

# Healthcare Rights & Responsibilities

*A Review of the European Charter of Patients Rights*

## Summary



**Irish Patients' Association**



## **Executive Summary**

The European Charter of Patients' Rights provides a set of standards and goals that can promote dialogue and understanding among everyone involved in the Irish health care system. Rights will not solve all the problems, but they can help people examine the issues and constantly strive to improve.

The Charter was originally developed by the Italian patients' rights organisation, Cittadinanzattiva-Active Citizenship Network. In Rome in 2002, the Charter was presented to, and discussed, by representatives of several European patients' rights groups, including the Irish Patients' Association (IPA).

The IPA subsequently procured funding to support an academic review of the Charter in Ireland. Following competitive tender, funding was awarded to a multidisciplinary research team from the School of Nursing and the School of Law and Government at Dublin City University.

The proclamation of fourteen patients' rights seeks to render the fundamental rights concrete, applicable and appropriate to the current transitory situation in the health services. These rights all aim to guarantee a "*high level of human health protection*" (Article 35 of the UN Charter of Fundamental Rights), to assure the high quality of services provided by the various national health services. Patients must be protected throughout the entire territory of the European Union.

The European Charter of Patients' Rights can provide guidance towards a better health care system. The Charter adapted and developed for an Irish context, can serve to promote patient-centred care. This will require collaboration among, and mutual respect for, patients, their families, health care professionals, administrators and public servants - all working together to build a better system.

# **European Charter of Patients' Rights (2002)**

## **The fourteen rights published in Rome in 2000**

### **1-Right to Preventive Measures**

*Every individual has the right to a proper service in order to prevent illness.*

The health services have a duty to pursue this end by raising people's awareness, guaranteeing health procedures at regular intervals, free of charge, for various groups of the population at risk, and making the results of scientific research and technological innovation available to all.

### **2-Right of Access**

*Every individual has the right of access to the health services that his or her health needs require. The health services must guarantee equal access to everyone, without discriminating on the basis of financial resources, place of residence, kind of illness or time of access to services.*

An individual requiring treatment, but unable to sustain the costs, has the right to be served free of charge. Each individual has the right to adequate services, independently of whether he or she has been admitted to a small or large hospital or clinic.

Each individual, even without a required residence permit, has the right to urgent or essential outpatient and inpatient care. An individual suffering from a rare disease has the same right to the necessary treatments and medication as someone with a more common disease.

### **3-Right to Information**

*Every individual has the right to access to all kind of information regarding their state of health, the health services and how to use them, and all that scientific research and technological innovation makes available.*

Health care services, providers and professionals have to provide patient-tailored information, particularly taking into account the religious, ethnic or linguistic specificities of the patient. The health services have the duty to make all information easily accessible, removing bureaucratic obstacles, educating health care providers, preparing and distributing information materials.

A patient has the right of direct access to his or her clinical file and medical records, to photocopy them, to ask questions about their contents and to obtain the correction of any errors they might contain. A hospital patient has the right to information which is continuous and thorough; this might be guaranteed by a "tutor". Every individual has the right of direct access to information on scientific research, pharmaceutical care and

technological innovations. This information can come from either public or private sources, provided that it meets the criteria of accuracy, reliability and transparency.

#### **4-Right to Consent**

*Every individual has the right of access to all information that might enable him or her to actively participate in the decisions regarding his or her health; this information is a prerequisite for any procedure and treatment, including the participation in scientific research.*

Health care providers and professionals must give the patient all information relative to a treatment or an operation to be undergone, including the associated risks and discomforts, side-effects and alternatives. This information must be given with enough advance time (at least 24 hours notice) to enable the patient to actively participate in the therapeutic choices regarding his or her state of health.

Health care providers and professionals must use a language known to the patient and communicate in a way that is comprehensible to persons without a technical background. In all circumstances which provide for a legal representative to give the informed consent, the patient, whether a minor or an adult unable to understand or to will, must still be as involved as possible in the decisions regarding him or her. The informed consent of a patient must be procured on this basis. A patient has the right to refuse a treatment or a medical intervention and to change his or her mind during the treatment, refusing its continuation. A patient has the right to refuse information about his or her health status.

