

Appendix II

INTERVIEWS WITH VOLUNTARY ORGANISATIONS, PATIENTS' ORGANISATIONS AND REPRESENTATIVES OF VULNERABLE GROUPS

Face to face interviews were conducted with the following organisations.

- College of Health (Marianne Rigge)
- Carers National Association (Francine Bates)
- Association of Community Health Councils for England and Wales (Toby Harris and ACHCEW Information Team)
- Age Concern England (Jane Whelan)
- National Consumer Council (Barbara Meredith, Mike Bartram and Anita Abell)
- Patients Association (Cathy Gritzner)
- MIND (Judi Clements)
- Long Term Medical Conditions Alliance (Judy Wilson and meeting of LMCA member organisations)

Although many of the themes in the literature review are echoed again here, it is important to locate ideas and opinions in their context. Very many of the issues summarised here were expressed in similar terms by different organisations and individuals. It would be tedious to attribute comments to sources in each case, but where there were differences of opinion on a particular issue, or where the source of a view is particularly relevant, it is recorded here.

Is a Patient's Charter important?

There were varied opinions. It is an important issue, but not one which patients and service users would nominate as one of their most important concerns. The Patient's Charter was definitely still seen by some as John Major's big idea, and closely associated with the last government. As such, it was still viewed with some suspicion. However, several organisations took a very active interest in some of the rights and standards covered by the Patient's Charter, even if they did not locate their concerns within a Patient's Charter framework.

The College of Health made the point that while charters and helplines are often characterised as middle-class tools, that was not their experience, and many 'ordinary people' used their helplines and were concerned about rights, including information and access to treatment. Other organisations, such as Age Concern England, felt that less than ¼ of one per cent of those that they are in touch with have used the Patient's Charter effectively, and they were among the more articulate people. Some people also made the point that there is such widespread confusion about how the NHS is run, that the chance of being able to invoke rights in a system that is not comprehensible are remote.

There was widespread cynicism that a review of the Patient's Charter would have much effect, as many of the limitations that had characterised it thus far were seen as likely to continue, despite the change of government. Even so, most voluntary organisations also wanted to seize opportunities for influencing change.

ACHCEW made the point that at least the Patient's Charter had put rights and standards on the agenda. It has also raised expectations, not because people know what their specific rights are, but because a Patient's Charter changes the culture, and patients assume that they must have some sort of right to a decent service.

No teeth?

Most of the organisations shared the view that the Patient's Charter had 'no teeth'. Even where rights and standards were seen as appropriate (and there was not unanimity on that), the chances of using the Patient's Charter to enforce them was seen as remote. ACHCEW was one organisation that had developed clear ideas on enforcement with their proposals for an independent Health Rights Commission.

Several organisations felt that it would be helpful to be more explicit about what could be expected from the Patient's Charter. There was uncertainty about what sanctions might be imposed on services that failed to meet the Patient's Charter. How would sanctions work in hospitals, for example?

Advocacy

The enforcement and implementation of rights was linked by several voluntary organisations to the need for better access to independent advocacy. MIND made this point particularly strongly, noting that a properly funded service needed adequate resources.

Too much stress on acute services

Many saw the Patient's Charter as too oriented towards acute services. Many of the voluntary organisations work for people with long-term conditions and people who are regular users of primary care and community services (both health and social care) such as older people and people with mental health problems. They wanted to make the Patient's Charter more relevant to their needs.

Second opinions

The limited right to a second opinion was seen as in need of revision (i.e. limited by the need for the GP's agreement, by lack of knowledge on who might be an appropriate specialist and also by possible difficulties in being referred to a provider with whom the purchaser did not have a contract). Many voluntary organisations would welcome an unconditional right to a second opinion, and that includes access to a second opinion in primary care, without having to change GPs. MIND's enthusiasm for second opinions was qualified by research drawing on the reports of the Mental Health Act Commission which showed that second opinions nearly always agreed with first opinions. Therefore, they are equally concerned about patients' rights to have alternatives explained and choices given to patients on their treatment options.

