



**PATIENTS ASSOCIATION
SURVEY OF THE UK PUBLIC:
*PATIENTS' RIGHTS***

Backgrounder

PATIENTS' RIGHTS IN EUROPE AND THE UK

DECEMBER 2005

PROJECT CONDUCTED WITH THE SUPPORT OF AN EDUCATIONAL GRANT FROM
MERCK SHARP & DOHME LTD

*QUESTIONNAIRE, ANALYSES, BACKGROUNDER AND REPORT BY PATIENTVIEW
PUBLIC OPINION POLL BY ROSSLYN RESEARCH*

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THE PATIENTS ASSOCIATION

SURVEY OF THE UK PUBLIC: PATIENTS' RIGHTS

BACKGROUNDER TO MAIN REPORT: PATIENTS' RIGHTS IN EUROPE AND THE UK

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WHY HAVE PATIENTS' RIGHTS BECOME IMPORTANT?

Backgrounder: Patients' Rights in Europe and the UK

WHY HAVE PATIENTS' RIGHTS BECOME IMPORTANT?

For centuries, patients have been relatively content to relegate the management of their healthcare to professionals—until recently. The growing number of older people in the population, coupled with a gradual rise in the incidence of chronic disease, have elevated both costs and demand to the point at which policymakers are having to ration healthcare services. Fiscal austerity measures within the healthcare system are altering the very nature of healthcare provision.

Patients are becoming unsettled about the implications of change. Patient surveys in individual countries, and across Europe, have revealed a high degree of dissatisfaction with even routine elements of healthcare. One of the most recent surveys* found that less than half of organisations representing the health interests of patients and the public in Western Europe were satisfied with various aspects of their national healthcare systems. The equivalent figure for England and Wales was 20%.

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* 'Users' perceptions of healthcare systems: a global survey', *Health and Social Campaigners' News International*, published by PatientView, issue 20/21, Summer 2005, pages 5-28 (plus accompanying 96-page Appendix).

FEATURE: THE WORLD HEALTH ORGANIZATION'S INITIATIVES ON PATIENTS' RIGHTS

■ 1948 DECLARATION OF HUMAN RIGHTS

Probably the original basis of most patients' rights initiatives; both legislative and consensual.

■ 1994 DECLARATION ON THE PROMOTION OF PATIENT RIGHTS IN EUROPE

Based on the understanding that healthcare systems and economic, cultural and social values vary, but that common approaches can be adapted to the needs of each country. The WHO called for cooperation between itself, the Council of Europe, and the European Union in support of patients' rights—with a critical supporting role to be played by international NGOs. The 1994 Declaration focused on:

- Human rights and values in healthcare (including respect and privacy).
- Information about health services, patients' own health condition, and access to second opinions.
- Informed consent is a pre-requisite for any medical intervention.
- Confidentiality and privacy of data.
- Care and treatment (quality and continuity of care).
- Application (entitlement to these rights without discrimination).

These principles have become the basis of laws and charters on patients' rights in many European countries.

■ 1996 LJUBLJANA CHARTER

Agreed to in 1996 by the health ministers of EU Member States, the Charter established a set of principles aimed at underpinning healthcare reforms within the specific context of Europe. The Charter is centred on the principle that healthcare should lead to better health and quality of life for people. The document stresses that the citizen's voice and choice should be as significant in shaping healthcare services as the decisions taken at the highest levels of economic, managerial and professional decision-making. The citizen should be heard on issues such as the content of healthcare, contracting, quality of services in the provider/patient relationship, the management of waiting lists, and the handling of complaints.

BACKGROUND TO PATIENTS' RIGHTS IN EUROPE AND THE UK

FEATURE: WHO INITIATIVES ON PATIENTS' RIGHTS

■ ONGOING INITIATIVES

The WHO maintains a number of other, relevant, continuing initiatives. The organisation's programme on legislation and patients' rights links it with national and international bodies in the field of healthcare systems. The WHO works with the latter to develop and promote patients' rights and individual involvement in decision-making on healthcare provision. Initiatives include:

- The World Alliance for Patient Safety, launched in October 2004 with WHO backing, hopes to reduce the incidence of unsafe patient care. The Alliance was formed in response to a 2002 World Health Assembly resolution proposing worldwide action to develop standards, promote evidence-based policies, recognise excellence in patient safety, and encourage research.
- The 2005 launch of the WHO Collaborating Centre on Patient Safety. This has six major areas of action: Global Patient Safety on healthcare-associated infection; Patients for Patient Safety (to mobilise NGOs); Taxonomy for Patient Safety (to develop international data standards); Research for Patient Safety (to build research tools); Solutions for Patient Safety (to disseminate proven interventions); and Reporting and Learning.

■ RELEVANT WHO PARTNERSHIPS

The European Observatory on Health Systems and Policies is a partnership between the WHO Regional Office for Europe, the governments of Belgium, Finland, Greece, Norway, Spain and Sweden, the Veneto Region of Italy, the European Investment Bank, the Open Society Institute, the World Bank, CRP-Santé Luxembourg, the London School of Economics and Political Science (LSE), and the London School of Hygiene and Tropical Medicine (LSHTM). The Observatory's objective is promotion of evidence-based health policy-making through comprehensive and rigorous analysis of the dynamics of healthcare systems in Europe.

The WHO is currently funding (with the European Commission) a research project monitoring European health consumers' use of, attitudes to, and needs for, information and communication technology in seven countries.

Useful reference sources on the WHO and patients' rights

- ▶ <http://www.un.org/Overview/rights.html>
- ▶ <http://www.eucomed.be/docs/WHO%20-%20A%20Declaration%20on%20the%20Promotion%20of%20Patients.pdf>
- ▶ http://www.euro.who.int/AboutWHO/Policy/20010927_5
- ▶ <http://www.who.int/patientsafety/worldalliance/en>
- ▶ <http://www.who.int/patientsafety/newsalert/issue2/en/index.html>
- ▶ <http://www.euro.who.int/observatory>

A GRASSROOTS MOVEMENT IN EUROPE

Specific issues that have worried patients are: the explosion in reported cases of adverse drug reactions and hospital-acquired infections (HAIs); accounts of medical negligence; and—worse still—rumours of cover-ups.