#### **5-Right to Free Choice**

*Each individual has the right to freely choose from different treatment procedures and providers on the basis of adequate information.*

The patient has the right to decide which diagnostic exams and therapies to undergo, and which primary care doctor, specialist or hospital to use. The health services have a duty to guarantee this right, providing patients with information on the various centres and doctors able to provide a certain treatment, and on the results of their activity. They must remove any kind of obstacle that could limit this right. A patient who does not have trust in his or her doctor has the right to designate another one.

#### **6-Right to Privacy and Confidentiality**

*Every individual has the right to the confidentiality of personal information, including information regarding his or her state of health and potential diagnostic or therapeutic procedures, as well as the protection of his or her privacy during the performance of diagnostic exams, specialist visits, and medical/surgical treatments in general.*

All the data and information relative to an individual's state of health, and to the medical/surgical treatments to which he or she is subjected, must be considered private, and as such, adequately protected.

Personal privacy must be respected, even in the course of medical/surgical treatments (diagnostic exams, specialist visits, medications, etc.), which must take place in an appropriate environment and in the presence of only those who absolutely need to be there (unless the patient has explicitly given consent or made a request).

### **7-Right to Respect of Patients' Time**

*Each individual has the right to receive necessary treatment within a swift and predetermined period of time. This right applies at each phase of the treatment.*

The health services have a duty to fix waiting times within which certain services must be provided, on the basis of specific standards and depending on the degree of urgency of the case. The health services must guarantee each individual access to services, ensuring immediate sign-up in the case of waiting lists. Every individual that so requests has the right to consult the waiting lists, within the bounds of respect for privacy norms.

Whenever the health services are unable to provide services within the predetermined maximum times, the possibility to seek alternative services of comparable quality must be guaranteed, and any costs borne by the patient must be reimbursed within a reasonable time. Doctors must devote adequate time to their patients, including the time dedicated to providing information.

### **8-Right to the Observance of Quality Standards**

*Each individual has the right of access to high quality health services on the basis of the specification and observance of precise standards.*

The right to quality health services requires that health care institutions and professionals provide satisfactory levels of technical performance, comfort and human relations. This implies the specification, and the observance, of precise quality standards, fixed by means of a public and consultative procedure and periodically reviewed and assessed.

### **9-Right to Safety**

*Each individual has the right to be free from harm caused by the poor functioning of health services, medical malpractice and errors, and the right of access to health services and treatments that meet high safety standards.*

To guarantee this right, hospitals and health services must continuously monitor risk factors and ensure that electronic medical devices are properly maintained and operators are properly trained.

All health professionals must be fully responsible for the safety of all phases and elements of a medical treatment. Medical doctors must be able to prevent the risk of errors by monitoring precedents and receiving continuous training. Health care staff that

report existing risks to their superiors and/or peers must be protected from possible adverse consequences.

### **10-Right to Innovation**

*Each individual has the right of access to innovative procedures, including diagnostic procedures, according to international standards and independently of economic or financial considerations.*

The health services have a duty to promote and sustain research in the biomedical field, paying particular attention to rare diseases. Research results must be adequately disseminated.

### **11-Right to Avoid Unnecessary Suffering and Pain**

*Each individual has the right to avoid as much suffering and pain as possible, in each phase of his or her illness.*

The health services must commit themselves to taking all measures useful to this end, like providing palliative treatments and simplifying patients' access to them.

### **12-Right to Personalised Treatment**

*Each individual has the right to diagnostic or therapeutic programmes tailored as much as possible to his or her personal needs.*

The health services must guarantee, to this end, flexible programmes, oriented as much as possible to the individual, making sure that the criteria of economic sustainability does not prevail over the right to health care.

### **13-Right to Complain**

*Each individual has the right to complain whenever he or she has suffered a harm and the right to receive a response or other feedback.*

The health services ought to guarantee the exercise of this right, providing (with the help of third parties) patients with information about their rights, enabling them to recognise violations and to formalise their complaint. A complaint must be followed up by an exhaustive written response by the health service authorities within a fixed period of time. The complaints must be made through standard procedures and facilitated by independent bodies and/or citizens' organisations and cannot prejudice the patients' right to take legal action or pursue alternative dispute resolution.

## **14-Right to Compensation**

*Each individual has the right to receive sufficient compensation within a reasonably short time whenever he or she has suffered physical or moral and psychological harm caused by a health service treatment.*

The health services must guarantee compensation, whatever the gravity of the harm and its cause (from an excessive wait to a case of malpractice), even when the ultimate responsibility cannot be absolutely determined.

