

**CONSULTATION DOCUMENT:  
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**THE PATIENTS' AGENDA**

**What the Patient's Charter leaves out - the rights you don't yet have in the NHS**

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## Introduction

The Patient's Agenda sets out a series of rights not included in the NHS Patient's Charter. Drawn up in consultation with Community Health Councils and patients' organisations, it highlights those areas where patients find their present rights are poor or non-existent and where their reasonable expectations are not met.

Since the Government launched the Patient's Charter in 1991 it has raised certain standards in the NHS, though sometimes at the expense of others. Most notably it has cut waiting times. Yet it could do far more to address important issues at the heart of the health service - equality of access to health care, the scope for patient participation on the basis of informed choice and the quality of care and treatment. These are the central concerns of the Patients' Agenda.

Many of the standards listed in the Government's Patient's Charter are described not as rights but as expectations. An expectation, we are told, is a standard of service which the NHS is aiming to achieve, and which, in exceptional circumstances, may not be met. Faced with this statement it is difficult for individual patients to know how to respond when one of these expectations is not satisfied.

The Patients' Agenda is proposing instead, not a set of expectations but a set of rights.

In this booklet we have not restated every Charter expectation as a proposed right, but we do consider that many of them should become rights if they are to be genuinely useful to patients.

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. This is proposed in the final section on Redress.

A number of the rights set out here call for new resources. In some cases an initial investment could lead to long term savings, but not in all. Improvements are rarely cost free. But more resources are vital if the health service is to remain true to the original and visionary promise that "everybody in the country - irrespective of means, age, sex or occupation - should have equal opportunity to benefit from the best and most up-to-date medical and allied services available".<sup>(1)</sup> It is essential to recognise

and resource both the continuing advance of effective medical care and the legitimate rise in patients' expectations of service standards, cultural sensitivity and full involvement in decisions which may affect their future lives.

We hope that the proposals outlined here will help to promote fresh debate about the kind of health service patients want and so set a new agenda for improving patient care throughout the NHS.

1. White Paper, 1944. A National Health Service Cmd 6502.

## **1. Access to Care and Treatment**

The Patient's Charter promises to uphold the fundamental values of the NHS as a comprehensive service available to all on the basis of clinical need. Yet thinly stretched resources mean patients' needs may not be adequately met. In some hospitals, shortages of beds and staff threaten to compromise care and even put lives at risk. While in the community, services for older people including chiropody, help with incontinence, physiotherapy and occupational therapy are failing to keep pace with demand. Young children with speech and language problems may face long waits for assessment and help, despite the importance of early intervention. Patients in chronic pain may wait many months for a first appointment with a pain clinic. Some cash strapped health authorities have refused to fund key fertility treatments while others set age limits that deny this treatment to women well within childbearing age. If patients are not to slip through the NHS net, health care must be backed by adequate resources to meet their needs. In the face of scarcity, the following rights aim to ensure that no patient is denied appropriate care.

### ***1.1. A right to appropriate care and treatment without discrimination on grounds of age, lifestyle, gender, ethnicity, class, religion, disability, sexuality or financial circumstances.***

The Patient's Charter sets out the right "to receive health care on the basis of your clinical need, not on your ability to pay, your lifestyle or any other factor" - a clear undertaking that health care should not discriminate. Yet there is evidence that some groups of patients receive poorer care. It has been found for instance, that women are less likely than men, and older people less likely than younger people to be offered cardiac surgery for the same condition.<sup>(1,2)</sup> The NHS breast screening programme does not routinely invite women of 65 or over to take part, despite the fact that the risk of breast cancer increases with age. It is estimated that routine breast scans for older women could save 2,000 lives a year.<sup>(3)</sup> Health services may also prove easier to use for some groups than for others. Communication problems and cultural differences can create barriers to good quality care for people from ethnic minorities. While some deprived areas have fewer GPs in relation to their needs than more affluent neighbourhoods.<sup>(4)</sup> In view of such inequalities, patients need an explicit commitment to outlaw health discrimination in any form.