The public, patients, their families and carers are all concerned by the increasingly numerous threats to the supply of their medical care and treatment. Now that governments across Europe are striving to devolve onto individual patients more responsibility for the management of their personal wellbeing, patients and the public are pressing for greater access to medical information, for added protection from possible medical blunders, and, above all, for authority in the shaping and delivery of their own healthcare.

EU MEMBER STATES THAT HAVE ADOPTED PATIENTS' RIGHTS LEGISLATION

Country	Date enacted
Finland	1992
Netherlands	1994
Lithuania	1996
Latvia	1997
Hungary	1997
Greece	1997
Denmark	1998
Norway	1999
France	2002
Belgium	2002
Estonia	2002
Cyprus	2005

Source:
Compiled by Walter Keim

A GRASSROOTS MOVEMENT IN EUROPE

A variety of initiatives currently seek to uphold and extend the rights of patients in other European countries. Some aim to extend the rights of users, and have been legislative. Others have merely taken the form of voluntary charters or entitlements [see tables on this page and the next]. The schemes have been united by a desire to rectify the diversity and inconsistency between national healthcare systems (and among regions within each country). The execution and policing of these patient laws and charters has been haphazard, at best, and largely ineffectual at national level—as the various patient satisfaction surveys continue to show.

To date, the influence of the European Commission has been limited by the EC Treaty, which precludes the Commission from dabbling in local healthcare politics. Successive European Commissioners with a remit for health have, however,

A GRASSROOTS MOVEMENT IN EUROPE

requested that healthcare across Europe share common values and goals. The Commission sees more collaboration at European level as a good way of making a tangible contribution to national health objectives. The forthcoming ratification of the European Constitution (scheduled for November 1st 2006), and various ongoing programmes at the Commission are likely to elevate the EU's future role in national healthcare policy (including patients' rights) [see end of this document for more information on why the EU may become a more potent influence in the debate about patients' rights].

Given the apparent inertia of European governments on the subject of patients' rights, a grassroots movement has begun to emerge, instigated by patient advocates and civic pressure groups. The NGOs are calling for a basic set of patients' rights to be established, in line with those suggested by the World Health Organization [see feature on a previous page]. The rights would slow or halt further erosion of healthcare standards, certify that all members of the public receive a basic level of healthcare services (to which they would be entitled), and guarantee access to the information necessary for them to manage their day-to-day care and treatment more effectively.

The appeal by NGOs for a universal set of patients' rights has grown more vigorous with the realisation that European health systems may otherwise never deliver the principles of universality to which they espouse. Equal access to healthcare remains a pipedream in most European countries. Inequities linger, and are deepening. The poor generally continue to be sicker than the rich.

EU MEMBER STATES THAT HAVE ADOPTED PATIENTS' CHARTERS

Country	Date enacted
UK	1991*
Spain	1994
Ireland	1995
France	1995
Portugal	1997
Poland	1999
Slovakia	2000
Austria	2001
Cyprus	2001
Germany	2002

* Abolished in England in 1997

Source:
Compiled by Walter Keim

HOW HOSPITALS IN 13 EUROPEAN COUNTRIES IN 2005 MATCH UP TO ACTIVE CITIZENSHIP NETWORK'S CHARTER OF 14 PATIENTS' RIGHTS

1. Right to preventive measures

Preventive medical practices are almost non-existent in European hospitals (except screening for female cancers).

2. Right of access to healthcare

Access to hospitals is good in all countries (except Portugal and Greece). But, in many instances, patients are unable to obtain medicines not yet authorised for use in their country (despite the drugs being available in neighboring states).

3. Right to information

The mechanisms for supplying information to patients are fairly uniform among the 13 countries. But the information provided is limited. Only France and the Netherlands offer data on patient satisfaction and clinical performance. Publicly-available information about waiting lists and patients' complaints is mostly unavailable in nine of the 13 countries.

4. Right to consent

Standard forms for patients' consent to participate in scientific research are unavailable in Denmark, the Netherlands and Sweden.

5. Right to free choice

Doctors in most of Europe's healthcare systems are required to obtain informed patient consent to prescribe particular treatments. Patient choice of treatment or treatment providers, however, is limited.

6. Right to privacy and confidentiality

Many cases of the following are reported: a.) terminally-ill patients forced to remain in public wards; and b.) disclosure of personal medical information to unauthorised personnel.

7. Right to respect patients' time

Waiting times for operations vary significantly between the 13 countries. Only Denmark and the Netherlands cap the length of waiting times. Reports of illnesses worsening because of delays, or patients turning to the private sector because they could wait no longer, are common.

8. Right to the observance of quality standards

All of the 13 countries have health performance standards. Those of Denmark, the Netherlands and Sweden are the most demanding. No countries utilised input from patients or the public.

9. Right to safety

All of the 13 countries have measures to reduce hospital-borne infections and to oversee the health risks that follow transfusions. But few hospitals regularly check to see whether their tests and treatments remain state of the art.

10. Right to innovation

Hospitals in only five of the 13 countries use electronic systems for patient records, appointments and referrals. The most primitive of Europe's various forms of electronic healthcare communication can be found in Finnish, Greek, Irish, Italian, Portuguese and Spanish institutions.

11. Right to avoid unnecessary suffering and pain

Hospitals in seven of the 13 countries are reported to be denying patients appropriate pain relief.

12. Right to personalised treatment

Few hospitals cater for the needs of patients who require religious or psychological support, or impart treatment that is appropriate for the terminally ill, or for victims of violence. Most hospitals, however, meet the demands made upon them by children.

13. Right to complain

Most complaints procedures are inadequate, with a slow (or even absent) rate of response. Few are independent.

