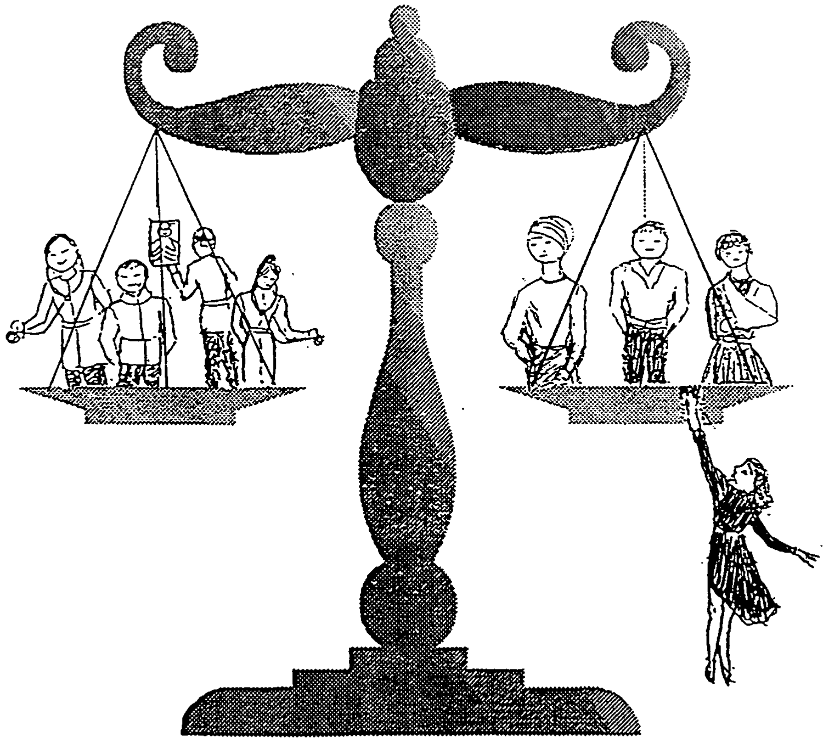
REDRESSING THE BALANCE

A Brief Survey of Literature on Patient Empowerment



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Foreword

> " We have a succession of people round to find out what's happening, but nothing actually happens!..."

This Derby resident could have been speaking for many people. User involvement in the NHS is a relatively new and under-researched area, and although the literature abounds with accounts of surveys, consultation exercises, focus groups and others, proper evaluation of the impact of the work is rare. It is therefore hard to determine what works and what does not.

This piece of work was undertaken in Spring 1995 to stimulate discussion at a seminar sponsored by the NHS Executive. The purpose of the seminar was to identify the elements of a national strategy for implementing patient empowerment in the NHS, to ensure that needs of patients and other users of health services are both expressed and acted upon. To inform the development of the strategy, this brief survey of the literature has been structured as follows: definition of terms; the balance of power in doctor-patient relationships; and the context and implementation of change in two distinct areas: the *individual* patient receiving care and treatment, and the *collective* participation of users and the public in shaping the NHS. It lays no claims to being comprehensive, but aims to highlight suggestions for and reports of effective practice in shifting the balance in favour of the user's needs.

Until recently few but a handful of enthusiasts would have believed in the likelihood of a central initiative taking practical action to build the patient's agenda into service planning and delivery. Many people may still question its ability to effect change, pointing to numerous attempts to involve consumers which have lacked effective outcomes. This new commitment to develop a policy from the centre may turn out to be the turning point.

Hilary Gilbert
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CONTENTS

Summary

This brief survey of current literature touches on issues surrounding the theory and practice of patient empowerment. It aims to highlight areas which need to be considered in response to questions raised by the NHS Executive's proposed strategy for patient empowerment in the NHS. What is patient empowerment? What issues does it raise in theory and practice? What structures are in place to address it? Are they effective? What needs to be changed? How should it be done?

Section 1 defines terms as follows:

Patient empowerment is used to describe the process of redressing the balance of power between the professional and the individual receiving care in a provider context.