### **Preliminary statements issued with the Charter (2002)**

With regard to the fourteen patients' rights, some preliminary statements are called for:

- The rights give both citizens and health care stakeholders their own responsibilities.
- The Charter applies to all individuals, recognising the fact that differences, such as age, gender, religion, socio-economic status and literacy etc., may influence individual health care needs.
- The Charter does not intend to take sides on ethical issues.
- The Charter is valid in contemporary European health systems and will be reviewed and modified to allow for its evolution, and the development of scientific knowledge and technology.
- The fourteen rights are an embodiment of fundamental rights and, as such, they must be recognised and respected independently of financial, economic or political constraints, taking the appropriateness of care into consideration.
- Respect for these rights requires a global reform of the way individual national health systems operate.
- Each article of the Charter refers to a right and defines and illustrates it, without claiming to foresee all possible situations.

## **Guidelines for the implementation of the Charter (issued with the Charter in 2002)**

The dissemination and application of the contents of this Charter will have to be carried out at many different levels, particularly at European, national and local levels.

### ***Information and Education***

As a means of informing and educating citizens and health care workers, the Charter may be promoted in hospitals, the specialised media and other health care institutions and organisations. The Charter may also be promoted in the schools, universities and all other places where questions regarding the construction of the “Europe of Rights” are addressed. Special attention should be devoted to training and educational activities for doctors, nurses and other health care stakeholders.

### ***Support***

Support for, and subscription to, the Charter could be gathered from health care stakeholders and citizens’ organisations. The special commitments of those health services and professionals that subscribe to the Charter should be defined.

### ***Monitoring***

The Charter may also be used as a means of monitoring the state of patients’ rights in Europe by civic organisations, the information media and independent authorities, with the use of appropriate tools. A periodic report could be published to further awareness of the situation and outline new objectives.

### ***Protection***

The Charter may be used to launch activities for the protection of patients’ rights, conceived as prevention as well as actions to restore rights that have been violated. Such activities may be pursued by active citizenship organisations, by institutions and bodies like ombudspersons, ethical committees or Alternative Dispute Resolution commissions, justices of the peace, as well as by the courts. Institutions, procedures and tools coming from the “European legal space” should be employed to this end.

### ***Dialogue***

A dialogue among the stakeholders can be pursued on the basis of the Charter’s contents, in order to work out policies and programmes for the protection of patients’ rights. Such a dialogue would take place among governmental authorities, public and private companies involved in health care, as well as professional associations and labour unions.



### ***Budgeting***

In relation to the patients' rights contained in this Charter, quotas, representing a percentage of the health budget to set aside for the resolution of specific situations (for example, waiting lists), or for the protection of those in particularly critical situations (like the mentally ill), could be set and applied. The respect for such quotas, or the degree of deviation from them, could be verified by annual reporting.

### ***Legislation***

The Charter rights may be incorporated into national and European laws and regulations in full or in part, to make the goal of protecting patients' rights an ordinary part of public policies, notwithstanding the immediate implementation of such rights in light of the European Union Charter of Fundamental Rights.

## **A Review of the ethical, legal and social implications of implementing the European Charter of Patients' Rights in Ireland**

A review of the ethical, legal and social implications of implementing the European Charter of Patients' Rights in Ireland was commissioned by the Irish Patients' Association and carried out by a research team comprising academic staff from a number of disciplines at Dublin City University.

The team included: members of the School of Nursing staff with backgrounds in nursing, health care ethics, psychology and pharmacy; and the School of Law and Government staff with backgrounds in medical law.

### **Summary of the Report's Recommendations**

#### *General recommendations*

- The European Charter of Patients' Rights is an important proposal that warrants serious consideration by all stakeholders of the Irish health care system.
- Rights place duties on others to fulfil them and rights also imply responsibilities for rights-bearers.
- Rather than focusing only on patients' rights, health care rights and responsibilities should be promoted.
- Health care involves collective ownership and collective responsibility. Therefore all stakeholders should engage in partnership and effective dialogue over health care rights and responsibilities.
- All the rights should be viewed as interlinked with each other, with the promotion of one helping to promote others.
- Rights provide an important language by which "moral strangers" can settle disputes and develop unity. Such discussions should promote arbitration rather than confrontation.
- The distinction between Civil and Political Rights and Economic and Social Rights is crucial. Increased public awareness of this distinction is needed.
- Effective implementation of rights requires an adequate infrastructure and mechanisms to facilitate their promotion and enforcement.
- The rights and responsibilities of health care professionals should be promoted through a variety of educational avenues.
- The language of any charter of rights should be carefully chosen and all significant terms clearly defined.

