THE WRITTEN EVIDENCE

Introduction

This Appendix summarises a survey of 182 organisations including health authorities, acute trusts, acute and community trusts, community and mental health trusts, ambulance trusts, general practitioners, voluntary organisations, Royal Colleges, professional organisations and trade unions. Details of the methods used and response rates are contained in Appendix V. The data in this report are based on 89 completed responses (ie 49% of the total sample).

The existing Patient's Charter

A mixed blessing

The existing Patients' Charter seems to have been found useful in some, limited ways. The overall impression from the replies to the questionnaire was that it had provided a starting point and a framework within which organisations had been able to tackle certain aspects of quality and service delivery. It was useful because it had provided a first definition of national principles and standards for the NHS. It had offered a focus for patient orientated services and was seen by some to redress the imbalance of a hitherto professionally-orientated service. It had also highlighted some specific issues like waiting times. Some organisations had found it a useful device for introducing change and reviews of procedures. One respondent said that it had been:

> *A tool which had made some contribution to change...*

Another said that it was seen as:

> *An initial attempt at improving standards....*

Health authorities said that it had acted as a useful starting point for performance improvements; for the identification of problems with services and with internal procedures. It had also helped to raise staff awareness of the need to make services more responsive to patients, particularly in relation to waiting times. Acute trusts and acute and community trusts expressed similar views. The response from the Royal Colleges and professional organisations was positive on the whole and welcomed the introduction of national standard setting.

The notable dissenters were GPs who expressed almost complete dissatisfaction with the Charter. It had encouraged patients to take their rights for granted and to ignore their responsibilities. However, the response from GPs was low (6 of 30) and may not reflect the views of GPs generally although it was also the view of the GPs who participated in the primary care focus group. The view expressed by the Association of Managers in General Practice in their written evidence may be a better reflection but confirms the general point.

> *The Association was involved in the original group discussions, launch and dissemination of information to managers in general practice. (There was a) consensus that the Patients Charter has had a limited use because it was too patient focused which gave rise to increased patient expectations beyond the capability of the service to deliver.*

Strengths of the Charter

Assessments of the Charter's strengths were that it had identified some key standards and the fact that it had acted as an educational tool for raising public and staff awareness of quality issues and standards. It was thought to allow national comparisons and to be useful for some monitoring purposes. It had identified some patient needs and had helped to focus attention on them.

Health authorities identified two main strengths of the Charter: the fact that it had encouraged greater awareness of patient and carer needs amongst staff; and that it had provided a set of standards or targets which could be monitored, enabling comparisons with other authorities and providing a basis for improvements. Acute trusts valued the way the Charter had helped them to identify priorities, set standards, improve performance in some areas and move towards more consistent standards. Two of them said that it had also helped them to put patients on the agenda in relation to access and the 'softer' quality issues. Acute and community trusts were more likely to say that one of the strengths of the Patient's Charter was that it had helped to them to change the culture in their trust towards the user perspective. Examples given included much greater emphasis placed on privacy and dignity and more individualised care through the named nurse concept. The community and mental health trusts said the Charter had raised patient and carer awareness of rights and standards and that, in some cases, it had also raised staff awareness of patients' needs. They also mentioned that it had provided a tool for quality improvements in the physical environment (privacy and dignity). The following quotation summarises most of the strengths mentioned by health authorities and trusts.

> *(The Patients Charter) has clarified what users of the service can expect from the NHS. (It) has to some degree addressed the issues around waiting lists/waiting times. (It) has encouraged innovative approaches to addressing some of the difficulties in demand within the NHS. It has defined measurable*

achievements. (It) has encouraged feedback from patients and service users as they are able to measure the service provided against the expectations raised by the Charter. (community and mental health trust)

Responses from the ambulance services indicated that they had found it useful as a focus on patient expectations; in promoting in-house materials to address issues of patient dignity, privacy, religion and culture and also for special needs (visual and hearing impairment). It had also helped to reinforce the need for essential service developments; and as a framework for complaints management. The two most commonly made statements however were that the Charter had identified a basic standard to which ambulance trusts should perform and had raised awareness of what patients should expect.