GP services

On the whole, the desire to extend the Patient's Charter to primary care was general rather than specific. But one specific point cropped up frequently that too many patients, especially older people, had difficulty registering or retaining their right to be registered with a GP. The GP's right to remove patients from their lists without giving reasons was seen as unfair and outdated.

Quality issues

Patients' organisations were concerned that the Patient's Charter had mainly been preoccupied with quantity and throughput. The quality issues that were of deep concern included:

- patients feel too rushed and out of control - possibly this leads to litigation to resolve difficulties
- attitudes and staff rudeness
- staffing levels
- workers of the same sex and single sex wards (especially in mental health)
- better attention to feeding patients in hospital
- access to bathing and showering at home for older people
- quality of information to patients (see also section on Information)

That is not to say that patients' organisations necessarily viewed a charter as the best vehicle for improving these quality issues. Rather, the discussions indicated that these were the kinds of issues that they wanted attention focused on, rather than diverting staff energy to things that mattered less to them.

Carers

There was a variety of views on how best to safeguard and promote carers' rights in the context of a charter. No-one doubted that carers should have rights, but the perennial issue of how to balance a patient's need for confidentiality with a carer's

need for information remained a problem, as did the question of how to resolve conflicts of interest between patients and carers. Potential conflicts are particularly sensitive in the field of mental health. There was also uncertainty on whether there should be a carer's charter, or whether carers' rights should be part of the Patient's Charter, or whether that would confuse the issues. However, the Carers National Association made out a strong and detailed argument for family and carer issues to be integrated more fully into the Patient's Charter. In particular, Carers National Association advocates better information for carers, including information about statutory rights, and more rights across the health/social care divide. Interestingly, concerns about waiting times at hospital that were not high on everyone's agenda, from a patient's perspective, *were* important to carers who had to return to their caring duties.

Information

Information was the key issue to the groups that were interviewed. It was seen as the cornerstone of being able to exercise rights meaningfully. The existing Patient's Charter is seen as very unambitious in this respect. The following information needs were mentioned:

- information on medical condition, including diagnosis (mental health patients in particular may have years of treatment without a diagnosis)
- information on social and medical implications of diagnosis
- information about health services and other related services
- information about self-help groups and organisations
- information on clinicians (qualifications, training, success rates, outcomes, number of procedures performed)
- information on rights to services (especially non-medical alternatives for mental health patients)
- comparable information that can be compared over time
- good infrastructure to help people get access to information
- information on the NHS and how it works - greater accountability
- information on how the NHS gets and spends its money
- anonymised reports of audits
- clinical guidelines and clinical indicators
- information on who will be operating/carrying out a procedure on patient

Consent

The right to informed consent was seen as a right in need of being strengthened. The need for high quality information also underlies this, but relatively simple rights, eg right to a copy of the consent form, would be welcomed.

Measuring performance

Echoing the literature, there was grave doubt about the efficacy of measuring and monitoring Patient's Charter data so far. In particular, there was a strong consensus on

the need to take a qualitative as well as a quantitative view. In summary, this could be stated as a need to listen to patients. Ways to do this were mentioned, including;

- focus groups
- market research techniques
- on-going panels of regular users
- opportunistic surveys and discussions in waiting areas
- publish local qualitative studies
- inspections by outside independent body
- expanded CHC role
- transparency about how the views of users are sought

In addition, it was stated that more attention should be paid to unmet need, using information from lay people. The role of GPs in giving feedback on services should also be recognised and more fully used.

Interface with non-NHS services

Voluntary organisations are very concerned that rights in the NHS are fairly meaningless unless they are backed by other rights. The National Consumer Council, (NCC) for example, pointed to the lack of a Charter for residential care homes. MIND pointed to the need for rights to a fair share of employment.

Complaints

Charter rights concerning complaints were seen as inadequate. In particular, the new complaints system was seen to be a failure in primary care, where the need for the patient to take the complaint up with the practitioner in order to seek local resolution was seen as off-putting to most dissatisfied patients.

The Patient's Charter was seen as conferring irrelevant rights, for example, the right to have a complaint investigated and eventually signed by the chief executive was irrelevant if nothing changed as a result. In any case, since most people unhappy with poor services do not complain, a concentration on formal complaints generated relatively little excitement in the groups that were interviewed.

