King's Fund

The Patient's Charter:

Past and Future

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Preface

The Labour Party's Election Manifesto (1997) contained a commitment to reviewing the Patient's Charter and to producing a new one. The King's Fund had been planning a piece of research on the Charter in the spring of 1997 and when the government's review was formally announced in the summer of 1997 they were commissioned by the NHS Executive to carry out this research.

The aim of the research was to review the workings of the Patient's Charter from the point of view of patients, carers, and NHS workers [managers and clinicians]. As well as reviewing views and experiences of how the Charter worked in the past its main focus was on what any health charter should cover in the future: that is, the Charter philosophy, the rights and responsibilities of the state provider and the citizen, areas and aspects of services and service delivery to be covered.

The study was designed as a five stage process starting with a review of the literature and moving through in-depth interviews with patient organisations, focus groups with patients, NHS managers and clinicians, written evidence from a sample of NHS trusts, community health councils, Royal Colleges, professional organisations and voluntary organisations and finally, in-depth interviews with representatives of vulnerable groups (the homeless, refugees, ethnic minorities and the physically disabled). This staged process allowed us to build the findings from the first stage into the design of the second, and so on. In this way, we were able to check out the extent of agreement or disagreement about the findings from one stage with the next. The research began in September 1997 and was completed in February 1998.

The report is in six parts. The first part is the *main report* which draws together the findings of the research. It is followed by five appendices. The first four are detailed reports of the findings of the separate parts of the research. Appendix V is an account of the research methods and the people who participated.

Summary

Consensus for a new charter

The existing Patient's Charter has had a contentious public reputation. In the light of that there is a quite remarkable and perhaps reassuring level of agreement between the different groups which took part in the research reported here below.

If a new Patient's Charter was drawn up solely by patients it would have much in common with the concerns of NHS staff but it would also reflect some differences of emphasis, particularly on the need for advocacy and information to enable people to make best use of the NHS. Comments of patients and staff on the current charter also overlap: the main report reveals differences of emphasis only in the details.

Advantages of the existing charter(s)

- has raised staff awareness of patients' needs, issues and rights
- helped set [some] standards and identify priorities for action
- set comparable standards for reviews of performance
- helped to move NHS culture towards a 'user perspective'

Disadvantages of the existing charter(s)

- lack of clarity about its aim - this engendered wide scepticism
- not enough user or staff involvement in creating the document
- too much emphasis on quantitative standards
- ignores clinical standards and outcomes
- some standards irrelevant to patients' real needs, especially those of vulnerable people
- hard to monitor - data costly to collect and sometimes fudged and/or ignored
- hospital services dominate at expense of primary care
- low patient awareness of charter
- patients' expectations unrealistically raised
- little stress on patients' responsibilities

A new NHS charter should contain:

- an unambiguous statement about its aims and its values
- reflect principles of openness, accountability and equity
- a much stronger focus on primary and community care
- a wider and clearer statement of patients' rights of access to services

- wider standards which focus on quality of service:
  - for clinical need, effectiveness, and outcomes
  - for equity and access to services/treatment
  - for the quality of the patient experience
  - for better communication and information in a usable form
- emphasise not only patients' rights but also their responsibilities and foster ways of encouraging such behaviour
- better publicity for the Charter
- regular reviews of the content and impact of the Charter

The process of creating this document must *involve patients and staff.* Better monitoring and feedback systems are essential to inform staff and patients about progress and standards achieved.

There is no substitute for a national charter, but local charters can be useful, provided they are based on consultation and create standards relevant to local conditions.

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INTRODUCTION

The Patient's Charter is one of those topics that elicit a response when mentioned; people either like it or they do not, but they are rarely indifferent to it. (Tschudin 1997) *

Ever since the Patient's Charter was launched in October 1991 it has been the subject of sustained argument. Are the contents appropriate? Does it provide a means to better services? Does it encourage unrealistic expectations, or empower patients to get the best from the NHS? Does it make any difference at all, and is a Patient's Charter an effective tool for driving up quality in the NHS? These are the kinds of questions that managers, clinicians, patients and carers ask, sometimes arriving at different answers.

The change of government and the greater emphasis on openness and accountability has provided an opportunity to re-visit some of the concerns of both patients and staff about the NHS. As the Prime Minister, Tony Blair, wrote in the foreword to a book about the NHS:

The NHS touches every one of us and it is particularly appropriate that we should reflect on this in the 50th Anniversary year of our National Health Service, whilst taking time to consider the opportunities for its future. (Rivett 1998)

Reviewing the Patient's Charter is just one aspect of considering opportunities for the future. However, although the existing Patient's Charter is undoubtedly flawed and constraining, it has many aspects which can be developed.

The NHS exists for patients, and the quality of NHS services for those who use it must be at the heart of any review of the Patient's Charter. However, in order to be truly effective, a charter must address the needs of potential patients as well as actual patients and their carers. There are still significant problems of access to the NHS for some sections of the community. There are also major inequalities in health status and to some extent in health care, across the country. The Green Paper *Our Healthier Nation (1998)* acknowledges that poor health has complex causes, and recognises that health inequalities are widening. Unless these inequalities are tackled and a collaborative approach that transcends bureaucratic and organisational boundaries is used, the development of the NHS will be limited in its nature.

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* All references are listed at the back of the report

Although the Patient's Charter is only a small 'tool' for change and for moving towards an NHS system which works to redress inequalities, it does have a part to play in the government's overall strategy.

It is also important that the needs and views of all staff in the NHS are taken into account. While there has been an increased awareness of the significance of clinical expertise from doctors and from nurses, other groups of staff must not be overlooked. Porters, administrative staff, technicians, managers and many others are all part of the NHS, and a charter and any other tools for improving the NHS must take into account their concerns and build on their experiences.

The new NHS White Paper (1997) stresses the modernisation of the NHS so that it is prepared for the next 50 years. It explicitly describes a modern NHS as providing information and services at home, in the community and in hospital. It also emphasises primary care as a driving force within the NHS. Any considerations of the Patient's Charter must reflect these priorities.

1. WHAT ARE THE PURPOSES OF A CHARTER IN THE NHS?

The changes that are signalled for the NHS by the White Paper (1997) and by the Green Paper, *Our Healthier Nation* (1998), make a fresh look at the Patient's Charter timely and appropriate. The Patient's Charter says that it is helping the NHS to:

- listen to and act on people's views and needs
- set clear standards of service
- provide services which meet those standards

It is worth examining the various possible uses of a charter for the NHS and seeing what sort of charter would be most effective in helping the NHS deliver a service. While different approaches to a charter are considered in turn, it is, of course, possible to combine several approaches in one document if there is sufficient clarity about these approaches and their aims.

