



## The EU Charter of Patients' Rights - A civic assessment Active Citizenship Network, 2011

### Abstract

In 2005, Active Citizenship Network (ACN) proposed a project, carried out between 2005 and 2007, for monitoring the implementation of the European Charter of Patients' Rights (attached) in the fourteen EU member states (Luxemburg excluded) in order to begin promoting and implementing the Charter, while at the same time putting in practice European active citizenship.

The aim was to put citizens at the centre of Health Policy, transforming their role from mere targets and users of health services to active citizens participating in health care policymaking and, at the same time, to produce information on the actual implementation of patients' rights at the EU level. The reasons for this second assessment work that we promoted in 2010 are very similar. In this moment in Health policies reform the following actions are particularly important: reinforcing alliance-building between organisations and groups, enlarging participation in the assessment (20 countries); producing civic information for policy input; being proactive, not only reactive, citizens; building partnerships with all of the stakeholders in the Health sector (professionals, local institutions, companies, universities, etc.); and, last but not least, sharing and learning from each other.

### PROJECT METHODOLOGY

In the implementation of this second round of assessment work, the methodological approach adopted in 2005 has been substantially confirmed, with a few changes having been made based on information that emerged from the first project. In the phases of definition, implementation and evaluation, the project methodology of this assessment work has been inspired by the method of "civic information", defined as *the capacity for organized citizens to produce and use information to promote their own policies and participate in public policymaking*.

The study was done by collecting three types of information (listed below), plus a fourth type, added as a complement in order to integrate the picture of information provided.

**A. Institutional actions for patients' rights:** the first type of information concerns the degree to which institutional bodies (government, public administration, Ministry of Health, etc.) are promoting norms, policies and actions relevant to the interests of the European Charter of rights.

**B. Actual conditions of hospital patients:** the second type of information concerns *the actual conditions of the citizens* who use the health care system and, consequentially, the concrete experiences of all those who have needed to turn to a hospital or a day hospital service (for example, on the time necessary to get a diagnostic exam or a surgical intervention in a hospital, on the existence of certain services to hospital patients, such as cultural mediation or interpreting services and etc. ).



This type of information is collected by citizens using a method well-established in Italy, that of the Civic Audit, an application of an aspect of civic information. In this and in the previous study, each right of the European Charter is associated with a group of indicators corresponding to fundamental phenomena relevant to the end of evaluating the implementation level of the right under examination. The process led to the identification of a group of **88 indicators** regarding the 14 patients' rights plus the right to active citizenship, to reveal the actual conditions of hospital patients.

**C. Alerts from civic organizations:** the third type of information regards the cognitive patrimony of civic organizations, in the conviction that such organizations, given the type of experience and work that they are engaged with, offer a wide range of information regarding health and the health care system. The civic partners organizations involved in the project have provided information and, in some cases, have interviewed other citizens' organizations.

**D.** The fourth type of information does not contribute to the evaluation, but is gathered and included in order to integrate the reading and interpretation of the other blocks of information. This type of information consists in *statistical data* collected by international agencies with the aim of documenting and describing, in a comparative way, the health conditions of the population and the various factors that determine these conditions.

In order to collect all of these types of information, four sources were utilized:

- an Official from the Ministry of Health
- direct observation of Hospitals (up to 5 Hospitals per country, according to the population) and meetings with Responsible Authorities
- partner organizations in each country
- statistical data at a European level

In order to permit a more "immediate" reading of the results, a **PRES (Patients' Rights Euro Score)** was calculated for each indicator<sup>1</sup>. The value of the score (from 0 to 100) expresses the degree to which the information gathered respects the legitimate expectations held by citizens.

The synthetic evaluation of each right was then formulated by calculating a general **index** as an average<sup>2</sup> of the Patients' Rights Euro Scores of the groups of information A, B and C.

The rights were evaluated according to the following labels, based on the value<sup>3</sup> reached by the general index: NOT RESPECTED, HARDLY RESPECTED, PARTLY RESPECTED, ALMOST RESPECTED, FULLY RESPECTED.

In this project have been involved: 20 countries, 56 hospitals, 23 Ministries of Health and 70 civic organizations.

