

HEALTH AND HUMAN RIGHTS

A GUIDE TO THE HUMAN RIGHTS ACT 1998

Jeremy Croft



The Nuffield Trust
FOR RESEARCH AND POLICY
STUDIES IN HEALTH SERVICES

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Foreword by John Wyn Owen CB

Human Rights



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59 New Cavendish Street
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Telephone: 020 7631 8450
Facsimile: 020 7631 8451

E-mail: mail@nuffieldtrust.org.uk
Website: www.nuffieldtrust.org.uk

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FOREWORD

Following the passing of the Human Rights Act in 1998 the Nuffield Trust organised a seminar on human rights and health with the help of the Constitution Unit of the School of Social Policy at University College London. At the seminar it became quite clear that health policy makers and practitioners were in need of guidance on the practical implications of the Act, which came into force in October 2000. The Trust therefore invited the Constitution Unit to assess the implications of the Human Rights Act for healthcare in the United Kingdom, and produce practical guidance on the implications of the Act, tailored to the needs of health policy makers, different healthcare professions and service users. This guide examines the manner and the extent to which the Human Rights Act 1998 may impact on the provision of health care in the UK. It explains the workings of the Act and the nature and significance of the rights contained in the European Convention on Human Rights which the Act has made part of our domestic law.

This guide is also relevant to a number of other Trust initiatives, such as the Buckingham Declaration on Care of the Dying and the NHS: the Human Rights Act relates to fundamental choices and decisions, particularly difficult end-of-life decisions. The Trust's project on the need for a modern public health bill for the United Kingdom points to the importance of giving serious consideration of human rights in connection with public health goals and the need, as Larry Gostin explains, to "revisit the issues of ethics and community and individual or collective freedoms". And the Trust's Policy Futures for UK Health project's second report, to be published in May 2005, will also demonstrate the importance of human rights in the context of health policy forward to 2020.

John Wyn Owen CB
Secretary
Nuffield Trust
February 2004

1. INTRODUCTION

- The Human Rights Act 1998 is a crucial development in the legal and constitutional history of the United Kingdom. It reaches into every area and activity of public life. Health care is no exception.
- This guide examines the manner and extent to which the new Human Rights Act 1998 (HRA) may impact upon the provision of health care in the United Kingdom. It explains the workings of the HRA and the nature and significance of the rights contained in the European Convention on Human Rights (ECHR) which the Act has made part of our domestic law.
- Health care is an increasingly litigious environment. This guide cannot substitute for legal advice in the course of any proceedings where Convention rights come into play. It can, however, help health care professionals to identify those areas where such issues are likely to arise. And it offers advice and strategies on how best to fulfil obligations under the Convention when making decisions (for example, on treatment and the allocation of resources) that could reduce the risk of later legal challenge.
- The Human Rights Act is more than a legal tool. It is the means by which a new ‘human rights culture’ of rights and responsibilities is being introduced in the UK. The guide considers the importance of the HRA as a vehicle for developing respect for human rights as ‘good practice’ within the health care sector.
- Health has long been recognised as an essential precondition for the capacity to realise and enjoy human rights and dignity. Health care and human rights offer complementary approaches to protecting and promoting human well being. The guide considers such questions as:
 - what is the *right to health* and how does it relate to the new legal framework established by the HRA and ECHR in the UK;
 - why public health care professionals should be concerned about respecting human rights; and

- how to reconcile and balance respect for human rights with public health goals.
- To the end of 2002, the Human Rights Act has generated a limited amount of case law in areas relevant to health care. The Government prepared thoroughly for the introduction of the Act. Its emphasis, during the preparation phase, on risk management has proved to be very effective in restricting the likelihood of breaches of the Convention being identified in the courts. This trend is likely to continue. At the same time, through the HRA, Convention rights have become part of the 'litigation scene' and a major factor in those cases dealing with social or ethical matters that often transcend Government policy. Health care has been shown to be just such an area. This is seen, most obviously, in the series of cases since October 2000 addressing extraordinarily difficult 'end of life' decisions. Convention rights have been fundamental to the choices and decisions made on these occasions.

2. THE RIGHT TO HEALTH

2.1. What is the 'right to health'?

- Health is a fundamental human right and an indispensable pre-condition for the enjoyment of other human rights.
- The Human Rights Act 1998 and the European Convention on Human Rights do not establish a *right to health* in the UK. For that you must look elsewhere in other international instruments that the UK has undertaken to observe. The most important are listed at Annexe A.
- These other instruments do not have the same force of law before domestic courts as the HRA and ECHR. However, the latter offer the most effective enforcement mechanism available to an individual in the UK, creating a strong imperative in litigation to make health matters fit within their sphere. While compliance with the HRA and ECHR does not mean the same as the realisation of the *right to health*, therefore, they now provide the fulcrum in the UK for the resolution of individual complaints on health and human rights matters.
- There are three aspects to the *right to health* enshrined in international instruments on human rights:
 - the declaration of health as a fundamental human right;
 - the setting of standards to meet the health needs of specific groups; and
 - the prescription of ways and means to implement the right to health.
- The *right to health* guarantees that every human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life of dignity. The preamble to the Constitution of the WHO defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”. The *right to health* is not a right to be *healthy*. Reference to the “highest attainable standard of health”

acknowledges that susceptibility to ill health will differ according to individuals, social conditions and the resources available for health care. Allowance is made, therefore, for the progressive realisation of the *right to health*.

- Health care policy has long been informed and shaped by respect for human rights. Health and human rights offer complementary approaches advancing human ‘well-being’ with an ‘added value’ gained by incorporating a human rights perspective in health care. This stems from the obligations accepted by Governments to **respect, protect and fulfil** the human rights of persons within their jurisdiction:
 - **To respect:** requiring a Government to refrain from interfering directly or indirectly with the enjoyment of human rights which means no health practice, policy, programme or legal measure should violate human rights. And the provision of health care should be available to all on an equal and non-discriminatory basis (while still paying special regard to vulnerable groups).
 - **To protect:** imposing obligations on a Government to prevent third parties (which may include private health care providers and health insurance companies) from interfering with human rights.
 - **To fulfil:** requiring a Government to adopt appropriate legislative, administrative, budgetary, judicial, promotional and other measures to achieve full realisation of the *right to health*.
- The relationship between health and human rights is not always harmonious. The achievement of public health goals especially concerning the prevention and treatment of infectious diseases can require limitations on individual freedoms and rights. The protection of public health is recognised, therefore, as an area where it may be necessary to curb individual human rights (and such provision is made in the ECHR) provided that this is not done in an arbitrary manner.

2.2. Realising the ‘right to health’ in the UK

- Within Europe, the Council of Europe (see section 3.1 below) establishes its right to protection of health in the European Social Charter (not the ECHR). Rights contained in the Charter are not directly enforceable in UK courts although there may be rare occasions where judges will consider them in determining issues raised under the ECHR. Compliance with the European Social Charter involves the submission of periodic reports for analysis by a Committee of Independent Experts. The Committee has indicated that a State will be considered to comply with the right to protection of health if it provides evidence of the existence of a medical and health system which offers:
 - adequate and generally available public health arrangements giving proper medical care for the whole community and ensuring the prevention and diagnosis of disease;
 - special measures to protect the health of mothers, children and the elderly; and
 - general measures aimed at the prevention of air and water pollution, protection from radioactive substances, noise abatement, food control and environmental hygiene,

vaccination programmes, a comprehensive school health service and the control of alcoholism and drugs.

- Other treaty monitoring bodies have expanded on the meaning of the *right to health*. Most influential are the views of the United Nations Committee on Economic, Social and Cultural Rights. The Committee focuses on the steps to be taken to realise the right to health, legal obligations and performance indicators. Again, the UK must indicate how it conforms to these requirements through the submission and examination of reports. There is no avenue, at present, for individual complaints relating to the International Covenant on Economic, Social and Cultural Rights to be taken before the Committee or, for that matter, the domestic courts.

The Human Rights Act and European Convention on Human Rights do not themselves establish a *right to health* in the UK.

- The realisation of the international *right to health* is set out in other instruments but these cannot be directly enforced in domestic courts. The absence of a legal remedy does not diminish the importance of the *right to health* but reflects that the right must be achieved in other ways most notably through the allocation of resources.
- The availability of an effective enforcement mechanism under the HRA and ECHR creates a strong incentive for those with grievances on health and human rights matters to frame their complaints to fit within the scope of these instruments.
- Compliance with the HRA and ECHR by health care providers is not the same as realising the *right to health*.

3. HUMAN RIGHTS ACT 1998 AND THE EUROPEAN CONVENTION ON HUMAN RIGHTS

- The Human Rights Act 1998 incorporates the provisions of the European Convention on Human Rights into UK domestic law.
- It is unlawful for a public authority (including those in the health field) to act in a manner incompatible with the rights contained in the ECHR.
- All legislation must be interpreted and implemented in a way that is compatible with the HRA.
- A person who feels that his or her Convention rights have been infringed may seek redress in the courts.
- The courts may use their existing powers (grant an injunction, award damages etc) to remedy a breach of the Convention.

3.1. European Convention on Human Rights

- The European Convention on Human Rights (ECHR) is a treaty of the Council of Europe – an organisation of European states established in the aftermath of the Second World War. The Council is a loose knit organisation with a broader membership than the European Union.
- In 1951, the ECHR was promulgated to prevent a repeat of the horrors of the Second World War (a period that saw the misuse of medical skills to conduct inhuman experimentation and forced sterilisation). The ECHR was the first human rights treaty to be enforced by an international court – the European Court of Human Rights (ECtHR) in Strasbourg. The Convention now applies to some 41 European countries protecting over

800 million people. It guarantees a developing range of civil and political rights (see Annexe B).

- Individuals in these countries who believe that their Convention rights have been breached may take their case to Strasbourg once they have exhausted all available domestic remedies. Decisions of the Strasbourg court are accepted as binding by the UK Government. However, the process of taking a case to Strasbourg is often slow. It may take up to 8 years before a case is decided.

3.2. The conceptual approach of the ECHR

- The ECHR is a 'living instrument' interpreted by the Strasbourg court in a broad, practical and effective manner which guarantees Convention rights according to present day conditions. Limitations to these rights are interpreted narrowly although a broad discretion (known as the 'margin of appreciation') is granted to domestic authorities in deciding the social standards and norms on which limitations are based in individual European countries.
- Convention rights are formulated as:
 - **Absolute rights** – rights which permit no compromise or infringement (eg. Article 3–the prohibition of torture);
 - **Limited rights** – rights applied in clearly defined sets of circumstances (eg. Article 6–the right to a fair trial); and
 - **Qualified rights** – rights where a balance may need to be struck with the broader public interest or the rights of others (eg. Article 8–the right to respect for private and family life).
- Interference with a **qualified right** is permissible only if what is done:
 - has a basis in law;
 - is done to secure a permitted aim of the Convention Article (eg. the protection of public health); and
 - is 'necessary in a democratic society'.
- For interference to be authorised by law:
 - there must be an identifiable legal basis for the restriction (this can include the common law but not codes of practice or internal guidance); and
 - the law must be accessible and understandable.
- The phrase **necessary in a democratic society** is not defined in the ECHR. It is given a purposive interpretation in accordance with the living instrument philosophy of the Convention. The two most important elements are that the restriction has:
 - a legitimate aim; and

3. HUMAN RIGHTS ACT 1998 AND THE EUROPEAN CONVENTION ON HUMAN RIGHTS

- is proportionate to the objective being pursued.
- **Proportionality** is the most crucial concept in the Convention. It is the means by which the Strasbourg court seeks to strike a 'fair balance' between the rights of an individual and the legitimate rights of others and the needs of society. Even where there is a legitimate purpose in restricting a Convention right, therefore, it must be shown that the actual restriction does not go beyond what is strictly necessary to achieve that purpose.
- To decide questions of proportionality, the Strasbourg court considers:
 - whether relevant and sufficient reasons for the restriction have been advanced;
 - whether there is a less restrictive alternative;
 - evidence of procedural fairness in the decision-making process;
 - what safeguards exist against abuse; and
 - whether the restriction accords with the essence of the right.
- Under the Human Rights Act, UK judges are now expected to be guided by Strasbourg case law in determining Convention issues raised in the domestic courts. Hitherto, the actions of UK public authorities could only be successfully challenged by way of judicial review on the grounds that they were unreasonable or irrational. In the words of Lord Diplock:

“a decision which is so outrageous in its defiance of logic or accepted moral standards that no sensible person who applied his mind to the question to be decided could have arrived at it.”
- With the HRA in place, the way is open for UK judges to consider the merits and proportionality of administrative decisions. As put by Lord Phillips, Master of Rolls in *R (Mahmood) v Secretary of State for the Home Department* [2001]:

“When anxiously scrutinising an executive decision that interferes with human rights, the court will ask the question, applying an objective test, whether the decision-maker could reasonably have concluded that the interference was necessary to achieve one of the legitimate aims recognised by the Convention.”
- There is no 'margin of appreciation' before the domestic courts but judges talk of recognising a 'discretionary area of judgement' in which they will defer to the specialist knowledge of decision-making bodies. At the same time, the obligation on judges to assess the proportionality of decisions means that these will be subject to a greater 'intensity of review' than was the case under the former 'reasonableness' test.

3.3. Why have a Human Rights Act?

- The UK was one of the last members of the Council of Europe to allow its domestic courts to make use of the ECHR. Incorporation of the ECHR or Convention rights was long considered a radical step to take because it would restrict the power of Parliament

and place a measure of that power in the hands of unelected judges. The essential dilemma in the UK, therefore, has been how to protect rights in the most effective manner possible and preserve, at the same time, democratic decision-making. There was no question of introducing entrenched rights in a written constitution binding on the Government and Parliament (as seen in Canada and South Africa). At the same time, there was no purpose in toothless legislation that posed no check on the actions of the Government and Parliament and could not achieve the stated aim of 'bringing rights home' from Strasbourg.

3.4. What does the Human Rights Act do?

- The Human Rights Act, enacted in the first term of the new Labour Government, steers a 'middle course' in extending the ways in which ECHR can be used before domestic courts. The Act makes it unlawful for any public authority to act in a manner incompatible with the rights contained in the ECHR. There is a general requirement that all legislation (past, present and future) be read and implemented in a way that is compatible with the ECHR. A person who believes that their Convention rights have been infringed by a public authority may challenge this in the courts (either directly or in the course of other proceedings – criminal trial, judicial review etc). A public authority will not have acted unlawfully if it could not have acted differently because of the requirements of primary legislation. The higher courts may, however, rule such legislation to be incompatible with the Convention with the expectation that the Government and Parliament will remedy the incompatibility.

3.5. Who is helped and how?

- Only **victims** (which may include corporate bodies) of breaches of Convention rights can bring proceedings under the Human Rights Act. Cases must be brought within one year of the alleged breach unless a court finds good grounds for an extension of time. However, if there is a stricter time limit for the type of proceedings involved that limit will apply (eg. an application for judicial review would normally need to be made within three months). Proceedings may be brought before the court or tribunal best placed to deal with the substance of the complaint (eg. a complaint concerning welfare benefits would normally start in the Social Security Appeal Tribunal). If proceedings are being brought by a public body (eg. a criminal prosecution) the 'victim' may rely on the Convention irrespective of when the events took place.
- The Human Rights Act does not create new powers for the courts. If a breach of a Convention right is found, a court or tribunal may use its existing powers to put right the complaint. These powers include the ability to:
 - quash the offending decision;
 - declare a policy illegal;
 - grant an injunction; and
 - award damages or compensation.