Patient is used as the preferred term for individuals receiving health care, in recognition of the passivity which traditional structures impose upon people in that setting.

Users is chosen as the preferred collective term for people currently using services, whether in provider or commissioner contexts.

Participation is used to define the fullest level of activity at which people can contribute to service planning and delivery.

Public engagement is the preferred term for for the commissioner function of bringing the wider community of citizens, taxpayers and potential users into questions of public interest.

Section 2 examines the policy framework of the reforms, noting the positioning of patients as *consumers* with rights under the Patient's Charter. It touches briefly on legal judgments concerning consent and negligence, and asks how well patients' rights are protected by the current system.

It then considers these factors as they affect the doctor-patient relationship, looking at the importance of information and open communication; the manner in which doctors and patients make decisions; and the reasons why they may make decisions. It asks what can be done to ensure that doctors are both able and willing to give good, evidence-based information to their patients to encourage shared decision-making.

Section 3 deals with the policy context of service delivery, and asks whether the Patient's Charter, and providers' quality mechanisms established by the reforms, are sufficient to secure empowerment.

It looks at three aspects of clinical care where practice might be changed - research, audit and changing professional attitude - and asks what needs to be done if patients are to be more fully involved. It then considers non-clinical care, pointing to organizational aspects which providers should address, and to the need for reform of the complaints procedures.

Section 4 moves on to issues which principally affect the commissioning function. It first looks at policy, and asks how decision-making can be made more accountable to the public.

It then examines evidence from evaluations of strategic attempts to involve users and the public, pointing to key operational factors that promote success. Finally, it asks where and how the public and current users can be effectively encouraged to participate in healthcare planning and delivery.

1: Terminology

1.1: Defining patient empowerment

It is worth starting with a generally accepted statement of the purpose of patient empowerment activity, since the discussion that follows is directly influenced by recognition of its discrete elements.

Barnes and Wistow (1992) identify two broad categories of purpose behind initiatives aimed at increasing what they term user involvement.

> 1: those which seek to improve the quality of services by making them more sensitive or responsive to the needs and preferences of individuals who use them;
>
> 2: those which seek to extend the capacity of users to participate in decisions about the design, management and review of services.

There is broad agreement that the aim of patient empowerment is to redress the balance of power between patient and professional, and to bring users of services into their planning and delivery. Different approaches to definition of terms are strongly influenced by this separation of the *collective* from the *individual*, and the need for this distinction is recognized throughout the growing literature on patient empowerment. It is one of the few areas where consensus does exist.

One of the few other things on which all recent authors agree is that there is no agreement on either the use or definition of terminology. This applies equally to appropriate names for users of health services, for the acts in which their participation is sought and for their condition once the balance of power has been redressed. Across several recent analyses everyone agrees the need for clarity of terms, but all use different definitions and conventions, often using words interchangeably . Some share an underlying approach due to a common analysis of the context of user involvement. Very few actually use the term *patient empowerment*!

It is worth unscrambling some of the messages implicit in the language. We might start by proposing an objective understanding of terms for the purposes of this paper.

Power itself could be defined at some length without adding much to a common understanding of the term. A simple working definition such as: "The ability to effect control by the exercise of professional or other authority, natural or invested" should meet our needs. Harrison, Hunter at 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*.

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 at all what a patient's advocate has in mind. Professionals may see it as a matter of magnanimity - the granting of something which is in their gift to bestow or withhold. Users will point rather to the fact that empowerment is about feeling - feeling able to play an active part on their own terms. It is for the professionals as power-holders to create the conditions in which people can feel empowered.

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 a definition of the user of health services - the person whose empowerment is sought - as a *patient*. A patient is, literally, one who suffers or is passive, and therefore inherently lacks power or control. This gives *patient* a unique etymological advantage in the context of potential empowerment - a sort of verbal 'value-added'! We can see in the term *patient empowerment,* a meaning greater than the sum of its parts. It contains within its hidden structure a message of equalization which is wholly fitting to this context.