14. Right to compensation

Doctors and hospitals in all 13 countries (except Greece) carry insurance that contains provisions for patient compensation in the case of medical negligence or errors. Six countries (Denmark, Germany, Ireland, the Netherlands, Portugal and Spain) do not give patients access to free legal aid.

A GRASSROOTS MOVEMENT IN EUROPE

Patients' rights are commonly thought to be desirable because they encompass citizens' ideals and the practical and personal interests of people in need of medical care. The subject has attracted widespread support, and has been incorporated into international conventions and national law.

Popular efforts to promote a patients' rights agenda have been both unilateral and bilateral. Spearheading the movement are the following very different organisations:

► **ACTIVE CITIZENSHIP NETWORK (ACN)**

<http://www.activecitizenship.net>

A European network of civic, consumer and patient organisations founded by the Italian civic movement Cittadinanzattiva. In 2002, ACN compiled its own European Patients' Charter—a valuable reference tool with which to compare the performance of

national healthcare systems in adopting its criteria. In March 2005, the preliminary results of a two-year study on the implementation of the ACN charter in 13 European healthcare systems was unveiled. ACN had cooperated with health campaigning groups in the 13 countries to examine how effectively each nation was matching the Charter's ideals. The 14 patients' rights were broken down into 160 different measurable indicators, to be assessed in each country's secondary-care system. Key healthcare stakeholders were interviewed, including medical professionals. Leading hospitals in each country's capital city were visited and assessed (hospital administrators in Germany, Ireland, Portugal and the UK refused to comply). [See page 10 for a summary of how European countries matched up to the ACN Patients' Charter.]

► **ASSOCIATION OF EUROPEAN CANCER LEAGUES (ACL)**

<http://www.ed.uicc.org>

The ACL was founded in 1981 from among national voluntary cancer leagues in Europe. The organisation adopted a 'Joint Declaration on Patients' Rights' during its General Assembly in Oslo in June 2002.

TWO THINK-TANKS EXAMINING THE ISSUE OF PATIENTS RIGHTS

In 2001, **Patient Navigation (Hamburg)** managed an EU-funded project to gather comparative data on patients' perspectives on quality of service in a number of European healthcare systems. http://www.patientnavigation.org/patnav_e.html

Brussels and Stockholm-based **Health Consumer Powerhouse (HCP)** is currently compiling the European Health Consumer Index (a measurement of the user-friendliness of the healthcare systems in European countries). The Netherlands, Switzerland and Germany hold the top three places in the Index at present. The UK is ninth. <http://www.healthpowerhouse.com>

A GRASSROOTS MOVEMENT IN EUROPE

▶ EUROPEAN PATIENTS' FORUM (EPF)

<http://www.europeanpatientsforum.org>

The Brussels-based EPF, which consists of 12 pan-European patient organisations, aims to exchange information, views and good practice in EU health policy. The organisation communicates EU initiatives of interest or concern to patients. The EPF also seeks to represent the views of patients to the European Commission. The group has pressed for the right of patients to access "all kinds of information about their health, medical conditions and the availability of treatments, including knowledge of the best-available management for their disease ... It is a question of solidarity, equity and patients' rights", the EPF argues.

▶ INDEX FOUNDATION

<http://www.index-bg.org>

The Index Foundation is a Bulgarian not-for-profit organisation that runs various campaigns, including one for the promotion and protection of patients' rights in Bulgaria. The Foundation analyses European and international law, disseminates best practices, works for greater NGO awareness and competence, sets up initiatives to create complaints procedures (such as the appointment of a health ombudsman), and publishes a bulletin on patient rights and the provision of consulting services on the subject.

▶ IRISH PATIENTS' ASSOCIATION (IPA)

<http://www.irishpatients.ie>

The IPA mission is to place the Irish patient at the centre of the country's healthcare system. The IPA works in partnership with providers, and advocates for the needs of patients to be paramount. Contact with patients and their families and carers allows the IPA to stay aware of ongoing (and emerging) patients' needs. On April 18th 2005, the IPA released the results of a study it had commissioned from Dublin City University. The study argued for the introduction of a statutory European Patients' Charter to ensure that patients' rights (including improvements to patient safety) are

WHAT A DOCTORS' ORGANISATION HAS TO SAY ON PATIENTS' RIGHTS

The World Medical Assembly (WMA) in Lisbon 1981, and later in Bali in 1995, endorsed the *World Medical Association Declaration on the Rights of the Patient* [<http://www.wma.net/e/policy/l4.htm>]. The Declaration recommended that patients should have the following rights: medical care of good quality; freedom of choice; self-determination (free choice of physician and hospital, and of a second opinion); information; confidentiality; health education; rights of unconscious or legally-incompetent patients; rights to protect patients from procedures used against their will.

In January 2005, the WMA joined forces with the International Council of Nurses (ICN), the International Pharmaceutical Federation (FIP), and the International Alliance of Patients' Organizations (IAPO) to offer suggestions that health professionals work more proficiently with patients' representatives, and that healthcare becomes more patient centred.

A GRASSROOTS MOVEMENT IN EUROPE

upheld in current and potential health reforms. At the press launch of the report, Stephen McMahon, Chairperson of the IPA, said: "A European Patients' Charter would reflect a commitment by our government to develop and provide a world-class health service. It would secure any present or future patient a place at the centre of our health service."

► FORO ESPAÑOL DE PACIENTES

<http://www.webpacientes.org>

Barcelona-based Foro Español de Pacientes was formed in May 2003. The centrepiece of its launch was the 'Barcelona Declaration of Patients' Associations', a Decalogue [literally, a book of ten commandments] of patients' rights that made a significant impact in the Spanish media. In a soon-to-be-published interview in *Health and Social Campaigners' News International*, Albert Jovell, President of the Foro Español de Pacientes, said of the organisation: "There was a vacuum in Spain on the subject of patients' rights—not so much at a legislative or a political level, but within civil society itself. So we thought that a Decalogue, setting out patients' rights in very clear and simple terms, would fill this gap in the public's thinking."