3. HUMAN RIGHTS ACT 1998 AND THE EUROPEAN CONVENTION ON HUMAN RIGHTS

- The Human Rights Act extends the power to award damages for a breach of the Convention to any court that has the power to order payment of compensation in a civil case. The court must follow the same criteria as the European Court of Human Rights which makes comparatively modest awards but which do cover both actual loss and moral loss (eg. anxiety or distress). Damages were awarded in only one case concerning a breach of the Convention before the UK courts in 2001. However, damages are a common feature of judgements of the Strasbourg court.
- Higher courts may make a 'declaration of incompatibility' to signify that primary legislation is in breach of the Convention. The Government may then choose to respond by way of a special 'remedial order' procedure in Parliament to correct the breach. However, it is not obliged to do so.
- Use of the 'declaration of incompatibility' and 'remedial order' procedure is rare and likely to remain so. The only remedial order introduced to the end of 2002 made amendments to the Mental Health Act 1983. Its use was not straightforward. (See Annexe C)

In March 2001, the Court of Appeal found Sections 72(1) and 73(1) of the Mental Health Act 1983 to be incompatible with Article 5 of the ECHR.¹ This was because of the manner in which the provisions placed the burden of proof on a patient to show that he was no longer suffering from a mental disorder warranting detention in order to be able to satisfy the mental health review tribunal that he was entitled to discharge. The Court of Appeal ruled that the shifting of the burden of proof to the patient did not allow the legislation to be construed in a manner that would guarantee his right to liberty under Article 5 and a declaration of incompatibility was made. The essential question was the nature of the test to be applied when determining a patient's entitlement for release. Lawyers for the Department of Health conceded that the same approach had to be applied when considering whether to admit a patient and when considering whether the patient's continued detention was lawful. The test was, therefore, whether it could be reliably shown that the patient suffered from a mental disorder sufficiently serious to warrant detention. Because Sections 72(1) and 73(1) of the Mental Health Act did not require the mental health review tribunal to discharge a patient if that could not be shown, they were incompatible with Articles 5(1) and 5(4) of the Convention.

- Limits have been set on the extent to which judges will find reason under the HRA and ECHR to reinterpret the will of Parliament. Judges have used Section 3 of the HRA on several occasions to reinterpret or 'read down' legislation to make it compatible with the Convention. In (1) *W & B (Children)*, (2) *B (Children)*², for example, the Court of Appeal 'read in' new powers of action by the courts under the Children Act 1989 in order to eliminate the potential for breaches of Articles 6 and 8 of the ECHR in the course of care proceedings. The powers would have given judges greater flexibility in the making of interim care orders and to intervene should important aspects of a care plan not be

1. *R v (1) Mental Health Review Tribunal, North and East London Region (2) Secretary of State for health, ex parte H* [2001] CA. 3 WLR 512.

2. (1) *W & B*, (2) *B* [23 May 2001] CA. T.L.R. 7 June 2001.

achieved, for example, because of changes in circumstances. However, in March 2002 the House of Lords upheld an appeal by the Secretary of State for Health on the grounds that the decision of the Court of Appeal had crossed the boundary between interpretation and amendment of the Children Act in seeking to give the courts additional powers to supervise care orders.

3.6. Who is covered by the HRA?

- All public authorities are required to act in a manner compatible with the HRA and ECHR [Section 6(1) of the HRA]. The term ‘public authorities’ is broadly defined in Section 6(3) of the Act and includes:
 - a court or tribunal; and
 - any person certain of whose functions are of a public nature.
- The HRA therefore applies to all Government departments, public authorities and certain private organisations (referred to as ‘hybrid bodies’) insofar as they perform public functions.
- Health authorities, NHS Trusts, Primary Care Trusts and their employees (while performing NHS work) are all public authorities for the purposes of the HRA. Bodies created by statute such as the National Institute for Clinical Excellence and the Commission for Health Improvement also fall within this category. Regulatory bodies such as the General Medical Council and the Royal Pharmaceutical Society Great Britain similarly fall within the scope of the HRA. Organisations set up to represent the health care professions such as the British Medical Association and the Royal Colleges do not.
- Private hospitals paid by the NHS to carry out work that the NHS cannot provide may be considered to be performing a public function under the HRA. Private hospitals or NHS doctors carrying out work under private health insurance schemes are unlikely to be covered by the HRA.
- In the case of *Regina (A) v Partnerships in Care Ltd*,³ the court considered that the decision of a private psychiatric hospital to change the use of one of its wards was an act of a public nature capable of judicial review. The court did not find that the statutory obligations of the health authorities had been assumed by the private hospital in providing care and treatment to patients with mental disorders. Rather, there were statutory obligations under the Registered Homes Act 1984 that put a direct duty on the hospital to provide adequate professional staff and adequate treatment facilities. The court noted:

“the need for the hospital’s patients to receive care and treatment which may result in their living in the community again is a matter of public concern and interest.”

Taking account of its functions, therefore, the hospital was held to be a hybrid public body.

3. *Regina (A) v Partnerships in Care Ltd* [2002] QBD.T.L.R. 23 April 2002.

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- GPs, although private contractors, are closely connected to the NHS by their terms of service, medical service directions and disciplinary code. It is likely that the treatment decisions and activities of an individual GP will not be considered to be those of a public authority within the meaning of the HRA. As at the end of 2002, however, this point has not been argued in the courts. It is clear that if GPs' individual decisions are driven by the policy of a Trust or Health Authority the patient would have redress against that body. And, when GPs combine to form Primary Care Trusts, as part of the rearrangement of health care purchasing and the strengthening of primary health care, they would become bodies of a public nature. Systems for supervising and handling complaints against GPs are also likely to come within the remit of the HRA. In these broader contexts, GPs would be considered 'public authorities'. The same would follow for dentists, opticians and pharmacists.
- The HRA may also apply in proceedings before a court or tribunal between a GP or private hospital and a patient, not involving NHS treatment, because of the obligation on the court or tribunal to act in a manner compatible with the HRA and ECHR. This is referred to as the 'horizontal effect' of the HRA. Whether the HRA exerts a 'horizontal effect' in the field of health care has not been tested, as at the end of 2002, in the courts. That there is such a principle, however, has been established in the case of *Wilson v First County Trust*. [2 May 2001] CA.
- Residential or nursing homes providing care for elderly persons with social services or NHS funding have been considered public authorities for the purposes of the HRA. However, in a case concerning the Leonard Cheshire Foundation (a charity providing residential care and support services for the disabled), the courts held that the charity was not a public authority under Section 6 of the HRA.

As no exhaustive definition is contained in the HRA, who is to be treated as a public authority falls to the courts to decide.

In *Popular Housing and Regeneration Community Association v Donoghue* [2001] 3 WLR 183, the Court of Appeal rejected the argument that simply supplying accommodation which would otherwise fall to the local authority rendered a housing association a public authority. However, given the proximity of the relationship between the housing body and the local authority, the court found that in providing rented accommodation on behalf of the local authority the housing association was a hybrid public body under the Human Rights Act.

In *Austin Hall Building Limited v Buckland Securities Limited* [2001] BLR 272, the court did not accept that an adjudicator appointed under the Housing Grants Construction and Regeneration Act 1996 was a public authority.

In *Callin v Leonard Cheshire Foundation* [2002] EWCA Civ 366, the applicants challenged the decision of the charity to close the residential home in which they lived. It was submitted that the Leonard Cheshire Foundation exercised public functions given that it received public funding, the home was state regulated, and that, had care not been provided by the Foundation, it would have been provided by the state. However, the

court held that state funding and regulation and the fact that local authorities were permitted to contract out the provision of services to third parties did not mean that the charity exercised public functions for the purposes of the HRA. This is an important ruling restricting the potential reach of the HRA. Leave to appeal to the House of Lords was refused in November 2002.

More recently, in *R v Hampshire Farmers Market ex parte Beer* [2002] EWHC 2559 Admin, the Administrative Court found that a private company running a farmers market was a functional public authority under the Human Rights Act. Although Hampshire County Council had set up the company to run the market, the court did not base its decision on the relationship between the company and the council. Instead, it considered the company to be public in nature because it “was a not-for-profit organisation engaged in promoting the public interest by facilitating access to trading outlets much needed by Hampshire’s farmers and producers” and because the virtual monopoly which the company enjoyed on weekend markets in the area meant farmers were dependent on it to sell their produce.

- The *Leonard Cheshire Foundation* case suggests that a private body performing public functions will not automatically fall within the scope of the Human Rights Act. Case law will clearly need to be watched and legal advice obtained, as the need arises, in this area. However, where there is doubt it is prudent to work on the assumption that a body is bound by the requirements of the Human Rights Act (until shown otherwise). This will mitigate the risk of legal challenge which may be costly and time consuming even if thrown out. Such an approach will also serve to implement the new ‘human rights culture’ proposed for the UK by respecting Convention rights as good organisational practice.

The Department of Health gives the following examples of public authorities in the health care field:

- NHS Trusts
- Private and voluntary sector contractors when undertaking public functions under contract to the NHS
- Local authorities, including Social services
- General Practitioners, dentists, opticians and pharmacists when undertaking NHS work
- Primary Care Trusts
- A body that has functions of a public nature (eg. a professional regulatory body), even if it had private functions.
- A body that has both public and private functions will be a public authority only in relation to its public functions (eg. bodies in the private sector who provide private health or social care but who also contract to provide health or social care for the NHS and Local Government, will be public authorities when providing health or social care under the NHS and Social Services).

4. IMPLEMENTING THE HUMAN RIGHTS ACT

- Implementing the HRA is not just a matter for lawyers.
- All public organisations and employees are expected to exercise ownership of human rights matters in their work areas.
- The HRA and ECHR also pave the way for the introduction of a new human rights culture as 'good practice' in all public sector organisations.
- Policy and decision-making must be conducted in ways that respect and observe the requirements of the HRA and ECHR.
- If this is done, the risk of being successfully challenged in the courts is very small.

4.1. A new approach

- The Government has determined to 'mainstream' the requirements of the HRA and ECHR placing the responsibility for and ownership of human rights matters on each and every public body and employee.
- Health care professionals and organisations make decisions every day that have to strike a balance between individual human rights and the more general interests of society.
- Under the Human Rights Act it is no longer the case that actions are permissible unless prohibited by law. Instead decision-makers need to consider:
 - Are an individual's human rights involved?
 - If so, can they be legitimately interfered with?
- Health care organisations must be able to demonstrate that what they do:

- Is based in law (expressed in clear and accessible terms);
- Has a legitimate aim (eg. protection of health);
- Is proportionate to that aim (does not use a 'sledgehammer to crack a nut').
- Health care organisations will need to record how the decisions they take satisfy the requirements of the HRA and ECHR. Good record keeping is essential in order to show why decisions were made should actions (or inaction) later be challenged in the courts.
- The courts have usually taken the view that health care organisations are best placed to exercise judgement and discretion over medical care. The courts have been reluctant to interfere with clinical decisions. However, health care organisations will have to be able to now demonstrate and justify that the decisions they take were cognisant of, and comply with, the requirements of the HRA and ECHR.
- The NHS is already a litigious environment. The HRA and ECHR are not generating many new or original ('free standing') human rights challenges. Human rights issues are being argued, however, as a 'make weight' in existing litigation. Areas affected include:
 - how clinicians practice;
 - access to NHS treatment; and
 - the management of staff.

4.2. Policy making and decision taking

- In developing policies and procedures or taking decisions on individual patient care, health care professionals need to be aware of the manner in which the HRA and ECHR could apply. Questions that should be in mind are:
 - what is the authority for the action or decision being taken?
 - Does the action or decision touch on a Convention right (is it vulnerable to challenge)?
 - Does the action or decision directly affect an individual who may have cause to complain (is there a genuine risk of challenge)?
 - Have you any discretion or choice in making the decision or taking action?
 - Are there grounds (set out in the Articles of the ECHR) for interfering with an individual's rights for the action or decision in question?
 - Would a failure to act, or not to take a decision, potentially infringe the requirements contained in the ECHR to take positive steps to protect and secure a person's Convention rights?
 - If there is interference with a person's Convention rights, is this being done in accordance with the law and in pursuit of a legitimate aim (as set out in the Articles of the Convention)?

- Given proper legal backing and a legitimate aim, will you be acting in a proportionate manner that will cause the minimum interference under the Convention necessary to secure your purpose?
- Is this the first occasion on which such issues have arisen – what guidance is available, should you be seeking legal advice?
- Above all, a sense of realism is crucial in considering the potential impact of the HRA and ECHR when taking action or making decisions on health care matters. The courts have shown that they will not tolerate frivolous claims and are receptive to well-founded arguments that demonstrate a firm grasp of Convention issues. The HRA and ECHR are not reasons, therefore, to abstain from taking action or making decisions (indeed to do so may give rise to a legitimate complaint under the Convention). The likelihood of a challenge being made and succeeding under the HRA and ECHR remains small. This said, the courts will not hesitate to protect individual Convention rights should it be clear that you have failed to do so.
- Two checklists to assist the decision-making process are provided at Annexes D and E.

4.3. Human rights culture

- A human rights culture is not new or alien to the health care sector. Health care objectives intuitively respect human rights in putting the individual at the heart of services, policies and procedures. Increasing use is being made in the health care sector of ‘user involvement’ as a standard element of health care planning and delivery.
- The Human Rights Act is intended to help build a new human rights culture in the UK focused on the rights and responsibilities of individuals. Most importantly, this includes developing a sense of awareness and respect for human rights within all public bodies and among all public employees.
- At its simplest, the new human rights culture is about ‘being seen to be fair’ or, in the words of the Human Rights Unit of the Lord Chancellor’s Department, ‘do-as-you-would-be-done-by’. Respect for human rights equates to good organisational and management practice. In this sense, the HRA and ECHR are the floor and foundation (the minimum level of compliance) on which to build the culture.
- However, it is not a simple matter to ‘buy in’ to the new culture. In many public organisations there has been a more marked sense of ‘infliction’ than ‘conviction’ about the introduction of the HRA. Preparing for the introduction of the Act has required that changes be made to long-established policies, working practices and laws. The risk assessment and auditing exercises undertaken for the HRA have imposed demands on time and resources. Having completed these steps, few organisations would now consider the prospect of being the subject of a successful challenge under the new law in a positive light. Hitherto, a focus on compliance and the avoidance of legal challenges under the HRA has been inevitable in most organisations. However, matters should not be allowed to rest there. The HRA needs to be viewed as a positive development. One that provides a framework for a better way of working that embraces fundamental human rights in the delivery of public services.

4.4. Progress in implementing the Human Rights Act in the health care sector

- The Department of Health has published guidance (HSC2000/25) and maintains a website on the implications of the Human Rights Act for the health care sector [www.doh.gov.uk/humanrights]. Health organisations are being reminded by the department:

“You need to continue to ensure best practice, a part of which is compliance and respect for Convention rights in all your work. If you are working in partnerships with other organisations or providers, you should make sure that your partners are alert to their obligations under the Human Rights Act. The Government’s aim in bringing rights home is to bring about a culture of respect for individuals’ rights and responsibilities across the UK.”

- Health organisations are encouraged to contact the relevant policy branch or the Equalities Strategy Group in the DoH if compatibility problems with the Convention arise from legislation or central guidance. General inquiries may be directed to the Equalities Strategy Group on [mb-humanrights@doh.gsi.gov.uk].
- The NHS Litigation Authority has also published guidance on Convention case law and intends to provide a dedicated online ‘Human Rights Information Service’ which will offer an up-to-date database of human rights issues and cases [www.nhsla.com]. In the interim, some information on cases and issues is available on the DoH human rights web pages. There are also many commercial providers of such information.
- Concerns have been expressed by regulatory bodies, health care professionals and human rights groups over the adequacy of the arrangements made for the introduction of the HRA and the new culture of respect for human rights in the health care field. The last two years have been a period of significant organisation change for the health care sector. This gives rise to fears that human rights issues have become buried or lost sight of in the organisational upheaval.
- In 2001, the District Audit surveyed how some 88 local government and health organisations were implementing the Human Rights Act. The size of the health sample is not known but the findings published in May 2002 revealed that:
 - 52 per cent of health bodies had gone to considerable lengths while 42 per cent had taken no action to raise awareness of the implications of the HRA for their work;
 - 65 per cent had no clear corporate approach to responding to the HRA;
 - 61 per cent had taken no action to assess policies and practices for compliance with the HRA; and
 - only 29 per cent of health bodies had put in place a mechanism for keeping abreast of developments concerning human rights.
- District Audit observed:

“Overall we found that health bodies are not as well prepared as local government.”

