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King's Fund

The Patient's Charter

In Northern Ireland

Christine Farrell

The King's Fund
11-13 Cavendish Square
London W1M 0AN

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PREFACE

This research was carried out at the request of the Northern Ireland Health and Social Services department to complement the work undertaken by the King's Fund for the NHS Executive on the English Patient's Charter. The aims of the research were to:

* establish whether patients, carers and staff views and experiences of the Patient's Charter were the same as, or similar to, those of English patient's, carers and staff

* to explore the range of views and experiences of social services clients and staff in relation to the social care elements of the Northern Ireland Charter.

The research was carried out during June and July 1998. Focus groups were held with patients, clients, carers and staff in Belfast, Omagh, Craigavon and Ballymena. The patient/client groups included people from Belfast, Ballymena, Antrim, Newcastle (Co. Down), Lisburn, Hillsborough, Omagh and surrounding villages in the west of the Province. The staff groups included acute and community managers, physicians, consultants, nurses, social workers and other support staff. Altogether 85 people participated in the focus groups; 43 patients/clients and carers and 42 managers and clinicians. A postal survey of the views and experiences of 504 organisations was also carried out and 61 responses were received (12%).

The report is in four parts. The first part is the main report which draws together the findings of the research. It is followed by three sections which provide detailed accounts of the findings from the focus groups with patients, clients and carers; the focus groups with managers and clinicians and from the written evidence. Appendix I is an account of the research methods.

SUMMARY

The Northern Ireland Health and Social Services Charter(s) had little impact on service users or their carers because, for the most part, they were unaware of their existence and contents. Managers and clinicians knew more about the charters and felt that they had been useful in some respects although there were serious criticisms of the more contentious standards and processes. There was some overlap between the comments of users and staff about the strengths and weaknesses of the charter and the levels of agreement about what a new charter should contain were high. The main report and the sections which detail the comments made by patients, clients, carers, managers and clinicians illustrate some differences in emphasis.

The most important finding for Northern Ireland perhaps, is that the existing charter(s) were not seen as being relevant to social care. Staff from social services felt that they had not influenced their work in any way although they felt that there was some resonation with the principles of their work. They made a special plea that a new charter should highlight the fact that social services were part of the integrated services.

Advantages of the existing charter(s)

- established a new culture based on patient/client views
- raised staff awareness of patient rights and views
- focused (some) services on quality improvements
- changed the culture of organisations in relation to performance monitoring

Disadvantages of the existing charter(s)

- unrealistic, wrong and confused standards
- monitoring procedures costly, created more paperwork, sometimes ignored
- raised patient/client expectations unrealistically
- no patient responsibilities included
- increased the number of complaints
- ignored clinical standards and outcomes
- staff and users not included in the development of the charter
- insufficient attention /emphasis given to social services

A new NHS and social services charter should contain:

- statements of principles behind the charter(s) including honesty about resources available for services, the need to involve users, carers and staff in charter developments and the principle of partnership between users and staff, between the NHS and social services and between these services and other community organisations and agencies.
- standards of care related to;
  - * clinical need, effectiveness and outcomes

  - * equity and access to services and treatment
  - * the quality of the patient experience
  - * better communication and information provided at appropriate times and in a style which made it easily accessible to people with hearing and visual impairments and to people whose first language is not English
- include patient and staff responsibilities possibly through a code of conduct
- include references to voluntary and community organisations which offer support to people with health and social care needs
- pay equal attention to standards and access to social services
- advice about monitoring charter standards

The process of creating a new charter must involve patients, clients, carers and staff. Regular monitoring, reviews and feedback systems are essential to inform staff and users about progress and standards achieved.

Advice and guidance about ways of developing local charters should be provided from the centre.

Strategies for and ways of publicising the charter's existence and contents should be considered by all service agencies before any new charters are launched.

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Supporting evidence from:

1. THE REPORT

The Patient's Charter in Northern Ireland is similar to the English charter with one important difference. It contains rights and standards for users of social services. In Northern Ireland, health and social care provision is integrated within the four Health and Social Services Boards - the equivalent of health authorities in England. Apart from this difference, the rights and standards contained in the Northern Ireland Patient's Charter are almost exactly the same as the ones in the English Charter. Nevertheless, it was felt to be important to establish whether the views and experiences of people in the Province were the same as, or similar to, the English experience, before a new Northern Ireland Charter was produced.

Patient, client and carer views of the charter

The detailed research findings discussed in section two suggest that people's experiences of health care and their views about the existing charter are indeed similar to the views and experiences of English patients and carers.

Knowledge of the contents of the charter amongst the patients, clients, and carers in Northern Ireland was limited. Although most people we talked to were aware of its existence, their knowledge was mainly restricted to a few of the more contentious areas like waiting lists and waiting times. The focus groups obviously raised peoples' awareness of the charter and they were critical of the fact that something so potentially useful had not been brought to their attention previously. No one knew that there were different charters for different client groups even though many of them had been using the relevant services for a long time.

If a new charter is to be used by the people for whom it is designed greater efforts should be made by staff of all health and social care agencies to bring it to their attention

Since knowledge of the charter was limited, people in the groups were asked about their experiences of using services to discover what kinds of things were important to them.

Quality of care

Positive views and experiences were primarily about individual general practitioners, nurses and social workers with whom people had had regular contact, although a few hospital doctors came in for praise too.

Quality of care was very obviously related to interactions with staff and whether people felt they had been treated with respect and with sensitivity. Comments about being 'listened to' and 'treated kindly' often followed praise for individual practitioners.

Good clinical outcomes were also important and for people using specific services like mental health, for example, the whole range of services provided was appreciated.

Wrong diagnoses and assessments were responsible for many bad experiences in health and social care and the problems people had in using the systems designed to assess eligibility for aids and adaptations, for access to therapies (eg physiotherapy) and to benefits, were a source of serious discontent.

Accurate clinical diagnoses and assessments for eligibility of benefits are important ingredients of good quality care for patients and clients.

People appreciate good quality care and staff who treat them with respect, listen to them and are aware of their vulnerability

Access to services and equity

Information to help people gain access to services was of particular importance and where good quality information had been given, it was much appreciated. The lack of information about services, clinical conditions and treatments and particularly about benefits and assessments had caused considerable distress. Information to meet carers needs was identified as vital in helping them to help their relatives.

The way information was communicated was also seen as essential to positive health care. The timeliness of information, where it was given, and by whom were thought to be as important or sometimes more important, then the information itself. This was where the need for advocacy was emphasised by clients, patients and carers particularly in relation to benefit systems and procedures and in relation to the needs of special groups like the deaf, the visually impaired and ethnic groups.

Information and good communication are vital ingredients of good quality care and access to it. More guidance and help with complex procedures and systems like benefits and assessments should be provided. Advocacy for people who need help with information and communication should also be provided

Less concern was expressed about equity than access although people were aware of geographical variations in quality. They were more concerned about inequities between the *have's and have nots* where they again emphasised the need for advocacy.

Patient and client responsibilities

Patients and clients readily accepted that they had responsibilities towards services and the people who provided them. They acknowledged that some people did misuse the system and abuse staff but felt that people who did this were few in number and may have particular needs or problems.

They identified their responsibilities as keeping or cancelling appointments, appropriate use of services and resources, looking after their own and others' health and treating staff with respect and civility. They also pointed out the responsibility employers had in relation to good health and the community responsibility to care for others less fortunate then themselves.

Responsibility was seen, in the main, as a principle of mutuality between staff and patients.... a shared responsibility to respect and treat each other well.

Patients and clients were aware of their responsibilities to services and to staff and emphasised mutual respect between patients, clients and staff. A code of conduct should be included in a new charter

A new charter

The suggestions people made for the contents of a new charter were based on the comments they had made as described above. In summary, they felt that a new charter should include:

- ***good standards of clinical treatment and assessments***
    - correct diagnosis and assessments
    - prompt referral and treatment
    - sensitive communication and information
- ***improved access to NHS and social care services***
    - reduced waiting times for GP appointments, out-patient appointments and operations
    - reasonable waiting times in casualty, out-patients and for assessments
    - more and better information about how to access services
    - equity of access
- ***good information about***
    - conditions, treatments and medication
    - discharge procedures
    - services available
    - complaints procedures
    - rights and benefits
    - keeping healthy
    - consultants' qualifications
    - sources of information
- ***advocacy services***
- ***a code of conduct for patients, clients and staff***

Other comments about a new charter included the need for it to be written in user-friendly language and to be made available in formats accessible to the deaf, visually impaired, and ethnic groups. Involving users in its development was thought to be a useful way forward. The fact that resources were limited was acknowledged but people felt that if a charter existed it should have resources to back it up. Most of all, these patients, clients and carers wanted the new charter to be available in places where they used services so that everyone could find out what help it may offer.

Differences between England and Northern Ireland

Most of the views and experiences expressed by people in Northern Ireland were the same as the ones expressed in England. There was a similar lack of awareness of the existing charter and similar concerns about health services. The major difference was clearly related to the fact that the Northern Ireland charter includes social services as well as health services. A major source of dissatisfaction was the benefit systems, especially the disabled living allowance, and assessments for benefits, aids and adaptations, which were rarely mentioned in the English research. The need for help with accessing these benefits underpinned the requests for advocacy. In England, although advocacy was raised as an issue for disadvantaged groups it was usually raised by patient organisations and not by the focus group participants themselves.

Other slight differences in emphasis were related to carers who complained that their needs were often ignored and who sometimes felt excluded from the important processes of diagnosis and care planning. This may have been due to the fact that carers were better represented in the focus groups in Northern Ireland but it is still an important point to note.

There was also a slight difference in the emphasis placed on clinical need and choice. The latter was rarely mentioned in the focus groups although several people had insisted on being referred to a different consultant when they experienced difficulties.

Altogether, users and carers experiences of health care and their views of the Patient's Charter were very similar to the ones expressed in England.

