



**PATIENTS' RIGHTS IN EUROPE:  
Civic Information on the Implementation  
of the European Charter of Patients' Rights**

Final Report  
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## Foreword

This document presents the main results and findings of the monitoring process of the European Charter of Patients' Rights carried out in 14 old member states<sup>1</sup> of the EU. This project<sup>2</sup> was a joint effort by Active Citizenship Network (ACN), the European policy program of the Italian movement Cittadinanzattiva<sup>3</sup> and the Tribunal for Patients' Right, the health policy program of the same movement along with civic organizations<sup>4</sup> in each of the monitored countries.

The European Charter of Patients' Rights was established at the end of 2002, after which a project aimed at gathering information on the state of patients' rights in the EU countries was set up. The project consisted in engaging citizens' organizations at the national level in gathering existing information on patients' rights, assessing its value and proposing additional information in order to reach a more comprehensive picture of the situation, which included the citizens' perspective.

An initial working paper was presented and discussed in Brussels in February 2005. After a further effort was made to complete the gathering of information in 14 EU countries. The results of this work are presented in this report, whose content is divided into three main parts:

1. The first part includes the background, rationale and context of the project;
2. The second part summarizes the main results of the study;
3. The final part focuses on the conclusions and policy recommendations.

The Appendix contains several documents with relevant information on the work developed and its background. *It is important to note that in this printed version of the report Appendix B and C are not included but can be found in the complete version of the report on the CD distributed with this report.*

FONDACA, the Active Citizenship Foundation, gave support specifically in the phase of data processing and reporting.

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<sup>1</sup> The project was implemented in Austria, Belgium, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Netherlands, Portugal, Spain, Sweden and United Kingdom. In Luxembourg we were unable to find a partner organization.

<sup>2</sup> This project and survey were sponsored by an unrestricted educational grant from Merck Sharp & Dohme.

<sup>3</sup> [www.cittadinanzattiva.it](http://www.cittadinanzattiva.it), [www.activecitizenship.net](http://www.activecitizenship.net)

<sup>4</sup> In Appendix D there is a list of the organizations that participated in the project.

# FIRST PART

## 1. Background of the project

The main elements regarding the background of the project are reported below.

### 1.1. The Italian experience of the Tribunal for Patients' Rights

The pioneering experience of Cittadinanzattiva's Tribunal for Patients' Rights, carried out in Italy since 1980, can be considered the first building block of this project. The Tribunal for Patients' Rights mobilizes common citizens and users as actors of health policy making in concrete ways<sup>5</sup> and presently involves some 5,000 people as permanent activists nationwide.

Among the elements, which characterize this experience and have special relevance to this project, are the following:

- Establishing 80 local Charters of Patients' Rights, through level collecting claims and reports from patients and users of health care structures, both public and private, at the local level.
- Organizing Patients' Rights Centers inside some 200 Italian hospitals, with the aim of checking troublesome situations, preventing threats to patients' rights and promoting organizational and material, in addition to cultural and behavioral changes in the management of care;
- Establishing advice-call centers both at the local and national levels with the aim to provide citizens with information, advice and counseling on the access and quality of health services as well as on the protection of their rights;
- Organizing a network of lawyers and forensic doctors to support citizens in the promotion of legal actions in case of damages and medical errors, as well as refusal of care;
- Promoting specific campaigns and programs aimed at innovating health services regarding, for example, safety and quality of hospitals, prevention of medical errors, pain therapy, waiting list, free access to medicine along with the reduction of waste in technical and financial resources;
- Coordinating a Coalition of more than 130 chronically ill associations, in order to promote a common policy aimed at putting the rights of chronically ill patients at the centre of the health system.

Moreover, the Tribunal for Patients' Rights acts as a permanent interlocutor with national and regional governments, professional associations and trade unions, industries. Over the years it has had a concrete affect on legislation, public budgeting, organizational and professional behaviors in addition to the public awareness on patients' rights.

Among the innovations that this initiative has given rise to, there is the practice of "civic information", that is, the production of data and information by organized citizens, both using expertise and established knowledge, as well as producing new information based on their own experience as citizens involved in public problems and acting in some policy fields. This experience has led also to the development of a methodology referred to as "Civic Audit". Cittadinanzattiva currently uses this methodology in evaluating health services, consumer issues, education services, civil defense activities etc. This methodology has been adapted and applied in this project. An article summarizing the basic elements and some applications of this methodology in Italy has been included in the Appendix C of this report.

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<sup>5</sup> Petrangolini T. (2002)

## **1.2. The EU Charter of Fundamental Rights and Health**

Another background element of crucial importance is the 2000 Nice Charter of Fundamental Rights. Its relevance is linked to two aspects. The first, the Charter is the juridical source that recognizes the individual rights of people living in the European Union. The second, the Charter makes the European Union responsible for the implementation of its content.

Moreover, some specific rights established in the Nice Charter have a direct link with issues regarding patients' rights and can be considered as a legal basis of the European Charter of Patients' Rights, itself.

Article 35 of the Charter provides for the *right to health protection* as 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*”.

Article 35 specifies that the Union must guarantee “*a high level of protection of human health*”, meaning health as well as health care are both an individual and social good. This formula sets a guiding standard for the national governments, which does not stop at the “minimum guaranteed standards”, but aims for the highest level, notwithstanding differences in the capacity of the various systems to provide services.

In addition to Article 35, the Charter of Fundamental Rights contains many provisions that refer either directly or indirectly to patients' rights, and are worth noting: the inviolability of human dignity (article 1) and the right to life (article 2); the right to the integrity of the person (article 3); to safety (article 6); to the protection of personal data (article 8); to non-discrimination (article 21); to cultural, religious and linguistic diversity (article 22); the rights of the child (article 24); the rights of the elderly (article 25); the right to fair and just working conditions (article 31); to social safety and social assistance (article 34); to environmental protection (article 37); to consumer protection (article 38); the freedom of movement and residence (article 45).

## **1.3. The European Charter of Patients' Rights**

### *Why a Charter on Patients' Rights*

Despite their differences, national health systems in European Union countries place the same rights of patients, consumers, users, their family members and vulnerable sectors of the populations at risk. Even though solemn declarations of the “European Social Model” on the right to universal access to health care have been repeatedly made there are a number of constraints that bring into question the reality of this right.

European citizens cannot continue to accept that rights be affirmed in theory, but then denied in practice, because of financial limitations. Budgetary constraints, however justified, cannot legitimize denying or compromising patients' rights. Therefore, it is unacceptable that rights be established by law, but then not respected, promised in electoral programs, but then put aside when new government comes to office.

For these reason, in 2002 ACN, together with some 15 citizens' organizations operating at the national and European level, drafted a European Charter of Patients' Rights. The main objective of the Charter is to strengthen and bring greater awareness concerning patients' and citizens' rights, which are presently at risk in all EU countries.

## *The 14 Patients' Rights*

### **14 Patients' Rights**

1. **Right to Preventive Measures**
2. **Right of Access**
3. **Right to Information**
4. **Right to Consent**
5. **Right to Free Choice**
6. **Right to Privacy and Confidentiality**
7. **Right to Respect of Patients' Time**
8. **Right to the Observance of Quality Standards**
9. **Right to Safety**
10. **Right to Innovation**
11. **Right to Avoid Unnecessary Suffering and Pain**
12. **Right to Personalized Treatment**
13. **Right to Complain**
14. **Right to Compensation**

The fourteen patients' rights seek to make the fundamental rights mentioned in the Charter of Nice, applicable and appropriate to the current transition process in health services. These rights all aim to guarantee a "*high level of human health protection*" (Article 35 of the Charter of Fundamental Rights) and assure the high quality of services provided by the various national health services. They must be protected throughout the entire territory of the European Union.

### *Active citizenship as a right*

In order to promote and verify the implementation of the patients' rights, the European Charter also proclaimed some active citizens' rights, which mainly concern groups of organized citizens (patients, consumers, advocacy groups, advice-givers, self-help groups, voluntary and grassroots organizations, etc.). These groups have the unique role of supporting and empowering individuals in the protection of their own rights. These rights are linked to the rights of civic association, contained in article 12, section 1, of the Charter of Fundamental Rights and are:

- the right to perform general interest activities;
- the right to carry out advocacy activities;
- the right to participate in policy-making.

ACN proposed a project to monitor the implementation of the European Charter of Patients' Rights in then 15 EU member states in order to begin promoting and implementing the Charter while at the same time putting in practice European active citizenship.

### **1.4. Steps forward in the European context for patients' rights**

Since the establishment of the European Charter of Patients' Rights in 2002 there has been a dramatic improvement in the public debate on patients' rights in Europe, also thanks to the Charter itself. It is testified by several documents, reports and position papers delivered by public institutions (European Council, European Commission, European Parliament, Economic and Social Committee), citizens' organizations and experts<sup>6</sup>.

Three main points seem to be emerging from the present debate on patients' rights in Europe.

First, it can be said that the issue has become part of the European policy agenda. It regards both public institutions and the policy community at large and has as a starting point the application of the principle of equality to the issue of patient mobility by the European Court of Justice<sup>7</sup>.

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<sup>6</sup> See, for example, Council of the European Union (2006), EU Health Policy Forum (2005), European Commission (2004), (2006b), (2006c), European Commission, High Level Group on Health Services and Medical Care (2006), European Observatory on Health Systems and Policies (2005), European Parliament (2005), Patients Associations (2005).

<sup>7</sup> Judgments of the Court of Justice of the European Communities ("European Court of Justice") in Decker (C-120/95, 28 April 1998), Kohll (C-158/96, 28 April 1998), Geraets-Smits & Peerbooms (C-157/99, 12 July 2001), Vanbraekel

Second, public institutions are becoming increasingly aware that they have to take the responsibility on the issue of patients' rights at the Community level, adding a European level of intervention to those developed in the member states.

Third, there is a greater recognition for the need to establish a clear framework of common principles and standards for the protection of patients' rights in Europe, to be implemented everywhere and in every case, and not only in the case of patients mobility.

This is a result worth mentioning, since until now health care has been considered an exclusive competence of national states. This competence has not been exercised in a shared way among the national states. In addition, it was not considered that in health systems some fundamental rights are at stake and in consequence a general responsibility of the European Union must be taken and exercised in concrete ways.

### **1.5. Rationale of the project**

Without a doubt, this ongoing process is very positive and even if for this reason alone the policy of the European Charter of Patients' Rights could be considered a successful experience. Nevertheless, it cannot be forgotten that the core issue at hand is the concrete condition of citizens who are patients, users and consumers of health care. From this point of view, a huge effort remains for improving health facilities' capability in delivering services that are accessible of high quality and centered on the rights of patients.

There are two main obstacles, among others, that hinder the fulfillment of this objective.

On the one hand, as shown in section 3, public policies regarding health care in Europe are still mainly focused on economic and financial matters, therefore considering patients' rights merely a variable to be interpreted by the sustainability of health services.

On the other hand, as shown in sections 4 and 5, data coming from public sources (comparable official data and legislation on national situations) lack significant information on the concrete condition of patients, consumers and users facing health services. These official data are of considerable importance, but are absolutely not sufficient.

If we want to continue to move forward in developing a policy on patients' rights in Europe, it is necessary that the question regarding the concrete condition of citizens facing health facilities in Europe is put on the table, and taken into account when discussing and more importantly when deciding on the sustainability of health systems. To this end, data coming from citizens' groups can help fill the information gaps resulting from the official sources.

Moreover, the fact that citizens organized in associations and movements operating at the national level are involved with full responsibility in such an activity is a concrete practice of the principles of "European Active Citizenship" program, currently under implementation in the European Union. This is indeed a program that needs to be put into practice rather than merely declared and this project does just that.

## 2. Project Methodology

In order to reach the general aim described above, the research proposed the following three objectives:

- contribute to creating an initial set of information on patients' rights, taking into account its scarcity, and the fact that it usually does not have a European basis;
- involve national-based citizens' and patients' organizations in an experience to produce Civic Information, which can be considered as a new form of active participation in European policy making;
- give value to the existing information on a European basis, by putting together pertinent data, coming both from official statistics and other sources.

### 2.1. The Civic Information Approach

The design and methodology of research has been inspired by a Civic Information approach, which comes from various scholars and successfully has been used as a framework in the Italian experience of Cittadinanzattiva<sup>8</sup>.

Civic Information can be defined as *the ability of organized citizens to produce and use information in order to promote their own policies and participate in public policy making*, in the definition and implementation phase, as well as in the evaluation.

According to this approach, despite their supposed lack of competence in the public sphere, when citizens get organized and act together in public policies, they are able to produce and use information, coming both from experts and other sources, along with their direct experience concerning the problems they face.

In this project, this approach was implemented by involving civic organizations in collecting information through the direct observation of hospital facilities and interviews of hospital authorities. This can be considered the most innovative aspect of the research since it provided citizens with the opportunity to practice their right to participate in evaluating services and policies. However, what citizens' groups carried out during the research did not seem to be a common practice in most countries and was met with difficulties and hindrances on the part of health authorities.

### 2.2. Methodological questions

The starting point for the research design was addressing what kinds of information regarding the state of patients' rights in Europe, which are relevant and useful for this research, can be found, where and how. Due to the link between patients' rights and complex social, economic and cultural elements, three kinds of information could be considered the most pertinent.

The first kind of information concerning patients' rights comes from *official statistics and information*. In the last decades a number of international agencies have been gathering health statistics with the aim of directing the health and social policies of European and non European countries towards common objectives<sup>9</sup>. In order to do this, the population's health conditions and

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8 Cf. Wildavsky (1993), Rubin, Rubin (1993), Lamanna, Terzi (2005), Moro (1998, 2005a).

9 See the work carried out by WHO, OECD, the European Observatory on Health Care Systems and Eurostat in setting up a monitoring system of countries' health systems.

the various determining factors (including the management of health care systems), are described in a structured and comparable manner. There is, therefore, a body of data that has already been collected at the national and international level, which could provide, if properly analyzed and interpreted, valuable information on the degree of implementation of patients' rights in Europe.

The second kind of information regards *legislation*, meaning the systems of norms, which institutional actors have adopted in order to protect and promote patients' rights. These norms are of different types and rank (from constitutions to regulations), and, despite their possible (and actual) implementation gaps, testify the level of attention to the protection of patients' rights at national level.

The third kind of information concerns *the actual conditions of patients-citizens* who come into contact with the health care system and, therefore, the concrete experiences of all those who have had to turn to their family doctor, an outpatient service or a hospital. These aspects are, for example, the time needed to obtain a diagnostic exam, how does communication take place between patients and medical personnel, available health equipment, etc. What little information that is available about the "encounter" between citizens and their health care systems is drawn from the citizens' opinions, and, therefore, the level of satisfaction with health care in their own country (the *subjective dimension*)<sup>10</sup>. On the other hand, there have been very few attempts, at the European level, to find out the facts and events (*objective dimension*), which underlie these opinions<sup>11</sup>, and, above all, to understand in concrete terms the actual situation of patients' rights.

Regarding these three areas of information on patients' rights, two different methodological problems arise. The first problem regards the relevance of the available information, while the second is the availability of information itself. This research had to face both problems in that while official statistics and legislations were available the information had little relevance, regarding patients' rights, and on the other hand the more relevant information on the actual condition of patients was not available.

### **2.3. The design of the research and the Civic Audit's Patients' Rights Matrix**

Taking into account these questions, this study aimed at assessing the state of implementation of the European Charter of Patients' Rights, identifying and measuring the level of attention to each right in the 14 countries (the 15 EU old member states except Luxembourg). This was done, as already mentioned, gathering information on three topics.

The first is health statistics. With respect to collecting the data from the existing health statistics, all the indicators, which directly or indirectly concern the phenomena linked to the implementation of these rights, have been taken into account.

The second topic is legislation. With reference to the national legislations, the research has attempted to verify if and which laws have been adopted to protect and promote patients' rights, and what information can be gathered from legislation.

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10 See, for example, the data collected from the Harvard/Commonwealth Fund/Louis Harris and Associates surveys and from the Eurobarometer surveys.

11 Recently, the Euro Health Consumer Index 2006 has been created. It represents an interesting attempt for the evaluation of a number of objective aspects of healthcare. Some 30 indicators have been taken into consideration and they deal with the following aspects: rights and information, waiting time for treatment, outcomes, provision levels, pharmaceuticals.

As for the third topic, since information on patients' actual conditions is not available on a European base, it was decided to use and apply a Civic Audit methodology, based on the well-structured experience developed in Italy<sup>12</sup>.

In the terms used above, Civic Audit refers to the direct production of information by citizens' organizations through gathering data on the problems they face. The Civic Audit methodology consists in citizens' organizations monitoring evaluation factors, which are areas perceived as particularly significant by citizens. Each evaluation factor contains a group of indicators, quantitative variables or qualitative parameters that allow us to assess the factor being examined.

In this study, each right of the European Charter has been linked with a cluster of indicators, which permits the observation of elementary phenomena, that considered together tend to express the level of implementation of the right being studied.

This operation led to the identification of a set of 174 indicators regarding the 14 patients' rights and the definition of a *Patients' Rights Matrix*.

The indicators, obtained from pertinent literature, legislative and institutional sources, documents produced by citizens' organizations, scientific associations, etc., were selected on the basis of five criteria:

1. relevance, that is, the level of closeness to the issues and problems contained in each right;
2. sensibility, i.e. the ability to register changes (for better or worst);
3. precision, meaning the ability to record exactly and only the phenomenon that one intends to register;
4. accessibility, that is, availability at no additional costs with respect to those of the research budget;
5. concreteness, that is, the ability to also record the more concrete aspects of health care.

The complete *Patients' Rights Matrix* can be found in Appendix A. Two examples, the right to safety and the right to personalized treatment, are presented in the following table.

*Table 1. Patients' Rights Matrix: indicators for the rights to safety and to personalized treatment*

<b>Right</b>	<b>Indicator</b>	<b>Kind of info</b>
Safety	Protocols for the sterilization of medical instruments used in hospitals	Y/N
	Protocols for the prevention of hospital infections used in hospitals	Y/N
	Risk management techniques used in hospitals	Y/N
	Epidemiological investigations of hospital infections carried out	Y/N
	Cases identified when the right was not respected	Y/N
	Procedures for reporting the following: <ul style="list-style-type: none"> <li>▪ Hospital acquired infections</li> <li>▪ Burns from fires</li> <li>▪ Falls</li> <li>▪ Pressure ulcers</li> <li>▪ Phlebitis associated with intravenous lines</li> <li>▪ Restraint-related strangulation</li> <li>▪ Preventable suicides</li> <li>▪ Failure to diagnosis or incorrect diagnosis</li> <li>▪ Failure to utilize or act on diagnostic tests</li> <li>▪ Use of inappropriate or outmoded diagnostic tests or treatment</li> <li>▪ Medication errors/adverse drug effects</li> <li>▪ Wrong-site errors; surgical errors</li> </ul>	Y/N

12 The methodological structure that come from the application of Civic Audit in Italian health care system are reported in the Appendix C.

	▪ Transfusion mistakes	
	Reporting of near misses	Y/N
	Office or person in the hospital responsible for coordinating activities for reducing the risk of infection	Y/N
	Written procedures (protocols) for checking and reducing risks control of hospital infections	Y/N
	Priority codes in triage procedure in Emergency Room	Y/N
	Emergency exit signs	Y/N
	Evacuation route for wheelchair users	Y/N
	Fire extinguisher	Y/N
	Evacuation maps	Y/N
	Special evacuation procedures for wheelchair users on map	Y/N
Personalized treatment	Personalized support given in hospitals - Choice of meals	Y/N
	Personalized support given in hospitals - Psychological support for terminal patients and their families	Y/N
	Personalized support given in hospitals - Spiritual support based on personal	Y/N
	Personalized support given in hospitals - Cultural mediation and/or foreign language interpretation	Y/N
	Personalized support given in hospitals - Educational support for children hospitalized	Y/N
	Cases identified when this right has not been respected	Y/N
	Distribution of patients meal	#
	Religious assistance available <ul style="list-style-type: none"> <li>▪ Protestant</li> <li>▪ Anglican</li> <li>▪ Catholic</li> <li>▪ Orthodox</li> <li>▪ Jewish</li> <li>▪ Muslim</li> </ul>	Y/N
	Psychological support to: <ul style="list-style-type: none"> <li>▪ terminal patients and their family</li> <li>▪ transplant patients and their family</li> <li>▪ women who have suffered violence</li> <li>▪ patients in other conditions</li> </ul>	Y/N
	Written procedures for second opinion	Y/N
	Number of hours for visiting the patients on: <ul style="list-style-type: none"> <li>▪ Sundays and holidays</li> <li>▪ Weekdays</li> </ul>	#
	Interpreters	Y/N
	Cultural mediators	Y/N
	Play areas inside pediatric wards	Y/N
	Appropriate furnishing inside pediatric wards	Y/N
	Parents be present 24 hrs. day	Y/N
	A place for relatives to sleep in the room that is appropriate	Y/N
	Use of cafeteria for parents	Y/N
	Educational support for children	Y/N

#### 2.4. Sources of information and technical tools

Following these methodological choices, five sources have been used to collect data on the Patients' Rights Matrix indicators.

*a. European-based statistical data*

This source was evidently used to collect the data concerning the first aspect of the survey, that is the information on patients' rights available from official sources. Dr. Fiorenza Deriu, from the Faculty of Statistics of Rome La Sapienza University, was asked to make a study on this topic. The complete study is published in Appendix B of this report.

*b. Key persons operating in health care at the national level (KP)*

These people, because of their work, also provided us with official and qualified information. Interviews were conducted with 6 experts selected as follows:

- an official from the Ministry of Health;
- a representative from the doctors;
- a representative from the nurses;
- an expert in the health field;
- a journalist specialized in health;
- a representative of a third-party payer (insurer).

*c. Partner organizations as qualified informers on the state of patients' rights in each country (PO)*

The above interviews were integrated with an interview with the partner organization (a civic organization that works on health issues at the national level); the idea being that citizens' organizations, because of the type of work they do and their experience, have a wide range of information concerning health and the health care system.

*d. First-hand observation of the hospitals (concrete situations which can be directly observed inside hospitals - DOH)*

The first-hand observation of the hospitals provided us with a first degree source of information, which is very important for the relevance of the report. The three main hospitals in the capital of each of the European countries selected were visited by groups from the partner organizations. The activity covered different areas of the hospitals (outpatient services, emergency room, collective areas and recovery facilities).

*e. Hospital authorities responsible for hospital management (HA)*

By consulting the authorities responsible for hospital management it was possible to integrate the data collected during the first-hand observation of the facilities. This integration concerned, primarily, all aspects that are not easily observable.

Different *technical tools* for the collection of information from the various sources were used, such as:

- a questionnaire on the existing legislation regarding patients' rights, answered by the partner organizations;
- a questionnaire for key persons and partner organizations;
- a checklist for monitoring hospitals, which included questions for the hospital authorities and indicators to be observed by the partner organizations.

## **2.5. The Index of Attention for Patients' Rights (IAPR)**

Finally, in order to allow for a more concise reading of the survey's results, an "Index of Attention for the Patients' Rights" of the Charter (IAPR) was calculated on the basis of the information collected from the various sources.

This index measures how much the gathered data correspond to standards relating to each right. Data regarding each source were analyzed and concisely classified according to the number of positive or negative results.

The Index includes all three sources, assigning to each a weight corresponding to the total information on patients' rights that each source contains. The weight has been defined as follows.

*Table 2. Components of the IAPR*

Source	Value (%)
Statistical Data (SD)	10
Legislation (LE)	10
Actual condition of patients (IAC)	80

Let us now describe how the data coming from each source were dealt with in order to give them a value. Of course, this operation was more complex in the case of the information gathered on the actual conditions of patients (Civic Audit), which comprises the majority of relevant information regarding the level of attention to patients' rights.

*a) Information from official statistics (SD)*

To each right a score ranging from 0 to 0.25 was assigned, with the following criteria:

- No indicator available: 0
- Only 1 indicator available: 0.10
- More than 1 indicator available: 0.25.

*b) Information coming from the analysis of legislation (LE)*

To each right a score ranging from 0 to 0.25 was assigned according to the following criteria:

- 0, in the case no legislation identified;
- 0.25, in case at least one piece of legislation identified.

*c) Information on Actual Conditions of Patients - Civic Audit (IAC)*

First of all, data regarding each right in each country were analyzed and classified according to a range which goes from + to +- to -, on the basis of the number of positive or negative results to the answers from the questionnaire and hospital observations. Each right in each country, therefore, was analyzed as follows.

*Table 3. Classification of Data*

	Prevailing positive results	Positive and negative results; results without a clear trend	Prevailing negative results
Checklist Observations	+	+ -	-
Questionnaire Answers	+	+ -	-

In particular, with respect to the hospital observations, the following were considered:

- “prevailing positive results”, when the positive observations have been recorded for at least 2 of the 3 hospitals for two thirds of the proposed observations;
- “prevailing negative results”, when the negative observations have been recorded for at least 2 of the 3 hospitals for two thirds of the proposed observations;

- “results without a clear trend”, in all the other cases.

For the data concerning the consultation of key persons, the following have been considered:

- “prevailing positive results”, when positive answers have been given by the majority of the interviewees on two thirds of the questions (giving a double value to the partner organization) and when not more than 3 of the 7 interviewees reported cases of violation of the right in question;
- “prevailing negative results”, when negative answers have been given by the majority of the interviewees for two thirds of the questions (giving a double value to the partner organization) or when all the interviewees reported cases of violation of the right, irrespective of the other answers;
- “results without a clear trend”, in all the other cases.

Particular criteria were adopted for those cases in which the number of indicators was too low or in the case of complex indicators.

The choice, to evaluate the answers of the key persons according to these criteria, was dictated by two reasons: give a greater weight to the answers provided by the partner organization – in light of the greater attention and sensibility they have on the issue of patients’ rights that they promote in their own countries; and give a negative meaning to the fact that all the key persons are aware of at least one or more cases of violation of a right in their own country.

Secondly, the following score was assigned to each of the combinations that were obtained.

*Table 4. Way in which scores were assigned*

<b>Score 2</b>			
Checklist Observations	+	+ -	+
Questionnaire Answers	+	+	+ -
<b>Score 1</b>			
Checklist Observations	+ -	-	+
Questionnaire Answers	+ -	+	-
<b>Score 0</b>			
Checklist Observations	-	+ -	-
Questionnaire Answers	-	-	+ -

As one can see, the score for each country and for each right is based in equal measure on the information collected through the questionnaire for key persons and partner organizations and the checklist for monitoring hospitals.

The only exceptions concern the right to access and the right to free choice. In the first case, two different dimensions correlated to the definition of the right as set forth in the Charter – “access to care” and “physical access” – have been separately evaluated, by taking into consideration, respectively, the information provided by the key persons and the results of the hospital observations. In the second case, we relied only on the information provided by the key persons since, given the particular aspects of the right to free choice, there were no questions on this right in the checklist for monitoring hospitals.

Finally, the overall index score was calculated by adding up the scores related to the three sources of information.

## 2.6. Development

The project began in 2003, with ACN establishing a working group to design the methodology of the monitoring process and its respective tools. The methodology and tools were then discussed and improved during a meeting with health experts and civic organizations in November 2003. The tools were then implemented in Italy in a pilot test and underwent further changes. During this same period, partner organizations, a national organization working on health issues in each country, were being identified and two training meetings were held in Rome (April and June 2004) to discuss methodological and operational features of the project. The research was carried out in 14 of 15 old EU member countries since in Luxembourg it was not possible to identify a partner organization to take part in the project. A list of the partner organizations and health experts that participated are in Appendix D of the report.

The implementation of the monitoring process took place in two phases. The first phase was from June until November 2004. In general, the most difficult aspect of the monitoring process, as mentioned before, was obtaining the authorization from the hospitals and then actually being able to set up a meeting with hospital authorities to complete the questionnaire for gathering the hospital information. The collecting and compiling of the information from the various countries took place in December 2004. In January and February the research staff analyzed the data and drafted a working paper. However during the first phase there was difficulty in collecting the following information:

- In Belgium the partner left the research project;
- In UK the hospital authorities refused interviews;
- In Portugal the hospital authorities refused interviews;
- In Germany hospital authorities refused interviews;
- In Ireland hospital authorities refused interviews.

Therefore in order to complete the missing information a second phase was implemented in 2005 – 2006. In the end a total of 42 hospitals were visited. In 37 hospitals it was possible to carry out both the direct observation and the interviews with hospital authorities, while in the remaining 5 hospitals (3 hospitals in Portugal and 2 in the UK) only the direct observation was conducted (see in Appendix E the list of the hospitals visited). With respect to the key persons, a total of 82 experts (Appendix F has the list of persons interviewed) and 14 partner organizations were interviewed.

The most significant fact emerging with respect to the implementation of the research was *the refusal of hospital authorities in Portugal and UK (only one hospital: Royal London Hospital facilitated the information and interview with health authorities) to provide information to the partner organizations*. The research in these countries, therefore, lacks this information, which was otherwise collected in the other countries. Consequently, information from other sources was used in order to include these countries in the report. However, it is important to point out that *such a refusal is in itself an indicator of the lack of transparency and openness of those countries' hospital authorities in relation to active citizens, and can therefore be considered a result, though unfortunately a negative one, of the research*.

The research work was directed by ACN staff, under the coordination of Melody Ross and included Alessandro Lamanna and Giovanni Moro. Charlotte Roffiaen, Simona Sappia, and Stefano Inglese cooperated in the phase of the methodological design. Fiorenza Deriu, of the Department of

Demography of the Faculty of Statistics of the University of Rome “La Sapienza”, provided a study on the European statistical data related to patients’ rights. Ilaria Vannini, from the FONDACA research unit, cooperated with Lamanna, Moro and Ross in the data processing and setting up of this report. Alessio Terzi, from Cittadinanzattiva, cooperated in the data processing.

## **2.7. Value and Limits of the Research**

In view of the highly experimental and innovative nature of the research, there are a number of aspects, which should be pointed out regarding its limits and value.

The main *limits* can be summarized as follows:

- Apart from the European-based statistical research results, the results coming from the Patients’ Rights Matrix do not reflect a sample with a full statistical significance and value, because of the low number of people interviewed and hospitals visited;
- Indicators related to each right are not necessarily homogeneous and have a different value according to the content of each right and to the research constraints; moreover the number of indicators vary from right to right;
- The research does not take into account the differences between the national health care systems, in terms, for example, of financing, public or private ownership or delivering of services, and so on;
- The research cannot reflect what happens at regional and local levels, even in the cases in which health policies are decentralized;
- The research does not (and could not) consider the critical issues related to the development of rights in the near future – for example, the effects of freedom of movement inside the EU, the possible changes in rules concerning information on drugs and the consequences of biomedical research – being limited to only examining existing factors and phenomena.