*Existing Trusts are leaving themselves vulnerable to risk and new Primary Care Trusts have to meet the challenge of establishing policies and procedures that are compliant.*⁴

- In 2002, health organisations were included among some 50 bodies whose performance in the area of human rights were subject to more detailed examination by the District Audit. A key feature of these ‘Human Rights Management Arrangements Diagnostics’ was the conduct of interviews with members of staff as well as a survey of staff across the organisation. The audit process is confidential but aggregated results will be published in a further bulletin in 2003.
- The audit process is known to have identified some good human rights practice in health organisations. There were organisations that have Board approved and costed action plans and timetables for reviewing policies and procedures. Some health organisations have used the need to prepare for the Race Relations (Amendment) Act 2000 as an opportunity to review personnel policies and practices for compliance with the HRA. Others have commissioned human rights training and newsletters. Some health organisations have undertaken assessments to identify contracts where there is a risk of legal challenge and then introduced clauses into these contracts setting out the contractor’s obligations to comply with the HRA.
- However, there are also health organisations (and perhaps the majority) where it appears little has or is being done to implement the HRA. In these organisations, the implications of the HRA have still not been addressed as a governance issue, policies and practices have not been audited for compliance with the Act, there is no corporate ‘human rights’ policy and no designated ‘human rights’ official. No arrangements exist for obtaining up-to-date information on human rights issues or case law. No arrangements are in place for ensuring that external contractors comply with the HRA. Levels of awareness among staff of the implications of the HRA remain low and training, where provided, has been conducted on an ad hoc manner with no recent reinforcement. In these organisations, response rates as low as 3 per cent have been recorded for health care staff who consider that they have received adequate information on the HRA.
- More positively, the audit process for these organisations also reveals high levels of awareness among clinical staff concerning specific human rights issues (such as the right to life and avoiding degrading treatment) where such implications have been taken on board in clinical guidance and practice (provided by the relevant professional bodies such as the BMA and GMC).
- At the moment, therefore, it would seem that in the health care sector, evidence of best practice and compliance with the HRA is not to be found in organisational practice but in the clinical practice of health care professionals. The health care sector appears noticeably slower in developing institutional arrangements to address the requirements of the HRA compared to other parts of the public sector such as local government.
- Since October 2002, health organisations (hospital and primary care trusts) have been supervised by strategic health authorities reporting in turn to regional directorates in the

4. District Audit – ‘The Human Rights Act. A Bulletin for Public Bodies’. [2002]. P2.

Department of Health. Human rights have no firm place in this structure. For example, the performance management frameworks used by the strategic health authorities to oversee hospital and primary care trusts include racial equality indicators but not human rights indicators.

- At present, there is a marked difference to be found in the treatment of human rights and race equality matters. For example, in London, a dedicated Race Equality Group formed by the five London strategic health authorities reports to the relevant directorate of the DoH and is actively engaged in appraising the quality of the race equality schemes prepared by London health organisations. Each trust has been given a one-page assessment of the steps to be taken to implement its race equality scheme and progress will be monitored through the performance management framework. In addition, all committee and board papers are now required to have a specific section addressing racial equality implications.
- Conversely, human rights are not covered by the performance management framework, there is no dedicated 'human rights' group, no requirement to report progress in this area and no requirement to address human rights implications in committee and board papers. As a consequence, human rights are less influential in the work of health organisations.
- A similar picture is found in the work of supervisory bodies for the health care sector. For example, the Commission for Health Improvement (CHI) is beginning to address race equality issues as part of its clinical governance reviews in order to meet its obligations under the Race Relations (Amendment) Act. For the current review exercise covering primary care trusts, some 20 per cent of these trusts are being asked by the CHI for evidence of the steps they are taking to implement their race equality schemes. It does not have plans, however, to introduce similar steps for human rights.
- The apparent difference in the manner in which health organisations and professionals grasp human rights and race equality matters has been considered briefly in the context of the inquiry being conducted (2001-2003) by the Joint Parliamentary Committee on Human Rights into the need for a human rights commission for the UK. It is observed that in the health care sector there appears to be a much stronger understanding of the need to tackle racial discrimination which has been translated into action in policy development, decision-making and service delivery. To an extent, this is attributed simply to the fact that health care professionals and organisations have more understanding and experience of race equality matters. Race discrimination is an issue they can identify with and see the need to tackle. However, this focus is also attributed to the manner in which race equality issues have been brought before the health care sector. The existence of an external driving force in the form of the Commission for Racial Equality with a specific mandate and new tools (race equality schemes and race equality councils) to pursue the racial equality agenda would appear to make a marked difference. By comparison, human rights are new, less well understood, do not have an established focal point and an active external driving force.
- Immediate and practical steps that can be taken to fulfil human rights obligations feature in the regional human rights 'road shows' organised by the Human Rights Unit of the

Lord Chancellor's Department. These are well attended by health officials.⁵

- For headquarters offices, these seminars advocate:
 - make the HRA an early and central policy consideration;
 - raise awareness in your guidance and instructions;
 - consider occasional handbills, aide memoire cards etc on particular relevant Articles;
 - show this is not just for the lawyers and specialists;
 - contribute to occupational periodicals etc and training events;
 - use inspectorates/audits to help give monitoring and feedback;
 - don't forget need for continuing formal training.
- For front line service managers:
 - check adequate plain language is available to you/your staff – and ask for more if you need it;
 - query HQ guidance/instructions which do not 'mainstream' relevant Convention points;
 - exploit opportunities for shared/free training and DIY awareness training;
 - get and share the free awareness-raising posters, publicity and guidance;
 - publicise relevant cases and good practice you know about.
- Above all, the seminars emphasis the need for – '*Commitment, Commitment, Commitment*' – something which may be taken on board by all health organisations.

4.5. Checklist

- Have you seen the DoH briefing material and Health Service Circular on Human Rights (HSC 2000/025)? [www.doh.gov.uk/humanrights/]
- Have senior management (your Board) discussed the HRA and how to mainstream human rights considerations in the work of your organisation?
- Does your organisation have a person responsible for human rights matters (a human rights champion)?
- Have you and your colleagues been briefed and trained about their responsibilities under the HRA?
- Are you familiar with the updated guidance on human rights matters provided for public authorities by the Lord Chancellor's Department? [www.humanrights.gov.uk/]

5. These free seminars for public officials are advertised on the LCD and DoH websites and through the Chief Executive bulletins.

- Have you/your organisation identified and corrected any areas where practices and procedures may fail to comply with the requirements of the HRA and ECHR?
- Have you/your organisation notified partners and contractors of their responsibilities under the HRA?
- Are you updating and sharing information on human rights matters?

5. WHAT RIGHTS?

- The European Convention on Human Rights covers a range of civil and political rights (a full list is given in Annexe B). Some of these rights are unlikely to have direct application on the provision of health care. Convention rights which are particularly relevant to the provision of health care are:
 - Article 2 – the right to life;
 - Article 3 – the prohibition of torture;
 - Article 5 – the right to liberty and security of the person;
 - Article 6 – the right to a fair trial;
 - Article 8 – right to respect for private and family life;
 - Article 12 – the right to marry;
 - Article 14 – prohibition of discrimination.

5.1. Article 2 – right to life

1. Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which the penalty is provided by law.

2. Deprivation of life shall not be regarded as inflicted in contravention of this article when it results from the use of force which is no more than absolutely necessary:

- (a) in defence of any person from unlawful violence;
- (b) in order to effect a lawful arrest or to prevent the escape of a person lawfully detained;
- (c) in action lawfully taken for the purpose of quelling a riot or insurrection.

- An important purpose of Article 2 is to impose strict limits on the circumstances and manner in which public authorities may cause the death of any person. The article has been extended by an optional protocol to the ECHR (accepted by the UK) prohibiting the use of the death penalty. In the health care context, Article 2 is relevant to decisions on access to life prolonging treatment, end of life decisions, resuscitation policies and abortion (see further section 7 below). The European Court has interpreted Article 2 to impose duties on public authorities to take positive steps (to allocate resources) to preserve life and to properly investigate deaths. Such issues have not only been raised at Strasbourg but also, with the coming into force of the Human Rights Act, in the UK courts.

- The BMA advises:

“1. The patient’s right to life under Article 2 should be specifically considered in any decision to withhold or withdraw life-prolonging treatment but this does not mean that treatment must always be provided. Treatment may be withdrawn if:

- *providing treatment would not be in the patient’s best interests;*
- *the treatment is considered futile; or*
- *the patient has effectively waived his or her right to have life prolonged by making an informed refusal of life-prolonging treatment.*

2. Article 2 may impose a duty on doctors to take steps to prevent life-threatening conditions and a duty to inform the public, or individuals, of threats to their life. Where this would involve a breach of confidentiality this should be balanced against the patient’s right to confidentiality.

Article 2 must be taken into account where potentially life-prolonging treatment is not provided on economic grounds. Any such decisions must be made in a non-discriminatory way and the decisions must hold up to scrutiny.”⁶

5.2. Article 3 – prohibition of torture

No one shall be subject to torture or to inhuman or degrading treatment or punishment.

- Article 3 protects persons from both physical and mental ill-treatment. Strasbourg case law has established that there are different thresholds of severity for determining if a case constitutes torture or inhuman or degrading treatment. Factors considered are the severity and duration of the treatment and the vulnerability of the victim. Matters relating to consent to treatment, the use of experimental treatments, and the conditions under which long term care is provided or the mentally incapacitated are detained, have the potential to fall within the definition of inhuman or degrading treatment. However, the threshold is still a high one leaving no excuse for violation.

6. BMA – ‘The Impact of the Human Rights Act 1998 on medical decision making’. October 2000

- The BMA has identified the following areas of possible risk in the health care field:
 - *“withholding proper medical care in a case where someone is suffering from a serious illness;*
 - *providing invasive treatment contrary to the patient’s best interests – where, for example, the burdens outweigh the benefit;*
 - *denying the patient the right to be allowed to die with dignity;*
 - *treatment without consent except where treatment is provided to an incompetent patient in his or her best interests;*
 - *providing treatment against the wishes of a competent patient;*
 - *providing treatment to an incompetent patient when it is known that he or she would not have given consent to the treatment, or had specifically refused the treatment by means of an advance directive;*
 - *refusing to provide treatment for a patient because of some personal characteristic, such as age, sexual orientation or physical or mental handicap.”*⁷

5.3. Article 5 – the right to liberty and security of person

1. Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure described by law.

- Article 5 goes on to specify in great detail what needs to be done to constitute the lawful arrest or detention of a person. The article is of direct relevance to the detention and treatment of mentally incapacitated patients. Changes have had to be made to the procedures for reviewing the continuing detention of patients where the courts have found existing arrangements to be in violation of Article 5 (see section 3.5 above).

5.4. Article 6 – the right to a fair trial

In the determination of his civil rights and obligations or of any criminal charge against him, everyone is entitled to a fair and public hearing within a reasonable time by an independent and impartial tribunal established by law.

- Article 6 goes on to specify the need for courts (in normal circumstances) to deliver public judgements and sets out the procedural steps required to guarantee a fair criminal trial.
- Under Article 6, courts and tribunals must conduct themselves according to the right to a fair trial. Most internal disciplinary processes, with the exception of decisions to suspend

7. Ibid.

employees from duty, are not covered. However, the proceedings of regulatory bodies such as the General Medical Council do need to fulfil the requirements of Article 6 and have been challenged accordingly under the Human Rights Act (see further section 13 below). Article 6 has also been raised, with some effect, in court cases relating to the form and functions of Mental Health Review Tribunals.

5.5. Article 8 – right to respect for private and family life

1. Everyone has the right to respect for his private and family life, his home and his correspondence.

2. There shall be no interference by a public authority with the exercise of this right except such as in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

- In the health care sector, Article 8 has direct relevance, for example, in matters relating to care proceedings. It has also been invoked in relation to questions of consent to treatment, medical confidentiality and access to medical records.

- The BMA advises:

“Under Article 8 a patient has a right to privacy and also a right to family life. This means that:

- *particularly careful attention should be paid to the amount of information to be provided for consent to be considered informed and valid;*
- *the patient should be involved with the treatment decision to the greatest extent possible;*
- *the parents of a child patient should be consulted about treatment and their views should be taken into account (this could include unmarried fathers who do not have parental responsibility for the child);*
- *a competent young person could use the Human Rights Act to challenge the provision of treatment against his or her wishes although it is unclear whether such a challenge would succeed;*
- *the relatives of an incompetent adult should be consulted about treatment and their views taken into account;*
- *if it is decided that the wishes of those close to the patient cannot be complied with in a particular case, the doctor must still show that these views have been taken fully into account and must be prepared to explain his or her reasons for adopting a different position;*
- *the protection of personal and, particularly, medical information is of fundamental importance to a person’s enjoyment of his or her right to respect for private and family life.”⁸*

8. Ibid

5.6. Article 12 – right to marry

Men and women of marriageable age have the right to marry and to found a family, according to the national laws governing the exercise of this right.

- Attempts have been made (so far without success) to use Article 12 to establish a right to found a family through access to the latest medical techniques to aid conception (see further section 10.4 below).

5.7. Article 14 – prohibition of discrimination

The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.

- Article 14 is termed a ‘parasitic’ right, meaning it may only be employed in relation to the enjoyment or protection of one of the rights or freedoms set out in the Convention. A new free-standing prohibition on discrimination has been added to the Convention (Protocol 12) but this is not likely to be adopted by the UK in the near future.
- ‘Blanket’ decisions on treatment (for example, based on age or medical condition) which do not give consideration to individual circumstances are vulnerable to challenge under Article 14.
- Strasbourg case law has established that the term ‘other status’ embraces other forms of discrimination not explicitly stated such as on the grounds of sexual orientation.

6. POSITIVE OBLIGATIONS

What remedy does a person have under the Convention where a public authority fails to act or acts in a negligent or incorrect manner?

6.1. Securing Convention rights

- A breach of a Convention right may occur through action or inaction. One of the fastest developing areas of Convention jurisprudence concerns what positive obligations exist not merely to refrain from interfering with an individual's rights but to take positive steps to secure those rights.
- Negative obligations require public authorities to refrain from actions which will breach Convention rights. Positive obligations require positive steps to be taken to protect the Convention rights of individuals.
- Positive obligations exist under the Convention because:
 - Article 1 requires that States shall **secure** Convention rights for everyone within their jurisdiction;
 - Convention rights must be practical and effective not theoretical and illusory; and
 - Article 13 requires that effective remedies be available to correct breaches of Convention rights.
- Implementation of the Convention imposes five main positive duties. To:
 - Put in place a legal framework for the effective protection of Convention rights;
 - Prevent breaches of Convention rights;
 - Provide information and advice relevant to the breach of Convention rights;
 - Respond to breaches of Convention rights; and
 - Provide resources for individuals to prevent breaches of Convention rights.

6.2. Life-prolonging treatment

- Article 2 (right to life) imposes positive and negative obligations on health authorities so that they have duties to take adequate and appropriate steps to protect the lives of individuals in their care as well as not to take life intentionally.
- A patient's right to life needs to be specifically considered in any decision to withhold or withdraw life-prolonging treatment but this does not mean that treatment must always be provided. Treatment may be withdrawn:
 - if providing treatment would not be in the patient's best interests;
 - the treatment is considered futile; or
 - the patient has effectively waived his or her right to have life prolonged by making an informed refusal of life prolonging treatment.
- Article 2 must be taken into account in any decision not to provide life-prolonging treatment on resource grounds. Any such decisions must be made in a non-discriminatory manner capable of holding up to scrutiny. Recording the full reasons for such decisions is essential.