A codification of rights

As we can see in the literature review (Appendix I) and to some lesser extent in the patients' focus groups (Appendix IV), the Patient's Charter has been criticised by some because it has not been apparent to what extent it is a document about rights. The Patient's Charter draws a distinction between rights and expectations in the following terms:

Rights -which all patients will receive all the time; and
Expectations - these are standards of service which the NHS is aiming to achieve. Exceptional circumstances may sometimes prevent these standards being met.

What emerges from our research is that the Patient's Charter created some confusion about rights and expectations. The rationale for what was a right and what was an expectation, and the differential monitoring of some standards may have obfuscated the purposes of the Patient's Charter as a whole.

One view, expressed by some patients in the focus groups, is that a new charter should be a codification of the rights of those who use the NHS. Some of the literature also argues for a firmer base in social rights (Bynoe 1996). Other writers express a preference for a "Bill Of Rights" approach (Thain 1992). A rights-based charter would emphasise those aspects of the NHS to which there was a clear and enforceable right. This is easier said than done, and the prospect of producing an accurate document that could be condensed into a manageable size would be enough to daunt the most intrepid draftsperson. A 'rights' approach also raises the question of the practice, rather than the theory of rights. For example, while there is a clear right for everyone to be registered with a GP, we know that enforcing that right is far from simple, especially for people who do not speak English or who are homeless.

Setting minimum standards

Another purpose of a charter in the NHS is to set out minimum standards. While this is a close cousin of a 'rights' approach, it is not so legalistic. It tends to be pragmatic, rather than principled, and to define a level of service which is deliverable, and where redress could reasonably be expected if it were not. This approach seems to have been influential in relation to the expectations which the Patient's Charter described. Typically, documents which set minimum standards tend to concentrate on areas where there has been considerable concern about standards in the past. Long waits for operations were a pressing issue when the Patient's Charter was being devised. As we shall see later, in the section on setting and monitoring standards, this approach did not deal adequately with patient and staff concerns.

While some people have been critical of the impact of defining minimum standards, others have welcomed the fact that the Charter has been an educational tool for raising the awareness of both the public and NHS staff about quality issues and standards.

Setting aspirational standards

A charter can also set standards which indicate the direction and speed of travel towards improved service standards. The notion of expectations in the Patient's Charter reflects this kind of approach. Aspirational standards are not so much a framework for monitoring current standards as an exhortation to move forward towards improvements. An aspirational charter can be used to change services in line with a strategic overview, or it can be used to apply pressure where performance has been unsatisfactory.

Aspirational standards may tend not only to encourage (or, depending on one's point of view, to empower) patients to press for improvements and clearer rights, but are also seen as putting unremitting pressure on those who deliver services. It is hardly surprising that views on the merits of setting aspirational standards reflected diverse

patient and staff roles. However, it is worth noting that patients and health advocates sometimes say that aspirational standards can actually obscure the here-and-now reality of services, in favour of a utopian view of how the NHS ought to be.

A management tool

Up to now, the charter has been styled a _Patient's_ Charter (our underline). In fact, in spite of its title, the Patient's Charter has, arguably, been a charter about what patients could expect as much as it has been a charter for patients to use, with its primary function being as a vehicle for managers to drive up standards. Some patients, however, have used the Patient's Charter as a means to getting better services, or to understand what they could expect from the NHS.

There is a widespread and clear impression that a significant impact of the Patient's Charter has been to concentrate the minds of staff on a number of centrally defined priorities for action. Appendices III & IV show that managers and clinicians are sometimes ambiguous about whether this has enabled or encouraged them to improve services. We also see from both the literature review (Allen 1995, Cohen 1994) and the interviews with voluntary organisations and patients' groups that there are widespread criticisms of the particular aspects of services that were chosen for the Patient's Charter, and the means by which particular rights and standards were selected. However, there seems to be agreement that the Patient's Charter did focus the minds of both managers and clinicians on how to make changes in some parts of the service, and that this benefited patients.

The 1983 management review conducted by Roy Griffiths identified the need for a general manager, regardless of discipline, at each level. While the introduction of general management was supposed to give NHS managers a clearly defined function and the power to enable integrated change to take place in line with agreed strategies, managers often found they lacked a framework for improving standards and performance. For all its shortcomings, the Patient's Charter may have helped provide such a framework.

Defining what the NHS can and cannot do

A charter may not only set out minimum standards in respect of particular aspects of the service, but may also set out what it would be reasonable to expect of the NHS in broad terms. In other words, it may try to define the core business of the NHS as a whole, or for particular services within the NHS. While the Patient's Charter, to date, has not travelled far along that route, it is a new direction for a charter that could be developed, if debates about prioritisation were more in the public domain, as the focus groups suggested it should be.

A statement of values

A charter can also make statements about the values of a service or organisations, and try to make plain the ethos of the service. By definition, this is a less precise task than the 'Rights' orientation described above or than the setting of particular minimum or

expected standards. The section in the Patient's Charter about respect for privacy, dignity and religious and cultural beliefs is an example of an attempt to make a statement about values and ethos. It is interesting to note that these expectations are located in a section entitled *Personal Consideration and Respect*, where in a single section, the Patient's Charter includes a statement about rights (to choose whether to take part in medical research or medical student training), a section on expected standards (staff wearing name badges) and a section on values and ethos (privacy, dignity and respect for religious and cultural beliefs.)

While a statement of values may be seen as general, rather than specifically about services, it can also be an essential foundation for real improvements in a service. Core values can also define the national benchmark as the foundation for genuinely local work to steer local action in line with national priorities, but at the same time reflecting local circumstances and needs. While some users and their organisations favoured very detailed and specific standards, there was also considerable support for a clear, unambiguous statement of values.

<u>Towards a new charter</u>

There is now an opportunity for the government to consider what it aims to achieve through a new NHS charter. While all the points discussed here have merits, a new charter needs to go beyond the limitations of all of them. A new charter should be a stimulus for change, while not attempting to produce expectations remote from what can practically be achieved. It is essential for a new charter to include a clear statement about its aims and what it can do to contribute to ensuring the delivery of quality services in the NHS. The clear lesson from the past is that staff and patients need to be involved in determining the contents of a charter for the NHS. Regular reviews of a new charter's content and impact must also involve all those who use and serve the NHS.