### ***1.2. A right to easily accessible NHS dentistry. If you cannot find an NHS dentist your Health Authority should be obliged to provide one.***

In some areas it has become difficult or even impossible for patients to register for NHS dentistry. Some people travel long distances to be treated on the NHS while others forgo treatment altogether. Those with poor dental health are less likely than others to be accepted as NHS patients.<sup>(5)</sup> The Patient's Charter says that if you are not registered with an NHS dentist your health authority will help you to find one. But patients have no automatic right to be registered with a dentist as they have to be registered with a GP.

***1.3. A right to remain in hospital until you are well enough to leave and adequate arrangements to ensure your continuing care are in place.***

Under the Patient's Charter "Before you are discharged from hospital, you can expect a decision to be made about how to meet any needs you may continue to have." The Charter adds that the hospital will agree arrangements with other agencies and involve patients in making these decisions. But Community Health Councils around the country report problems in discharge arrangements exacerbated by pressures on acute beds and moves to reduce the number of days spent in hospital. Once home, patients may not receive the support they need. One region-wide study, conducted by CHCs found more than four out of ten elderly patients said no member of staff had discussed with them the sort of help they might need after leaving.<sup>(6)</sup> It has been shown that with small amounts of extra support at home patients are less likely to return to hospital as emergencies.<sup>(7)</sup>

***1.4. A right to an explanation from a GP who removes you from the list or who refuses to take you on as a new patient, and to an appeal if not satisfied.***

At present doctors who refuse to accept patients, or remove them from their lists have no obligation to give their reasons. In England and Wales, more than 80,000 patients were removed from GP lists in one year. Many patients are struck off after making a complaint. Some, including the elderly and people with mental health problems, experience particular difficulty in finding a new GP.<sup>(8)</sup> The General Medical Council states "Since the NHS began a few general practitioners have used their right to remove patients from their lists for reasons which have included, for example, old age, severe disability or drug addiction, on the grounds that such patients are too costly in terms of time and effort needed to provide care."<sup>(9)</sup> An obligation to give a clear explanation for removing or refusing to accept a patient would guard against discrimination on any grounds and make it easier to monitor the causes of removals and refusals.

***1.5. A right, for patients and their carers being assessed for community care services, to an assessment which reflects their needs rather than the resources available.***

Community care means providing some of the most vulnerable people in our society - elderly people and people with physical disability, long term mental distress or learning difficulties - with support to remain in their own homes rather than long stay institutions. With the introduction of this policy local authorities have become responsible for care once offered by the NHS. In a 1995 court case<sup>(10)</sup> it was ruled that in assessing a person's need for community care the authority could take account of available resources. As a result, hard up councils can draw up assessments which merely reflect the services they can afford. Using this approach people can be provided with inadequate support, while their real needs and the authority's failure to meet them, remain invisible. Yet care in the community should be funded in accordance with people's needs. It should not be viewed as a cheap option, but as a

way of extending choice and independence and enhancing the quality of life. [NB To be updated after appeal on May 8th]

***1.6. A right, for people with mental health difficulties living in the community and their carers, to 24 hour emergency crisis care and support.***

People in extreme distress and their carers may have great difficulty in obtaining appropriate help out of hours. At present emergency care is usually provided through acute psychiatric units in district hospitals. Many patients are unwilling to contact the service in a crisis, fearing an institutional atmosphere or a readiness to resort to drugs and ECT treatment. Those who do seek help at a hospital may not gain admission.<sup>(11)</sup> Lack of emergency crisis care puts patients and carers at risk. A community based crisis service should offer a help line, counselling, home treatment or a place of refuge and provide a link with longer term care and support as needed. It would reduce hospital admissions and enable more patients to remain in the community.<sup>(12)</sup>