► A DUTCH INITIATIVE

On October 11th 2005, a group of 15 national and international Dutch patient organisations presented a so-called 'base document' to the European Parliament. The paper pressed for legislation to be amended so that patients can have more influence over the daily decisions made on their behalf by insurers, doctors and other healthcare stakeholders. The ACN Patients' Charter was used as the platform for the 'base document'.

Gaining momentum

The grassroots movement for patients' rights is gaining momentum. At least half of the 290 health campaigning organisations responding to a 2004 global survey* said that they were campaigning on the right of patients to have a voice, and be included and represented in all aspects of healthcare policymaking. The survey found that similar numbers of groups were active on the right of patients to access treatments that could improve the quality of life, on the right of patients to know about the existence of new treatments and diagnostic tests, on greater patient freedoms within the doctor-patient relationship, and on the right of patients to healthcare information.

* 'Health campaigners reflect on 2004 and plan for 2005: a global survey', *Health and Social Campaigners' News International*, published by PatientView, issue 13/14, January 2005, pages 5-48 (plus accompanying 43-page Appendix).

'Update on what health campaigners did in 2004 and plan to do in 2005', *Health and Social Campaigners' News International*, issue 17, April 2005, pages 34-43.

PATIENTS' RIGHTS IN THE UK

**Bodies and processes
within the English NHS:
some definitions**

Trusts: financially autonomous organisations which may run hospitals (Hospital Trusts) or primary care services within a given area (Primary Care Trusts, or PCTs), or other types of services (including mental health). Trusts are separate from local government.

PCTs: manage GP practices and frontline community health services. By October 2006, all PCTs are to be merged with larger regional bodies, known as Strategic Health Authorities (**SHAs**).

The Healthcare Commission, launched on April 1st 2004, replaced inspectorates of private and NHS care. The new independent healthcare inspectorate (full name Commission for Healthcare Audit and Inspection) is charged with inspecting health services, reviewing their performance, and publishing the results. The Commission will also work with other bodies to reduce the bureaucracy of regulation.

PATIENTS' RIGHTS IN THE UK

When the Labour Party came to power in the UK in May 1997, the new government pledged to improve public health services and the National Health Service (NHS). The 'NHS Patients' Charter', which had been introduced by a previous (Conservative) government in 1991, was quietly abolished in 1997 to make way for the radical improvements promised by the Labour party.

In keeping with the Labour government's pledge, the July 2000 NHS Reform Plan [<http://www.dh.gov.uk/assetRoot/04/05/57/83/04055783.pdf>] argued the virtues of a patient-focused healthcare system. The Plan was probably the first occasion in which any country had produced a blueprint that placed patients at the heart of a process of healthcare restructuring.

The framework and principles by which a new patient-oriented philosophy would be inserted into every level of the NHS were further outlined in a January 2002 government publication, *Shifting the Balance of Power: The Next Steps* [<http://www.dh.gov.uk/assetRoot/04/07/35/54/04073554.pdf>]. The vision for the next five years was reiterated in a forward-looking document, *The NHS Improvement Plan: Putting People at the Heart of Public Services* [<http://www.dh.gov.uk/assetRoot/04/08/45/22/04084522.pdf>]. Published in June 2004, the report set out the NHS programme for 2004-2008.

In a nutshell, the grand vision originally proposed by the then new Labour administration was a decentralised NHS. Government control over the NHS would be downgraded to three functions: setting national standards; overseeing regulation; and funding the NHS. Healthcare services would be managed and supervised locally. Patients and the public would have a greater say in how their NHS should be run.

The Government's top two long-term goals were abolishing inequities in access to healthcare services, and

PATIENTS' RIGHTS IN THE UK

The NHS conducts annual patient opinion surveys of primary care, via the Healthcare Commission and the Picker Institute.

The 2005 survey found that the majority of patients indicated trust in their doctors. And 60% said that they were as involved as they wanted in decisions about their medication.

However, 18% of patients said that they did not receive any information about side-effects. 70% were not given copies of correspondence between their GP and their specialist in cases of referral. And 25% were unable to see a doctor within two working days.

fashioning an NHS that reflected the needs of diverse local populations. Administrative bodies were created to represent the patient perspective, and high-level appointments announced. Some of the new entities were situated centrally, within the Department of Health (DoH). Others were located at a local level. These novel structures included:

- All Trusts (local bodies managing healthcare provision) were obliged to establish a **Patient Advice and Liaison Services (PALS)** from April 2002. The PALS provide resources to patients, their relatives and carers. They help patients resolve concerns with NHS services. The PALS also act as general advisors, and aspire to enabling patients to utilise the NHS to their best advantage.

- Harry Cayton, formerly chief executive of the Alzheimer's Society, was appointed **National Director for Patients and the Public** in May 2002. His brief was to advise ministers on how best to build a patient-centred NHS.

- First piloted in September 2002, the **Independent Complaints Advocacy Service (ICAS)** became

available nationwide by the end of 2003. The ICAS provides a free, local, confidential service, allowing patients to make formal complaints about their experiences within the NHS.

- New legislation known as the 'Local Authority Overview and Scrutiny Committees Health Scrutiny Functions Regulations 2002' came into force in January 2003. **Overview and Scrutiny Committees (OSCs)** have legal rights to intervene on healthcare matters within their own local area. The Committees marked the first point at which democratically-elected local government was given the authority to tackle NHS problems.

- Established in January 2003, but not officially launched until February 2004, the **Commission for Patient and Public Involvement in Health (CPPIH)** represented the final piece in the jigsaw that was the Government's plan to create a patient-focused NHS. The CPPIH was allocated a first-year budget of £36 million by the DoH. The organisation was originally supposed to act as an umbrella group, providing administrative support to 572 **Patient and Public Involvement Forums (PPIFs)**. One PPIF is based in each Health Trust in England. Staffed by local volunteers (who might be patients, or members of the public interested in health issues), the PPIFs provide input from patients on the running of local NHS services—concentrating, in particular, on how these services can be improved.