Whatever the detailed content of the charter, our research clearly indicates it should reflect a number of fundamental principles. These are:

- openness and accountability
- equity
- partnerships between patients and NHS staff
- access to services on the basis of clinical need

2. PERCEPTIONS AND EXPERIENCES OF THE PATIENT'S CHARTER

The common response from patients when they were asked about the Charter was that they had heard about it but were not familiar with its contents. They usually, in fact, had some awareness of what the Charter was about and could, when encouraged, give an example of what it might include but lacked a clear understanding of its contents. This corresponds with existing survey findings (NOP 1994) and confirms findings in France and Finland - the only other European countries which have health charters. (Bourgine P. 1984; Tugend & Harris, 1997)

None of the patients in the focus groups recalled having seen a copy of the Patients' Charter but they did remember some references to it in the press or in local hospitals. They also imagined that the purpose of the Charter might be:

- improving NHS service quality and choice
- demonstrating performance against targets
- ensuring fairer distribution of resources by setting a framework of patients' rights regardless of where they lived or their ability to pay
- giving patients the right to complain or ask questions if they felt their rights had been infringed
- providing a means of monitoring the service

A degree of scepticism about the Charter was evident in all components of the research. The literature review found several sources which commented on what might be termed 'political taint'. Patient organisations and voluntary groups hinted at 'political manipulation'. The representatives of vulnerable groups were particularly sceptical and emphasised the lack of awareness amongst the vulnerable people whom they represented. Once these reservations had been expressed however, all participants in the research were happy to move on and discuss the positive contribution the Charter had made to NHS services and patients' use of them.

Experiences of the Charter

The overwhelming view of the Charter amongst those who had experience of it, was that it was of limited usefulness. Most commentators acknowledged some positive aspects but these views were much less enthusiastically expressed than when the weaknesses of the Charter were mentioned.

Strengths of the Charter

The literature review offered a limited perspective on the usefulness or strengths of the existing Charter which can be summarised as: informing patients about the standards they could reasonably expect (NOP 1994); and the effect on day-to-day running of hospitals in terms of helping patients to identify failures in the standards of services (Tailor & Mayberry 1995).

Our research with voluntary organisations and patient groups identified three main strengths of the Charter. That it had:

- raised awareness of NHS staff of patient needs, issues and rights
- helped to set [some] standards and identify priorities for action
- set standards for performance which allowed comparisons and reviews of performance.

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The interviews with representatives of vulnerable groups also showed that the Patient's Charter had been important because it had set out some rights and expectations. Inside the NHS, staff commented on the value of the Charter in stimulating debates about standards and offering basic, minimum targets which they must meet and improve on. Probably the most important point to emerge from NHS staff was that by raising awareness of patients' needs and experiences, it had helped to change the culture towards the user perspective.

Weaknesses of the Charter

All sources of evidence confirmed each other in the identification of the weaknesses of the Charter, focusing on what it *did not* do as much as on the difficulties to which it had given rise. The chart below illustrates the major weaknesses identified.

CHART 1 WEAKNESSES OF THE PATIENT'S CHARTER

Problems with standards/rights

- lack of clarity
- too much emphasis on quantitative [waiting times] standards, not enough attention to quality standards
- ignores clinical standards/need/outcomes

Difficulties with monitoring

- uncoordinated, incompetent data collection systems
- extra work in collecting data
- 'fudged' statistics
- lack of clear definition of standards which complicates monitoring

Raised patients' expectations too high

- expectations raised beyond the resources of services to meet
- no patient responsibilities included

Problems with Standards/Rights

The lack of clarity in the existing charter and the confusion between 'rights' and 'standards' were points much commented upon in the literature (Hogg 1994, Carr Hill & Ng 1992, Bynoe 1996). Criticisms of the way the Charter concentrated on acute services and on quantitative aspects of services were even more pronounced (Lorentzon 1996, Cohen 1994, Benton 1993). All the evidence from this research

supports these criticisms. The relative neglect of non-acute services was a point often raised, particularly in relation to people wit. .ng term conditions, the mentally ill and other groups whose care is offered in comm...ity and primary care settings. NHS staff in the focus groups reinforced these views.

> *It [the Patient's Charter] never actually looked at the care and it was never meant to look at the care and I think, that was most frustrating to clinicians because..... from a clinicians' point of view it wasn't measuring what we perceived to be quality.* (clinician)

Specific issues were raised, such as the way in which charter standards had 'distorted' the good management of care by focusing on one part of the system whilst neglecting others but the primary concern was with the way in which charter standards had led to prioritisation by time rather than clinical need.

> *Very few people are going to come to any great harm if they don't have their varicose veins done, and yet they could be displacing more worthwhile - dare I say it - procedures. So that's a kind of meaningless [standard], just having a crude, you mustn't have anybody waiting more than...18 months.* (clinician)

Difficulties with monitoring

NHS managers expressed particular concern about Charter monitoring systems and methods. Their criticisms fell into four main categories:

- inadequate infrastructure to support monitoring
- difficulties with the reliability of the data produced
- inadequate tools to measure quality
- inadequate feedback mechanisms from results to performance review

> *Our trust didn't have very sophisticated information technology and so to capture a 30 minutes wait in outpatients, that was all done by hand on a little form. We had to devise a form and you had to write down the time they arrived, the nurses had to write down... time of arrival, time of appointment, and time of departure. That, in itself, could be open to abuse of course, but it was that kind of thing, because we didn't have the infrastructure to capture that in any other way...* (manager)

Another recurrent theme was a lack of confidence that the statistics produced were a true reflection of what actually happened (Friend 1995, Hart 1996). Managers questioned the reliability of the data, pointing out that reasons for this might include staff failure to give priority to monitoring, pressure of work, and inadequate tools for measurement of some quality standards like privacy and dignity for patients. Some of them also expressed frustration that when they did make attempts to record the required statistics, little use was made of them internally.

> *I once put extra time and effort into looking at precisely where the problems (with trolley waits) were... [but] nobody was interested anyway. So we've just*

resorted to the minimum data collection we can possibly attempt now.....
(clinician)

Raised expectations

In some ways the most interesting category of complaints about the existing Charter was the one which expressed concern about the rise in patient expectations. Managers and clinicians, especially general practitioners, felt this had put extra pressure on them at a time when resources were not available to meet them. Yet it is difficult to reconcile this pressure given the low patient awareness of the Charter.