1. M Petticrew, M McKee, J Jones, May 1993. British Medical Journal, vol 306 p1164-6. Coronary artery surgery: are women discriminated against?
2. CJ Pycock, A King, AJ Marshall, January/February 1995. Journal of the Royal College of Physicians of London, vol. 29, no. 1. Management of heart disease in the elderly in the Plymouth Health District.
3. Age Concern, January 1996. Not At My Age, Why the present breast screening system is failing women aged 65 and over.
4. Michaela Benzeval and Ken Judge, March 1996. Journal of Public Health Medicine vol. 18 part 1. Access to health care in England; continuing inequalities in the distribution of GPs.
5. ACHCEW, November 1992. Evidence to the House of Commons Health Committee inquiry into NHS Dental Services.
6. South Thames (West) Association of Community Health Councils, 1995. Relative Comfort, A survey of the elderly discharged from hospital.
7. J.Townsend, S. Dyer, J. Cooper, T. Meade, M.Piper, A. Frank, 1992. Health Trends vol. 24 no. 4. Emergency hospital admissions and readmissions of patients aged over 75 years and the effects of a community-based discharge scheme.
8. ACHCEW Annual Report, 1993/4. Survey of Community Health Councils on the patient/GP relationship.
9. General Medical Council, May 1992. Contractual arrangements in health care: Professional responsibilities in relation to the clinical needs of patients.
10. Times, 21 June 1995. R v Gloucestershire County Council ex parte Mahfood.
11. College of Health, Deborah Rutter, February 1996. Getting In: Staying Out, Users' and Carers' Views of Mental Health Services in East Kent
12. MIND Breakthrough, Making Community Care Work, 1995. Mind's Model of a 24 Hour Crisis Service.

## **2. Health Care Regardless of the Ability to Pay**

At its inception in 1948 the NHS promised health care free at the point of delivery. The Patient's Charter restates the principle that services should be provided "regardless of the ability to pay". Yet NHS patients face mounting charges for some elements of their health care. In real terms, the maximum cost for a course of dental treatment is three times higher [to be updated as necessary]; prescription charges more than nine times higher than in 1979. Some people are exempt from paying. But many who are not, are discouraged by cost from visiting their dentist or obtaining prescribed medicines.<sup>(1,2,3)</sup> Where fees have been introduced these should never be so high that they deter people from necessary treatment. The following rights aim to ensure that patients can choose health without hardship.

### ***2.1. A right to free eye tests and dental check ups.***

People should not have to pay for services which are vital in identifying and preventing disease. Yet general entitlement to free dental check ups and sight tests ended in 1989. Eye tests can detect glaucoma, cataract and diabetes related problems - all conditions which need to be treated as early as possible to prevent partial sight or blindness. A Bristol study concluded that the number of patients being identified as requiring treatment or follow up for potentially blinding glaucoma was nearly a fifth less than expected following the introduction of test charges.<sup>(4)</sup> Although some people are eligible for free examinations about 60 per cent are not. The problem is particularly serious for the over-65s who are more vulnerable to eye disease, yet have no general right to a free eye test. Regular dental check ups encourage the early detection and treatment of tooth decay, gum disease, oral cancer and other conditions.

### ***2.2. A right to receive any item which is a necessary part of your health care free of charge or on prescription.***

NHS services must normally, by law, be free of charge to NHS patients. Yet gaps in the service can force patients to finance their own care or do without. People cared for in residential homes have been obliged to buy their own incontinence pads because some health authorities refuse to supply them. Seriously ill patients cared for at home have had to pay for large specialised wound dressings essential to their comfort, but not available on prescription. Also unavailable through a GP are needles for insulin pen injectors, the treatment of choice for many diabetics. The National Asthma Campaign is regularly contacted by patients whose consultants have recommended that they use a home nebuliser but who are not provided with one. This equipment, which allows severe asthmatics to ward off or recover from an attack by breathing in a mist of high dose medication, costs more than £100.

### ***2.3. A right to receive continuing health care free of charge from the NHS if you need it. Criteria to determine whether you have this need should be agreed nationally.***

Old people, people with mental illness, or physical and learning difficulties who would once have received free long term care from the NHS may now face means tests for care provided by local authorities in a community setting. As a result, many can expect to spend much of their life savings on care in old age. In theory, those who need continuing NHS care for health reasons are entitled to receive it. But criteria for deciding who is and is not eligible are drawn up by each individual health authority. While a person in one area may be granted free long term care, someone with identical needs living elsewhere may be denied it. Patients refused care also need a clear means of appeal to an genuinely independent body whose decision is binding.