As for the *value*, the following can be stated:

- The research provides information on the state of patients’ rights by identifying phenomena that can be considered indicators of attention towards those rights;
- It reflects an approach to health care issues based on the point of view and the condition of citizens, patients or users of health facilities;
- It makes it possible to begin comparing different national situations from the point of view of the attention to patients’ rights;
- It enabled the setting up and testing of a research methodology, which can be further and more widely used to build an appropriate database regarding patients’ rights on a European basis, which could then be used together with other sources in health care-related issues.

Particular attention must be given to the collection of information in hospitals. On the one hand, the 42 hospitals visited are clearly not a statistically significant sample, neither at the national nor European level; on the other hand, they are still 42 of the largest and most important health facilities in Europe and for that reason can be considered as a point of excellence at the national level. Therefore, what occurs in these structures is meaningful.

### 3. European Health Systems between new demands and financial constraints<sup>13</sup>

Before starting to analyze the main results coming from the official statistics, the national legislations and the civic audit, it's important to look at the main characteristics of the European countries' healthcare systems, in order to understand better the context in which this research has been conducted.

#### *Introduction*

European Union countries' health systems are amongst the most advanced in the world, both in terms of legislation and public health protection. Naturally, there are differences among countries, which are rooted in the different social protection systems that can be basically traced to four great welfare models or families: the Social-democratic, the Liberal, the Continental or Corporate and the Mediterranean model (Esping-Andersen, 1990, 1999, 2002, Ferrera, 1996). Having in common the participation, in varying degrees, of families (communities), the state and market, these models differ in the role played by these three actors.

The *Social-democratic* or *Scandinavian* model, adopted by countries such as Finland, Sweden and Denmark and, to a certain extent, by the Netherlands, finance the social protection with the general fiscal system and guaranteed services to all citizens (universalism), relieving the family from a number of costs, mainly concerning children, the disabled, elderly, employment, as well as family care services. Thanks to this model, these countries register the highest employment rates for women and continue to have strong fertility rates, unlike what is happening in the rest of the Europe-15 countries. However, because of the economic recession of the nineties, governments of these countries have had to increase taxes and significantly reduce public spending.

The *Continental* or *Corporate* model, adopted by Germany, France, Belgium, Luxembourg, Austria and the Netherlands, bases its social protection model on the complementary responsibility of the state and family. The social protection programs in these countries are usually quite fragmented and diversified according to categories; they are more generous with public employees and are financed through social contributions, differentiated according to the different spending institutions<sup>14</sup>. In these systems there are, however, a number of social transfers (i.e. guaranteed minimum income), aimed at providing a social safety net against the risk of poverty and social exclusion. The delivery of social services is, nevertheless, subordinated to the "means testing", that is the verification of economic means and of the willingness to work<sup>15</sup>. During the Nineties, spending levels in these countries were among the more stable in Europe, while since 2001 there has been a slight increase, especially in Germany and France.

The *Mediterranean* welfare state model, adopted in Italy, Greece, Spain and Portugal, though quite similar in a number of aspects to the Continental one, assigns a critical social protection role to the family, and is characterized by the lowest level of social spending or support of employment or child care around Europe. This model has adopted family benefits, but they are not universal (as in Northern Europe) and linked to means testing.

Moreover, it doesn't provide for forms of guarantees with respect the minimum income entry levels, even if a number of experiments have been launched. With the onset of the second demographic

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<sup>13</sup> This note is an extract of the study that Fiorenza Deriu, from the Department of Demography of the Faculty of Statistics of the Rome University "La Sapienza", conducted on the European healthcare systems. The complete study is in Appendix B of this report.

<sup>14</sup> Zoli M. (2004).

<sup>15</sup> Inpdap (2003).

transition and its initial effects (the delay in creating new households, their lower stability, the reduction in fertility rates, the weakening of family support networks, as well as the ageing of the population), the structural deficiencies<sup>16</sup> of these countries' welfare systems, such as their fragmented guarantee system according to occupational categories, non effective verification mechanism of the contributive and spending capacity of those requiring assistance<sup>17</sup>, the lack of measure to promote a greater increase in female employment and a recovery in fertility rates, have emerged.

Finally, there is the *Liberal* welfare model (to which Great Britain and Ireland belong), whose main objectives consist in reducing extreme poverty and marginalization, through welfare programs and benefits, which are awarded according to means testing, while all the other needs are to be met by the family and the market. The State should intervene only when these two institutions cannot manage certain situations, such as for education or healthcare<sup>18</sup>. The financing varies according to the different sectors: healthcare is fully financed by taxation, while paid services are financed through social contributions. Particular attention is, therefore, placed on the individual's participation to the labor market, in so far as access to the benefits provided by the welfare protection system is conditional to having a job. Because of the close relation between work and assistance, these systems provide for aggressive employment policies. The unemployment rate in the United Kingdom is, in fact, one of the lowest ones in the EU-15.

#### *A glimpse at the healthcare systems and at the more recent reforms introduced by a number of EU-15 countries*

At present, in *Finland*, the jurisdiction over healthcare lies with the 455 urban and rural municipalities (an average of 11.000 people) that play an active role in planning and organizing healthcare services, but the State's power over healthcare policymaking is still strong. The Finnish healthcare system relies primarily on public financing, even if since 1993, as part of the reform of State subsidies, the municipalities can make citizens pay for a number of services, deciding also the tariffs (up to a ceiling established by the Government). In recent years, the Finnish Government has introduced a series of measures aimed at: strengthening and increasing the system of combined social and health services, developing government agencies, increasing the autonomy of local bodies, revising social safety benefits, strengthening relations between NGOs and the State for a better protection of public health, supporting scientific research, as well as continuing in its commitment to promote public health issues in European Union policies.

In *Denmark*, the National Health System is based on the principles of free and equal access to public health and hospital care for all resident citizens. The services include general practitioner and specialist services free of charge, as well as subsidized services, that vary according to the medical treatment utilized and are deducted from the health bill (card) of the beneficiary, for a number of specific consultations. There are two types of health insurance, which resident citizens can sign up for, requiring or not the selection of a family doctor or health centre.

Moreover, private health insurance is utilized to integrate public health insurance; in fact, it is used in part to cover the costs sustained by the citizen within the public health care, and in part to cover the tariffs of hospital and private clinics' care. The health service is structurally decentralized; the local bodies take operative decisions in accordance to the guidelines provided by the Ministry of Interior and Health.

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<sup>16</sup> Sgritta G.B. (2004).

<sup>17</sup> Inpdap (2003).

<sup>18</sup> Benassi D.(1994).

In *Sweden* as well, the system of healthcare services is first of all a public responsibility. In the seventies, a devolution process was initiated, which led, during the nineties, to an important transfer of responsibilities to the local level. Currently, the system's structure is articulated along three levels: national, regional and local. Its financing is provided for through three channels: local taxation (mainly regional and municipal), which guarantees the healthcare coverage to all the residents, irrespective of their nationality; the system of national social insurance; and the private insurance companies<sup>19</sup>, which are still, however, a limited form of coverage, and exclusively play a complementary role to the public service. The outcome of this season of profound reforms has been an increase in the efficiency and productivity of the healthcare system at the regional and municipal level, as well as a progressive reduction in healthcare spending in terms of GDP. There are still, however, a number of problems, in particular with reference to the coordination of the different administrative levels, the fragmentation of management, as well as the general vision of the reform process. Unlike the other European countries, the Swedish health system adopted an ethical platform to help guide those in charge of health structures and systems in deciding the selection of priorities according to three fundamental ethical principles<sup>20</sup>: human rights (human dignity); need and solidarity; and cost-efficiency<sup>21</sup>. Nevertheless, it is not clear at what level such strategies are actually implemented, in view of the fact that, in the end, it is the health personnel who makes the final decision<sup>22</sup>.

In *France*, the healthcare system provides coverage to all residents and is financed primarily through a health insurance regulated by law. There are three coverage schemes: a general one, which assists 84% of the population; one for farmers, which offers protection to 7.2%; one for self employed workers, which covers 5%. In 2000, France rated first in the ranking of healthcare systems of the World Health Organization (WHO), both for the level of health of its population, as well as for the degree of the freedom of choice of patients and doctors, for the ease of access to treatment, for the lack of waiting lists and for the universal coverage of the population. This system has had high costs. Spending on health has never gone below 9-10 points of GDP. Therefore, also in France, in the second half of the nineties<sup>23</sup>, a series of control measures were introduced, which included the reduction of compensations, an increase in the participation of citizens to health spending, a decrease in the number of doctors, an improvement in the planning at the hospital level and the control of pharmaceutical spending. Moreover, at the same time, there has also been a significant transfer of responsibilities from health insurance funds to the State, accompanied by a gradual decentralization process at the regional level. The increase of the costs for citizens has led to a growth of private insurance coverage. In 2000, 85% of the population utilized voluntary forms of integrated insurance health protection.

Even in *Germany* there are problems revolving around healthcare spending, which by the nineties had reached French levels, concerning more the financing of the expenditure, rather than its magnitude. The German health system, until recently, placed at the centre of its program initiatives aimed at favoring the free access and free choice of citizens with respect to treatment, the

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<sup>19</sup> European Observatory on Health Care Systems, Hit Summary, Sweden (2002).

<sup>20</sup> The first priority category includes the treatment of critical life threatening diseases and those illnesses, which if not cured, will lead to permanent disabilities or premature death, as well as the treatment of chronic diseases, terminal palliative care and the treatment of individuals with limited autonomy; the second category includes individual prevention during visits with medical services, rehabilitation, etc., as defined in the Law on health and medical services; the third category includes the treatment of the less critical and chronic diseases; while the fourth includes marginal cases and the fifth, the treatment for reasons different than diseases and injuries (extracted from Bariletti, A., Cavicchi, I., Dirindin, N., Mapelli, V., Terranova, L. (1999)).

<sup>21</sup> Swedish Parliamentary Priorities Commission, 1995, p.20; European Observatory on Health Care Systems, Hit Summary, Sweden (2002); Bariletti, A., Cavicchi, I., Dirindin, N., Mapelli, V., Terranova L (1999).

<sup>22</sup> European Observatory on Health Care Systems, Hit Summary, Sweden, (2002).

<sup>23</sup> In particular with the Juppé reform of 1996.

possibility of a wide range of service and care providers, as well as the use of the most advanced technologies, without having to worry too much about the cost-efficiency ratio and the problem of rationalizing resources. Each citizen is free to choose which health insurance fund to sign up for, and is also free to decide which hospital facility to be treated in and/or which physician or specialist to be treated by. Since 1994, there has been a growing deficit in the mandatory healthcare insurance system, and in 2002 the Government intervened by increasing contributions, thus determining a rise in the cost of labor, and announced a series of changes: hospitals would be allowed to provide specialized care, while health insurance funds would be able to stipulate individual contracts of clearly defined quality standards with individual physicians. For chronic diseases, there would be a strengthening of Disease Management programs, aimed at providing integrated hospital outpatients and home care packages, based on common guidelines for all funds<sup>24</sup>.

The *Dutch* experience, whose health system is quite different from those of the other EU countries, is associated to the so-called *administered competition* or *managed competition*, which aims mainly at providing access to good quality healthcare. The Government's regulatory action is directed, first of all, towards promoting mandatory health insurance for all citizens, with insurance premiums not linked to individual risk, antitrust measures, scrutiny on the selection mechanisms of insured individuals, quality control and access to information. Nevertheless, still today, the profound separation of the financing and organizational system of healthcare, within which one can find "coexisting" a mandatory health insurance scheme with one, that is much more extensive and private in nature, continues to have significant effects in terms of the acquisition of resources and fairness of the system.

In *Austria*, on the other hand, the delivery of health services and assistance, as well as the quality control of the system, represent one of the major public responsibilities. Over two thirds of the Austrian healthcare system is financed through contributions for social insurance, paid out by workers and from general taxation. Around a third, instead, is financed privately, directly from families. Public bodies, non-profit organizations, private for-profit organizations and individuals provide healthcare services<sup>25</sup>. Healthcare and programming activities are encouraged and supported through the cooperation with decentralized agencies and institutions, as well as partners, in particular, in primary healthcare. The experience and the know-how acquired in the field of healthcare are thus integrated with the support of local groups' independent assistance centers<sup>26</sup>.

In *Belgium*, the healthcare system is characterised by a strong heterogeneity and fragmentation that derives largely from the division of responsibilities and from the very nature of the structure of the Belgian State. While there is a respect for safeguarding the individual freedom of choice among a range of service providers, healthcare is managed and provided privately by non-profit organizations, whereas the responsibility of their financing and supervision lies with the public sector, through the work of numerous administrative authorities. During the economic crisis of the seventies, a season of reforms was launched with the aim of containing costs and studying strategies for a more efficient allocation of resources within the healthcare system.

Special attention was given to eliminating waste and the inefficient use of resources, by introducing a number of exceptions to the tariffs regulations for the financing of the services, by increasing the tickets paid by patients for a number of services, by setting the maximum growth rate allowed for healthcare spending at 1.5% per year<sup>27</sup>.

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<sup>24</sup> Inpdap (2003).

<sup>25</sup> European Observatory on Health Care Systems, Summary, Austria (2002).

<sup>26</sup> Implementation of Agenda 21: *Review of progress made since the UN Conference on Environment and Development 1992*, New York, aprile 1997.

<sup>27</sup> *Ibid.*

In *Italy*, the framework of the existing healthcare system continues to be the same one that was introduced with Law 833/1978, instituting the National Healthcare System (Servizio Sanitario Nazionale – SSN), with which the previous mutualistic compensation model was abandoned in favor of an integrated public model inspired by universalistic criteria of protection. At the beginning of the nineties, a number of reforms were implemented<sup>28</sup>, which opened the way to the entrepreneurization of health facilities, introducing private management rules and competitive mechanisms among service providers. In 1999<sup>29</sup>, the option for a mixed model of healthcare assistance was reaffirmed, by limiting the areas of competition to the signing of agreements by the Regional Authorities and of contracts between the Asl (local health authorities) and private facilities<sup>30</sup>. This has accompanied the transition towards the completion of the regionalization and entrepreneurization processes of hospital facilities. To this end, basic assistance levels (Livelli Essenziali di Assistenza – LEA) have been identified and the universalistic concept of the Law 833/78 was reaffirmed. Outside this approach, macroeconomic compatibility principles are applied. There is, therefore, a range of incentives aimed at supporting complementary forms of healthcare assistance<sup>31</sup>.

*Spain*, starting in the second half of the eighties, has also gone through the transition from an insurance healthcare system to a public universalistic one, financed by means of taxation. Moreover, Spain has completed in 2002 a devolution process, which gives full autonomy to the ten regions, together with a reorganization of the financing mechanisms, in favor of the local entities. At the same time, the State continues to play a central role in the healthcare system, in particular with reference to: an equitable distribution of services and resources; the definition of a minimal services' package and of pharmaceutical and human resources policies; the setting of quantity and quality standards for services, in order to guarantee equal access across the country<sup>32</sup>. Even in Spain, the most important challenges of the future are represented by the search for a sustainable model to finance healthcare spending, the development of information in this sector, management self-sufficiency and the expansion of community and social assistance within the wider framework of the national healthcare system.

In *Portugal*, after the introduction of the National Healthcare System (1974-1984), a decentralization process was initiated, in which the private sector played a new role, especially with respect to the need to control public spending. Nevertheless, between 1996 and 2001, as a result of the severe imbalance, which favored the private component of healthcare spending, an attempt was made – through a series of reforms – to find a better balance between the public and private sphere within healthcare. One of the more important challenges which Portugal is facing nowadays, in addition to the need to reduce the healthcare system's inequalities and the improvement in the coordination between primary and secondary healthcare, is that of the creation of new form of entrepreneurial management of the healthcare system, which will give more autonomy to the local administrations, produce changes in the pharmaceutical policy, optimize and regulate prices and medical prescriptions.

As in many other European countries, Portugal is also experimenting with forms of public management and public and private partnerships, with the aim of controlling the costs of the healthcare system.

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<sup>28</sup> with legislative decrees n. 502 of 1992 (De Lorenzo Reform) and n. 517 of 1993.

<sup>29</sup> with legislative decree n. 229 of 1999.

<sup>30</sup> Zoli, M. (2004).

<sup>31</sup> *Ibid.*

<sup>32</sup> as set forth in the recent law on Health Cohesion.

*Greece* as well, instituted, under the direction of the first Socialist Government of Pasok in 1983, a national healthcare system with Law 1397/83, founded on the principle for which the state is fully responsible for the health care services to all citizens. Greece brought the whole system of health treatments under the central responsibility of the State, assigned the planning of local healthcare to the 52 districts, put an end to the “practice” of informal payments of treatments and significantly reduced the number of private care providers. In the following decades, the goal has been to focus on improving the patient’s freedom and possibility of choice, which has led to a new process aimed at identifying a better form of cooperation between the public and private sphere in the management of healthcare, as well as to the removal of a number of restrictions on the private sector. The challenges that the Greek national healthcare system will be facing lie primarily in supporting and promoting higher standards of services and care and guaranteeing a wider access to treatment, even to those who are poorer.

In the *United Kingdom*, the National Health Service was created in the fifties to provide for universal and complete access to healthcare on the basis of need and not on the capacity to pay for services. The system was financed through general taxation and not through social insurance companies as in other European countries. In the nineties, the conservative government of Prime Minister Margaret Thatcher, with the adoption of internal market systems or quasi-markets, introduced some important changes. The hospitals’ budget constraints, however, reduced the degree of patients’ access to health services. However, the new White Paper seems to have solved this problem, by establishing that hospitals will be reimbursed for patients’ costs at prices equal for all, on the basis of the covered market share. Moreover, it calls for measures supporting the transformation of hospitals into foundations, the use of project finance and the strengthening of private hospital care within the National Health Service. The support to the freedom of choice that the Blair Government intends to guarantee to its citizens will generate additional costs, of which the Government is perfectly aware. Moreover, it is also aware of the need to exercise control over the adequacy of the services provided<sup>33</sup>.

#### *Common challenges of European Union healthcare systems*

Because of the unfavorable economic conditions of the nineties, the crisis of the different welfare models (including the more advanced ones), the need to deal with continually decreasing economic financial and human resources, European Union countries’ national healthcare systems, despite their most advanced legislation, have not always been able, in practice, to guarantee the rights of patients, end-users, consumers, families, weaker groups and ordinary citizens.. Moreover, there are some challenges to be dealt with in the beginning of the Third Millennium: the impact of the ageing population on healthcare systems and on spending (1); the development of new technologies and of more advanced therapies (2); the meeting of patients’ expectations (3).

1) The ageing of the population is linked to two phenomena: the reduction in fertility rates and the extension of life expectancy at birth. The young segment of the population is very small all across the EU-15 Europe, except in the Northern countries, which, with their particularly generous welfare systems also sensitive to women issues, have been able to maintain relatively high overall fertility rates.

With respect to longevity, technical-scientific progress in the medical-health field has favored, in the last thirty years, the extension of life expectancy at birth, increasing, at the same time, the “oldest” segment. Moreover, life expectancy in “good health” and/or without disabilities has also increased. Eurostat estimates that in the next fifteen years, the greatest increase in the population will take place in that age category, in so much that the over 80 will grow by 50%.

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<sup>33</sup> Inpdap (2003).

Furthermore, the dependency indexes will increase, even if fertility rates in Europe are expected to grow. The EU population has aged and continues to age. It is an almost “zero growth” population, supported by migration flows which, in over a decade, have represented the major factor of demographic growth. Furthermore, the impact of new Member States’ birth rates (that have younger population) on the EU–25 will not change the trend towards a progressive ageing of the population<sup>34</sup>, because of a reduction in overall fertility rates. An ageing population must necessarily support greater costs in order to meet the growing demand for social and health care. Such demand could grow even further, as a result of the profound transformations taking place in the family structure in many countries, even in the new Member States, with the exception of Poland and Cyprus: the increase of divorces, the increasingly smaller households, made up of a couple and, at the most, one child, or of people living on their own at all ages, the strong increase in the number of single parent households, generally the mother, with one or more children.

The EU is about to adopt measures to tackle these problems, both at the national and European level. Action must be taken on different issues: improvement of public finance, employment, social welfare and healthcare, in a way that the respective social objectives can be met even when the pressure from the ageing process will increase. To cope with the increase in spending, especially for long term care, healthcare facilities, their financing mechanisms, as well as the organization of services being provided, will necessarily have to evolve: there will be a greater need for more qualified personnel, since facilities and family networks, which are less numerous and more unstable, are no longer capable of providing support and solidarity<sup>35</sup>.

2) The rapid progress of medical science, both with respect to the technical innovation of preventive diagnostic instruments and to the clinical and therapeutic strategies to be developed to cure many of this century’s diseases could provide patients with many advantages in terms of reducing pathological risks, as well as for preventive treatments. Since the implementation of these new technologies and therapeutic strategies presents costs that are higher than the current financing possibilities of the different healthcare systems, it has become necessary to encourage the development of transparent and efficient evaluation mechanisms in order to guarantee to the greatest number of patients accessibility to these new products or therapies<sup>36</sup>.

3) In order to meet patients’ expectations, the European Commission has set three long term goals as part of its commitment in favor of health protection: accessibility, quality and sustainability<sup>37</sup>.

*Access to healthcare services* is a right set forth by the European Union Charter of Fundamental Rights, and the different national governments are committed to maintaining universal and complete access to care, in contrast to and despite the increase of costs<sup>38</sup>.

The national action plans promoting social integration aim at: encouraging prevention and health education; easing the spending burden for healthcare for people with low incomes; planning for measures to meet the health requirements of people belonging to disadvantaged sectors.

The *guarantee of quality services* poses other critical issues, because of the difficulties in setting comparable quality standards for very different healthcare systems, operating facilities and the

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<sup>34</sup> European Commission (2003).

<sup>35</sup> European Commission (2001).

<sup>36</sup> *Ibid.*

<sup>37</sup> This communication of the European Commission follows the conclusions of the European Council of Lisbon (March 2002), in which the need for a reform of the social protection systems to provide quality assistance was emphasised, and complies with the request of the European council of Göteborg (June 2001) to prepare a report for the European Council that was going to take place in the spring of 2002, containing recommendations in the field of healthcare and, more specifically, in the care for the elderly.

<sup>38</sup> European Commission (2000).

levels services offered, as well as for the heterogeneity of the available technological and therapeutic instruments. To deal with this problem, WHO's European Observatory on Health Care Systems has organized a unique instrument for a qualified and expert analysis of the world's health systems, producing interesting information on: the allocation for health spending; the organizational structure and the management of the different systems; the method of financing of healthcare and the composition of this expenditure; the combination of the services being offered; the legislative reforms in this field. Nevertheless, as it will be highlighted in the following chapter, there is still no information that would allow one to assess how much of the benefits generated by these systems actually do reach citizens, thus fulfilling their citizenship rights. There are rights, such as the right to information, to consent, to privacy, to free choice, to avoid unnecessary pain, to complain, as well as to respect the patients' time, for which very little is known, but which are the essence of a healthcare system created for individuals and citizens.

*Sustainability* represents a critical problem common to European social protection models: the spending for health is the second component, in order of importance, of total social spending in EU-15. In the last ten years, there has been a decrease in the growth rates of healthcare spending, as a result of the measures adopted by many Governments to control this component of overall social spending and the growth in importance of the private sector<sup>39</sup>. The incidence of healthcare spending on social spending continues to be, on average, lower in the Northern European countries (except for Sweden), as well as in Greece and Italy, where the private sector has expanded its role. Levels of incidence higher than the European average are reported in Spain, the Netherlands, Portugal, Germany and France, notwithstanding the launching of spending control strategies; in Ireland, healthcare spending receives the highest public budget allocation. The reforms of healthcare system activated to tackle the economic crisis of nineties have already impacted on the demand and supply side; in the first case, by increasing the contributions or costs to be covered by the end user; in the second case, by putting an end to the allocations to service providers and by contractualizing the relations between citizens and service providers.

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<sup>39</sup> Zoli M.(2004).

## SECOND PART

### 4. Analysis of available statistic data

In order to collect the most comprehensive information about the level of implementation and the effectiveness of the 14 rights established in the Charter of Patients' Rights around Europe - in addition to the analysis of data from the interviews and the visits to the hospitals presented in the following chapters - an analysis of the comparable official data on issues regarding patients' rights was conducted by Dr. Fiorenza Deriu, from the Department of Demography of the Faculty of Statistics of the Rome University "La Sapienza". This study, enclosed in the report (see Appendix B), is the main reference of this chapter<sup>40</sup>.

The main aim of this chapter is to verify, through the analysis of the data from the existing health statistics, the state of the Charter's rights implementation, by looking at the indicators, which directly or indirectly concern them. Starting from the indicators that exist at the European level<sup>41</sup> to monitor the many aspects of existing healthcare systems in the different EU countries, it was possible to identify a subset of indicators to measure the implementation of the rights established in the Charter (see table below).

*Table 5. Available indicators in official statistics on the 14 Charter's rights*

<i>Rights of the Charter</i>	<i>Available indicators</i>
Right to preventive measures ( <i>Right n. 1</i> )	<ul style="list-style-type: none"> <li>▪ Vaccinations against the principal infant and non infant infectious diseases;</li> <li>▪ Preventive and screening tests for cardio-circulatory diseases, breast cancer and tumor markers;</li> <li>▪ Hypertension monitoring;</li> <li>▪ Prenatal care coverage;</li> <li>▪ Monitoring of life styles, such as smoking, alcohol, and nutrition;</li> <li>▪ Indicators of healthy life expectancy at birth and at 60 years;</li> <li>▪ Indicators of the incidence for some infectious (hepatitis, pertussis, measles, rubella, mumps, tuberculosis, HIV-AIDS) and tumoral (breast, lung, digestive track, colon, etc.) diseases.</li> </ul>
Right to access ( <i>Right n. 2</i> )	<ul style="list-style-type: none"> <li>▪ Public hospital facilities (number of beds per ward);</li> <li>▪ Personnel employed in these facilities (doctors, pharmacists, dentists, nurses, midwives, also in relation to labor force);</li> <li>▪ Frequency of the consultation of the general practitioner or a specialist by people;</li> <li>▪ Hospital discharges for all principal diagnostic categories according to the International Classification of Diseases (ICDIX last revision);</li> <li>▪ Time taken to reach hospital facilities, general practitioners and healthcare centers (out-patients clinics);</li> <li>▪ Consumption expenditure of private households for health (at current prices and in percentage of total household consumption expenditure);</li> <li>▪ Social benefits for sickness and health care as far as for disability in percentage of total benefits.</li> </ul>
Right to information ( <i>Right n. 3</i> )	<ul style="list-style-type: none"> <li>▪ Population using internet to look up information on health, diseases, injuries and nutrition, divided by type of activity (active population, students and by age categories);</li> <li>▪ Diffusion of the use of telemedicine services;</li> <li>▪ use of the web to set up appointments with practitioners and specialists.</li> </ul>

<sup>40</sup> Every information and data that are outside doctor Deriu's study will be explicitly quoted in the text.

<sup>41</sup> The only sources of structured and comparable statistics about patients' rights nowadays are Eurostat, Oecd and World Health Agency.

Right to consent ( <i>Right n. 4</i> )	<b>Indicators to monitor the implementation of the right to consent are not available.</b>
Right to free choice ( <i>Right n. 5</i> )	<ul style="list-style-type: none"> <li>▪ Frequency of the consultation of the general practitioner or a specialist by people.</li> </ul>
Right to privacy and confidentiality ( <i>Right n. 6</i> )	<b>Indicators capable of assessing the degree of implementation of this right of the Charter have not yet been identified.</b>
Right to respect of patients' time ( <i>Right n. 7</i> )	<ul style="list-style-type: none"> <li>▪ The only information available has been extracted from the Hit Summary of the European Observatory on Health Care Systems or from national reports.</li> </ul>
Right to quality standards ( <i>Right n. 8</i> )	<b>Indicators capable of assessing the degree of implementation of this right of the Charter have not yet been identified.</b>
Right to safety ( <i>Right n. 9</i> )	<b>Indicators capable of assessing the degree of implementation of this right of the Charter have not yet been identified.</b>
Right to innovation ( <i>Right n. 10</i> )	<ul style="list-style-type: none"> <li>▪ Diffusion of organ transplants;</li> <li>▪ The average survival rate after five years for heart, lung, kidney and liver transplant patients.</li> </ul> <p><b>At present, there is no available official and comparable information at the intra-European level on other innovative intervention procedures.</b></p>
Right to avoid unnecessary suffering and pain ( <i>Right n. 11</i> )	<ul style="list-style-type: none"> <li>▪ Use of opiates in pain therapy<sup>42</sup>.</li> </ul> <p><b>With respect to the right to avoid suffering, no comparable indicators have been identified on the spread of palliative cures or access to such treatments.</b></p>
Right to personalized treatment ( <i>Right n. 12</i> )	<p>Indirect indicator:</p> <ul style="list-style-type: none"> <li>▪ Average length of stay in hospitals.</li> </ul> <p><b>No other indicators have been identified.</b></p>
Right to complain ( <i>Right n. 13</i> )	<b>Indicators capable of assessing the degree of implementation of this right of the Charter have not yet been identified.</b>
Right to compensation ( <i>Right n. 14</i> )	<b>Indicators capable of assessing the degree of implementation of this right of the Charter have not yet been identified.</b>

The existence and the scores<sup>43</sup> of the indicators analyzed allow one to assess the level of implementation and the effectiveness of each right of the Charter. However, before analyzing each right separately, it is possible to make an initial observation from the analysis of the table above, the presence of just a limited number of indicators for each right or rather the unavailability of indicators for some rights reveal the existence of problems and confirm the lack of a base for the implementation and the monitoring of the rights in question.

### *1. Right to Preventive measures*

Health prevention comprises measures both to avoid the emergence of a number of diseases (primary prevention) through the control and the reduction of the risk factors and to stop its spreading or to reduce its consequences once they have occurred (secondary and tertiary prevention).

Available indicators that refer to the primary prevention are the percentage of coverage of vaccinations against the principal infant and non-infant infectious diseases, which are greater than 90% and cover almost the entire population<sup>44</sup>.

The state of secondary prevention can be analyzed through data about:

- screening tests for cardio-circulatory diseases, breast cancer and tumor markers;
- hypertension monitoring;

<sup>42</sup> This indicator is not described on doctor Deriu's analysis.

<sup>43</sup> In the part that follows, data refers to the 14 countries that participated to this study, therefore the means calculated are not that of EU-15.