In what follows, the term *patient empowerment* is used to describe the process of redressing the balance of power in healthcare between the individual receiving care - the patient - and the healthcare professional in a provider setting.

1.2: Defining people

Every commentator, from whatever area of health or social care, has their own label for the people whose 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 may provoke misunderstanding and even outrage amongst those with differing perspectives. To ensure that contrasting responses, all of which may lay claim to political correctness, don't obscure the central issue, it is important to keep the debate open enough to accommodate many viewpoints, and to celebrate the validity of each one. Recognizing the value of people's subjective experience of healthcare is, after all, at the heart of this issue. However, rational differences do underlie the use of different terms, and it is worth examining how they work.

For the purposes of this paper it has been decided to use *patient* as the preferred term for *individuals* undergoing health care, in acknowledgement of the passivity which traditional structures impose on people in that setting. It is acknowledged that some people would prefer a definition which emphasises the patient's potential for active participation rather than imposed passivity. The use of *patient*, however, will serve as a reminder of the context of individual care in provider settings.

Whether people viewed collectively are termed *consumers, clients* or *users* (- for 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 (eg 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 geared to ensuring their participation is integral.

Choice or voice

The NHS reforms, by introducing market principles into the NHS, have had the effect of casting recipients and potential recipients of healthcare in the role of 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 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.

The concept of consumer choice extends also to primary and community care, with patients involved in choosing their care package on the one hand, and exercising choice by proxy through their GP (provided they are in a fundholding practice) on the other. All these initiatives serve to reinforce the concept of the patient as consumer: one who exercises choice, and in so doing makes the market work. By providing patients and potential patients with information - on waiting times, quality standards and even hospital mortality rates - it is hoped to keep providers on their toes, anxious to avoid losing contract income to more successful or attractive competitors.

Consumer choice is arguably a rather tenuous mechanism for delivering patient empowerment in the system as it currently operates. The only field in which most patients can exercise choice which influences the market - ie, choice with resources attached - 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 and so on - are not designed to empower patients, as many purport to do, but rather to increase the market share of their organization. The aim is to appeal to potential purchasers; ie those with the real choice and the resources to effect it.

Saltman notes the following distinction, in highlighting the difference between the commercial/economic (ie 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" (my italics). 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 (eg Donahue and McGuire, 1995) point out that by emphasizing individual choice and consequent responsibility for choices made, market-led healthcare 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 and Wistow amongst 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 services 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) has established a more participative approach. It sets 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. Whilst mechanisms for involving users and carers in developing services 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 in any of its incarnations.

It is perhaps unsurprising, then, that whereas reported 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- or user-led services in Social Services or Community Care settings. The terminology follows suit: this approach is most frequently characterized 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, has been dealt with in detail , by Barnes and Wistow and Saltman amongst others.

1.3: Defining action

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 - amongst others - in Hamilton-Gurney (1993) , Barnes and 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 characterized 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. For the purposes of this paper, *participation* will be used to describe the highest level of activity undertaken by people currently using services. Bringing the wider community into questions of democratic interest has been characterized by Sullivan (1994) as *public engagement.* Using this term will allow us to distinguish 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 approach in this paper.

2: Patients and Professionals

Patient empowerment at an individual level seems to be about enabling individuals to move from a traditional, passive role towards more active participation in their own care and treatment. The next two sections look at the issues which need to be addressed in order to make this happen. The first section examines the dynamics of doctor-patient relationships, and the structural and policy frameworks in which they currently operate. The second section considers actions which may be taken by providers to promote change in practical service delivery.

2.1: Doctor-patient relationships: external influences

2.1.1: Policy

The policy framework of the NHS Reforms is overtly 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), summarizing 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 choice;
- the opportunity to exercise choice;
- readiness to make quality comparisons; and
- 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 (eg by geographical differences in access to services); the inherently 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, with the Patient's Charter 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 healthcare 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 (my emphasis);
>
> - 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. Local purchasing and extra-contractual referral policy, lack of access to choice of GP practice and restrictions on fundholding may all affect a patient's ability to enjoy these rights. It seems to be the case in practice that individuals in positions of power can avoid meeting these rights with little or no redress for the patient (as can be seen from the regularly published Epitomes from the Health Service Commissioner's caseload.). Some commentators (eg, Saltman (1994), Winkler (1987) have seen consumer rights as specious in the absence of resources directly linked to the exercise of consumer choice.