1. Kidderminster and District Community Health Council, April 1995. *Do Prescription Charges Deter People From Having Treatment? A study of Prescription Uptake in the Kidderminster Area.*
2. *Journal of the Institute of Fiscal Studies*, February 1990. *Modelling The Effect of Prescription Charge Rises.*
3. *Which? Way to Health*, February 1995. Survey.
4. DAH Laidlaw, PA Bloom, AO Hughes, JM Sparrow, VJ Marmion, 10 September 1994. *British Medical Journal* vol. 309. The sight test fee: effect on ophthalmology referrals and rate of glaucoma detection.



### **3. Choice and Information**

Choice and information go hand in hand. Both are essential if patients are to take part in decisions about their own health care. There is evidence that patients who participate more in consultations enjoy more successful treatment (1) and that people with serious illnesses suffer less distress when they believe they have been given enough information. (2) The following rights aim to ensure that all patients have the opportunity to make fully informed choices.

#### **3.1. A right**

*- to share in decisions about your condition and treatment on the basis of full and sensitively communicated information.*

#### **3.2. - for carers, to enough information about conditions and treatment to make informed judgements about care.**

The Patient's Charter says you have the right to "have any proposed treatment, including any risks involved in that treatment and any alternatives, clearly explained to you before deciding whether to agree to it." Patients, especially those with long term conditions, express a strong desire for more information as of right, including explanations about the diagnosis and prognosis, the consequences of not treating and the known benefits and side effects of any proposed treatment considered in the context of a patient's individual lifestyle. Health staff should communicate sensitively and clearly with patients in a way which empowers them to participate in decisions about their treatment. In-service training in communication skills would help to improve the quality of communication between professionals and patients and be especially useful to more senior staff who are less likely to have been taught these skills in their initial training. Consultations should take place in a comfortable and private environment. Patients need to be given the time and opportunity to take in news and consider the options available, and to have access to a health professional they can contact again if they need to talk some more. At the same time, a patient's desire for limited information must be respected.

#### **3.3. A right to written information about your condition and treatment in an appropriate format.**

Information given verbally by health professionals needs to be backed up with written information so that patients can remember what they have been told and share it with their family and friends if they wish. Leaflets or information sheets should be clearly printed, accessibly written and available in different languages and formats including Braille or audio cassette. They should explain where to find out more and if appropriate, give details of a relevant support group.

#### **3.4. A right to a second opinion whether from a GP or a consultant.**

Individual doctors frequently have different views and different approaches. It is only fair that people taking decisions about their health which may have long term consequences should be allowed to compare the advice of one professional with that of another. At present patients have no right to a second opinion from a GP. The Patient's Charter says you have a right to be referred for a second opinion from a consultant "if you and your GP agree this is desirable". In practice, this agreement may be difficult to obtain if the GP sees the request as a criticism of the consultant or simply agrees with the consultant's advice. But a second opinion is an important safeguard for patients and should be available automatically to anyone who requests it.

### ***3.5. A right to choose your hospital and consultant, and to have access to meaningful information about the choices available to you.***

In general, patients will receive more successful care and treatment from doctors who specialise in their condition. Yet they often know little about the skills and experience of the health professionals who treat them. Nor is there any guarantee of referral to an appropriate expert. Many women diagnosed with breast cancer, for instance, never see a consultant who specialises in their illness. The Patient's Charter says you have the right to "be referred to a consultant acceptable to you, when your GP thinks it is necessary". This would imply that people can exercise some choice about who treats them. In practice, unless the GP is a fundholder, they are likely to be restricted to those hospitals where the health authority has a contract. Treatment at a different hospital requires "an extra contractual referral" and is paid for from a limited budget. It is probably unrealistic to suggest that patients should always have complete freedom of choice as to where they are treated. But as a rule, the more specialist the treatment required, the further the patient should be entitled to go to receive it, while a patient who is unhappy with a particular hospital or consultant should always be offered an alternative.

Meaningful information about the choices available should include:

- How long you might have to wait for an appointment and treatment.
- Where you might receive aftercare.
- The qualifications, further training and special interests of the proposed consultants.

And, if you are being referred for a specialist procedure:

- Who will be carrying out the procedure.
- The number of these procedures the consultant\* is responsible for each year.
- Indicators of the consultant's\* success rate in carrying out the procedure, as these are developed within the health service.

\*In practice these figures would relate to the team working under the consultant.

