MAIN THEMES FROM THE LITERATURE REVIEW

Most of the literature on the Patient's Charter is from professional journals, the majority of which are not refereed in an academic sense. The literature tends to be journalistic and there has been an apparent dearth of serious academic interest in the Patient's Charter. Whether this reflects the current nature of academic interests, funding sources or indeed, the relative newness of the Patient's Charter, is impossible to gauge.

<u>Variety of views</u>

The literature overall strikingly demonstrates two characteristics. Firstly, a very wide variety of views on the value, or otherwise, of the Patient's Charter; and secondly, a degree of ambivalence on both the fundamental idea of a Patient's Charter and the particular rights and standards that are in it and the ways in which they are monitored.

Some of this ambivalence is noted in an editorial by R. K. Ryland in the *Journal of Advanced Nursing* (Ryland, 1996):

> *It would appear that many people working in the NHS resent the way in which the government departments have imposed the new rights and standards across the UK. This is, perhaps, a curious view. Firstly, some working in the NHS have complained in the past that the government has been too concerned with volume and not enough with quality. So as soon as the government becomes concerned with quality there is an argument about the way in which it is done.*

Ryland goes on to note that opposition parties (in 1996) argued that the NHS is breaking up, and so should be reassured that 90% of patients are assessed in A&E within five minutes. Ryland describes this as:

> *A curious mind set: damned if you do and damned if you don't*

In similar vein, on waiting lists, Ryland argues:

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

However, other commentators would probably consider Ryland's view naive or disingenuous, perhaps because much of the published commentators are based on the

views of NHS staff rather than on the views of users. For example, in a Viewpoint Readers' Panel in *the Nursing Standard*. (Viewpoint Readers' Panel, 1995), there is a largely negative or hostile view reported tov ds the Patient's Charter. Concerns include:

- manipulation of statistics
- volume-related throughput targets are presented as qualitative standards
- Patient's Charter inadequate on patients' responsibilities
- wrong measures used to indicate quality
- inadequate resources

However, some positive views are also expressed, including:

- a real step towards a better service for patients
- useful to set clear standards

Perhaps the most telling comment is one headed *Good as a patient, bad as a nurse*. As a nurse, the Patient's Charter is seen as "a bludgeon to beat staff when the real problem is resourcing". As a patient, the Patient's Charter is "a useful means of exerting pressure which gets a response".

Sometimes, the hostility to the very idea of a Patient's Charter is expressed in strong terms. Writing in *Mental Health Nursing*, Cris Allen (Allen 1995) says that the latest Patient's Charter standards for mental health guarantee nothing except more pressure on services and more disappointment and frustration for users. Allen also feels that achieving the standards would require "a miracle", and fears that while raising expectations may be good, unrealistic charter standards "merely raise hope". But it is unclear whether Allen's doubts are pragmatic or principled, for we also see that the author states that:

> *Healing and therapeutic relationships cannot be charterised.*

Cynicism

Cynicism is a constant theme in the literature. We can explore this further under several sub-headings:

- Public attitudes
- Political taint
- Concerns about veracity of statistics
- Lack of independent monitoring

Public attitudes

We have interesting information from a study carried out by NOP Consumer Market Research (NOP 1994) prepared for the Central Office of Information (COI) and the Department of Health. Just prior to releasing the revised Patient's Charter in 1991, the

COI on behalf of the Department of Health commissioned a research study to ensure that the views of the public were taken into account in finalising the Patient's Charter. The study sought to explore a number of issues, including current awareness of the Patient's Charter, the ability to understand the purpose and scope of the Patient's Charter leaflet, reactions to design and format, comprehensibility, what people wished to see included in the Patient's Charter and opinions of the new standards that ministers had already decided should be included in the Patient's Charter.

The following points emerged about attitudes to the Patient's Charter:

- There was a low awareness of and interest in the Charter initiative, including the Patient's Charter
- the Patient's Charter was seen as informing the patient what they could reasonably expect in the way of NHS services - entitlement to services was seen as the main issue
- Dissatisfaction with politics and politicians had a negative effect on the Charter, especially when it was linked with central government.

We also have interesting information from a survey of general hospital out-patient views of their rights and ability to exercise them (Tailor and Mayberry 1995). This shows that the codification of patients' rights in a charter has begun to have significant effects on the day-to-day running of hospitals in Britain, and patients can point to failures in the standard of service, However, this depends on awareness in the community and on conviction that these rights can be exercised successfully.