<sup>44</sup> Data from the *Health For All Database*, World Health Organization, 2003

- prenatal care coverage;
- incidence for some tumor diseases.

In particular, information<sup>45</sup> can be found on persons who have taken preventive exams using instrumental-diagnostic and manual instruments (mammography and manual breast controls) or who have participated in screening programs for the control of heart conditions and of the main tumor indicators.

The prevention of breast cancer seems not to be too widespread: the percentage of women reporting preventive examinations is, on average, low even for the older aged and most at risk categories (45,1% of women reporting preventive examinations as mammography by x-ray and 31,9% of that reporting preventive breast examination by hand). The same could be said about the participation in screening programs for hearth check-up and cancer test, to which, on average, respectively only 4,7% and 5,4% of European population between the age of 45 and 54 participate.

All the European countries encourage healthy life styles and, with respect to smoking, it seems that where information campaigns have been conducted with greater intensity they had been successful (Finland, Portugal and Italy).

Looking at country based data, Austria is the only European country in which the primary and secondary preventive system is guaranteed in all phases of life cycle while Netherlands seems to be the country more sensitive with respect to developing a culture of prevention.

Available data, in particular regarding the primary prevention, seem to show that there is an increasing chance for *the right for every individual to a proper service in order to prevent illness* to be carried out, thanks to the widespread culture of prevention existing all over Europe.

## 2. Right to access

Existing available indicators that could be related to the right of access to the health service are:

- number of beds per ward in public hospital facilities and of personnel employed in these facilities (doctors, pharmacists, dentists, nurses, midwives also in relation to the labor force)<sup>46</sup>;
- number of hospital discharges for all the principal diagnostic categories according to the International Classification of Diseases (ICDIX last revision)<sup>47</sup>;
- frequency of the consultation of the general practitioner or a specialist by people<sup>48</sup>;
- time taken to reach hospital facilities, family doctors and healthcare centers (outpatients clinics)<sup>49</sup>;
- consumption expenditure of private households for health (at current prices and in percentage of total household consumption expenditure);
- social benefits for sickness and health care as far as for disability in percentage of total benefits.

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<sup>45</sup> Coming from the 2002 Eurobarometer Survey, with the data standardized within the Eurostat database

<sup>46</sup> Data come from Eurostat database that collected mainly the administrative records from several European Union member States, about the number of hospital beds by type of stay, the number of doctors, of chemists and paramedical and assistance staff. This fact required caution when comparing these data as each national reporting system is affected by its own specific organization.

<sup>47</sup> Data come from Eurostat database that collected mainly the administrative records from several European Union member States. (see the note 6).

<sup>48</sup> Data come from the 2001 ECHP UDB European Community Household Panel, whose data are harmonised in the Eurostat database

<sup>49</sup> Data come from 1999 Eurobarometer survey, whose data are harmonized in the Eurostat database.

All over Europe, especially in the North, there is a significant reduction of the number of hospital beds available due to the policy of expanding outpatient assistance as well as day-surgery services (such as in Finland and Denmark) or to the policy of improving the efficiency and effectiveness of services, rationalizing the resources (such as in Italy). These reductions of hospital beds have been counterbalanced by the supply of alternative services (offered even by the private and non-profit sectors) limiting inconveniences everywhere except Spain, where it has led to an increase in waiting time and of people sharing the same hospital room, and Portugal, where the structural resources are inadequate and not distributed on the territory.

On average, the number of doctors per 100,000 inhabitants at European level is 370,0 with 8 countries out of 12 (for the other 2 countries this data is not available under this level). In all European countries the number of medical personnel seems to be lower than the actual demand: even in Spain and Italy, where the number of doctors is high and exceed the demand, there is a lack in qualified nursing personnel.

Analyzing the number of hospital discharges per 100,00 inhabitants for the different diagnostic categories (ICD diagnosis, virus infections, malignant neoplasms, Parkinson's disease, multiple sclerosis and complication of pregnancy, childbirth and puerperium), it seems that the lower rates of discharges are that of the highly invalidating diseases (such as Parkinson and multiple sclerosis). It means that there is a recourse to family assistance services and assisted healthcare residence facilities, that is however impossible to quantify because of the lack of available data.

During 2000, on average, 40% of European citizens had three or more consultations of general practitioners (in Austria, Belgium and Italy over 50% of population), and 16,8% of medical specialists (in Austria, Belgium and Greece more than one fifth of population).

Data about the easiness of access to the treatment centers show that most of the population (on average, about 80%), including people over the age of 65, is able to reach their general practitioner or the local ambulatory clinic in quite always less than 20 minutes, while reaching hospitals needs less than 20 minutes to about 50% of population, even the elderly. Despite the general proximity of treatment services, according to available data, there are some structural problems that don't allow European countries to implement effectively the right of access to the health services. Furthermore, it is noticeable that the only kind of available information refers to what the healthcare system offers without being able to measure the actual ability for patients or citizens to access the healthcare system and without taking into account the aspects referring to the actual demand of healthcare service.

### *3. Right to information*

Right to information has to do with different types of information: technical and specific knowledge about health and the existence of health services available to citizens.

Much progress has been made with respect to these kind of information, through their dissemination on the web: most European countries possess information systems that help direct the citizen/patient to the nearest available and operating health services. Young people, in particular students, are the ones benefiting the most from the opportunities offered by internet and the new technologies when researching information in the field of medicine, nutrition, on accidents and on diseases, mainly in the North European countries and in the UK, where more than 50% of students use internet to access health information, while in the Continent and in the Mediterranean this ratio decreases to 6%<sup>50</sup>.

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<sup>50</sup> Data come from the 2003 Community Survey on Information Technologies (ICT)

However, these web-based instruments are only accessible to those with a computer and access to Internet, excluding the more vulnerable and fragile sectors of the population who do not have such tools or are simply too old to learn how to use them.

The available data or rather the lack of data about the right to information, in this case, do not allow one to evaluate how the right to be informed is implemented.

#### *4. Right to consent*

**Data are not available** regarding another fundamental aspect that also regards the right of information. This refers to the patients' actual knowledge and understanding of their state of health and illness, in order to *actively participate in the decisions regarding people's health* in order to give "informed consent".

**Information is not available** neither about patients' likelihood to be informed on their illness, nor the actual possibility of accessing to their own medical records and asking for their correction in case of errors, or about patients' understanding of medical language.

#### *5. Right to free choice*

Availability of data regarding the degree of implementation of *the right to free choose from among different treatment procedures and providers on the basis of adequate information* is limited to one indicator that concerns the share of the population that turns to the family doctor or specialized doctor over a number of times<sup>51</sup>, that could be used as indicator of the possibility of the citizen/patient to turn to a doctor regarding onset diseases. During 2000, on average, 40% of European citizens had three or more consultations of general practitioners (in Austria, Belgium and Italy over 50% of population), and 16,8% of medical specialists (in Austria, Belgium and Greece more than one fifth of population).

Apart from this indicator, there aren't any others capable of assessing the degree of implementation of the right to free choice. As stated in Dr. Deriu's analysis, the only way to evaluate this right, at least in theory, is to study the different European healthcare systems<sup>52</sup>, that seem to adopt different modalities with respect to the implementation of this right: some of them have introduced gate-keeping mechanisms which force patients to go through a number of compulsory filters before accessing particular therapies or specialized doctors; others foreseen the freedom of the citizen/patient to go autonomously to its family doctor, the specialized doctor, the outpatient service or the hospital.

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

**Indicators capable of assessing the degree of implementation of the right to privacy and confidentiality have not yet been identified.**

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

The individual's right to *receive necessary treatment within swift and predetermined period of time* has been analyzed looking at available data about the waiting times/waiting lists<sup>53</sup>. It is a critical problem in most of the European health systems and, during the last years, almost all the European

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<sup>51</sup> obtained from the ECHP (see note 7).

<sup>52</sup> about which it is possible to acquire information through the "Hit Summary" published by the European Observatory on Health Care Systems.

<sup>53</sup> As official European data about the issue of waiting time are not available, the data contained in this paragraph comes mainly from the Hit Summary of the European Observatory on Health care Systems or from the national reports.

countries are committing themselves to solve it, thanks to the implementation of specific policies or general reforms to the health care systems.

Some of them are having success:

- Finland, waiting times have been significantly reduced thanks to policies which have focused on establishing medical teams which have been assigned to a precise and territorially limited share of the population;
- Denmark, in July 2002, a law came into force establishing a limit of two months for the period in which patients shall make use of the requested health service;
- Sweden, in 1997, it was decided that after a defined waiting time the health service can be offered by another county and measures towards the strengthening of the territorial networks and the cooperation between family doctors and specialized doctors were introduced;
- Belgium, the health system is being subjected to a number of reforms whose main advantages include the reduction of the waiting times;
- Netherlands, in 2004 the Dutch government, following the adoption of a series of measures proposed by an ad hoc commission, has seen an improvement in the situation: 68% of those signed up on the waiting lists can today receive the requested service within 4-5 weeks;
- Spain, since 1996, a strategy of territorial decentralization has been adopted which has led to a reduction, on average, of 70% of waiting times in the ten regions that before the completion of the devolution process had been centrally administered;
- United Kingdom, the speediness of waiting lists represents an important efficiency indicator of the health system: for its monitoring, an indicator that measures the number of patients in waiting lists for 100.000 inhabitants is calculated (data not available).

On the contrary, despite their efforts to reduce waiting time, in Portugal and Italy, whose reform agendas in 2001 and 2002 focused on this issue, waiting lists remain an unresolved issue.

Information collected show that even though the margin of implementation of the right to respect patients' time is increasing all around Europe, more needs to be done much more in the future.

#### *8. Right to quality*

**Indicators capable of assessing the degree of implementation of the right to quality services have not yet been identified.**

According to Dr. Deriu's study the respect of this right requires the establishment of standards to which the health infrastructures and health professionals should abide by from a scientific, technical, human and relational point of view. Presently, the establishment of quality standards has been one of the key issues of the political agenda of many governments, even if it is not always an easy task to solve due to the concurrent pressure to balance national budgets. But, at the moment, it is not possible to assess the degree of implementation of this right at the European level through indicators linked to these quality standards.

#### *9. Right to safety*

**Indicators capable of assessing the degree of implementation of the right to safety have not yet been identified.**

## 10. Right to Innovation

An appropriate indicator to monitor the access to highly innovative health services is represented by the number of transplants carried out per million of inhabitants<sup>54</sup> and the average survival rate after the operation<sup>55</sup>. Nowadays, transplants are a very sophisticated therapy that nevertheless should be considered a normal and not an extraordinary procedure. While, on average, kidney and liver organ transplantations are quite widespread, respectively with 33,3 and 12,1 transplantations per 1 million of inhabitants, heart, lung and pancreas transplants are less diffused, respectively with 4,6 operations, 2,8 and 1,3 per 1 million inhabitants. The average survival rate after five years for patients from heart transplants is 80%, from lung transplants is 50-60%, for kidney is 70 to 90% and for liver transplants is 70%. At the national level, in the Netherlands there is a commission for the evaluation of the new technologies to help select those which will ensure high quality standards and the Health Insurance Fund also provides coverage for certain tissue and organ transplants. Nevertheless, policies aimed at strengthening and spreading a culture of organ donation are not too diffused, such as in Italy, where there is even a problem concerning waiting lists for transplantations.

The implementation of the right to innovation is often hindered by economic and financial aspects: they represent an indisputable limitation to certain choices, but should not influence nor prejudice the right of the citizen/patient to access to innovative procedures and technologies, despite their costs. In this respect, the Swedish “ethical platform” is an example, which deliberately guarantees medical services beyond any economic criteria. This system, although it makes the administration of public spending quite difficult (health expenditure is the highest among the former 15 members’ EU in terms of % of GNP with 8.9%), is extremely respectful of the dignity and human rights of each individual.

## 11. Right to avoid unnecessary suffering and pain

*The right to avoid as much suffering and pain as possible, in each phase of individual’s illness* consists in palliative treatment and pain therapy. The palliative treatment is directed to the patients affected by a disease that no longer responds to any other form of specific treatment.

These matters are well defined and studied: implications of the palliative treatment are accurately described by the National Council for Hospice and Palliative Care Services WHO-OMS of 1990 while in “*Palliative Cancer Care. Policy Statement based on the recommendations of a WHO consultation*”, the World Health Organization conducted an exhaustive survey of the use of opiates in pain therapy. This indicator, which is considered to assess the pain management in healthcare system<sup>56</sup>, occur in different amount around European countries: it varies from 39,315 daily doses per 1 million inhabitants in Ireland to a lower amount in the Netherlands (4,234), Austria (3,988), Finland (3,256), Italy (1,890), Portugal (1,723) and Greece (1,551)<sup>57</sup>.

The most appropriate facilities providing palliative treatment are the hospitals of palliative treatment and the hospices. Nevertheless, in many countries, it is difficult to access these treatments or to centers specialized in pain therapy. The most common barriers to the use of such treatments are to be found in the insufficient economic resources available, in the cultural representation of pain as an unavoidable element of the disease, in the inadequate training of doctors on this issue and in the resistance to utilizing opiates, etc.

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<sup>54</sup> Data come from 2003 Eurostat Database.

<sup>55</sup> Data come from Italian health website, *Nuovi farmaci che rendono più sicuro il trapianto*, Servizio Sanitario Web, by Didamed, 2004, while the International Agency for Research on Cancer (IARC) provides the survival indicators for all tumors for adults and children in the EU countries, described in IARC (1999) cfr. [www.dep.iarc.fr/accis.htm](http://www.dep.iarc.fr/accis.htm).

<sup>56</sup> This indicator is monitored by the International Narcotic Control Board.

<sup>57</sup> OMS (2000).

According to Dr. Deriu's study, an indicator of the degree of implementation of this right could be the spread of palliative cures or access to such treatments, but no comparable information at the European level have been identified. The indicator, relating to the average amount of morphine per person utilized for therapeutic purposes<sup>58</sup>, was identified from a ranking of 65 countries worldwide (of which 12 were considered for this study).

### *12. Right to personalized treatment*

As stated in Dr. Deriu's study, monitoring the implementation of the individual's right *to diagnostic or therapeutic programs tailored as much as possible to his/her needs* is not easy, mainly due to the fact that each patient is a different case and it is difficult to set general standards. But looking at the available information on the health systems' fundamental orientations for treatment (for instance the priority or not of economic criteria over citizenship ones, based on rights) it is possible to use indicators that refers to the way in which patients are considered and, indirectly, to the right in question.

As a matter of fact, in different European countries some policies have been implemented to provide health assistance in the patients' home in order to guarantee their stay in the family. Available information referred to this issue are the average stay in hospital of patients by each type of diagnosis<sup>59</sup> (with the shortest length of less than a week for Italy and Sweden and the longest of 8-10 days for Finland, Austria and Netherlands) and the development of home care system around European countries or of equivalent measures such as specialized centers (for example, with Italy where the networks of assisted healthcare residences and social support centers for long admittance patients are predicted to increase).

Though hypothesizing that home care or turning to specialized centers allow more appropriate and specific care and treatments to patients, however, this kind of information is not sufficient for a comprehensive analysis of the state of the implementation of the right of personalized treatment.

### *13. Right to complain*

**It was not possible to identify official data that could provide useful information to monitor possible violations of this right.**

### *14. Right to compensation*

**Indicators capable of assessing the degree of implementation of this right of the Charter have not yet been identified.**

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Analyzing information collected with respect to the 14 rights of the Charter, three kinds of remarks can be made: first, regarding the availability of information on patients' rights; second, on the kind of information they provide and third about the contents and typology of the available information.

Regarding the first, it emerges that in only a few cases official data are available that allow one to assess the state of implementation of the right or, even if not sufficient, consent at least to hypothesize on the right's future development (*right to preventive measures, right to access and right to information*). However, sometimes, even if some data are available, they are insufficient to

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<sup>58</sup> Developed by the International Narcotic Control Board in 1995, on the basis of a survey conducted in collaboration with WHO and 65 national Government.

<sup>59</sup> Data come from administrative sources, made with specific goals, different from country to country. For this reason comparison between countries shall be made very carefully.

assess the degree of implementation of the right (*right to free choice*) or too specific to be significant (*right to innovation*) and, therefore, need to be integrated with other information, such as data about new specific indicators (*right to access*). Moreover, available data are not often comparable at the European level and come from non-official sources of data (*right to free choice, right to respect of patients' time, right to personalized treatment*).

But, in almost half the cases, indicators useful for evaluating the level of implementation of the rights in question are inexistent and ad hoc indicators or new techniques of data collecting and analysis need to be created (*right to consent, right to privacy and confidentiality, right to quality standards, right to safety, right to complain, right to compensation*).

Regarding the second consideration, the main problem of concerning the official information is that it does not contain information on patients' rights. This is probably the result of a specific focus given to this information. Regarding this it can be mentioned, attention on outputs (what health systems have done) rather than on the outcomes (what actually happened to people); a priority given to the offer of services rather than on the demand and/or the encounter between offer and demand; an effort to identify macro-phenomena while the actual condition of patients is made of several micro-phenomena that even have a relevant quantitative dimension.

Regarding the third consideration, instead, some strengths and weaknesses about the implementation of patients' rights do emerge. The strengths regard the positive evolution that involves some rights such as the right to preventive measures, the right to information and the right to respect of patients' time. Even if the implementation of the last two rights still needs to be demonstrated effectively, some margins of improvement seem to exist. There are, however, weaknesses coming from the existing indicators' analysis. The main weakness regards the access to health services, increasingly difficult especially for patients with more serious diseases. Also information coming from data related to the right to innovation and the right to avoid pain, though very limited, confirm the existence of critical situations.

## 5. Information coming from National Legislations

The second source of information with respect to the state of patients' rights in Europe has been the legislation regarding these rights that exist at the national level. Partner organizations were asked to check for the existence of at least one law or regulation for each right in their countries. When possible, partners' data were verified in the light of a recent mapping exercise on the National Health Service carried out by the European Commission's High Level Group on Health Services and Medical Care, which partly covers patients' rights (European Commission 2006d)<sup>60</sup>.

It must be stressed that this was not designed as an exhaustive research on the legal framework of patients' rights, but rather as part of this more general research on the degree of attention towards patients' rights in some EU countries. For this reason, what has been considered as relevant from the point of view of the countries' attention to rights was simply the existence of any national legal recognition, whatever it maybe whether constitution, general law, specific legislature, regulations, Charters etc. It is important to mention that the differences in legislation habits, such as the distinction between common law and continental law, characterizing the EU countries, were not taken into consideration neither was it be possible to verify to what extent the actual legislation in the countries surveyed favors the implementation of these rights.

The existence of only *one law* (whatever type: constitutional, general or specific kind) or regulation was considered an indicator of attention to patients' rights because the research team considered, there exists no direct relation between the number of laws and the implementation of the right. In other words, more laws does not necessary imply a greater level of attention to (and obviously not even a greater implementation of) patients' rights. One good and adequately implemented law can indeed be more relevant and effective than several specific laws and regulations on the same right that remains only on paper.

The following table summarizes the partners' information reported on the existing legislation.

*Table 6: Number of countries where at least one national legislature exists regarding the 14 Patients' Rights*

<b>Right</b>	<b>No. of countries</b>
Information	14
Consent	14
Quality	14
Prevention	12
Access	13
Privacy	13
Complain	13
Personalized treatment	11
Choice	10
Safety	11
Compensation	11
Avoid Pain	9
Innovation	7
Time	6

The rights to information, consent, quality and prevention are legally recognized in all the surveyed countries. In general, patients' rights show a high level of legal coverage. The three rights recognized less in national legislations are the right to avoid pain, the right to innovation and the right to time. The right to time is acknowledged in less than half of countries, while the right to innovation in hardly more than half of them.

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<sup>60</sup> In UK this part of the research was not carried out by the partner organization but rather the research team collected the data from the already mentioned European Commission (2006d) and other national sources available on the Internet.

Let us now consider the existence of norms protecting patients' rights in the 14 countries. They are highlighted in the following table.

*Table 7. Number of rights recognized in at least one legislative act by country*

<b>Country</b>	<b>No. of rights</b>
Greece	14
Denmark	14
Italy	14
Portugal	14
Finland	13
France	12
Netherlands	12
Germany	11
Sweden	11
Austria	10
Spain	10
Ireland	8
Belgium	7
UK	8

In four countries (Greece, Denmark, Italy and Portugal) it results that all the 14 patients' rights have some legal recognition while in Ireland and Belgium only 8 out of the 14 rights have such recognition. As it was mentioned above, in some cases these differences could be due to different legal systems beside legislative customs.

What can be taken from these data can be summarized in two main points.

The first, at the national level in the majority of countries there seems to exist a good degree of legal coverage of patients' rights, observing a relevant level of attention.

The second point, it cannot be concluded that there is a general correlation between the legal recognition of patients' rights and their actual implementation. This means that a right established by law is not necessarily, for this reason, fully implemented in practice. As illustrated in the next section, in fact a number of rights that are fully or almost fully recognized in national legislations are not implemented well. On the other hand, it emerged in countries where several problems or incumbent risks do exist, patients' rights were widely recognized, and vice versa.

It is evident that laws and norms should be neither proclaimed nor applied only by tribunals, but also enforced through appropriate and effective policies, initiated and supported by all actors of health care: governments, citizens' organizations, professionals, third payers, pharmaceutical and other private companies, trade unions, the media, legal systems and the scientific community.

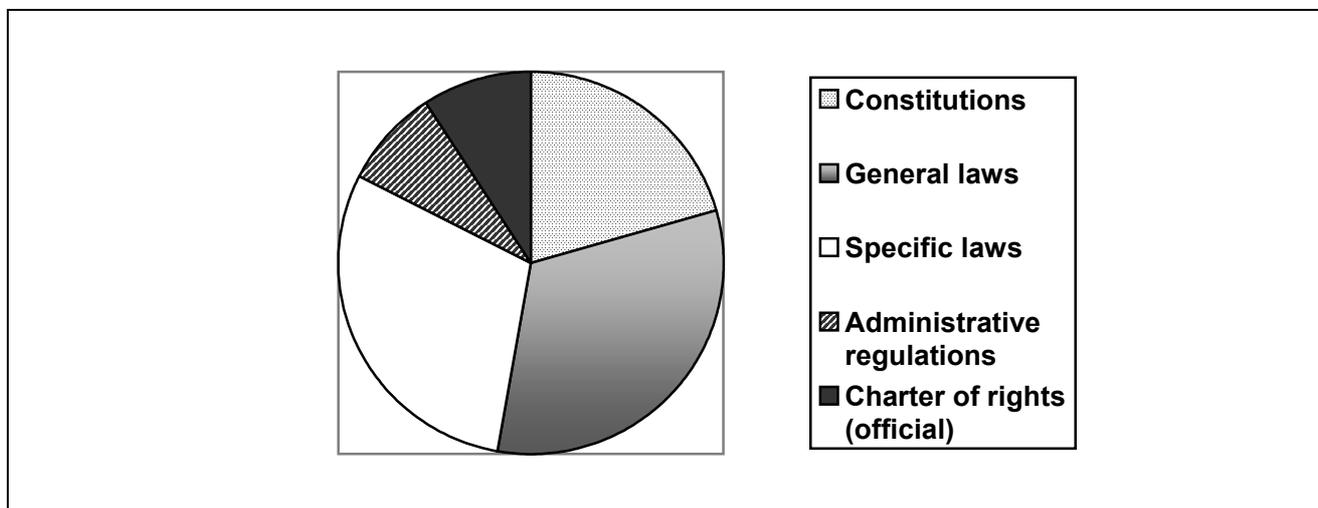
Another piece of information reported regards the kind of legal documents in which patients' rights were recognized. Partner organizations were asked to indicate if the rights were set up in a Constitution or stated as constitutional principles, in a general framework law, in specific legislation, in administrative regulations or in a charter of rights (intended as an official document). Since the question was if each rights was recognized in at least one legal document, we cannot consider the partners' answers as representing the entire national legislative framework. Nevertheless, the amount of information they provided has been so numerous (on average, they mentioned 21,6 legal documents for each country and 20 of them for each right) that reporting them can only enrich the available information on legislation.

The aggregated results for this information are summarized in the following table.

*Table 8. Kind of legal documents where patients' rights are established at national level*

Kind of documents	No. of docs	%
Constitutions	58	20,56
General laws	91	32,26
Specific laws	84	29,78
Administrative regulations	23	8,15
Charters of rights (official)	26	9,21
TOTAL	282	100,00

It can be noticed that more than 60% of documents mentioned are laws, of general or specific scope, while one fifth of documents are of constitutional rank, while a little more than 8% are regulations of administrative rank and more than 9% are official charters of rights. The ratios above mentioned can be better seen in the following chart.



*Chart 1. Kind of legal documents in which patients' rights are established at national level*

A number of remarks can be made on these data. The first one is that, since constitutions are mentioned only in one fifth of the cases, it could be considered that patients' rights are not generally considered directly part of basic or fundamental rights, as it is in the European Charter of Patients' Rights, based on the EU fundamental rights. Secondly, the low number of administrative regulations is ambivalent in that it could mean on the one hand, that patients' rights are not reduced to just an administrative matter, while on the other hand they could risk remaining only on a level of principle or declaration. Finally, the amount of general and specific laws establishing patients' rights (more than 60% of all the documents reported) attests a relevant degree of attention to patients' rights, at least as a matter of principle.

In addition, with such a large number and diversity of laws that entitle patients' rights one can imagine that it must be quite difficult for citizens to know and understand their rights as citizens in regards to health and healthcare services.

Finally, this brief overview also allows us to see that the majority of rights (and in some cases all the 14 rights) are in some way legally recognized in each country. Therefore one could conclude that the European Charter in most part has legal foundation in the majority of countries studied.

## 6. The Civic Audit Information

As described in chapter 2, in order to collect information about patients' actual conditions at the European level, the research developed a series of actions, based on the civic audit methodology used by Cittadinanzattiva. These activities are the following:

- Direct observation of 3 main hospitals in the capital of each European country selected (DOH);
- Interview with hospital authorities responsible for management of the 3 hospitals that were directly observed (HA);
- Interview with 6 key persons operating in health care at the national level (KP);
- Questionnaire for partner organizations' to answer similar to the above mentioned ones (PO).

During these different activities, information was gathered on 174 indicators regarding the 14 patients' rights, verifying the existence or not of procedures adopted by the hospitals and health care services to guarantee the implementation of the rights in question.

This information collected, regarding the 14 Charter's rights, is analyzed on a right-by-right base. For each right the main critical and positive elements that can be extrapolated from the data collected are summarized.

In the section on each right are the following:

- **A List of indicators** used to verify the implementation of the right and grouped according to the source of information;
- **IAC Countries' score** which illustrates the score obtained for this right by each country according to the methodology described in chapter 2.5 Index of Actual Condition (IAC).
- **IAC Right score** reports the overall score this right obtained as well as the score range, which consists in the maximum and minimum points obtained by the other rights.
- **Critical elements and positive elements** that emerge in the implementation of the right, according to the different sources of information (DOH and HA; KP and PO), are reported. Specifically, there are:
  1. Among the Critical Elements:
    - facts and events with positive meaning that are observed in a limited number of countries (4 or less);
    - facts and events with negative meaning observed in a large number of countries (10 or more);
    - highly negative facts and events that were observed in a number of countries (less than 10).
  2. Among the Positive Elements:
    - facts and events with negative meaning observed in a limited number of countries (4 or less);
    - facts and events with a positive meaning in a large number of countries (10 or more).
- **Violations of this Right** that key persons (KP) and partner organizations (PO) knew – either directly or indirectly – during the last year are reported in a list by country.
- **Elements characteristic of the countries with the lowest score**, whether either alone or in combination, have been report and when it was possible the countries with these characteristics have been identified.
- Finally, there is a **brief comment** containing the main conclusions regarding the information collected.

## 6.1. Right to Preventive Measures

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

### Indicators Used

#### **Direct Observation Hospital (DOH)**

- Material on Prevention for the public (Y/N)
  - *early diagnosis of cancer affecting women*
  - *prevention of sexually transmitted diseases*
  - *dental prevention*
  - *quitting smoking*
  - *treating drug dependence*
  - *cardiovascular disease prevention*
  - *neurovascular disease prevention*
  - *domestic and recreational accidents*
  - *nutrition*

#### **Hospitals authorities responsible for hospital management (HA)**

- Primary and secondary prevention program (Y/N)
  - *cervical cancer PAP*
  - *colorectal cancer FOBT*
  - *breast cancer mammography*
  - *hypertension*
  - *lipid disorders*
  - *amblyopia and strabismus*
  - *diminished visual acuity*
  - *drinking problems*
  - *HIV/AIDS*
  - *other sexually transmitted diseases*
  - *smoking*

#### **Key persons operating in health care at the national level and partner organizations (KP)**

- Screening programs currently available free of charge in the health care system (Y/N)
  - *cervical cancer PAP*
  - *colorectal cancer FOBT*
  - *breast cancer mammography*
  - *hypertension*
  - *lipid disorders*
  - *amblyopia and strabismus*
  - *diminished visual acuity*
  - *drinking problems*
- Public communication campaigns (Y/N)
  - *HIV*
  - *early diagnosis cancer affecting women*
  - *fight against smoking*
  - *alcohol abuse*
  - *nutritional abuse*
  - *depression*
  - *heart disease*
  - *domestic accidents*
  - *road safety*
  - *dental care*

## IAC - Countries' Score

Preventive Measures	AUT	BEL	DEN	FIN	FRA	GER	GRE	IRE	ITA	NET	POR	SPA	SWE	UK
DOH and HA	-	+ -	-	+ -	+	-	-	-	-	+	-L	+ -	-	+*
KP and PO	+	+ -	-	+ -	+	+	+ -	+	+	+	+	+ -	+	+
	1	1	0	1	2	1	0	1	1	2	1	1	1	2

DOH: Direct Observation in Hospitals- HA: Hospital Authorities - KP: Key Persons – PO: Partner Organization

\* HA= only from one hospital L = Hospital Authorities missing

## IAC - Right Score:

Prevention 15                      Max 26              Min 10

## **Critical Elements**

*Facts and events with positive meaning that are observed in a limited number of countries (4 or less)*

### Direct Observation in Hospitals and Hospital Authorities

The results are:

- Limited diffusion of the following free primary or secondary prevention programs currently running in the hospital:
  - Screening programs for colorectal cancer for all persons aged 50 and older with annual fecal occult blood testing (available only in *Belgium, Germany, The Netherlands, UK*);
  - Screening programs for hypertension in adults aged 18 and older (available only in *Belgium, The Netherlands, UK*);
  - Screening programs to detect amblyopia and strabismus for all children prior to entering school (available only in *Sweden, UK*);
  - Screening programs to detect drinking problems in adult and adolescent patients (available only in *Belgium, France, UK*);
  - Prevention programs for HIV/AIDS (available only in *Belgium, France, Greece, UK*);
  - Prevention programs for other sexually transmitted diseases (available only in *Belgium, France, UK*).
  