6.3. Providing information on health risks

- The ECHR can impose a positive obligation to take steps to prevent life-threatening conditions and a duty to inform the public or individuals of threats to health. This right to health advice has been most fully developed in relation to the health consequences of possible exposure to radiation. In the case of *LCB v UK* [1999] 27 EHRR 212, a serviceman's daughter developed leukaemia and argued that her father should have been informed that this was a possible risk arising from his involvement in nuclear testing. The European Court seemed prepared to consider that, within reason, where a State was aware (or should have been aware) that an individual had been exposed to a risk of serious injury then it was under a positive obligation derived from Article 2 to provide medical advice and care to that person. However, it did not consider that there was such a link in this case.
- In *McGinley and Egan v UK* [1998] 27 EHRR 1, the European Court identified a positive obligation under Article 8 which required the UK Government to inform persons who may have been exposed to radiation during nuclear testing of the potential consequences for their health. The Court stated that:

“Where a Government engages in hazardous activities ... which might have hidden adverse consequences on the health of those involved in such activities, respect for private and family life under article 8 requires that an effective and accessible procedure be established which enables persons to seek all relevant and appropriate information.”
- Article 8 has also been successfully used to challenge the failure of public authorities to notify persons of possible environmental hazards to their homes and family life. In *Lopez Ostra v Spain* [1995] 20 EHRR 277 and *Guerra v Italy* [1998] 26 EHRR 357, the European Court established that there was a positive obligation on States to provide

information on environmental risks that could affect an individual's right to respect for private and family life. In *Guerra*, the court found a breach of Article 8 on the basis of the long delay in passing on the relevant information to the applicants after the authorities became aware of the risks of their living in the vicinity of a chemical factory.

6.4. Resource limitations

- The Convention does not establish or impose levels of acceptable expenditure on health and social programmes. It recognises that resources are not limitless and that hard choices will need to be made which can interfere with individual Convention rights. However, the Convention can come into play if resources are allocated in a discriminatory manner without valid justification. A failure to demonstrate awareness of the Convention in developing allocation priorities, not recording the reasoning behind those priorities or operating arbitrary or blanket allocation systems which do not consider individual circumstances are all vulnerable to challenge under the Convention. However, a proper assessment based on medical needs and benefits would be unlikely to pose a violation of the Convention.
- Where persons are deprived of their liberty, the Convention does require the provision of resources to provide humane and acceptable standards of detention or care. In April 2002, for example, the right to a fair and timely hearing under Article 6 was successfully invoked in seven test cases to challenge delays in arranging hearings before Mental Health Review Tribunals. One of the cases involved cancellations over a period of 27 weeks. The court considered that the Department of Health had failed to provide adequate funding for the fees and training of sufficient tribunal members. A large number of compensation claims are likely to follow. The first successful claims were made in February 2003.

6.5. Osman ruling

- The case of *Osman v UK* [1998] has provoked considerable debate over the extent to which the Convention imposes positive obligations on the conduct of public authorities in the UK. In the *Osman* case the European Court established that there had been a violation of the Convention because the relevant authorities could not demonstrate that they had done all that could be reasonably expected of them to avoid a real and immediate risk to life. In this case, to investigate death threats, of which they ought to have knowledge, that resulted in murder. The blanket immunity granted by the domestic courts to the police (over liability for possible negligence) was deemed to be disproportionate and a breach of Article 6 because an action against the police had not been allowed to proceed to trial. The *Osman* ruling caused great concern to UK judges who were alarmed at the way in which the ruling could allow the liability of public authorities for the failure to deliver public services to turn on the right to a hearing before a tribunal. This had potentially momentous consequences for the delivery of public services in the UK.
- However, the implications of the *Osman* ruling have been mitigated by a subsequent case of *Z and others v UK* [2001] where the European Court appeared to admit to a

misunderstanding of the English law of negligence by indicating that the domestic courts' ability to strike out actions where they did not find that the defendant owed a duty of care was not a breach of Article 6 (denial of access to a court) but rather a breach of Article 13 in that the applicants were deprived of a remedy. *Z and others* arose from the decision of the House of Lords in *X and others v Bedfordshire County Council* [1995] where five children neglected and mistreated by their parents had been prevented from taking negligence proceedings against the county council. The European Court found that the council's failure to prevent the neglect and mistreatment had resulted in a breach of Article 3. However, although the applicants had been prevented from pursuing a negligence claim, the matter had been properly examined by a court (the House of Lords). Therefore, the court determined that they had been denied a remedy (Article 13) not access to a court (Article 6). The ability to exploit Article 6 as a means to create new rights and obligations under the Convention is constrained by this ruling. How matters develop in future will need to be watched carefully as this process will increasingly define what positive obligations bear on public authorities under the Convention.

6.6. Duty of care

- The *Osman* ruling was taken into account in *Kent v Griffiths and others* [2000] 2WLR 1158 where the Court of Appeal determined that an ambulance service owed a 'duty of care' to a person on whose behalf a 999 call was made if it failed to respond (due to carelessness) within a reasonable time. In this particular case the patient, who was asthmatic, waited for 90 minutes for the ambulance and suffered respiratory arrest on the way to hospital. An important feature of the case was that there was no conflict of priorities or problems of ambulance availability.

7. RIGHT TO LIFE AND THE PROVISION OR WITHHOLDING OF LIFE-PROLONGING TREATMENT

The best interests of the patient are the crucial determining factor in reaching decisions on the provision or withholding of life-prolonging treatment.

There is a presumption in favour of taking all steps capable of preserving life, save in exceptional circumstances.

Where these circumstances exist, for example in the case of patients in a permanent vegetative state with no prospect of recovery, artificial feeding and hydration may be withdrawn and resuscitation not attempted even where death may result.

A competent adult is entitled to refuse medical treatment even if this decision will result in his or her death.

Parents' decisions on behalf of their children are subject to the overriding view of the courts on what is in the best interests of the child.

Policies and decisions on these matters must be made with full regard to the requirements of Articles 2 and 3 of the Convention.

7.1. Right to life

- Article 2 imposes a duty to provide adequate and appropriate medical provision to preserve life. The ECtHR has indicated that a lack of proper care in circumstances where someone is suffering a serious illness may infringe Article 3.
- The purpose of medical treatment is to restore or maintain the health of patients. If a treatment does not benefit a patient or has been refused (on an informed basis) the justification for treatment is removed.

- Prolonging a patient's life would usually be considered beneficial to a patient. However, it is not a goal of medical treatment to prolong life at all costs without regard to a patient's wishes and quality of life.
- Under existing law, no one (not even a medical practitioner with the patient's consent) may deliberately hasten a person's death [see *R v Nigel Cox* (1993) 12 BMLR 38]. It is accepted, however, that there are circumstances where futile treatments, artificial feeding and hydration may be withdrawn and resuscitation not attempted even where death may result.
- Such circumstances can raise extremely difficult issues for health care professionals and the courts. In *R v Portsmouth Hospital NHS Trust ex parte Glass* [1999] Lloyd's Rep Med 367, for example, a dispute over treatment ended in the death of the 12 year old patient and the arrest of relatives for attacking a doctor. The child who suffered from cerebral palsy and epilepsy was being treated for various post operative infections after a tonsillectomy. The doctors made him the subject of a 'do not resuscitate' order believing it was in his best interests to be allowed to die without distress or pain. This was objected to by the parents who wished their son to live out his natural life. The death of the child occurred before the matter was resolved in court.
- In exceptional circumstances, the courts have approved medical treatment that will result in the death of a patient. In *Re A (Minors) (Conjoined twins: Medical treatment)* [2000] TLR, 10 October 2000, the Court of Appeal decided that it was lawful for doctors to carry out an operation to separate conjoined twins although this would result in the death of the weaker twin because the clinical evidence showed that:
 - the weaker twin only lived because a common artery enabled the stronger twin to circulate blood for both;
 - an operation to separate could be performed successfully; and
 - both would die unless separation occurred within six months.
- The parents, who were Roman Catholics, would not consent to the operation. However, the court exercised its overriding control to ensure that the stronger twin received proper treatment. It considered that a defence of necessity meant that it was not a criminal offence for the doctors to carry out the operation. In the absence of legislation, however, this defence would have to develop on a case by case basis. The judges heard arguments from the parents' lawyers that Article 2 of the ECHR, given effect through the HRA, did not admit a defence of necessity. However, this argument was rejected. Without giving details, the judges considered that the coming into force of the HRA confirmed and did not alter pre-existing law.

7.2. Resuscitation

- For patients suffering cardiac or respiratory arrest, there is a presumption that health care professionals should make all reasonable attempts to revive the patient. This does not apply where a competent patient has previously made an informed decision not to undergo cardiopulmonary resuscitation or where the patient is in the terminal phase of

illness and the burden of treatment outweighs the benefits.

- Each case must be considered on its individual merits. Blanket policies imposed without regard for individual circumstances (eg. on the basis of age) are unlikely to withstand challenge under the HRA and ECHR.
- Decisions are best made in advance and discussed with the patient as part of an overall care plan. A prior decision that resuscitation will not be attempted should be made only after appropriate consultation and consideration of the patient's condition. Relevant considerations are :
 - *“the likely clinical outcome, including the likelihood of successfully restarting the patient's heart and breathing, and the overall benefit achieved from a successful resuscitation;*
 - *the patient's known, or ascertainable, wishes; and*
 - *the patient's human rights, including the right to life and the right to be free from degrading treatment.”*

[Decisions relating to Cardiopulmonary Resuscitation; a joint statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing (2001)].

- The joint statement considers that a decision not to attempt resuscitation (DNAR order) may be appropriate where such treatment will be 'futile' given the particular circumstances of the patient:
 - where attempting CPR will not restart the patient's heart and breathing;
 - where there is no benefit in restarting the patient's heart and breathing; or
 - where the expected benefit is outweighed by the burdens.
- The reasons for a DNAR order need to be carefully recorded and made known to the patient (and with their consent) to those close to the patient. Health care professionals treating the patient will need to be informed. The guidance recommends that the entry in the medical records should clearly document and date the decision and the reasons for it, and should be made by the most senior member of the team available. The decision and reasons need to be reviewed regularly by the medical team.
- The courts are likely to approach claims that a health care body or clinician failed to take adequate and appropriate steps to protect a patient's right to life in a similar manner to clinical negligence cases. Such cases can be defended if a responsible body of medical opinion regards the treatment provided as reasonable.
- Cases involving a patient's consent to, or refusal of, treatment will be affected by the HRA and ECHR:
 - cases where patients are not properly involved in treatment decisions
 - 'Do not resuscitate' decisions
 - withdrawal of artificial feeding and hydration.

- Recent cases have highlighted the desirability of consultation with patients and their relatives before making a decision not to resuscitate. When hard choices need to be made there may be a tendency for communication to go ‘out of the window’. Health care providers need to be able and prepared to explain and justify DNR decisions as a justified interference with the right to life under Article 2 of the Convention.

7.3. Withdrawal of life-prolonging treatment

- It is lawful for doctors to withdraw artificial feeding and hydration from those in a permanent vegetative state if it is not in the best interests of the patient to continue treatment where there is no hope of recovery? The courts are unlikely to overturn decisions where a patient’s life is ended by the withdrawal of treatment but it may be more important than ever to obtain the court’s sanction before treatment is withdrawn. In two of the earliest cases heard after the HRA came into force – *NHS Trust A v Mrs M* and *NHS Trust B v Mrs H* [2000] EWHC 29 – the Family Court considered the circumstances of:
 - Mrs M who had been in a permanent vegetative state for three years after an anaesthetic problem during a gynaecological operation: and
 - Mrs H who had been an epileptic all her life and suffered cardiac arrest while undergoing hospital treatment for pancreatitis which had left her in a permanent vegetative state for the previous nine months.

The families of both patients wanted them to be allowed to die. Dame Elizabeth Butler-Sloss ruled that artificial feeding was not in the best interests of either patient and could be withdrawn. She determined that the principles laid down by the House of Lords in the case of *Airedale NHS Trust v Bland* [1993] AC 789, were not affected by the coming into force of the HRA. In that landmark case, the House of Lords approved the withdrawal of artificial feeding on the grounds that continued treatment was not in the best interests of the patient. Tony Bland had been left in a persistent vegetative state after being crushed in the Hillsborough football stadium tragedy. The hospital’s application to the courts to cease treatment was approved because the House of Lords accepted that there was no duty for a medical practitioner to continue to treat such a patient where medical opinion was that there was no prospect of recovery and, therefore, no benefit to the patient.

- The Irish courts have had to address similar issues. In *Re Ward of Court (Withholding Medical Treatment)* [1999] 50 BMLR 140 (Ireland), it was determined that withdrawing treatment from an individual in a persistent vegetative state did not violate the right to life in the Irish Constitution. The patient in question had suffered severe brain damage some twenty years before the case was brought. The family’s application for an order to withdraw artificial feeding was opposed by the Irish Attorney General as a breach of the constitutional right to life. However, the court held that the process of dying was a necessary part of life and considered that the right to life also implied a right to die naturally with dignity rather have life prolonged by artificial means. Artificial feeding and antibiotic treatment could be withdrawn even though death would follow.

- In *A National Health Service Trust v D* [2000] 55 BMLR 19, the roles were reversed. D was a baby born with multiple organ failure and a short life expectancy. The NHS Trust applied for the right not to resuscitate him if he suffered respiratory or cardiac failure. Only palliative care would be given to allow him to die peacefully and with dignity. This decision was strongly opposed by the parents who considered it to be premature. The views of three consultant paediatricians maintained that providing artificial ventilation would be a painful and intrusive process that would bring no lasting benefit. It could not be considered to be in the best interests of the child.
 - In reaching his judgement, Mr Justice Cazalet observed that there was a clear presumption in favour of taking all steps capable of preserving life, save in the most exceptional circumstances. It was the best interests of the patient that were paramount in deciding whether medical treatment should be given or withheld. The wishes of the parents were important in this regard but the court had the final view of what was in the best interests of the child.
 - Mr Justice Cazalet also considered the application of Article 2 and Article 3 of the Convention. He indicated that Article 2 did not require the prolongation of life in all circumstances. He found nothing in the Strasbourg jurisprudence to indicate that to provide palliative care only, in the best interests of the child, would breach this article. He also noted that Article 3 encompassed the right to die with dignity. He determined, therefore, that withholding life-prolonging treatment did not breach Convention rights because the decision was made on the basis of the best interests of the child. In other words, a death with dignity would not infringe human rights.

7.4. Right to life-prolonging treatment

- The coming into force of the HRA affects the manner in which decisions should be taken on the provision of life-prolonging treatment. The HRA does not empower a patient to compel health authorities to provide treatment but it will open new avenues of argument for dissatisfied patients and their relatives before the courts. At the very least, it will put the processes by which policies and decisions are made on the provision of life-prolonging treatment under closer scrutiny than before. It will also bear down heavily on any form of discrimination or 'blanket' process in the taking of such decisions that cannot be justified under the Convention.
- The provision of treatment that could prolong life is inevitably dependent upon the availability and allocation of resources. Expensive or experimental treatment that could prolong life may sometimes not be provided on resource grounds. These decisions are vulnerable to challenge under Article 2 and Article 3 of the ECHR. However, for a case to have a chance of success, the courts will need to be convinced that failing to provide treatment would result in a real risk of death and that providing treatment would be likely to avert that risk. The courts might also act on evidence of procedural impropriety. Health practitioners making decisions on the provision of life-prolonging treatment will need to be able to demonstrate, therefore, that they have properly considered their patients' Convention rights. Such decisions will need to be rational, transparent and able

to withstand scrutiny. Where all these criteria are met, the courts are very unlikely to find reason to use Article 2 or Article 3 to overturn or interfere with health authority decisions on the allocation of resources.

- A definitive case has yet to arise under the HRA. However, some of these issues were addressed in the case of *Jaymee Bowen (Child B) – R v Cambridge and Huntingdon HA ex parte B* [1995] 2 All ER 129. Jaymee was dying from a rare form of leukaemia. The health authority was prepared to pay for palliative care but not for expensive experimental therapy which had poor prospects of success. The High Court overturned the HA's refusal to pay with Mr Justice Laws arguing that it was not enough for the authority to 'toll the bell of scarce resources'. It had also to explain why treatment could not be provided and how it had set its priorities in reaching its decision. At the Court of Appeal, however, the court was convinced by the clinical evidence that the treatment would not be in Jaymee's best interests. Coming before the introduction of the HRA, questions of the right to life under the Convention or the possibility of the court substituting its own wisdom for that of the health authority over the allocation of resources did not arise.
- Elsewhere, in *Shortland v Northland Health Limited* [1999] 50 BMLR 255 CA, NZ, the New Zealand Court of Appeal determined that the right to life in the New Zealand Bill of Rights did not impose an obligation on a health authority to provide expensive medical treatment to prolong life.
- The applicant suffered from dementia and a potentially fatal kidney disease requiring dialysis until a kidney transplant could be arranged. The health authority, after consultation with qualified experts and following medical guidelines, refused a transplant and ceased dialysis. The applicant's representatives argued that he had been refused life saving treatment in breach of his constitutional rights but the court considered that he had not been deprived of life or denied the necessities of life.
- In *Soobramooney v Minister of Health, Kwazulu-Natal* [1997] 50 BMLR 224 SA Constitutional Court, the applicant was also in need of continuing dialysis treatment, was suffering from heart disease and had been refused treatment because of a lack of resources. Section 27(2) of the South African Constitution requires the state to take reasonable steps to ensure that individuals have access to proper health care. Section 11 guarantees the right to life. The Constitutional Court rejected the argument that the refusal to provide treatment was a breach of these sections indicating that the constitutional right to health care had to be determined in accordance with the state's duty under that right to provide everyone with access to healthcare services within existing resources.