In the minds of some NHS staff, the Charter ignored patient responsibilities, putting all the onus on staff. This 'bias' in the Charter was connected to the rise in aggression, some people believed.

> *Its all very one-sided and patients, particularly relatives, have become very aggressive towards nursing staff...*(clinician)

Added to this was a definite feeling among staff that the Charter had encouraged people to complain.

> *A lot of people feel there is a focus on complaining rather than either commenting or complementing...a lot of staff feel that patients are almost encouraged to complain...but when you're struggling.....with a busy clinic...* (clinician)

Yet comments from patient organisations suggested that the Charter named irrelevant rights and that as far as primary care services were concerned, the new complaints system was a failure.

These are areas where patient and staff perceptions and experiences were widely different. Ways of resolving such discrepancies surely need to be addressed.

In summary, the difficulties which managers and clinicians experienced with the Charter were specific and detailed and the limited gains it had introduced did not compensate for this. On the other hand, whilst patient organisations identified similar difficulties and limited virtues, patients themselves did not see the Charter as an important part of their experiences of the NHS. Patient's concerns were with the services themselves; their access to them, and the way in which they were treated when they had to use them.

3. **NATIONAL AND LOCAL CHARTERS**

It is hard to know how many and what kind of local charters have been developed. Carr, Hill and Ng (1992) examined local charters from 140 health authorities and 50

family health service authorities. They found that only a third (30%) separated national and local standards.

For this research a specific question was asked to address this issue. Five main concerns were identified:

- a national charter is essential to maintain the NHS as a *national* service with national standards
- only a national charter can ensure the principle of equity in the NHS
- local charters are important to set standards relevant to local circumstances
- local charters should involve all key stakeholders (staff, patients, carers, and commissioners) in their development to ensure effective ownership and implementation
- the problem of confusion between national and local charter standards could be avoided by introducing a national framework which should be mirrored and built upon by local charters

There was a considerable amount of support for this last proposal. Its virtues were seen as enabling local standards to be set within the context of local priorities and resources. More importantly, perhaps, it would maintain national standards (and therefore equity) whilst allowing local people to be involved in the development of local standards.

Some worries were expressed about proliferation of standards and causing confusion in the minds of patients and the public. Nevertheless, the desire to maintain national standards at the same time as having standards relevant to local conditions, gained almost universal approval.

Progress towards this position may be slow if good outcomes are required. As McIver and Martin noted:

> *The key to producing local charters is to develop them with service users so that standards relate to aspects of the service they consider important.* (McIver & Martin 1996)

The process of involving users and staff will take time and need careful handling. There may well be competing interests, not all of which can be served. But if the national framework can offer a model acceptable to the majority of staff, patients and carers, that process will be a means, not only of producing a local Charter, but also of educating NHS staff and patients and helping all the stakeholders in health to understand each others' perspectives. This in turn should help to develop the patient partnership approach so clearly desired by many staff.

4. SETTING AND MONITORING STANDARDS

In this section, we consider some of the issues about the setting and monitoring of standards that have emerged from the various components of the research.

Standards should relate to clinical need and should be evidence-based

Much of the concern about standards focused on the particular standards chosen to be enshrined in the Patient's Charter, rather than with the actual principle of defining standards in a charter, for which there was qualified support. As one commentator asked:

> *Who in their right mind could possibly argue against these kinds of standards when previously there were none at all and there was no frame of reference for patients to assess whether or not the waiting time was excessive or against the rules?* (Ryland 1996)

In a similar vein, some patients' groups felt that it was helpful to have rights and standards defined, as a vehicle for ensuring an appropriate level and quality of service delivery.

Among staff, there was widespread concern about the factors which had driven the particular standards on reducing waiting times. The imperative of meeting Patient's Charter standards was sometimes perceived as a pressure to overlook clinical need.

> *Surely the priority of the day is determined on the basis of clinical need of each patient who comes in, and I think the charter has actually interfered with that to a certain extent...* (clinician)

> *Many of the standards do not focus on clinical need but on something else, e.g. time waited. Also the standards work against each other, e.g. 12/18 months waited versus cancelled operations....* (health authority)

There were fears that improvements in the waiting times for some treatments may increase waiting times for others. The research showed that some patients were critical of a system that sought to deal with long waits for hospital admission without providing extra resources to make a genuine difference overall. Staff were no less critical, and in one instance the Patient's Charter was described as:

> *A bludgeon to beat staff when the real problem is resourcing...* but ... *a useful means of exerting pressure [as a patient]* (Viewpoint Readers' Panel 1995.- Nursing Standard)

Benton (1993) noted that most of the measures applied in the Patient's Charter are either process or *output* oriented, and not *outcome* oriented. Our research found that both patients and staff expressed concerns about standards which concentrated on process, rather than on outcome. For example, we heard from several sources that patients may be assessed in accident and emergency departments within five minutes,

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but may then wait several hours for treatment. The 'hello nurse' has become symbolic of the triumph of process over outcome, and of the ability of 'coal-face' staff to subvert top-down policy if it is perceived to be of little relevance to real life.

Our interviews confirmed the suggestion in the literature (Lorentzon 1996) that from the patient's point of view, long waits in out-patients may not be the most important aspect of the out-patient experience. There was also concern that long waiting times were not measured in relation to the severity of the patient's clinical condition. Patients also tended to stress the need for appropriate standards for primary care, noting that the best known Patient's Charter standards related mostly to acute hospital care.

Lack of a strategic framework

There is little evidence that Patient's Charter standards have enabled or encouraged a strategic approach to improving services for patients. A high level of cynicism pervaded the research findings from all sources, as the Patient's Charter was seen by many people to be a hotchpotch of short-term imperatives rather than part of a strategic programme for improvement and change.

A related point is the separation of a whole system into discrete parts for setting service standards and monitoring. Staff in the focus groups were concerned that standards about waits on trolleys in accident and emergency needed to be seen as part of a wider system of bed management. Carers express concerns that standards aimed at faster throughput in hospital might overlook the needs of carers as well as falling short of meeting the needs of patients.