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<sup>1</sup> The total number of indicators used for the Report is 156.

<sup>2</sup> In the general Index, the score for "Alerts from Civic Organizations" has contributed as a weighted average, calculated considering the populations of the single countries. Sources for populations: <http://europa.eu> - data 2007 - For Macedonia: <http://ec.europa.eu/enlargement> - data 2006.

<sup>3</sup> 0 – 50: NOT RESPECTED, 51 – 60: HARDLY RESPECTED, 61 – 70: PARTLY RESPECTED, 71 – 90: ALMOST RESPECTED, 91 – 100: FULLY RESPECTED



## AN OVERVIEW OF THE RIGHTS

Ordering the indexes attained by the rights<sup>4</sup> assessed, from low to high, it is possible to obtain a classification of the degrees of respect of the rights on the basis of the Patients' Rights Euro Scores.

As can be easily seen, no single right may be considered fully implemented:

Right	Assessment	PRES
7. RIGHT TO RESPECT OF PATIENTS' TIME	NOT RESPECTED	41
5. RIGHT TO FREE CHOICE*	NOT RESPECTED	43
2. RIGHT TO ACCESS – care	NOT RESPECTED	46
3. RIGHT TO INFORMATION	HARDLY RESPECTED	54
15. RIGHT TO ACTIVE CITIZENSHIP	HARDLY RESPECTED	54
11. RIGHT TO AVOID UNNECESSARY SUFFERING AND AVOIDING PAIN	HARDLY RESPECTED	58
9. RIGHT TO SAFETY	HARDLY RESPECTED	60
8. RIGHT TO THE OBSERVANCE OF QUALITY STANDARDS	PARTLY RESPECTED	61
10. RIGHT TO INNOVATION	PARTLY RESPECTED	63
4. RIGHT TO CONSENT	PARTLY RESPECTED	64
14. RIGHT TO COMPENSATION	PARTLY RESPECTED	64
13. RIGHT TO COMPLAIN	PARTLY RESPECTED	66
12. RIGHT TO PERSONALIZED TREATMENT	ALMOST RESPECTED	74
1. RIGHT TO PREVENTIVE MEASURES	ALMOST RESPECTED	75
6. RIGHT TO PRIVACY AND CONFIDENTIALITY	ALMOST RESPECTED	77
2. RIGHT TO ACCESS - physical	ALMOST RESPECTED	84
<b>TOTALS - MEAN VALUES</b>	<b>PARTLY RESPECTED</b>	<b>62</b>

\*Only considering Civic Partner Organizations answers

Source: Active Citizenship Network

### Critical areas: time, free choice, access to care

Despite the differences in the methodology adopted for the preceding survey carried out by ACN, the rights with the worst scores are the same in both surveys. It is possible to conclude therefore that these three areas are effectively the most critical and that this is true in almost all countries.

The low score of the **right to respect of patients' time** is particularly affected by the alarming situation denounced by the civic organizations: in 19 Countries out of 20 they have regularly or frequently reported violations of this right, emphasizing not only the pure issues about time, but also the serious consequences that citizens have suffered because of the delays in treatments or diagnoses.

Only in 4 countries maximum wait times both for specific exams and not urgent surgical procedures have been legally established. Moreover a problem of transparency emerges, both at institutional and at hospital level, as citizens can hardly find information on the waiting lists for diagnostic exams, treatments and elective surgery. In the hospitals assessed of 15 countries a clear problem of tied-up waiting lists for Hip prosthesis and/or Head TC Scan has been detected.

<sup>4</sup> In order to correctly evaluate the "Right to access" it is necessary to distinguish between "physical access" to hospitals (transportation, parking, absence of barriers, etc.) and "access to care and treatments".



The violations of the rights denounced by the civic organizations are also decisive for the positions of the rights to free choice and access to care.

The **right to free choice** is recognized in principle in all of the countries, but is often in fact limited by organizational procedure, by limits imposed by insurance companies or by other factors. According to 60% of the civic organizations interviewed, administrative authorities and insurers tend to provide incentives for access to determinate hospitals and centres. In sum, what emerges is a “choice” that is not in fact very free and that is burdened with many obstacles.