It clearly identifies what the public can expect from the NHS in certain areas. It can be used as a tool to explain to staff both the obligations of our own service and how they relate to the rest of the NHS (eg all staff receive a copy of the revised Patents' Charter in 1996 and copies are given to new recruits). The reference to 'softer' standards - respect for dignity, privacy and religious and cultural beliefs, commitment to providing information and treatment, the right to have complaints investigated - has prompted debate on these areas, although this was starting to happen anyway. (ambulance trust)

Three of the six responding GPs said there were no strengths to the Charter. The other three said that it had been useful in setting some ground rules; that:

It clearly set out the patient right to expect

and that it had been helpful in relation to hospital waiting times. The Association of Practice Managers said that it had:

raised awareness of quality issues and standards in primary care (and) shifted the focus onto patients

Chart A below shows the main categories of strengths of the Charter identified by respondents in the survey.

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┌─────────────────────────────────────────────────────────────┐
│           CHART A - STRENGTHS OF THE PATIENTS CHARTER         │
│                                                               │
│     • raised awareness of patients' needs/ issues/rights      │
│     • helped with standard setting/identification of priorities│
│     • set standards for performance/comparison/performance review│
│     • a tool for quality initiatives                          │
│     • useful for monitoring                                   │
│     • useful for complaints management                        │
│     • useful emphasis on information provision                │
│                                                               │
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Providers and non-providers in the survey placed different emphasis on the value of the Charter in raising awareness of patient issues and rights. It is only to be expected that CHCs and voluntary organisations would have a different view to health authorities and trusts. However, apart from the first category in the chart, similar proportions of providers, CHCs, and voluntary organisations also mentioned these strengths in their responses. This is reassuring evidence that there is a fair amount of agreement on what the strengths of the Charter were.

The findings from the focus groups with NHS managers and clinicians (Chart 4. in Appendix IV) confirm, to some extent, the positive comments about the Charter in the written evidence. The focus groups with clinicians also confirmed the more negative feelings of clinicians illustrated in the written evidence from general practitioners

Weaknesses of the Charter

Responses about the weaknesses of the Patient's Charter were much less restrained, and focused not only on what the Charter *did not do* but also on the difficulties which it created.

The reported down side of the Patient's Charter was that it had raised patient/public expectations beyond the services' capacity to meet them. It had also created confusion about rights and expectations. Other criticisms were that it had ignored staff needs and diverted resources away from service and clinical priorities. Some respondents pointed out that it had ignored major quality issues such as clinical outcomes and the quality of the patient experience. The emphasis on acute services was seen as a disadvantage by some, as was the fact that national standards were not always achievable locally.

Health authorities pointed to the fact that by focusing on waiting times, the Charter's focus had distracted attention from clinical need which should have been the real priority.

> *Many of the standards do not focus on clinical need but on something else eg time waited. Also the standards may work against each other eg 12/18 months waited versus cancelled op(eration)s. and may have a perverse effect on quality eg triage in A&E -full assessment time (this should improve with the new standard).* (health authority)

They were also critical of the emphasis on quantitative standards; 'bean counting' as it was often described. These criticisms were echoed by acute trusts, acute and combined trusts and also by community and mental health trusts, whose most frequent comments related to the extra work involved in collecting the necessary statistics and that statistics were often 'fudged'. The trusts were equally concerned with the way the Charter had raised patient expectations.

> *(The Charter has caused) confusion for public and staff alike between rights and expectations - and the public certainly regard expectations as rights ! (It has caused) Bureaucratic and time consuming monitoring requirements (very problematic if data not available from PAS or other minimum data set systems .* (acute trust)

The criticisms of monitoring requirements and the quantitative aspects of the Charter included the fact that there was a lack of clarity and definition about many standards which led to extra work.