Quality

There was a strong, widespread concern about the impact of the Charter on quality. Time and again people said the Patient's Charter had tended to concentrate on aspects of quality that did not adequately reflect patients' concerns or experiences. The Patient's Charter was sometimes perceived as concentrating on access to services, but mainly in a rather narrow sense, such as waiting times. There was also undue emphasis on those aspects of quality that could be quantified, hence this comment:

> *Quantitative indicators are nearly always seized upon because they measure that which is measurable, rather than that which is significant.* (Hart 1996)

The same sentiment emerged in the focus groups.

> *It felt like a political move, so that the government could demonstrate some form of quality going on in a service, which didn't necessarily reflect the real issues on the ground, as far as quality was concerned....* (manager)

There were some positive views about the use of the charter as a vehicle for considering issues of quality, including some aspects that were broader than the rights and standards listed in the Patient's Charter. Other responses were highly critical of

the contribution of the Patient's Charter to quality. Interviews with patients' organisations, specialist groups and the review of the literature indicate that patients take a fairly dim view of the Patient's Charter's impact on quality. Most of the positive comments were about the benefits, in broad terms, of making an *attempt* to set out rights and standards, rather than about specific quality improvements as a result of the Patient's Charter.

It is clear that patients particularly value aspects of quality that are difficult to quantify, such as a positive staff attitude, friendliness and dignity. They also express a keen interest in the quality of the outcome of their actual health care intervention, including whether they are treated by professionals with appropriate qualifications and competence, and whether they were kept as free as possible from pain and indignity. The quality of information is also very important to patients and is discussed further below. The environment within which care is delivered is also a significant quality consideration for some patients and some managers, although it does not appear prominently as a Patient's Charter standard.

Interviews with organisations which had a particular concern about access to the NHS, as in the case of homeless people and refugees, for example, indicated that the kinds of quality issues to which the Patient's Charter had given greatest attention might be quite irrelevant for some potential patients, since some patients lack basic access to services. Thus, for homeless people, a waiting list that depended on writing to a patient at home was doomed to fail whatever the length of the waiting time. Or, for the health advocate who was told not to tell a non-English speaking patient about GP services [because the service could not communicate with the patient and vice versa], Patient's Charter notions of quality, for example, in relation to the speed of transfer of medical records to a new GP, must appear somewhat meaningless.

The written evidence indicates six main categories identified by providers and patient organisations as the most important quality standards. They were standards:

- for clinical effectiveness
- for access to services/treatment
- for user involvement/partnerships
- for effective information/communication
- for staff training/qualifications and behaviour
- for general aspects of care, including privacy, dignity and respect.

Monitoring standards

In addition to the fundamentally important question of whether the Patient's Charter identifies the most important aspects of quality, there was also much concern, across the board about how the Patient's Charter was monitored. The emphasis within quality on quantifiable standards was reflected in monitoring procedures.

It is widely acknowledged that, a climate of great pressure has been engendered, that may on occasions lead to distortions in data collection or presentation. In its worst manifestation, we see from the literature (Friend 1995) that there are allegations that

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nurses have been threatened by disciplinary action if they do not meet Patient's Charter targets. The focus groups provided insight into a charter-related culture of blame, which did little or nothing to improve services.

Many patients and their organisations appear to be well aware of these factors, and to some extent the credibility of the Patient's Charter has been undermined. However, taking the interviews as a whole, patients and their organisations had many suggestions for ways in which quality could be monitored in a more realistic way, including the use of:

- focus groups to listen to patients' views
- market research techniques to survey patients' views
- on-going panels of regular users to ascertain patients' views over time
- opportunistic surveys and discussions in waiting areas
- publication of local qualitative studies
- inspections by outside independent bodies
- expanded role for Community Health Councils (CHCs)

Patients with long term conditions, who are regular users of the NHS, are often particularly keen, well informed and able to supplement numerical data with genuine personal experience of how services are working in practice. Patients tend to see the value of qualitative research, and tend to be wary and suspicious of anything that resembles a box-ticking approach to performance management.

"League tables" were seen by many staff and many patients as simplistic or misleading. They also seemed to be construed by staff as a temptation to be less than truthful about the realities of the service. Focus groups with staff confirmed literature sources and patient views in indicating that 'unsatisfactory' figures might simply not be acceptable and could be sent back by managers for revision, without any alteration to the service as such.

The Association of Community Health Councils for England and Wales (ACHCEW) proposed an independent Health Rights Commission to monitor patient's rights and ensure that they are implemented. Other organisations and individual patients express their willingness and enthusiasm to be seen as part of a regular and ongoing quality monitoring mechanism. Focus groups also suggested greater involvement of CHCs and patients in monitoring.

5. INFORMATION AND THE PATIENT'S CHARTER

Information for patients and staff is recognised as central to the effective use and provision of NHS services. The Audit Commission pointed out in 1993 that information and communication were particularly important to users of the service and its report identified poor communication as a primary source of dissatisfaction. Although the present Patient's Charter includes a section on the right to information of certain kinds, there is still concern about the lack of communication in the NHS. Other commentators (LeTouze 1997, Rigge 1997) have noted patients' and users'

need for information and that it is sometimes unavailable or difficult to get. The current research confirms the importance patients, carers, and NHS staff attach to good information and communication.

The existing Patient's Charter includes the rights to information about conditions and treatments, (including any risks involved in those treatments) clearly explained before a patient decides whether to agree to it; access to a patient's own records in most circumstances; detailed information on local services and a prompt investigation of, and a full reply to, any complaint about NHS services. Whilst this kind of information is generally welcomed by patients, each of these information 'rights' is limited in some way. Patients themselves identified the following kinds of information as being important:

- information about conditions, treatments, medications with risks and benefits clearly explained
- information about NHS services available and how to access them
- information about standards of NHS services
- information about non-NHS support services

Information about clinical conditions, diagnoses, treatment, and alternatives

When asked to say what kinds of information was most useful to people using NHS services, two-thirds of NHS staff identified clinical information about individual conditions and treatments; the risks and benefits of treatments and medications, as *the* most important.

> *If they are to be informed partners in their own health care, patients need clinical information; for example on what tests are being carried out, why, and their results; on why a certain intervention has been chosen or drugs have been prescribed and how they will work; on rehabilitation care and on what is expected of then and why...* (manager)

Patients in the focus groups also identified information about conditions and treatments as important and there was a sense that this kind of information helped them to feel more in control of what was happening to them and to feel less anxious.