As regards the **right to access to needed health care** and treatments, the civic organizations report an overall high frequency of violations in relation to services (financial resources, place of residence and kind of illness): they found no or only occasional violations only in 3 countries out of the total 20.

### **The mediocrity: safety, quality and innovation**

Significant is the performance of three important rights dependent on facilities: the rights to safety, quality and innovation.

As concerns **the right to safety**, while the respect of hospital patients’ safety is rather reassuring, except for frequent lacks of attention towards people with disabilities, the institutional actions for patients’ rights, together with the frequent violations detected by civic organizations, are responsible of seriously lowering the score of this right: in 17 countries out of 20 no form of legal protection has been established for people who report an adverse event and in 9 countries there are no national recommendations for the implementation of the “WHO Surgical Safety Checklist”. These results are even more pregnant when considering that in matters of safety, values deemed acceptable must be very close to the maximum score.

Some indicators deeply affect the score attained by the **right to observance of quality standards**: standing out among the indicators is the nearly complete absence of nationally-issued lists reporting the quality ranking of health services, with the sole exception of the United Kingdom. The indicator for the presence of national governmental accreditation programs for health services reveals consistent underdevelopment in many countries.

The **right to innovation** in hospitals is not worrying, but the absence of electronic patient records, which are adopted by all hospitals only in 5 countries, and the use of Patient Controlled Analgesia (although with several “gaps”) and of telemedicine are only bit more widespread. The distribution of violations detected in the 20 countries is highly varied, but in half of the countries violations concerning delays in the introduction of innovative diagnostic tests, of innovative treatment and delays in particular areas of medical research were reported frequently and, in four cases, even regularly.

The statistical data, which do not contribute to the general index of PRES, reveal very widespread gaps relative to the availability of certain innovative drugs and certain technologies.

### **“Without praise or blame”: consent, compensation, and complaint**

Three rights characteristic of the empowered users result as partially respected and have attained about the same scores. Their positions in the assessment, with some slight variation, find verification in the previous survey: it is possible to talk about stagnant rights.



As concerns the **right to consent**, a significant result is the scant spread of complete governmental guidelines for informed consent for elective surgery, indicator fully met only in 5 countries. In hospitals, a problem regarding specific consent forms with proper contents for four elective surgery operations clearly emerges, with also sensitive (and partly surprising) differences among countries and common coherence within individual countries. The peculiar situation requires a special reflection upon the meaning of “consent”, from a civic point of view (see below).

Being indicators selected for the two levels (institutional one and hospital assistance) very similar, it is possible to maintain that the respect for the **right to compensation** in hospitals is considerably weaker by comparison. In particular, there is an almost total absence of independent committees or structures supporting parties in reaching a final agreement on compensation, together with many lacks in the area of insurance.

Although the mean scores of the **right to complain** at the institutional level and at the hospital level are sufficient, a suspicion has emerged: the filing of complaints is facilitated, even through organizational measures, but such complaints are not often taken into consideration as useful sources of information for the management of services. Health authorities lack in publishing a report on the complaints presented by citizens. This has emerged also at the hospital level in many countries: there are no systematic analyses, nor reports of the complaints gathered. Moreover, it is more difficult to find procedures designed to incorporate recommendations based on the reports, which should in fact be the sole purpose of receiving complaints on behalf of hospital authorities.

Moreover it is important to consider the highly alarming situation denounced by the civic organizations, which have detected frequent or regular violations of the right to complain.

#### **Almost respected: personalized treatment, prevention, privacy and physical access**

At the top of the classification there are four rights, none of which have been assessed as “fully respected”.

While a considerable attention towards the **right to personalized treatment** at a national level has emerged, it does not appear to produce practical and concrete attention (hospital assistance). In fact legislative indications regarding non-discrimination and personalized care that take into account culture, religion, gender and age are uniformly present everywhere, but there are significant gaps in effective implementation of the personalization of care in hospital facilities: for instance the linguistic aspect (interpreting service, both classic and, above all, sign language) and the cultural aspect (cultural mediator and religious assistance) are definitely ignored in most of the hospitals. Other aspects tied to hospital culture (like visitor hours and choice of meals) attain a very low average score.