To assist patients and health professionals in making decisions about referral and treatment, the following information should be made public:

- The results of "clinical audit", the system by which doctors evaluate their own performance and success (anonymised to protect the identities of individual patients).

- Information about the safety and effectiveness of medicines from tests conducted before the products were licensed for sale - currently kept secret by law.

1. SH Kaplan, S Greenfield and JE Ware, 1989. *Medical Care*, vol. 27 (supplement 3) S110-27.

Assessing the effects of physician-patient interactions on the outcome of chronic disease.

2. FJ Fallowfield, A Hall, GP Maguire and M Baum, 1990. *British Medical Journal* vol. 301 p575 -

80. Psychological outcomes of different treatment policies in women with early cancer outside a clinical trial.

## **4. Advocacy, Support and Appropriate Care**

The provision of universal health care is a founding principle of the NHS. Yet many people face formidable barriers in communicating with health staff or using health facilities. If the health service is to provide appropriate care for everyone, free from discrimination, it must adapt to meet the needs of all its users and potential users. The following rights aim to lift the barriers some groups face.

### ***4.1. A right to have access to an independent advocacy service, free of charge, and to be made aware that this service exists.***

Patients using the NHS may have difficulty in communicating their needs and views for any number of reasons - because they lack specialist knowledge, because English is not their first language or simply because they are too ill to be able to speak for themselves effectively. A trained advocate, who is independent from health staff and the patient's relatives, can offer support in discussions with professionals. Through an advocate, patients can participate more fully in decisions about their own treatment, and ensure that their views are heard and understood. It has been found that patients using bilingual advocacy schemes are more likely to feel they can ask any question about their medical care and that the doctor has explained what will happen next.<sup>(1)</sup>

### ***4.2. A right, for people whose first language is not English or who have a sensory disability or communication disorder, to an interpretation service, free of charge, which reflects the needs of the local population.***

Communication difficulties can damage your health. Patients may receive inappropriate treatment if they are unable to make themselves understood. Asking a friend or relative to interpret threatens confidentiality and is often unsatisfactory. The patient may feel reluctant to discuss intimate health information in front of a family member, particularly if the interpreter is a child. One study found that two thirds of patients who believed they needed an interpreter were not offered this help.<sup>(2)</sup>

### ***4.3. A right, for people who have a disability, to have independent access to all NHS services, whether as patients or visitors.***

The Patient's Charter says: "You can expect the NHS to make it easy for everyone to use its services, including children, elderly people or people with physical or mental disabilities." Many NHS premises are old buildings which have been added to over time and are not fully accessible to disabled people. Facilities should be adapted to at least meet the requirements specified in Part M of the building regulations.<sup>(3)</sup> The needs of disabled users with sensory impairments should be considered. Altering premises to provide access should be carried out in consultation with people with disabilities. Until accessibility has been achieved, disabled patients who need access should have a right to alternative services without compromising the standard of their care and treatment.

**4.4. *A right for children to have their health care provided by staff with the specific skills and training to meet their needs, and to receive their hospital treatment in appropriately equipped facilities. Children should not ordinarily be cared for in adult wards.***

It is important that all professionals working with children understand that they have different physical and emotional needs from adults. (4) GPs should have specific training in the care of sick children while a surgeon or anaesthetist operating on a child should be experienced and regularly undertake surgery on children. (5) All staff coming into contact with children should be offered in-service training if they lack appropriate skills. Children in hospital should be cared for with others in the same age group in a child friendly environment. The Patient's Charter Services for Children and Young People goes some way to recognising this. It promises: "You can expect your child to be cared for in a children's ward under the supervision of a consultant paediatrician" and "to have a qualified children's nurse responsible for his nursing care". However, many children are still cared for in adult wards and receive care from health professionals without specialist training in their needs.

**4.5. *A right to be accommodated in a single sex ward if this is your preference, without delaying your treatment by more than four weeks.***

The practice of mixing men and women in the same ward is unacceptable to many patients. Mixed wards can cause particular discomfort for people whose cultures encourage the separation of the sexes and anyone who has experienced sexual abuse. The Patient's Charter says that on this issue "your wishes will be respected wherever possible", but adds that patients choosing single sex accommodation may have to wait. Hospitals should be striving to offer all patients access to single sex facilities. Where truly exceptional circumstances make this impossible the delay should be strictly limited. A preference for single sex accommodation should be recognised as legitimate grounds for referral to a hospital outside the health authority's usual contractual arrangements if this is what the patient wants.