Staff views and experiences of the Patient's Charter

The views and experiences of managers and clinicians in the NHS were almost an exact replica of those expressed in England. Here too, the main difference related to social services. The views and experiences of social services staff who took part in the focus groups provided a clear indication that the charter had no direct bearing on their work. To start with, the fact that it is called the **Patient's** Charter may have misled many staff together with the fact that the bulk of its contents do relate to health care.

Nevertheless, social service participants saw it as a potentially useful document and said that some of it's principles coincided with many of those contained in their statutory instruments and guidelines. Principles like user-involvement, partnerships and responsibilities for example. During the research, social services staff provided useful references to practices which could be extended to health care situations, some of which are already incorporated into the mental health charter. Mental health services are, of course, one of the places where health and social care are closely connected. In spite of this several health service staff working in mental health were not aware of that charter or its contents.

The following summary of findings from the research with staff in health and social care incorporates the views and experiences expressed in the focus groups and in the written evidence. There were few differences between these two sources and the one often reinforced the other.

Positive aspects of the Patient's Charter

There were four main areas where staff felt that the charter had been useful. They were; that it had encouraged staff to become more aware of patient's rights and views and thus had begun to establish an organisational culture based on these principles. Secondly, it had generally raised patient and staff awareness of the importance of the quality of care. It had also been seen as a useful tool for managers to focus on key areas for quality improvements and to introduce monitoring mechanisms. Finally, its major contribution had been to identify principles, rights and common standards for patients and clients and for staff to work towards.

Weaknesses of the charter

Standards

Although the existence of a common set of standards was seen as a positive aspect of the charter the standards themselves had caused some serious difficulties for managers and some clinicians.

The most common complaint was that the standards were unrealistic and difficult to achieve especially in the light of the resources available. It was also pointed out that there were no standards related to clinical effectiveness or need, which was felt to be an important omission. Other comments about standards were that they did not deal with difficult to measure aspects of quality and that they were too oriented to acute care and waiting times. There was a strong feeling amongst managers that if they themselves had been involved in setting the standards, these kinds of difficulties would not have occurred.

Monitoring

The monitoring of standards had also created problems for staff although they had welcomed the principle of performance monitoring. Some of the difficulties they had experienced included the costs in time and money of monitoring charter standards; the increase in paperwork and systems and the tendency in some places to manipulate figures to meet requirements. Staff definitely felt under pressure from the fact that the results were published and used to compare the performances of trusts.

Raised patients' expectations

Some managers and clinicians, particularly general practitioners, felt that patient expectations had been raised too high by the charter. This 'feeling, was often evidenced by the increase in the number of complaints received since the charter was introduced. However, when the question was explored in greater depth during the focus groups, this rather simple 'cause and effect' approach appeared less secure. Clearly there has been a rise in the number of complaints made by patients and their relatives but managers and some clinicians agreed that it was not all attributable to the charter. The main problem seemed to be that staff felt squeezed between two pressures; those from patients and those of a service which they felt to be under-funded. The charter simply added one more pressure. Many people in the focus groups and the written evidence qualified their comments about rising expectations by adding that patient expectations had risen beyond the capacity of the service to meet them.

Included patient rights without commensurate responsibilities

The concern about patient expectations was fuelled by the fact that the charter was seen as a document giving everything to patients and nothing to staff. Almost everyone felt that this should be put this right in a new charter by including patient responsibilities as well as rights.

Resources

Scarce resources in the NHS and social services meant, for many staff, that the charter had added another burden. Although one or two managers mentioned that they had used the charter to get more resources for some aspects of services, most people said that they had to try to meet standards at a time when resources were shrinking and national policies encouraging reduced administrations.

Positives and negatives

In spite of the many criticisms of the charter, staff were, on the whole, willing to learn from their experiences and move forward to a new charter. This was particularly true of managers working in trusts, including community trusts. The people who were most opposed to the charter were general practitioners and some clinical staff working in acute trusts. Not all GPs were against the charter however and some of the GP members of the primary care focus group had a positive approach to its future.

TOWARDS A NEW CHARTER

Principles

There was a considerable amount of support for a charter which was honest, especially about the resources available to meet standards. There was support too for the principle of involving users and local communities in the development of any new charter. Staff involvement in the development of new standards was seen to be essential if the mistakes of the past were to be avoided. The principle of partnership between users and staff was acknowledged especially in relation to the need for patient responsibilities to be included.

Rights and standards

The main emphasis from managers and clinicians about standards to be included in a new charter was that they should be realistic and achievable. There was some disagreement about whether the charter should contain a set of minimum standards or a set of targets which could be worked towards and raised once they had been achieved. In this way the principle of continuous quality improvement could be achieved. The question of rights was also contentious in that it was seen to be legalistic and to create a 'them and us' (patients v staff) situation.

Organisations giving written evidence were asked to say what their priorities for quality standards were. The list which follows represents the aspects of care which they said should have priority.

- **clinical effectiveness and outcomes**
- **access to services and treatment and equity**
- **the quality of patient care (privacy, dignity)**
- **information for and communication with patients, clients and carers**
- **monitoring and improving services**
- **patient and staff responsibilities**
- **staff training**

These were areas which emerged as important during the focus groups with staff and with patients too and aspects of all of them should be considered for a new charter.

Clinical effectiveness and outcomes

The lack of any standards or indicators of clinical need, effectiveness or outcomes was seen to be a major gap in the existing charter. The kinds of issues highlighted here were the need to have clinical standards which could be monitored and be available publicly so that patients and the public could be reassured that they would be given the best clinical quality of care and treatment. The need for professionals to be clinically accountable was a point addressed by all the groups in the study.

Access to services and treatment and equity

Access to services was a key area of concern to patients, clients and carers and their representative organisations. Given the difficulties people had experienced in getting assessments and benefits, the need for advocacy services was also a strong feature of the discussions and written evidence. Access for people with sight and hearing impairments and for ethnic groups and disadvantaged groups added to the strength of feeling about information and the need for advocacy.

Information and communication

Without good information about clinical conditions and services most people are powerless to act on their own behalf or on behalf of others. The lack of information in these areas was seen as a major failing by patients, clients, carers and staff and one which they all believed a new charter could go some way to correcting. The kind of information required and suggested by participants for inclusion in a new charter covered some subjects already listed in the charter and some which are not. Information requirements for good quality care and services were given as :

- conditions, treatments and medication
- how to keep healthy
- services available and procedures
- complaints procedures
- entitlements and benefits
- staff qualifications

In addition to the information itself the way in which it was provided was acknowledged to be important. For the most part, patients, clients and carers wanted information about conditions and treatments to be provided verbally by clinicians but to be backed up by written information. Information about services should be provided, in writing and other formats in locally accessible places. The attitudes of staff were of great importance to patients and clients in terms of how they were spoken to and how they were made to feel during interactions with staff. This point was supported by managers and clinicians who recognised the need for sensitivity.

The need to provide information for special groups was also emphasised and facilities for communication with the visually and hearing impaired, especially deaf people using mental health services were said to be very limited.

Monitoring charter standards

Monitoring systems for charter standards were of particular relevance for managers and their difficulties focused on the way in which the charter had led to an increase in paperwork, the lack of evaluation of quality aspects of care and the increased 'costs' caused by monitoring requirements.

Patient and staff responsibilities

Patients themselves were more than willing to accept that they had responsibilities towards services and staff and saw them as using services appropriately and not wasting time or materials; keeping healthy and behaving politely. They said that the new charter should include a code of conduct for patients and staff in recognition of the need for mutual respect and civility.

Staff also recognised the need to treat people well and thought that a new charter which included the principle of patient and staff responsibilities would put right the existing charter's failure to acknowledge that staff had rights too.

Staff training

The need for staff to be trained in communication techniques was a point made most frequently by staff but patients, clients and carers also made reference to this need.

Regional and local charters

The support for a Northern Ireland charter was substantial but there was disagreement about the value of local charters. The main reasons for supporting them were that they could identify local issues and priorities and involve local people and staff in their development. Opposition was based on the fact that proliferation of charters would be costly and cause confusion.

Conclusions and Recommendations

The research demonstrated high levels of agreement about the strengths and weaknesses of the existing charter amongst managers and clinicians and high levels of agreement about the contents of a new charter between staff, users and carers. Preceding sections have outlined key areas for development. They are:

- clinical effectiveness, outcomes, needs
- access to services and equity
- the quality of the patient and client experience
- effective information and communication
- patient and staff responsibilities
- primary and community care with special attention to social services
- staff training, qualifications and attitudes
- advocacy and special attention to the needs of vulnerable groups

Apart from the need to pay particular attention to the social services and to highlight assessment processes and procedures, these key areas are virtually the same as the ones identified in the research for the Patient's Charter in England. Given this fact, the recommendations here repeat those made for the NHS Executive and the government's advisory group with the exception of those relating to social services.

Principles

A new charter should include a statement of aims and set out the underlying principles. These principles should include honesty and openness, partnerships and staff and user involvement.

Standards

Priorities for charter standards identified by all groups in the research were clinical effectiveness; the quality of the patient, client and carer experience; access to services and equity and effective information and communication. The national framework for assessing performance (NHS Executive 1998) covers all these areas and it would be sensible for charter standards to match those included in that framework where they are relevant. In some cases, these performance assessment criteria may be relevant to social services but there will be areas where they are not and new criteria relevant to social services provision should be identified.

Process

Staff, user and carer involvement

If a decision is made to have local charters as well as the regional charter for Northern Ireland, local standards and criteria will also need to be developed by trusts, primary care groups and social service agencies. The important point to remember here is that local charters allow staff and patients to be involved in standard setting and to feel some 'ownership' of the contents of a charter. This process can also act as a way of informing local people about local services and some of the constraints imposed on providers. The overwhelming feeling expressed by staff that existing charter standards were 'unrealistic' makes this process of development essential if a new charter is to work more effectively than the current charter.