What kind of charter?

This is one of the areas on which a great deal more work needs to be done, for while there was no shortage of ideas on what is important to patients, there was a range of views on whether a Patient's Charter would most usefully be a long or a short document, based around national and/or local charters, whether or not disease-specific charters would be most useful, whether Patient's Charter should concentrate on rights to which there was a legal redress, or whether it should essentially be a standard-setting document.

Responsibilities

Most people agreed that patients had responsibilities as well as rights, but the interviews did not yield much on how to make these responsibilities anything other than tokenistic. There was also some concern that the impetus for stressing responsibilities came from managers and clinicians wanting to curb demands from patients. Some organisations had already conducted work on some aspects of patients' responsibilities, such as ACHCEW's work on patients who do not attend hospital. Patients often try to behave responsibly, but find that NHS systems make it difficult for them to do so. Others, especially patients with long-term conditions, felt that they were always trying to take responsibility, and what was needed was a recognition of their rights to be involved in discussions about self-management.

However, patients' responsibilities can be construed much more widely, and possible responsibilities mentioned included:

- behaving courteously and understanding staff pressures
- taking responsibility for self-care when appropriate and when given adequate information
- taking part in qualitative feedback - seeing oneself as in partnership with professionals
- healthy lifestyles, with assistance and support and possibly with incentives to do so
- to consider information that is given (but mental health patients especially would be wary of anything that suggested a responsibility on the patient to accept the prescribed treatment)
- to provide information about oneself and one's condition

It was also mentioned that patients need to be clearer on what the NHS can and cannot do, and further public debate on NHS functions, and on rationing, are needed. The Patients' Association also suggested that the NHS had to be clear about when they could not help, and hand over to the voluntary sector who could sometimes deliver care far better than the NHS.

A further concern was that sanctions on patients who do not act responsibly should not exclude them from essential care. It was also felt that a right to treatment should not be conditional on lifestyle, and that an educational approach, rather than the heavy hand of sanctions was the better way forward.

INTERVIEWS WITH REPRESENTATIVES OF VULNERABLE GROUPS

We conducted interviews with organisations or groups for whom there was reason to suppose that access to the NHS or quality within the NHS posed particular difficulties.

We identified the following areas where interviews could be particularly enlightening:

- physical disability
- sensory disabilities (blind and deaf)
- ethnic minorities
- refugees
- HIV/AIDS
- homelessness

We interviewed a representative or representatives from each of the following groups:

- Greater London Association of Disabled people (GLAD)
- Royal National Institute for the Blind (RNIB)
- Royal National Institute for the Deaf (RNIB)
- Multi-ethnic women's project
- Refugee Council
- London Lighthouse Service Users Consultative Forum (HIV/AIDS)
- Crisis (homelessness)

The interviews were conducted by telephone except for the multi-ethnic women's project, that was a group meeting with a large group of health advocates. The material from these interviews is not intended to stand alone. The interviews allowed us to gain an in-depth understanding of issues that had also been explored in other parts of the research, but in these final interviews we were able to take a very clear focus on problems of discrimination, access to services or exclusion from services for people who may have had historic difficulties in getting the best from mainstream health services.

Main concerns from the interviews

Usefulness of the Patient's Charter

While other parts of the research gave an impression of a very wide range of opinion on the Patient's Charter, these groups as a whole took a dimmer view of it.

Some groups did have positive comments to make, at least about the principles behind the Patient's Charter. The RNIB felt the Patient's Charter had been important in so far as it laid down rights and expectations. They felt that as a first step in setting out standards, it empowered blind and visually impaired people across the board, not just in relation to sight issues. The RNID and the Refugee Council also welcomed the Patient's Charter as a limited step in the right direction.

On the other hand, the multi-ethnic women's project variously described the Patient's Charter as 'a waste of paper', 'window dressing', and as 'worthless'. It was also seen as a hypocritical 'cover-up' for lack of resources and cuts to spending on health. It was suggested that what was achieved in local health services was a result of advocacy, and not through the Patient's Charter. Nor was the Patient's Charter seen by

Crisis as having made much of a contribution for homeless people in the NHS, since it did not address key issues of access for homeless people.