1. MORI, July 1994. Evaluation of Bilingual Health Care Schemes in East London, Evaluation Study Conducted for East London Consortium.
2. Ruchira Leisten and Jane Richardson, April 1994. Access to Health: A Minority Ethnic Perspective.
3. Department of Environment and Welsh Office, 1992. Part M of the building regulations, Access and facilities for disabled people, HMSO.
4. Christine Hogg, Action for Sick Children, 1996. Health Services for Children and Young People, A guide for commissioners and providers.
5. Confidential Enquiry into Perioperative Deaths, 1990. The report of the national confidential enquiry into perioperative deaths, London.

## **5. Good Quality Care in Matters of Life and Death**

Patients should be able to rely on good quality care and treatment in all areas of the health service but especially where safety is at stake. All round quality is hard to ensure through rights and standards alone: if staff and facilities are over stretched then meeting one measure of quality may mean neglecting another. Nevertheless, the following rights highlight instances where the quality of service could make the difference between life and death.

### ***5.1. A right, if you call the ambulance service in an emergency, to receive appropriate advice from a trained operator on what to do until the ambulance arrives.***

In Derbyshire, a caller to the ambulance service will be asked to stay on the line once the ambulance has been despatched. Using set questions a trained operator establishes further details of the patient's condition and relays expert advice explaining, for example, how to give artificial respiration, stop the flow of blood or keep the patient comfortable. The service calms callers and can save lives.

### ***5.2. A right, at an accident and emergency department, to have the standard of your treatment safeguarded by the presence of an experienced accident and emergency doctor on duty or available within the hospital site at all times.***

If you suffer a life threatening injury your treatment during the first hour is likely to determine whether you live or die and what level of complications you experience. Yet most accident and emergency patients are seen by relatively inexperienced doctors, often unsupervised by consultants. Although a consultant may be available by telephone, junior staff can be reluctant to seek advice if they have to contact a senior doctor at home. At some hospitals, experienced accident and emergency doctors are only present on site during the working week despite the fact that most 999 patients arrive out of hours. The proposed right is in line with a recommendation from the Audit Commission that there should be a senior or middle grade A&E doctor in all A&E departments for at least 15 hours a day, seven days a week and a middle-grade on call within the hospital for the remaining time. (1)

### ***5.3. A right to receive appropriate care and treatment at the hospital attached to your nearest accident and emergency department. There should be enough intensive care facilities to cope with fluctuations in demand.***

As a result of shortages in intensive care facilities patients who are critically ill have been driven long distances to find life saving care and treatment - sometimes too late. The lack of facilities also leads doctors to push patients too quickly through an overburdened system and has been blamed for patient deaths. It has been found that the chances of dying in an intensive care unit here are one quarter higher than in the United States.(2) While it is recognised that some particularly specialist equipment will not always be available within the hospital, facilities should include enough intensive care, high dependency and acute beds, facilities for babies and children,

emergency operating theatres and appropriate levels of staff. The UK spends less on intensive care than New Zealand, Japan, France and the USA.<sup>(3)</sup>

1. Audit Commission, 1996. By Accident or Design: Improving Emergency Care in Acute Hospitals.

2. South Thames (West) Regional Intensive Care Committee, March 1996. Evidence of the Inadequacy of Intensive Care Provision.

3. Department of Health, 1993. Study of provision of intensive care in England.

## **6. Confidentiality and Control over Personal Information**

Respect for the confidentiality of personal information is an essential component of trust between patients and health staff. The Patient's Charter says: "everyone working for the NHS is under a legal duty to keep your records confidential." But this "legal duty" is based on judge-made case law which does not lay down explicit ground rules about the circumstances in which disclosures are lawful. Patients' organisations, professional bodies and the Data Protection Registrar have all called for clear legislation. Patients' rights to have access to their own health information are clearer in law, but can also prove inadequate. The following rights aim to give patients better safeguards to confidentiality and more control over their personal health information.