Vulnerable groups

The primary concern of vulnerable groups such as the visually and hearing impaired, ethnic minorities and other disadvantage groups, was with access to services. If these concerns are to be taken on board it will be essential to include them and their representatives in the development process.

Infrastructure

Resources

Users, carers and staff groups made the point repeatedly that if charter standards were to be achieved, some dedicated resources would need to be provided. Although almost everyone was aware that resources were limited and needed to be used carefully, some of the difficulties of achieving standards were seen to be related to scarce resources. Although many features of a new charter may be achieved without additional resources there will be some financial implications of introducing one. The resource implications of a new charter should be explored during the development process and, where possible, savings and expenditure identified. If the principles of honesty and openness are to be followed, each charter should make a statement about the resources available for charter work.

Monitoring

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

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

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

Advocacy

If one of the aims of the charter is to help vulnerable people to gain access to the NHS and social services, some forms of advocacy will be essential. The need for advocacy was emphasised by patients, clients and carers particularly in relation to the complex procedures related to assessments and applications for benefits. Such services will need to be offered in each community and supported by resources for language, advice and outreach work.

Staff training and attitudes

Staff involved with complaints procedures told us that the majority of complaints were about the way staff talked to or treated users and carers. Certainly the evidence from the patient, client and carer groups indicated the way people were treated by staff made the difference between good and bad experiences of health and social care. Managers and front line staff however, made the point that staff felt under pressure a lot of the time and felt vulnerable to complaining patients, clients and relatives. The lack of appropriate training and support for staff, particularly nursing staff, was said to be one reason why staff sometimes treated people in an unfortunate manner. This is not necessarily an issue for a charter except that a new charter will should address the responsibilities of patients and staff. If the partnership and mutual respect aspects of services is to be achieved and to be part of a new charter, the needs of staff for training and support to deal with and communicate appropriately with users, should be addressed.

Awareness of the charter and its contents

Levels of awareness of the Patient's Charter, its companion charters and contents, was very low amongst users and carers and almost as low amongst some managers and clinicians. If a new charter is to work more effectively, these levels of awareness must be raised. This issue will be dealt with to some extent if the development process involves users and staff but not entirely.

Clearly the high profile launch and distribution of the existing charter did not fix it's existence in many people's minds for very long. The important thing for users and carers is for it to be available in places where they go for treatment and advice and at a point when they may need to know about it's contents. All health and social services agencies providing care and advice falling within the remit of the charter should make special efforts to display copies in areas used by the public. Voluntary organisations should also be encouraged to give it to people who might benefit from the information contained within the charter. It may also be necessary to provide copies for staff together with briefings and regular feedback, based on reviews of it's effectiveness, achievements and areas where improvements may be needed.

The context of a new Northern Ireland NHS and social services charter will be very different from the one in which the existing charter was launched. As well as a new national government and new health and social care policy documents, the Province is in the process of establishing it's own new system of representatives which will enable it to determine some policies regionally. Although a health and social care charter is only one way to improve care, it does commit to the principles behind all charters. To quote from ***Services First; the new charter programme (Cabinet Office 1998)*** these principles are:

that people have a right to good quality, convenient and responsive services; to service that are co-ordinated, and use modern methods and new technology; to services that focus on the customer, and give help to those most in need of it fairly and effectively.

The nine specific principles of public service delivery which all charters should help to deliver are:

- to set standards
- be open and provide full information
- consult and involve
- encourage access and promotion of choice
- treat all fairly
- put things right when they go wrong
- use resources effectively
- innovate and improve
- work with other providers

Our research has demonstrated that these principles are supported by people using and providing health and social care services in Northern Ireland. A new charter will help services to meet them.

2. SUPPORTING EVIDENCE

Patient, client and carer views of the patient's charter

Knowledge of the charter

Few patients, clients or carers in the groups had heard of the Patient's Charter and those who had heard of it had little detailed knowledge of its contents. Knowledge of the charter's existence was greater in Northern Ireland than it was in England but this was probably due to the way in which people were selected. (See Appendix 1)

Two main kinds of comments were made about the Charter, depending on the extent of people's knowledge; those who knew generally of its existence but had scarcely any knowledge of its contents; and those who knew the details of some sections, usually the ones they had been advised to read or to use.
Although one or two people had obtained copies when they were selected for the groups, no one had extensive knowledge of its contents. It would certainly be true to say that it had not been an important part of anyone's experience of health or social care.

People in the first category, who knew of its existence but not its contents, made comments like:

I think we got one through the post....but it's such a long time ago....it's hard to retain all the information unless you read it regularly.

The second category of people who had some knowledge included a carer who had asked to read the notes about her child; an elderly lady who had made a written complaint but not because of the Charter; two patients who had spent some time in A&E departments who knew that there were specified waiting times but not what they were; and one carer who knew that the Charter contained information on discharge procedures but not precisely what it said:

...there is a thing in it about discharge from hospital and a plan and a care plan that you should have and your GP...

This information had come from her professional role as an assessor and not from the Charter itself.

No one appeared to know that there were different charters for mental health, maternity services or for children and young people.

Views of the charter

Those people who knew something about the charter expressed a variety of views about it, most of them critical.

What is the point of all these charters if people here don't have access to them and can't implement what's in them because they don't know what's in them ?

Another person expressed doubts about whether anyone would use it even if people knew what entitlements it contained.

But how many people will ask for them (records). With a lot (of people) you're automatically seen as ' Oh, here's a troublemaker'. It's very much that if you ask. If you were sitting for more than 30 minutes how many people actually go up and ask why you're being kept and how many get a polite answer ?

There were several comments about the language not being user friendly and that it was possible to learn more from other people but others said that if it was given more or better publicity it would be useful.

One person, echoing comments made by managers and clinicians, pointed out that the charter aims were not always achievable because so much was determined by the money available. Another expressed doubts that a charter was the best way to bring about change anyway.

Is it the best way to bring about change ?...I do have doubts about whether that's the most effective way of having change...very often making the important change in quality is somebody spotting what little things need to be done which revolutionises the way in which things actually happen and I think our concentration on charters has gone a little bit overboard...

Experiences of NHS and social services

Due to the limited knowledge people had of the charter they were asked about their experiences of using services to gain some insights into the issues which concerned them. Naturally they tended to focus on the difficulties they had experienced but there was also a considerable amount of praise given to staff and to services. Box 1 below summarises the positive aspects people had experienced.

Box 1 Positive views of NHS and Social Services

- **good care, treatment from**
  - doctors (especially GPs)
  - nurses
  - PAMs
  - social workers
  - chemist

- **good services from**
  - child and adolescent
  - pain clinic
  - mental health
  - day centre

- **good information and communication**
  - from social services
  - with carers
  - between NHS staff and social services

Praise for individuals who had helped by sorting out difficult situations, by the provision of continuously good quality services or by being willing to listen, was given by many people.

My community psychiatric nurse is excellent. If I have any queries she seems to answer them straight away.....you can say everything to her...

Some specific services too were singled out for praise.

Because of the condition, I have in the past found myself frustrated, because of the pain that I've had to endure and the physiotherapist has done a wonderful job and I've also attended the pain clinic and the staff there have also been excellent....

The emphasis in this section was very definitely on individuals although several people commented that the NHS and social services were very good 'by and large'. The majority of criticisms were reserved for systems although a few individuals were said to have been responsible for bad experiences. The following section reveals where the criticisms were directed.

Negative experiences of NHS and social services

Box 2 Summary of negative experiences

*** problems with quality of care**
- lack of privacy (including mixed wards)
- wrong assessments/diagnoses; problems getting assessments/diagnoses

*** poor information/communication**
- poor information about the services available and particularly about benefits
- carers not given essential information

*** poor administration and systems**
- long waits in casualty and out-patients
- long waits for operations - forced to go private
- lost records
- time-consuming and confusing benefit systems
- too many trusts

Problems with quality of care

Privacy

Several people had experienced situations where they were left to wait or treated in full view of other people and one woman had been given extremely bad news in front of a group of relatives and friends. Another woman had been in a mixed ward and had felt exposed to the stares of 'young lads' and nervous about using the lavatory where the doors were difficult to close.

Wrong diagnoses and assessments

There was deeper concern where people had been given wrong diagnoses and assessments and where the former had led to long periods of suffering and the latter to serious financial difficulties.

Poor information and communication

The root of many people's problems lay in the lack of information they had about the services available and where to get the information they needed. Not all of this was due to the NHS or social services of course but there were numerous cases where people should have been given information but were not. Carers' needs for information and their exclusion from the process of treatment led, in several cases, to distress for them and failure to find the right kind of advice to help their relatives. Lack of sensitivity towards patients' vulnerability was also a feature of some of these experiences. The information needs of patients, clients and carers is discussed in more detail below (pp23-25).

Poor administration and systems

Several people had experienced long waits in casualty and out-patient departments and whilst, on the whole they didn't mind waiting, they did feel that an explanation for the wait would have helped. The long waiting time for operations caused more problems and several people said they had paid for private care because they could not wait for a year or 18 months to have the condition treated.

It's the long waiting lists when you go to your GP and you're told you have to wait a year for that clinic. Well, you either let your condition deteriorate or you pay up front and you go privately

On the whole other people agreed that going privately was something they had been or might be forced to do, but at the same time they expressed the view that this was an unfair system because not everyone would be able to afford this option.

Lost records had also caused some people to experience difficulties and delays in appropriate treatment.

Criticisms of the benefits system including difficulties in getting assessments for aids and adaptations appeared to have caused more problems than almost anything else. There were several cases where the length of time that elapsed between the assessment and the implementation of the adaptations was so long (four and a half years in one case) that the patients died shortly after they had been secured. In one group nearly everyone had experienced difficulties with the disabled living allowance (DLA).......either getting it, not getting it or having it cut once they had it. One person who had breast cancer and was also the main carer for her mother described her difficulties:

....I applied for DLA because I didn't know anything about the benefit system, hadn't the foggiest even though I worked in local government..and I was refused the DLA because I could lift my arm...I find it financially dreadful, my finances are just unbelievable..