- Limited distribution of material on prevention for the public produced by the national health services on the following topics:
  - Early diagnosis of tumors affecting women (available only in *Finland, Ireland, The Netherlands, UK*);
  - Prevention of sexually transmitted diseases (available only in *France, The Netherlands, Spain, UK*);
  - Dental prevention (available only in *France, The Netherlands, UK*);
  - Neurovascular disease prevention (available only in *The Netherlands, UK*);
  - Domestic and recreational accidents (available only in *The Netherlands, UK*);
  - Nutrition (available only in *Finland, France, The Netherlands, UK*);

## Key Persons and Partner Organizations

The results are the following:

- Limited availability of the following free primary or secondary prevention programs currently running in the hospital:
  - Screening program for colorectal cancer for all persons aged 50 and older with annual fecal occult blood testing (FOBT), or colonoscopy (available only in *Austria, Germany, Italy*);
  - Screening programs for hypertension in adults aged 18 and older (available only in *Austria, Spain, UK*);
  - Screening programs for lipid disorders (available only in *Spain*);
  - Screening programs for diminished vision acuity for elderly (available only in *Spain*);
  - Screening programs for detecting drinking problems in adult and adolescent patients (available only in *Spain*).
- Limited existence of public communication campaigns carried out by public health services in the last year on the following topics:
  - Depression (available only in *Belgium, Finland, Spain, UK*);
  - Dental Care (available only in *Spain, Austria*).

## **Positive Elements**

*Facts and events with a positive meaning in a large number of countries (10 or more)*

## Direct Observation in Hospitals and Hospital Authorities

- There were no positive elements found.

## Key Persons and Partner Organizations

The main results are the following:

- General availability of the following primary or secondary prevention programs free of charge in the health care system:
  - Screening programs for cervical cancer with Papanicolaou testing in women who have been sexually active (*11 countries*);
  - Screening programs for breast cancer with mammography for women aged 50 and over (*11 countries*).
- Good diffusion of the following public communication campaigns carried out by public health services in the last year:
  - Fight against smoking (*13 countries*);
  - Road safety (*13 countries*);
  - Alcoholism (*12 countries*);
  - HIV prevention (*12 countries*);
  - Early diagnosis of tumors affecting women (*11 countries*);
  - Prevention of sexually transmitted diseases (*10 countries*).

## Violations of this right identified during the last year

Right to Preventive measures	AUT	BEL	DEN	FIN	FRA	GER	GRE	IRL	ITA	NET	POR	SPA	SWE	UK
Cases identified by KP and PO		x		x								x		

*Legend: X =majority of the key persons and Partner Organization interviewed identified cases when this right had been violated during the last year:*

### Elements characteristic of the countries with the lowest score

- Absence of screening programs currently available free of charge in the health care system, reduced number of public campaigns, absence of material on prevention available to the public in the hospital (*Denmark*).
- Reduced number of screening programs currently available free of charge in the health care system, absence of material on prevention for the public of the hospital (*Greece*).

### Comment

There is evidence that in the majority of the countries screening programs and public communication campaigns, which are directed to prevention, exist.

The screening programs, however, focus on women's cancer and are not present in all of the countries. Moreover, only a few countries appear to have extended these initiatives to other forms of cancer, for which there are today efficient preventive diagnostic tools (colon rectal cancer).

The public communication campaigns cover a wide range of issues (smoking, road safety, alcoholism, HIV prevention and other sexually transmissible infections, women cancer prevention) and in a few countries they have also touched on other important topics (dental care, depression, etc.).

What also emerges is a poor diffusion of these prevention activities in hospitals. Traditionally, hospitals deal primarily with diseases and health treatment and care, but in recent years the World Health Organization, through the Vienna Recommendations<sup>61</sup>, emphasized the need for hospitals to tackle health from a wider perspective, given the enormous potential they have in these fields.

Finally, as further evidence of this right's somewhat poor performance, there is the fact that only three countries obtained the highest score for this right (*France, The Netherlands and UK*).

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<sup>61</sup> 3rd Workshop of National/Regional Health Promoting Hospitals Network Coordinators, WHO, 1997

## 6.2. Right to 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*

The state of the right to access was surveyed taking into consideration two different dimensions, both related to the definition of this right as expressed in the Charter.

The *first* dimension refers to what is explicitly stated in the right, that is, the *access to the health services needed*. This dimension was surveyed using the information reported by key persons.

The *second* dimension, on the other hand, refers to the actual *physical access* to health structures, meaning all elements that either favor or hinder the possibility for health care users to enter a health structure in order to get care or to visit a relative or a friend. This second dimension is not explicitly stated in the right. Nevertheless it can be considered, due to its “elementary” nature, as a basic requirement in order to fully implement the principles expressed in the right to access. The assessment of this dimension has been done through direct observation of the hospitals carried out by the monitoring groups.

### 2.1. Access to care

#### Indicators used

##### Key persons operating in health care at the national level and partner organizations (KP)

- Residents (legal or illegal) who are not covered by NHS (Y/N)
- Obstacles that in reality limit certain groups of the population from fully benefiting from NHS (Y/N)
- Facts that indicate the difficulty to access health care service (Y/N)
  - Important health care issues not covered in NHS package
  - Lack of health care for patients with rare diseases
  - Forced migration for health care
  - Complaints due to administrative and/or economic obstacles in accessing NHS services
  - Complaints and protests due to the lack of coverage by public insurance for health services considered essential by the public
  - Complaints and protests due to the lack of specialized centers for treating a particular rare disease
  - Complaints and protests regarding access to drugs which have been approved in other countries, but not yet in yours
  - Cases where this right has not been respected (Y/N)

#### IAC - Countries' Score

Access to care	AUT	BEL	DEN	FIN	FRA	GER	GRE	IRL	ITA	NET	POR	SPA	SWE	UK
KP and PO	+/-	+/-	+/-	-	+/-	+/-	+	+/-	-	+/-	-	-	+/-	-
	1	1	1	0	1	1	2	1	0	1	0	0	1	0

KP: Key Persons – PO: Partner Organization

## **IAC Right Score**

Access to care            10                    Max 26            Min 10

### **Critical Elements**

*Facts and events with negative meaning observed in a significant number of countries (10 or more)*

#### **Key Persons and Partner Organizations**

- Existence of residents (legal or illegal) not covered completely by NHS (*11 countries*);
- Lack of coverage by public insurance for health services considered essential by the public (*10 countries*).

### **Positive Elements**

*Facts and events with negative meaning observed in a limited number of countries (4 or less);*

#### **Key Persons and Partner Organizations**

- Forced migration to other countries to receive health care (present only *Denmark, Greece, Portugal*);
- Lack of health care for patients with rare diseases (present only in *Germany, Ireland, Portugal, UK*).

### **Violations of this right identified during the last year**

<b>Right to Access</b>	<b>Aut</b>	<b>Bel</b>	<b>Den</b>	<b>Fin</b>	<b>Fra</b>	<b>Ger</b>	<b>Gre</b>	<b>Ire</b>	<b>Ita</b>	<b>Net</b>	<b>Por</b>	<b>Spa</b>	<b>Swe</b>	<b>UK</b>
Cases identified by KP and PO	x			A				x			x		x	x

*Legend: X =majority of the key persons interviewed and partner organization identified cases when this right had been violated during the last year: A = all key persons*

### **Elements characteristic of the countries with the lowest score**

- Residents (legal or illegal) who are not covered by NHS, obstacles that limit certain groups of the population from benefiting completely from NHS, and elevated number of situations that indicate a difficulty accessing health care service (*Italy, UK, Spain*).
- A elevated number of situations that indicate a difficulty in accessing health care service (*Portugal*).
- All key persons identified cases during the last year when this right was violated (*Finland*).

### **Comment**

The results show that there are at least two concrete obstacles jeopardizing the protection of health, which are quite widespread among the countries:

- the existence of groups of people who do not have any health protection is a problem that Europe needs to confront;

- the existence of services, which are considered essential by citizens, but are not covered by health insurance, shows the need to try to reach a mutual understanding of what the common priorities should be in the field of health or at least try to reduce this perception gap between citizens and those managing healthcare.

The apparent low importance of the phenomenon of health migrations could actually be hiding an underestimation of the real dimensions of the phenomenon (which has been highlighted by numerous studies) on the part of the key persons. Only one country reached the maximum score on this right.

In general, the results show the need to work at the European level to ensure effective and equal access to treatment for all EU citizens, especially taking into account patient mobility.

## 2.2. Physical access

### Indicators used

#### Direct Observation in Hospitals (DOH)

- Hospital entrances clearly marked (Y/N)
- Accessibility for persons with disability clearly marked (Y/N)
- Structural barriers which have not been remedied (Y/N)
- Street signs near the hospital indicating its location (Y/N)
  - Patients with motor difficulties dropped off at main entrance (Y/N)
  - Hospital accessible by public transportation (Y/N)
  - Parking for visitors (Y/N)
  - Reserved parking for persons with disability (Y/N)

### IAC - Countries' Score

Access	AUT	BEL	DEN	FIN	FRA	GER	GRE	IRL	ITA	NET	POR	SPA	SWE	UK
DOH	+	+	+	+	+	+	+ -	+	+	+	-	+	+	+
	2	2	2	2	2	2	1	2	2	2	0	2	2	2

DOH: Direct Observation in Hospitals

### IAC - Right Score

Physical Access      25                      Max 26              Min 10

### **Critical Elements**

*Facts and events with positive meaning that are observed in a limited number of countries (4 or less)*

- No elements were identified.

## **Positive Elements**

*Facts and events with a positive meaning in a large number of countries (10 or more)*

### Direct Observation in Hospitals

The results are:

- Public transport to hospital (*14 countries*);
- Street signs indicating the hospital's location (*13 countries*);
- Main hospital entrance clearly marked (*13 countries*);
- No structural barriers at hospital entrance (*13 countries*);
- Possibility to drop off patients with motor difficulties at the main entrance (*13 countries*);
- Reserved parking for persons with disabilities (*12 countries*);
- Visitors parking (*11 countries*).

### **Elements characteristic of the countries with the lowest score**

Presence only of “street signs indicating the hospital's location” and “public transport to hospital” (*Portugal*).

### **Comment**

As highlighted by the indicators used, this specific aspect regarding the right to access seems to be respected in almost all of the countries. There are also positive results with respect to facilities for disabled persons.

### 6. 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.*

#### Indicators used

##### Direct Observation in hospitals (DOH)

- Information available to the public in the hospitals (Y/N)
  - Information regarding the hospital and regulations
  - Sheet on patients rights regarding inpatients and outpatients
  - Notices regarding waiting list for diagnostic exams and surgery
  - Reports on complaints received from the public
  - Data on outcomes of health services
- Data compared with other hospitals – benchmarking (Y/N)
- Areas for voluntary and public interest associations (Y/N)
- Indications where to locate the associations posted at main entrance (Y/N)
- Information service at main entrance (Y/N)
- Updating of the Hospital Directory (Y/N)

##### Hospitals authorities responsible for hospital management (HA)

- Telephone number (Y/N)
- Information Desk (Y/N)
- Hospital Website (Y/N)
- Possibility for patients to receive hospital record after discharge (Y/N)
- Average number of days to receive hospital record after discharge (*value*)

##### Key persons operating in health care at the national level and partner organizations (KP)

- Publicly available lists of all the hospitals, specifying their particular facilities and services (Y/N)
- Information centers where citizens can access these lists (Y/N)
- Lists are update periodically (Y/N)
- Health authorities provide directly or indirectly comprehensible consumer ratings (“consumer satisfaction” information) related to health services (Y/N)
- Possibility to make comparison between hospitals: benchmarking (Y/N)
- Health authorities provide directly or indirectly comprehensible information on clinical performance measures related to the health services (Y/N)
- Organizations that perform the role of Independent Advisor (Y/N)
- Cases where this right has not been respected (Y/N)

#### IAC - Countries’ Score

Information	AUT	BEL	DEN	FIN	FRA	GER	GRE	IRL	ITA	NET	POR	SPA	SWE	UK
DOH and HA	+	+	+	+	+	+ -	+	+	+	+	-L	+	+	+*
KP and PO	-	-	+	-	+ -	+	-	+	+ -	-	-	+ -	+ -	+
	1	1	2	1	2	2	1	2	2	1	0	2	2	2

DOH: Direct Observation in Hospitals - HA: Hospital Authorities - KP: Key Persons – PO: Partner Organization

\* HA only in one hospital L Hospital Authorities missing

## **IAC - Right Score**

Information      21                              Max 26      Min 10

### **Critical Elements**

*Facts and events with positive meaning that are observed in a limited number of countries (4 or less)*

#### **Direct Observation Hospital and Hospital Authorities**

The results are:

- Scarce diffusion in the hospitals of the following elements:
  - Notices regarding waiting lists for diagnostic exams and surgery (available only in *Denmark, The Netherlands, Spain and Sweden*);
  - Reports on complaints received from the public (available only in *Denmark, The Netherlands, Spain and Sweden*);
  - Data availability for benchmarking (available only in *Denmark, France, The Netherlands and Sweden*);
  - Data on outcomes of health care service regarding patient satisfaction and clinical performance measures (available only in *France and The Netherlands*).

#### **Key Persons and Partner Organization**

The main results are:

- Scarce presence of the following elements:
  - Health authorities provide directly or indirectly comprehensible information on clinical performance measures related to the health services (available only in *Sweden, Spain, Germany and UK*);
  - Health authorities provide directly or indirectly comprehensible consumer ratings (“consumer satisfaction” information) related to health services (available only in *Italy, Spain and UK*);
  - Possibility to make comparison between hospitals: benchmarking (available only in the *UK*).

### **Positive Elements**

*Facts and events with a positive meaning in a large number of countries (10 or more)*

#### **Direct Observation Hospital and Hospital Authorities**

The results are:

- Good presence in the hospitals of the following elements:
  - Information office or service at the main entrance (*14 countries*);
  - Regularly updated directory in main lobby (*13 countries*);
  - Hospital web site (*13 countries*);
  - Information sheets about the hospital and the regulation concerning inpatients (*13 countries*);
  - Telephone number of the hospital that the public can call (*12 countries*).

## Key Persons and Partner Organization

The results are:

- Good presence in the hospitals of the following elements:
  - Publicly available lists of all the hospitals, specifying their particular facilities and services (*10 countries*).

### **Violations of this right identified during the last year**

<b>Right to information</b>	<b>Aut</b>	<b>Bel</b>	<b>Den</b>	<b>Fin</b>	<b>Fra</b>	<b>Ger</b>	<b>Gre</b>	<b>Ire</b>	<b>Ita</b>	<b>Net</b>	<b>Por</b>	<b>Spa</b>	<b>Swe</b>	<b>UK</b>
Cases identified by KP and PO	x			x							x	x	x	

*Legend: X =majority of the key persons and partner organization interviewed identified cases when this right had been violated during the last year: A = all key persons*

### **Elements characteristic of the countries with the lowest score**

Presence only of an “information service or service at the main entrance” and “regularly updated directory in main lobby” along with negative responses from key persons to all questions regarding this right (*Portugal*).

### **Comment**

In general, the results are quite satisfactory, even if the information tools more widely spread are quite “elementary” and aimed mainly at providing information on the available services being offered.

Lacking are those information tools directed at being accountable to citizens for the functioning of healthcare services (i.e. benchmarking, consumer ratings). Moreover, the key persons interviewed indicate that for a third of the countries there are cases of this right being violated, thus showing that citizens’ expectations are not being met.

Also the presence of areas reserved to patients’ and citizens’ associations inside hospitals not quite yet widespread, not reaching even 10 countries. The fact that patients’ and citizens’ associations are not seen as part of the hospital could be linked to the obstacles encountered, in a number of countries, by the monitoring groups when visiting hospitals and the obtaining answers from health authorities.

What emerges is the need for a common effort to empower citizens in making choices.

## 6.4 . 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.*

### Indicators used

#### Hospitals authorities responsible for hospital management (HA)

- Existence of standardized forms to get consent from the patient (Y/N)
  - Scientific research
  - Invasive diagnostic exams
  - Surgical operations

#### Key persons operating in health care at the national level and partner organizations (KP)

- Specific forms to get consent from the patient (Y/N)
  - Nature of the treatment or procedure
  - Risks
  - Benefits
  - Alternatives
  - Information sheet on specific treatment or procedure (Y/N)
  - Information sheet or forms in more than one language (Y/N)
  - Procedures for involving minors or incapable adults in the informed consent process (Y/N)
  - Cases where this right has not been respected (Y/N)

### IAC- Countries' Score

Consent	AUT	BEL	DEN	FIN	FRA	GER	GRE	IRL	ITA	NET	POR	SPA	SWE	UK
HA	+	+ -	+ -	+ -	+	+	+	+ -	+	+ -	<b>L</b>	+	+ -	+*
KP and PO	+ -	+ -	-	-	+ -	+ -	-	+ -	-	+ -	-	+ -	-	+ -
	2	1	0	0	2	2	1	1	1	1	0	2	0	2

DOH: Direct Observation in Hospitals - HA: Hospital Authorities - KP: Key Persons – PO: Partner Organization

\* HA only in one hospital L Hospital Authorities missing

### IAC - Right Score

Consent            15                            Max 26      Min 10

### **Critical Elements**

*Facts and events with positive meaning that are observed in a limited number of countries (4 or less)*

### Hospital Authorities

There were no elements identified.

## Key Persons and Partner Organization

The main findings are:

- Limited use of specific forms to get consent from the patient which include the following information:
  - Risks (available only in *Ireland, UK*);
  - Benefits (available only in *Austria*);
  - Alternatives (not available in any country).
- Limited use (presence) of information sheets available in more than one language to inform patients on the procedure or treatment (available only in *Germany and The Netherlands*).

## **Positive Elements**

*Facts and events with a positive meaning in a large number of countries (10 or more)*

## Hospital Authorities

- Existence of standardized forms to get consent from the patient in scientific research (*13 countries*).

## Key Persons and Partner Organization

- Specific forms to get consent from the patient (*10 countries*).

## **Violations of this right identified during the last year**

<b>Right to Consent</b>	<b>Aut</b>	<b>Bel</b>	<b>Den</b>	<b>Fin</b>	<b>Fra</b>	<b>Ger</b>	<b>Gre</b>	<b>Ire</b>	<b>Ita</b>	<b>Net</b>	<b>Por</b>	<b>Spa</b>	<b>Swe</b>	<b>UK</b>	<b>Tot</b>
Cases identified by KP and PO	x				x										2

*Legend: X =majority of the key persons and partner organizations interviews identified cases when this right had been violated during the last year: A = all key persons*

## **Elements characteristic of the countries with the lowest score**

There is a limited use of standardized forms to get patient's consent in the hospitals visited. Key persons mentioned a lack of information sheets and consent forms in more than one language as well as a lack of information sheets on specific treatments.

## **Comment**

Hospital observation highlighted a widespread use of standardized forms to get consent from patients in case of research (*13 countries*), while less used are the forms in cases of invasive diagnostic exams e surgical operations.

The consultations with the key persons emphasized, instead, a use of consent forms with reference to the nature of the procedure. In general, there is no information regarding risks, benefits and possible alternatives.



## Violations of this right identified during the last year

Trend to limit free choice	Aut	Den	Bel	Fin	Fra	Ger	Gre	Irl	Ita	Net	Por	Spa	Swe	UK	Tot
New measures adopted in the last year identified by KP and PO				x			x	x	x		A	x		A	7

Legend: X =majority of the key persons and partner organizations interviews identified cases when this right had been violated during the last year: A = all key persons

### Elements characteristic of the countries with the lowest score

- All key persons agree that there is a trend aimed at limiting the right to free choice (*UK and Portugal*).
- The presence of all obstacles identified that limit the right to free choice (*Portugal*).

### Comment

In recent years, many European countries have taken actions regarding the right for citizens to freely choose, in the framework of their public insurance system, doctors or health structures, either by extending or limiting this right. This has taken place mainly in two ways:

- by restructuring welfare health systems, with the aim of making them sustainable from a financial point of view;
- by recognizing a new, more autonomous roles of citizens in health systems.

In this context, it becomes evident that the situation is quite critical with reference to the respect of this right: only two countries scored the maximum IAC score; in 7 countries the majority of the key persons interviewed (in 2 countries all of them) agreed that there is a trend aimed at limiting the right to free choice. In addition, an obstacle to the free choice, such as “the need to get authorization for some treatments” was identified in all 14 countries.

Finally, it is important to point out the fact that a number of obstacles to free choice, even if they did not exceed the threshold of diffusion of 10 countries, were nevertheless quite widespread in many countries (the existence of differential fees in public and private hospitals in 8 countries, and the coverage of supplementary insurance only for some hospital in 7 countries).

## 6.6. 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.*

### Indicators used

#### Direct Observation in Hospitals (DOH)

- Dividers between outpatient rooms (Y/N)
- Hear or see the patient's surname (Y/N)

#### Hospitals authorities responsible for hospital management (HA)

- Single room for terminal patients (Y/N)

#### Key persons operating in health care at the national level and partner organizations (KP)

- Cases where this right has not been respected - Normative medical information disclosed to non-authorized persons (Y/N)
- Cases where this right has not been respected - Patients' case files disclosed to non-authorized persons (Y/N)
- Cases where this right has not been respected - Violation of the confidentiality of HIV/AIDS patients (Y/N)

### IAC - Countries' Score

Privacy & Conf.	AUT	BEL	DEN	FIN	FRA	GER	GRE	IRL	ITA	NET	POR	SPA	SWE	UK
DOH and HA	+/-	+	+/-	+	+	+	+/-	+	+/-	+/-	+L	+/-	+/-	+
KP and PO	+	+/-	+	+	+/-	+	+	+	+	+	+/-	+/-	+/-	+/-
	2	2	2	2	2	2	2	2	2	2	2	1	1	2

DOH: Direct Observation in Hospital - HA: Hospital Authorities - KP: Key Persons – PO: Partner Organization

\* HA only in one hospital L Hospital Authorities missing

### IAC - Right Score

Privacy            26                    Max 26            Min 10

### Critical Elements

*Highly negative facts and events that were observed in a number of countries (less than 10)*

#### Direct Observation in Hospital

- Seen or heard a patient's surname in the course of the direct observation in the hospitals (Denmark, The Netherlands, Spain and Sweden).

## Positive Elements

Facts and events with a positive meaning in a large number of countries (10 or more)

### Direct Observation in Hospital

- Presence of dividers or curtains in the outpatient examination rooms (13 countries).

### Violations of this right identified during the last year

Right to Privacy and Confidentiality	Aut	Bel	Den	Fin	Fra	Ger	Gre	Irl	Ita	Net	Por	Spa	Swe	UK	Tot
1. Normative medical information disclosed to non-authorized persons					x		X				x	x	x		5
2. Patients' case files disclosed to non-authorized persons							X						x		2
3. Violation of the confidentiality of patients with HIV/AIDS															0

Legend: X =majority of the key persons interviews and partner organizations identified cases when this right had been violated during the last year: A = all key persons

### Elements characteristic of the countries with the lowest score

- Observe or hear the surname of a patient during the hospital observation and key persons mentioned knowing of cases when normative medical information was disclosed to non-authorized persons and/or patients' case files were disclosed to non-authorized persons (present in *Sweden*).
- The unavailability of single rooms in the hospital for terminal patients and key persons that mentioned knowing of cases when normative medical information was disclosed to non-authorized persons (present in *Spain*).

### Comment

This right reached the highest score of all the rights, and there no countries with a minimum score. In fact, however, the habit of reserving single rooms for terminal patients, does not reach the diffusion threshold of 10 countries (present only in 9 countries).

There are only a few reports concerning serious violations, such as patients' case files being disclosed to non-authorized persons, and observing or hearing the surname of a patient. There are, however, no cases of violation of the confidentiality patients with HIV/AIDS.

One should, however, keep in mind the limits of the evaluation of this right, since there are not many indicators used.

## 6.7. 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.*

### Indicators used

#### Hospitals authorities responsible for hospital management (HA)

- Diagnostic or therapeutic treatment impossible to get appointment in the last 30 days (Y/N)
- Differentiated access routes for different levels of seriousness and urgency (Y/N)
  - *Ecocardiograms*
  - *Mammography*
  - *CAT*
- Maximum time period within which the hospital must provide the diagnostic and therapeutic treatments required for patients (Y/N)
- The hospital guarantee the patient can get treatment in another facility without additional cost if hospital cannot provide diagnostic or therapeutic treatment within the max. time (Y/N)
- Reimbursed cost when it is an additional cost (Y/N)
- Unified contact point for appointments (Y/N)
- Waiting lists for diagnostic exams and surgery available to public (Y/N)
- Appointments for specialists can be made by phone (Y/N)

#### *Relevant but not taken into account for the scoring*

- Waiting period for urgent exams (*value*)
- Waiting period for non urgent exams (*value*)
- Waiting time for elective surgery (*value*)

#### Key persons operating in health care at the national level and partner organizations (KP)

- Cases where this right has not been respected -Cases in which an illness has worsened because of a delay in treatment (Y/N)
- Cases where this right has not been respected - Need to use services that the patients has to pay for due to the long waiting time (Y/N)
- Cases where this right has not been respected - Need to use services that the patients has to pay for due to the long waiting time (Y/N)

### IAC Countries' Score

Time	AUT	BEL	DEN	FIN	FRA	GER	GRE	IRE	ITA	NET	POR	SPA	SWE	UK
HA	+ -	-	+	+ -	+ -	-	-	-	+ -	+	<b>L</b>	+ -	+	+*
KP and PO	+	+	-	-	+ -	+ -	+ -	-	-	+ -	+ -	-	-	-
	2	1	1	0	1	0	0	0	0	2	1	0	1	1

HA: Hospital Authorities - KP: Key Persons – PO: Partner Organization

\* HA only in one hospital L Hospital Authorities missing

### IAC- Right Score

Time 10 Max 26 Min 10

## Critical Elements

*Facts and events with positive meaning that are observed in a limited number of countries (4 or less)*

### Direct Observation in Hospital and Hospital Authorities

- Limited use of the practice of establishing a “limit on waiting time” (except in *Denmark, Germany and The Netherlands*);
- Scarce presence of “waiting list available to public” (except in *Denmark, Sweden and UK*);
- Scarce presence of “a single unified contact point for appointments” (except in *Denmark, Greece, Italy and UK*).

*Facts or events with negative meaning, even though observed in not a large number of countries (less than 10)*

- The presence of diagnostic or therapeutic treatments that have been impossible to get an appointment in the last 30 days present in *9 countries*.

## Positive Elements

*Facts and events with a positive meaning in a large number of countries (10 or more)*

### Direct Observation in Hospital and Hospital Authorities

- Existence of a differentiated access route for different levels for accessing certain treatments depending on seriousness and urgency (*12 countries*).

## Violations of this right identified during the last year

Right to respect patient's time	Aut	Bel	Den	Fi	Fra	Ger	Gre	Ire	Ita	Net	Por	Spa	Swe	UK	Tot
1. Cases in which an illness has worsened because of a delay in treatment			x	A		x		x	x	x	x	x	A	x	<b>10</b>
2. Waiting time for important diagnostic exams is too long			x	A	X	A	x	x	x	A		x	A	x	<b>11</b>
3. Need to use payable services due to the long waiting time			x	A	X		x	x	A		x	x	x	x	<b>10</b>

*Legend: X =majority of the key persons interviews and partner organizations identified cases when this right had been violated during the last year: A = all key persons*

## Elements characteristic of the countries with the lowest score

Key persons reported cases of violation concerning the right to respect patients' time in one or more of the following situations:

- Cases in which an illness has worsened because of a delay in treatment;
- Need to use services that the patient has to pay for due to the long waiting time.

Hospital Authorities reported the presence of two or more of the following situations:

- Diagnostic or therapeutic treatments that have been impossible to get appointment in the last 30 days;
- The absence of a differentiated access routes that take into account the urgency of treatment;
- The absence of a maximum time period within which the hospital must provide the diagnostic and therapeutic treatments required for patients.

### Comment

This right has the lowest score, and in fact, there was only one indicator which scored positive in 10 or more countries.

Even those relatively simple measures, such as establishing a time limit on waiting time, waiting list available to the public or even, the existence of a single unified contact point for appointments, were recorded only in a few countries.

The existence of treatments that have been unavailable in the last 30 days for outpatients is so widespread that it is quite likely that there are closed waiting lists in most of the EU countries.

In this context, what is particularly striking is the fact that there have been many episodes of violation of this right in most of the countries; episodes, on which, in a number of cases, all the key persons and partner organizations interviewed agreed on. Among the episodes reported there is also the case of illnesses getting worst because of a delay in treatment. This episode can be considered a real “warning sign”, in the sense that it is an episode which in itself highlights the gravity of the situation.

The data on the waiting time for diagnostic exams or surgeries have not been calculated when assigning the scores, due to the impossibility of setting a single standard for all the countries taken into consideration. Nevertheless, there are a series of critical situations, which have been highlighted in the table below.

Table – Waiting times for elective surgery, no. days (Hospital interview)

	Cholecystectomy by laparoscopy		Tranurethral Resection of the Prostate		Cataract Surgery		Total hip replacement surgery		Coronary Bypass	
	Max	Min	Max	Min	Min	Max	Max	Min	Min	Max
<b>Austria</b>	30	18	30	7	180	30	240	240	42	28
<b>Belgium</b>	NR	NR	+360	NR	NR	NR	+360	NR	NR	NR
<b>Denmark</b>	98	56	56	42	84	56	119	56	63	63
<b>Finland</b>	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
<b>France</b>	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
<b>Germany</b>										
<b>Greece</b>	15	15	7	7	NR	NR	NR	NR	NR	NR
<b>Ireland</b>	120	NR	60	NR	NR	NR	None	None	60	NR
<b>Italy</b>	90	40	420	30	90	64	360	90	120	30
<b>Netherlands</b>	70	21	42	21	60	0	180	150	35	35
<b>Spain</b>	80	43	80	43	80	43	80	43	30	30
<b>Sweden</b>	180	30	90	63	90	90	336	180	21	21

Legend: \* Information not available NR= No response\

The difficulties encountered in receiving necessary treatment within a swift and predetermined period of time are evident also when one examines surgical operations (the 336 and 240 days of maximum waiting time for Total Hip Replacement surgery in Sweden and Austria, the 420 days for Transurethral Resection of the Prostate in Italy, the 180 days for Cataract Surgery in Austria). In general, waiting times for Total hip replacement surgery tend to be extremely long in most countries.