Others (eg Donahue and 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 readily to blaming individuals who are perceived to have made the wrong choices, irrespective of the complex social circumstances that may have influenced them. This applies particularly to lifestyle choices, where factors contributing to poor health are often seen as avoidable - eg, in the case of smokers who contract lung cancer or coronary heart disease. This approach already has 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-publicized example in 1994. It might reasonably be asked how meaningful was his Charter right to 'receive healthcare 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 empowerment. 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."

To what extent, then, does the law recognize patient's rights within the doctor-patient relationship, with or without the safeguard of the Patient's Charter?

2.1.2: Law

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 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 recognize patients' rights. Whilst 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 judgment."

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 patient's rights in the field of consent (on which there is an entire body of literature outside the scope of this discussion). According to Brooke and Barton (1994), English law is unlikely to apply any particularly rigorous test of a patient's capacity to understand what he was being told before deciding whether he in fact gave consent. According to the *Sidaway* judgment (1985): " The decision 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 judgment."

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 sterilization 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 (ie: " 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 maximization 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 proposes that the Government establish a formal review, "to focus on the whole area of compensation in relation to health care."

Recently 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 empowerment from this quarter are slight. Here there is real scope for change.

2.2: Doctor-patient relationships: internal dynamics

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. And yet, as we shall see, many patients do want to be involved in their care and may positively benefit from doing so. What factors hold the key to shifting the balance in favour of a more active patient role? Examples in the literature suggest that there is a range of elements, many closely interrelated, where positive change is possible.

2.2.1: Information and communication

The imparting of information about the relative risks of treatment is still broadly held in law to be as much a matter of clinical judgment as the giving of treatment itself (Lord Diplock, quoted in Brook and Barton 1994). Legal rulings promote the view that the doctor's volunteering of information about relatively minor risks may lead a patient to imagine them greater than they are (Lord Bridge, quoted in Brook and Barton 1994). With the legal framework favouring reticence, it is small wonder that doctors have not always been noted for their openness in communicating with their patients.

Nonetheless, information is power, and there is ample evidence that people do want information given to them, both about their condition and treatment. There is evidence that they may feel better if they are given more information and feel more in control . In addition to receiving this kind of information, it has 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 general, and apparently independent of social or other factors. Vertinsky et al (1974) found that, whilst 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 and Ware, 1989) found that, however they chose to measure health (clinically, behaviourally or subjectively by the patient), 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 feelings - 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 and Kaplan, 1985) found that patients who were coached to interpret and understand their own medical record 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 assertive and 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. Here is a powerful argument for improving both communication and information in order to redress the traditional balance of power between doctors and patients.

2.2.2: Decision-making

Although they are major factors, good communication and the availability of patient information are by no means the only determinants of how decisions are made in medical consultations. There is an entire discipline devoted to the analysis of decision-making (again, beyond the remit of this paper). In the present context, we might say that one key factor is the balance of power between doctor and patient, and the extent to which the patient is prepared or permitted to act autonomously in the context of the consultation. Woodcock and Francis (1992) put forward a model of decision-making styles which usefully 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 and telling, deciding and selling* and *deciding and consulting*, through *proposing and consulting, consulting and deciding, consulting and steering* to *defining and 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.* He found that, whilst the patients in his 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 variables in relation to the desire to be actively involved. Other studies (eg 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 patient empowerment we need to ensure that, whilst no-one is denied the chance to decline, the many people who would choose to participate actively are given the opportunity to do so.