Another common problem around benefits was the time and complexity involved in completing the paperwork.

Some people are put off terribly by the amount of paperwork. Another problem is, unless you are very articulate and very capable, it can be a very daunting experience attempting any of these forms unless you've somebody like the Citizens Advice behind you to guide you through them .

In these discussions reference was often made to voluntary organisations and the good quality help that people had received from them

Building on these experiences, both good and bad, people were keen to discuss ways in which a new charter could help to improve services.

Towards a new charter

The quality of care

It is apparent from the descriptions people gave about their experiences of health and social care services that they had formed their own judgements about what constituted good quality care. Although they were uncertain, for the most part, that a charter would guarantee them anything, they appeared willing to believe that it might help.

The specific aspects of quality with which they were concerned included good clinical care given by people who were sensitive to their needs, who were prepared to listen to them and who would provide advice and information to help them. Frustrations and difficulties were felt to arise primarily from poor systems, administration and lack of information. It follows then that, if a new charter would help them to get these things, it should include statements about all of them.

There was little discussion about rights and entitlements in the Northern Ireland groups where there was in England but people did mention certain rights which they thought a charter should offer. In fact, all the 'rights' mentioned specifically are already in the existing charter. The right to be registered with a GP; the right to information about conditions and treatments; the right to needs assessments; waiting times and waiting lists. The fact that people didn't know that the charter included these 'right' is probably the most important failure of a system which produces a charter but fails to ensure that people who need to use it, have ready access to it.

Equity

People were aware that the quality of care varied from place to place and this did cause them concern, especially if they lived in areas where they felt the quality was poor. However, geographical equity appeared to concern them less than the inequalities between poor or under-privileged people and the better off or more articulate, and this was reflected in the emphasis placed on advocacy services.

Information and communication

The importance of information in gaining access to services and to managing illnesses and social care situations as well as those of people they cared for, emerged as one of the most important features of the research. Box 3 below summarises the kinds of information people wanted and which they would like to see recorded in a new charter. Once again, many of these things are in the existing charter.

Box 3 Information and communication needs for a new charter

Information about:

- conditions and medication
- services available
- discharge procedures
- rights and benefits
- keeping healthy
- consultants
- complaints procedures

The special needs of people with hearing and sight impairments and of ethnic groups received particular attention as well as the needs of other disadvantaged groups. Some examples of good practice were mentioned although the general feeling was that the needs of these groups were not well catered for.

I can't speak for all hospitals but there is a good hospital in .... and I have to give credit to the efforts they have made in providing a good service for the deaf and hard hearing people. They've made great efforts to provide their staff with awareness training and some of the staff are still going on sign language training. They have a text phone that allows deaf people outside the hospital to phone in and some of their leaflets have mentioned how deaf people can contact the hospital.

The needs of ethnic groups for interpreter services was also pointed out

If you're from an ethnic minority and don't have good understanding of English, it should be made where there are small ethnic groups that local councils or whatever must pledge that it (new charter) will be interpreted in those languages and displayed and distributed to those ethnic groups and distributed among voluntary organisations.

More generally people had experienced difficulties with communication between themselves and doctors or nurses and with the system. Some of these experiences have been described above and it was not surprising that people wanted a new charter to include statements about the need for good communication. These comments tended to focus on the attitudes of staff and/or their lack of sensitivity about the way in which they communicated with patients, clients and carers.

Can I make a small point ? I think their (staff) attitude needs to be right and not patronising because 'Are you alright ?' in a loud voice, makes me feel low and down, I think that's very important.

Another person criticised the fact that people had to ask for information rather than having it provided during visits or consultations and ' being listened to' was felt to be an important part of communication which was often missing in their experience. On the other hand some people expressed satisfaction with this aspect of communication and the way in which some staff talked to them.

I've always found it pleasurable to visit my GP...he has time to talk to you. You never get the impression that he's sort of looking at his watch and wondering when the next patient is coming in...

Patient responsibilities

The question of whether patients had responsibilities as users of the NHS and social services was an issue which certainly concerned staff (see below) but patients were willing to, and indeed did, accept that they had responsibilities. Whilst they agreed that some people abused the system, they felt that most people tried to co-operate. They acknowledged too, that some people failed to understand their responsibilities because they had particular needs. Nonetheless, they expressed little sympathy for those who did abuse the system.

I'm sure there are people who do abuse the system and you find that in every walk of life and I suppose there are people who waste the doctor's time and quite often then it's the person who needs the doctor's time who doesn't get enough of it because someone else has wasted it.

The kinds of responsibilities which patients acknowledge they had are summarised in Box 4.

Box 4 Patients' views about their own responsibilities

Patients should

- **use services appropriately by**
  - keeping appointments and being punctual
  - not '*wasting doctors' time*'
  - giving good notice for repeat prescriptions
  - not wasting tablets or other things provided on prescription or free
- **behave well by**
  - being polite
  - asking questions and giving information
  - looking after their own and others health

The fact that several people mentioned that not everyone was able to use services appropriately because they may have some 'mental' problems, reflected the uncertainty they felt about what was 'appropriate' use. It was clear too, from the section on information, that they had a need for good information about services and how to use them. This was something they felt a new charter could provide or help to provide.

The responsibilities of others

People also recognised that responsibility was not one-sided and that mutual respect should be offered from patient to staff and from staff to patients:

I give my consultant and my CPN and all the nurses the respect they're due and I would like to think that they would do the same for me.

The notion of responsibility was extended from individuals to the wider community when several people mentioned the fact that they felt they had responsibilities to help others to stay healthy. Employers too were seen as having responsibilities:

I would like to add... that employers have responsibilities because nowadays employees are cutting back so much so that they're placing a greater and greater workload on people and that's resulting in more illness and more stress.

One way in which people felt a new charter could help to deal with the issue of responsibilities was to include a code of conduct for patients and staff. A code of conduct which:

could have matters about behaviour for staff and patients.

Advocacy services

Earlier paragraphs have illustrated the ways in which people felt they needed help to use services and to use them appropriately. At many points in their stories people said how they had felt the need for 'someone to be on their side' and others mentioned the help and guidance they had received from voluntary organisations.

Complaints was one area where this kind of help was needed:

I think for many people and even for myself too, a lack of confidence about using the system, you always need an advocate to work with you....and a complaints system on which we put so much store in recent years I don't think is the method by which you actually get at the problem. I don't know how you do it, possibly by having an independent advocacy system.

The benefits system too was an area where an urgent need for information, help and support was identified.

It was not that people did not want to help themselves and several references were made to self-help groups and their importance but the complexities of some systems and procedures clearly baffled even the most capable people.

The case was well-made too for advocacy services for vulnerable people even though they were more likely to have the support of voluntary organisations.

These then were the ways in which people felt a new charter could help. Box 5 illustrates the details.

Box 5 Patients priorities for a new charter

- **equity in access to services**
- **good information about**
  - conditions and drugs
  - services available
  - rights and benefits
  - consultants
  - discharge procedures
  - complaints procedures
  - keeping healthy
  - where to go for advice and help
- **good standards of clinical treatment**
  - correct diagnosis and assessments
  - prompt referral and treatment
  - sensitive communication of diagnoses and assessments
  - mutual respect including privacy and dignity
- **improved access to NHS and social care services**
  - reduced waiting times for GP appointments, out-patient appointments
  - reduced waiting times in casualty, out-patients and for assessments
  - better communication between services (GPs, hospitals, social care services)
- **advocacy services**
- **a code of conduct to include patient and staff responsibilities**

These priorities were complemented by suggestions about the need for a charter to be written in clear language and provided in a form which would make it accessible to ethnic groups, people with hearing and sight impairments and to other disadvantaged groups. Some people mentioned that the development of a new charter should involve patients. Others that it should be backed up by resources which made implementation feasible.

One of the clearest messages to emerge, although it was not mentioned specifically in relation to the new charter, was that if it was to work, it should be available and accessible to the people who might need to use it. This did not mean glossy publications delivered to every household but publicity and availability in places where people were using health and social services.

3. SUPPORTING EVIDENCE

Staff views and experiences of the patients charter

Staff in the NHS and social care services who took part in the focus groups had, of course, more detailed knowledge of the contents of the charter than the patients although some of them admitted to having to refresh their memories just before the meetings. Their early expectations of the charter, when it was first introduced were coloured by two main facts. The first, that it had been 'imposed from above' and that they had not been consulted about its contents. The second, that it was seen by some as a political instrument with politically imposed standards.

Initially some staff had welcomed the introduction of the charter believing that it would enable them to deliver improved quality of services and, by raising public awareness, would help patients to be better informed about services. These early hopes were dashed for many managers and clinicians when the implementation began to reveal the difficulties of achieving targets and other problems.

Criticisms of the Charter

Standards unrealistic, wrong, confused

Unrealistic standards

One of the major complaints from both clinicians and managers was that the charter had set unrealistic targets. Unrealistic in the sense that resources were not available to support delivery of such targets and unrealistic in the sense that it would never be possible to achieve some of the targets. Examples of the latter included the right to a named midwife in maternity services, the right to see a consultant once during pregnancy and the right for women to choose the form of maternity care and delivery. These three 'rights' were said to be unrealistic and in the last case, impossible to achieve.

..as you know there's a lot more choice involved now in maternity care but one of them...the domino system where a community midwife looks after them during their pregnancy and comes into hospital...but because of the way the Boards work we can't meet that choice...if mother lives in the Northern Board....the community midwives don't come into the Eastern Board to do deliveries...so they don't have that choice.

Other examples of unrealistic standards given were waiting times in accident and emergency departments and outpatient clinics and for discharge; for non-emergency mental health appointments and for non-urgent community and social care assessments.