The Tailor and Mayberry study investigated the views of patients on the contents of the Charter and whether they believed they could make use of it. Several interesting points emerged. At the end of the range 98% knew of the right to be registered with a GP, and a 95% were aware of the right to receive emergency care at any time. But numbers plummeted down to just 42% awareness of the right to receive detailed information on local health services and 44% who knew about the right to have any complaint about the NHS investigated. Also, there was in all instances a considerable gap between the percentage of patients who were aware of a particular right and the percentage who believed they exercise that right. Thus, for example, of the 80% of patients who knew of their right to be referred to a consultant acceptable to them, only 64% thought they could exercise this right.

Political taint

The point about the Charter being seen as tainted with a somewhat Machiavellian political agenda is made by several sources. NOP reports:

> *The more publication was seen as emanating from central government the more its purpose was believed to be political and the less credible its message.* (NOP, 1994)

Phil McSweeney (McSweeney 1994) sees the NHS reforms as a two pronged attack, firstly seeking to raise quality of care and cost efficiency through internal

competition, and secondly through empowering consumers by raising their expectations. The possibility of nurses being 'caught in the crossfire' between trying to manage patients' expectations and yet not knowing about what has been purchased is raised. McSweeney recognises that there appear to be gains, such as improvements in waiting times for admission and in out-patients, the growth of immediate assessment in A&E and standards for readmission following cancellation of admission. However, it is not clear exactly what such improvements are due to. McSweeney lists a range of ways in which performance is reviewed, quite apart from the Patient's Charter. The author concludes that poor reception of the Patient's Charter is due to:

> *Being unable to divorce it from its political context.... it is a major top-down imposed management project.....the Patient's Charter, though stopping short of taking away nurses' will to live, has robbed them of ownership of their quality initiatives.*

A similar point is also made by Phil Cohen (Cohen 1994) who states that nurses have had little input into charter policy, which has largely been imposed.

Concerns about the veracity of statistics

Some of the concerns about the reliability of Patient's Charter figures are expressed in the strongest possible terms. Friend (Friend 1995) claims that pressure to meet Patient's Charter standards means that some hospitals are fiddling the figures. By way of illustration:

> *In the worst account of charter cheating, patients were said to have been transferred from trolleys to chairs to comply with A&E waiting time limits.*

Friend also claims that hospitals only offer appointments when they know they can meet the relevant targets. However, she notes that the Department of Health denies that there is hard evidence of problems, and that the Audit Commission inspects the data collection system to ensure that information is accurate and chief executives personally have to sign off the data.

However, given pressures on staff, it would be surprising if some did not feel that fiddling the figures was in order, as Friend reports also that a Royal College of Nursing adviser has been contacted by nurses who have been threatened by disciplinary action if they do not meet Patient's Charter targets.

There is also some concern in the literature about whether measured improvements are real improvements. This is not just a comment on whether figures are to be believed, but also on whether the figures throw adequate light on complex problems. Or, as Hart puts it:

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

MacAlister (MacAlister 1994) also suggests that crude data may mislead. For example, improvements in the waiting times for some treatments may increase writing times for others. Carr Hill and Ng (Carr Hill and Ng 1992) also doubt the reliability of monitoring data. They conclude that the NHS Executive seems ignorant of how hospitals work and of the complexity of monitoring data. They also suggest that Performance Related Pay generates the potential for anomalies in reporting of data. Staff polls such as the one previously referred to (Viewpoint Readers Panel 1995) also tend to show a high level of disbelief of 'official' figures.

Lack of independent monitoring

Worries about the figures are not greatly eased by the relative lack of independent monitoring of the data that is collected. McIver and Martin (McIver and Martin 1996) point out that there is little research into whether rights are being upheld. They point out that the NHS Executive does not monitor or investigate compliance with the rights in the same way that it does some of the standards.

For some commentators, this is a fundamental issue. The Association of Community Health Councils for England and Wales argues for a strengthened rights-based Charter, backed by more effective enforcement:

> *In proposing new or stronger rights the question obviously arises as to how we think such rights should be enforced. We do not consider that patients should have to resort to law in order to obtain them. Instead we suggest that the monitoring and assurance of all charter rights demands a more effective machinery than that which is currently available to patients.* (ACHCEW 1996)

ACHCEW goes on to propose an independent Health Rights Commission for this purpose.

Status of the Patient's Charter

Enforceable rights?

Confusion about the exact nature and status of the Patient's Charter crops up several times in the literature. There is confusion about the extent to which (if any) Patient's Charter rights and standards can be enforced, and uncertainty as to whether the Patient's Charter is actually concerned with real rights, or is just a wish-list.