Since many of these studies may be recording principally the results of people's natural differences in personality, the strongest message would seem to be that doctors should get to know their patients as individuals, and agree with them an approach best suited to their personality and preference. This does lay an onus on doctors to be adaptable in ways which have not traditionally characterized professional dealings with patients. It requires a change of approach not only in decision-making style, but, just as fundamentally, in the reasoning behind decisions made.

2.2.3: The basis of decision-making

Doctors' reasoning

How do doctors choose what treatment to offer their patients? Logic suggests that treatment choices should be based on published evidence about the likely outcome of one option or another. Evidence, however, suggests otherwise. Hammond (1995) proposes a model of judgment which ranges from unstructured to structured: judgments move from *intuitive* to *peer-aided* and *system-aided*, through to the more structured *quasi-experiment, controlled trial* and *scientific experiment.* Hammond suggests that the majority of medical decision-making takes place at the unstructured end of the spectrum: 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. In the context of patient empowerment we might then ask whether the patient's subjective response to different treatment options should not also influence the decision made?

This proposition is borne out by a wealth of epidemiological studies undertaken in many countries over many years. The scope of the work can be judged from Sanders, Coulter and McPherson's (1989) review of literature on variations in hospital admission rates. Such works highlight 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 epidemiologist, to coin the phrase : " Geography is destiny". In other words, for many patients, what happens to them depends more on locally accepted practice than rigorous clinical evidence. Again, we might ask whether, in acknowledging their own subjectivity, medical decision-makers should not accommodate the patient's subjective perspective alongside their own.

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 recognize the value and validity of patients' subjective experience, and seek to accommodate it in clinical decision-making. Kassirer (1994) notes the importance of individualizing 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 standardized practice, in offering better outcomes to the many, might reduce choice for those whose individual preferences do not conform to a professionally-defined norm. How can doctors help patients assess the degree of risk entailed in any procedure, standardized or otherwise, so as to arrive at a decision which feels right to both parties?

Patients' reasoning

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. Much patient literature is produced in this way. A recent survey by the King's Fund Centre (Hyatt, 1994) found only a tiny proportion 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 patient's 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 (ie the average number of years patients live after the treatment) rather than cumulative probability data (ie 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 hemorrhagic 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. The most notable example of such materials is the series of Interactive Video Shared Decision-making Programs produced in the USA (Kasper, Mulley and Wennberg, 1992). The programs grew out of Wennberg's work, referred to earlier. Each program 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 reaction 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 video 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. Whilst it is important to note that not every condition, treatment or patient is suitable for this type of treatment, the American Shared Decision-making Programs provide an excellent model for genuinely empowering patients in the context of individual care.

3: Patients and Providers: Service delivery

The NHS reforms have given providers in primary and secondary care, 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 their patients. What practical changes can providers make to the way services are delivered which will give greater control to individuals who use them? 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 the people who use it. The case-studies in the Health Services Commissioner's Epitomes 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 providers tackling situations which disempower people receiving care, and how effective are current attempts to produce change?

3.1: Policy and context

The Patient's Charter, arguably, is the most important mechanism for patient empowerment to emerge from the reformed NHS. However, its value is far from being universally accepted. Arguments against the Charter 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' organizations 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 approach taken to local community care Charter development (DoH, 1994) suggests 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 which were undreamed of three years ago, 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 really 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 (eg Andrews and 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 ethnic food. 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 afoot to improve the quality of service to patients (the NHSME'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. The fact that quality, of necessity, plays second fiddle to activity is a powerful rider, however : the best- intentioned purchasers can only invest 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. Whilst 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 that improved quality would release remain entangled in wasteful processes.

The NHS reforms have been characterized by the widespread introduction of Total Quality Management, 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, again, falls outside the scope of this discussion. Ovretveit'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 organization. (Saltman's (1994) analysis suggests that altruism in managers is a rare attribute!) The conversion of professional and non-professional staff to their transatlantic enthusiasm tends to be patchy, however, which limits their effectiveness as agents of change. Quality initiatives tend to remain localized and low-key, the preserve of small bands of enthusiasts; whilst activity on the one hand, and clinical freedom on the other, retain their pre-eminence at the top of the organizational 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 organizations. 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.