Staff had experienced anger and frustration at their inability to reach some of the standards and had felt squeezed between patients and the system. Two main reasons were given for the frustration they felt. The fact that they had not been involved in setting these standards and the fact that the money was not available to achieve them:

The impetus behind a lot of these things are well meaning, very well meaning...but what they don't tend to work out is what the resource implication will be. It's sometimes better putting the resources in first and then implementing all these changes but that doesn't work in the NHS, it doesn't happen.

Resources for the implementation of charter standards were a continuous theme throughout the discussions with staff. Not simply the fact that they were limited but also the way the purchaser/provider system failed to deal with their existence.

Wrong standards

The majority of comments about standards were in fact about their lack of realism. However, some people did question whether the right standards had been included.

We're back to the issue of whether or not the standards themselves addressed the right issues and whether or not they were supported by the professionals who were delivering them...

One or two people commented on the fact that standards did not include clinical need or outcomes but this point was made much less frequently than it was in England. When it was made, it was made in relation to waiting lists and the way these charter standards had distorted services by treating non-urgent conditions and neglecting more serious problems.

Confusion about standards

Managers in particular felt that there was some confusion about what charter standards were meant to be. Were they about outcomes ? If so, they were almost impossible to measure. Were they statements of intent or quality statements ? In which case only some of them were measurable. Another person said that they were a mix of quality issues for the user and quantitative standards for the provider. If this was the case then it led to confusion for everyone.

Monitoring standards

These kinds of discussions and comments often led on to another kind of criticism of the Charter - the difficulties of monitoring standards. The points made here included the costs of monitoring; the increased amount of paperwork created by monitoring procedures; the manipulation of figures produced by monitoring requirements and the increased pressure on staff when the results of monitoring were published.

Costs of monitoring

There was some feeling that the charter had created additional costs in that time was spent by front line staff and management in monitoring charter standards:

If there is an expectation that we will monitor and we will produce information, that requires management time whether it's professional management time or other managers or administration staff, and in that situation there is validity in saying that those management costs should be excluded from the management costs that we're required as trusts to reduce.

Created more paperwork

The increase in paperwork and administration created by the need to monitor standards is, of course not unrelated to the costs mentioned above. Several staff mentioned this as a weakness, pointing out that this happened at a time when policy initiatives were driving in the opposite direction:

Even currently the government's committed to reducing bureaucracy and reducing management costs and yet the charter, it's a machine that does require administration and particularly in relation to information flows and monitoring.....

Manipulation of figures

Several people gave accounts of how waiting list figures were manipulated so that waiting times would not appear to be so long. Another manager said that her department tended

To cut corners ..more on the paperwork side of things, which is a shame because in a way we leave ourselves more vulnerable....

Increased pressure on staff

All these difficulties with monitoring were felt to put increased pressure on staff not only because they wanted to do the 'right' thing and do their jobs well but also because it created tension for them when it conflicted with delivering the services:

I wonder if there's a conflict created for staff in that the charter is all about processes and getting into the system and once you have the processes in place, in many areas you could be ticking all of the boxes and appear to be achieving the accepted standard but...staff have the frustration of not being able to deliver and give care to the quality that they would want....

Raised expectations

A fourth criticism, related particularly to unrealistic standards, was the way in which the charter had raised not only the expectations of patients but also the expectations of staff.

I think from the nursing point of view there was a bigger impact on the actual staff than there was on the patients because we were acutely aware of the response times and the implications on resources.......It also to me compliments a sort of change in ethos in nursing philosophy where people were more empowered and had more choice and also more responsibility for their own health care....

The latter part of this quotation illustrates another point made by several staff that although people did feel that patient expectations had been raised during the life of the charter, they were not always convinced that the charter was wholly responsible. This was particularly true for social services staff who said that their work was primarily influenced by legislation and national policies and hardly at all by the charter.

Not everyone agreed that the Charter had raised patient expectations. In primary and community care few staff felt that it had affected patients or their approach to services in any significant way

..having thought that it might have created lot of work I don't think that it really has because....patients either didn't read it or weren't really aware of what it was all about

Social services staff working in the community did not feel that the Charter had affected their work or clients either because the prime factor there was the new legislation (Children's Order). Nevertheless, they felt that the spirit of the Patient's Charter was reflected within those regulations in terms of client views and choice.

No obligations for patients

In spite of the fact that many staff felt that the Charter had not really had a major impact on patient or client or carer, one or two people did express concern that it put all the onus on staff and none on patients. One person thought that this was due to the fact that the initial charter was driven by politicians seeking votes;

I think the timing of the Charter, just before the '92 election was geared to get votes, it wasn't written to say you have obligations.....it was used for a political end at that time and I think a redraft of the Charter should certainly have something about the patient's obligations as well.

Although many staff felt that patients did have obligations to the services (see below) the failure of the current Charter to incorporate these responsibilities, was rarely aired as a criticism.

Complaints

The rise in public expectations attributed to the charter was connected in the minds of some staff to an increase in the number of complaints. One manager had documented this rise and pointed out that in their accident and emergency department they had received only 38 complaints in the three years before the charter was introduced. After its introduction they received over 100 complaints a year.

Although some staff believed the charter was responsible for the increase in complaints, others disagreed pointing out that there had been a change in public attitudes generally.......a rise of consumerism and the development of a culture of materialism and that this was responsible for the rise. Others believed that the increase was attributable to the greater publicity given to the complaints procedures and the general encouragement in their trust's information packages, which encouraged people to complain. One person felt that it was the staff 's interpretation:

We've engineered all this you know, the patient's right to complain..now, not only do you get a patient's booklet when you come in, you get how to complain if you're dissatisfied.....I think it's us, we have engineered this to take place, it's not just the Patient's Charter, it's our interpretation of it.

Although almost all managers and clinicians agreed that there had been a rise in the number of complaints, not everyone thought it was a negative development. Several people thought that if complaints were analysed and used to focus attention on parts of the service which were not satisfactory, they were a useful tool for improvement. Managers in particular saw the importance of a well organised complaints procedure as a positive way forward for them and for patients.

Let's look at the information that complaints are giving. The majority are about attitudes. Does that mean we need to redirect our energies into the training of professionals ?

An illustration of the way to implement a more positive approach to complaints was provided by another manager who described the way her trust had introduced a drop-in service and patient advocate to help patients and, if they had a complaint, made it for them to the trust board.

Although staff, particularly clinicians, were vociferous in their criticisms of the Charter for increasing the number of complaints, when the problem was explored in greater depth, most of them agreed that it was only a small proportion of people, usually relatives or carers, who were making these complaints. There were also several comments which supported the patients' views that it was the articulate middle classes who were more likely to complain or make trouble than poorer people who might have more cause.

our most awkward clients...or relatives rather, are the professional sort of middle-class-types..who feels that straight bullying and setting ultimatums is the way to achieve results. It's not your typical...drunken lout in A&E..physical and verbal abuse-type thing...

Positive effects of the charter

Although there were not quite as many positive comments about the impact of the Charter staff had found that it's existence had led to improvements both in the quality of care and of the systems supporting services. Box 6 summarises what these positive developments were.

Box 6 Positive aspects of the patient's charter

- established a new culture based on patients' views
- raised staff awareness of patients right and views
- focused (some) services on quality improvements
- changed the culture of organisations in relation to performance monitoring

Established a more patient oriented culture

Managers in particular felt that the Charter had positive benefits in the way it had raised organisational awareness of the patients' views and experiences:

I think there was a very significant, positive impact on staff who became even more aware of the relationship issues and the rights of patients and clients.

In two groups these kinds of comments led to discussions about a shift in the balance of power between patients and staff. On the whole this was seen as a positive development although a few people added that staff had felt threatened by this aspect of the charter's impact.

I think it was very important in terms of shifting power and basically power went from professionals and institutions to people who use the service.....and I think that professions by and large disliked it - almost universally disliked it because they saw it as intrusive...

Raised staff awareness of patient rights and views

An important feature of this changing culture was that staff were said to have become more aware of patients, their rights and views. However, few examples were provided to illustrate ways in which this awareness had influenced provision or changed relationships with patients.

Focused (some) services on quality improvements

More illustrations of the positive impact of the Charter were provided in this category and it may be that in the minds of staff procedural changes led to changes in staff awareness. Managers and clinicians were able to give examples of ways in which the Charter had focused attention on quality improvements.

In one acute hospital examination of waiting times in the A&E department had led to changes in the way the nursing and medical teams were organised which had, in turn, led to improvements in waiting times. A similar exercise in an out- patient fracture clinic had led to changes in the appointment system and efficiency improvements were said to have been achieved through an examination of the waiting list for psychiatric appointments. Community clinics had engaged in similar projects where physical adjustments were made to provide privacy for patients and greater attention paid to preventive work. In one locality an alliance of community organisations and staff had led to significant changes in provision:

We've got quite vibrant communities in ------ and we have examples of committees of health providers and local community activists can meet together to try to develop ways of more effectively delivering services....our local family planning clinics now have an evening service...we have an example of a maternity hospital where we used some of the principles of the Patient's Charter to influence services...

Changed the culture of organisations in relation to performance monitoring

The competition between organisations when the results of charter monitoring were made available was thought by a few people to be a positive development. The competition was said to encourage consideration of reasons for poor performance.

Positives and negatives

This examination of the impact of the Patient's Charter on managers and clinicians demonstrates a generally positive experience. In spite of the many criticisms and problems, the staff who participated were on the whole willing to learn from them and to move forward to a new charter. There were, of course a few people who had written it off, sometimes before they had really experienced it. But they were in a minority. Managers, perhaps because they were more involved with it, appeared to know more about it's impact and some lively debates took place between them. Clinicians gave the impression that it had had little effect on their services, although nurses in the community displayed positive attitudes towards it. Social work staff had very little experience of it possibly because their clients had little knowledge of it. Their contribution to the discussions however were constructive in that they pointed out their usually positive experiences of implementing the principle of user involvement in their own settings.