> *Weaknesses include the lack of clarity of definition. It should be in line with league table definitions so when collecting data it is only collected once and suffices both purposes, not collected in three different ways for three definitions (Köner, Patient's Charter, League Tables).* (acute and community trust)

In summary, the main focus of health authority and trusts' criticisms fell within five categories:

- problems with Charter standards
- the emphasis on waiting times rather than clinical need
- the emphasis on quantitative standards rather than quality of services and patient experience
- the problems of monitoring
- raised patient expectations beyond the capacity of the services to deliver

These categories also covered the comments made by other organisations, although the emphasis was sometimes different. Ambulance trusts, for example, pointed to the fact

that the Patient's Charter failed to focus on clinical need/priorities. All six GP respondents said the major weakness of the Charter was that it had raised patient expectations beyond GPs' capacity to meet them. No other weaknesses were mentioned. The Royal Colleges and professional organisations also commented most often about raised patient expectations and creating a 'rights' mentality and pointed to the weakness of quantity not quality. CHCs and voluntary organisations mentioned raised patient expectations, problems with standards and too much emphasis on quantity, but they also made a wider range of comments about the special needs of specific client groups.

Chart B below shows the major categories of complaints about the Charter.

CHART B: WEAKNESSES OF THE PATIENTS CHARTER

- problems with standards/lack of clarity/too narrow/wrong
- difficulties with monitoring/stats collection
- raised peoples' expectations too high/beyond the resources of the services to meet
- ignores clinical need/outcomes
- too much focus on quantity
- too acute oriented
- no patient responsibilities included

One of the most interesting findings around the perceptions and experiences of the existing Charter is the discrepancy between the patients' perceptions and NHS staff perceptions. On the one hand, patients in the focus groups knew little about the Charter, what it contained or how to use it; on the other hand, staff perceived patients' expectations to have risen because of the Charter and felt this as a pressure and a threat.

Priorities for quality in the NHS

When the survey participants were asked to name the most important quality issues for their organisation: *the quality of clinical outcomes* was identified as a priority more than any other. Altogether six main categories were identified. Chart C below identifies them.

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CHART C  PRIORITIES FOR QUALITY STANDARDS

  •  clinical effectiveness
  •  access to services/treatment
  •  user involvement/partnership
  •  effective information/communication
  •  staff training/qualified/staff attitudes/behaviour
  •  quality of patient care including patient privacy/dignity/respect
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Comments which fell outside these categories but were made by only a handful of respondents included:

- volunteering
- continuity of care
- relationships with non-NHS organisations such as local authorities and voluntary organisations

The emphasis changed somewhat in the responses to the next question which asked specifically about standards for inclusion in a new Patient's Charter. Two new categories appeared which were:

- greater focus on community services including primary care
- more focus on vulnerable care groups such as the mentally ill and groups which found access to care difficult, such as the homeless, refugees, the elderly, and black and ethnic minorities

Chart D below shows the priorities identified for inclusion in a new Patient's Charter. The list is arranged with the categories attracting most comments at the top.

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│                                                                 │
│          CHART D:   QUALITY STANDARDS FOR INCLUSION IN          │
│                     A NEW CHARTER                               │
│                                                                 │
│        •   clinical effectiveness/outcomes                      │
│        •   partnerships/involvement of patients in treatment and service planning │
│        •   effective information and communication              │
│        •   access to services                                   │
│        •   community and primary care services                 │
│        •   the patient experience including privacy, dignity, and respect │
│        •   staff training, qualifications and attitudes         │
│        •   focus on vulnerable groups                           │
│                                                                 │
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Some of the respondents to this question offered useful advice. One comment from an acute trust emphasised the need for a new charter to include a clear statement about the purpose of the charter and went on to explain why this (and other points) should be included:

> *Clarity of purpose of the objectives and need for a Charter. The press has already suggested that Britain has Charters because it cannot provide the service. The current Charter is a statement of standards for the NHS. Apart from the hard quantitative waiting times information, the other standards are not easily measurable. There are thousands of indicators and data sets that could be included in the new Charter......whatever is included should be achievable.....* (acute trust)

Involving patients/users and carers in their own treatments and in other aspects of services gained considerable support here:

> *Increased patient/user participation with service providers and users working in partnership with a greater emphasis on locally based services and agreed priorities for health service provision.* (community mental health trust)

was a sentiment supported by a third of all respondents.

Good systems of communication and information provision also received strong support:

> *Some aspects such as communication should be mandatory.* (community health council)

Local communication systems (should be) established and monitored.
(community mental health trust)

Vulnerable groups received special attention. One voluntary organisation recommended:

Listening to the views of older people and people with dementia and their families and friends and designing the services to meet their needs. Attention to the rights of vulnerable residents within Homes and how their health care and rights of redress can be covered in the Charter. (voluntary organisation)

Another point made in several ways related to the special needs of ethnic groups and suggested that the new charter should include:

Provision of bi-lingual staff....provision of trained interpreters familiar with health jargon.....training of all staff on religious, cultural practices, equal opportunities.. (voluntary organisation)

It was not only voluntary organisations who made such points. In fact, there were proportionately more comments from provider trusts in this category. Non-provider organisations offered more comments in the 'access to services' category and the effective information and communication category and the emphasis on community and primary care category. One professional organisation said:

Continuity of care should be an objective of all health care providers; patients have the right to expect as seamless a transition as possible between different health care providers and between health and social services. (Royal College)

It is interesting to note that this section reflects very closely the evidence from the in-depth interviews and from the patient focus groups, although the NHS managers and clinicians in the written evidence gave as much emphasis to these priorities for a new charter as did voluntary organisations and patients groups. Agreement on the agenda for the new charter appears to be spread across the divide, albeit with some differences in emphasis.

Information needs

In answer to questions about information needs, respondents overwhelmingly identified information about conditions and treatments as being the most important.

People should be informed about the name of the condition, the prognosis, possible treatment and the way it is likely to affect their lives. This helps people come to terms with what is happening and what will happen in the future. It allows them to plan and organise and provides the basis for talking to others... which may further their understanding and enables others to provide appropriate support. (voluntary organisation)

When asked to say what kinds of information they thought were most useful to people using NHS services the majority (two thirds) identified clinical information about individual conditions and treatments.

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

Drugs, medication their effects and reasons for prescribing them were also mentioned quite frequently.

The second most frequently mentioned information need was identified as how to access services.

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

The third most frequently mentioned information need was about standards of services and what to expect of local services.

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

Two other kinds of information needs were mentioned with equal frequency. They were: information about non-NHS support services and organisations - self-help groups for example, and complementary therapies. The other was information about staff qualifications, particularly of doctors. This information, it was felt, was important because it would enhance patient choice and allow their GPs to exercise choice on their behalf.

Chart E below shows the range of information that respondents felt should be available to patients and the public.

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│                                                               │
│         CHART E:  INFORMATION NEEDS OF PATIENTS               │
│                   AND THE PUBLIC                              │
│                                                               │
│         •  conditions/treatment/medications with risks and benefits │
│         •  access to services                                 │
│         •  standards of services                              │
│         •  Non-NHS support services                           │
│         •  staff qualifications                               │
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The importance of providing patients and the public with the kinds of information identified here, is supported by the literature review and the interviews with patient organisations.

National and local charters

The written evidence suggested that there would be considerable support for a national charter which provided a framework of standards, with local charters providing local flexibility. Those who felt that there should be a national charter acting as a framework for local standards (over half the respondents) emphasised the fact that the NHS is a national service and that a national charter was essential to maintain this important concept and to ensure equity across the country.