Hogg distinguishes between different kinds of Charters:

> *A Charter is a statement of fundamental principles, which may incorporate rights and standards. There is a distinction between charters produced for people and charters or declarations of rights produced by people themselves.* (Hogg 1994)

She states that rights in health care are 'largely symbolic', and few rights in health care meet the criteria normally used for rights, ie they are not inalienable or enforceable in law. Hogg sees the Patient's Charter as more of a consumer's charter than a citizen's charter to empower patients.

The issue of how far legal redress might be used is further explored by Wilder (Wilder 1995). Wilder notes that some Patient's Charter rights, (such as the right of access in certain circumstances to one's own medical records, or the right to have any proposed treatment, its risks and alternatives explained) are already statutory or common law rights. However, what about other Patient's Charter standards, such as maximum waiting times for admission of 18 months, or a maximum of 26 weeks wait for an out-patient appointment? Wilder poses the question of whether a failure to comply with the Patient's Charter would amount to a breach of statutory duty to provide an adequate health service. Cases in the 1980s where patients sued the Secretary of state and regional and area health authorities failed as the NHS Act 1977 gives clear discretion on how financial resources are used. However, through promises in the Patient's Charter, Wilder asks whether the Secretary of State for Health has not already determined how at least some of the available resources are to be spent. This poses the question of whether a health service body can be acting reasonably if the result of its decision is a failure to achieve a standard which the Secretary of State has said all patients are entitled to receive. These questions have not yet been answered by the courts.

Several commentators argue that as it stands, the Patient's Charter does not safeguard rights. Thain argued in 1992 that a Bill of Rights and not a Patient's Charter is urgently needed to protect elderly patients from the uncertainties of a market driven NHS. He states:

> *In creating a Patient's Charter the government is shirking responsibility for many of the problems patients are experiencing as a result of changes in the health service.* (Thain 1992)

A firmer basis in social rights is also strongly supported by Bynoe (Bynoe 1996). Bynoe is critical of many aspects of the Citizen's Charter, and its offshoots such as the Patient's Charter, but he also acknowledges that the Charters have strengths that merit further development, for example:

- improving the information given to those seeking or using services
- measuring differences between comparable services to reveal the inequities between them and help locate the causes
- the Charter Mark award scheme
- reforms to complaints and redress systems
- lay involvement in inspection and complaints adjudication

On behalf of The Institute of Public Policy Research , Bynoe goes on to propose a programme based on the following six principles:

- fair treatment - to guarantee fair treatment to those seeking or using public services
- entitlement - to meet the public's informed expectations of entitlement
- participation - to ensure that services are responsive to users and to encourage greater public involvement in planning services and holding them accountable
- openness - to render public services more open in their dealings with users and the public
- accountability - to improve public accountability by making audit and inspection more effective
- co-operation - to stress to citizens and users their respective responsibilities and the value of a co-operative approach.

Each of these principles is supported by a proposal for action.

The blurring of rights and standards in the current Patient's Charter has also been noted as a source of confusion. Carr Hill and Ng (Carr Hill and Ng 1992) looked in 1992 at local charters in 140 health authorities and 50 family health service authorities. They noted that in many local charters, 'rights' were being included under 'standards' and vice versa, sometimes sensibly. Sometimes, the reason for designation as a right was not so clear, for example where the 'right' to be seen within a certain time at an out-patient clinic is actually dependent on available resources at the time, and is therefore not a rights-based entitlement.

Carr Hill and Ng comment:

> *Pronouncing 'rights' and 'standards' without agreement on the desired outcomes and without, apparently, understanding the processes by which their attainment can be monitored flies in the face of the little we have all learned from the quality assurance movement over the last decade.*

Local and national charters

The confusion between local and national charter standards was also examined by Carr Hill and Ng. They found that only 30% of the charters they examined separated national and local standards. Moreover, few staff knew how the local Patient's Charter varied from the national charter, or even where it was posted in their unit.