Towards a new charter

Earlier sections, especially criticisms about unrealistic standards, demonstrated that NHS staff felt that these problems would not have arisen had they been involved in discussions about them before the charter was introduced.. The focus groups offered an opportunity for them to put forward their thoughts about a new charter which they used to some advantage.

Principles

The existence of a charter was rarely disputed and there was little disagreement with the idea that it should contain a statement of principles. One person saw it as an umbrella for a range of concepts like clinical governance, national and local standards which would be supported by an organisational strategy which gave life to those principles. Another person saw it as a contract between staff and users offering opportunities to consult users and to redefine their understanding and expectations of that contract. Other people felt that it should be a set of targets which would be worked towards and that it should set out the relationship between those targets and other policies. There was a lot of support for a charter which was honest, particularly about resources and what could and could not be provided. There was support too for user involvement and working in partnerships with users, carers, other agencies and with teams of other staff.

Rights and standards

Obviously people felt that any standards which were included should be realistic and achievable but there was disagreement about whether a new charter should have a set of minimum standards or a set of targets which could be pursued, or both.
The word 'rights' was also seen to be contentious and several people felt that it should not be used in a new charter. One person suggested that rights and standards should be replaced by principles of good practice; and another that:

Rights to me are kind of constitutionally enshrined in that it's my right to receive equity of treatment Now that's a challenge for government as much as anything else. I hadn't thought of it in terms of moving away from rights into a partnership but there's something in that. The only thing about rights is, if they're enshrined in the constitution or in law, then they have to be the absolute bottom line and they're not negotiable.

Several people repeated the point that the word 'rights' created a 'them and us' situation and that a partnership approach would be preferable.

Resources

There was strong support for a new charter to include information about resources in an attempt to help the public understand that the NHS and social services could not afford everything. The production of a new charter without such a statement seemed unreasonable in the light of resource constraints and there was some concern that a new charter would raise expectations even further if it did not mention these constraints.
The need for honesty at the local level as well as nationally was mentioned:

It would be nice if politically someone, somewhere could be honest and say ' Look, there just isn't enough money here.

Local charters were seen as one way of addressing resource issues and there was some discussion about the way commissioners could prioritise local services or produce guidelines about priority services.

Maybe certain areas need to be identified within the Charter, certain clinical and certain nursing areas should be identified as priority areas. Having said that, if you're sitting waiting for your big toe to be operated on and you're told you have to wait 18 months because the doctor doesn't think it's a priority, you're the one in pain and it's a bit tough.

These discussions did not resolve the difficult problems of resource constraints or rationing but everyone seemed to agree that a new charter would need to include some statements about resource issues.

Partnerships and user involvement

The principle of partnerships with patients and carers was generally endorsed particularly as a way of working with and of involving people in health and social care. It was also seen as a way of educating people about services and of re-defining public expectations and of getting feedback about services.

I think the user focus aspect is positive and if that helps all of us to develop better practice...that's a useful spin-off.

I think the whole concept (partnership) is to try to get greater equality between two sides, isn't it ? Essentially, I will treat you with respect, I'll treat you on time, I'll treat you reasonably, I will explain things to you, you will understand on the other side that from time to time, it may take a little longer than you'll be happy with or I may not be able to give you the treatment you want because clinically I think that it's not the right treatment for you and it's that sort of dialogue.

Not everyone agreed that partnerships led to equality:

At the end of the day I don't think it could ever be equal..because you as the patient may feel very strongly that you want this treatment but I mean I am the specialist and I say 'No'....at the end of the day there is not equality there but I think certainly we should be striving to work in partnership with families.

This dialogue was followed with a reference to legislation in the Carers Act and the Children's Order where legal rights and responsibilities are ascribed to both organisations and to individuals.

Collaboration with other agencies and team working were also mentioned under this heading although not so frequently. One social services participant mentioned joint care planning as a good example of collaboration and another person offered an example of multidisciplinary team working in acute mental health services where the principle of introducing the patient into the group had been established, if not implemented.

In the managers and primary care groups, social service participants mentioned several ways in which their practice could provide some tried and tested ways of involving clients in their care and of collaboration with teams and other agencies. It was clear however, that they had not felt that the Patient's Charter had applied to their services and a plea was made for a new charter to correct this.

There is a difference between Northern Ireland and England and the charters which were produced, other than the one for children and young people and they were viewed as health oriented and only relating to health professionals.

Patient and client responsibilities

On the whole staff did feel that the existing charter was geared to patients and not to staff and that a new charter should include some things about patient responsibilities. Clinicians, especially those working in the acute sector, were more likely to feel strongly about this than other staff. Patient responsibilities to be included in a new charter are summarised in Box 7 below.

Box 7 Patient responsibilities for a new charter

Patients should:

- keep appointments
- behave acceptably
- lead healthy lifestyles
- take medication properly

This list is almost exactly the same as the one produced by patients.

Front line staff said that they often found it difficult to deal with some clients and carers; sometimes because they were abusive or abused the system, sometimes because they failed to comply with the treatment; sometimes because staff themselves felt under pressure when they did not have the time or resources to meet all the demands placed on them.

I find that people more and more hold us as personally accountable for the lack of what they want out there and that's very hard to take...it's very hard to know sometimes how to remain helpful and outline choices when you're being attacked and blamed....

In spite of some strong feelings about patient responsibilities there seemed to be a general feeling that staff had responsibilities too and that a new charter should make it clear that this was so.

I certainly think we need to move away from the consumer ethos of the previous Patient's Charter and move into a more contractual type of arrangement where there are parts to play on both sides....it should take a more egalitarian approach, involving everyone and working more collaboratively where people take responsibility for their own health...

Staff also acknowledged that deficiencies in other public services might well prevent some people from meeting these kinds of responsibilities.

If you're thinking about why people don't turn up for appointments, have we looked at the transport system, have we looked at their child care, have we looked at the education that they can read, have we looked at travellers and the fact that the post office doesn't deliver to a caravan on the roadside ?

Several suggestions were made about ways in which patient could be helped to meet their responsibilities. They included negotiated care contracts and care pathways:

...they do work very well and it means that we feel more responsible in involving the patient as well because we know that they know what they're supposed to get, so it works two ways.

Someone else referred to the Mental Health Charter, pointing out that it contained a section on how patients and clients could help with their treatment and the people responsible for their care.

This topic demonstrated a genuine willingness of most staff to work with patients and clients to help them fulfil the responsibilities which they (and the patients) acknowledged to be theirs.

Communication and information

Staff acknowledged the importance to patients of information and good communication in respect of clinical treatment and clinical governance. They also thought that people should have more information about services, what they provided and what the NHS and social services could achieve. This kind of information would help users and carers to understand better the constraints on services and to help them have more realistic expectations of what could be provided.

Good communication was thought to be essential particularly in relation to complaints. Staff who managed complaints procedures said that the reason for many complaints was poor communication and misunderstanding. Some of these communication difficulties could be overcome by better training and support for staff. Junior nurses were said to be especially vulnerable when complaints were made about them and nursing staff were critical of the lack of support and training for them. Another critical area of communication for patients was in out patient or A&E departments where staff acknowledged that most people did not mind waiting past their time if they were given a reasonable explanation for the delay. The need for training for front line staff in these forms of communication was identified and an example of the way social care staff were being trained in negotiation skills was used as an illustration of the way such training could be provided.

Communication with ethnic minorities, the hearing and visually impaired and other disabled people was not raised as an issue by staff although it was an important feature of information needs identified in the patient groups. These needs were recognised though in the comments staff made about the need for advocates in the services where it was recognised that disadvantaged groups should have access to them. Three people mentioned that their trusts had an advocacy service to help people, usually in relation to complaints.

National and local charters

There was some support for the idea of a national charter framework supported by local charters although one person felt the Northern Ireland *was* local. Support for the idea was based on the value of being able to involve local staff and users in the development of standards and priorities and the principle of equity across the province. Not everyone agreed that there should be a regional framework with details worked out locally and concern was expressed about increasing costs, paperwork and causing confusion. The principle of equity raised in this context was thought by some to be unachievable but by others as an essential statement of principle.

4. SUPPORTING EVIDENCE

The written evidence

To support the evidence provided by the focus groups with patients, carers, clients and staff a questionnaire was sent to 504 health and social care organisations in Northern Ireland. These organisations included acute trusts, acute and community trusts, community and mental health trusts, the ambulance trust, health boards and regional agencies, general practitioners, local health councils, voluntary organisations, professional organisations and trade unions. The data in this section are based on 61 completed responses to the questionnaire. The overall response rate of 12% is very low but disguises some major differences in response from types of organisations. A hundred per cent response was achieved from trusts, for example. Details of the response rates can be found in the Appendix but the main reason for the high non-response rate was that the questionnaire was sent to all general practitioners in the province (365) of which 5% replied. There was also a low response from the 64 voluntary organisations of which 11% replied. The data cannot be said to be representative in any sense except that they also present the views of a range of health and social care organisations in Northern Ireland.

The existing patient's charter

Use, strengths and weaknesses

The existing charter had been found to be useful in some ways by most groups of organisations. Replies from trusts indicated a generally positive experience with every one saying it had been useful in some respects. In contrast, general practitioners were seriously critical of the charter and felt that it had not been useful at all. The responses from local health councils and voluntary organisations were more muted but with most of them able to identify some positive and negative aspects of its usefulness. Other agencies gave similar replies which indicated that they had found it to be of some use, in some ways. The overall view of the existing charter was that it had been useful with some strengths and some weaknesses.

Its usefulness was to be found in the fact that it had:

- been a useful tool for identifying, monitoring and focusing on areas where improvements were needed
- provided a focus on quality issues for staff and purchasers
- given a patient/client focus to services
- identified principles, rights and standards for patients/clients and the NHS and social services

Strengths of the charter

The strengths of the charter identified by respondents reflected the points made in relation to its usefulness with the addition of more detailed comments.