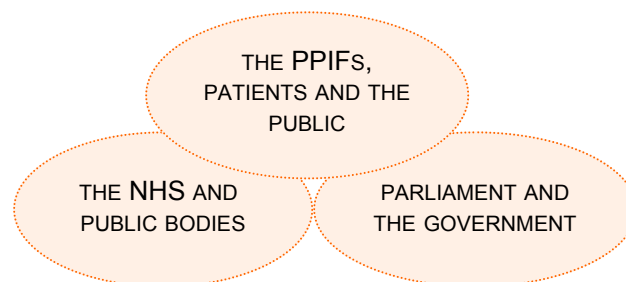
PATIENTS' RIGHTS IN THE UK

The CCPIH and the PPIFs were intended to be the hub of the plan to position patients at the heart of healthcare policy. The CCPIH was charged with the responsibility of changing the NHS' customary 'top-down' approach to one that was bottom-up—in other words, led by need, rather than by apportionment.

PPIFs, meanwhile, were given a statutory duty (under section 11 of the 'Health and Social Care Act of 2001') to consult with patients, and involve them in most NHS initiatives. PPIFs also have statutory rights under the 'NHS Reform and Health Professionals Act 2002' to inspect healthcare premises, to obtain explanations for patients' concerns, and to refer those concerns to the local government OSCs.

The CCPIH's image, however, became quickly and unexpectedly tarnished by accusations of inadequate management, resources, and clarity of purpose. In July 2004, the government used the occasion of a healthcare cost-cutting assignment (in which a number of 'arm's-length' bodies related to the DoH were abolished) to disband the CCPIH. The PPIFs were retained, their forums receiving a new form of administrative support.

PPIFs: the bridge between local government and local healthcare provision



Source: Socialist Health Association (SHA) meeting, May 15th 2004

PATIENTS' RIGHTS IN THE UK

'PATIENT CENTRED' BECOMES 'PATIENT LED'

2004 saw the accent in NHS reform switch subtly from 'patient centred' to 'patient led'. The revised aim (as outlined in the June 2004 publication, *NHS Improvement Plan: Putting People at the Heart of Public Services*) is for the NHS to support patients, so that they can make choices about, and take control of, their health and healthcare. The new 'improved' plan promises to provide personalised care by listening and responding to patients.

The main goals of the NHS Improvement Plan of 2004 are as follows:

How safe are patients in NHS hospitals?

The National Audit Office (NAO) states that patients have a one-in-ten chance of experiencing an adverse incident in hospital.

The NHS Litigation Authority reports that the cost of clinical negligence in 2002-3 was £422.5 million in England, and £43 million in Wales.

The Department of Health estimates that approximately 850,000 medical accidents occur in English hospitals each year (half of which, it insists, could have been avoided).

- Patients to be given as much choice and control as possible across all areas of healthcare, and to receive high-quality information and support.
- Superior standards of clinical governance to be developed and implemented, and new safeguards fashioned to ensure patient safety.
- NHS organisations to become better at understanding patients and their needs. The NHS to deploy new and different methodologies, and enhance its sources of information about patient preferences and satisfaction levels.
- Emphasis to be placed on empowering people to improve their own health by furnishing them with information about, and encouragement on, taking important lifestyle decisions (such as smoking cessation, improvements to nutrition, and more exercise).

The proposal for delivering the 2004 NHS Improvement Plan, *Creating a Patient-Led NHS: Delivering the NHS Improvement Plan* [<http://www.dh.gov.uk/assetRoot/04/10/65/07/04106507.pdf>] stated that the NHS had reached the capacity and the capability to move on from being an organisation that simply delivers services to people. Instead, insisted *Creating a Patient-Led NHS*, the NHS is now in a position to metamorphose into a totally patient-led organisation, with all internal processes measured for success against their impact upon patients. The proposal maintained that the NHS must:

- Understand that it has to undergo a change of ethos (as well as a change of systems) if it is to become truly patient-led.
- Respond to patients' needs and wishes.

The proposals are still in a process of consultation.

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THE UK'S DEBATE ON PATIENT-LED HEALTHCARE: THREE MAIN TOPICS

Three topics currently dominate government thinking on patient issues: patient safety; patient choice; and patient confidentiality (including access to medical records).

■ PATIENT SAFETY

The UK has had an unenviable record of medical accidents in recent years. Especially notorious were a series of unusually high death rates and risks of complications in children's heart surgery at the Bristol Royal Infirmary (BRI) in the late 1980s and early 1990s. The *BRI Inquiry Report* [http://www.bristol-inquiry.org.uk/final_report/rpt_print.htm], published in January 2001, attempted to uncover the causes of the Bristol medical accidents. The *Report* attributed the unwarranted childhood deaths to a whole string of failings at the facility, including: poor organisation; regular failures of communication; a lack of leadership; entrenched paternalism; and a hearty 'gentlemen's club culture'—as well as an institutionalised failure to put patients at the centre of care. But the Bristol inquiry's spotlight did not fall upon the hospital alone. The *Report* also drew attention to the dearth of NHS standards for evaluating performance and for assessing quality of care. The *Report* was particularly scathing about the absence of clarity—both at local and at national level—as to where the responsibility for such assessment lay. The document's analysis was accepted by the DoH; the force of its recommendations has been felt far beyond Bristol.

The BRI inquiry sparked a fundamental review of the NHS, undertaken with the aim of forging a new relationship between government and the NHS, and between the NHS and patients. *Standards for Better Health* [<http://www.dh.gov.uk/assetRoot/04/08/66/66/04086666.pdf>], which was published in July 2004, required the NHS to employ new national standards of care and services, with new bodies appointed for standard-setting and inspection.

THE GOVERNMENT PLEDGES TO OVERHAUL THE NHS AND MAKE IT SAFER FOR PATIENTS ...