However, local charters are also seen to have a number of positive attributes by McIver (McIver 1996). McIver notes that commissioners and providers are encouraged to develop local charters, and she asks whether these will duplicate the national Patient's Charter or if local charters can address different issues? Her conclusion is that local charters can build on the clear set of standards because they can address local concerns and be monitored locally. Local charters can also provide

the detail necessary to cover aspects that are important to specific groups of users, e.g. children, elderly people and minority groups, and to those using a particular service, e.g. mental health service users. McIver notes:

> *The key to producing local charters is to develop them with service users, so that standards relate to aspects of the service they consider important.*

<u>Quality or quantity?</u>

Much of the literature is concerned with the thorny issue of whether the Patient's Charter has had a positive, negative or neutral effect on the quality of health services. We have already noted Hart's concerns that quantitative information tends to be more sought and more highly valued than possibly more significant qualitative data (Hart 1996) . Benton observes that little advice was given on qualitative methods in the Technical Guidance for the Patient's Charter, issued in 1992 (Benton 1993). He also notes that most of the measures applied in the Patient's Charter are either process or output oriented, and not outcome oriented. Benton's concerns about quality also rest on the possible conflicts between individuals and purchasers. He states that the Patient's Charter is focused on the rights of individuals, whereas the purchasing authority ultimately focuses on local population needs. To achieve value for money, purchasers may place larger (and therefore fewer) contracts, which limit individual choices. He argues that commissioners need also to pay attention to quality.

An editorial in the *British Journal of Nursing* (MacAlister 1994) questions the value of NHS league tables. Since 1974, star ratings have been given for performance on various criteria drawn from the Patient's Charter, such as the percentage of patients seen within 30 minutes of their appointment time, the percentage of patients assessed within five minutes of their arrival in A&E, the numbers of patients who fail to be readmitted following cancellation on the day of an operation, the percentage of people treated as day cases for specified conditions and waiting times for admission for in-patient treatment for specified surgical conditions. However, the league tables have nothing to say about the quality of clinical care that is provided by hospitals. As MacAlister comments:

> *This being so, it is easy to envisage a situation where hospitals providing the highest standards in clinical care may be unfairly discriminated against by purchasers on the basis of their lesser position in the league tables. Surely, if there is any case at all for distinguishing between hospitals in this manner, it is important to ensure that the criteria used are related to worthwhile measures of quality.*

MacAlister and others also warn that it is important to interpret the performance ratings as data do not always speak for themselves. For example, patients may be assessed at A&E within five minutes, but may then wait several hours for treatment. Also, crude data may mislead, and improvements in waiting times for some treatments may simply increase waiting times for others.

Further comments on quality and waiting times are made by Lorentzon et. al. (Lorentzon 1996). Lorentzon and colleagues conducted a review of literature on patients' views about out-patient services, with special emphasis on the role of nurses. They discovered a central emphasis on easily measurable factors, such as waiting times in out-patient departments, and a comparative neglect of more qualitative aspects, which may be of greater importance to patients. They point out that from the patients' point of view, long waits in out-patients may not be the most important aspect of the out-patient experience. Also, generally waiting times were not measured in relation to the severity of the patient's clinical condition. Long waits may be more acceptable when patients attend for routine, non-acute conditions than they would be for seriously ill patients.

In general, Lorentzon notes that in addition to waiting times, patients were concerned about staff attitudes, physical comforts and transport to and from out-patients. In other words, the main focus was on

The doctor-patient encounter and on conditions which would make this easier.

Another doubt about the quality vs quantity debate is implicit in Cohen, in relation to two year waits for admission (Cohen 1994). Although the reduction in two year waits was reportedly being met on the whole, many CHCs observed that shorter waits were adversely affected, and cases were reported of priority being given to patients with less clinical need than others. This raises fundamental issues on the nature and quality of patient care, and on what drives the agenda for seeing and treating patients.

Friend bluntly asserts that the quality of care is being sacrificed to attain star ratings. She asks, somewhat rhetorically, whether the scramble to meet targets is pushing out good quality patient care in favour of *'have-a-nice-day culture'*. (Friend 1995)

Quality and what users want

As we have seen, an improvement in that which can be easily measured may not go far enough to meet the aspirations of users for improved service quality. LeTouze (LeTouze 1997) reports on a study by McIver (McIver 1992) in which the key issues for users are:

- information and communication
- treatment and care (including outcome)
- staff friendliness and competence
- the efficiency of procedures including admission and discharge
- ward environment and facilities

Information and communication are particularly important to users, as the Audit Commission confirms (Audit Commission 1993). This report identified poor communication as the primary source of dissatisfaction with health care, and found that common complaints included:

- not enough information
- information not clear
- information not what the patient wants
- information given too late
- information given in too much of a rush

However, there are indications (Bruster et. al. 1994 and LeTouze 1996) that in spite of the Patient's Charter stipulating certain (albeit limited) rights to information, e.g. on proposed treatments, risks and alternatives, such information is not always provided adequately. (see section on information, below)