7.5. Right to end life or refuse treatment

- It is accepted under civil law that an adult of sound mind is entitled to refuse medical treatment even if this decision will result in his or her death. Mentally competent patients therefore have the right to personal autonomy and to make decisions concerning their care notwithstanding the consequences of their decisions. The reasons for refusing treatment do not have to be rational.

- Subject to the overriding control of the courts, parents may refuse treatment on behalf of their children. In *Re T* [1997] 1 All ER 906, the court refused the doctor's plan to perform a kidney transplant in favour of the parents' desire that their child should have a short life of quality rather than a life of uncertain quality and duration.
- In an important recent judgement, in *R v B* (22 March 2002), the Family Division Court confirmed that a seriously physically disabled patient, who was mentally competent, was entitled to refuse consent to life-sustaining medical treatment. The administration of artificial ventilation against the patient's wishes constituted an unlawful trespass on her person.
- The court set out and restated principles and guidelines for dealing with issues of mental capacity:
 - there was a presumption that a patient was mentally competent to make decisions whether to consent to or refuse treatment;
 - where competence was not in question and the patient had been given all relevant information and advised of the available options, the decision of the patient had to be respected by health care professionals;
 - concerns over a patient's mental capacity should be resolved as quickly as possible pending which the patient should be cared for according to his or her best interests as judged by the medical staff in charge of their care;
 - the consequences of the patient's decision (no matter how grave) should not influence or cloud the assessment of the patient's mental capacity to make the decision;
 - where there was disagreement over the competence of a patient, the patient should be kept fully informed and involved in the process. Independent medical advice from outside the treating hospital should be sought. Matters should not be left deadlocked or allowed to drift on unresolved; and
 - if medical staff were unable for any reason to carry out the treatment wishes of a mentally competent patient, it was their duty to find others who would do so.
- The decision of the Family Division Court accords with Strasbourg jurisprudence. In *Widmar v Switzerland* [Appl No 20527/92], the Commission found that allowing a person to die by withholding treatment may be permitted. However, the European Court has not embraced the idea of taking active steps to end life.

7.6. Assisted suicide (*Diane Pretty v the UK*)

- Diane Pretty suffered from motor neurone disease, a disease for which there is no cure. She wished to be able to control the manner of her death but could not do this without assistance as she was paralysed from the neck down. It is not a crime to commit suicide in the UK but it is an offence, under Section 2 (1) of the Suicide Act 1961, to assist another person to commit suicide. Ms Pretty wished to be assisted by her husband and sought a guarantee from the Director of Public Prosecutions that he would not be

prosecuted after her death. The Director's refusal to give immunity was upheld by three UK courts including the House of Lords. The case was heard as an urgent matter by the ECtHR in March 2002. The court delivered judgement on 29 April 2002.

- Lawyers for Ms Pretty argued that:
 - Article 2 allowed an individual to choose whether to live or die. The State was under a positive obligation to allow individuals to exercise that right;
 - Article 3 required that the State take positive steps to prevent Ms Pretty suffering inhuman or degrading treatment which in her circumstances meant allowing her husband to help end her life with dignity;
 - Ms Pretty's right to self determination under Article 8 and to manifest her beliefs under Article 9 were violated by the failure to provide a lawful scheme for assisted suicide; and
 - The blanket ban on assisted suicide breached the non discrimination requirements of Article 14 given that an able bodied person could exercise the right to die under domestic law.
- The European Court was not persuaded that the 'right to life' guaranteed in Article 2 could be interpreted as conferring a diametrically opposed 'right to die'. Neither did it create a right to self-determination in the sense that a person could choose death rather than life. The court concluded, therefore, that no 'right to die', whether at the hands of a third person or with the assistance of a public authority, could be derived from Article 2.
- The court did not accept the argument advanced under Article 3. It considered that Article 3 had to be construed in harmony with Article 2. Article 2 existed as a prohibition on the use of lethal force or other conduct that might lead to the death of a person. It did not confer any right on an individual to require the State to permit or facilitate his or her death. There was no positive obligation under Article 3, therefore, which could require the State to sanction actions that would end life.
- The claims under Articles 8, 9 and 14 also failed. The court did not consider that the blanket nature of the ban on assisted suicide was a disproportionate interference with Article 8. Assisted suicide did not fall within the definition of 'beliefs' protected by Article 9. There was an objective and reasonable justification for the purposes of Article 14 in not distinguishing between those who were and were not physically able to commit suicide given the intent of the Suicide Act to preserve life.
- Diane Pretty died in May 2002.

7.7. Is guidance in place and acted on in health organisations?

- It would appear that the guidance prepared by the BMA and GMC has not been adopted into the policies and practices on the provision and withholding of life prolonging treatment in every hospital or health organisation. The Disability Rights Commission, for example, still has concerns over the apparent use of 'Do Not Resuscitate' notices for some

disabled people receiving hospital treatment without the knowledge of the patient or their close relatives. The Commission has examined the results of clinical governance reviews undertaken by the Commission for Health Improvement for a sample of 19 NHS hospital trusts. These reviews revealed that three trusts had a policy on DNR, three trusts were reviewing or planned to review their policy, three trusts had detailed policy and practice guidelines and reports on the other ten disclosed concerns, some serious. Having guidance in place was not a guarantee that this would be acted upon by staff. According to the DRC, a resuscitation audit in two hospitals found that correct documentation of DNR status existed for only 23 per cent of patients and for only 10 per cent of those identified as 'Not for CPR'. A survey by students at one hospital found that just over half its doctors had read the Trust's guidelines.⁹ In such an environment, the possibility of Convention related challenges on the provision or withholding of life prolonging treatment must remain high. The DRC intends to conduct a formal inquiry into resuscitation practices as applied to disabled people.

9. Speech delivered by Lakhvir Rellon, Commissioner, Disability Rights Commission at an expert seminar on 'Withholding and withdrawing medical treatment' on 14 November 2002. Available at [www.drc-gb.org].

8. CLINICAL NEGLIGENCE

- A health care professional owes a duty to exercise reasonable skill and care in the treatment of a patient.
- A health care professional may be guilty of negligence if failing to demonstrate the level of skill of an ordinary practitioner of their profession.
- Health care professionals may differ over the best course of action for a patient. The courts allow for the exercise of reasonable 'clinical discretion' and differences of opinion in the treatment of patients.

8.1. The Bolam test

- A health care professional owes a duty to exercise care in the treatment of patients. If adequate and appropriate care is not provided, a medical practitioner may be held liable under the law of negligence. The test for negligence on the part of a medical practitioner (best known as the Bolam test) was first formulated in the nineteen fifties.
- The test as originally stated in *Hunter v Handley* [1955] SC 204 considered:

“In the realm of diagnosis and treatment there is ample scope for genuine difference of opinion and one man clearly is not negligent merely because his conclusion differs from that of other professional men, nor because he has displayed less skill or knowledge than others would have shown. The true test for establishing negligence in diagnosis or treatment on the part of a doctor is whether he has been proved to be guilty of such failure as no doctor of ordinary skill would be guilty of if acting with ordinary care.”
- In *Bolam v Friern Hospital Management Committee* [1957] 1 W.L.R. 582, the judge directed the jury:

“The test is the standard of the ordinary skilled man exercising and professing to have that skill. A man need not possess the highest expert skill... it is sufficient if he exercises the

ordinary skill of an ordinary competent man exercising that particular art.”

“[A doctor] is not guilty of negligence if he has acted in accordance with a practice accepted as proper by a responsible body of medical men skilled in that particular art.”

“a doctor is not negligent ... merely because there is a body of opinion that takes a contrary view.”

- With modifications, the Bolam test continues to be applied by the courts. Lord Scarman reformulated the test in *Sideways v Governors of Bethlem Royal Hospital* [1985] AC 871 as:

“a doctor is not negligent if he acts in accordance with a practice accepted at the time as proper by a responsible body of medical opinion even though other doctors adopt a different practice.”

- In *Bolitho v City and Hackney Health Authority* [1998] A.C.232 H.L., the House of Lords examined a decision not to intubate a child. The Law Lords declined to substitute their own judgement for that of the medical experts but also stressed that they would hold that a body of medical opinion is not reasonable or responsible, if it was demonstrated that that body of opinion did not have a logical basis. In the words of Lord Browne-Wilkinson:

“In the vast majority of cases the fact that distinguished experts in the field are of a particular opinion will demonstrate the reasonableness of that opinion ... But if, in a rare case, it can be demonstrated that the professional opinion is not capable of withstanding logical analysis, the judge is entitled to hold that the body of opinion is not reasonable or responsible.”

- The Convention as applied through the Human Rights Act has yet to make its presence felt in the area of medical negligence. Some legal practitioners question whether the Bolam test (concerned as it is with doctors’ standards) meets expectations for the protection of patients’ rights under the Convention. So far, however, the domestic courts have not taken Article 2 to impose a different or higher standard than the common law duty of care.

8.2. Clinical negligence and the ECHR

- Cases of medical negligence are rarely heard by the European Court. In *Buckley v UK* [1997] 23 EHRR CD 129, the applicant complained about the treatment and circumstances surrounding the death of her son. In deciding that the complaint under Article 2 was inadmissible, the Commission was influenced by the fact that the applicant’s medical and legal advisors had been unable to point to any negligence on the part of the hospital and, consequently, had initiated no action in the domestic courts.
- However, the European Court did consider the case of *Cavelli and Ciglio v Italy*¹⁰ in which it determined that Article 2 of the Convention does not require the provision of a

10. *Cavelli and Ciglio v Italy* (application No. 32967/96) 17 January 2002.

criminal law remedy for deaths caused by alleged medical negligence if there is a civil remedy available.

- In this case, a doctor had been accused of involuntary manslaughter and sentenced to a year's imprisonment by the Italian Criminal Court for failing to take adequate precautions for the safe birth of a child known to be at high risk. However, the Italian Appeal Court ruled that the prosecution was time barred because of delays in arranging the first trial.
- The child's parents took the matter to Strasbourg arguing that their Article 2 and Article 6 (1) rights had been infringed because of the procedural delays and time bar on prosecuting the doctor. The European Court accepted that Article 2 was engaged but did not find a violation in this case. It considered that the positive obligation on a state to investigate violations of Article 2 did not require the provision of a criminal remedy in every case where death occurred involuntarily. The court noted that the option had been open to the applicants to pursue civil proceedings but they had chosen to settle. By doing so, a majority of the judges found that the applicants had denied themselves access to the best means of obtaining a remedy.
- The conclusion reached by the court argues that there are circumstances (in this case involuntary manslaughter arising from medical negligence) in which the availability of civil proceedings satisfies the obligation on a state to investigate and deal with violations of Article 2.
- Strasbourg has, on rare occasions, been required to consider whether medical treatment of an experimental nature could constitute a breach of Article 3. In *X v Denmark* [1983] 32 DR 282, the applicant complained that a failed sterilisation operation had been performed in a different way than that to which she had consented. However, the Commission determined that the operation was not experimental in nature and did not, therefore, constitute a violation of Article 3.
- In the UK courts, it has been stated recently by Scott Baker J in *R (Howard) v Health Secretary* [2002] 3 WLR 738 that clinical negligence, no matter how bad, can not found a claim under Article 3.

9. CONSENT TO TREATMENT

- A competent patient's consent is required before any medical procedure is undertaken.
- Consent is a continuing process and should be reaffirmed as treatment progresses.
- Where a patient is not competent, a decision on whether to provide treatment must reflect his/her best interests (including clinical interests).
- Be familiar with and use the BMA consent toolkit. [www.bma.org.uk]

- Decisions by competent and informed patients are to be respected by medical practitioners. A competent adult has the right to refuse any medical treatment even if that refusal results in his or her death. While reasonable attempts may be made to persuade such a patient to accept treatment, his or her decision is legally binding on health care staff.
- Patients do not need to justify their decisions, but need to ensure that they are communicated to the health care professionals responsible for their treatment. Decisions may be conveyed verbally or recorded in the form of a written 'living will'. Patients may change their minds about decisions at any time.
- In the recent case of *R v B* [2002] 2 All ER 449 (see also section 7.5 above), Ms B won the right to have the ventilator keeping her alive switched off. While she had the mental capacity to make this decision, it was not acted on because no doctor within the hospital caring for her was willing to carry out her wishes and the NHS Trust concerned failed to find another doctor who would do so. Dame Elizabeth Butler-Sloss found that the Trust had been guilty of trespass to the person in treating Ms B once she had been found to be competent to make the decision to discontinue her treatment. Dame Butler-Sloss highlighted the "serious danger ... of a benevolent paternalism which does not embrace recognition of the personal autonomy of the severely disabled patient". Considerations of what might be in the best interests of the patient were irrelevant in such a case and Dame

Butler-Sloss laid down clear guidelines explaining that a competent patient's wishes must be respected even if another doctor must be found to do so.

9.1. Informed consent

- In *Sideway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital* [1985] A.C. 871 H.L, the Law Lords decided that a doctor's duty to inform a patient is an aspect of the doctor's duty to exercise reasonable care and skill. This duty forms part of the Bolam test (see section 8.1 above) under which a doctor must give the patient information that a responsible body of medical opinion considers appropriate. As explained by Lord Diplock:

“In matters of diagnosis and the carrying out of treatment the court is not tempted to put itself in the surgeon's shoes; it has to rely upon and evaluate expert evidence, remembering that it is no part of its task of evaluation to give effect to any preference it may have for one responsible body of opinion over another, provided it is satisfied by the expert evidence that both qualify as responsible bodies of medical opinion.”

- In the *Sideway* case, the Law Lords relied upon expert evidence that a body of skilled and experienced neurosurgeons would have regarded it as acceptable not to warn of a slight, but well recognised, risk of serious harm that Mrs Sideway did in fact suffer following surgery.
- In a dissenting opinion, however, Lord Scarman proposed a rights based approach known now as 'informed consent' under which the patient should have the right to choose whether to accept a slight, but well recognised, risk of harm.
- The application of the HRA and ECHR is likely to lead to greater emphasis on the ability of patients to make informed decisions on receiving treatment. There will be room for tension and litigation over what the reasonably competent medical practitioner regards as being significant to the making of a decision and what the typical patient regards as being important. However, if a medical practitioner can demonstrate that the patient's best interests were properly considered and can justify any decision not to inform the patient of a risk, this is unlikely to be deemed a negligent act by the courts.
- The GMC counsels that doctors find out what patients want to know and ought to know about their condition and its treatment. Information which should be provided includes:
 - the purpose of the investigation or treatment;
 - details and uncertainties of the diagnosis;
 - options for treatment including the option not to treat;
 - explanation of the likely benefits and probabilities of success for each option;
 - known possible side effects;
 - the name of the doctor who will have overall responsibility; and
 - a reminder that the patient can change his or her mind at any time.

9.2. Consent by young people

- Competent young people are entitled to give consent to medical treatment. Where they lack competence it is generally their parents who make decisions on their behalf. In England, Wales and Northern Ireland, refusal of treatment by competent young persons is not necessarily binding on doctors since the courts have ruled that consent from people with parental responsibility, or the court, still allows doctors to provide treatment. Where a competent young person refuses treatment, the harm caused by violating the young person's choice must be balanced against the harm caused by failing to treat. In Scotland, it is likely that neither the parents nor the courts are entitled to override a competent young patient's decision.
- The HRA and ECHR have not been used yet (as at the end of 2002) to challenge consent issues for young people in the domestic courts.