Trusts

Acute, acute and community and community trusts said that the charter had set a range of common standards which all staff could work towards; that it had encouraged staff to improve patient care; that it had emphasised 'softer' standards of quality and promoted organisational cohesiveness. As far as patients were concerned they thought it had given them more information on rights, services and standards and the opportunity to comment on them; that it had improved patient choice and communication; that it had made complaining easier for them (a positive step) and that it had under-pinned the concept of user involvement encouraging public awareness and better informed users.

Other strengths identified by trusts were that it had made the NHS more accountable; that it had provided common standards and improved the management of specific areas of like waiting times, appointment systems and waiting lists. There were no differences in the emphasis the different kinds of trusts placed on the strengths of the charter.

The strengths identified by the ambulance trust were similar but also identified the fact that by including ambulance services as part of the health and social care team the charter had been a positive step.

General practitioners

General practitioners were able to identify some positive points about the charter in spite of their generally negative views of it. They felt that it's strengths lay in the fact that it had identified goals and standards for health services and given some clarity about what services should aim to provide; and that it had made some GPs aware of quality issues.

Health and social service boards and regional agencies

The strengths of the charter identified by the boards and regional agencies tended to focus on the fact that it had encouraged the provision of information for users and that it had set measurable standards which allowed comparisons of provider performances.

Professional organisations.

Professional organisations also commented on the importance of the charter in relation to establishing a set of standards and that this allowed staff and users to know what to expect. They welcomed the emphasis the charter placed on consumers and the fact that it tried, in their view, to shift the balance of power from professional staff to patients.

The Pharmaceutical Society of Northern Ireland felt that it had been helpful in raising awareness of pharmaceutical services.

Local health councils and voluntary organisations

The main strengths of the charter as seen by local health councils and voluntary organisations were that it had a patient focus, had increased patient/client expectations and that it had provided measurable standards. Additional strengths were that the charter had provided a further motivation for staff and shifted the onus to providers to meet agreed standards.

Despite some of the differences in emphasis between types of organisations, it is clear that there was a strong measure of agreement about the strengths of the existing charter. Box 8 summarises them.

Box 8 Strengths of the patient's charter

The patient's charter:

- provided a set of common, measurable standards for patients, clients and staff
- helped identify services and systems where change and improvement required
- raised awareness of patients and staff of patient rights, needs and views
- provided a focus for quality and quality improvements
- stimulated more information and choice for patients with improved communication
- made the NHS more accountable
- improved some specific services like waiting times, lists and appointment systems

Weaknesses of the charter

Criticisms of the patient's charter fell into five main categories. They concerned:

* standards * staff * patients * resources * monitoring

Comments in these categories were made by all types of organisations with few differences in emphasis. There seemed to be greater agreement about the nature of the weaknesses of the charter than any other aspect of the charter.

Standards

The most common weaknesses of the charter related to the standards contained in it. Standards were said to be unrealistic, vague, or the wrong ones and some important standards were not included like clinical need or effectiveness. They were insufficiently focused on quality and the patient experience, difficult to deliver and not owned by staff. Other kinds of comments made by one or two people included the fact that the standards were not relevant to all local services; were too focused on acute services, and waiting times, were not as high as they should be and were not raised over time to ensure continuous improvements. Finally one or two people mentioned the fact that there were no sanctions against providers who failed to meet charter standards.

Monitoring

Comments about monitoring charter standards included the fact that it cost money to monitor; that there were no measures of clinical effectiveness; that some of the 'softer' standards were difficult to measure; that complaints were not a good way to monitor and that the publication of charter performance and league tables did not always compare like with like. Added to this there had been no review of monitoring arrangements and no feedback to staff or patients on the effectiveness of the charter.

Staff

Staff felt under pressure to perform to the specified standards which they often felt them to be unrealistic. They also felt that their rights were not acknowledged and that 'there was nothing in it for them.'

Patients

Patients were said to suffer because the charter had raised their expectations unrealistically and several organisations complained that patient responsibilities were not included.

Resources

The lack of resources for health and social care was a continuous theme throughout this research but in relation to charter standards the comments were primarily to do with the way in which expectations had been raised beyond the capacity of the services to deliver.

Complaints

Although a few people made the point that the charter had been responsible for an increase in the number of complaints and had created a complaints 'culture', these comments were not made as strongly as they were during the focus groups with managers and clinicians.

It was mentioned earlier that there were few differences in emphasis between the different types of organisations, in the comments they made about the weaknesses of the charter. The one main difference was that general practitioners were more likely to comment on the problems of raising patient expectations unrealistically than were other groups.

Priorities for quality standards

When the survey participants were asked to name the most important quality issues for their organisation they identified eight categories of quality issues. Box 9 identifies what these categories were.

Box 9 Priorities for quality standards

- clinical effectiveness and outcomes
- access to services and treatment
- the quality of patient care
- information for and communication with patients/clients and carers
- monitoring and improving services
- equity
- user involvement
- staff attitudes/ behaviour/ rights and training

Clinical effectiveness and outcomes

Trusts, general practitioners and professional organisations were more likely to say that clinical effectiveness was a priority issue than boards, agencies, local health councils and voluntary organisations. This is not to say that it was ignored by the latter but that it was less likely to be mentioned.

The kinds of issues which were highlighted under this heading were the need to adhere to professional standards and guidelines and to practice evidence-based clinical care with appropriate follow-up.

Access to services and treatment

This area was of particular significance to local health councils, voluntary organisations and general practitioners although it was seen as a priority also by trusts and other agencies. Waiting times, waiting lists, accessible and flexible appointment systems featured here as did provision for emergency admissions and choice of services for patients. The special needs of some groups such as the visually impaired, the deaf , the disabled and ethnic groups were pointed up in relation to access and the importance of advocacy services to meet these needs.

The quality of care

Non- clinical quality of care was mentioned by all groups and included the need for respect, privacy and dignity for patients; good quality environments and facilities; open and accessible organisations; empathy and time for patients to be heard; the involvement of patients and carers in care plans and confidentiality.

Information for users and carers and communication with them

Another major quality issue for all organisations was the provision of good information about services and good communication between staff, patients and carers. Carers were seen as people whose needs for information had been neglected in the past and this was something that be put right. Details about the types of information to be provided through the charter are discussed below.

Monitoring

Monitoring was an issue which was regarded as a priority by trusts and boards mainly although it was mentioned by two voluntary organisations. Issues about complaints are included here because the comments related specifically to the fact that complaints could be used as a way of monitoring services. There was one plea to move away from input measures for monitoring and another for the introduction of effective quality monitoring. One person said:

Remove all banal measurements like 5 minutes waiting times and replace with quality issues agreed by all stakeholders

Equity

Equity was rarely mentioned specifically but it was implied in many other comments about quality standards. The specific comments included the need to provide the resources to ensure equity of service delivery and that the lack of equity caused difficulties for some voluntary organisations.

User involvement

The need to involve users in service planning and delivery and in setting charter standards was mentioned by all organisations except general practitioners. The value of this involvement was accepted by many respondents as a way of making services more responsive to their needs. It was also seen to be important as a way of developing partnerships in care and treatment.

Staff attitudes, behaviour and training

There was some recognition that staff and their training were a priority but not as much as might have been expected. This may, of course be due to the fact that the charter was not seen to be the right place for it but it is interesting that staff were aware that many complaints were received about their attitudes and that they themselves are an essential ingredient of good quality care.

Quality priorities for inclusion in a new charter

The emphasis on quality priorities changed very little when respondents were asked to identify quality standards for inclusion in a new charter. The only substantive change was that several organisations, particularly general practitioners, said that patient responsibilities should be included. Another priority identified for a new charter was that social care services and carers should be given more emphasis than they had had in the existing charter.

Box 10 Quality priorities for inclusion in a new charter

- clinical need, effectiveness and outcomes
- access to services and equity
- information to patients, clients and carers
- quality of care
- monitoring and improving services
- patient responsibilities
- user involvement
- staff roles, skills, attitudes and training

Information and communication

All organisations recognised the importance of the need for good information for patients, clients and carers. The two major areas identified were information about clinical conditions and the range of treatments available and information to help people get access to services .

Information about clinical conditions and treatments

All respondents agreed that information about clinical conditions was essential for patients as a right and to enable them to make choices. The kinds of things mentioned included information about diagnosis, treatment options and outcomes; the processes involved in treatment like what to expect post-operatively and what was regarded as good practice.

Information about services

Equally important was the provision of information about services; how to access them; what was available; where they were located; opening times of clinics and surgeries and out-of- hours pharmacists. Waiting times for operations and in clinics were mentioned often and several people mentioned that people should be given guidance on the appropriate use of services particularly ambulance services and emergency services.

Resources

Given the importance organisations had attached to the difficulties of achieving charter standards with limited resources, it was not surprising that they felt patients and clients should be given information in the charter about resource constraints. Issues mentioned here included the need to tell people bout these limitations, how they could help by using services responsibly and the need for clinical priorities. Some felt that patients and clients should also be told which services were 'free' and which they should expect to pay for.

Staff

Explanations of the roles of different kinds of staff, the skills they have and their limitations was also felt to be important information by some organisations.

Complaints

The charter should spell out complaints procedures and how to use them most effectively.

Other services

Several organisations pointed out the need for a charter to provide details of other kinds of support available in the community like self-help groups and voluntary organisations.

Information formats

A considerable amount of comment was provided on the importance of written information to back-up information given verbally. The importance of clear, user-friendly language without jargon and of information provided in different formats appropriate to the needs of special groups like the deaf and visually impaired. The need for information to be made available in different languages for people whose first language was not English and of the need for advocates to help these special groups, was also emphasised

The involvement of patients and clients and carers in the development of information and consulting them about their information needs were other points made.

Box 11 below summarises the kinds of information organisations thought patients, clients and carers should have in the charter.