## 6.8. Right to Quality

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

### Indicators used

#### Hospitals authorities responsible for hospital management (HA)

- Fixed standards (Y/N)
  - Set with participation of consumer association
  - Regarding technical offerings
  - Regarding human relations
  - Regarding comfort
  - With periodic controls
  - With controls carried out with participation of consumer associations
  - Sanctions for violations of standards
- Quality Unit (Y/N)
- Studies to measure patient satisfaction

#### Key persons operating in health care at the national level and partner organizations (KP)

- Procedures to accredit or certify the quality level of hospitals (Y/N)
- Fixed standards (Y/N)
  - Established with the participation of consumers' associations
  - Regard technical offerings
  - Regard human relations
  - Regard comfort
  - With periodic controls
  - With controls carried out with participation of consumer associations
  - Sanctions for violations of standards
  - Sanctions imposed
- Cases where this right has not been respected (Y/N)

### IAC - Countries' Score

Quality	AUT	BEL	DEN	FIN	FRA	GER	GRE	IRE	ITA	NET	POR	SPA	SWE	UK
HA	-	+	+	+/-	+/-	+/-	+/-	+	+/-	+	<b>L</b>	+	+	+*
KP and PO	+/-	+/-	+	+/-	-	+	+/-	+/-	+	+	+/-	+/-	+/-	+/-
	0	2	2	1	0	2	1	2	2	2	1	2	2	2

HA: Hospital Authorities - KP: Key Persons – PO: Partner Organization

\* HA only in one hospital L Hospital Authorities missing

### IAC - Right Score

Quality            21                            Max 26            Min 10

## Critical Elements

*Facts and events with positive meaning that are observed in a limited number of countries ( 4 or less)*

### Hospital Authorities

The results are:

- Scarce presence of standards set with the participation of consumer and/or patient associations (except in *Ireland and The Netherlands*);
- Limited practice of controls being carried out with the participation of consumer and/or patients associations (except in *Ireland and UK*);
- Limited/ scarce presence of sanctions for violations of standards (except in *Sweden and UK*).

### Key Persons and Partner Organization

The main results are:

- Scarce presence/existence of fixed standards established with the participation of consumers' associations (except in *France*);
- Scarce presence of fixed standards with controls carried out with the participation of consumer associations (except in *France*);
- The absence of sanctions imposed for violations of standards (in all countries).

## Positive Elements

*Facts and events with a positive meaning in a large number of countries (10 or more)*

### Hospital Authorities

The main results are the following:

- A widespread presence of fixed performance standards (*11 countries*);
- A widespread presence of studies that measure patients' satisfaction (*12 countries*);
- A widespread presence of a Quality Unit (*11 countries*).

### Key Persons and Partner Organization

The main results are:

- A widespread presence of procedures to accredit or certify the quality level of hospitals (*14 countries*);
- A widespread presence of procedures to accredit using fix standards (*13 countries*);
- A widespread presence of fixed standards regarding technical offerings (*13 countries*);
- A widespread presence of fixed standards regarding human relations (*12 countries*).

## Violations of this right identified during the last year

Right to Quality	Aut	Bel	Den	Fin	Fra	Ger	Gre	Ire	Ita	Net	Por	Spa	Swe	UK	Tot
Cases identified by KP and PO				X	A									X	3

*Legend: X =majority of the key persons interviews and partner organizations identified cases when this right had been violated during the last year: A = all key persons*

**Elements characteristic of the countries with the lowest score**

All key persons mentioned the existence of cases when this right was violated. During the hospital interviews there resulted only studies that measure patient satisfaction.

**Comment**

The widespread presence of quality and standard certification procedures indicate that most of the European countries are developing policies aimed at promoting improvements in the quality of healthcare services.

However, these policies are apparently being developed without a real and concrete involvement of citizens, whether it be in the definition of standards (even those concerning relational aspects and comfort of services), or in the controls carried out. This lack of citizens' involvement testifies to the limits of these policies and to the fact that quality process in its different phases (plan, do, check, act) tends to be auto-referential. Most of the time, in this process, the actors are those managing or providing the healthcare services and almost never those using such services.

Finally, it is worth emphasizing the near absence of a control procedure capable of inflicting fines in case of quality standard violations. It is significant, however, that in this framework of apparent rules and procedures, there are countries in which all or the majority of the key persons agree on the presence of violations on the right to quality.

## 6.9. 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.*

### Indicators used

#### Direct Observation in the Hospital (DOH)

- Priority codes in triage procedure in Emergency Room (Y/N)
- Emergency exist signs (Y/N)
- Fire extinguisher (Y/N)
- Evacuation maps (Y/N)
- Special evacuation procedures or routes for wheelchair users on map (Y/N)

#### Hospitals authorities responsible for hospital management (HA)

- Procedures for reporting the following (Y/N)
  - Hospital acquired infections
  - Burns from fires
  - Falls
  - Pressure ulcers
  - Phlebitis associated with intravenous lines
  - Restraint-related strangulation
  - Preventable suicides
  - Failure to diagnosis or incorrect diagnosis
  - Failure to utilize or act on diagnostic tests
  - Use of inappropriate or outmoded diagnostic tests or treatment
  - Medication errors/adverse drug effects
  - Wrong-site errors; surgical errors
  - Transfusion mistakes
- Reporting of near misses (Y/N)
- Office or person in the hospital charged with coordinating activities for reducing the risk of infection (Y/N)
- Office or person in the hospital charged with coordinating the activities for reducing the risk of transfusions (Y/N)
- Written procedures (protocols) for checking and reducing risks control of hospital infections (Y/N)
- Epidemiological investigations of hospital infections carried out (Y/N)

#### Key persons operating in health care at the national level and partner organizations (KP)

- Protocols for the sterilization of medical instruments (Y/N)
- Protocols for the prevention of hospital infections (Y/N)
- Risk management techniques (Y/N)
- Epidemiological investigations of hospital infections (Y/N)
- Cases when the right not respected

### IAC Countries' Score

Safety	AUT	BEL	DEN	FIN	FRA	GER	GRE	IRE	ITA	NET	POR	SPA	SWE	UK
DOH and HA	+/-	+	+	+/-	+	+	+/-	+	+	+	<b>L</b>	+	+	+*
KP and PO	+/-	+	+/-	+/-	+/-	+	+/-	+	+/-	+	+/-	+	+/-	-
	1	2	2	1	2	2	1	2	2	2	0	2	2	1

DOH: Direct Observation in Hospitals - HA: Hospital Authorities - KP: Key Persons – PO: Partner Organization

\* HA only one hospital L Hospital Authorities missing

## **IAC Right Score**

Safety      22                      Max 26      Min 10

### **Critical Elements**

*Facts and events with positive meaning that are observed in a limited number of countries (4 or less)*

#### **Direct Observation in Hospitals and Hospital Authorities**

The result is:

- Scarce presence of special evacuation procedures or routes for wheelchair users marked on the map (except in *Belgium, Germany and Sweden*).

#### **Key Persons and Partner Organization**

There were no elements identified.

### **Positive Elements**

*Facts and events with a positive meaning in a large number of countries (10 or more)*

#### **Direct Observation in Hospitals and Hospital Authorities**

The results are the following:

- A widespread presence of emergency exist signs (*12 countries*);
- A widespread presence of fire extinguisher signs (*12 countries*);
- A widespread presence of an office or person in the hospital responsible for coordinating activities for reducing the risk of infection (*13 countries*);
- A widespread presence of procedures for reporting the following:
  - Hospital acquired infections (*13 countries*);
  - Falls (*11 countries*);
  - Burns from fires (*10 countries*);
  - Pressure ulcers (*10 countries*);
  - Transfusion mistakes (*10 countries*).
- A widespread use of written procedures (protocols) for checking and reducing risks control of hospital infections (*13 countries*);
- A widespread presence of an office or person in the hospital responsible for coordinating activities for reducing the risk of infection (*13 countries*);
- A widespread presence of Office or person in the hospital charged with coordinating the activities for reducing the risk of transfusions (*12 countries*).

#### **Key Persons and Partner Organization**

The findings are:

- A widespread use of protocols for the sterilization of medical instruments (*14 countries*);
- A widespread use of protocols for the prevention of hospital infections (*13 countries*).

## Violations of this right identified during the last year

Right to Safety	Aut	Bel	Den	Fin	Fra	Ger	Gre	Ire	Ita	Net	Por	Spa	Swe	UK	Tot
Cases of violation identified by KP and PO				x					x		x		x	A	5

Legend: X =majority of the key persons interviews and partner organizations identified cases when this right had been violated during the last year: A = all key persons

### Elements characteristic of the countries with the lowest score

From the indicators used only the presence of Fire extinguishers were detected during the direct observation of the hospitals and the majority of key persons and partner organizations reported cases of violation of this right (*Portugal*).

### Comment

The direct observations of the hospitals allowed us to verify important risk management practices that are widespread in most of the European countries and have reached satisfactory levels of diffusion.

Within this overall satisfactory situation, there are, however, a number of weaknesses, which, even if they concern only a few countries, are nevertheless significant. This is the case regarding the presence of evacuation maps in hospitals that do not reach even the threshold of 10 countries (8 countries), or the presence of emergency exit signs and fire extinguisher signs (absent in two countries). Moreover, there have been reported cases of violation of this right in 5 countries.

Finally, there is a critical element, which should be studied in view of the national norms; that is the low diffusion in hospitals of special evacuation procedures or routes for wheelchair users marked on the map.

## 6.10. 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.*

### Indicators used

#### Hospitals authorities responsible for hospital management (HA)

- Use of (Y/N)
  - Telemedicine
  - Electronic patient record
  - Internet
  - Personal cards
  - Special mattress to prevent pressure ulcer
  - Patient Control Analgesia
  - Less invasive surgical techniques
    - Laparoscopic Cholecystectomy
    - Laparoscopic Prostatectomy
    - Microendoscopic discectomy (MED)
    - Minimally invasive direct coronary artery bypass (MIDCAB)
    - Laparoscopic Inguinal hernia repair
    - Laparoscopic Adrenalectomy
    - Laparoscopic Repair of paraesophageal hernia

#### Key persons operating in health care at the national level and partner organizations (KP)

- Diffusion innovative techniques (Y/N)
  - Telemedicine
  - Electronic patient record
  - Use of internet
  - Less invasive surgical techniques
  - Personal cards
  - Use of special mattress to prevent pressure ulcer
- Cases when the right not respected: delays introducing innovative diagnostic tests (Y/N)
- Cases when the right not respected: delay in introducing innovative treatments (Y/N)
- Cases when the right not respected: delay in particular areas of medical research (Y/N)

### IAC - Countries' Score

Innovation	AUT	BEL	DEN	FIN	FRA	GER	GRE	IRE	ITA	NET	POR	SPA	SWE	UK
DOH and HA	+	+	+	+	+	-	-	+	+	+	L	-	+	+
KP and PO	-	-+	+-	-	+-	+-	-	-	-	-	-	-	-	+-
	1	2	2	1	2	0	0	1	1	1	0	0	1	2

HA: Hospital Authorities - KP: Key Persons – PO: Partner Organization

\* =HA from only one hospital, L= HA missing

### IAC - Right Score

Innovation      14                                      Max 26      Min 10

## Critical Elements

*Facts and events with positive meaning that are observed in a limited number of countries (4 or less)*

### Hospital Authorities

- Limited use of Personal cards (except in *The Netherlands and Denmark*).

### From Key Persons and Partner Organization

- Absence of Telemedicine (present in no countries);
- Limited use of :
  - Electronic patient records (available in *Spain*);
  - Internet to access treatment appointments, medical referrals etc. (available in *Germany*);
  - Personal cards (available in *Finland and Spain*);
  - Patients Controlled Analgesia: PCA (available in *France and UK*).

## Positive Elements

*Facts and events with a positive meaning in a large number of countries (10 or more)*

### Hospital Authorities

- Widespread use of:
  - Less invasive surgical techniques (*11 countries*);
  - Special mattress to prevent pressure ulcers (*12 countries*);
  - Patients Controlled Analgesia: PCA (*10 countries*).

### Key Persons and Partner Organization

- A widespread use of less invasive surgical techniques (*10 countries*)

## Violations of this right identified during the last year

Right to Innovation	Aut	Bel	Den	Fin	Fra	Ger	Gre	Ire	Ita	Net	Por	Spa	Swe	UK	Tot
1. Delays in the introducing of innovative diagnostic tests				X				X	X			X	X		5
2. Delays in the introducing of innovative treatments				X				X	X		X	X	X	X	7
3. Delays in particular areas of medical research			X	X	X				X			X	X		6

*Legend: X =majority of the key persons interviews and partner organization identified cases when this right had been violated during the last year: A = all key persons*

### **Elements characteristic of the countries with the lowest score**

According to the majority of Key Persons there are limited to no use at all of innovative techniques (*Portugal and Greece*), as well the majority of Key Persons identified violations in all three cases (*Spain*) while Health Authorities mentioned there are few innovative techniques (*Greece, Spain, Germany*).

### **Comment**

There seems to be an unexpected delay in the technological innovation of healthcare facilities, as reported in particular by the key persons. The key persons stated that there is little use in healthcare facilities of technologies like telemedicine, internet to access treatment appointments, medical referrals or even the use of personal cards or of patients controlled analgesia (PCA).

There are however, some differences between the information obtained from the hospitals and that from the key persons. The most likely explanation for this is that in the hospitals, because of their size and their location in the capitals, the use of innovative technologies is definitely above average in relation to the countries' health facilities in general.

## 6.11. 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.*

### Indicators used

#### Hospitals authorities responsible for hospital management (HA)

- Protocol for pain management (Y/N)
- Palliative Care Unit (Y/N)
- Pain Medicine Center (Y/N)
- Record pain scores (Y/N)

#### Key persons operating in health care at the national level and partner organizations (KP)

- Pain management procedure - Assess pain systematically (Y/N)
- Pain management procedure - Believe what the patient and family reports on pain (Y/N)
- Pain management procedure - Choose pain control options appropriate (Y/N)
- Pain management procedure - Deliver interventions in a timely, logical and coordinated manner (Y/N)
- Pain management procedure - Empower patients to self-manage pain (Y/N)
- Cases when the right not respected: not administrating morphine in cases when it is recommended by the international procedures (Y/N)
- Cases when the right not respected: not administrating painkillers in the case of or after painful treatments (Y/N)

### IAC - Countries' Score

Avoid Pain	AUT	BEL	DEN	FIN	FRA	GER	GRE	IRE	ITA	NET	POR	SPA	SWE	UK
HA	+/-	+	+	+	+	+/-	+/-	+	+	+	L	+/-	+	+
KP and PO	+/-	+	+	-	-	+	-	+	-	+	-	-	-	-
	1	2	2	1	1	2	0	2	1	2	0	0	1	1

HA: Hospital Authorities - KP: Key Persons – PO: Partner Organization

\* HA in only one hospital, L; HA is missing

### IAC - Right Score

Avoid Pain            16                                    Max 26                    Min 10

### Critical Elements

*Facts and events with positive meaning that are observed in a limited number of countries (4 or less)*

#### From Hospital Authorities

- No elements were identified.

#### From Key Persons and Partner Organization

The results are the following:

- Limited use in countries of the following rules to pain management:
  - Record pain systematically (available only in *UK and Sweden*):

- Empower patients and their family to self manage pain (available only in *Germany, The Netherlands, Ireland and Sweden*).

### Positive Elements

*Facts and events with a positive meaning in a large number of countries (10 or more)*

#### Hospital Authorities

The results are:

- The use of guidelines or protocols for pain management (*11 countries*);
- The presence of a Pain Center and/or Palliative Care Unit (*12 countries*).

#### Key Persons and Partner Organization

- No elements were identified.

### Violations of this right identified during the last year

Right to Avoid Pain	Aut	Bel	Den	Fin	Fra	Ger	Gre	Ire	Ita	Net	Por	Spa	Swe	UK	Tot
Not administrating painkillers in the case of or after painful treatments							x		x		x	x	x	X	<b>6</b>
Not administrating morphine in cases when it is recommended by the international procedures on severe pain treatment							x					x	x	X	<b>4</b>

*Legend: X =majority of the key persons interviews and partner organizations identified cases when this right had been violated during the last year: A = all key persons*

### Elements characteristic of the countries with the lowest score

A limited use of pain management rules respected in the country; presence of cases of not administrating morphine in cases when it is recommended by international procedures; not administrating painkillers in the case of or after painful treatments identified by the majority of key persons (*Spain, Greece and Portugal*).

### Comment

The diffusion of pain management tools seems to be somewhat limited in the hospital that were visited; yet this situation is even less satisfactory according to what was reported by key persons on the general picture of their own countries. According to these sources, in fact, the practices to evaluate pain and strengthen the ability of patients and their families to manage issues connected to pain and its control are not generally widespread.

It is worth highlighting that in 6 countries the majority of key persons reported one or more cases regarding the violation of this right.

## 6.12. 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.*

### Indicators used

#### Direct Observation in Hospitals (DOH)

- Play areas inside pediatrics wards (Y/N)
- Appropriate furnishing inside pediatrics (Y/N)
- Parents can be present 24 hrs. day (Y/N)
- Place for relatives to sleep in the room that is appropriate (Y/N)
- Use of cafeteria for parents (Y/N)
- Educational support for children (Y/N)

#### Hospitals authorities responsible for hospital management (HA)

- Choice of meals (Y/N)
- Distribution of patients meal (Y/N)
- Religious assistance available in the hospital or on call for more than three religions (Y/N)
  - Protestants
  - Anglican
  - Catholic
  - Orthodox
  - Jewish
  - Muslim
- Psychological support service to assist patients and their families in specific situations (3 or more reported) (Y/N)
  - Terminal patient and their family
  - Transplants patients and their family
  - Women who have suffered violence
  - Patients in other conditions
- Procedures to ensure that patients may demand a second opinion (Y/N)
- Foreign language interpreters present at the hospital (Y/N)
- Cultural mediators present at the hospital (Y/N)
- More than six hours a day available for visiting patients (Y/N)

#### Key persons operating in health care at the national level and partner organizations (KP)

- Personalized support given in hospitals (Y/N)
  - Choice of meals
  - Psychological support for terminal patients and their families
  - Spiritual support based on personal
  - Cultural mediation and/or foreign language interpretation
  - Educational support for children hospitalized
- Cases when the right not respected (Y/N)

### IAC - Countries' Score

Personalized Treatment	AUT	BEL	DEN	FIN	FRA	GER	GRE	IRE	ITA	NET	POR	SPA	SWE	UK
DOH and HA	+	+	+	+	+	+	+ -	+ -	+ -	+	+ - L	+ -	+	+*
KP and PO	+ -	+	+	+ -	+ -	+	-	+	+ -	+	+ -	+ -	-	-
	2	2	2	2	2	2	0	2	1	2	1	1	1	1

DOH: Direct Observation in Hospitals - HA: Hospital Authorities - KP: Key Persons – PO: Partner Organization

\* HA in only one hospital, L: HA missing



**Comment**

The results for this right are among the best, even though there are only 5 of the positive elements reported above. There are, in fact, other elements that emerged in the hospital visits, which reach levels of diffusion that are slightly lower, but which testify to the trend, in many countries, of trying to meet the needs of individuals and of different types of users. Among these, the most important ones are the availability of: religious assistance (more than three religions in *9 countries*); foreign language interpreters (*9 countries*); psychological support services to assist patients and their families in specific situations (3 or more reported in *7 countries*); and, finally, the possibility of parents' visits lasting more than six hours a day (*8 countries*).

In this situation, the only negative aspects reported by the key persons refer to the limited presence of cultural mediators in the hospitals, as well as the limited possibility for hospital patients to ask for a second opinion.



## Positive Elements

Facts and events with a positive meaning in a large number of countries (10 or more)

### Hospital Authorities

The results are the following:

- Existence of Committee to receive complaints and resolve conflicts between the public and the hospital (13 countries);
- Existence of official procedures for dealing with patients' complaints (13 countries);
- Existence of a specific time limit for the hospital to respond to patient complaints (12 countries);
- A general respect for the time limit (10 countries).

### Key Persons and Partner Organization

The results are:

- Existence of fixed procedures for handling patients' complaints (14 countries);
- Existence of independent organizations to assist citizens in presenting their complaints (13 countries).

## Violations of this right identified during the last year

Right to Complain	Aut	Bel	Den	Fi	Fra	Ger	Gre	Ire	Ita	Net	Por	Spa	Swe	UK	Tot
1. Specific cases where this right was not respected															
2. Lack of a response to citizens' complaints	x	x					x	x	x			x	x	X	8
3. Too long to respond to citizens' complaints	x	x	x	x	x		x	x	x		x	x	x		11
4. Threats, intimidations or retaliation towards patients that have complained															0

Legend: X = majority of the key persons interviews and partner organizations identified cases when this right had been violated during the last year; A = all key persons

## Elements characteristic of the countries with the lowest score

According to the majority of Key Persons and Partner Organization, independent organizations don't exist to assist citizens in presenting their complaints (Portugal).

## Comment

Together with the right to privacy, this is the right with the highest score. There are, however, cases of violation reported in all of the countries except for The Netherlands and Germany, which raise doubts about the actual respect of this right. The cases, in fact, concern the lack of response to citizens' complaints and/or the exceedingly long time to respond to citizens' complaints, which risk, moreover, to disappoint citizens' expectations and lower their trust in the institutions.

## 6.14. 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.*

### Indicators used

#### Hospitals authorities responsible for hospital management (HA)

- Hospitals insured (Y/N)
- Hospital's doctors have additional insurance (Y/N)
- Committees or structures to assist patients in reaching a final agreement on compensation (Y/N)
- Committee or structures are independent from the hospital (Y/N)

#### Key persons operating in health care at the national level and partner organizations (KP)

- Hospitals insured (Y/N)
- Hospital's doctors have additional insurance (Y/N)
- Commissions/structures, operating outside the regular litigation process (Y/N)
- Independent organizations which provide legal aid free of charge or at a reduced cost (Y/N)
- Cases when the right not respected (Y/N)

### IAC - Countries' Score

Compensation	AUT	BEL	DEN	FIN	FRA	GER	GRE	IRE	ITA	NET	POR	SPA	SWE	UK
DOH and HA	+	+	+ -	+	+ -	+	-	+ -	+ -	+	<b>L</b>	+ -	+	+*
KP and PO	+	+	-	+ -	+	+ -	-	+ -	+ -	-	-	-	+ -	+
	2	2	0	2	2	2	0	1	1	1	0	0	2	2

HA: Hospital Authorities - KP: Key Persons – PO: Partner Organization

\* HA in only one hospital, L: HA missing

### IAC- Right Score

Compensation      17                      Max 26      Min 10

#### Critical Elements

*Facts and events with positive meaning that are observed in a limited number of countries (4 or less)*

#### Hospital Authorities

- No elements are identified.

#### Key Persons and Partner Organization

- No elements are identified.

## Positive Elements

Facts and events with a positive meaning in a large number of countries (10 or more)

### Hospital Authorities

- In general Hospitals are insured to compensate patients (11 countries).

### Key Persons and Partner Organization

- In general hospitals insured to compensate patients (12 countries).
- In general the Doctors within the hospital have additional insurance (10 countries).

## Violations of this right identified during the last year

Right to compensation	Aut	Bel	Den	Fin	Fra	Ger	Gre	Ire	Ita	Net	Por	Spa	Swe	UK	Tot
Cases identified by KP and PO				x									x		2

Legend: X =majority of the key persons and partner organization interviews identified cases when this right had been violated during the last year: A = all key persons

## Elements characteristic of the countries with the lowest score

The majority of Key Persons and Partner Organizations noted the complete absence of all indicators or the existence only of an “Independent organizations which provide legal aid free of charge” or only the presence of hospitals being insured. (Denmark, Greece, Portugal and Spain).

## Comment

Satisfactory results since there were no critical elements identified in any country. The signing of insurance policies on the part of hospitals and doctors seems to be a consolidated practice. Worthwhile highlighting are also those elements that have nearly reached the threshold of 10 countries, such as the presence, in hospitals, of committees to assist patients in reaching a final agreement on compensation (8 countries) and the presence of independent organizations providing legal aid free of charge (7 countries).

## THIRD PART

### 7. Conclusions

#### 7.1. Main Findings

Analyzing the three types of information on patients' rights – official statistics, legislations and actual conditions of patients – allow us to shed light on some significant phenomena, which characterize the state of patients' rights in Europe. This section focuses on reporting these phenomena.

##### 7.1.1 Right to Prevention

###### **A right which is well studied ...**

The right to prevention is one of the topics on which there is a great deal of information from the official statistics. There is information on a number of preventive practices implemented in European countries, and it is possible – in some cases – to identify differences, even the significant ones, among the individual countries. This is the case of Austria and The Netherlands, where about one fifth of the population between the age of 24 and 54 reports having been subjected to heart checkups and exams for the evaluation of cancer markers, while the same age group of the other EU countries barely reaches 10%.

###### **.... and legally recognized**

The legislation information shows that most of the EU countries have norms safeguarding this right.

###### **public communication campaigns are widely carried out**

HIV prevention (in 12 countries), prevention of sexually transmitted diseases (10), early diagnosis of tumors affecting women (11), fight against smoking (13), alcoholism (12), road safety (13 countries), are the topics of public communication campaigns – a growing activity in all the countries surveyed.

###### **and cancer prevention screening initiatives that specifically focuses on women ... but the rest?**

In 11 countries a good diffusion of screening activities related to cancers that specifically affect women have been reported. However, prevention activities regarding other diseases do not have the same diffusion. This is the case of screening programs for colorectal cancer for all persons aged 50 and older with annual fecal occult blood testing (FOBT), or colonoscopy (reported only in 3 countries), screening programs for hypertension in adults aged 18 and older (3), screening programs or lipid disorders, screening programs for diminished visual acuity for elderly persons (1), screening programs to detect drinking problems for all adult and adolescent patients (1).

###### **Limited prevention in hospitals**

The involvement of hospitals in primary and secondary prevention activities is in general very low. Moreover, the availability of materials on prevention is very limited in the majority of the hospitals visited. With respect to this phenomenon it must be pointed out that the European Region of WHO, in the Vienna Recommendations on Health Promoting Hospitals, stressed the crucial role of hospitals as actors of prevention.

## 7.1.2 Right to Access

### *Access to care*

#### **It is a good description of what healthcare systems can offer**

Official statistics offer a wide range of indicators allowing us to assess what the healthcare system can offer, in terms of human resources and facilities available in the EU countries. On the other hand there are few indicators available to evaluate in a comparative manner if this offer can adequately satisfy the citizens' demand for health or if citizens can effectively access the services offered.

#### **and considered a right to be protected**

There are laws protecting the right to access care in almost all of the countries.

#### **But a limited universalism emerges**

In all of the countries the fact that there are groups of people either not covered by national health services or facing obstacles limiting their access to adequate care was reported.

#### **as well as a substantial inequality of access among the different countries**

In almost all of the countries the presence of obstacles to accessing care was reported. In particular, these obstacles are:

- lack of coverage of public insurance for health services considered essential by the public (services that patients must pay for and which are not reimbursed) (10 countries);
- existence of administrative and/or economic obstacles to access services (8 countries);
- obstacles to access drugs which have been approved in other countries, but not yet in their own (7 countries).

### *Physical access*

#### **How far are health services from home?**

The indicator available in the official statistics considers the time taken to reach hospital facilities, family doctors and health care centers.

#### **Accessible, at least physically.**

In general the public has a satisfactory level to the hospital structures except for two countries with a lower level of attention.

## 7.1.3 Right to Information

### **New information systems**

The official statistics available are limited and are aimed at describing the new information systems, which countries are adopting in order to help citizens know about the services offered in their territory.

### **Widespread recognition of this right**

Reference to this right is included in the legislations of all the countries.

### **Widespread instruments for citizens' information ...**

In most of the hospitals visited the existence of tools for providing information to patients and users emerged. They are, for example, a telephone number available to the public (12 countries), an information office at the main entrance of the hospitals (14 countries), a hospital website (13 countries) and an updated directory of available services in the hospital (13 countries).

### **... but little material on hot topics**

While information materials on hospital regulation and on patients' rights are widespread in most of the countries' hospitals, this is not the case for materials on critical topics such as information on waiting lists, complaints received by the public (only in 4 countries), data available for benchmarking (only in 4 countries) and for material on data outcome, such as patients' satisfaction and clinical performance, available only in 2 countries.

### **Active citizens seen as intruders**

Areas reserved for patients' and citizens' associations inside hospitals are practically non-existent. The fact that organizations (active citizens) are not seen as part of health care services, but rather only users could explain the obstacles encountered in a number of countries during hospital visits and why in some countries health authorities even refused to provide information.

## **7.1.4 Right to Consent**

### **Statistics not available**

Currently official statistical data on the implementation of this right are not available.

### **But acknowledged in all countries**

Reference to this right is included in all the countries' current legislation.

### **Written consent ...**

Standardized forms to obtain consent are widely used, but mostly for scientific research rather than for invasive diagnostic exams and surgical operations.

### **... but not informed**

The contents of consent forms emerged as containing only partial information and not very thorough. Only in a few countries they report precise information on risks (2 countries) and benefits (1 country). Moreover, there is a limited use of information sheets available in more than one language (2 countries).

## **7.1.5 Right to Free Choice**

### **How frequently are specialists consulted?**

From the official statistics, the only available indicator, which can be used to evaluate the right to free choice, is the number of times family doctors and specialists have been consulted. This proves to be quite limited.

### **Moderate attention in legislation**

No reference is made on the right to free-choice in the national legislation in four countries.

### **“Free” choice with many obstacles**

Some structural limitations to citizens actually being able to make choices emerged in the majority of monitored countries.

These obstacles are:

- The need to get authorization for some treatments (all 14 countries);
- Different fees in public and private hospitals (and thus different reimbursements) (8 countries);
- Coverage of supplementary insurance only for some hospitals (7 countries).

### **7.1.6 Right to Privacy and Confidentiality**

#### **Statistical indicators not available**

In the official statistics currently there is no available data for evaluating the level of implementation of the right to privacy and confidentiality.

#### **even though covered by legislation**

This right is part of the national legislation in 13 countries.

#### **Privacy in the examination room and for terminally ill patients**

A satisfactory level of respect for the right to privacy was observed with the fact that examination rooms have dividers or curtains were reported in 13 countries, as well as the attention to privacy for terminally ill patients (with single rooms reserved in 9 countries).

#### **Personal data**

In 4 countries monitoring groups happened to observe or hear the surname of patients while visiting the hospital.