> *Given the diversity of cultures, languages, values and beliefs nationally I feel that a national framework backed up by local charters is the most valuable way forward. There is a strong feeling in particular around devolution where this might be crucial.* (professional organisation).

Although there was strong support for this approach, worries were also expressed about the proliferation of standards possibly causing confusion.

> *As a national service we should have a national charter embodying standards that all citizens can expect to receive. Local charters can give scope to talk in more detailed ways that may be more relevant to specific populations and address local issues. They present the opportunity to lever up standards between areas. However, they may also lead to confusion in the minds of the public as do subject-specific charters.* (ambulance trust)

The organisations which preferred the option of a national charter only (a quarter of respondents) felt that only a national charter would have the 'teeth' to set the standards and avoid the scope for confusion in having a plethora of local charter standards.

> *There should be one national charter to avoid local interpretation. Everyone, irrespective of where they live, should be entitled to the same basic standard of service. There should be nothing in this to prevent local services aiming to improve on the basic standards particularly as the emphasis is now switching from competition to collaboration.* (community health council)

Three organisations said that they felt that there should only be local charters.

> *The reality for NHS users is the translation of the priorities and planning document, charter etc into the Trusts business, purchaser quality specification, annual report, quality strategies/frameworks. Therefore, a local charter which combines these may be more informative to staff and public.* (acute trust)

Experience of working in areas which had local charters was limited to about a quarter of respondents. Their comments about the strengths and weaknesses of these charters obviously reflected their own experiences. One consistent theme among them, however, was the value of involving users in the preparation of the local Charter. Some people mentioned the fact that this kind of process had led to patients and staff feeling ownership of their charter and others referred to the importance of a joint, collaborative standard setting process as being a valuable aspect of local charter development. Other factors mentioned included the possibility of setting higher standards locally than the national charter; and the capacity to reflect local needs and priorities which made local standards more relevant than the national ones. This point was also reinforced by NHS staff views expressed in the focus groups.

> *Our local charter has been very useful in involving users......It has raised expectations and, in turn, quality.* (managers focus group)

On the other hand, local charters were criticised for having 'loose' or 'woolly' standards; for confusing patients; for the cost (time and money) of producing them and keeping them up-to-date; for the fact that no one used them 'despite wide publicity'; and for a bias towards acute services; and the failure to monitor 'softer' standards. Ambulance services pointed to particular difficulties created by local charters because their areas sometimes involved several different local charters. They made a special plea for collaboration between health authorities, purchasers and ambulance trusts to agree locally relevant performance targets in relation to emergency response times.

> *It would have been more helpful if the Charter had, for example, stated the need for the local health authority and ambulance trust to collaborate to reach 95% of patients in (x) minutes say. This approach would... have concentrated more energy on the misuse of 999 services sooner than it has. In future the achievement*

of standards has to be a genuine shared responsibility between purchasers and providers, particularly when the maximum performance targets are not financially achievable. (ambulance trust)

Standards to be included in local charter

Where respondents supported the idea of a national charter framework backed up by local charters they made a wide variety of suggestions about the standards they would like in a local charter. It was here that people commented on the need for charters to highlight ways in which resources limited services. Some of the aspects which they had identified for inclusion in the national charter were mentioned in relation also to local charters. These were: access to services, waiting times/lists, clinical standards.

Reference was made to some specialist services; cardiac, cancer, palliative care, mental health and children's services. The need to include standards for special groups like minority ethnic groups and refugees was also mentioned by several organisations.

A local charter would need to include: provision of information in languages of the local community: the right to access to professionals in the NHS who speak the languages of the communities. Respect for all religions and cultures. (voluntary organisation).

Some organisations mentioned the need to include information on staff training and professional development and the need to include information about local voluntary organisations and carer groups. All these suggestions are relevant to local services and communities but there was also a range of comments which gave the impression that what people were suggesting was something more like a local annual report than a charter. Comments like, 'intentions against morbidity', 'cost comparisons between providers' and 'details of how national standards are to be met' indicated the provision of a more substantial document than a local charter could be. However, this comment from a health authority might be the answer.