There has also been some attention in the literature to quality issues in A&E (Britten and Shaw 1994). This study evaluates the Patient's Charter from the perspective of patients admitted via the A&E department. It uses qualitative data obtained about issues of concern to these patients to judge whether the standards set out in the Patient's Charter are appropriate to their priorities, and conversely, if there are issues of importance to these patients which the Patient's Charter ignores. On the whole, they conclude that the rights and standards in the Patient's Charter are generally appropriate to these patients' experience, but that definitions may be too narrow. Some important issues of quality not given appropriate attention in the Patient's Charter are as follows:

- pain relief - not always timely or adequate
- giving information - patients sometimes perceived requests for information as irrelevant or repetitive
- receiving information - poor information on waiting times and long periods of not knowing what was happening
- reception staff - concerns about receptionists' interpersonal skills
- examinations and investigations - sometimes painful and humiliating
- physical environment - including smoking and non smoking areas, car parking, phones, ventilation, smells, lack of pillows and the pharmacy being closed
- other people in casualty - numbers and conduct of others, and need for a visible security presence in A&E

Britten and Shaw state that:

> *The patient wants rather more than the recent British government documents suggest*

Hogg (Hogg 1994) also indicates that users' charters (as opposed to government charters) are concerned about a number of quality issues that are not central to the current Patient's Charter, including:

- the boundary between home and hospital and health and social care, where present charters concentrate on acute hospital care
- other services that affect their ability to cope with their illness, such as income, housing and child care
- access to services where using them may lead to discrimination and even a loss of civil rights
- the way the service is provided and whether their autonomy is respected
- defining in detail what is meant by the general expressions of goodwill in the charter.

User involvement

There are indications in the literature (Hogg 1994, McIver 1996) that user involvement and the development of partnerships are of central importance. Hogg states:

> The process by which they [charters] are developed and monitored is more important than the words that make up the charter. Involving users in planning and evaluating services requires commitment, expertise, patience and resources. There is a need for a national framework within which local charters can be developed and monitored. It is as much on the process as the actual standards that the national framework needs to focus.

Information

Concern about information have already been noted in this paper. This section re-visits the issue to look further at the nature of the information that is given and required, and not just at the quality of the information that is actually given in accordance with the requirements of the Patient's Charter. Rigge (Rigge 1997) asks a very fundamental question. She points out that the Patient's Charter sets out a right to be referred to a consultant acceptable to the patient, but how can any patient know if the consultant is acceptable, since:

> There is no acceptable way to get reliable up-to-date information about centres of excellence, or within their specialty, about consultants who specialise.

She notes that this is a problem even for GPs, who may have to make referrals to a specialist whom they have not explicitly selected, since they have no information on which to base their choice. Rigge notes that the NHS Code of Practice on Openness suggests that information about a consultant's training, qualifications and special interests should be made available on request. However, a telephone survey of every

acute trust in one NHS region revealed that half provided no information at all on their consultants either to GPs or patients.

Some of the difficulties of collecting and disseminating such information are related by Berliner, drawing on the American experience. Looking forward, Berliner briefly discusses the possible use of the Internet for consumer information about doctors and hospitals, but warns of the lack of regulation or quality control of Internet sites. (Berliner 1997)

Responsibilities

Rights and responsibilities are closely linked. Some of the literature views the Patient's Charter as having enhanced patients' rights without a corresponding growth in patient responsibilities. The Editor's note to Cohen (Cohen 1994) raises the issue of increased complaints as a problem.

> *The Patient's Charter, many health professionals would agree, has been more trouble than it is worth and does little to ensure consumers of health services get a better deal. Indeed, many feel it has done little more than raise clients' expectations and encourage them to complain. As one GP sees it, it is 'merely another excuse for the chattering classes to put pressure on nurses and doctors who are already stretched to the limit'.*

The above quotation is interesting as it sets a context for a debate about responsibilities that emphasised damping down patients' expectations and complaints. This is in contrast to Bynoe, whose concept of responsibility is rooted in citizenship, participation and co-operation, and which is seen as leading to improved services and a responsible use of services by informed citizens. (Bynoe 1996)

The Association of Community Health Councils for England and Wales deals with the issue briefly:

> *It is accepted that patients also have certain responsibilities, for example, to let health service staff know if an appointment cannot be kept, to inform the surgery of a change of address or to return equipment when it is no longer needed.* (ACHCEW 1996)

It seems that while there is considerable interest, particularly from certain staff groups, in developing responsibilities, not much has been published to suggest how they could be developed meaningfully. Some of the articles on patients' needs and views (Rigge 1997, Hogg 1994) address the issue of responsibilities by implication, but there is not much direct tackling of this challenge.