Patient safety is a central tenet of the latest ten-year NHS Improvement Plan. Much of the Plan's energy is focused on the National Patient Safety Agency (NPSA), which was established in 2001 to improve the safety and quality of care by reporting, analysing and learning from adverse incidents and 'near misses' involving NHS patients.

A section of the NPSA website—'Reporting Incidents'—allows patients and the public to report problems with NHS treatment. Since 2004, the organisation has run the world's first 'National Reporting and Learning System' (NRLS) for patient safety problems. The NPSA is optimistic that the system will draw together anonymous

PATIENTS' RIGHTS IN THE UK

reports of patient safety errors and system failures across England and Wales, to help the NHS learn from its mistakes.

... BUT THE NHS HAS A LONG WAY TO GO IF IT IS TO PROVIDE A SAFE ENVIRONMENT FOR PATIENTS

However, a July 2004 report from the Chief Medical Officer, *Learning How to Learn: Compliance with Patient Safety Alerts in the NHS* [<http://www.dh.gov.uk/assetRoot/04/11/57/84/04115784.pdf>], provided a detailed analysis of four separate types of medical accidents. The report concluded:

- Compliance with patient safety alerts after patients had been harmed was slow.
- Some NHS Trusts reporting compliance to safety alerts were, on further inspection, found to be non-compliant.
- The NHS has not yet fully embraced the concept of patient safety.

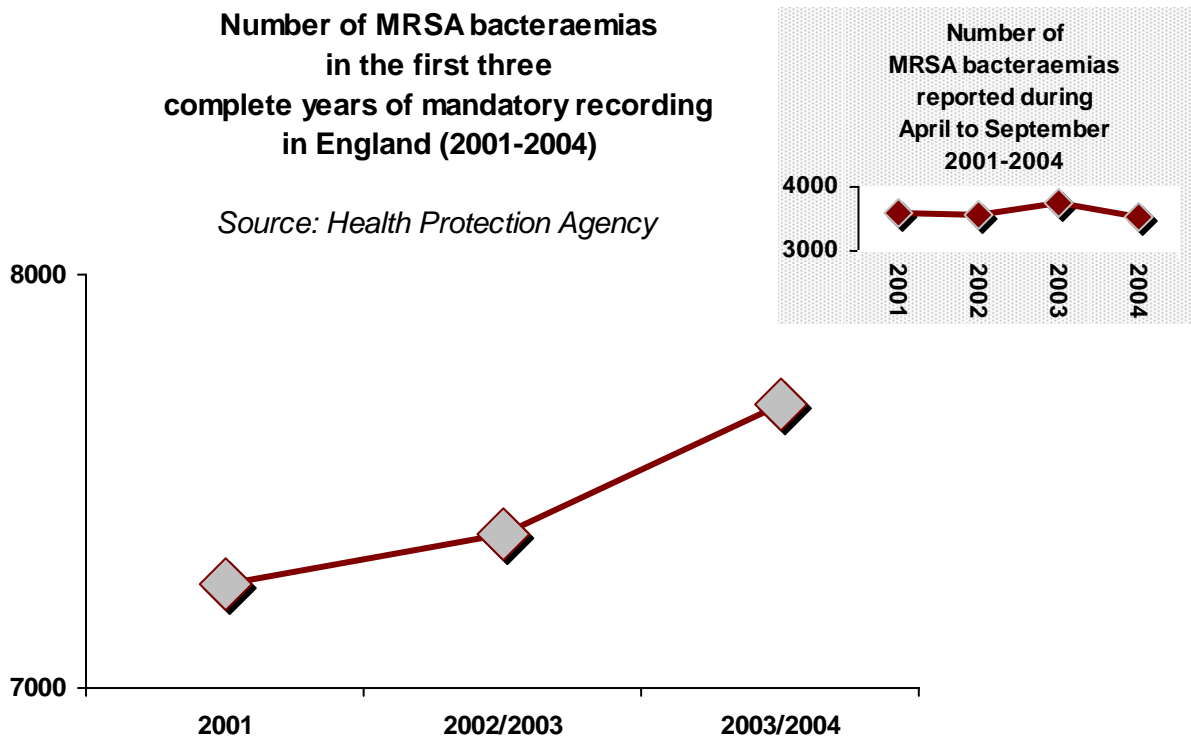
A November 2005 report by the National Audit Office (NAO), *A Safer Place for Patients: Learning to Improve Patient Safety* [http://www.nao.org.uk/publications/nao_reports/05-06/0506456.pdf], found that although one million people are successfully treated by the NHS every day, 974,000 patient safety incidents were reported in 2004-2005. Of these, 2,081 were accidental deaths—a figure much larger than the 840 calculated by the NPSA. The NAO report believed that the average patient could face a one-in-ten chance of being involved in an 'adverse event' during a stay at hospital.

A previous report by the NAO, *Improving Patient Care by Reducing the Risk of Hospital-Acquired Infection: A Progress Report* [<http://image.guardian.co.uk/sys-files/Society/documents/2004/07/14/0304876.pdf>], published in July 2004, noted another safety problem—patchy implementation of surveillance measures designed to check on the extent and costs of hospital-acquired infections (HAIs). The UK's reported incidence of MRSA* stands among the world's highest. Simon Williams, Director of Policy at the Patients Association, suggests some explanations:

"Reasons for the large numbers of HAIs in the UK must include overcrowding and high bed occupancy—staff and patients are crammed together. Hospitals with low occupancy rates tend to experience the lowest levels of infection. Poor hygiene is a factor, too, of course."

* **Methicillin-resistant *Staphylococcus aureus* (MRSA)**: a type of bacteria resistant to certain antibiotics, including methicillin and other, more common, antibiotics (such as oxycillin, penicillin and amoxicillin). Staphylococcus infections (including MRSA) occur most in hospitalised people and individuals in other healthcare facilities (notably nursing homes and dialysis centres) who have weakened immune systems.

PATIENTS' RIGHTS IN THE UK



Following successful re-election at the May 2005 general election, the Blair Administration announced that legislation would be introduced to improve hospital cleanliness and fight the epidemic of HAIs.