Local charters should reflect how the national one has been interpreted locally. We adopt this method locally and report through annual reports. (health authority)

Given the amount of support expressed for a national charter framework backed up by local charters, this is probably the most appropriate and useful way forward for the future. It certainly is if the process includes patients and local people in setting the standards since it will incorporate their views and experiences and, at the same time help them to understand some of the limitations on service provision . However, there will be a number of issues to confront, such as the time it takes, the costs, and how to relate local standards to the national ones. There is also the question of monitoring local as well as national standards. One of the most common complaints about the national charter from NHS staff was the difficulty of collecting and presenting good quality information about

charter standards. Although the need for local as well as national standard setting is clear, it may not be achieved easily.

Publicity for a new Patient's Charter

The majority of suggestions about publicising a new charter fell into one of three main categories:

- national and local media;
- NHS services;
- information in public places.

Respondents often suggested a combination of all three. Nevertheless it seemed to be that the most frequently mentioned way to publicise a new charter was by launching it through the national media or through national and local media. Media here includes TV, radio, press, magazines. Altogether two-thirds of respondents mentioned these sources. In contrast about a quarter of respondents said that it would be better to direct publicity towards targeted audiences through clinics, GP surgeries, and hospitals because a great deal of money had been wasted sending the previous charter to all households; and yet few members of the public (or even patients)were aware of the Charter's existence.

> *The first Charter was meant to go to every home - an expensive exercise that nonetheless did not lead to the widespread knowledge that might have been hoped for. A press campaign at the launch and wide availability of the Charter at all places that health care is delivered would probably be better.* (ambulance trust)

Few respondents said that they thought it should again go to all households.
For continuing publicity about a new charter, about a third of respondents felt that copies of the Charter or information about how to get a copy, should be made available in places such as libraries, council offices job centres, cinemas, market stalls and post office counters. Regular advertising with posters, wall charts and leaflets in NHS clinics, surgeries and hospitals as well as on buses and at bus stops, was suggested as away of publicising a new charter. A few mentioned the scope for using the Charter publicity for educating children and young people to stay healthy. Several organisations referred to the need to find ways of publicising the charter to ethnic groups and others, such as people with visual and hearing impairments. Some organisations mentioned that the most effective form of publicity was to involve people in the process of developing the Charter.

One sceptic said that the whole charter idea should be scrapped to save money and another advised that it should not be called a Charter. Someone advised:

> *Charter fatigue is a real problem: any new charter will face a wall of 'been there, done that' attitude. It is essential therefore, to make it fresh in form as well*

as substance. Public involvement in the NHS must be improved; public involvement with the Charters and their implementation. (Royal College)

There were several suggestions that 'soap operas' should be used as a way of publicising a new charter and one person suggested that 'Charter Champions' should be found, celebrities perhaps, who could carry the charter messages forward regularly.

Suggestions for publicising a new charter within the NHS focused on:

- staff training/cascade methods
- information in in-house magazines and professional journals
- internal briefings with discussion and guidance
- building charter standards into performance review of both staff and the organisation

Other suggestions made by smaller numbers included putting leaflets/handouts into pay slips; putting messages on internal e-mail; leaving materials in staff rooms and lockers; involving staff in charter development; and building it into the culture of the organisation.

<u>Encouraging effective use of NHS services by patients, carers and the public</u>

Earlier sections have pointed to the dissatisfaction many NHS managers and clinicians felt with what they perceived to be irresponsible use of services by patients. The survey invited them to comment on ways in which patients could be encouraged to use services responsibly and what problems people may have (or have had) in meeting these responsibilities. Chart F below indicates how respondents felt this could be accomplished.

CHART F: PATIENTS CONTRIBUTION TO BETTER WORKING RELATIONSHIPS WITH NHS STAFF.