3.2: Changing clinical services

Both the Patient's Charter and local quality systems confine themselves almost exclusively to non-clinical aspects of care, and we shall 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 organizations. Recognition of the validity of patients' involvement in both assessing quality of treatment and demanding clinical effectiveness is gaining currency. Dunning and Needham (1994) bring together a number of arguments supporting the need for user participation in areas from which non-professionals have traditionally been excluded.

3.2.1: 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 has been issued (DoH, 1991) providing for at least two lay members, one of whom should be appointed Chair or Vice-Chair. It has been argued (Brotchie and 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 five percent of cancer patients 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. This example (reproduced in full for its stunning effect) is quoted in 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 suggested method of promoting involvement is to design trials around patients' own treatment preferences. Brewin and 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 and Boulton et al, 1984) of self-management methods for people with diabetes focussed 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 gone one step further than this, by involving patients in the design of the trials 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 and Smith, 1995). More recently, 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 to work with clinicians and researchers in involving patients in trial design and patient information. Their work at the Royal Marsden Hospital asks women to identify issues of importance to them as cancer patients. Trials can then be designed to take account of those factors, including the careful design of information and consent forms. Early experience from a recent 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 and 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 clearly that one treatment is more effective than another: the use of one would secure better outcomes for patients who received it. Haines and Jones (1994) point to the role which better-informed patients could play in demanding evidence-based medicine of proven effectiveness. They cite the interactive video shared decision-making programmes 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 Centre are designing other means of giving effectiveness information to patients in order to promote empowerment through shared decision-making. The Centre for Review and Dissemination at York is collaborating 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 and 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 empowerment 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 and Jones note the 'heterophily' (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 pointedly than in the field of audit.

3.2.2: Audit and outcomes

The Department of Health, in guidance issued recently (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 very little say in what should be audited, and are rarely asked to participate in studies of the quality of 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 and Wann (1992) in respect of Ethics Committee members: hostility, marginalization, 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 qualititative 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 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) characterize as "the hotel aspects of health care or the personal qualities of staff". The patients in Pound'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 empowerment in this field? Ross Davies points out that (despite widespread statements of commitment to continuous quality improvement) most organizations still concentrate on one-off measurement or piecemeal monitoring of outcomes. These are far easier to accomplish than systematically and routinely completing the audit cycle, thus ensuring that outcomes are managed: that is, that clinical and administrative processes are systematically improved so as to produce outcomes patients identify as desirable. Whilst providers' quality systems should be reforming processes in pursuit of this aim, one entrenched obstacle blocks its widespread achievement: the attitude of many professionals to their patients.

3.2.3: Professional attitude

It is possible 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 attitude. 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 of twenty-eight identified points referred to the way in which doctors relate to patients, with training in communication and listening skills highlighted as the most urgently-needed development. This view is underlined by a glance at the complaints handling records of any hospital, FHSA or CHC: 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. Why should this be, in a profession founded on promoting patients' welfare?

We have seen that the law supports the traditional pattern of beneficent paternalism as the governing approach of doctor to patient. From their traditional power base, only a minority of doctors seem to be seeking the clinical benefits of greater patient autonomy. Medical training, too, 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 news that the Wilson Committee's (1994) recommendations will be implemented. 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. 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."

3.3: Non-clinical change

3.3.1: Organization

What organizational issues should providers be addressing if they are committed to empowering patients by changing non-clinical aspects of care? By empowering patients we want to produce people who know where they are going, who will treat them, when, and for what reason; people who have access to information but absolute confidence that their own information stays within the care team; people who feel their caregivers understand their cultural and personal needs; people who feel they are part of a dialogue, but have access to support and redress if dialogue breaks down. We are aiming to enable patients to feel: "confident, competent and in control" (Liddle 1991).

In practice, the way in which many aspects of care and treatment are provided clearly detract from this aim. Identified areas where providers need to improve can be found throughout the healthcare 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 Epitomes 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 (eg, 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 groups are amply documented (eg Hopkins and Bahl,1993; Henley,1991), but less successfully addressed (Chan, 994 Smaje, 1995).