Box 11 Summary of information needs of users, carers and the public

- clinical conditions and treatment
- services available and how to access them/waiting times
- resources and responsible use/constraints on them
- complaints procedures and how to use them
- staff roles, skills and limitations on them
- voluntary and community support services

Regional and local charters

There was overwhelming support for a Northern Ireland Charter. Two main reasons were given for this support. The first was that health and social care were integrated in the province and a charter should reflect that difference from the English system. The second was based on the fact that different regions faced different issues and a charter should reflect those differences. The few people who did not want a separate Northern Ireland charter argued that one national charter should cover all regions.

There was greater disagreement about the need for local charters. Those who supported them said that local charters could provide more realistic standards for local services and allow comparisons across the province. Others said that local charters would enable users to be involved in their development and ensure that they were aware of local issues.

Those who were opposed to local charters were concerned about the costs of developing them and about the fact that they would simply repeat the standards set in a Northern Ireland charter as some of the existing local charters were said to do. Others said that Northern Ireland *was* local and that the province was too small for local charters.

Overall, the written evidence produced finding very similar to those provided by the managers and clinicians and primary care groups. The responses from trusts revealed generally positive feelings about the existing charter despite some genuine concerns. Replies from general practitioners were not positive but revealed some interesting discrepancies. Almost all of them accused the charter of being responsible for raising patients' expectations and the number of complaints yet they also said that people were largely unaware of it. It appeared that the charter had little influence on their own practices even where they had introduced their own charters. Its greatest influence was said to have been on waiting list times over which they felt they had little control. The response from voluntary organisations was disappointing and as a result there was little evidence from organisations representing patient groups. The best evidence from that quarter came from the local health councils who provided detailed comment on quality standards and information needs which complemented that given by patients and carers in the focus groups.

APPENDIX 1 RESEARCH METHODS

The focus groups

Six focus groups were conducted with patients, clients, carers, managers, clinicians, social services personnel, primary and community care staff during the week June 22 to 25, 1998.

The aims of the focus groups were to :

- explore awareness and knowledge of the Patient's Charter amongst patients, clients and carers
- obtain the views and experiences of managers, clinicians, social services personnel and primary care staff working in the NHS and social services
- to explore in particular the impact of the charter on social services staff and clients
- generate suggestions from each of these groups about the principles and issues which they would wish to be included in a new charter

Focus groups were chosen as the most appropriate means of gathering the views and experiences of the various stakeholders because they are open-ended, provide a useful forum within which people can share their views and experiences and are a particularly effective way of brain-storming and generating ideas about possible ways forward. They also provide a means for gathering a range of viewpoints within a fairly short time scale and the breadth of experiences obtained forms a sound basis on which to build further research. In the Northern Ireland situation where comparisons with the evidence gained from the research on the Patient's Charter in England were required, it seemed essential to use the same method for collecting views and experiences as had been used there.

Focus groups are interactive in nature but each group was conducted using a topic guide to ensure that similar issues were covered in each group. The discussions were recorded, with the permission of the participants, and assurances of confidentiality and anonymity were given in relation to the analysis and reporting of the data.

Sampling

Participants for focus groups are usually selected using purposive sampling methods which involve screening interviews in selected local areas. On this occasion there was insufficient time to carry out the normal screening procedures and a slightly different form of purposive sampling was used. Organisations representing patients - local health councils and voluntary organisation were approached by the King's Fund to ask if they could help to find people wishing to take part in the three focus groups. If they were able to help they were provided with a list of the kinds of people to be included. The criteria for selection were the same as they would have been using a random screening method ie people with recent experiences of using health and social services from all age groups except children who had used acute primary care and community health services; people who had used social services and carers.

The final composition of the focus groups did include this range of people and was remarkably similar to the composition of the English groups where people were screened first and subsequently selected. The main difference appeared to be that the participants were all known to local councils or voluntary organisations and were thus more likely to have sought help from these sources.

The study areas for patients included Belfast and surrounding areas and Omagh and surrounding areas. This gave a spread of people from urban and rural areas across the province.

Overall 42 people took part in the patient focus groups. In acknowledgement of their time participants were given a payment of £15 and their travel costs were reimbursed. Staff travel costs were also reimbursed.

Analysis

The tape recordings of the focus group discussions were transcribed and analysed using the framework method developed by Social and Community Planning Research (SCPR). This involves charting data from the transcripts into a series of thematic matrices which allows comparisons between and within cases.

The questionnaires were analysed in a similar fashion and making sure that differences between different organisational types were taken into consideration.

The written evidence

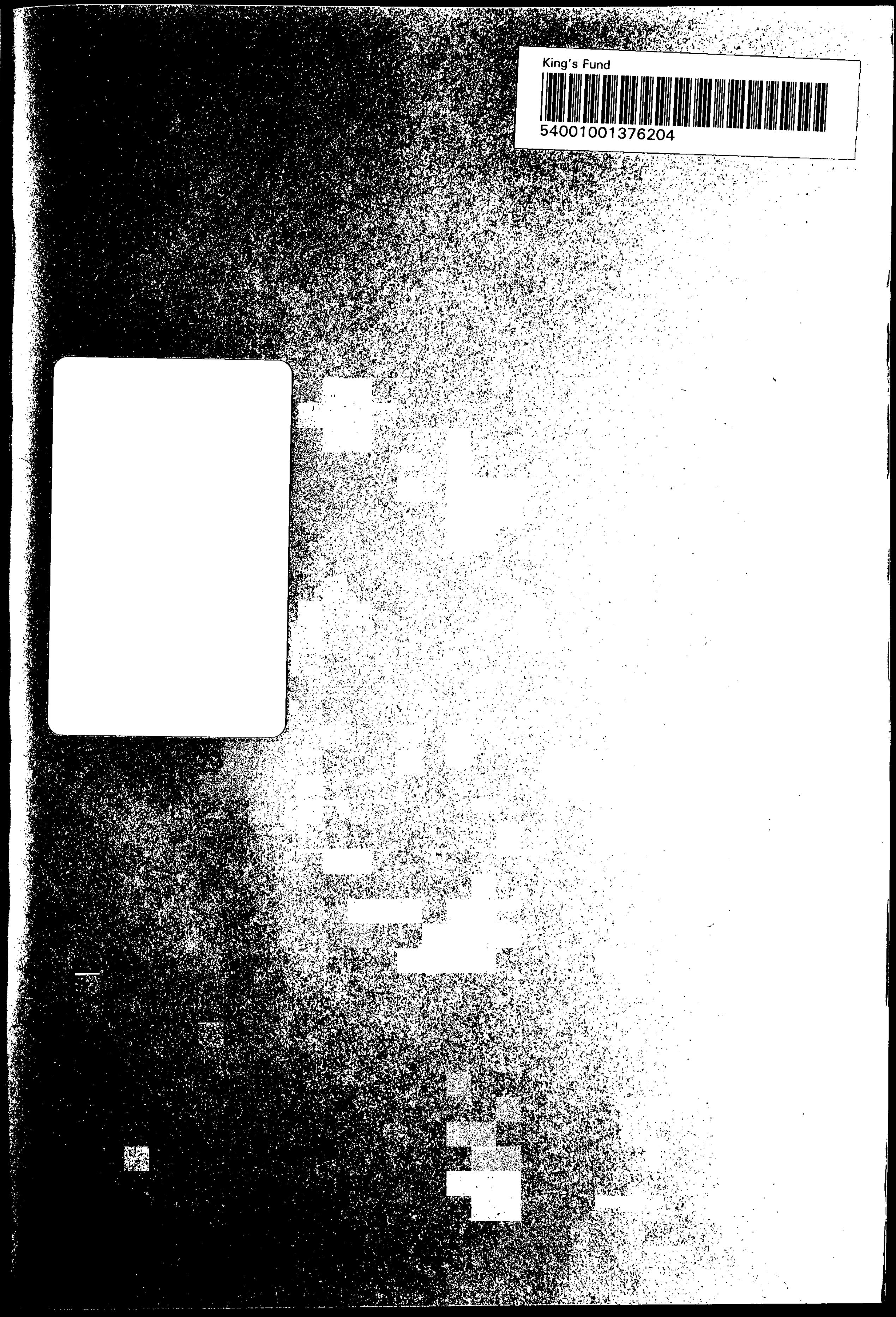
All health and social services organisations, general practitioners, health related trade unions, voluntary and professional organisations and health agencies in Northern Ireland were sent a questionnaire and letter inviting them to contribute to the review of the Patient's Charter. Responses were slow and after a month another letter was sent reminding organisations of the invitation. By the end of July, 43 replies had been received. Telephone calls were made to non-responders and during the following two weeks a further 18 questionnaires were received. The overall response was poor, at 12 % but this figure disguises some substantial differences in the response from types of organisations. Table 1 shows the numbers and types of organisations sent questionnaires and Table two the composition of the final 61 responses.

TABLE 1 Total sample and response rates

Organisation type	number sent	number replied	total response %
trusts	20	20	100
boards	4	3	75
health councils	4	4	100
health agencies	5	4	80
professional organisations	16	6	38
voluntary organisations	64	7	11
general practitioners	365	18	5
trade unions	3	0	0
volunteer organisations	5	0	0
TOTAL	**504**	**61**	**12**

TABLE 2 Number and types of organisations included in the analysis

type of organisation	number sent	response %
acute trusts	7	11
acute & community trusts	6	10
community trusts	5	8
ambulance trust	1	2
total trusts	19	31
general practitioners	18	30
boards	3	5
health councils	4	6.5
other agencies	4	6.5
professional organisation	6	10
voluntary organisations	7	11
Total	**61**	**100**



All queries related to this report should be referred to:
Christine Farrell; Tel: 0181 883 7940
Further copies of the report are available from Pat Tawn,
The King's Fund, 11-13 Cavendish Square, London W1M 0AN;
Tel: 0171 307 2672