The culture of the **right to prevention** appears to be well-rooted in Europe, above all insofar as concerns traditional vaccinations, but the system does include some “flaws”, also in relation to the screening programs in some countries.

As regards the **right to privacy and confidentiality** of patients, the presence of laws or guidelines regarding the protection of patients’ information would appear to be an unquestionable standard throughout Europe. In hospitals assessed the general level of respect of this right is good, except for some worrying lacks: in hospitals of 11 countries patients’ surnames have been seen or heard and in 6 countries there have been cases of non-authorized circulation of medical information.



The **right to physical accessibility** of hospitals and orientation of patients towards reaching the hospital buildings appear to be standards that are by now shared at a European level. In some countries serious gaps remain regarding the free use of the parking lot and, more serious in importance from a civic point of view, lacks of attention in providing facilities for people with disabilities, like a reserved parking and the possibility to be dropped off in front of the main entrance.

### **Alarm bells: information, active citizenship and avoiding pain**

The right to active citizenship, the right to information and the right to avoid unnecessary suffering and pain attain unsatisfactory results, unacceptable because of the importance of these issues from a civic perspective.

The right to active citizenship and the right to information, in particular, deal with matters of accountability and transparency of institutions. Besides they can be defined as “soft” rights”: the implementation of the majority of actions and initiatives necessary for improving respect for these rights are neither cost-intensive nor time-intensive for institutions and hospital management, that is why weak results in the respect of these rights are considered more serious.

The following initiatives, for example, would not be expensive or difficult to be implemented, but could make the difference in terms of concrete democratic participation and accountability of health authorities: the cost of hospital websites has already been sustained and they would only need to be updated and/or integrated; the legal establishment of the inclusion of citizens in the groups for quality assurance; the periodical consultation of citizens’ organizations on behalf of hospitals.

Particularly weak is indeed the average outline of the institutional actions for patients’ **right to active citizenship**: what emerges is a worrying legislative problem, regarding the recognition itself of the role of citizens and of organized citizens. For instance only in 7 countries there are any kinds of laws stating the right for citizens’ organizations to evaluate or fix standards regarding the quality of health care services, and only in 8 countries laws recognize that information produced by citizens’ and patients’ organizations should be used for evaluating health policy.

As concerns the **right to information**, the mean scores of the institutional level and of hospital level are not really weak. It is important, nonetheless, not to ignore the common failure by health authorities to provide information regarding consumer satisfaction related to clinical performances. In hospitals there are widespread problems regarding the patient access to free clinical records, the existence of a free information line and the websites contents. Moreover the hospitals only in 7 countries attained a assessment at least “good” for the indicator concerning indicated areas for voluntary and public interest associations: we can confirm that active citizens are viewed as intruders. This situation is probably linked to the obstacles encountered in many countries by the monitoring groups during hospital visits and in obtaining information from the health authorities.

Indeed what deeply lowers the synthetic PRES index of the right to information is the high frequency of violations denounced by civic organizations.

Finally, one must forcefully underline the unacceptably low score for **the right to avoid unnecessary suffering and pain**: the governments of only 4 countries have conducted researches on the existence of national norms that excessively restrict the use of