Information on local services

The evidence also pointed to the need for information about the standards of services and what to expect of local services. Having access to local services and using them appropriately is highly dependent on the availability of good information. This type of information was thought to be of great importance by most participants in the research. Patients felt that without it they were unable to exercise any rights which the Charter may give them. Representatives of vulnerable groups pointed out that without this kind of information, provided in minority languages and/or in places where disadvantaged people such as the homeless and refugees had access to it, use of any NHS service was likely to be difficult or inappropriate. This is supported by

Tailor and Mayberry's study [1995] which reports that only 42% of people were aware of their right to receive detailed information on local health services.

In the written evidence, where respondents were specifically asked about the need for information, access to services was identified as the second most important category of information.

> *First, people need information about how to access the NHS in an emergency or for routine care. As suggested in the Chief Medical Officers' Review of Emergency Care in the Community, they may need information to assist them in judging the nature and severity of their condition in order that they can make an informed decision about how to access the services.....* (ambulance trust)

> *Information on what can realistically be expected within any given health situation. More comprehensive information to members of the public of services available in districts.... would enable them to make choices.* (community & mental health trust)

Information about non-NHS services, particularly voluntary organisations and self-help groups was another category of information ranked as useful. The importance of information about local social services was noted by organisations for people with long-term medical conditions and vulnerable groups.

Information about standards of NHS services

Patients wanted information about the quality of care. NHS staff said they were keen to help patients understand more about the clinical performance of NHS services locally, particularly that which might help them make more informed choices about doctors. Patients wanted this too but felt that they had to rely upon and trust the quality assurance systems within the NHS to ensure that any clinician would perform to a high clinical standard.

Information about complaints procedures

Tailor and Mayberry (1995) reported that only 44% of people knew about the right to have any complaint about the NHS investigated. Our research also pointed to a host of factors that make patients unwilling to complain whether or not they know their rights.

At the most basic level, patients fear - and sometimes with good reason - that if they complain about a GP they will be removed from the GP's list. Many other factors, including gratitude and a general unwillingness to complain when staff are doing their best under pressure, also inhibit complaints. Some staff also said that they felt patients did not generally wish to complain and suggested several reasons why they might not do so even if they were dissatisfied. Despite this there is a widespread sense that the Patient's Charter has somehow made patients more likely to complain.

Information matters

It is clear that patients (and NHS staff) have information requirements far wider than the Patient's Charter specifies. It is clear also that more information is required to enable patients to make use of existing rights. For example, the Patient's Charter sets out a right to be referred to a consultant acceptable to the patient, but it is difficult for a patient (and sometimes also difficult for the referring doctor) to get up to date information on who would be the most suitable specialist.

The information issue is more than a matter of just wanting facts. It is also a matter of wanting a wider range of factual information, of being given the information in a usable and appropriate form at an appropriate time and, perhaps most important of all, a friendly and encouraging delivery of information, so that the patient can put it to use.

6. ACCESS TO SERVICES

In a limited way, the Patient's Charter made a serious attempt to improve patients' access to the NHS. The Patient's Charter set out a right to receive health care on the basis of clinical need, and not on ability to pay, lifestyle or any other factor.

It also stated that a patient has a right to:

- register with a GP
- change their GP easily and quickly
- get emergency medical treatment
- be referred to a consultant who was acceptable to the patient, when the GP thinks it necessary, and
- be referred for a second opinion if the patient and GP agreed that it was desirable

The Patient's Charter also sought to improve access by ensuring that certain kinds of information on services were made available, and by setting standards that limited the maximum length of time that patients should wait for appointments at out-patients departments in hospitals, or for admission for treatment as an in-patient. All these aspects of access are important for patients, and all the evidence indicates that patients view access to services as one of the most important considerations. It seems clear that the existing Patient's Charter's efforts to improve access to the NHS have not been wholly successful.

The main criticisms of the Patient's Charter in relation to access to services can be summarised in three points:

- the Patient's Charter's concern with access is too narrowly defined
- the Patient's Charter has not focused on primary care

- access is particularly difficult for groups who experience social exclusion or discrimination in society

A narrow definition of access

If a patient cannot get access to services when needed, it does not matter to that patient how good those services are. Although the Patient's Charter did break new ground in guaranteeing admissions to hospital and delineating expectations about out-patient waiting times, the targets set were modest. Since the length of waiting lists for hospital admissions was such a visible window on NHS performance, and so susceptible to political concern, it became the aspect of access that received the greatest attention. As we have seen, the imperative to admit patients as they neared the 18 month ceiling did not necessarily reflect clinical need. For those who were very ill and possibly in pain, a wait of up to 18 months still seemed like an unacceptable time to wait, and a maximum 12 month wait for coronary artery bypass grafts, which was introduced in April 1995, did little to change these concerns.

For out-patients, a maximum wait of 13 weeks (for 90% of the population) or 26 weeks (for the remainder) still seemed too long, especially since the patient may have waited a week or two to get an appointment with a GP, and then a further wait for the referral letter to be written. There has also been concern, confirmed by the interviews, about how waiting lists for admission are compiled and presented, with reports of informal waiting lists to get onto waiting lists, so that the published figures concealed the full extent of the problem.

For cancelled operations, the Patient's Charter standard was very modest. It stated:

> *Your operation should not be cancelled on the day you are due to go into hospital or after you have gone in. If it is.....you can expect to be admitted again within one month of the cancellation.*

It was, therefore, not a violation of charter standards to cancel operations two days before admissions, and it is therefore not possible to quantify the scale of the problem of those cancellations. But even taking the Patient's Charter's limited ambition, the standards were breached on many occasions, as the NHS Performance Guides (commonly known as league tables) demonstrate.

In sum, even on the fairly limited aspects of access that are within the scope of the Patient's Charter, much was left to be achieved.

Access for vulnerable people

For the most vulnerable people in society, access to services is particularly difficult. Invoking even quite limited rights and standards is exceedingly difficult if access is impeded because of communication difficulties or disability, or as a result of attitudes which exacerbate social exclusion. The interviews with vulnerable groups concerned

with disability, homelessness, race and ethnicity, and the written material, confirmed that there is a need for a much wider view of the problems of access to NHS services.

It was suggested that the Patient's Charter fails to address access for homeless people, where waiting lists for admission to hospital and waits of several months for out-patients are simply irrelevant. And even when homeless people are able to comply with the structures of current systems, they sometimes find that, in practice, their access to services is limited by a lack of understanding and sympathy from some staff within the system.

