntary organisations and officially funded agencies. All these initiatives are welcome but there is still a long way to go before user involvement becomes an integral part of health service planning and delivery. We hope that the following recommendations will help to ensure that the process of embedding the principles and practice of patient and public involvement in health care happens sooner rather than later.

Recommendations for change

Some of the ways in which these changes may be brought about are outlined below.

1. Information and support for patients

Improvements in the quality and quantity of patient information

The King's Fund Development Centre has identified eight criteria for good quality information materials. Information should:

- inform the patient about the clinical condition and include information about all available treatment or management options, including non-intervention;
- provide comprehensive and unbiased information about outcomes (risks and benefits) based on systematic review of the research evidence;
- outline uncertainties and gaps in scientific knowledge;

- be simple in language and design, attractive and easily understood;
- cater for a variety of users, including people who do not speak English and people with sensory or learning disabilities;
- be regularly reviewed and updated;
- be integrated into a planned programme for shared clinical decision-making;
- involve users and professionals in the development and evaluation of the materials.

These criteria are being applied in the new projects funded by the King's Fund Grants Committee and will be evaluated throughout this initiative. A way of disseminating these criteria and of evaluating patient materials against them should be established.

Improved access to good quality information

A national centre of research, development and dissemination of patient information materials should be established to encourage the development of good quality materials and good practice.

Consumer health information services

Consumer health information services should be concentrated in regional centres so that local centres – for example, those in trust hospitals – have an accessible source of materials and expertise. The recent devolution of these services may risk fragmenting the achievements of the past five years.

Local resource centres

Local trusts, fundholding practices and GPs should develop resource centres where patients could find and use materials relevant to their conditions. Advocates could be based at some of these centres to help people use the information.

2. Professional attitudes

Professional training should engender a climate of respect for patients in the context of a relationship based on the principles of a partnership in care. This should involve two-way communication in a consultation long enough to allow patients, with professional encouragement, to express their feelings and concerns, and for professionals to have time to listen. The outcome of such a consultation should be improved mutual understanding and a willingness on both sides to share decision-making, if the patient chooses to do so. In practice this partnership approach would be encouraged by:

- audit and monitoring systems which involve patients and feed back results to all users;
- treatment protocols and service specifications based on the partnership principle;
- patients who understand the restrictions placed on professionals (e.g. time limitations) and respect the need to share responsibility for the outcomes;
- involvement of patients in professional training.

3. A health service users council

There is no central agency, apart from the National Association of Community Health Councils of England and Wales, which ministers can consult to inform policy decisions. Although consultation does take place with a range of voluntary organisations, the force of their views is weakened by their disparity. A national body which brings together voluntary organisations and patient groups, and which has regular discussions with ministers and civil servants would be a strong link between decision-makers and health service users. It could provide a powerful user voice to influence policy development.

4. Strengthened CHCs

CHCs play an important statutory role in representing the interests of their local populations in the health service. In particular they play an important part in local consultation activities. Their role and activities should be strengthened and clarified so that local people can be encouraged to use their resources.

5. Increased accountability in primary care and GP fundholding

Given the current policy initiatives to shift the balance of care to primary care, making GPs more directly accountable to their patients should be seen as a matter of the greatest importance. There is an urgent need to review this situation. Many initiatives exist already to involve users in primary care developments but there is little knowledge of how effective they are. A review and assessment of these initiatives would enable models of good practice to be established. GP fundholders and other primary care agencies could then be encouraged to introduce them.

6. Greater openness in the NHS system

In 1995 the NHS Executive published a Code of Openness. There has been insufficient time so far to assess the impact of these recommendations. There is a strong case, however, for the promotion of greater openness about the criteria used for the selection of lay non-executive members of trust boards and health authorities; and for lay membership of review bodies, audit and monitoring systems. Commissioning processes which involved local people *before* draft plans are produced would ensure that their views were built into the process and that they were better informed about local health needs and issues.

SUMMARY OF RECOMMENDATIONS

1. Better quality information for patients and the public

- Development and evaluation of criteria for good information
- Establishment of a national centre for research, development and dissemination of patient/public information materials
- Support and strengthening of regional consumer health information centres
- Development of local trust and GP practice resource centres

2. Development of professional attitudes

- Professional training to include communication based on the ethos of partnership with patients
- Audit and monitoring systems which involve patients and feedback to all users
- Treatment protocols and service specifications based on the partnership principle
- Involvement of patients in professional training
- Education of patients to understand their equal responsibility for satisfactory outcomes of care

3. A health service users' council

4. Strengthened CHCs

5. Increased accountability in primary care

6. Greater openness in the NHS system

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