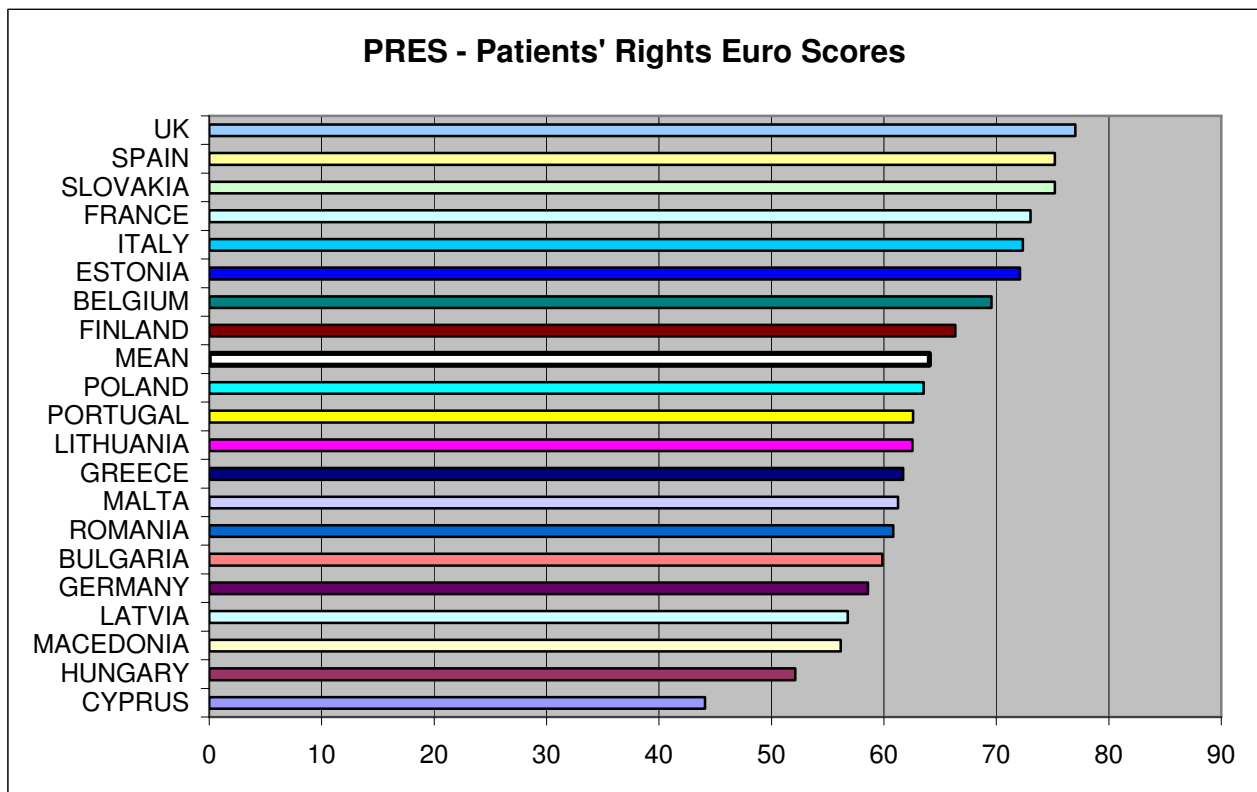


pharmaceutical narcotics and on measures to be adopted to avoid that this causes citizens' unnecessary suffering.

While, with the few exceptions of some countries, hospitals assessed have demonstrated a good attention towards patients' pain, frequent cases were found which may be defined as violations of the right to avoid unnecessary suffering and pain from the point of view of civic organizations. This gap suggests that effective respect for this right is blocked by organizational behaviour and resistance that diminish the efficacy of available services and hospital initiatives.

### PATIENTS' RIGHTS EURO SCORES IN THE EUROPEAN COUNTRIES<sup>5</sup>

The calculation of PRES related to individual countries was not directed towards establishing classifications of the quality or general efficacy of a system but rather, and more simply, towards evaluating the attention to the rights proclaimed by the European Charter.



Source: Active Citizenship Network , 2011

There are no situations in which the implementation of the rights may be considered reasonably complete and, even in the best case (that of the UK), a scant level of respect for the ideal situation remains above 20% and must therefore be considered significant.

<sup>5</sup> The result for Germany, which is partly surprising, could depend on the fact that the verification of some indicators would have required a survey on the level of Laender. This however bears on, and even more directly, lack of collaboration on the part of hospital authorities, which made part of the matrix inapplicable. By European countries is here meant the 20 countries participating in the project.



It is also probable that, due to the diversity of systems and of organizations, the relevance and pertinence of the proposed indicators vary notably from country to country. The evaluation of these variations will be an integral part of a work to improve the indicator matrix.

Moreover, civic partner organizations will be able to utilize the data of its own country as well as benchmarking data for detailed public comparison with experts and authorities.

A group of 8 countries results above average and includes Slovakia and Estonia, where strong dynamics towards adjusting the system are under way, as also noted by other observers (HCP, 2009).

On the other hand, 6 countries attain PRES of less than 60.

## A BASIC VOCABULARY OF PATIENTS' RIGHTS

This assessment work did not produce only scores of indicators. While looking for data in order to monitor the respect of the rights included in the European Charter, we have discovered something else: a further result, a “collateral” but possibly more significant result, that has provided an added value.