The Refugee Association and the London Lighthouse Service Users Consultative Forum pointed out, as did others, that the Patient's Charter might be more useful if more people knew it existed and what was in it.

Several groups raised concerns about a lack of enforcement or implementation of some of the rights and standards in the Patient's Charter and several groups criticised the emphasis in the Patient's Charter to date, which largely excluded primary care services and professions allied to medicine such as physiotherapy, and the specialist community and rehabilitation services used by some of the groups.

Quality issues in the NHS

These very diverse groups, not surprisingly, prioritised a wide range of quality issues. A common theme, however, was that all patients, needed to be treated as individuals, and should not be stereotyped in the way that many of them had actually experienced within their groups. Awareness among staff of the issues and difficulties faced by particular sections of the community was universally acknowledged as important, though awareness training was never seen as a substitute for tackling prejudice.

Another theme that was echoed by several groups was the need for independent advocacy, as a prerequisite to achieving access to quality in the NHS for those groups that were disadvantaged or suffered discrimination or prejudice. The multi-ethnic women's project health advocates said that there could be no quality without equality. For groups where prejudice and discrimination still blighted their experience of the NHS, access to services was seen as the most fundamental aspect of quality. As well as advocacy, interpreting (for languages other than English, including signing) was seen as a cornerstone of access. Information in relevant media, such as large print for those with a visual impairment and text telephones for those with hearing difficulties was seen as essential if the principles of a charter were to apply to all.

Groups had different priorities for inclusion in a new charter, though access and communication were most often mentioned as key areas.

Information

Many groups expressed concern that information should be genuine information about what is really available. For example, the view was expressed that it is not useful to homeless people to say that everyone has a right to register with a GP, as in practice, many cannot do so.

The multi-ethnic women's project had a full list of the kinds of information that is required, including:

- letters from the hospital in community languages and in plain English on interpretation and advocacy

- information about GPs
- information on out-of-hours services
- information about rights
- information about what to do after discharge from hospital, and about after-care (all translated as appropriate)
- information on specific illnesses and conditions (oral and written information) and especially when bad news is given
- information on how to complain
- politely worded information on how to cancel appointments etc.

The London Lighthouse Service Users Consultative Forum also added that they required information on developments in medical treatments, long-term outcomes and other matters specifically related to their medical conditions since they feared that long-term budget decisions are being taken on information from short-term research. Each of the disability groups also stressed the need for information in appropriate formats.

National or local charters

Perhaps because these groups had suffered from a lack of equity within the NHS, they were all roundly in favour of national rather than local charters, though some saw a role for work at a local level to make standards real in relation to local need. A powerful view was that the real question is how a charter is used. Crisis suggested that each locality could be asked to identify their three most vulnerable groups and to report on how they had applied the charter to those groups.

Rights and responsibilities

All groups recognised the importance of patients having both rights and responsibilities and welcomed the idea of increased partnership with NHS staff. It was suggested that NHS staff need to have positive attitudes to patients to encourage them to take responsibility.

In order to enable people to be responsible partners, several facilitative approaches were identified, including:

- advocacy (not just to enable people to use services)
- educating patients on their responsibilities
- effective NHS systems to enable people to behave responsibly
- greater involvement of service users
- Better information to support self-management by patients

However, it was also noted that a uniform view of how patients could behave responsibly as partners needed to take account of the realities of life for different groups of patients. For example, it is easy to say that homeless people should turn up for appointments on time, but how easy is it to be responsible for yourself when your life is out of control? There is a need to understand why people behave 'irresponsibly'.

Similarly, for homeless people, even some very basic aspects of responsible partnerships may need to be understood in a particular context. For example, some refugees, particularly those who have suffered torture, may find it difficult to discuss their condition with staff and may be seen as unco-operative, when that is not their intention.

The need for consultation

While a review of the Patient's Charter was welcomed, the need for future standards to be the subject of real consultation was seen as central to the chances of a new charter being relevant and effective.