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

Even if progress in some quarters is seen as frustratingly slow at times, the Patient's Charter in its several versions 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 (eg. *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 turn to their own use.

Strict observance of Charter rights and standards is one way for providers to reorganize their service for patients' benefit. Another has been successfully demonstrated by many Nursing Development Units (Copperman and Morrison, 1995). Another more radical - and controversial - solution is offered by recent moves to restructure the care process along 'Patient Focussed 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 centralized 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 multidisciplinary 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.

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 users' passage through the system, will improve both their experience and their confidence in the caregiving team. But if that confidence breaks down or something goes wrong, do we empower patients to complain without fear?

3.3.2: Complaints

It is a fundamental right of patients - especially in a system geared to viewing them as consumers - to make a complaint without fear of retribution. However, few would argue that current NHS complaints procedures defend the rights of patients any more than does the law. The current system seems to serve nobody's interest. Professionals see themselves as subject to arbitrary attack from increasing numbers of demanding patients. Patients soon realise that the system is stacked against them in principle and in practice. It offers no redress even if a complaint is upheld.

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

Hospital procedures are less rigidly enacted and generally less formal. However they can be frustratingly inconclusive. Unlike primary care systems they do not exist to discipline doctors. Complainants can be left with unsatisfactory answers and little redress. Even if a clinical complaint progresses to Independent Professional Review the complainant is not told the outcome. The Health Service Commissioner can only investigate procedural issues, not matters of clinical judgment. Reform seems long overdue.

Two developments give cause for optimism. 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. Whilst lacking the formal independence of a CHC representative, they have the great advantage of instant access. Patient's Representatives who acquire credibility in their workplace can be powerful advocates and change agents. Of course, a higher profile generates more complaints; this aspect of patient empowerment needs to be recognized. Providers are justifiably wary of introducing good practice while purchasers still publish league tables of complaints performance which favour low scores.

The second potential factor in achieving improvement is *Being Heard* (1994), the report of the Wilson Committee's investigation of NHS complaints procedures. The committee made wide-ranging recommendations for the reform of procedures in both primary and secondary care, including review panels for unresolved complaints, and the extension of the HSC's role to clinical complaints. In line with current thinking Wilson also stressed the need to use complaints as quality indicators; to encourage informality and good communication; and to appoint dedicated staff to give the process a human face.

The document was generally 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 a reformed system. It should be ensured that the role of CHCs as independent advocates for complainants is recognized and supported. In the field of complaints as elsewhere, CHCs have done more than any other body to bring about patient empowerment.

As this paper is being printed it has been announced that the NHS is to have a new Complaints Procedure based on the Wilson committee's recommendations (DoH 1995). In the context of patient empowerment *Acting on Complaints* is an important development.

4: Communities and Commissioners: Service Planning

4.1: The policy framework

There is clear policy guidance from *Local Voices*, and to some extent from the Patient's Charter, 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 what they choose to do. Unpopular or inept decisions may go unchallenged for want of a mechanism for removing the decision-makers. Davis and 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 these questions is the issue of accountability. Who bears ultimate responsibility for decisions made, and how are they held to account? Much discussion has been generated recently by the case of a young Cambridge leukaemia patient. 'Girl 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 alone did not dictate the authority's decision.

The case has 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 organizations; what scope have their local populations for influencing and challenging their decisions? "

Should public opinion influence rationing decisions? Hoffenberg (1992) warns that, whilst 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, he notes, puts doctors into " an extraordinarily difficult position". However, it has the political advantage of leaving rationing in the murky realm of clinical judgment. How can decision-making be made more accountable to the public?

The problem of democratic accountability in the new NHS, noted by Harrison, Hunter 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 legitimize 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 - perhaps more importantly still - 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 cradle to 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.