#### **Who can get medical information?**

The majority of key persons in 5 countries reported situations when medical information was disclosed to non-authorized persons.

### **7.1.7 Right to Respect of Patients’ Time**

#### **In official statistics only a limited number of available indicators**

At present, there are very few indicators available in this area.

#### **and a scarce attention given in the countries’ legislations**

There is no reference made to this right in the legislation of eight countries.

#### **Hidden rationing ...**

There is a widespread phenomenon of freezing the waiting list with respect to one or more exams. This specific phenomenon was reported in 9 countries. This situation represents a hidden form of restriction to the access to health care, which could be considered a form of service rationing.

#### **... damaging for citizens ...**

The consequence of this practice can be seen in the cases reported by the key persons that occurred in the last year:

- cases in which an illness has worsened because of a delay in treatment (10 countries out of 14);
- waiting time for important diagnostic exams too long (10 countries out of 14);
- need to use payable services because of the long waiting time (10 countries out of 14).

**... without a safety mechanism ...**

As a confirmation of this problem, it emerges that there is results is a generalized practice of not establishing a time limit to when diagnostic exams or therapeutic treatment are actually carried out, with respect to the moment they were prescribed by the hospital doctor. The only three countries where a time limit mechanism was reported were The Netherlands, Germany and Denmark.

**... and without elementary tools.**

In a number of countries the lack of tools allowing citizens to face this situation was reported:

- availability to the public of the waiting lists for diagnostic exams (present only in Denmark, Sweden and UK);
- a single, unified contact point for appointments (reported only in Denmark, Greece, UK and Italy).

### **7.1.8 Right to the Observance of Quality Standards**

**Lack of official indicators...**

At this time it is not possible to evaluate the degree of implementation of this right in Europe by utilizing the statistical data, as they are linked to the quality standards present in the countries.

**But covered in all countries' legislations**

Reference to this right is made in the legislation of all the countries.

**A widespread system for quality assessment...**

Tools, procedures and institutions aimed at accrediting or certifying quality of services appears to be fairly common in the surveyed countries. Quality standards tend to concern not only technical and medical performances, but also human relations.

**... but privileging the easiest way by measuring customer satisfaction ...**

Nevertheless, the most used forms of quality assessment are the studies on customer satisfaction (reported in the hospitals of 12 countries out of 13), which represents, of course, the least complex way to improve and check quality.

**.... with controls but without sanctions...**

Moreover, there are control activities carried out to verify the observance of standards, however when these standards are not met sanctions are quite limited, and the actual imposition of sanctions for the lack of compliance to these standards is practically non-existent (Sweden and UK only).

**... and without involving citizens.**

Finally, involving citizens' organizations in the definition of these standards and in the activities to monitor and control are reported only in two countries.

### **7.1.9 Right to Safety**

#### **Lack of indicators using official statistics...**

At the moment it is not possible to evaluate the degree of implementation of the right in Europe, as there are no official statistics, which can be used to compare the different countries.

#### **but adequate attention in legislation**

In 11 countries there is legislature, which covers this right.

#### **Many risk-reducing actions in many countries**

A structured practice aimed at reducing the risk of adverse events has emerged in most of the countries.

#### **Still, too many reports of violations of this right**

Nevertheless, cases of violation of the right to safety in the last year have been reported in 5 countries out of 14.

#### **Serious deficiencies of emergency in some countries**

Evacuation maps have been observed in the hospitals of only 8 countries out of 14, while emergency exit signs and fire extinguisher signs were absent in two countries.

### **7.1.10 Right to Innovation**

#### **Limited availability of statistics**

The only indicators, which are available and comparable through official statistics, are those on organ transplants.

#### **and little recognition**

Reference to this right is made in the legislation of only seven countries.

#### **A two-speed innovation**

From the key persons' interviews, there was no significant evidence on the widespread use of new technologies in nine countries. From the hospital visits, on the contrary, positive information emerged. This result could mean that, while in some central and big structures innovative technologies are currently used, in the rest of the country the level of their availability is quite low.

#### **Delays**

Extensive situations of violation of this rights were reported. In particular:

- delays in introducing innovative treatments (7 countries);
- delays in medical research (6 countries);
- delays in introducing innovative diagnostic tests (5 countries).

### **7.1.11 Right to Avoid Unnecessary Suffering and Pain**

#### **Only one statistical indicator ...**

The only indicator, which is available and comparable through official statistics is the consumption of opiate drugs used to control pain.

### **and legislation not always concerned**

There is no reference to this right in the legislation of five countries.

### **An upcoming issue**

In most of the countries it emerged that this problem is beginning to be tackled through the diffusion of guidelines or protocols for pain management (11 countries) and Pain Center/ Palliative Care Unit (12 countries). However, there are still difficulties in recording pain and empowering patients and their families in the self management of pain.

### **Still unnecessary pain**

Cases of the non administration of painkillers or morphine even when recommended by international standards were reported in 4 of the countries monitored, while in 6 countries, cases of non administration of analgesic drugs before or after painful treatments were also reported.

## **7.1.12 Right to Personalized Treatment**

### **Only indirect statistics...**

At present, it is only possible to use indicators, which can provide information on the general approach to care (prevalence of economic criteria or criteria linked to the person).

### **But legislation adequately concerned**

There is no reference to this right in the legislation of only three countries.

### **Attention to diversities....but not in all countries**

In only about half of the countries there emerged a widespread and structured commitment to respecting the individual's different social and cultural needs when delivering health treatments. Such a commitment concerns, for example, contact with relatives, food, cultural diversities, religious services and psychological support.

### **Top attention for children**

In almost all of the countries, there exists a high level of attention towards children's needs.

## **7.1.13 Right to Complain**

### **Lack of official data ...**

At present, there are no official statistics and data available to evaluate the degree of implementation of the right in Europe.

### **but recognized in the countries' legislations**

Reference to this right is missing in only one country's legislation.

### **A well-defined route for citizens' complaints ...**

In all of the countries there is a structured procedure aimed at gathering and processing citizens' complaints, involving committees to collect complaints and mediate between the public and the hospital.

### **but lacking effectiveness**

However, cases were reported concerning the lack of response to citizens' complaints and/or exceedingly long response time to citizens' complaints in 12 countries.

#### **7.1.14 Right to Compensation**

##### **Lack of official data ...**

At present, it is not possible to use official statistics to evaluate the degree of implementation of the right in Europe.

##### **and legislation fairly concerned**

There is no reference made to this right in the legislation of only three countries.

##### **Insurance policies ...**

In almost all of the countries there are insurances schemes covering the compensation for possible damages to patients.

##### **A good practice to extend**

In about half of the countries there are committees to assist patients in reaching a final settlement compensation, as well as independent organizations providing legal aid free of charge.

#### **7.2. An Overview**

With respect to information, the research project showed that the official sources of information on patients' rights are inadequate, often of marginal value and affected by serious cognitive distortions (privileging outputs over outcomes, offer instead of demand, macro and not micro dimension). On the other hand information directly gathered thanks to the Civic Audit tools has shown, though in an experimental and limited way, to be able to fill these information gaps, by providing data of the utmost importance on the actual conditions of patients. It should be pointed out that the rights of active citizenship allowing citizens to have direct access to data and situations are still far from being concretely recognized by their stakeholders, especially the public authorities operating in health care services.

The state of patients' rights in Europe, which emerges from the research project, is at the same time disquieting and in progress. It is disquieting because in all of the European countries where the research was conducted the enforcement of patients' rights is affected by the narrow criterion of sustainability, based on economic and financial considerations to the detriment of the fundamental rights at stake in health care systems; what – could be considered sort of a “hidden standard”. This can be observed especially, both from the very low level of attention to rights of great importance for patients, such as the rights to time, to free choice, to access to care, to innovation, as well as from a number of “sentinel events” directly observed or reported by the key persons in the last two years, such as a worsening of patients' conditions due to the delay in care, or even the lack of those pieces of information enabling patients to assess and actually freely choose services and professionals.

On the other hand, the situation appears to be progressing, because both national and European authorities, citizens' organizations, professionals and important stakeholders show an increasing level of attention to patients' rights. This can be observed from, both the existing national legislation as well as the attention and practice regarding the rights of patients to complain, the respect of privacy and physical access. Even though there are evident implementation gaps, as in the case of the right to information, which seems to be much more declared than practiced seriously.

These relatively positive situations show that implementing patients' rights is a challenge that can be overcome. Strengths and weaknesses of each country situation show that a lot of work has to be done to definitely improve the level of attention to patients' rights in the entire European Union.

### **7.3. The question of information on patients' rights**

In light of the fact that the main aim of the project was to check if an adequate amount of information on patients' rights is available from official sources or can be gathered thanks to civic information, one can say that, while official sources emerged as incapable of providing effective information on the actual condition of patients, the data directly gathered by active citizenship organizations have shown to be able to integrate those sources.

The main problem of official information is that it does not contain sufficient data on patients' rights. This is probably the result of a distortion affecting these sources. With reference to this one can point out, a focus on outputs (what health systems have done) rather than on the outcomes (what actually happened to people); a priority given to the offer of services rather than on the demand and on the actual relation between offer and demand; an effort to identify macro-phenomena while the actual condition of patients is made of several micro-phenomena that have a significant quantitative dimension.

On the other hand, the experience of mobilizing citizens' organizations operating at the national level on patients' and consumers' rights as civic information actors, capable of gathering relevant information both from a number of sources and based on their own observation and experience can be considered quite positive. In particular, the Civic Audit methodology and the related Patients' Rights Matrix emerged as tools capable of shedding light on the actual condition of patients and the problems they face. Of course, in this case, the application of this methodology, which has been widely and successfully used in Italy for a number of years, in this case has been experimental and limited, due to time and resources constraints. Nevertheless, it can be said that this experiment succeeded and therefore that this methodology can be further implemented.

It should be pointed out that, overall both authorities and professionals had quite a negative attitude, when confronted by active citizenship organizations trying to gather data through interviews and direct observation of health facilities, and in a number of cases created obstacles to this activity. This can be considered a disturbing indicator regarding the real situation of the rights of active citizenship in Europe.

### **7.4. Degree of attention on patients' rights**

#### *Concise data on the European situation*

The analysis of the Index for Attention on Patients' Rights (IAPR) values allows us to acquire a concise vision of the state of citizens' rights in the European Union countries.

The following table illustrates the values of the index for each of the rights of the Charter. One can observe that the rights can be divided into two groups: the first group with high IAPR values (above the average) and the second one with low IAPR values (below the average).

Table 9. General classification of Patients' Rights according to the Degree of Attention

DEGREE OF ATTENTION	RIGHT	Actual conditions of patients IAC (1)	Statistics (2)	Legislation (3)	IAPR (4)
<b>HIGH</b>	<b>Complain</b>	26	0	3.25	<b>29.25</b>
	<b>Privacy</b>	26	0	3.25	<b>29.25</b>
	<b>Information</b>	21	3.5	3.5	<b>28</b>
	<b>Access – Physical</b>	25	1.4	-	<b>26.4</b>
	<b>Personalized Treatment</b>	21	1.4	2.75	<b>25.15</b>
	<b>Safety</b>	22	0	2.75	<b>24.75</b>
	<b>Quality</b>	21	0	3.5	<b>24.5</b>
	<b>LOW</b>	<b>Prevention</b>	15	3.5	3
<b>Compensation</b>		17	0	2.75	<b>19.75</b>
<b>Avoid pain</b>		16	1.4	2.25	<b>19.65</b>
<b>Consent</b>		15	0	3.5	<b>18.5</b>
<b>Innovation</b>		14	3.5	1.75	<b>19.25</b>
<b>Free choice</b>		14	1.4	2.5	<b>17.9</b>
<b>Access – Care</b>		10	3.5	3.25	<b>16.75</b>
<b>Time</b>		10	1.4	1.5	<b>12.9</b>

(1) Score: min 0, max 28

(2) Score: min 0, max 3.5

(3) Score: min 0, max 3.5

(4) Score: min 0, max 35

Active Citizenship Network, 2007

Among the eight worst situations in terms of care for patients' rights, three of them – the right to **Free Choice, Access to Care and Respect of Patients' Time** – refers to the same problem, that is, *the crisis of the "European Social Model"* with respect to the universal entitlement to health care. The starting point of the European Charter of Patients' Rights, namely that patients' rights, irrespective of national differences, are at risk because of political orientations and financial constraints, seems to be definitely confirmed by this survey. A further element of concern is also given by the fact that the two rights to **Free Choice and Respect of Patients' Time**, have a value that is lower in all three of the IAPR components. This means that, in addition to the difficult situation that citizens face, the legislative recognition of the right is not widespread and, above all, there is a lack of statistical data from official sources.

The fact that the rights to **Compensation** and **Consent** show a low level of attention, leads us to believe that the better results recorded by the rights to **Complain**, to **Safety** and to **Information** should be carefully considered. It could indeed mean that the commitment to place citizens first in health services runs the risk of remaining only on paper, while the difficult issues are not being dealt with. Good quality information must be linked to the practice of comprehensively informed consent on treatments; good policies on complaints management and on the safety of treatments must be linked to the actual possibility for citizens and patients to be fully compensated for possible damages.

The **right to Prevention** recorded in the group of rights, with the lowest level of attention. Though Europe is probably the region in the world where, thanks to the welfare systems, the highest success in preventing diseases has been reached, this result could be considered as a warning of a possible decrease in the commitment of governments and professionals. The low score could also in part be explained by the fact that among the indicators used, there were a number of them, which made

reference to the prevention actions carried out in hospitals, places which focus instead, in spite of WHO indications, primarily on the treatment of illnesses.

Finally, the fact that the level of attention towards the **rights to innovation and to avoid unnecessary suffering and pain** is below average in the above classification seems to confirm the possibility of a decrease in the commitment of governments and professionals.

In this respect, an interesting way to interpret the ranking of the rights can be made by taking into consideration – for each right – the factor which, in theory, plays the most important role in its implementation. There are, in fact, a number of rights – such as the right to quality and to innovation – which interact with a whole range of factors, among which are structural factors, and therefore depend on the availability of new materials and new technologies, the economic needs, etc. Other rights, on the other hand, like the right to privacy, are related in a more exclusive manner to the value which, in a specific context, is given to the individual and to his needs. In other words, in some cases, the respect of rights is based primarily on a strong orientation towards citizens and on a consolidated awareness concerning their role. In other cases, however, the protection can be a sort of an “indirect effect”, not really sought, but the result of changes in other fields.

With the intent of trying to outline this difference, the rights have been divided in the following table, by indicating for each one, the letter P (persons) and S (structure).

*Table 10 .Rights classification according to their referring to persons or structures*

<b>RIGHT</b>	<b>IAPR</b>	<b>Persons or structure</b>
<b>Complain</b>	29.25	P
<b>Privacy</b>	29.25	P
<b>Information</b>	28	S
<b>Access – Physical</b>	26.4	S
<b>Personalized Treatment</b>	25.15	P
<b>Safety</b>	24.75	S
<b>Quality</b>	24.5	S
<b>Prevention</b>	21.5	P
<b>Compensation</b>	19.75	P
<b>Avoid pain</b>	19.65	P
<b>Innovation</b>	19.25	S
<b>Consent</b>	18.5	P
<b>Free choice</b>	17.9	P
<b>Access – Care</b>	16.75	S
<b>Time</b>	12.9	P

In fact, of the 8 rights with the lowest score, 6 can be classified as rights linked to the person, while among the 7 rights with the highest score, only 3 are linked to the person.

There seems to be, therefore, a difficulty in fully placing citizens at the heart of the healthcare system, and holders of rights, and consequently of establishing a vital cycle of listening to citizens when preparing programs and implementing and controlling them. It also means that problems affecting patients’ rights do not depend only on structures or resources, but rather on culture, habits and behaviors.

Two further considerations can be made if one examines the values of the index of legislation on patients’ rights at the national level and those of the IAPR.

It should be pointed out that, in general, *there is no correlation between the number of laws or regulations and the degree of attention towards patients' rights*. For example, the right to complain and the right to access to care, which are, according to the information gathered, respectively in first place and in second to last place, have the same score of the index of legislation.

In second place, it is clear that *laws and norms must be not only proclaimed nor enforced by courts, but also implemented through appropriate and effective policies*, activated and supported by all the actors of health care: governments, citizens' organizations, professionals, third party payers, pharmaceutical and other private companies, trade unions, the media, legal systems, scientific community.

In conclusion, the values of IAPR of the rights show that *more than half of the patients' rights scored below the average line (score 22.3)*. This denotes a very critical situation concerning the attention on patients' rights at the national level. Moreover, those rights that have been classified in the highest cluster are not free from problems, as it emerged in Part 2 of the report.

The IAPR values for the countries are illustrated in the following table. It is however important to point out that the part of the information provided by hospital authorities is missing for Portugal (three hospitals out of three) and the UK (two hospitals of the three visited), and that, therefore, the results of these two countries have to be carefully considered.

Table 11. IAPR score for each country

IAPR	Actual conditions Of citizens	Statistics	Legislation	Total
Austria	21	1.5	2.5	<b>25</b>
Belgium	24	1.5	1.75	<b>27.25</b>
Denmark	21	1.5	3.5	<b>26</b>
Finland	19	1.5	3.25	<b>23.75</b>
France	24	1.5	3	<b>28.5</b>
Germany	24	1.5	2.75	<b>28.25</b>
Greece	12	1.5	3.5	<b>17</b>
Ireland	21	1.5	2	<b>24.5</b>
Italy	19	1.5	3.5	<b>24</b>
Netherlands	25	1.5	3	<b>29.5</b>
Portugal	5	1.5	3.5	<b>10</b>
Spain	16	1.5	2.5	<b>20</b>
Sweden	20	1.5	2.75	<b>24.25</b>
UK	23	1.5	2	<b>26.5</b>

## 7.5. Improvement Priorities

Analyzing the country score assigned to each right allows us to make some general considerations regarding priorities for improvement in the countries involved in the project<sup>62</sup>. When a right scored 0 on the IAC rating, this reveals a very low attention to this right and consequently actions for its implementation should be considered a priority in future health care decisions. When a right scored 1 it illustrates a medium to low level of attention and therefore, can be considered a matter that needs to be looked at in order to improve the actual implementation of patients' rights.

<sup>62</sup> This country analysis doesn't consider Portugal or the UK due to the limitation in the information gathered from these two countries. Portugal has no information from hospital authorities and in the UK only one hospital authority provided information. Regarding the right to access only the aspects concerning access to care dealt with since physical to health cares structures doesn't present any real critical aspects.

*Austria* should focus primarily on the right to quality, which obtained the lowest score of all the 14 rights in this country. There are also areas of improvement needed with respect to the rights to access to care, respect for patients' time, innovation, safety, free choice, information, avoiding suffering and pain, which are rights that, in general, scored low overall in Europe. However, it is important to note that Austria is one of the few countries to score high on the right to compensation, followed by the right to complain, consent, respect to patients' time, personalized treatment, privacy and confidentiality. Austria provides a high level of attention on rights that focus on the person, which demonstrates a particular concern to put citizens' needs first.

*Belgium* is one of the two countries, the other being The Netherlands, where none of the 14 rights received a score of 0. Nevertheless, there remains room for improvement regarding the rights to access care, respect of patients' time, consent, free choice, information and preventive measures. These rights, which received the lowest scores are related to patients, rather than to health care structures, demonstrating a need for Belgium to place citizens in the center of their health care policy. These are the same rights that scored below average on the general IAPR.

*Denmark* presents a rather balanced distribution of rights over high level and low level scores. The priorities for improvement concern compensation, consent and preventive measures, followed by access to care, free choice and respect to patients' time. In general, these rights refer to the person or patient, rather than the structure, showing the same need, as pointed out above, to direct priorities for improvements centered on the patient.

*Finland* is characterized by medium to low attention to the rights. Priority should be given to difficulties regarding consent, access to care and the respect to patients' time, which coincide with the rights that received the lowest score at the European level. However, in Finland, all key persons reported cases where illnesses had worsened due to delay in treatment and exceedingly long waiting time for diagnostic exams, which resulted in the need to use payable services. There should also be improvements made in the rights to avoid suffering and pain, innovation, safety, quality, free choice, information, as well as preventive measures.

*France* shows, over all, a medium to high level of attention towards patients' rights. Nonetheless, the right to quality should be considered a priority regarding its implementation, since all the key persons reported cases of violation of this right in the last year. There is area for improvement, specifically regarding the right to avoid suffering and pain, free choice, respect to patients' time and access to care. Preventive measures and the right to complain scored the highest, showing a high level of attention to these rights.

*Germany*, in general, demonstrates a high to medium level of attention to patients' rights. The right to respect patients' time and innovation represent priorities for improvements, followed by access to care and preventive measures.

*Greece*, on the other hand, presents quite a different picture, demonstrating low attention to the majority of rights. The right to avoid suffering and pain needs to be a priority, as only in one other country did this right receive such a low score. Among other rights, which demonstrate a low attention and requiring actions are the right to innovation, compensation, personalized treatment, preventive measures and respect for patients' time. However, it is interesting to note that the right to access received the highest score, contrary to the overall European situation. Therefore, in Greece, access to care doesn't seem to be the problem, but rather the quality of that care is what needs to be addressed.

*Ireland* presents a situation where there are a few rights that have a high level of attention while the majority show a low level. The right to respect patients' time should be considered a priority, as with most of the other countries. The right to free choice, consent, innovation, preventive measures and access to care require actions to improve their level of attention.

*Italy* is one of the few countries, which do not have any rights that receive a high level of attention, but rather almost all the rights receive a medium-high to medium-low level. The right to respect patients' time represents a critical situation, as it receives the lowest attention of all. All the key persons identified cases where patients needed to use payable services due to the long waiting times. For this reason, actions and strategies are required to effectively deal with the problem of waiting lists and delays in exams and treatments. Other areas for improvement are the rights to avoid suffering and pain, innovation, personalized treatment, consent, free choice and preventive measures.

In *The Netherlands* almost half the rights receive a high level of attention (preventive measures, free choice, quality, avoid suffering and pain, personalized treatment and right to complain), while none of the rights obtained a very low score. Nevertheless, there are a number of rights that need to be looked at, such as: the right to information, consent, safety, innovation, compensation and access to care. Actions and strategies that promote these rights, relating to the interest of the patient, are essential. This reflects a similar situation at the European level.

In *Spain* the situation is quite different. The majority of rights obtain a medium to low level of attention. For this reason there are a number of rights that need to be prioritized; the right to avoid suffering and pain, innovation, compensation and access to care.

In *Sweden* there is a tendency that rights linked to health structures such as quality, safety, innovation receive a higher level of attention than rights that are centred on the patients, like the right to free choice, respect of patients' time, avoid suffering and pain. This is quite consistent with the general trend that we have seen in other countries. One should note the right to consent received the lowest score and therefore needs to be addressed and given priority.

Table 12: Summary of improvement priorities for each country

Country	Priority
Austria	<i>Urgent:</i> right to quality <i>Needs improvements:</i> rights to access to care, respect for patients' time, innovation, safety, free choice, information, avoiding suffering and pain
Belgium	<i>Urgent:</i> No right scored 0 on the IAC <i>Needs improvements:</i> rights to access care, respect of patients' time, consent, free choice, information and preventive measures
Denmark	<i>Urgent:</i> right to compensation, consent and preventive measures <i>Needs improvements:</i> access to care, free choice and respect to patients' time
Finland	<i>Urgent:</i> right to consent, access to care and the respect to patients' time <i>Needs improvements:</i> rights to avoid suffering and pain, innovation, safety, quality, free-choice, information and preventive measures
France	<i>Urgent:</i> right to quality <i>Needs improvements:</i> right to avoid suffering and pain, free-choice, respect to patients' time and access to care to avoid suffering and pain, free-choice, respect to patients' time and access to care
Germany	<i>Urgent:</i> The right to respect patients' time and innovation <i>Needs improvements:</i> access to care and preventive measures

Greece	<i>Urgent:</i> right to avoid suffering and pain, innovation, compensation, personalized treatment, preventive measures and respect for patients' time <i>Needs improvements:</i> right to information, consent, free choice, quality and safety
Ireland	<i>Urgent:</i> right to respect patients' time <i>Needs improvements:</i> free-choice, consent, innovation, preventive measures and access to care
Italy	<i>Urgent:</i> right to respect patients' time <i>Needs improvements:</i> right to avoid suffering and pain, innovation, personalized treatment, consent, free-choice and preventive measures
Netherlands	<i>Urgent:</i> No right scored 0 on the IAC <i>Needs improvements:</i> right to information, consent, safety, innovation, compensation and access to care
Spain	<i>Urgent:</i> right to avoid suffering and pain, innovation, compensation and access to care <i>Needs improvements:</i> free choice, respect for patients' time, personalized treatment, privacy and confidentiality as well as preventive measures
Sweden	<i>Urgent:</i> right to consent <i>Needs improvements:</i> free-choice, respect of patients' time, avoid suffering and pain

*Urgent: rights that received a score of 0 on the IAC, Needs improvements: rights that scored 1 on the IAC*

## 7.6. Policy priorities

On the basis of the results of the survey, the following seven priorities can be identified.

1. *Patients' rights must become the common point of view and a standard for managing policies on health care*, as well as a shared commitment of European and national institutions and of all the actors of health policies. The present critical situation of health services, as well as the questions emerging on patient mobility throughout Europe, requires that a strong reference point, clearly linked to the general interest, be identified. This point can be precisely that of patients' rights.
2. *Existing data and information on health care at the European level would be enriched with those regarding patients' rights*, integrating the traditional methodologies and sources with those used in this survey such as *Civic Audit* activities, which involve citizens not only as actors but also sources in producing information.
3. *A European agenda on patients' rights* should be set up and implemented with an appropriate plan of action, involving both European and national authorities, as well as health care stakeholders. Since patients' situation is a matter of fundamental rights, a stronger role of the EU should be established, while fully respecting national responsibilities.
4. *The practice of the "Rights of Active Citizenship"* stated in the European Charter of Patients' Rights (to perform general interest activities; carry out advocacy activities; participate in policy making), *should be supported and guaranteed in the entire European Union*, as an expression of European citizenship. It can no longer be accepted that active citizens are not allowed to gather information and cooperate in assessing rights, as occurred during this survey.
5. *The financing of health structures by the governments and other payers must be conditioned to the success of these structures in protecting patients' rights*. Appropriate standards and indicators should be identified and assessed, so that the ability to respect patients' rights becomes a competitive advantage in health care market.

6. *Firm action towards the changing of cultural, professional and organizational models in health care must be taken.* As it was shown by this survey, the protection of patients' rights does not depend only on financial matters, but is linked also to the behavior of professionals, ways of managing services and attitudes towards the public. They can and must change quickly.

7. *Finally, a patients' right-based approach is required to deal with the new trends and upcoming situations* that are going to characterize the European scenario of health care. While our survey could get information only on the existing factors affecting patients' rights, an approach based on patients' rights is needed in managing new situations such as *EU enlargement*, as well as the measures and decisions that are now under discussion or going to be discussed, like the *liberalization of information on drugs* or the *use of biotechnologies*.