9.3. Where a patient lacks capacity to consent or withhold consent to treatment

- A medical practitioner may treat a patient who lacks the capacity to give or withhold consent provided the treatment is in the best interests of the patient and the minimum necessary is done. This is not expected to change under the HRA and ECHR.
- The legal test to capacity is set out in *Re C* [1994] 1 WLR 290. The courts have also considered the question of when capacity should be re-examined. In *St George's Healthcare NHS Trust v S* [1998] 3 WLR 936, the court held that a declaration was only required when there was serious doubt as to capacity. In *R v Portsmouth Hospital Trust ex parte Glass* [1999] Lloyds Rep Med 367, the Court of Appeal modified this to indicate that it was appropriate to apply to the court for a declaration where there was serious disagreement between the parties. This requirement is reinforced by the application of Article 6 of the Convention. The right to a fair trial makes it more likely that clinical decisions disputed by the patient's relatives will end up in the courts.
- In *R (Wooder) v Fegetter and the Mental Health Commission* [2002], 24 April, CA, the Court of Appeal determined that the coming into force of the HRA has extended the duty to give reasons when determining to give treatment without the consent of the patient. The applicant sought written and adequate reasons for the decision of a 'Second Opinion Appointed Doctor' under Section 58 of the Mental Health Act 1983 that he should be given medication against his will. The court ruled that a detained person should be informed in writing of the reasons for such a decision unless these were likely to cause serious harm to the physical or mental health of the patient or any other person.

9.4. Best interests of the patient

- The BMA recommends that the following factors should be taken into account in considering treatment in the best interests of the patient:
 - the patient's own wishes and values (where these can be ascertained), including any advance statement;

- clinical judgement about the effectiveness of the proposed treatment, particularly in relation to other options;
- where there is more than one option, which option is least restrictive of the patient's future choices;
- the likelihood and extent of any degree of improvement in the patient's condition if treatment is provided;
- the views of the parents if the patient is a child;
- the views of the people close to the patient especially close relatives, partners, carers or proxy decision-makers about what the patient is likely to see as beneficial; and
- any knowledge of the patient's religious, cultural and other non-medical views that might have an impact on the patient's wishes.

9.5. Emergency treatment

- In an emergency where consent cannot be obtained, doctors may provide medical treatment that is immediately necessary to save life or to prevent significant deterioration in a patient's health. If, however, the patient is an adult and there is clear evidence of a valid advance refusal of treatment that treatment should not be given. A doctor may provide emergency treatment in the best interests of a child where the child cannot give consent and nobody with parental responsibility is available.

9.6. Consent by proxy (Scotland)

- There is a perception that people close to a patient may have the final say about medical treatment for an adult patient who lacks decision-making capacity. In England, Wales and Northern Ireland there is no such legal entitlement. In Scotland, adults may appoint a health care proxy to give consent to medical treatment.
- The Adults with Incapacity (Scotland) Act allows persons over 16 to appoint a proxy decision maker who has the legal power to give consent to medical treatment where the patient loses capacity. Unless to do so would be unreasonable or impractical, the proxy must be consulted about treatment decisions. Proxy decision-makers cannot demand treatment that is judged to be against the patient's interests. The Act also requires doctors to take account, so far as is reasonable and practical, of the views of the patient's nearest relative and his or her primary carer.

10. ACCESS TO TREATMENT

- In making resource allocation decisions, decision-makers should ensure that:
 - decisions not to fund treatment are based on substantial and objective grounds;
 - if budgetary factors play a part in a decision, a reasoned analysis of these considerations should be made and kept;
 - the decision-making process is carefully documented; and
 - pay particular attention to any right to life (Article 2) dimension.
- Will the HRA and ECHR have an impact on the extremely sensitive questions of rationing or different practices between health care organisations (the ‘postcode lottery’) in the allocation of health care resources?
- The provision of health care will always be restricted by the availability of resources. Attempts to develop a consensus on rationing strategies have debated the value of approaches assessing:
 - the need or ability of people to benefit from a treatment. Should an existing and more cost-effective treatment be used to benefit a greater number of people than could be helped through a new and more expensive treatment?
 - how treatment would affect a person’s life span and quality of life. Should high cost treatment be provided where the quality and duration of life will only improve to a limited extent?
 - whether treatment would result in a fairer distribution of healthcare across society as a whole. Known as the ‘fair innings’ approach, should the provision of resources be weighted to prioritise the young over the elderly or improving the health of disadvantaged groups?
- Decisions on the allocation of health care are liable to scrutiny under the HRA and ECHR. However, the DoH does not anticipate that the HRA will radically increase the

chances of patients successfully arguing for access to NHS treatment in the courts. It advises:

“ Under the Act a person cannot compel the NHS to give him treatment or an operation except through the courts. It is not possible to predict whether challenges to treatment refusals may be successful where they would not have been before but it is unlikely that courts will adopt a very different approach, in cases where resources are an issue, to past cases involving refusals of treatment. What may happen is that the decision-making process will come under greater scrutiny than before. In the future there may be test cases where the deployment of ECHR points may make a difference. Health authorities and trusts would need to identify these potential areas early if it is necessary to take prior action, for example, because important policy or operational considerations are at stake.”¹¹

- Historically, decisions on the provision of treatment have been made by individual doctors, in individual health bodies, using their clinical judgement to assess the needs of individual patients. In 1999, the National Institute for Clinical Excellence (NICE) was set up to provide guidance for health care professionals on decisions about treatment and health care. NICE guidance covers:
 - the use of new and existing health technologies (medicines, medical devices, procedures etc);
 - the management and care of specific conditions; and
 - the use of new surgical procedures.
- NICE guidance does not override the responsibility of individual health care professionals to make decisions based on the circumstances of individual patients. However, it is expected that NICE guidance will be taken fully into account when making clinical decisions. Since January 2002, the NHS has been required to provide funding for treatments and drugs recommended by the NICE appraisal process.

10.1. Seeking treatment through the courts

- We saw in Section 7 the reluctance of the courts, before the HRA and ECHR came into force, to intervene in decisions on the allocation of healthcare resources. In *R v Cambridge Health Authority ex parte B* [1995] 2All ER 129, the Court of Appeal held that the health authority was entitled not to fund expensive medical treatment that was unlikely to prolong the life of a young child by more than a few months. As Sir Thomas Bingham argued:

“Difficult and agonising decisions have to be made as to how a limited budget is best allocated to the maximum advantage of the maximum number of patients. This is not a judgement a court can make.”

- In practice, therefore, health authorities have been left to decide how to allocate limited resources. The courts will only intervene where decisions appear manifestly unreasonable.

11. DoH – ‘The Human Rights Act 1998 – Questions and Answers’. [www.doh.gov.uk/humanrights/qa.htm].

- The case law of the European Court discloses little to indicate that decisions on the allocation of medical resources will be subject to close scrutiny under the Convention. In the case of *Taylor, Crampton, Gibson and King v UK* [1994] Application No. 23412/94, the Commission considered the extent to which Article 2 might impose obligations to allocate the means to conduct an inquiry into the murders carried out by Beverley Allitt at Grantham District Hospital. However, the Commission found that these were matters of public and political debate falling outside the scope of Article 2.
- In the case of *Passanante v Italy* Application No. 32647/96, the applicant complained of a breach of her rights under Article 8 because of delays in making an appointment for a neurological examination (for migraine). The Commission said:

“where the State has an obligation to provide medical care, an excessive delay of the public health service in providing a medical service to which the patient is entitled and the fact that such delay has, or is likely to have, a serious impact on the patient’s health could raise an issue under Article 8 (1) of the Convention.”

However, the case was deemed inadmissible because the applicant’s medical condition was not sufficiently serious to warrant the intervention of the court.

- In the UK courts, in *North West Lancashire Health Authority v ADG* [1999] Lloyds Med Rep 399 (argued before the HRA came into force), the Court of Appeal considered the refusal of the health authority to fund gender reassignment treatment for three transsexuals on the basis that such treatment had a low priority because of the perceived lack of health gain. The court rejected the proposition that Article 8 could impose a positive obligation on the health authority to provide specific treatment. Buxton LJ said:

“the ECHR jurisprudence demonstrates that a state can be guilty of such interference simply by inaction, though the cases in which that has been found go beyond an obligation to adopt measures to prevent serious infractions of private or family life by subjects of the state... such an interference could hardly be founded on a refusal to fund medical treatment.”

- However, in the first successful judicial review of a clinical resourcing decision, the North Derbyshire Health Authority was ordered to retract its decision not to provide the high cost drug Betainterferon for the treatment of a man suffering from the relapsing form of multiple sclerosis. The authority was instructed to formulate and implement a policy (reflecting national policy) and to prescribe the drug.
- In South Africa, the Constitutional Court has taken a more interventionist stance in assessing the adequacy of health care against the human rights guarantees contained in the South African Constitution. Section 27 of the Constitution provides for a right to health services. In the case of *Minster of Health and others v Treatment Action Campaign and others*, the court considered a challenge using this section to the restricted availability of AIDS treatment in the public health sector. In a far reaching judgement, it upheld the applicants’ arguments that the government was obliged to devise and implement, within its available resources, a comprehensive and co-ordinated programme to reduce the risk of HIV transmission between mother and child.

10.2. Blanket decisions

- Article 14 guarantees that all individuals enjoy Convention rights without discrimination. Blanket decisions – based on age or medical condition – are vulnerable to challenge under the Convention. Clinical indicators demonstrating that older people, for example, benefit less from a treatment do not justify blanket decisions without an assessment of individual circumstances. Clinical judgements that have the effect of covert rationing may be found to be in breach of the Convention. For example, questions may be posed over the concept of Quality Adjusted Life Years (QALY) as constituting age discrimination in the provision of medical treatment. Even more vulnerable to challenge are ‘sham’ policies that attempt to disguise discrimination in the availability of medical services.

10.3. Assisted reproduction

- The right to found a family under Article 12 is now being used by couples seeking to use advances in medical techniques to aid conception. Under the ECHR there is an absolute right to found a family but this right does not extend to the birth of children.
- In *R v Secretary of State for the Home Department ex parte Mellor* [2001] 3 WLR 533, the court determined that Article 12 did not require provision to be made for a prisoner to have a child with his wife by artificial insemination. In *Briody v St Helens and Knowsley Area Health Authority* [29 June 2001], the Court of Appeal determined that Article 12 did not establish a right to have a child by means of artificial insemination or surrogacy at public expense. In *R v Human Fertilisation and Embryology Authority ex parte (1) Assisted Reproduction and Gynaecology Centre (2) H* [31 January 2002], the Court of Appeal refused permission for judicial review of a treatment decision by the Human Fertilisation and Embryology Authority on the basis that this was a matter of scientific expertise and could not be reviewed unless the Authority exceeded its statutory authority. The applicants wished to challenge the HFEA's Code of Practice that allowed only three embryos to be implanted (because of the risks of multiple births). However, the court did not consider that the appellant's Article 8 and 12 rights were sufficiently engaged for it to proceed to deliberate on the merits and proportionality of the HFEA's procedures.

11. MEDICAL CONFIDENTIALITY

“The protection of personal data, not least medical data, is of fundamental importance to a person’s enjoyment of his or her right to respect for private and family life as guaranteed by Article 8 of the Convention. Respecting the confidentiality of health data is a vital principle in the legal systems of all the Contracting Parties to the Convention. It is crucial not only to respect the sense of privacy of a patient but also to preserve his or her confidence in the medical profession and in the health services in general.”

ECtHR – *Z v Finland* [1998] 25 EHRR 371.

11.1. Article 8

- Disclosure of confidential medical records is an interference with a patient’s right to respect for private and family life under Article 8 of the ECHR. This can only be justified where there is a legitimate purpose and where there are adequate safeguards against abuse.

11.2. Effect of the Human Rights Act

- Confidentiality is a vital part of the relationship between the health care professional and patient. Prior to the HRA coming into force, it was accepted that the doctor patient duty of confidentiality could be set aside:
 - to comply with a court order;
 - as required under NHS legislation;
 - for the investigation of a serious crime;
 - for the registration of births and deaths; and
 - in connection with communicable diseases, abortion, drug misuse and serious accidents.

- These reasons may be considered to fall within the permitted limitations to the right to respect for private and family life as set out in Article 8(2) of the ECHR. However, requests for disclosure by law enforcement agencies conducting criminal investigations and by regulatory bodies in respect of allegations of professional misconduct can be especially sensitive.
- The HRA and ECHR shift the burden of argument away from the persons contesting the disclosure of their medical documents to the body seeking the information which must demonstrate that disclosure is necessary and will be handled in a proportionate manner.
- It is important that health care bodies review their arrangements for the handling of patient information and, in particular, the approach taken to the disclosure of information without the patient's consent. Where this is done it will be necessary to be able to demonstrate and document that it has been done for reasons that conform with the requirements of the Convention.

11.3. General Medical Council advice

- The General Medical Council has considered the implications of the Human Rights Act in stressing the importance of the sanctity of the doctor patient relationship.

“Patients have a right to expect that information about them will be held in confidence by their doctors. Confidentiality is central to trust between doctors and patients. Without assurances about confidentiality, patients may be reluctant to give doctors the information they need in order to provide good care. If you are asked to provide information about patients you should:

seek the patient's consent to disclosure of information wherever possible, whether or not you judge that patients can be identified from the disclosure;

anonymise data where unidentifiable data will serve the purpose;

keep disclosures to the minimum necessary”. [GMC 2000]

- The GMC also advises:

“In cases where you have considered all the available means of obtaining consent, but you are satisfied that it is not practicable to do so, if the patients are not competent to give consent, or exceptionally, in cases where the patients withhold consent, personal information may be disclosed in the public interest where the benefits to an individual or to the society of disclosure outweigh the public and the patient's interest in keeping the information confidential.

“In all such cases you must weigh the possible harm (both to the patient and to the overall trust between doctors and patients) against the benefits which are likely to arise from the release of information.” [GMC 2000]

11.4. HRA and ECHR cases

- Prior to the HRA coming into force, the Court of Appeal accepted, exceptionally, that the confidentiality of medical records could be overridden by public interest considerations arising from the need for transparency in consultation procedures. In the case of *R v Secretary of State for the Home Department ex parte the Kingdom of Belgium and R v Secretary of State for the Home Department ex parte Amnesty International and others* [15 February 2000] CA, the court agreed that the applicants could see the confidential medical reports on which the Secretary of State had based his decision that Senator Pinochet should not stand trial for extradition on medical grounds. The Secretary of State had given Senator Pinochet an express assurance that the medical report prepared by an independent team of medical experts on his state of health would remain confidential. However, the court considered that the failure to make available copies of the report as part of the consultation process under the Extradition Act did not meet the requirements of fair decision-making.
- With the HRA in force, in *A Health Authority v X and others* [10 May 2001], a Health Authority asked a GP practice to disclose medical records relating to care proceedings in respect of patients of that practice. These included documents created in the course of the care proceedings (List A documents) and the GP records of named patients of the practice (List B documents). Two patients did not consent to the release of the documents.
- There was no dispute over the obligation to comply with a court order obtained by the health authority but this had to be reconciled with the duty of confidentiality owed to the patients. The court accepted that the public interest required the disclosure of the List A documents to the health authority provided there were effective and adequate safeguards against abuse. These were:
 - respecting the confidentiality of the documents themselves;
 - keeping to a minimum the public disclosure of any information derived from the documents; and
 - protecting the patients' anonymity.
- The court also accepted that the public interest required disclosure of the List B documents. The interference with each patient's right to respect for private and family life under Article 8 of the Convention was permissible on condition that the List B documents would remain confidential and that every public body which received a copy would also be subject to the obligation to take effective and adequate safeguards against abuse.
- In a significant case before the Strasbourg court, *MS v Sweden* [1999] 28 EHRR 313, the applicant made a claim for compensation from the Social Security Office arising from a back injury caused by a fall at work. She was a long-term sufferer of chronic back pain. The Office requested the applicant's medical records from the clinic. These indicated that an abortion had been performed due to previous back pains without mention of her alleged injury at work. The Office therefore rejected her claim.
- The applicant claimed that the unauthorised disclosure of her medical records breached Article 8. However, the ECtHR held that a legitimate aim was being pursued. The

information was relevant to the allocation of public funds and the economic well being of the country.