4.2: 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 are only a small sample: Jones, Leneman and Maclean, 1987; Thompson/NCVO, 1991; DoH, 1992; Barnes and Wistow, 1992; Sykes et al, 1992; NAHAT, 1992; McIver, 1992; Deakin and Willis, eds, 1992; DoH, 1993; Bowling, 1993; Hendessi, 1994; Hogg, 1994; Hamilton-Gurney, 1994. Harding and Upton, 1991 and 1994, have catalogued hundreds of user involvement initiatives in social care in a two-volume bibliography!) They illustrate different methodologies, 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 Ovretveit (1995) characterizes as 'justifiable commissioning' - commissioning as a service to the public. Purchasers as service organizations have to decide which services they will and will not purchase. They need to: " seek guidance about prioritizing decisions in a way which upholds its (ie, the purchasing authority's) purpose in the eyes of the public as a service to them".

Ovretveit and others (eg Sullivan, 1994; Lupton and Taylor, 1995) stress that the first need for commissioners is to be clear about their purpose in involving the public in prioritizing. He notes that the purpose may include: "educating and informing (eg 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 and Taylor, 1995), which records a range of different objectives amongst 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 and Taylor, the outcome and focus of public participation activity tends to depend on which part of the organization 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 and Taylor identify as central to effective development of public participation. They are:

> "- where there is senior management understanding of and practical commitment to public 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 organizations;
>
> - where there is a positive organizational 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 organization."

Lupton and Taylor note that the best-intentioned commissioners may be hampered by various factors. They identify particular difficulties when "the organization, 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 organizational 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.

4.2.1: 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. Ovretveit (1993) suggests that the three key functions of of commissioners for health gain are assessment of population health status and need; evaluation of effectiveness of treatment and cost-effectiveness of services; and 'social value prioritizing'. 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 prioritization. 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, district health authorities 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 prioritizing services, especially where judgments 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 analyzing priorities within individual service areas rather than across services (see 4.2.2 below).

Absence of information to guide priority setting (especially about clinical- and cost-effectiveness) was seen as a problem everywhere. Health authorities recognized that: "priority setting cannot be reduced to a technical or scientific exercise " (a judgment 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 prioritization means making judgments 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." Ovretveit (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 at 4.2. They include focus groups, tapping into existing networks, community and voluntary groups, rapid appraisal techniques and a range of possible survey methods. Whatever methodology is chosen it is clear that many pitfalls await researchers.

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 and 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 and 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 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 changing services 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 expected to presage 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 and 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."

4.2.2: User participation

There are clearly a number of practical issues which commissioners must address if they wish to create opportunities for fruitful public engagement. Many of these factors apply equally when bringing people currently using services into the picture.

Involving services users seems more likely in recent experience to be related to the quality assurance aspect of the commissioning function. 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 organizations such as the Patient's 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 analyzed involvement in social care. It echoes the feelings of the Derby resident quoted earlier: commissioners should be prepared to let users set the agenda. 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 influencing of how services should be planned and delivered.

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 and 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 service areas. 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 and Bradley (1989) for patients who participate selectively in research trials. Care would need to be taken, however, to avoid Pollock and Pfeffer's worst-case scenario: users unwittingly signing up to cuts in services that affect them.

The different methods open to commissioners and providers who wish to involve users have been extensively discussed in many of the publications already listed. Most methods listed as suitable to engaging the public can also be used to involve smaller groups of service users or community groups. McIver (1991), amongst 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.

The message, once again, is that 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 greatly by learning from past experience.

5: Conclusion

This review, undertaken within a tight timetable, is not comprehensive. Nonetheless, it provides a body of evidence which supports the formulation of a national policy and strategy for patient empowerment. Areas for policy development have been highlighted. Clinical reasons for rebalancing doctor-patient relationships have been discussed. Operational aspects of service delivery which providers should address have been noted. Several publications have been mentioned which give details and examples of methods of involving users and the public. Other studies referred to have illustrated factors which make the difference between successful initiatives and frustrating ones.

In all these works - and many others besides - there is a wealth of learning to inform the development of a strategy. With careful planning, experience shows that patient empowerment can become a reality.

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