### **6.1. *A right to have your identifiable personal information strictly protected and not disclosed to others except when this is required for your treatment or other essential purposes.***

In certain circumstances doctors have a duty to break confidentiality - to comply with legal requirements to report births and deaths for instance. But Department of Health guidance supports disclosures of information for a far broader range of purposes. These include administration, teaching, research and co-ordination with organisations outside the NHS, such as local government and private health care companies. Patients may be unaware of this when they entrust personal information to doctors and nurses. Confidentiality is also compromised by poor practice, for example, leaving patient records unattended or allowing private discussions to be overheard. The accessibility of computerised information presents another threat. Effective steps are long overdue. Patients' consent should be routinely sought before identifiable information is used for education, research, or administration or passed outside the NHS. Practical guidelines, staff training and disciplinary measures are all needed to prevent unjustified access to personal information.<sup>(1)</sup>

### **6.2. *A right***

***- to be told if you are being denied access to part of your medical records on health grounds.***

### **6.3. *- of appeal when access to your medical records is denied, delayed or restricted or when the record holder refuses to correct your record.***

### **6.4. *- to see medical records made before November 1991.***

The Patient's Charter states that you have the right to "have access to your health records". This is misleading since patients can legally be refused access to all or part of their records if the doctor thinks they or someone else could be seriously harmed as a result. A patient may not know if something is held back since the record holder does not have to say so. Even a patient who asks directly about this will not necessarily learn the truth. NHS guidance suggests that the record holder may simply



reply that requirements under the Access to Records Act have been complied with. A patient denied access can complain but if still refused may only appeal to a court of law - a time consuming and expensive process. There is also no automatic access to records made before November 1991 - a right which would require new legislation.

1. ACHCEW; May 1995. Health News Briefing, Keeping information confidential.

## **7. Redress**

For people to have meaningful rights they must be offered an adequate form of redress when these rights are not met. Patients do have certain rights in law. But obtaining your rights within the NHS should not normally involve going to court. The rights proposed in this booklet are therefore not generally put forward as legal rights, though in some instances a change in law may be necessary. Instead they are envisaged as Charter rights, enforceable through the powers of an effective monitoring body. For this reason we propose:

### ***7.1. An independent Health Rights Commission with statutory powers to monitor and enforce all Charter rights and standards.***

The Patient's Charter says that if you think your Charter rights are being denied, you can write to the Chief Executive of the NHS at the Patient's Charter Unit, who will ensure the matter is "investigated and put right." In practice, the Charter Unit will ask the NHS centre involved to comment and put matters right, but has not the power to insist on any particular action. Hospitals currently monitor their own performance in meeting Charter standards. An independent Health Rights Commission would evaluate how well the NHS was fulfilling all the commitments in the Charter. It would be especially useful in assessing performance on so called "soft standards", such as respect for patients' privacy, dignity and religious and cultural beliefs. The Health Rights Commission would have statutory powers to order corrective measures and so give force to Charter rights.

### ***7.2. A right, if you are unhappy with the initial response to your complaint, to an investigation by a genuinely independent panel.***

Under the NHS complaints system a complaint may be referred to an "independent review panel", but patients have no automatic right to this referral. Moreover the panel itself is not truly independent of the health service, since it is convened by the NHS trust or health authority. Genuine independence is essential to patient confidence in the handling of complaints. If such a panel were set up it would also offer a more satisfactory means of appeal when a health authority refuses to pay for a patient to be referred to a particular hospital or consultant, or when access to medical records is denied.

### ***7.3. A right to make a complaint about any aspect of care or treatment without the constraint of any imposed time limit.***

Under the complaints system a complaint must normally be made six months from the time of the event complained about or from discovering the problem. But someone who is unwell may be too involved in recovering from illness or adjusting to traumatic events to take action within this time. Many patients spend a considerable period reaching a decision to complain only to find they have left it too late. Where

hospitals have decided to respond to complaints without a time limit, few problems have arisen as a result.(1)

1. Department of Health, 1994. Being heard, The report of a review committee on NHS complaints procedures.

The Patients' Agenda was drawn up in consultation with Community Health Councils and has received broad support from (list of voluntary and professional organisations)

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