### ***Legal recommendations***

- The constitutional right to life should be revised to include the implied rights recognised by the Irish Courts and contained in international human rights instruments.
- The Constitution of Ireland should be amended (or a Statute of the Oireachtas be enacted) to include some aspects of the economic and social rights of the European Charter of Patients' Rights.
- Specific duties should be enshrined in Irish law, including:
  - ❑ The duty to respect the rights and liberties of others.
  - ❑ The duty to promote, protect and attend to one's health and that of the community.
  - ❑ The duty to pay taxes and, possibly, a health tax.
- The Irish Human Rights Commission should be put on a constitutional basis as opposed to its current statutory basis.

### ***Recommendations for specific rights of the Charter***

- ◆ Public discussion should be regarding which particular rights should be accepted and the order in which their implementation should be prioritised.
- ◆ The Right to Preventive Measures can be recommended, but raises questions about patients' responsibility for their health.
- ◆ The Right of Access can be recommended, but its practical implementation will require much discussion regarding resourcing.
- ◆ The Right to Free Choice is a laudable goal, but would generate significant resource problems. It is recommended that an equitable and transparent process be developed so that patients understand why they are given the choices available to them.
- ◆ The Right to Respect of Patients' Time can be whole-heartedly recommended, though research is needed to understand why waiting lists develop and how they can be eliminated.
- ◆ The Right to Innovation is important, but must be balanced with the right to safety.
- ◆ The Right to Personalized Treatment can be recommended, but is often hindered by structural designs. It is recommended that such issues be recognised in decisions about the design and refurbishment of health care facilities.

- ◆ The Right to Information can be wholeheartedly recommended. Legal and practical steps should be taken to increase the availability to the public of unbiased, evidence-based health care information.
- ◆ The Right to Consent exists in health care policy, professional codes of ethics and Irish law. It should be given a statutory basis and stakeholders should continue to develop better procedures for securing informed consent, especially within the mental health services.
- ◆ The Right to the Observance of Quality Standards has been accepted in Ireland. Evidence-based practice should continue to be promoted and that health care practices and facilities be evaluated regularly to continuously improve their quality.
- ◆ The Right to Safety can be wholeheartedly recommended. We recommend that data be collected to promote safety within health care for patients and professionals. The work of the Health Information and Quality Authority should be supported.
- ◆ The Right to Avoid Unnecessary Suffering and Pain can be wholeheartedly recommended. A holistic understanding of suffering and its different components is recommended so that all aspects of pain and suffering are acknowledged and addressed as well as possible.
- ◆ The Right to Privacy and Confidentiality exists in professional ethics codes and Irish law. We recommend that it be given a statutory basis and that it be considered when health care facilities are designed and refurbished.
- ◆ The Right to Complain can be recommended, especially if implemented as part of a broader feedback system designed to improve quality and safety.
- ◆ The Right to Compensation is controversial. It is recommended that the focus be shifted from financial compensation onto factors like providing answers to patients' questions and ensuring that complaints improve quality and safety.

*Are the Charter rights reflected in Irish constitutional rights?*

It is necessary to classify each right of the European Charter of Patients' Rights as either a civil and political right or an economic and social right. Whether these Charter rights are reflected in the constitutional rights can then be considered. It is possible to dispute aspects of this classification. For example, the right to compensation is an economic and social right in light of its monetary implications. However, traditionally, Western liberal democratic legal systems classify this right as a civil and political right.

<i>Civil and Political Rights</i>
<b>4. Right to Consent</b>
<b>6. Right to Privacy and Confidentiality</b>
<b>9. Right to Safety</b>
<b>11. Right to Avoid Unnecessary Suffering and Pain</b>
<b>13. Right to Complain</b>
<b>14. Right to Compensation</b>

<i>Economic and Social Rights</i>
<b>1. Right to Preventative Measures</b>
<b>2. Right of Access</b>
<b>3. Right to Information</b>
<b>5. Right to Free Choice</b>
<b>7. Right to Respect of Patients' Time</b>
<b>8. Right to the Observance of Quality Standards</b>
<b>10. Right to Innovation</b>
<b>12. Right to Personalised Treatment</b>

*\*Two classes of rights in the European Charter of Patients' Rights*

Many of the civil and political rights of the European Charter of Patients' Rights are found in Irish law. Nevertheless, these rights are fragmented across a variety of sources and there is a significant degree of uncertainty as to the exercise of these rights in the various circumstances that arise when providing health care. It would be possible to guarantee all these rights and remove uncertainty as to the exercise of these rights through either a constitutional amendment and / or legislation.