Supporting civic partner organizations in carrying out the project and looking at the data, it has been so clear that citizens and civic organizations are not enough informed about which their rights are, and how to demand them. If citizens do not know their rights, they cannot stand for and exercise them.

This problem of awareness of one's own rights has demonstrated that in order to monitor the respect of patients' rights, there is a big preliminary work which must be carried out.

The commitment can be synthetized in building a basic vocabulary of patients' rights, in two steps:

- *first step* - it is necessary to **agree on the meaning of terms and concepts**, from a civic point of view, in order to overcome the **terminological difficulties** deriving from the varied “languages” of health care existing across Europe. This is important since it allows to make the rights concrete even in spite of very different contexts. The aim of the first step is trying to clarify the problems impeding the real possibility of demanding rights. Focus are on:
  - Clinical record: a civic definition of “clinical record” is drafted, as patients all over Europe should firstly know that they have right to demand it, and then what they could ask for;
  - Informed consent: a discussion on the meaning of this concept and a further analysis of how the countries implement the right to consent are needed, basing on the surprising data;
  - Active citizenship: citizens are often treated and considered as intruders. The legal and cultural recognition of their role is a necessary condition for “exercising” active citizenship.
- *second step* – there is a strong need of working for a common and shared **awareness of one's own rights**: we have found out that many civic organizations have difficulties in playing the role of claiming citizens' rights, because they lack in information, and thus in





capacity of training citizens in their local communities. Key words for this step of work: **information, training, exchanging best practices** among European citizens' organizations.

Working for these goals constitute a process, through which making patients' rights easily demandable.

## CONCLUSION

This assessment work is part of an experimental process - begun in 2002 with the European Charter of Patients' Rights -, "of developing the content and practices of European citizenship that could have a [general] meaning and significance" (Moro, 2009).

The data gathering has underlined four issues: the general status of the rights; the situation in the different countries; the development of a European framework; an unfinished empowerment of users.

**The general status of the rights.** No single right is fully implemented and thus respected. As in the assessment work carried out in 2007, the worst result concern the respect of patients' time, free choice and access to health care and treatments. As already observed previously (ACN, 2007), this result - together with the mediocre *behaviour* of the rights to safety, quality and innovation -, is connected to the crisis of the "European Social Model" insofar as concerns the universal right to health care and the consequential reduction of levels of protection.

Too low is also the score of the right to avoid unnecessary suffering and pain.

The best rights (personalized treatment, prevention, privacy and physical access) may be, instead, considered as factors characteristic of European health care systems.

**The Situation in the different countries.** The calculation of the PRES indexes measures the attention to the rights of the European Charter and cannot be used as a basis for a classification of the health systems. As shown (see the chart above), even the best countries do not attain excellent scores. More generally, the comparison of countries highlights a decidedly broad field of variability, with a gap equal to around 40% separating the best situation from the worst. This confirms that residence is still a powerfully discriminating factor.

**Development of a European framework.** The Civic Audit methodology adopted in this assessment work has highlighted the differences among European health care systems, but also the existence of important common characteristics:

- a good physical accessibility of hospitals, nearly always reachable by public transport;
- a fair implementation of the right to privacy and confidentiality, supported by national guidelines;
- a good protection of the right to preventive measures, with vaccinations and screening programs;
- the spread presence of legislative indications regarding non discrimination and personalized care that take into account culture and religion, gender and age.



Other twelve indicators regarding safety, quality and care personalization are present and complied in almost all the countries, so that it is possible to talk about a common European culture in health care.

**An unfinished empowerment of users.** Many countries, in the last years, have recognized rights - to informed consent, to free choice, to complaint, and to compensation - which can contribute to the training of an “empowered user”. The process, nevertheless, is still widely incomplete: indeed these same rights have unsatisfactory scores; informative means are scarce and the active citizenship is not favoured.

It is possible to assert that, in general, citizens can be, in the best situations, the main *object* of the attention, but they are not yet recognized as *subjects* able to participate in the governance.