Attitudes and awareness of specific needs, such as particular media for communication, are important aspects of access for other people too. The Director of the Greater London Association of Disabled People identified an awareness problem in the NHS which limits access of disabled people to appropriate services.

> *Sometimes disabled people are admitted to hospital for a particular complaint, but as their needs are not considered as a whole, they come out less mobile than when they went in. Their needs in terms of their disability and in terms of other aspects of their health care and their individuality need to be recognised.*

Inadequate awareness of the needs of blind and deaf people were reported by the Royal National Institutes for the Blind (RNIB) and the Royal National Institute for the Deaf (RNID), respectively.

The multi-ethnic women's health project in East London described racism and direct and indirect discrimination in the NHS against people from ethnic minorities which in practice severely limited access to services. This could be a matter of attitude or actual practice within the NHS. Attempts to deal with such problems simply through improved cultural awareness were seen as inadequate.

Tools for access

The NHS has to make further progress in addressing the barriers to access that remain for some of the people who most need health care. Access cannot be guaranteed by words alone or by the setting of maximum waiting times. The following "tools" need further development and support if any future charter is to improve access to the NHS for the whole population.

Information and communication

Information to patients and potential patients and their carers is a basic tool for enabling people to gain access to NHS services. In fact, information is too simple a concept, and the provision of information should be seen within the wider concern for effective communication, in which patients are active partners, rather than passive recipients of information. The provision of information is discussed fully above [section 5].

use it. However, our focus groups showed that some patients felt that a charter should restrict itself to setting out rights. Most patients, however, said that they would be more than willing to take account of their own responsibility to the NHS. They suggested four basic ways in which patients can meet their responsibilities to the NHS:

- to make appropriate use of services
- to behave civilly to staff
- to try to co-operate in their own health care
- to fund the service through taxation

There are clearly two distinct views of responsibilities within the Patient's Charter. On the one hand, a view that tends to be expressed by hard-pressed staff is that responsibilities of patients should be stressed in order to make patients behave reasonably and to encourage realistic expectations of what the NHS can offer. On the other hand, Bynoe (1996) is echoed by many patients' groups in seeing *responsibility* as a foundation of citizenship, participation and co-operation, and as a means of securing improved services and a responsible use of services by informed citizens.

<u>What can patients do?</u>

Many of the comments from patients and their organisations showed considerable understanding of the ways in which patients could be responsible, including:

- behaving courteously and understanding staff pressures
- taking responsibility for self-care when appropriate and when given adequate information
- taking part in qualitative feedback - seeing oneself as in partnership with professionals
- maintaining healthy lifestyles, with assistance and support
- to consider carefully information that is given
- to provide material information about oneself and one's condition

However, several interviewees emphasised that most patients already behave in a responsible way, and that only a minority fail to understand pressures on those who work in the NHS. Patients with long-term medical conditions and disabilities pointed out that they *were* responsible partners in their own care, and welcomed further opportunities to be responsible partners with professionals.

While accepting the need to encourage and support patients to behave in a responsible fashion, interviewees explained that there are particular difficulties which prevent some patients behaving in a model fashion. To take an extreme example, some refugees and asylum seekers have been victims of torture, and even a simple expectation that they provide relevant information to health care professionals may be daunting.

A spokesperson for Crisis pointed out:

> *It would be easy to say that homeless people should turn up for appointments on time and not be drunk or violent, but how easy is it to be responsible for yourself when your life is out of control? When people are vulnerable, it is necessary to facilitate responsibility (e.g. helping them to keep appointments, getting them advocates etc.). It is necessary to understand why people behave 'irresponsibly'.*

What the NHS can do to support patients

The majority of patients are generally responsible and courteous and well aware of the pressures on services. Much can be done to support and reinforce patients who wish to use services wisely and well.

Honesty about services

The NHS must be honest about what can be provided. Raising expectations unrealistically leads to frustration, which in turn may provoke rudeness or worse. An honest approach must extend to the nature, quality and availability of services, and to the scope of what the NHS can and cannot do. This approach requires a much larger investment in raising fundamental issues such as rationing and prioritisation with the public.

Staff attitudes

NHS staff need to have positive attitudes to patients to encourage them to take responsibility. While most staff are sensitive and understanding, there is still evidence of staff behaviour that rests on untested assumptions about how certain types of patient are likely to behave.

Education and information for patients

Patients need to be fully informed on what is expected of them, e.g. cancelling appointments, how to use services appropriately etc.

Effective systems

Effective systems are required to support patients' responsible behaviour, e.g. dedicated phone lines for patients to use if they wish to change appointments, workable schedules for clinics, and staff who are trained to understand communication difficulties.

There is considerable evidence from both interviews and published material that patients' efforts to use the NHS wisely are sometimes frustrated by poor systems within the NHS. This evidence is backed up by our research. Almost three-quarters of providers and a third of non-providers identified problems with NHS systems as contributing to difficulties that patients might have in meeting their responsibilities.

Towards real partnerships

Taken too far, the debate about rights and responsibilities can be very sterile and rather naive. It can also be a vehicle for 'honesty', a licence for staff and patients to give vent to intransigent perceptions. In reality, most patients wish to be helpful and co-operative while getting the best from the NHS. Most staff wish to offer a good service within the constraints of available resources. A blame culture that suggests that all would be well if only someone *else* behaved properly will lead nowhere. What is required - and what is achievable - is a genuine progression towards partnership in the NHS, valuing the integrity and goodwill of those who use services and those who work in the NHS.

8. WHAT SHOULD A NEW CHARTER DO?

The context of the new Patient's Charter is very different from the last one. There is a new government committed to a stakeholder society. There are new policy documents:

- the White Paper, *The New NHS: Modern - Dependable*, 1997;
- a Green Paper, *Our Healthier Nation: A Contract for Health*, 1998;
- and a new consultative document about performance standards *The New NHS: Modern and Dependable: A National Framework for Assessing Performance*, 1998.

All these documents describe the context within which the new charter will exist. It is a context which emphasises health care at home, in the community, and in hospital, with primary care providing the main forum for health care for most people. It is a context in which partnerships between patients, carers, professionals, voluntary organisations and other statutory organisations are seen as essential ingredients of providing health care. This is a context where people take responsibility for their own health and behaviour when they are able, and when they cannot, services will take particular care of them.