- The Strasbourg court did not consider that the applicant had waived her right to confidentiality of her medical records by making a compensation claim. This differs from the rule established in *Hipwood and others v Gloucester Health Authority* [1995] PIQR 447, that a claimant should disclose the entirety of his or her medical records relevant to a claim. Where medical records are to be disclosed in support of a claim, questions of proportionality and safeguards against abuse could now be raised under the HRA.
- Maintaining the confidentiality of medical records is an area to exercise the tensions between Article 8 and Article 10 (freedom of expression). In the case of *Ashworth Hospital Authority v MGN Ltd* [2002], the House of Lords determined that the need to preserve the integrity of hospital medical records justified an order to be made against the publishers of an article using information obtained from a person's medical records in order to seek disclosure of the source of the information. It was noted that:

*“the care of patients at Ashworth was fraught with difficulty and danger. The disclosure of the patients’ records increased that difficulty and danger. To deter the same or similar wrongdoing in the future it was essential that the source should be identified and punished. That was what made the order necessary and proportionate and justified.”*¹²

11.5. Access to medical records

- Patients have extensive rights of access to their own medical records under existing legislation. In most cases, access is provided for by the Access to Health Records Act 1990 or the Data Protection Act 1998 (in respect of records created since 1991). There are exceptions where information may be withheld if its release to the patient would be likely to cause them serious physical or psychological harm. The HRA and ECHR do not add significantly to these rights. They may, however, give rise to a need for health care bodies to make more information available to patients about the risks of treatment or particular problems in the provision of a treatment arising from, for example, individual negligence or a systematic failing in a screening programme.
- Health care professionals should not simply assume that because it is possible to withhold information under statute that it follows that such withholding will be lawful. In the recent case of *S v Plymouth City Council*, the Court of Appeal ruled that the nearest relative (mother) of a patient in guardianship was entitled to direct access to the patient's medical records, social service files and to the recommendations and reports leading to guardianship, in order to be able to exercise her nearest relative functions.¹³ The Court of Appeal considered that, in this case, the local authority had not sought to strike the right balance (under the common law and Article 8 of the Convention) between maintaining patient confidentiality and affording the disclosure of information for the purpose of allowing the nearest relative to obtain proper professional and legal advice.

12. *Ashworth Hospital Authority v MGN Ltd*. [2002] HL, T.L.R. 1 July 2002.

13. *S v Plymouth City Council* [2002] EWCA Civ 388 CA.

12. LONG TERM CARE

- Long term care is an area with high exposure to challenge under the HRA and ECHR.
- The National Service Framework for Older People details the Government's expectations of service that should be available to older people and the manner of their delivery.
- Decisions about the provision of long term care should be based on an assessment of individual need, not based on cost.

12.1. The rights of older persons receiving long term care

- Article 8 (the right to respect for private and family life, home and correspondence), in particular, may be invoked in a number of circumstances relating to long term care. The article is relevant to:
 - decisions on whether to provide a person with domiciliary care or residential care;
 - the needs of carers;
 - standards and practices in care homes; and
 - decisions on the closure of care homes and the arrangements to be made for residents.
- A useful description of the areas where violations of Convention rights may occur is to be found at [www.schwehrcare.co.uk].¹⁴ This outlines that people in residential care are entitled:
 - *“to maintain independence as far as possible including the right to make decisions which may involve a degree of risk to themselves but not others;*
 - *to privacy and dignity;*

14. A small annual subscription is necessary to view all parts of this website devoted to health and social care.

- to exercise cultural and religious and sexual preferences;
 - to maintain existing relationships and to develop new ones;
 - to retain control of their own financial affairs;
 - to retain control of their own medication and health care;
 - to take an active part in all decisions about their life and future care;
 - to complain, comment or compliment;
 - to protection and security from the effect of a criminal act;
 - to information;
 - to an ongoing assessment of needs from appropriately qualified staff and an appropriate level of care to meet their needs; reasonable choice in all aspects of life;
 - to receive in full state benefits and personal allowances.”
- Any interference in these areas must be done within the limitations described in the Convention – to protect the rights of others etc (see section 3.2 above).

12.2. Legitimate expectation and long term care

- In the case of *R v North and East Devon Health Authority, ex parte Coughlan*¹⁵ the Court of Appeal used Article 8 to uphold a complaint by a resident over the closure of a care home where she had been promised a ‘home for life’. Mrs Coughlan was tetraplegic and accommodated in a purpose built facility (Mardon House). Closure of the home would have meant giving up non-means tested care under the NHS for means tested care provided by social services. Although the health authority’s decision was challenged by judicial review before the HRA came into force, the court’s decision was strongly influenced by the imminent incorporation of the Convention. It found that Mrs Coughlan had a legitimate expectation to remain at Mardon House as this was her ‘home’ protected under Article 8 of the Convention.
- The court was guided by a previous ruling that “the more substantial the interference with human rights, the more the court will require by way of justification before it is satisfied that the decision is reasonable” and therefore concluded that the Health Authority could not make the decision to move Mrs Coughlan without providing alternative accommodation which would meet her needs.
- The *Coughlan* judgement has prompted a number of similar challenges since the HRA has come into force. The DoH has published consolidated guidance on the implications of the judgement for the provision of continuing care.¹⁶ The guidance outlines NHS responsibilities for arranging and funding continuing care services and introduces new procedures for complaints handled by review panels. The guidance observes:

15. *R v North and East Devon Health Authority ex parte Coughlan* [199] COD 340.

16. DoH Health Service Circular – ‘Continuing Care: NHS and Local Council’s responsibilities.’ [HSC 2001/015] 28 June 2001

“The Coughlan case illustrated that decisions about the respective responsibilities of the NHS and social care must be made on the basis of a careful assessment of the facts in each individual case. This should be borne in mind at all times.”

It reminds health organisations that:

“The NSF for older people emphasises the importance of a high quality single assessment process (including nursing care needs). The importance of ensuring this has been properly carried out before embarking on the review process cannot be underestimated.”

- This is a good example of the manner in which a successful Convention challenge need not be a destructive process but a catalyst for improvements in procedures and better service delivery. Unfortunately, in February 2003, the Health Service Ombudsman ruled that, in a number of cases, the new guidance had not been followed and patients had been charged unfairly for their nursing care.

12.3. Awareness of the Human Rights Act in the long term care sector

- In 2002, the British Institute of Human Rights (BIHR) commissioned research on the extent that the Human Rights Act was being used by voluntary agencies to protect the human rights of individuals. One of the areas covered by the research concerned the treatment of older people. Interviews were conducted with a variety of voluntary agencies which recounted a series of disturbing stories which illustrated a lack of respect for the human rights of older people. The BIHR’s report observed:

“Participants from this sector presented overwhelming evidence that older people are routinely treated with a lack of dignity and respect that would simply not be accepted in relation to other social groups. It seems that many of those working in care settings have no idea of the principles that the Human Rights Act contains, nor do they understand their role in promoting or upholding these.”¹⁷

- There is much still to be done to ensure that the Convention rights of older persons are respected.

17. Jenny Watson – ‘Something for Everyone: The impact of the Human Rights Act and the need for a Human Rights Commission’ [2002] BIHR p56. See further pages 45-46 for some of the questionable practices identified by voluntary agencies.

13. REGULATION OF HEALTH CARE PROFESSIONS

- Article 6 (1) of the ECHR provides that:

“In the determination of his civil rights and obligations or of any criminal charge against him, everyone is entitled to a fair and public hearing within a reasonable time by an independent tribunal established by law.”

13.1. Disciplinary proceedings

- Disciplinary proceedings that may affect an individual's right of practice in a profession fall within the scope of 'civil rights and obligations' under Article 6. Prior to the HRA coming into force, Article 6 had been used on a number of occasions in the domestic courts (and at Strasbourg) to challenge the proceedings of disciplinary hearings which might result in a medical practitioner being prevented from practising his or her profession. In *Darnell v UK* [1994] 18 EHRR 205, a case involving dismissal from a Regional Health Authority, the Strasbourg court found a breach of the Convention because of the extended period of some nine years it took for this decision to be appealed through an industrial tribunal and judicial review. In *Stefan v UK* [1998] 25 EHRR CD130, the Commission noted a number of safeguards required under Article 6 were missing in the disciplinary procedures of the General Medical Council – members were not appointed for any particular term, their adjudications were not necessarily independent of GMC policy and the only legal assessor had no part in the final determination. However, the Commission considered that these defects were remedied by the right of appeal to the Judicial Committee of the Privy Council.
- Steps have been taken by professional bodies to ensure that disciplinary procedures comply with the ECHR. The General Medical Council, for example, investigates cases where a doctor is:

- convicted of a criminal offence; or
- accused of conduct which falls seriously short of accepted standards.

Complaints received by the Council are screened by a medically qualified ‘screener’ who may recommend no further action (subject to confirmation by a lay member of the GMC) or refer the matter to the Preliminary Proceedings Committee (PPC) for investigation. The PPC meets in private except in the most serious cases where the doctor who is the subject of the investigation will be asked to appear. The PPC may decide that no further action is required, issue advice or a warning or refer the matter for public hearing by the Professional Conduct Committee (PCC). A doctor’s registration can be suspended until the PCC hearing takes place. At the PCC, a doctor may be legally represented. The PCC uses rigorous criminal standards of proof for its investigations (the possibility of using civil standards for lesser offences is being debated). If found guilty, the committee has the power to impose conditions on a doctor’s freedom to practice medicine or suspend or remove a doctor from the register. In such cases, the doctor has the right of appeal to the Judicial Committee of the Privy Council.

- These procedures have been developed and tested against a backdrop of Convention related challenges. In *R v General Medical Council, ex parte Toth* [6 July 2000] QBD, it was determined that a complaint to the GMC should be heard in public unless there was a pressing reason not to do so. Openness was considered to be an important factor in maintaining the confidence of the public in the medical profession and complainants had a legitimate expectation of a public investigation. Where a doctor would continue in practice, the ‘screener’ should exercise caution in discontinuing the investigation of a complaint if there was any doubt over this decision.
- As a result of the *Toth* case, the GMC revised its preliminary screening procedures so that complainants could know the reasons on which screening decisions are made. In *Ghosh v General Medical Council* [25 June 2001] PC, the Privy Council decided that the importance of the appeals brought to it meant that they should be conducted in the form of a rehearing before its Judicial Committee.¹⁸ The GMC has also had to reconsider its arrangements whereby administrative staff retire with the PCC to record decisions to ensure that the staff who service the committee are separate from those who may have prepared the ‘prosecution’ case.
- The GMC is not the only regulatory body to be challenged in the courts under the HRA and ECHR. In *R v UK Central Council for Nursing, Midwifery and Health Visiting, ex parte Margaret Simpson Tehrani* [25 January 2001] Outer House, Court of Session, judicial review was sought of a decision to refer a charge of misconduct against the petitioner to the Council’s Professional Conduct Committee on the grounds that the committee was not an independent and impartial tribunal under Article 6 of the Convention. The judge noted that there could be reasonable doubt about the independence and impartiality of the council’s procedures because the same members of the UKCC sat on the Preliminary Proceedings Committee and the Professional Conduct Committee (though they could not

18. There is the possibility that the right to appeal decisions of the Professional Conduct Committee to the Judicial Committee of the Privy Council will in future be directed to a new (dedicated) appeal tribunal.

sit on both bodies for the same case). However, the judge ruled that it was not necessary for the UKCC to meet all the requirements of Article 6 given that there was an automatic right of appeal to the Court of Session regarding any decision to strike a member from the register.

- In *Brabazon – Denning v UK Central Council for Nursing, Midwifery and Health Visiting* [31 October 2000] DC, however, a decision of the Preliminary Proceedings Committee of the UK Central Council for Nursing, Midwifery and Health Visiting was overturned because disciplinary action was taken in the absence of the petitioner and without reasons being given was found to be in breach of Article 6.

13.2. Reasons for decisions

- Although a tribunal is not under a duty to give a detailed answer to every argument, written reasons should be given of sufficient clarity to enable the exercise of any right of appeal. Under the HRA and ECHR, decisions will be subject to closer scrutiny by the courts to see if those decisions are proportionate. The recording of reasons will assist both in focusing the mind on the requirements of the proportionality test (see section 3.2 above) and in resisting legal challenges. It is important that decisions are communicated to the persons concerned within a reasonable time.

13.3. Article 6 checklist:

- Do the proceedings involve the determination of a criminal charge?
- If not, do the proceedings involve the determination of a civil right or obligation?
- In either case, have the fair trial requirements of Article 6(1) been met?
- Are any further guarantees required to ensure a fair trial?
- Are there any relevant implied limitations to the Article 6 requirements?
- In the criminal context, has the presumption of innocence been respected?
- In the criminal context, have the minimum guarantees of Article 6(3) been complied with?

14. FUTURE CHALLENGES

- If proper regard is paid to its requirements, the Human Rights Act is unlikely to require fundamental changes in the delivery of health care in the UK. There are very few areas where best medical practice should not now already conform to the requirements of the HRA and ECHR. However, to date, the response of the health care sector to the introduction of the HRA has been patchy leaving it vulnerable to challenge under the Convention. The information and guidance to avoid this is available, but the risk remains because of the absence of institutional mechanisms to make the HRA part of the clinical and management practices of the health care sector. Lack of awareness of the requirements of the ECHR and a failure to translate these into the arrangements for providing health care therefore pose the main risk of a successful challenge under the Convention. Only on rare occasions will best clinical practice, if followed properly, fall foul of the Convention.
- Some areas and practices will be more susceptible to challenge than others no matter how thorough the steps taken to address obligations under the Convention. Three particular flashpoints for the future are likely to be:
 - **Long term care and the closure of nursing homes:** challenges relating to the resettlement of long term patients and patients' legitimate expectations on the provision of care and the ability to stay in care homes have been made and will continue to occur;
 - **Service reconfiguration:** the rationalising of hospital services where there is less need for acute provision and more for community services is an area that arouses community concern especially if involving the relocation or closure of hospital services. Community groups are likely to challenge such moves through judicial review and to utilise Convention points in their arguments – for example, by equating the withdrawal or relocation of a service as a failure to take steps to protect the rights to life guaranteed under Article 2 of the Convention.

- **Public inquiries:** following the Bristol and Alder Hay inquiries and recent Strasbourg case law on the duty of a state (under Article 2 of the Convention) to investigate deaths, there will be an increased focus on the question of when it is necessary to conduct an inquiry and whether that inquiry should be conducted in public. Decisions not to conduct an inquiry or not to conduct an inquiry in public are likely to be challenged under the HRA and ECHR.
- In all such areas, the importance of giving proper regard to the requirements of the Convention in policies, procedures and decision-making and recording how this is done will be crucial in limiting the likelihood of legal challenge or withstanding such a challenge if made.

Annexe A

WHO Constitution (Preamble)

The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social conditions.

Universal Declaration of Human Rights

Article 25 (1):

“Everyone has the right to a standard of living adequate for the health of himself and of his family, including food, clothing, housing, and medical care and necessary social services.”

International Covenant on Economic, Social and Cultural Rights

Article 12(1):

“The States Parties to the present Covenant recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.”

Convention on the Rights of the Child

Article 24(1):

“States Parties recognise the right of the child to the enjoyment of the highest attainable standard of health.”

Convention on the Elimination of All Forms of Racial Discrimination

Article 5(e)(iv) provides that States Parties undertake to prohibit and eliminate racial discrimination in the enjoyment of “the right to public health, medical care, social security and social services”.

Convention on the Elimination of All Forms of Discrimination Against Women

Article II(I)(f) provides that States Parties shall take all appropriate measures to eliminate discrimination against women in the enjoyment of “the right to protection of health and to safety in working conditions, including the safeguarding of the function of reproduction”.

Article 12 of the same Convention provides that all appropriate measures should be taken by States Parties to eliminate discrimination against women “in the field of health care in order to ensure on a basis of equality between men and women, access to health care services, including those related to family planning”.