■ **PATIENT CHOICE**

When the UK government refers to patients' choice, it means—at a practical level—letting patients choose when and where they receive treatment. The latest attempt to expand the concept of patient choice is a reform that will allow patients to choose their own hospitals—though only within certain limitations. By the end of 2005, all NHS patients in England will be allocated four hospitals, one of which they must select as their sole choice for elective treatment. An individual's preference of secondary-care facility will probably be largely based on information about hospital waiting lists (primarily garnered from the Internet by the potential patient). Patients will be provided with the facility to book their first hospital appointment online. This piece of reform will affect over ten million people per year.

PATIENTS' RIGHTS IN THE UK

Although the service sounds attractive, Health Link [<http://www.health-link.org.uk>], a non-profit organisation that aims to strengthen public influence in the NHS, warned in one of its publications, *The Challenge of Choice* [<http://www.health-link.org.uk/publications/fileupload/index2.php>], published in April 2004, that a service has to be accessible to all—and not just available to some—if it is to be judged a real improvement. More often than not, argued the Health Link document, new services encounter lower-than-expected uptake among people who are poor, or of ethnic origin, or who are not fully literate. The literacy skills of no less than seven million adults in the UK fall below those expected of an ordinary 11-year old. Therefore, the introduction of the new Section 11 duty to consult and involve patients means that the NHS' relationship with its community (especially on patient choice) will have to be completely recast, Health Link concluded.

■ **PATIENT CONFIDENTIALITY AND ACCESS TO RECORDS**

Patients have a right to expect that information about them is managed under legal and ethical conditions of **confidentiality**—that is, personal data should not be used or disclosed in any manner capable of identifying a patient (unless that patient has first given consent). Weaknesses in the way that parts of the NHS handled confidential patient data were identified in the *Caldicott Report* [<http://static.oxfordradcliffe.net/confidential/gems/caldrep.pdf>], published in December 1997. The report's recommendations included the appointment of 'Caldicott Guardians'—NHS staff with a responsibility to ensure that patient data is kept securely. NHS guidelines on the confidentiality of patient data were introduced in 2003.

Access to the health records of living patients is governed by the Data Protection Act 1998, which came into force in the UK in March 2000. As of that date, the public were given the right to access all their manual and electronic medical records (though the right could be overruled by a healthcare professional who considered that such an acquisition would harm the patient or another individual). Many patients (particularly older people) are believed to be unaware of their right to see their own medical records. Large numbers of other patients are known to be too afraid of potentially causing offence to their doctor by asking to see their record. Other hindrances to the exercise of this patient right include:

- The often slow, cumbersome, and bureaucratic nature of the procedures entailed in releasing records.
- A fee (payable if copies of the records are required).
- The sometimes scarcely-veiled air of disapproval still radiated on occasion by certain medical support staff involved in releasing records.

Even when records are provided, the patient can still be disappointed—crucial sections may be missing, with little apparent reason why.

SO, WHAT RIGHTS DO NHS PATIENTS HAVE?

SO, WHAT RIGHTS DO NHS PATIENTS HAVE?

The Labour Administration has forced the NHS to adopt reforms that might be of benefit to patients. Since the current government came to power in May 1997, countless laws, guidelines, frameworks and policies have been dedicated to the achievement of that goal. Yet, despite the legislative flurry, patients in the UK are afforded only the following few rights:

- A UK citizen is entitled to receive **free treatment** [excluding prescription charges] **and access to primary and secondary care within the NHS**. Members of the public may select their GP practice, but they must live within their chosen practice's catchment area. As noted on the previous page, the government has pledged that NHS patients needing secondary care will be allowed a limited choice of hospitals, as of December 2005.
- UK citizens have a **legal prerogative to see their medical records**, outlined in the Data Protection Act of 1998 (which, as mentioned above, came into force on March 1st 2000)—implementing EC Directive 95/46/EC on the protection of individuals with regard to the processing of personal data and on the free movement of such data. UK citizens have a right to a copy of their medical records if they are willing to pay the costs of reproducing the material incurred by the holding organisation.
- UK citizens can obtain an **appropriate response to their complaints**, as stipulated in the NHS Redress Bill of 2005. This Bill aims to reform handling of lower-value clinical negligence cases in the NHS, to provide appropriate redress, including investigations, explanations, apologies and financial compensation where appropriate, without the need to go to court.
- Several high-profile court cases over the past decade have clarified doctors' responsibilities to obtain **informed consent** from patients. Doctors who do not provide enough information about the potential treatment, or obtain such consent, have been considered negligent. Patients also have the right to refuse treatment, in most circumstances.
- In principle patients are entitled to get any **information about the NHS** under the Freedom of Information Act 2000.
- Finally, the **packaging of any prescription medicine treatment is legally required to contain a patient-information leaflet (PIL)**, the content of which is specified by EU legislation [Directive 2001/83/EC] and implemented by the Medicines and Healthcare products Regulatory Agency (MHRA).

Aside from these prerogatives, patients in the UK have no other concrete entitlements.



FEATURE: WHY THE EU MAY PICK UP THE BANNER OF PATIENTS' RIGHTS

The European Union has limited responsibilities in matters of health and health policy. Article 152 of the EC Treaty (2002) allows the EU to legislate only on issues of blood safety, organs, and products of human origin, and phytosanitary and veterinary health.

Any harmonising legislation in the area of public health is strictly limited by the notion of 'subsidiarity'—the EU term for not obstructing the Member States' national responsibilities. All liability for the provision of healthcare services falls entirely with individual Member States. The EU may only complement national policies in relation to improving public health, preventing human illness and diseases, and reducing sources of danger to human health.