A clear purpose

This report shows how staff and patients were confused about the aims of the Patient's Charter and how this led to pressure for staff and uncertainty for patients. A first requirement for a new charter is that it should be open and honest about its purpose. It should define clearly what its aims are and state where meeting its standards will cost extra money. Improving quality does not always mean that money has to be spent but sometimes it does.

Charter development

A second important consideration is the way in which a new charter is developed. There is little doubt that any charter which is perceived to be imposed from the top and does not involve staff and patients at the very least, will lead to even more dissatisfaction this time around than with the existing Patient's Charter. All parts of the research emphasised the importance of involving users, carers, and staff in the processes of drawing up a new national charter and the development of local charters.

Equal attention to primary and community care services

The early version of the Patient's Charter came under fire for its concentration on acute, hospital services. Contributors to the research were still voicing these complaints in 1997 despite the fact that additional charters had, to some extent, corrected this bias. Given the shift in policy towards primary care during the past four years and the fact that primary and community care are where the majority of people experience health care, any new charter must redress that former imbalance.

The content of the charter

Managers, clinicians and patients mentioned many topics which they wanted in a new charter. Organisations submitting written evidence were asked to prioritise quality standards for inclusion. Top of their list were standards for clinical effectiveness followed by standards for effective information and communication. Access to services; standards for primary and community care; standards which covered the quality of the patient experience including privacy, dignity and respect and; standards for staff qualifications and attitudes. They also wished to see more focus on vulnerable groups and on partnerships with patients.

Patients in the focus groups produced a similar list of priorities for inclusion which emphasised equity in access to and quality of services: clear information, positive interaction with staff, good quality clinical treatment, assurance of privacy and confidentiality and more choice in terms of registration with a GP and consultant referral. The fact that these rankings are so similar adds weight to the case for including them.

The ethos of a new charter

NHS staff and clinicians in our research were particularly keen for patients' responsibilities to be part of a new charter. Patients themselves and their organisations supported this idea, though with reservations. It will be important not to appear to blame patients in any way. Most are aware that staff are often under pressure and that resources are limited. Many people are so concerned not to 'bother doctors' that they sometimes avoid asking for help until it is unavoidable, and by then it is sometimes too late.

It is also clear that some aspects of services are not user friendly. In clinics where 'failure to attend' rates have been audited and remedial action taken, problems have been resolved with little difficulty. Where staff complain that patients do not turn up for appointments and do not let them know, action can be taken to make it easier for patients to get in touch; it is not that patients are incorrigibly inconsiderate. Equally important is to remove what NHS staff identified as the 'negative context' of the existing charter and its management. They felt they were often scapegoated by managers and patients, when things went wrong or standards were not achieved, even when the problems were to do with resources and/or demand. They wanted the government publicly to acknowledge the strengths of the NHS and its staff, and for the Charter not to be used as a weapon against them.

Managing and implementing a new charter

The content and ethos of a new charter are undoubtedly important but so are the processes by which it is introduced and implemented. Still suffering from some of the effects of the poor way in which staff were prepared for the introduction of the current Charter, several suggestions were made about better ways of doing this. They included:

- making allowances for the transition to the new charter by allowing time to implement it
- giving better guidance on how to deal with overlapping and inconsistent standards
- encouraging an environment where staff can be less defensive about complaints
- involving staff in the development of standards to ensure ownership and relevance

Staff had clearly found the monitoring of charter standards difficult and inappropriate and they made useful suggestions here, too, for improving monitoring systems. They were:

- consider and improve the methods of monitoring standards
- improve the quality of data collected by integrating with other data collection systems
- use appropriate (eg qualitative) methods for standards which cannot be quantified (eg dignity and respect)

9. CONCLUSIONS AND RECOMMENDATIONS

Our research has demonstrated considerable levels of agreement between patients and staff about the strengths and weaknesses of the Patient's Charter and the issues which a new charter should address.

An analysis of the priorities for inclusion in a new charter by staff (Chart D Appendix III and Chart 6 Appendix IV) and patients (Chart 4 Appendix IV) identified eight key areas for discussion and development.

They were:

- clinical effectiveness/outcomes/need
- partnerships/involvement of patients and staff
- effective information and communication
- equity and access to service
- community and primary care services
- the quality of the patient experience
- staff training, qualification and attitude
- emphasis on vulnerable groups

In this context our recommendations for the development of a new Patient's Charter are grouped under the following headings:

- standards
- process
- infrastructure

Standards

Given the strength of support for a Patient's Charter a new charter should identify the values and principles to underpin all Patient's Charters and offer a model within which local standards can be set. Key standards should be discussed nationally and locally, and should cover:

- clinical need, effectiveness, and outcomes
- the quality of the patient experience
- equity and access to services
- information and communication.

All these categories are covered in the draft national framework for assessing performance (NHS Executive 1998) and it would be sensible for charter standards to match those included in that framework where they are relevant.

Partnerships

The development of the national and local charters should follow a process which includes staff, patients and carers, so that everyone feels some ownership of their local charter. This process will also help patients and staff to understand each other's perspectives and, hopefully, begin to lay the groundwork for future partnerships in health care.

Vulnerable groups

This process of development should pay particular attention to vulnerable groups in the community, inviting them and their representatives to participate in the development and monitoring of charters. Their primary concerns are with achieving access to services and special consideration should be given to this.

Infrastructure

Resources

Although many of the features of a new charter may be achieved without financial resources, others will need money to be spent. The resource implications of a new charter should be considered during the development process and, where possible, savings and expenditure identified. Each charter should make a clear statement about resources available for charter work.

Monitoring

The implementation and management of a new charter will also need careful thought, particularly in relation to monitoring and feedback mechanisms.

Complaints should be managed in a positive way and used to inform service changes. Data from complaints analysis should be fed back to managers, clinicians and patients.

Ways of 'listening' to patient and carer experiences need to be found and this information fed back to managers and clinicians.

Advocacy

If one of the aims of the new Patient's Charter is to help vulnerable people to gain access to the NHS, some form of advocacy service will be essential. Such a service will need to be offered in each community and supported by resources for language and outreach work.

This review of the Patient's Charter and the chance to rethink its aims and purpose have provided a welcome opportunity to involve patients and NHS staff in future

developments. Although charters are only one way to improve the quality of patient care, they can make a difference to the patient experience. It should be remembered, however, that any charter can only achieve so much. Access to services and the quality of each patient's experience will be primarily determined by the principles, values and resources with which we all collectively endow our national health service.