## APPENDIXES

### A. Matrix of Patients' Rights

Indicators	Source
<b>1. Right to Preventive Measures</b>	
Material on Prevention for the public (Y/N) <ul style="list-style-type: none"> <li>– <i>early diagnosis cancer affecting women</i></li> <li>– <i>prevention of sexually transmitted diseases</i></li> <li>– <i>dental prevention</i></li> <li>– <i>quitting smoking</i></li> <li>– <i>treating drug dependence</i></li> <li>– <i>cardiovascular disease prevention</i></li> <li>– <i>neurovascular disease prevention</i></li> <li>– <i>domestic and</i></li> </ul>	DOH
Primary and secondary prevention program (Y/N) <ul style="list-style-type: none"> <li>– <i>cervical cancer PAP</i></li> <li>– <i>colorectal cancer FOBT</i></li> <li>– <i>breast cancer mammography</i></li> <li>– <i>hypertension</i></li> <li>– <i>lipid disorders</i></li> <li>– <i>amblyopia and strabismus</i></li> <li>– <i>diminished visual acuity</i></li> <li>– <i>drinking problems</i></li> <li>– <i>HIV/AIDS</i></li> <li>– <i>other sexually transmitted diseases</i></li> <li>– <i>smoking</i></li> </ul>	HA
Screening programs currently available free of charge in the health care system (Y/N) <ul style="list-style-type: none"> <li>– <i>cervical cancer PAP</i></li> <li>– <i>colorectal cancer FOBT</i></li> <li>– <i>breast cancer mammography</i></li> <li>– <i>hypertension</i></li> <li>– <i>lipid disorders</i></li> <li>– <i>amblyopia and strabismus</i></li> <li>– <i>diminished visual acuity</i></li> <li>– <i>drinking problems</i></li> </ul>	KP
Public communication campaigns (Y/N) <ul style="list-style-type: none"> <li>– <i>HIV</i></li> <li>– <i>early diagnosis cancer affecting women</i></li> <li>– <i>fight against smoking</i></li> <li>– <i>alcohol abuse</i></li> <li>– <i>nutritional abuse</i></li> <li>– <i>depression</i></li> <li>– <i>heart disease</i></li> <li>– <i>domestic accidents</i></li> <li>– <i>road safety</i></li> <li>– <i>dental care</i></li> </ul>	KP

Indicators	Source
<b>2. Right to access</b>	
<b>2.1 Access to care</b>	
Residents (legal or illegal) who are not covered by NHS (Y/N)	KP
Obstacles that in reality limit certain groups of the population from fully benefiting from NHS (Y/N)	KP
Facts that indicate the difficulty to access health care service (Y/N) <ul style="list-style-type: none"> <li>– Important health care issues not covered in NHS package</li> <li>– Lack of health care for patients with rare diseases</li> <li>– Forced migration for health care</li> <li>– Complaints due to administrative and/or economic obstacles in accessing NHS services</li> <li>– Complaints and protests due to the lack of coverage by public insurance for health services considered essential by the public</li> <li>– Complaints and protests due to the lack of specialized centers for treating a particular rare disease</li> <li>– Complaints and protests regarding access to drugs which have been approved in other countries, but not yet in yours</li> <li>– Cases where this right has not been respected (Y/N)</li> </ul>	KP
<b>2.2 Physical access</b>	
Hospital entrances clearly marked (Y/N)	DOH
Accessibility for persons with disability clearly marked (Y/N)	DOH
Structural barriers which have not been remedied (Y/N)	DOH
Street signs near the hospital indicating its location (Y/N) <ul style="list-style-type: none"> <li>– Patients with motor difficulties dropped off at main entrance (Y/N)</li> <li>– Hospital accessible by public transportation (Y/N)</li> <li>– Parking for visitors (Y/N)</li> <li>– Reserved parking for persons with disability (Y/N)</li> </ul>	DOH
<b>3. Right to Information</b>	
Information available to the public in the hospitals (Y/N) <ul style="list-style-type: none"> <li>– Information regarding the hospital and regulations</li> <li>– Sheet on patients rights regarding inpatients and outpatients</li> <li>– Notices regarding waiting list for diagnostic exams and surgery</li> <li>– Reports on complaints received from the public</li> <li>– Data on outcomes of health services</li> </ul>	DOH
Data compared with other hospitals – benchmarking (Y/N)	DOH
Areas for voluntary and public interest associations (Y/N)	DOH
Indications where to locate the associations posted at main entrance (Y/N)	DOH
Information service at main entrance (Y/N)	DOH
Updating of the Hospital Directory (Y/N)	DOH
Telephone number (Y/N)	HA
Information Desk (Y/N)	HA
Hospital Website (Y/N)	HA
Possibility for patients to receive hospital record after discharge (Y/N)	HA
Average number of days to receive hospital record after discharge (value)	HA
Publicly available lists of all the hospitals, specifying their particular facilities and services (Y/N)	KP
Information centers where citizens can access these lists (Y/N)	KP
Lists are update periodically (Y/N)	KP
Health authorities provide directly or indirectly comprehensible consumer ratings (“consumer satisfaction” information) related to health services (Y/N)	KP
Possibility to make comparison between hospitals: benchmarking (Y/N)	KP

<b>Indicators</b>		<b>Source</b>
	Health authorities provide directly or indirectly comprehensible information on clinical performance measures related to the health services (Y/N)	KP
	Organizations that perform the role of Independent Advisor (Y/N)	KP
	Cases where this right has not been respected (Y/N)	KP
<b>4. Right to consent</b>		
	Existence of standardized forms to get consent from the patient (Y/N) <ul style="list-style-type: none"> <li>- <i>Scientific research</i></li> <li>- <i>Invasive diagnostic exams</i></li> <li>- <i>Surgical operations</i></li> </ul>	HA
	<ul style="list-style-type: none"> <li>▪ Specific forms to get consent from the patient (Y/N) <ul style="list-style-type: none"> <li>- <i>Nature of the treatment or procedure</i></li> <li>- <i>Risks</i></li> <li>- <i>Benefits</i></li> <li>- <i>Alternatives</i></li> <li>- <i>Information sheet on specific treatment or procedure (Y/N)</i></li> <li>- <i>Information sheet or forms in more than one language (Y/N)</i></li> <li>- <i>Procedures for involving minors or incapable adults in the informed consent process (Y/N)</i></li> <li>- <i>Cases where this right has not been respected (Y/N)</i></li> </ul> </li> </ul>	KP
<b>5. Right to Free choice</b>		
	Different fees in public and private hospitals (and thus different reimbursements) (Y/N)	KP
	Incentives to seek treatment in certain hospitals or centres (Y/N)	KP
	Coverage of supplementary insurance only for some hospitals, and thus the option of seeking treatment in just those hospitals (Y/N)	KP
	Need to get authorization for some treatments (ex. for rehabilitative treatments) (Y/N)	KP
	Indigent (poor, needy) patients only able to receive treatment in certain hospitals (Y/N)	KP
	Right limited in the last year(Y/N)	KP
<b>6. Right to Privacy and Confidentiality</b>		
	Dividers between outpatient rooms (Y/N)	DOH
	Hear or see the patient's surname (Y/N)	DOH
	Single room for terminal patients (Y/N)	HA
	Cases where this right has not been respected - Normative medical information disclosed to non-authorized persons (Y/N)	KP
	Cases where this right has not been respected - Patients' case files disclosed to non-authorized persons (Y/N)	KP
	Cases where this right has not been respected - Violation of the confidentiality of HIV/AIDS patients (Y/N)	KP
<b>7. Right to respect patient's time</b>		
	Diagnostic or therapeutic treatment impossible to get appointment in the last 30 days (Y/N)	HA
	Differentiated access routes for different levels of seriousness and urgency (Y/N) <ul style="list-style-type: none"> <li>- <i>Ecocardiograms</i></li> <li>- <i>Mammography</i></li> <li>- <i>CAT</i></li> </ul>	HA
	Maximum time period within which the hospital must provide the diagnostic and therapeutic treatments required for patients (Y/N)	HA
	The hospital guarantee the patient can get treatment in another facility without additional cost if hospital can not provide diagnostic or therapeutic treatment within the max. time (Y/N)	HA
	Reimbursed cost when it is an additional cost (Y/N)	HA
	Unified contact point for appointments (Y/N)	HA
	Waiting lists for diagnostic exams and surgery available to public (Y/N)	HA
	Appointments for specialists can be made by phone (Y/N)	HA
	Waiting period for urgent exams (value)	HA

Indicators		Sources
	Waiting period for non urgent exams ( <i>value</i> )	HA
	Waiting time for elective surgery ( <i>value</i> )	HA
	Cases where this right has not been respected -Cases in which an illness has worsened because of a delay in treatment ( <i>Y/N</i> )	KP
	Cases where this right has not been respected - Need to use services that the patients has to pay for due to the long waiting time ( <i>Y/N</i> )	KP
	Cases where this right has not been respected - Need to use services that the patients has to pay for due to the long waiting time ( <i>Y/N</i> )	KP
<b>8. Right to Quality Standards</b>		
	Fixed standards ( <i>Y/N</i> ) <ul style="list-style-type: none"> <li>- <i>Set with participation of consumer association</i></li> <li>- <i>Regarding technical offerings</i></li> <li>- <i>Regarding human relations</i></li> <li>- <i>Regarding comfort</i></li> <li>- <i>With periodic controls</i></li> <li>- <i>With controls carried out with participation of consumer associations</i></li> <li>- <i>Sanctions for violations of standards</i></li> </ul>	DOH
	Quality Unit ( <i>Y/N</i> )	DOH
	Studies to measure patient satisfaction	DOH
	Procedures to accredit or certify the quality level of hospitals ( <i>Y/N</i> )	KP
	Fixed standards ( <i>Y/N</i> ) <ul style="list-style-type: none"> <li>- <i>Established with the participation of consumers' associations</i></li> <li>- <i>Regard technical offerings</i></li> <li>- <i>Regard human relations</i></li> <li>- <i>Regard comfort</i></li> <li>- <i>With periodic controls</i></li> <li>- <i>With controls carried out with participation of consumer associations</i></li> <li>- <i>Sanctions for violations of standards</i></li> <li>- <i>Sanctions imposed</i></li> </ul>	KP
	Cases where this right has not been respected ( <i>Y/N</i> )	KP
<b>9. Right to safety</b>		
	Priority codes in triage procedure in Emergency Room ( <i>Y/N</i> )	DOH
	Emergency exist signs ( <i>Y/N</i> )	DOH
	Fire extinguisher ( <i>Y/N</i> )	DOH
	Evacuation maps ( <i>Y/N</i> )	DOH
	Special evacuation procedures or routes for wheelchair users on map ( <i>Y/N</i> )	DOH
	Procedures for reporting the following ( <i>Y/N</i> ) <ul style="list-style-type: none"> <li>- <i>Hospital acquired infections</i></li> <li>- <i>Burns from fires</i></li> <li>- <i>Falls</i></li> <li>- <i>Pressure ulcers</i></li> <li>- <i>Phlebitis associated with intravenous lines</i></li> <li>- <i>Restraint-related strangulation</i></li> <li>- <i>Preventable suicides</i></li> <li>- <i>Failure to diagnosis or incorrect diagnosis</i></li> <li>- <i>Failure to utilize or act on diagnostic tests</i></li> <li>- <i>Use of inappropriate or outmoded diagnostic tests or treatment</i></li> <li>- <i>Medication errors/adverse drug effects</i></li> <li>- <i>Wrong-site errors; surgical errors</i></li> <li>- <i>Transfusion mistakes</i></li> </ul>	HA
	Reporting of near misses ( <i>Y/N</i> )	HA
	Written procedures (protocols) for checking and reducing risks control of hospital infections ( <i>Y/N</i> )	HA
	Office or person in the hospital charged with coordinating the activities for reducing the risk of transfusions ( <i>Y/N</i> )	HA

<b>Indicators</b>		<b>Source</b>
	Office or person in the hospital charged with coordinating activities for reducing the risk of infection (Y/N)	HA
	Epidemiological investigations of hospital infections carried out (Y/N)	HA
	Protocols for the sterilization of medical instruments (Y/N)	KP
	Protocols for the prevention of hospital infections (Y/N)	KP
	Risk management techniques (Y/N)	KP
	Epidemiological investigations of hospital infections (Y/N)	KP
	Cases when the right not respected	KP
<b>10. Right to Innovation</b>		
	Use of (Y/N) <ul style="list-style-type: none"> <li>- Telemedicine</li> <li>- Electronic patient record</li> <li>- Internet</li> <li>- Personal cards</li> <li>- Special mattress to prevent pressure ulcer</li> <li>- Patient Control Analgesia</li> <li>- Less invasive surgical techniques <ul style="list-style-type: none"> <li>▪ Laparoscopic Cholecystectomy</li> <li>▪ Laparoscopic Prostatectomy</li> <li>▪ Microendoscopic discectomy (MED)</li> <li>▪ Minimally invasive direct coronary artery bypass (MIDCAB)</li> <li>▪ Laparoscopic Inguinal hernia repair</li> <li>▪ Laparoscopic Adrenalectomy</li> <li>▪ Laparoscopic Repair of paraesophageal hernia</li> </ul> </li> </ul>	HA
	Diffusion innovative techniques (Y/N) <ul style="list-style-type: none"> <li>- Telemedicine</li> <li>- Electronic patient record</li> <li>- Use of internet</li> <li>- Less invasive surgical techniques</li> <li>- Personal cards</li> <li>- Use of special mattress to prevent pressure ulcer</li> </ul>	KP
	Cases when the right not respected: delays introducing innovative diagnostic tests (Y/N)	KP
	Cases when the right not respected: delay in introducing innovative treatments (Y/N)	KP
	Cases when the right not respected: delay in particular areas of medical research (Y/N)	KP
<b>11. Right to avoid unnecessary suffering and pain</b>		
	Protocol for pain management (Y/N)	KP
	Palliative Care Unit (Y/N)	KP
	Pain Medicine Center (Y/N)	KP
	Record pain scores (Y/N)	KP
	Pain management procedure - Assess pain systematically (Y/N)	KP
	pain management procedure - Believe what the patient and family reports on pain (Y/N)	KP
	Pain management procedure - Choose pain control options appropriate (Y/N)	KP
	Pain management procedure - Deliver interventions in a timely, logical and coordinated fashion (Y/N)	KP
	Pain management procedure - Empower patients to self-manage pain (Y/N)	KP
	Cases when the right not respected: not administrating morphine in cases when it is recommended by the international procedures (Y/N)	KP
	Cases when the right not respected: not administrating painkillers in the case of or after painful treatments (Y/N)	KP

Indicators	Source
<b>12. Right to personalized treatment</b>	
Play areas inside pediatrics wards (Y/N)	DOH
Appropriate furnishing inside pediatrics (Y/N)	DOH
Parents can be present 24 hrs. day (Y/N)	DOH
Place for relatives to sleep in the room that is appropriate (Y/N)	DOH
Use of cafeteria for parents (Y/N)	DOH
Educational support for children (Y/N)	DOH
Choice of meals (Y/N)	HA
Distribution of patients meal (Y/N)	HA
Religious assistance available in the hospital or on call for more than three religions (Y/N) <ul style="list-style-type: none"> <li>- Protestants</li> <li>- Anglican</li> <li>- Catholic</li> <li>- Orthodox</li> <li>- Jewish</li> <li>- Muslim</li> </ul>	HA
Psychological support service to assist patients and their families in specific situations (3 or more reported) (Y/N) <ul style="list-style-type: none"> <li>▪ Terminal patient and their family</li> <li>▪ Transplants patients and their family</li> <li>▪ Women who have suffered violence</li> <li>▪ Patients in other conditions</li> </ul>	HA
Procedures to ensure that patients may demand a second opinion (Y/N)	HA
Foreign language interpreters present at the hospital (Y/N)	HA
Cultural mediators present at the hospital (Y/N)	HA
More than six hours a day available for visiting patients (Y/N)	HA
Personalized support given in hospitals (Y/N) <ul style="list-style-type: none"> <li>- Choice of meals</li> <li>- Psychological support for terminal patients and their families</li> <li>- Spiritual support based on personal</li> <li>- Cultural mediation and/or foreign language interpretation</li> <li>- Educational support for children hospitalized</li> </ul>	KP
Cases when the right not respected (Y/N)	KP
<b>13. Right to complain</b>	
Fixed procedures for handling patients' complaints (Y/N)	HA
Committees to receive complaints (Y/N)	HA
Committee independent of the hospital (Y/N)	HA
Time limit to answer complaints (Y/N)	HA
Respect of the time limit (Y/N)	HA
Fixed procedures for handling patients' complaints (Y/N)	KP
Independent organizations to assist citizens in presenting their complaints (Y/N)	KP
Cases when the right not respected - - Lack of a response to citizens' complaints (Y/N)	KP
Cases where this right has not been respected - Too long to respond to citizens' complaints (Y/N)	KP
Cases where this right has not been respected - Threats, intimidations or retaliation towards patients that have complained (Y/N)	KP

Indicators	Sources
<b>14. Right to compensation</b>	
	Hospitals insured <i>(Y/N)</i>
	Hospital's doctors have additional insurance <i>(Y/N)</i>
	Committees or structures to assist patients in reaching a final agreement on compensation <i>(Y/N)</i>
	Committee or structures are independent from the hospital <i>(Y/N)</i>
	Hospitals insured <i>(Y/N)</i>
	Hospital's doctors have additional insurance <i>(Y/N)</i>
	Commissions/structures, operating outside the regular litigation process <i>(Y/N)</i>
	Independent organizations which provide legal aid free of charge or at a reduced cost <i>(Y/N)</i>
	Cases when the right not respected <i>(Y/N)</i>

## B. Comparing European health systems in the framework of the European charter of patient's rights

By Fiorenza Deriu

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### Introduction

European Union countries' health systems are amongst the most advanced in the world, both in terms of legislation and of public health protection. This is demonstrated by the results obtained in: life expectancy at birth; the number of years spent in good health, free of disabilities; the population's growing awareness of the importance of physical and psychophysical wellbeing, thanks also to the development of technologies and therapies which have allowed to "add life to years and not only years to life". However, notwithstanding these results, there are still great inequalities in terms of access to assistance and treatment, as well as severe shortfalls with respect to patients/citizens' rights.

Naturally, there are differences among countries, which are rooted in the different social protection systems that can be basically traced to four great welfare models or families: the Social-democratic, the Liberal, the Continental or Corporate and the Mediterranean model (Esping-Anderson, 1990, 1999, 2002, Ferrara, 1996). What is common to all these models, is the participation, in varying degrees, of families (communities), the state and the market, the three principal social institutions on which all welfare systems are based on. None of these actors or social structures would be able to function without the other two to guarantee the functioning of the different social protection models. In this respect, one refers to a welfare mix, in which one of these three actors plays a dominant role. In publicly predominant systems, it is the State which is responsible for the social life of all the citizens and when certain risks occur; in situations where the market is dominant, the State allows the free competition to regulate the internal balance and it is the private sphere which dominates over the public one; in community based systems, the social protection role is played by intermediate institutions, such as families, parental networks, neighbours, self help groups and voluntary associations, on which fall most of the social responsibilities.

The *Social-democratic* or *Scandinavian* model, adopted by countries such as Finland, Sweden and Denmark and, to a certain extent, by the Netherlands, considers social protection as a citizen's right and, for this reason, the services provided are guaranteed to all citizens when certain events take place (universalism). To this end, the system "socialises in advance the costs of family care"<sup>64</sup>, assigning to the public domain a number of costs, which the family, and the community in general, is relieved from. This model, which is financed through the general fiscal system, has the highest levels of social expenditure for children, the disabled, the elderly, occupation, as well as for care services for families. It is thanks to this extensive support networks, that these countries register the highest employment rates for women and continue to have strong fertility rates, unlike to what is happening in the rest of the Europe-15 countries. The economic recession of the nineties, however, has had its effects on these countries, as their governments have had to increase taxes and significantly reduce public spending. A trend which culminated in the year 2000, with a decrease in social spending of 6% of the GDP for Sweden and around 9% for Finland with respect to 1991<sup>65</sup>. In 2001, there was an increase for Denmark and Sweden, whose social protection spending commitment was respectively 2 and 4 GDP points higher than the EU-15 average (27.5%); Finland was the exception, with social spending being lower for the first time (25.8%) (see Table 4).

The *Continental* or *Corporate* model, of Bismarkian origin, adopted by Germany, France, Belgium, Luxembourg, Austria and the Netherlands, bases its social protection model on the complementary responsibility of the state and the family, and calls for a close link between the individual's employment condition and social performance. The underlying logic is one of subsidiarity, or in other words, of a particularistic and restricted solidarity (Sgritta, 2004). The social protection programs in the countries belonging to this "welfare" family are usually quite fragmented and diversified according to categories, more generous with public employees and are financed through social contributions, differentiated according to

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<sup>63</sup> Department of Demography of the University of Rome "La Sapienza" (Faculty of Statistics).

<sup>64</sup> Benassi, D., *La varietà dei sistemi di welfare*, in: Kazepov, Y., Mingione, E., *La cittadinanza spezzata*, Messina, Armando Siciliano, 1994.

<sup>65</sup> Eurostat Database, 2003.

the different spending institutions<sup>66</sup>. In these systems there are, however, a number of social transfers (i.e. guaranteed minimum income), aimed at providing a social safety net against the risk of poverty and social exclusion. The delivery of social services is, nevertheless, subordinated to the so called “means testing”, which requires the verification of economic means and of the willingness to work<sup>67</sup>. In these countries, social expenditure (which includes health), varies between 27 to 30% of GDP. During the Nineties, spending levels in these countries were among the more stable in Europe, while since 2001 there has been a slight increase, especially in Germany and France.

The *Mediterranean* welfare state model, adopted in Italy, Greece, Spain and Portugal, though quite similar in a number of aspects to the Continental one, assigns a critical social protection role to the family. In these countries, social spending in favour of the family, or in support of employment or child care, has always been significantly lower than the European average, since one could rely on strong family support networks, stable households and high levels of fertility. With the onset of the second demographic transition and of its initial effects (such as the delay in creating new households, their lower stability, the reduction in fertility rates, the weakening of family support networks, as well as the ageing of the population), problems finally emerged. The “equilibrium” which had characterised these countries’ welfare systems, came less, highlighting its structural deficiencies<sup>68</sup>. The guarantee systems of this group of countries are highly fragmented according to occupational categories and are characterised by verification mechanisms that are not always effective in ascertaining the contributive and spending capacity of those requiring assistance<sup>69</sup>. There are no forms of guarantees with respect to minimum income entry levels, even if a number of experiments had been launched. Moreover, employment and family support systems are poorly developed. The principal instrument adopted by these governments has been family benefits; a measure which is not universal (as in Northern Europe) and whose award is subject to means testing. Therefore, in these countries it would be necessary to strengthen a primary safety net and extend social services to families in order to promote a greater increase in female employment and a recovery in fertility rates.

Finally, there is the *Liberal* welfare model (to which Great Britain and Ireland belong to), of Beveridgian origin, and whose main objectives consist in the reduction of extreme poverty and of marginalisation, through welfare programs and benefits which are awarded subject to means testing. The financing varies according to the different sectors: healthcare is fully financed by taxation, while paid services are financed through social contributions. The model is based on the concept that the individual’s needs are to be met by the family and the market, while the State should intervene only when these two institutions cannot manage certain situations, such as for education or healthcare<sup>70</sup>. Particular attention is, therefore, placed on the individual’s participation to the labour market, in so far as access to the benefits provided by the welfare protection system is conditional to having a job. Because of the close relation between work and assistance, these systems provide for aggressive employment policies. The unemployment rate in the United Kingdom is, in fact, one of the lowest ones in the EU-15.

### ***European health systems in transition***

In defining the different welfare systems, it is always useful to keep in mind the different distributional-regulatory arrangements that take place in the course of time and in the different contexts. Between the eighties and the nineties, many European countries moved from redistributive dominated welfare systems to exchange dominated ones. However, the experience of free competition in a free market, especially in the field of health, has revealed its weakness, thus leaving the way open for the emergence of a logic of reciprocity. “With reciprocity, the allocation of resources is symmetrical and takes place within a solidarity system or of close relations within the community” (Paci 1989, p.34).

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<sup>66</sup> Zoli M., I sistemi di welfare state nei paesi dell’Unione Europea, Luiss Lab on European Economics LLEE, January 2004.

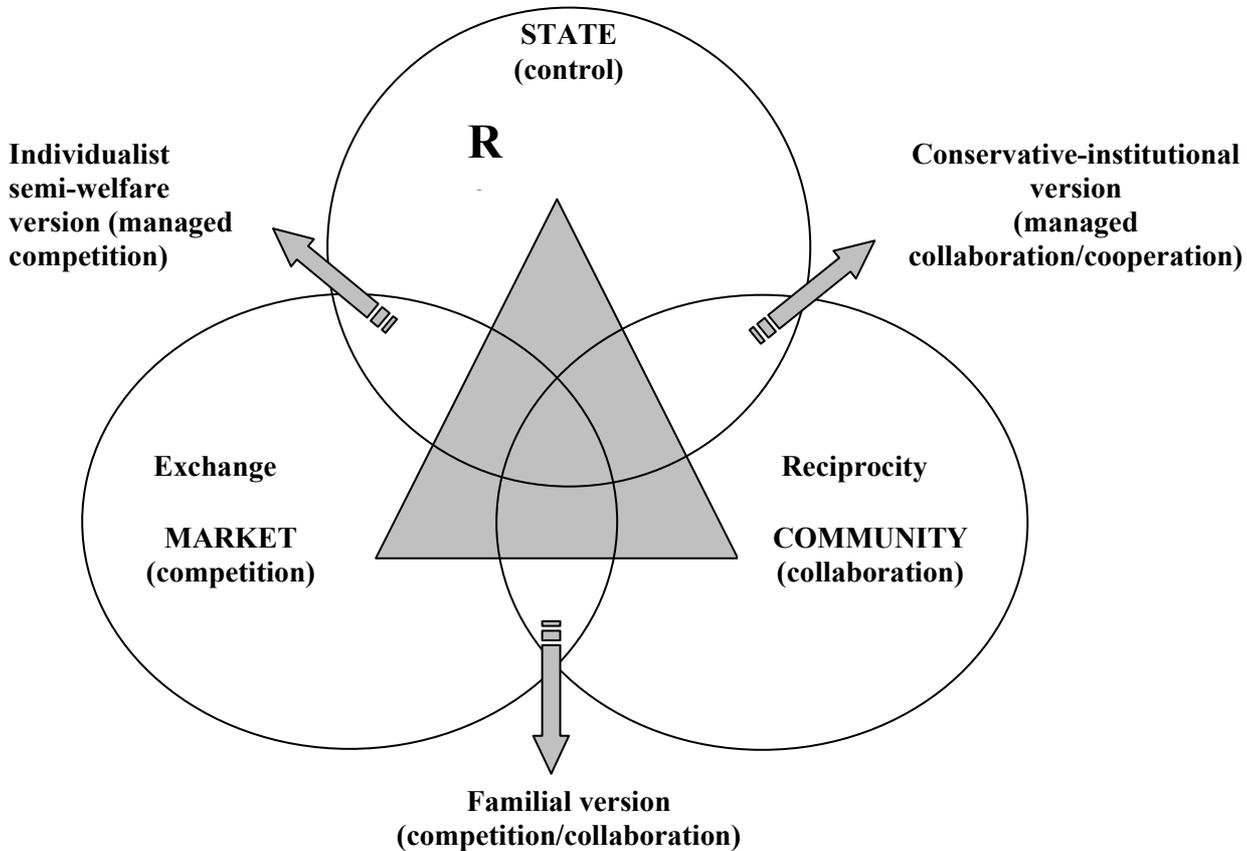
<sup>67</sup> Inpdap, Rapporto Annuale sullo Stato Sociale, p. 91, Roma, 2003.

<sup>68</sup> Sgritta G.B., *L’Europa delle generazioni: l’ipoteca del passato*, International Conference “Europe’s coming generations. Demographic trends and Social Change” organized by the European Observatory on the Social Situation, Demography and Family, Brussels, 27-28 September 2004.

<sup>69</sup> Inpdap, Rapporto Annuale sullo Stato Sociale, p.91, Roma, 2003.

<sup>70</sup> Benassi D., *Origini e sviluppo dei welfare state*, in: Kazepov Y., Mingione E., *La cittadinanza spezzata*, Armando Siciliano Editore, Messina, 1994.

Fig.1 Dominant welfare formulas and the new forms of regulation of health systems



These considerations, which are valid for social protection systems in general, are even more when dealing with healthcare systems which are in some ways even more complex and diversified than the former.

Until the eighties, European healthcare systems could be classified essentially into two models: on one side, there were the national health systems, of Beveridgean origin, typical of liberal (Great Britain) and Mediterranean countries (such as Italy, Spain, Portugal and Greece); on the other, the corporative system, with the social insurance and health insurance funds, typical of continental (France, Germany and the Netherlands) and Northern European social-democratic countries. Even back then, there were differences: the boundaries between the different healthcare models, and between the different ways of implementing them in each country, were not so clearly defined. Moreover, the changes and deep transformations which modern society has undergone in the last forty years have led most of the European Union countries, starting in the early eighties, to reconsider many of the choices previously made, and thus embark on an unprecedented season of reforms with respect to healthcare. A series of factors, which will be examined more closely in the following pages, have had an effect from a demographic and economic point of view, causing an increase in public health spending. Therefore, the rationalisation of resources and their more effective and efficient allocation has become a critical concern.

By adopting what is typically a demographic concept, one can state that the reforms in the field of healthcare have undergone two great “*transitions*”, one of which is still ongoing. The interpretation of these changes is naturally not unequivocal. The first transition, which started in the early seventies and continued in the first half of the eighties, was characterised by the introduction of spending control macroeconomic policies (OECD, 1996), the intensification of direct and indirect controls by the State (Mossialos, Le Grand, 1999), within a top-down political strategy, which developed, thus, from the top to the base (Bianchi, 1997).

This approach was driven by a “strong rationality” principle, which was based on the existence of a *deciding party able to establish objectives, order them, determine their implementation and capable of providing certain and coherent answers*<sup>71</sup>. This appears to be simpler in countries adopting National Health Systems (NHS), but it is also true for those countries with an insurance welfare system, where a central authority can impose, through direct and non negotiated processes, the controls it decides to enforce. In Ireland and Spain, cutbacks in costs have been made by reducing hospital personnel, regulating the prices of medicines and hospital admissions, reducing the number of hospital beds, acquiring new technologies and medical prescriptions. Therefore, “cutbacks”, “spending ceilings” and “tickets”, as well as “negotiations” (Germany) of health contributions, represent a more or less direct way of intervention in this strategy of control in healthcare spending. It is a strategy that soon revealed all of its limits, due primarily to: the inability to govern, at the central level, an open and complex system such as the healthcare one; the transfer of spending towards non controlled areas or towards private markets, with negative effects in terms of fairness and dissatisfaction of patients/citizens; as well as the decline of standards in the quality of services.

It was necessary, then, to define new regulatory forms, which would, this time, develop from the bottom to the top (bottom-up) (Bianchi, 1997) and be aimed at decentralising the management of services’ systems at the local level, as well as separating the financing and production of services. Therefore, within the first “transition”, a new season of reforms was launched in the eighties, which was characterised by shifting political actions from a macroeconomic level to a microeconomic one. The dominant strategy was one focused on rationalising resources (Pierson, 1999), and was pursued by a number of countries which relied on the so called budget setting, or on the capacity of the different players of the healthcare system to efficiently manage the available resources (Mossialos & Le Grand, 1999) (see Figure 1). OECD studies have highlighted how, in this phase, there was a proliferation of *managed competition* or administered competition strategies. In actual fact, administered competition draws from an internal market or quasi-market approach, which was introduced by Alain Enthoven in the United States and imported in Great Britain during the healthcare reform of 1991 carried out by the Thatcher Government. With quasi-markets, the financing of the healthcare system is separated from the production and supply of services. The State is still responsible for the financing and for the spending budget allocation to the decentralised public bodies, while the production and supply of services is entrusted to public and private bodies<sup>72</sup>. This separation should, in theory, initiate a virtuous process on the basis of which the healthcare agency entrusted by the State to manage the budget for a clearly defined number of end-users, will search for the most economic and highest quality services, while the producer will try to increase its profits by lowering production costs and keeping quality under control. In practice, this model has generated two versions: *negotiated competition* and *managed cooperation*. The former, based on the negotiation of prices of services between the financing bodies and suppliers, can easily lead to a lowering of quality and efficiency standards of services; the latter does not allow to keep under control the number of services and, thus, can easily lead to an increase in overall spending<sup>73</sup>. After the elections of 1997, the Labour Government focused on cooperation rather than on competition, as a strategy to reach its objectives in the field of health, and committed itself to eliminate the inequalities in healthcare. In countries such as Germany and the Netherlands, where there are insurance welfare systems, *managed competition* takes place by promoting competition among hospitals and insurance companies, *in the belief that the latter can provide for greater controls, maintaining, what seems to be, the distinctive quality of these reforms, that is the efficiency/effectiveness equation*<sup>74</sup>.

With the decline of economic predominant regulatory-distribution strategies that had characterised the reforms of the seventies and eighties, a new season of changes has begun, one which I believe can be traced back to a second “transition”, that is still going on. It is a season of reforms based on principles of reciprocity, solidarity and multilateralism, according to a dialogue programming model, which calls for a netlike system in which the economic component, while not disappearing, is placed within a wider framework, where equity and cooperation represent the priority to be pursued<sup>75</sup>. This leads to the emergence of new forms of dominant regulation systems: in addition to the three traditional systems of control, competition and collaboration (triangle) there are also those of managed competition, managed cooperation

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<sup>71</sup> Vicarelli, G., *ibid.*

<sup>72</sup> Corcione, A., *Le politiche sanitarie*, in: Pugliese E. (edited by) *Lo stato sociale in Italia*, Rapporto Irpps-Cnr 2003-2004, Donzelli Editore, Rome, 2004.