European Social Charter

Article 11:

The right to protection of health

With a view to ensuring the effective exercise of the right to protection of health, the Contracting Parties undertake, either directly or in co-operation with public or private organisations, to take appropriate measures designed *inter alia*:

- 1 to remove as far as possible the causes of ill-health;
- 2 to provide advisory and educational facilities for the promotion of health and the encouragement of individual responsibility in matters of health;
- 3 to prevent as far as possible epidemic, endemic and other diseases.

The European Union Charter of Fundamental Rights

Article 3: Right to the integrity of the person

Everyone has the right to respect for his or her physical and mental integrity.

In the fields of medicine and biology, the following must be respected in particular:

the free and informed consent of the person concerned, according to the procedures laid down by law;

the prohibition of eugenic practices, in particular those aiming at selection of persons;

the prohibition on making the human body and its parts as such a source of financial gain;

the prohibition of the reproductive cloning of human beings.

Article 35: Health care

Everyone has the right of access to preventive health care 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 European Convention on Human Rights and Biomedicine

The Convention [www.coe.fr/oviedo/edito-e.htm] came into force in December 1999 but has not been signed or ratified by the UK. The Convention stands as an important statement of principle covering such matters as:

- consent to treatment;
- confidentiality of health information about individuals;
- genetics;
- organ and tissue transplantation;
- exploitation of the human body; and
- medical research.

Annexe B: The Convention rights

Article 2: Right to life

Article 3: Prohibition of torture

Article 4: Prohibition of slavery and forced labour

Article 5: Right to liberty and security

Article 6: Right to a fair trial

Article 7: No punishment without law

Article 8: Right to respect for private and family life

Article 9: Freedom of thought, conscience and religion

Article 10: Freedom of expression

Article 11: Freedom of assembly and association

Article 12: Right to marry and found a family

Article 14: Prohibition of discrimination

Article 16: Restrictions on the political activity of aliens

Article 17: Prohibition of abuse of rights

Article 18: Limitations on use of restrictions on rights

First Protocol

Article 1: Protection of property

Article 2: Right to education

Article 3: Right to free elections

Sixth Protocol

Article 1: Abolition of the death penalty

Article 2: Death penalty in time of war

Annexe C: The First Remedial Order

What impact did this have? A declaration of incompatibility does not alter the law in either the case in which it is raised or other cases. Nonetheless, the implications of the declaration needed to be explained quickly to the chairpersons and members of mental health review tribunals. This was done the day after the declaration had been made. The guidance made clear that tribunals should continue to function as before. Internally, the Mental Health Branch informed Ministers and the International and Constitution Branch which has responsibility for co-ordinating human rights matters within the department. The Cabinet Office, Home Office and National Assembly for Wales were notified (Scotland had different legislation) and the subject became a topic of discussion in the various lawyers' networks within Government.

The decision to rectify the incompatibility by way of a Remedial Order was not automatic or straightforward. All options were put to Ministers in the Department of Health. A decision was made somewhat easier by the fact that the ruling appeared to have direct implications for only one other department – the Home Office's responsibilities for restricted patients.

The Remedial Order was presented to Parliament on 19 July 2001 using the 'standard' procedure and not the emergency 'fast track procedure' allowed for under Schedule 2 of the Human Rights Act. This chosen path required that the document be before Parliament for at least 60 working days during which time representations might be made. Given the nature of the legislative year, under this track it was conceivable that the Order would not be able to take effect until March 2002. This did not really sit well with the purpose of introducing a Remedial Order. However, the standard track was initially chosen by the Department of Health because it was felt that, given the circumstances (no one was being detained unlawfully), it could not be argued that this was an extremely urgent matter warranting curtailing of parliamentary scrutiny. And as this was the first occasion on which the Remedial Order procedure was being used, it was thought desirable to establish a precedent allowing a degree of parliamentary scrutiny.

Within Parliament, the Joint Committee on Human Rights is charged with examining “proposals for remedial orders, draft remedial orders and remedial orders laid under section 10 of and Schedule 2 to the Human Rights Act”. Having considered the issue internally, the Committee put a series of questions to the Department of Health querying such diverse matters as whether the department had been correct to accept the court’s ruling, how many restricted patients were affected by the ruling, would there be a compensation scheme and why was the department using the non-urgent procedure to change the law? Pending the department’s reply, the Committee used the first part of the 60 working day period to canvass opinions and seek written evidence from interested groups outside Parliament. The small number of representations received supported the remedial order although it was pointed out that similar requirements to those made on restricted patients also applied for guardianship under Section 72(4) of the Mental Health Act and provisions concerning release by the Parole Board of discretionary life sentence prisoners under the Crime (Sentences) Act 1997. These other provisions could not be dealt with in the context of the remedial order as they had not been found to be incompatible with the ECHR by a court, but they were flagged in the Committee’s report as issues the responsible departments might wish to address.¹⁹

The DoH responded in detail to the Committee’s questions. It explained that it had been advised that an appeal would have:

*“no realistic prospect of success. We understand that there was no discernible error of law in the judgement of the Court of Appeal and an application for leave to appeal to the House of Lords had been refused by the Court of Appeal. In addition the judgement was not out of line with the direction of Government policy intentions for new mental health legislation as set out in the White Paper Reforming the Mental Health Act 1983.”*²⁰

No other restricted patients were considered to be detained in contravention of the Convention and in the case of ‘H’ the mental health review tribunal had made a positive finding in August 2001 that there was a mental disorder of a nature and degree warranting detention in hospital. The department did not envisage the need for a statutory compensation scheme: the small number of people likely to be affected by the court’s ruling could be catered for through ex gratia payments. It had adopted the non-urgent procedure because no patient was currently affected by the ruling, and it would allow for a higher degree of scrutiny by Parliament.

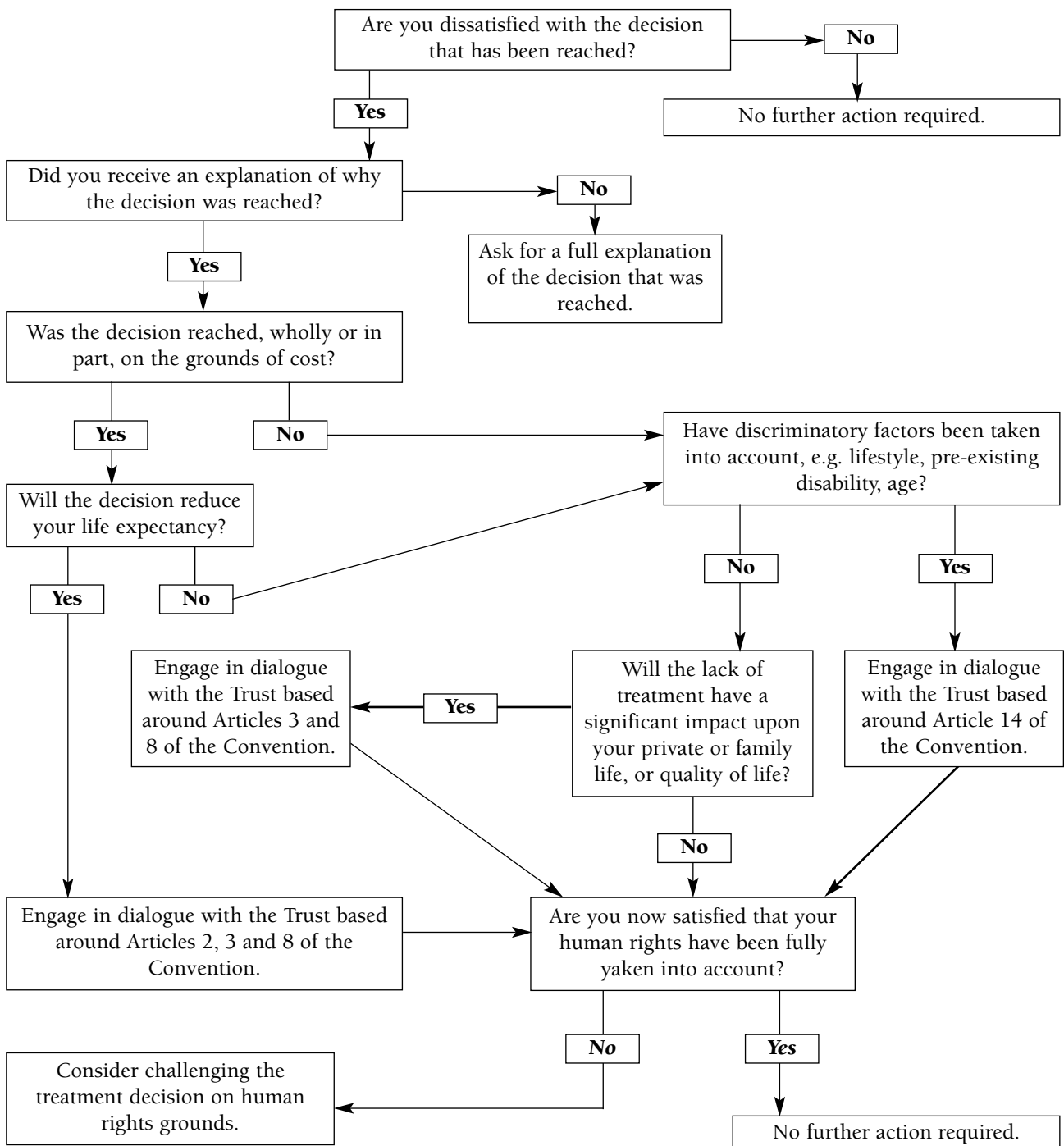
The Committee responded by pressing further for the implementation of a statutory scheme, which it considered was necessary to fulfil the requirement in Article 5(5) to an enforceable right to compensation for detention in contravention of the Article. It was not able to convince the department on this point. The Committee was more successful on its second issue, however, that the fast track procedure should be adopted as “there should be a presumption that the remedying of any incompatibility which could affect the liberty of the individual should be regarded as an urgent matter”.²¹ The department switched to the fast track procedure – the Order being laid on 19 November and coming into force on 26 November 2001.

19. ‘Mental Health Act 1983 (Remedial) Order’. Sixth Report of the Joint Committee on Human Rights, para 17. Published on 19 December 2001.

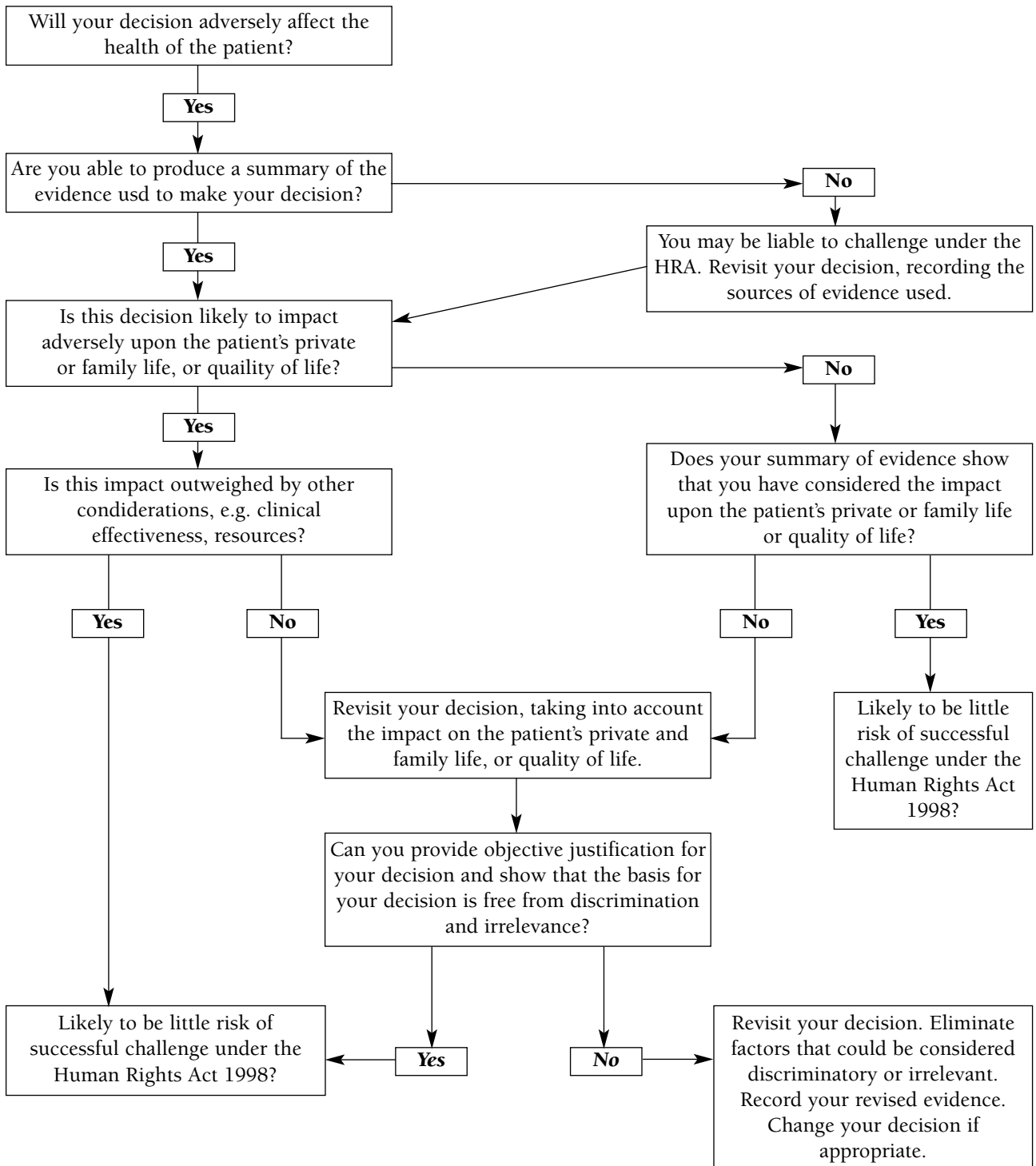
20. Letter dated 15 October 2001 from Jaqui Smith MP, Minister of State, Department of Health Appendices JCHR sixth report.

21. Letter to the Secretary of State, Department of Health. Appendices JCHR sixth report.

Annexe D: Treatment decision checklist for service users



Annexe E: Treatment decision checklist for health care professionals



[Annexe D and Annexe E are reprinted from 'The Human Rights Act 1998 and Access to NHS Treatments and Services: A Practical Guide – Elizabeth Haggart, Constitution Unit. 2001].

Annexe F: Further sources of information

Publications:

- The Human Rights Act 1998 and Access to NHS Treatments and Services: A Practical Guide – Elizabeth Haggett, Constitution Unit [2001].
- Understanding the Human Rights Act: A Toolkit for the Health Service – Roy Lilley, Paul Lambden and Christopher Newdick, Radcliffe Medical Press [2001].
- The Human Rights Act: A Practical Guide for Nurses – Rosie Wilkinson and Helen Caulfield, Whurr Publishers [2000].
- Healthcare Law: the impact of the Human Rights Act 1998 – John Tingle, Austen Garwood-Gowers, Cavendish Publishing [2001].
- NHSLA Review. Human Rights – Special Edition. Issue 19 Summer 2000.
- Decisions relating to Cardiopulmonary Resuscitation: a joint statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing [2002].

Websites:

[www.humanrights.gov.uk] – HRA guidance and advice provided by the Human Rights Unit of the Lord Chancellor's Department. Also, the full text of the Human Rights Act.

[www.doh.gov.uk/humanrights/index.htm] – DoH advice on the implications of the HRA and brief case notes on significant human rights challenges.

[www.humanrights.org.uk] – free human rights update service provided by One Crown Office Row.

[www.schwehr.co.uk/index.asp] – subscription service offering guidance and advice for health and social care practitioners on human rights and other matters.

[www.nhsla.com/] – proposed updating service for human rights court cases.

[www.bma.org.uk] particularly for:

- 'Impact of the Human Rights Act 1998 on medical decision taking' [2000]
- 'Withholding and withdrawing life-prolonging medical treatment: guidance for decision making' [2001]
- Consent toolkit.

[www.hsph.harvard.edu/xfbcenter/] – website of the Francois – Xavier Bagnoud Center for Health and Human Rights.