- changed behaviour
- keep appointments and inform
- proper use of services
- take responsibility for own health
- improved communication

The chart illustrates that the main contribution to be made by patients was to change their behaviour. The kinds of comments included in this category were primarily related to good manners; that is being polite, demonstration of mutual respect (patients for staff and staff for patients), and acknowledging that staff were human too. Some strong feelings

were expressed about patient/carer abuse of staff and violence, with the request that sanctions might be used against people who did behave in this way.

Keeping appointments, being on time and letting staff know if they could not be kept, was the second most frequently mentioned category although CHCs and voluntary organisations did not mention this as often as NHS staff.

Third on the list was the appropriate use of services. This category included three comments from ambulance trusts who were concerned about the inappropriate use of the 999 services:

> *This is a big area for ambulance services as we find that many of our callers seek help for conditions that are not urgent.*

Other providers who made similar comments did however, emphasis that people needed information to use services appropriately.

There was a smaller category of comments on people's responsibility to keep themselves healthy. The category labelled 'communication' should properly be included in changing behaviour but was isolated because it focused on the need for staff and patients to improve channels of communication whereas the behaviour category was almost entirely about patient behaviour. The follow-up question to this one asked respondents to identify the problems people might have (or had had) in meeting their responsibilities to NHS services. This section is particularly interesting because it is much less 'blaming' of patients and identifies some important areas where the NHS system could be changed to help patients deliver their responsibilities.

Chart G below indicates that the two main categories covered poor information and understanding (ie communication problems) and NHS system problems as areas where changes could be made to encourage responsible use of services.

CHART G: PROBLEMS PATIENTS MIGHT HAVE IN MEETING THEIR RESPONSIBILITIES TO THE NHS.

- lack of inform/understanding/poor communication
- problems with NHS systems
- public/patient perceptions need changing
- problems with society

The first and largest category was primarily about the fact that patients had little understanding of the way NHS services worked and how resources limited them. It also included comments about the difficulties people might have in understanding their conditions and treatment which may prevent them from following the advice given to them. This sympathetic comment from a community and mental health trust illustrates some of the difficulties patients and staff faced.

> *This (meeting responsibilities) is an extremely complex problem which deserves a thesis! A succession of governments have failed to address the class divide, poverty, elitism and human frailty. I sincerely hope that one day we can sufficiently empower people so they feel valued and, in turn, value themselves and their environment. Education in the broadest sense is a key to problem solving and facing responsibilities.* (community and mental health trust)

The second category which related to problems with NHS systems included difficulties of accessing out-of-hours services and getting through telephone exchanges to cancel appointments; the mistakes which are sometimes made in recording attendance so that what was a cancellation turns into a *'did not attend'*; lack of resources to deliver services adequately; staff attitudes when under pressure and the fact that they often need training to help them evaluate their own standards of dealing with patients.

Comments included in the third category about the need to change patient/public perceptions covered (again) the fact that expectations had risen too high for services to meet; anxieties about using services and fear of illness.

> *People are afraid and vulnerable when attending clinics or when being admitted for treatment, therefore they feel they cannot challenge the system or do not know what questions to ask. Some people feel if they complain it will affect the care they are given...* (acute and community trust)

Comments about problems in society included poverty, public transport difficulties to reach services, an increasing level of aggression; lack of respect for people and property... all of these were cited by at least one respondent as a reason why people might be prevented from meeting their responsibilities to the NHS. Of course, it is not within the power of the NHS to do anything about these kinds of problems. Fortunately, the bulk of problems identified fell into the first two categories about which something can be done within the NHS.

The written evidence was weighted towards NHS managers and providers although CHCs and voluntary organisations were well represented. What is reassuring is that all respondents made a similar range of comments although the emphasis was often different. Altogether, this part of the research offered a useful critique of the existing charter and positive contributions about the content and form of a new charter.