## CITIZENS’ RECOMMENDATIONS

The stake - the protection of the universality of health care systems – requires a general effort in order to avoid that illness causes social exclusion, with adequate resources and guarantees of protection of weak people and with proper supporting policies in five ambits.

1. Adoption of the European Charter of Patients’ Rights as a common standard and tool for the assessment of quality and accessibility of Health services.
2. Time, free choice and access to care must be declared as a priority to achieve an acceptable Health policy in Europe.
3. Disparities in treatment among European citizens must be reduced. The implementation of the European Directive on cross-border care must be supported through the spread of shared quality standards, information and safety, through the removal of impediments to the exercise of free choice, through a better management of the waiting lists.
4. The development and the training of “empowered users” must go on, as a contrast with the reductions of levels of protection caused by the crisis of the social model, by promoting active citizenship all over Europe, by implementing the right to information and by spreading the patient centred care.
5. Local communities must be in conditions of freely make use of their own resources, in the framework of subsidiarity, with adequate and certain flows of financial resources as well as with actions for the support and training of local leadership.



## EUROPEAN CHARTER OF PATIENTS' RIGHTS

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

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

### **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.

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

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

### **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.

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

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

### **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.

### **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.

### **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.

### **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.



### **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.

### **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.

### **12 - Right to Personalized Treatment**

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

### **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.

### **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.

### **Rights of Active Citizenship:**

In order to promote and verify the implementation of the above stated patients' rights, some citizens' rights must be proclaimed some citizens' rights must be proclaimed. They mainly regard different groups of organized citizens with the unique role of supporting and empowering individuals in the protection of their own rights. These rights are contained in article 12, section 1, of the Charter of Fundamental Rights.

1. Right to perform general interest activities
2. Right to perform advocacy activities
3. Right to participate in policy-making



## ACTIVE CITIZENSHIP NETWORK

**ACN's mission** is twofold:

- To contribute to the development of a European Active Citizenship;
- To promote the participation of citizens' organizations in European and national public policies.

**ACN's strategy** is to promote the point of view of European citizens in all public policies areas, focusing on healthcare, consumers and corporate social responsibility issues.

- This point of view is always based on civic information, i.e. data collected and analyzed by citizens' organizations themselves.
- It is embodied in civic instruments such as: the European Charter of Patients' Rights, the European Charter of Active Citizenship, the Guidelines for good CSR partnerships in Europe, etc.
- ACN website and newsletter are two essential networking and advocacy tools.

**ACN is an open and flexible network**, with a strong national base.

- Flexible. ACN's organization is based on partnership rather than membership. Some 100 citizens' organizations from 30 EU.
- Open. ACN is open to all civic organizations that defend citizens' rights and/or public goods in Europe and that are willing to contribute to its strategy.
- National base not Brussels. ACN is based in Rome and works together with Cittadinanzattiva, in accordance with its objective of building a direct link between national organizations and EU institutions.

**Funding:** ACN activities and projects are financed by public and private funds.

- Public funds. Most projects carried out by ACN are co-financed by the European Commission in the framework of calls for proposals.
- Private funds. ACN projects are also supported by private foundations and companies through the creation of partnerships. It is one of the strategic instruments used by ACN to reach its goals.

**Some projects: 2002 - 2011**

### Civic participation

- Rethinking The Principle Of Subsidiarity
- Citizens for the New Europe:
- Assessing and Reviewing the Criteria of Representativeness of Civic NGOs
- European Charter of Active Citizenship
- Monitoring and Evaluating the State of the Rights to European Active Citizenship
- EUproact: a website on European active citizenship

### CSR

- Citizens as CSR Partners
- Lisbon Minus 3: Evaluating CSR partnerships

### Consumer Rights

- A Civic Evaluation of National Regulatory Authorities (NRAs)



- Civic Analysis of Bank Contracts

#### Health

- European Charter of Patients' Rights
- Monitoring Patients' Rights in Europe (15 countries, 21 countries)
- European Patients Rights Day ( 2007, 2008,2009,2010,2011)

#### Impact regarding EU Policy and national policy

- Citizens view not only patient, not only one illness
- Use of tools developed by the Project
- Increasing number of partners and countries
- Multi-stakeholders

#### Networking activity

- Building an active citizenship in Europe: an experience of mentoring