THE IMPACT OF THE EUROPEAN CONSTITUTION

However, the influence of the EU over national matters of healthcare may increase after ratification of the European Constitution. The Constitution sets into one measure the structure, operation, scope, responsibilities, and rights of the European Union and its citizens, and is scheduled to come into force on November 1st 2006. The measure will give legal weight to the European Charter of Fundamental Rights adopted at the Nice European Council in December 2000. These fundamental rights will be legally binding on the Union, its institutions, agencies and bodies, and on the Member States (but only with regard to the implementation of EU law).

In particular, Article II-95 of the Constitution provides:

"Everyone has the right of access to preventive healthcare, and the right to benefit from medical treatment under the conditions established by national laws and practices. A high level of human health protection shall be ensured in the definition and implementation of all Union policies and activities."

The ratification of the Constitution may therefore encourage the EU to boost its remit in healthcare, and make decisions that will have more impact on Member States' healthcare policies than ever before.

The Constitution also contains many other provisions that relate, to some extent, to the following patients' rights: concerning human dignity (II-61); the right to life (II-62); the right to the integrity of the person (II-63); the right to security (II-66); to the protection of personal data (II-68); to non-discrimination (II-81); to cultural, religious

FEATURE: WHY THE EU MAY PICK UP THE PATIENTS' RIGHTS BANNER

The WHO and the EU are looking into the effects that national under-investment in healthcare might have on a country's economic performance and the personal wellbeing of its citizens.

The October 2005 European Health Forum, Gastein, Austria, noted the importance of government expenditure on healthcare: "There is evidence that investing in health brings substantial benefit also for the economy. The WHO has concluded that an increase of 10 years in average life expectancy leads to a growth of 0.35% in a country's GDP. On the other hand, ill health is a heavy financial burden. 50% of the growth differential between rich and poor countries is due to the impact of ill-health and reduced life expectancy."

"A change is taking place: health expenditure can no longer be considered a burden, but must be seen as an investment in the future of a country."

"Good healthcare is identified as a factor that promotes greater participation in the labour market, a longer working life, higher productivity, and lower healthcare and social costs. Investment in health infrastructure plays a significant role in developing human capital. The return on investment is people's wellbeing and a healthy workforce."

In other words, keeping populations healthy produces dividends at a national level.

and linguistic diversity (II-82); to fair and just working conditions (II-91); to social security and social assistance (II-94); to environmental protection (II-97); to consumer protection (II-98); to the freedom of movement and of residence (II-105); the rights of the child (II-84); the rights of older people (II-85); and the rights of people with a disability (II-86).

THE EUROPEAN COMMISSION IS ACTIVE IN SEVERAL PATIENT-RELATED AREAS

The European Commission is already showing an interest in the following patient-related areas—and for reasons other than those of health policy:

■ PATIENT MOBILITY

During 2003, the Commission conducted a consultation procedure in which anyone involved in the concept of patient cross-border mobility was invited to share their views with the organisation. The results of the project backed the argument that European patients should have the freedom to move between Member States in search of healthcare. Healthcare providers, the Commission deems, ought to be allowed to impart their services to all EU citizens. Recent test cases at the European Court of Justice have established the case law surrounding the provision of medical care to patients from other countries. One specification insists that if a patient needs medical treatment which can only be obtained from another Member State, then the home state should reimburse the cost of the treatment.

Such a right can, of course, be difficult for patients to apply. They would first need to obtain information about the quality and suitability of the available treatment, and then about how to achieve payment from the national healthcare system or health insurer. Patient mobility does, however, yield a clutch of advantages for national healthcare systems, including:

FEATURE: WHY THE EU MAY PICK UP THE PATIENTS' RIGHTS BANNER

- Allowing healthcare providers to exploit the spare capacity of other Member States.
- Enabling the growth of networks of excellence, particularly in new health technologies.
- Aiding the exchange of best practices.

■ PATIENT SAFETY

Patient safety is another subject generating interest at the European Commission. The topic is one of seven key issues on the agenda of an EU High-Level Group on Health Services and Medical Care. The High-Level Group was set up following the Commission's 2003 consultation period on patient mobility, is concerned with health services and medical care. Its objective is to explore the potential for cross-border collaboration on national health policies. Other matters on the Group's agenda are: cross-border healthcare purchasing and provision; recruitment, quality assurance, and migration of health professionals; development of European centres of reference [for instance, for conditions requiring specialised care and a limited number of patients]; assessment of health informatics technology; an overall health information strategy to address the availability of e-health services; and impact assessment of other EU policies on health. Some of these considerations will have a bearing upon patients' rights.

■ HEALTH AND CONSUMER PROTECTION

The third area of relevance to patients' rights presently absorbing the Commission's attention is health and consumer protection. This subject is now the focus of an EU 'action programme'—a proposal from the Commission for European Community action in the fields of health and consumer protection during 2007-2013. The project, if accepted, will build on and develop two existing EU schemes on public health and consumer protection, concentrating on the following consumer issues:

- ▶ Protecting citizens from risks and threats which are beyond the control of individuals, and which cannot always be effectively tackled by individual Member States alone (such as health threats, unsafe products, and unfair commercial practices).
- ▶ Increasing the ability of citizens to take better decisions about their health and consumer interests.
- ▶ Putting health and consumer issues at the centre of policy-making.

FEATURE: WHY THE EU MAY PICK UP THE PATIENTS' RIGHTS BANNER

In the area of public health, the programme proposes the following objectives:

- Protecting citizens against health threats.
- Promoting policies that lead to a healthier way of life.
- Contributing to efforts to reduce the incidence of major diseases in the EU.
- Encouraging national health systems to be more effective and efficient by fostering cooperation between them, and by providing health information and analysis.

Bridging health inequalities, and addressing the problems of ageing populations and children's health are all expected to be priority themes.

Useful sources of reference on the EU and patients' rights issues

- ▶ http://europa.eu.int/scadplus/constitution/index_en.htm
- ▶ <http://europa.eu.int/eur-lex/lex/JOhtml.do?uri=OJ:C:2004:310:SOM:EN:HTML>
- ▶ http://europa.eu.int/comm/health/ph_overview/co_operation/mobility/high_level_hsmc_en.htm



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