The economic and social rights of the Charter, are to a large extent, not found in the different legal rights in Irish law. These economic and social rights are of pre-eminent concern to most patients. These economic and social rights require not only a constitutional amendment and legislation but also significant financial resources. Any constitutional amendment seeking to guarantee these economic and social rights must ring-fence a percentage of the annual tax revenue taking into account the size and age of the population.

Any constitutional amendment or legislation guaranteeing these civil and political and economic and social rights for patients should also make corresponding duties and responsibilities explicit. Any constitutional amendment or legislation should impose at minimum two duties: an individual duty and a collective duty. The individual duty of every patient is to safeguard and enhance his or her health. The collective duty on everyone is to contribute tax to ensure that there are sufficient financial resources to guarantee the economic and social rights of the European Charter of Patients' Rights or any subset of such rights that might be enacted.

### **Limitations with a rights-based approach to health care**

A rights-based approach to health care has limitations. It could promote a "them and us" atmosphere, especially if every right is viewed as an absolute entitlement. Rights can reinforce individualistic leanings, rather than promote community. Identifying the bearers of rights can be controversial. While the Charter's civil and political rights already exist to some extent in Irish law, most economic and social rights do not. As with all economic and social rights, the right to health care is laudable; but it costs money.

Enacting the Charter's rights will further destabilise the Irish health care system if we are not willing to pay for them.

Ireland can endorse many of the Charter's specific rights to the extent that they promote patients' welfare. Each right gives entitlements and responsibilities that can unite people if viewed holistically. For example, the right to preventive measures entitles patients to certain services, but also reminds patients of their responsibilities for their health.

For example the right to innovation entitles patients to certain procedures, but also opens opportunities for health care professionals to develop expertise and engage in research. When the aim of improving patient care is kept central, the rights can work to bring all stakeholders together. Mutual rights and responsibilities should remind us of our interconnectedness and promote collaboration, not divisive individualism.

Working together, a commitment to rights and responsibilities, along with mutual respect, will put us on the path to continuously improve the Irish health care system.

Although the Charter focuses on patients' rights, we would rather call for a commitment to health care rights and responsibilities. This reminds us that we are in this together and share a common destiny. We should keep in mind that almost all of us will one day experience the system as patients ourselves.

Before being able to promote the rights in the European Charter of Patients' Rights, much discussion will be needed on many of the details contained therein. For example, the right of access to health care services is laudable, but it requires determination of which health services everyone has a right to access. Much public discussion is needed in many areas like this. To assist in examining the details of the Charter, the Report grouped the fourteen rights into five major themes. This grouping was not part of the Charter, and the details could, and should be, debated. These categories provide a more workable framework within which to examine the rights. These themes are set out in the subsequent table.

## Themes within the European Charter of Patients' Rights

Theme	Right with Number from the Charter
<i>A. Access to Health Care</i>	1. Right to Preventative Measures 2. Right of Access 5. Right to Free Choice 7. Right to Respect of Patients' Time 10. Right to Innovation 12. Right to Personalised Treatment
<i>B. Informed Consent</i>	3. Right to Information 4. Right to Consent
<i>C. Safety and Quality Assurance</i>	8. Right to the Observance of Quality Standards 9. Right to Safety 11. Right to Avoid Unnecessary Suffering and Pain
<i>D. Privacy and Confidentiality</i>	6. Right to Privacy and Confidentiality
<i>E. Redress</i>	13. Right to Complain 14. Right to Compensation



## Research

This report is the result of several months of research by the members of the Patients' Rights Research Team at DCU. The Research Steering Group was convened in response to a tender for funding of this project by the Irish Patients' Association under the leadership of Mr Stephen McMahon. This funding support came via an educational grant from Merck Sharp & Dohme Ireland (Human Health) Ltd and Pfizer Healthcare Ireland. The Research Team thanks these organisations for this funding which made it possible for the three research assistants to dedicate much time to the project. Their work laid the foundation for the initial draft of the Report. The research team also carried out interviews with people who have experienced the Irish health care system from different perspectives. We are very grateful for the time and thought put into the project by these interviewees.

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