<sup>73</sup> *Ibid.*

<sup>74</sup> Vicarelli, G., *ibid.*

<sup>75</sup> *Ibid.*

and competition-collaboration (see Figure 1). Current healthcare policies can be placed in a meso-economic dimension, based on the principle of spending effectiveness, which are implemented through the following strategies: *managed cooperation* (OECD, 1996); *budget shifting*, which highlights the need to coordinate and possibly integrate the behaviour of the plurality of actors called to cover the costs and health protection activities<sup>76</sup>; as well as programming by *integrating settings* (Bianchi, 1997). In fact, in this highly innovative scenario, it is important to define a shared approach to examine problems and thus make it possible for all the social actors to participate actively in the common project of building possible solutions.

In Italy, for example, the reforms of 1992 and of 1999 were inspired by this second type of system, which replaces the principle of competition as the basis of the quasi-market, with that of cooperation among all the financing/purchasing and producing bodies. The State plays a very important role in defining and regulating the system, in establishing protection objectives, efficiency and effectiveness criteria, including also those for the quality of services and of performance, as well as in asking producers to cooperate in trying to reach certain specific objectives. The producers commit themselves to respect such objectives and to accept the assessment and the control of the services they provide<sup>77</sup>. Such agreements are usually signed for three or five years. In this way, even though market mechanisms are introduced, the public regulatory and control function of the public health system is safeguarded, so as to guarantee the fairness and the principle of solidarity on which it is based. The Scandinavian countries and the Blair Labour Government for the United Kingdom appear to be headed towards this model. Moreover, a more innovative approach appears to be that of competition- collaboration (see Figure 1).

### ***A glimpse at the healthcare systems and at the more recent reforms introduced by a number of EU-15 countries***

Before examining the challenges posed to the current European health systems, it is worthwhile to briefly describe them, indicating, if possible, the recent or soon to be approved reforms.

*Finland*, which can boast one of the most advanced and illuminated political and organisational strategy in public health, experienced between 1990 and 2000, a period of profound changes, both in terms of a reversal in the trend of employment rates, as well as in the acceleration of the urbanisation process, which is still in progress. Nevertheless, notwithstanding the unfavourable economic climate and the reduction in spending for overall social protection, Finland has been able to maintain the healthcare standards that had been guaranteed to the population up to that moment, by introducing a number of elements typical of the continental model (means testing)<sup>78</sup>. At present, in Finland, the jurisdiction over healthcare lies with the 455 urban and rural municipalities (an average of 11.000 people). However, even though the municipalities play an active role in planning and organising healthcare services, the State's power over healthcare policymaking is still strong.

The Finnish healthcare system relies primarily on public financing. Until 1992, assistance to out patients in public health centres was financed almost entirely with State funds. Since 1993, however, as part of the reform of State subsidies, the municipalities can make citizens pay for a number of services, deciding also the tariffs (up to a ceiling established by the Government). In order to receive hospital care (except in case of emergencies), patients need to have a request from a general practitioner of a health centre, even if a significant number of requests now come from the private sector<sup>79</sup>.

In recent years, the Finnish Government has introduced a series of measures aimed at strengthening and increasing the system of combined social and health services, developing government agencies, increasing the autonomy of local bodies, revising social safety benefits, strengthening relations between NGOs and the State for a better protection of public health, supporting scientific research, as well as continuing in its commitment to promote public health issues in European Union policies.

In *Denmark*, the National Health System is based on the principles of free and equal access to public health and hospital care for all resident citizens. The services include general practitioner and specialist services free of charge, as well as subsidised services for a number of specific consultations. Subsidies vary

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<sup>76</sup> *Ibid.*

<sup>77</sup> Corcione, A., *Le politiche sanitarie*, in: Pugliese E. (edited by) *Lo stato sociale in Italia*, Rapporto Irpps-Cnr 2003-2004, Donzelli Editore, Rome, 2004.

<sup>78</sup> European Observatory on Health Care Systems (WHO), *Health Care Systems in Transition*, Finland, 2002.

<sup>79</sup> Extracted from the summary of the working document edited by the General Directorate of Studies of the European Parliament, prepared by the National Psychologists Association.

according to the medical treatment utilised and are deducted from the health bill (card) of the beneficiary. There are two types of health insurance which resident citizens can sign up for: the first type, which is the more common one, allows citizens to select the family doctor or the health centre as their point of reference. Consultations of general practitioners and specialists are free of charge: however, the latter require a specific request from the family doctor. In this category of assistance, a number of services, such as dental, psychological, physiotherapeutic consultations are subject to a subsidy that is deducted from the patient's health bill (card). The second health insurance category does not require the selection of a family doctor or health centre, however, the amount of expenditure exceeding the corresponding service in the first category will be deducted from the patient's health bill (card). Private health insurance is utilised to integrate public health insurance; in fact, it is used in part to cover the costs sustained by the citizen within the public health care, and in part to cover the tariffs of hospital and private clinics' care. The health service is structurally decentralised; the local bodies take operative decisions in accordance to the guidelines provided by the Ministry of Interior and Health.

In *Sweden*, the system of healthcare services is also first of all a public responsibility. In the seventies, a devolution process was initiated, which led, during the nineties, to an important transfer of responsibilities to the local level. Currently, the system's structure is articulated along three levels: national, regional and local, and its financing is provided for through three channels: local taxation (mainly regional and municipal), which guarantees the healthcare coverage to all the residents, irrespective of their nationality; the system of national social insurance; and the private insurance companies<sup>80</sup>, which are still, however, a limited form of coverage, and play exclusively a complementary role to the public service. The outcome of this season of profound reforms has been an increase in the efficiency and productivity of the healthcare system at the regional and municipal level, as well as a progressive reduction in healthcare spending in terms of GDP. There are still, however, a number of problems, in particular with reference to the coordination of the different administrative levels, the fragmentation of management, as well as the general vision of the reform process. The Swedish health system presents a striking peculiarity with respect to the other European countries in terms of rationalisation strategies and in the choice of the priorities of the healthcare services. In fact, starting in 1992, a so called ethical platform was discussed and subsequently adopted to guide those in charge of health structures and systems in deciding the selection of priorities. Sweden does not have, therefore, a list or a "package" of health goods and services to include in or exclude from a hypothetical list of primary healthcare services, but rather a set of services grouped in five broad priority categories, defined according to three fundamental ethical principles<sup>81</sup>: human rights (human dignity); need and solidarity; cost-efficiency. The Swedish ethical platform is characterised, therefore, by the strong moral content of its principles, which it draws from and by the unequivocal refusal of the efficiency criterion which leads to economically evaluate the benefits<sup>82</sup>. Nevertheless, it is not clear at what level such strategies are actually implemented, in view of the fact that in the end it is the health personnel who makes the final decision<sup>83</sup>.

During the nineties, in countries such as France, Germany and the Netherlands, whose healthcare systems were based on the social insurance systems and where there already was a separation between insurance companies/funds and producers of services, elements of competition were introduced with respect

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<sup>80</sup> European Observatory on Health Care Systems (WHO), *Health Care Systems in Transition*, Hit Summary, Sweden, 2002.

<sup>81</sup> The first priority category includes the treatment of critical life threatening diseases and those illnesses, which if not cured, will lead to permanent disabilities or premature death, as well as the treatment of chronic diseases, terminal palliative care and the treatment of individuals with limited autonomy; the second category includes individual prevention during visits with medical services, rehabilitation, etc., as defined in the Law on health and medical services; the third category includes the treatment of the less critical and chronic diseases; while the fourth includes marginal cases and the fifth, the treatment for reasons different than diseases and injuries (extracted from Barilelli, A., Cavicchi, I., Dirindin, N., Mapelli, V., Terranova, L., *La sanità tra scelta e ragionamento. Efficienza economica ed equità: una ricerca delle compatibilità possibili*, p.130, Il Sole 24 ORE, Milano, 1999).

<sup>82</sup> Swedish Parliamentary Priorities Commission, 1995, p.20; European Observatory on Health Care Systems (WHO), *Health Care Systems in Transition*, Hit Summary, Sweden, 2002; Bariletti, A., Cavicchi, I., Dirindin, N., Mapelli, V., Terranova L., *La sanità tra scelta e ragionamento. Efficienza economica ed equità: una ricerca delle compatibilità possibili*, p.128, Il Sole 24 ORE, Milano, 1999.

<sup>83</sup> European Observatory on Health Care Systems (WHO), *Health Care Systems in Transition*, Hit Summary, Sweden, 2002.

to financing (Corcione A., 2004)<sup>84</sup>; a sort of “liberalisation” of the healthcare services, which sees the producers of those health services that are additional to the mandatory basic package competing against one another, with the aim of attracting customers on the basis of better prices and qualitative standards. In this manner, the freedom of choice of citizens increases, while the State maintains its role as regulator and guarantor of the system.

In *France*, for example, the healthcare system provides coverage to all residents and is financed primarily through a health insurance regulated by law. There are three coverage schemes: a general one, which assists 84% of the population; one for farmers, which offers protection to 7.2%; one for self employed workers which covers 5%. In 2000, France placed first in the ranking of healthcare systems of the World Health Organisation (WHO), both for the level of health of its population, as well as for the degree of the freedom of choice of patients and doctors, for the ease of access to treatment, for the lack of waiting lists and for the universal coverage of the population. This system has had high costs. Spending on health has never gone below 9-10 points of GDP. Therefore, also in France, in the second half of the nineties, a series of control measures were introduced, which included the reduction of compensations, an increase in the participation of citizens to health spending, a decrease in the number of doctors, an improvement in the planning at the hospital level and the control of pharmaceutical spending.

Subsequently, the Juppé reform of 1996 marked the passage from a social insurance model based on salaries to one financed with a greater fiscal levy on the basis of aggregate incomes (CSG - *General Social Contribution*). One should keep in mind that 87.8% of the health insurances' total revenues comes from the contributions of employees and employers and from the CSG. Moreover, at the same time, there has also been a significant transfer of responsibilities from health insurance funds to the State, accompanied by a gradual decentralisation process at the regional level. The increase of the costs for citizens has led to a growth of private insurance coverage. In 2000, 85% of the population utilised voluntary forms of integrated insurance health protection.

Even in *Germany*, the problems revolving around healthcare spending, which by the nineties had reached French levels, finally emerged, thus paving the way to the introduction of forms of regulation. The problem, in this case, concerns more the financing of the expenditure, rather than its magnitude. High levels of unemployment undermine the foundations of the social protection system, since social insurance is based exclusively on the contributions from employment. The German health system, until today, has in fact placed at the centre of its program initiatives aimed at favouring the free access and free choice of citizens with respect to treatment, the possibility of a wide range of service and care providers, as well as the use of the most advanced technologies, without having to worry too much about the cost-efficiency ratio and the problem of rationalising resources. Each citizen is free to choose which health insurance fund to sign up for, and is also free to decide which hospital facility to be treated in and/or which physician or specialist to be treated by. Since 1994, with the introduction of the Health Care Structure Act, the number of health insurance funds has significantly decreased and consequently competition has increased among them: by law, health insurance funds have the right and the duty to collect contributions from their members, as well as determine the amount needed to cover the expenditure. In 1996, the Health Insurance Contribution Exoneration Act imposed by law to all the health insurance funds contribution rates of 0,4%. The federal associations of the health insurance funds are responsible, on the other hand, to negotiate with the federal hospital organisation the list of cases and tariffs for each service, and with the federal association of physicians, the available services and their respective value. The most critical issues revolving around the corporate system, which have been included in the German political agenda, are: the changes to implemented in compensation mechanisms, which currently favour unnecessary or unneeded treatments; the evaluation of the technological resources being utilised; the fragmentation of healthcare into different sectors and among the taxpayers; the dispute between collectivism and competition. In 2002, in view of the growing deficit in the mandatory healthcare insurance system, the newly elected Social-democratic Government intervened by increasing contributions, thus determining a rise in the cost of labour. Moreover, the Government announced a reform, whose main guidelines have already been revealed. Hospitals should be allowed to provide specialised care, while health insurance funds will be able to stipulate individual contracts of clearly defined quality standards with individual physicians. For chronic diseases, there should be a strengthening of Disease

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<sup>84</sup> Concione, A., *Le politiche sanitarie*, in: Pugliese E. (edited by) *Lo stato sociale in Italia, Rapporto Irpps-Cnr 2003-2004*, Donzelli Editore, Rome, 2004.

Management programs, aimed at providing integrated hospital, outpatients and home care packages, based on common guidelines for all funds<sup>85</sup>.

The *Dutch* experience, whose health system is quite different from those of the other EU countries, represents a clear example of how difficult it can be to combine a market competitive approach with solidarity principles and fair financial accessibility; moreover, of how it is important to provide for an institutional framework within which to govern competition in the field of healthcare, that is in line with socially desirable conditions (competition and insurance). These are slow processes, whose objectives can be only reached in the medium to long term. The Dutch approach relates to the so called *administered competition* or *managed competition*, intended as a system within which the Government does not have direct control on volumes, prices and the productive capacity of the health sector, but instead its conduct is aimed at creating the conditions to prevent the undesired effects of the free market, which in turn, thanks to the Government's intervention, should be able to reach the objectives set by society with respect to health. Access to good quality healthcare is the main goal of such a health protection system. The Government's regulatory action is aimed, first of all, towards promoting mandatory health insurance for all citizens, with insurance premiums not linked to individual risk, antitrust measures, scrutiny on the selection mechanisms of insured individuals, quality control and access to information. Nevertheless, still today, the profound separation of the financing and organisational system of healthcare, within which one can find "coexisting" a mandatory health insurance scheme with one, that is much more extensive and private in nature, continues to have significant effects in terms of the acquisition of resources and fairness of the system.

In *Austria*, on the other hand, the delivery of health services and assistance, as well as the quality control of the system, represent one of the major public responsibilities. Over two thirds of the Austrian healthcare system is financed through contributions for social insurance, paid out by workers and from general taxation. Around a third, instead, is financed privately, directly from families. Healthcare services are provided by public bodies, non-profit organisations, private for-profit organisations and individuals<sup>86</sup>. Healthcare and programming activities are encouraged and supported through the cooperation with decentralised agencies and institutions, as well as partners, in particular, in primary healthcare. The experience and the know-how acquired in the field of healthcare are thus integrated with the support of local groups' independent assistance centres<sup>87</sup>.

In *Belgium*, the healthcare system is characterised by a strong heterogeneity and fragmentation. Such fragmentation derives largely from the division of responsibilities and from the very nature of the structure of the Belgian State. While there is a respect for safeguarding the individual freedom of choice among a range of service providers, healthcare is managed and provided privately by non-profit organisations, whereas the responsibility of their financing and supervision lies with the public sector, through the work of numerous administrative authorities. The *National Office of Social Safety* collects all the resources needed to finance the budget of all of the country's social protection sectors, including, therefore, healthcare. Since 1963, from this office depends the *National Institute for Sickness and Invalidity Insurance* (INAMI/RIZIV), a non governmental public body in charge of the organisational and financial management of the health insurance system, which also provides for the transfer of resources to the insurance mutualities of the different categories of citizens covered by mandatory social insurance<sup>88</sup>. There is also a Supplementary Fund, an additional public agency, for those people who do not want to sign up with any of the existing insurance mutualities. These insured citizens directly pay the assistance and services to the provider and will be reimbursed later by the insurance mutualities. These mutualities are private not-for-profit organisations, entrusted, however, with a public interest mission. Therefore, they are members of the executive and consultative commissions of the INAMI/RIZIV, which evaluate medical care, verifying that services have actually been carried out and that the requested tariffs are compliant with the existing laws<sup>89</sup>.

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<sup>85</sup> Inpdap, *Rapporto annuale sullo Stato Sociale*, Roma, 2003.

<sup>86</sup> European Observatory on Health Care Systems (WHO), *Health Care Systems in Transition*, Summary, Austria, 2002.

<sup>87</sup> Implementation of Agenda 21: *Review of progress made since the UN Conference on Environment and Development 1992*, New York, aprile 1997.

<sup>88</sup> The insurance mutualities are organized according to political or religious affiliation, into five national alliances: the National Alliance of Christian mutualities, the National Union of neutral mutualities, the National Union of Socialist mutualities, the National Union of Liberal mutualities and the National Union of the Free and Professional mutualities. The Christian and Socialist mutualities have a dominant position in the market, covering respectively 45 and 29% of the population.

<sup>89</sup> European Observatory on Health Care Systems (WHO), *Health Care Systems in Transition*, Summary, Belgium, 2002.

During the economic crisis of the seventies, a season of reforms was launched with the aim of containing costs and studying strategies for a more efficient allocation of resources within the healthcare system. Special attention was given to eliminating waste and the inefficient use of resources, introducing a number of exceptions to the tariffs regulations for the financing of the services, increasing the tickets paid by patients for a number of services, by setting the maximum growth rate allowed for healthcare spending at 1.5% per year<sup>90</sup>.

In *Italy*, the framework of the existing healthcare system continues to be the same one that was introduced with Law 833/1978, instituting the National Healthcare System (Servizio Sanitario Nazionale – SSN), with which the previous mutualistic compensation model was abandoned in favour of an integrated public model inspired by universalistic criteria of protection. The first two reforms of the system were brought about only at the beginning of the nineties, with legislative decrees n. 502 of 1992 (De Lorenzo Reform) and n. 517 of 1993, with which the way was opened to the entrepreneurisation of health facilities, thanks to the introduction of private management rules and the introduction of competitive mechanisms among service providers. The third reform was introduced with legislative decree n. 229 of 1999, thanks to which an attempt was made to reaffirm the meaning of global collaboration and cooperation, by limiting the areas of competition to the signing of agreements by the Regional Authorities and of contracts between the Asl (local health authorities) and private facilities<sup>91</sup>. It is a reform which contributed to reaffirm the option for a mixed model of healthcare assistance, which has accompanied the transition towards the completion of the regionalisation and entrepreneurisation processes of hospital facilities, already introduced at the beginning of the nineties. To this end, basic assistance levels (Livelli Essenziali di Assistenza – LEA) have been identified and the universalistic concept of the Law 833/78 was reaffirmed. Outside this approach macroeconomic compatibility principles are applied. There are, therefore, a range of incentives aimed at supporting complementary forms of healthcare assistance<sup>92</sup>.

*Spain*, starting in the second half of the eighties, has also gone through the transition from an insurance healthcare system to a public universalistic one, financed by means of taxation. In the same years, a gradual devolution process in favour of the Country's seventeen regions was initiated, which was completed in January 2002, with the recognition of the full autonomy of the ten regions that had been until then under the Central Government. Naturally, the decentralisation process was preceded by a profound reorganisation of the financing mechanisms. There was an increase in the incidence of the regions' revenues, which are responsible for seven of the thirteen national taxes<sup>93</sup>. Although the process of devolving responsibilities to regions has been completed, the State continues to play a central role in the Spanish healthcare system, in particular with reference to an equitable distribution of services and resources, the definition of a minimal services' package and of a pharmaceutical and human resources policies, the setting of quantity and quality standards for services; this in order to guarantee equal access across the country, as set forth in the recent law on Health Cohesion. A specific non-contribution scheme based on the proof of means is envisaged for the disadvantaged segment of the population. Even in Spain, the most important challenges of the future are represented by the search for a sustainable model to finance healthcare spending, the development of information in this sector, management self-sufficiency and the expansion of community and social assistance within the wider framework of the national healthcare system.

*Portugal*, without a doubt, embodies more than any other country in this group of nations, the commitment to search for policies capable of bringing together the actions of the public, private and social sector. After the introduction of the National Healthcare System (1974-1984), a decentralisation process was initiated, in which the private sector played a new role, especially with respect to the need to control public spending. Nevertheless, between 1996 and 2001, as a result of the severe imbalance which favoured the private component of healthcare spending, an attempt was made – through a series of reforms – to find a better balance between the public and private sphere within healthcare. “Portugal is divided into 5 health regions: one in the North (with headquarters in Oporto), one in the Centre, one in the South (with headquarters in Lisbon), one in Madeira and one in Algarve. The regional health Administrations are overseen by an Administration Council nominated by the Ministry of Health. Thanks to the reform, they will have strong management, finance and control decision making powers; while at the moment, there is no

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<sup>90</sup> *Ibid.*

<sup>91</sup> Zoli, M., *I sistemi di welfare state nei paesi dell'Unione Europea*, Luiss Lab on European Economics LLEE, January 2004.

<sup>92</sup> *Ibid.*

<sup>93</sup> Inpdap, *Rapporto Annuale sullo Stato Sociale*, Roma, 2003.

autonomy for local authorities. Work is being conducted to create a network of support units for chronic treatment and for the care of the elderly and chronically ill. Finally, with respect to the pharmaceutical policy, the objectives are: setting of reference prices for the active ingredient or for the therapeutic category; optimisation of medical prescriptions, also through the adoption of the common international designation; introduction of generic drugs. Citizens pay only for part of the medicines they purchase, while the rest is covered by the State (in the future by the Regions), through agreements with pharmacies. The 31 hospitals which will experiment the new form of entrepreneurial management will take on the form of joint-stock public companies<sup>94</sup>. This is, in fact, one of the more important challenges which Portugal is facing nowadays, in addition to the subsequent need to reduce the healthcare system's inequalities and the improvement in the coordination between primary and secondary healthcare. As in many other European countries, Portugal is also experimenting with forms of public management and public and private partnerships, with the aim of controlling the costs of the healthcare system.

Greece as well, instituted, under the direction of the first Socialist Government of Pasok in 1983, a national healthcare system with Law 1397/83, founded on the principle for which "*the state has a responsibility for providing health care to all citizens, regardless of their financial, social or professional status*". Since then, many significant steps forward have been made, and the results are confirmed by the statistics available at the European level. Greece has had to, first of all, bring the whole system of health treatments under the central responsibility of the State, in order to ensure fairness in the delivery of healthcare services; on the other hand, it assigned the planning of local healthcare to the 52 districts. It put an end to the "practice" of informal payments of treatments and significantly reduced the number of private care providers. To guarantee an efficient medical association, it prohibited combined private and public medical practice; it intensified the training activities aimed at strengthening the nursing component. In the following decade, the focus has been on improving the patient's freedom and possibility of choice: to this end, private clinics and hospitals have been allowed to open, and a number of restrictions on the private sector have been removed. One can see, therefore, that also in Greece, there is the same process already taking place in the other countries, which is aimed at identifying a better form of cooperation between the public and private sphere in the management of healthcare. The challenges that the Greek national healthcare system will be facing lie primarily in supporting and promoting higher standards of services and care; guaranteeing a wider access to treatment, even to those who are poorer.

In the *United Kingdom*, the National Health Service was created in the fifties to provide for universal and complete access to healthcare on the basis of need and not on the capacity to pay for services. The system was financed through general taxation and not through social insurance companies as in other European countries. In the nineties, some important changes were introduced by the conservative government of Prime Minister Margaret Thatcher, with the adoption of *internal market* systems or *quasi-markets*. However, it is a system which has shown its limits. In fact, according to the internal markets logic, local authorities would negotiate a specific budget with hospitals, on the basis of price and quality estimates. Patients would then be directed to selected hospitals, and hospitals could find themselves in the position to have to refuse patients in order to meet the budget. According to the new White Paper, patients will be able to go directly to hospitals, on the basis of qualitative data, and hospitals will be reimbursed at prices equal for all, on the basis of the covered market share. The same White Paper calls for measures supporting the transformation of hospitals into foundations, the use of project finance and the strengthening of private hospital care within the National Health Service. The support to the freedom of choice that the Blair Government intends to guarantee to its citizens will generate additional costs, of which the Government is perfectly aware of. To this end, and not in line with all the other European countries, the Labour Government has adopted a contribution increase of 1%. Moreover, it is also aware of the need to exercise control over the adequacy of the services provided<sup>95</sup>.

### ***Common challenges of European Union healthcare systems***

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<sup>94</sup> Extracted from a document which reports on the experience of an Italian delegation of regional counsel members, composed of the members of the III Commission on "Health and Assistance" and of the Special Commission on "the penitentiary situation and for the respect of the prisoners' civil rights", during a fact finding mission in Spain and Portugal. The aim was to study in depth the health and penitentiary systems, highlighting its more important features, as well as the elements that differentiate them from the Italian, and more specifically, the Lombardia Region ones (20-26 November 2002).

<sup>95</sup> Inpdap. *Rapporto annuale sullo stato sociale*, Roma. 2003.

If it is true that European union countries' national healthcare systems present the world's most advanced legislation, thanks to which it has been possible to provide universal coverage for illness and invalidity risks; extend life expectancy, as well as improve its quality; spread a culture of prevention and a wider health education; it is also true that, in practice, the norms are often not enforced: the unfavourable economic conditions of the nineties, the crisis of the different welfare models (including the more advanced ones), the need to deal with continually decreasing economic-financial and human resources, has put at great risk the rights of patients, end-users, consumers, families, weaker groups and ordinary citizens. This is the background against which the European Charter of Patients' Rights has taken its first steps; these are the conditions in which the European Union has begun taking on the common challenges that the former EU- 15 countries and the New Member States' healthcare systems are facing.

Among the challenges to be dealt with in the beginning of the Third Millennium: the impact of the ageing population on healthcare systems and on spending; the development of new technologies and of more advanced therapies; the meeting of patients' expectations.

The ageing of the population is linked to two phenomena which, in the last fifty years, have taken place at the same time: the reduction in fertility rates and the extension of life expectancy at birth. The population of the EU-15 countries is characterised by a very small young segment of the population. In some countries, like Italy, Germany, Greece and Spain, the elderly population (over 65) has overtaken in numbers the youngest one (0-14 years). In others, this process is taking place and will soon lead to the same results. Northern European countries, characterised by particularly generous welfare systems and sensitive to women issues, present, on the other hand, relatively young populations with the percentage of children in the 0-14 segment above 18%, and relatively high overall fertility rates, when compared to the other EU-25 member countries (Sweden, 1.6; Denmark, 1.8; Finland, 1.7). In these countries, assistance programs to help out in domestic care, as well as the introduction of measures aimed at encouraging flexibility of working hours and of labour contracts, have had a significant effect on reproductive patterns. This has not happened in other EU countries – such as Italy and, more in general, the Mediterranean area countries – where women have always had to divide themselves between domestic care and professional work, until they decided to change their reproductive behaviour by postponing the age of their first maternity or, giving it up altogether (Table 1).

**Table 1. Comparison of selected indicators typical of an ageing population European Union 25 – Year 2002**

<b>COUNTRIES</b>	Annual population growth rate (%)	Dependency ratio (%)	Percentage of population 60+ years	Overall fertility Rate	Life expectancy in health (in years) at birth – total population	Life expectancy at birth (in years) – total population
Austria	0.3	47	21.3	1.3	71.4	79.4
Belgium	0.3	53	22.2	1.7	71.1	78.4
Denmark	0.3	50	20.4	1.8	69.8	77.2
Finland	0.3	49	20.3	1.7	71.1	76.2
France	0.4	53	20.5	1.9	72.0	79.7
Germany	0.2	48	24.0	1.3	71.8	78.7
Greece	0.7	49	23.8	1.3	71.0	78.4
Ireland	1.0	47	15.3	1.9	69.8	77.1
Italy	0.1	49	24.5	1.2	72.7	79.7
Luxembourg	1.5	49	18.3	1.7	71.5	78.8
Netherlands	0.6	48	18.5	1.7	71.2	78.6
Portugal	0.2	48	21.1	1.5	69.2	77.1
Spain	0.4	46	21.6	1.2	72.6	79.6
Sweden	0.2	55	22.9	1.6	73.3	80.4
United Kingdom	0.3	53	20.8	1.6	70.6	78.2
Poland	0.1	44	16.6	1.3	65.8	74.7
Czech Republic	-0.1	42	18.8	1.2	68.4	75.8
Slovenia	0.2	42	19.8	1.2	69.5	76.7
Estonia	-1.4	48	21.5	1.2	64.1	71.1
Lithuania	-0.6	51	19.7	1.3	63.3	71.9
Slovakia	0.2	43	15.5	1.3	66.2	74.0
Hungary	-0.4	45	20.0	1.2	64.9	72.6
Latria	-1.3	48	21.8	1.1	62.8	70.3
Malta	0.7	47	17.5	1.8	71.0	78.1
Cyprus	1.2	51	16.1	1.8	67.6	77.3

The other factor of ageing is longevity. Technical-scientific progress in the medical-health field has favoured, in the last thirty years, the extension of life expectancy at birth, which in 2002 was over 78 years for the EU-15 countries. Longevity has also led to an increase in the so called “oldest” segment, which represents, on average, 3.6% of the population. Moreover, life expectancy in “good health” and/or without disabilities has also increased.

In 2005, Eurostat estimates that most of the former 15 Member States will have an elderly population more numerous than the young one, and a percentage of people of 80 years or more, on average, above 4% of the total. Moreover, in the next fifteen years, the greatest increase in the population will take place in that age category, in so much that the over 80 will grow by 50%. In Italy, in particular, in 2005, it is estimated that there will be the lowest rates of the EU with respect to the young population (13.9%), and highest for the elderly (19.6%) and the “oldest” (4.9%). Furthermore, the dependency indexes will increase, even if fertility rates in Europe are expected to grow (from 1.47 in 2001 to 1.56 in 2002)<sup>96</sup>. These are values that remain, nevertheless, below the substitution level of 2.1, needed to guarantee a generational replacement.

What can one say about the new Member States of the EU which have joined in May 2004<sup>97</sup>?

Compared to the situation described above, these countries have a younger population, due largely to the high fertility rates reached in the seventies and eighties (the population of 65 years and over represents, on average, 13%, children under 15 years, 19%). Nevertheless, the impact of these countries’ birth rates on the EU-25 will be quite weak and the trend towards a progressive ageing of the population will not vary<sup>98</sup>. By examining the estimates for 2005 for the new Member States, one can, in fact, observe a decrease of the younger population, due primarily to a reduction in overall fertility rates; a trend which will continue over time, in so much that the number of elderly in 2020, in these countries, will reach the current levels of the former EU-15 member states. Probably, therefore, in the medium and long term, the new Member States will contribute to strengthening the process of demographic decline, instead of slowing it down; a process which has already been going on for quite a while in the former EU-15 member states, even if underestimated.

In fact, the EU population has aged and continues to age (Table 2). It is an almost “zero growth” population, supported by migration flows which, in over a decade, have represented the major factor of demographic growth. In the former EU-15 countries, in 2001, the annual net migration rate was, on average, 3.1 for 1,000 inhabitants, representing around 74% of the overall demographic growth<sup>99</sup>.

**Table 2. Demographic structure of the EU-25 Member States Year 2000 and forecast to 2005**

COUNTRIES	2000			2005		
	% 0-14	% 65+	% 80+	% 0-14	% 65+	% 80+
Austria	16.7	15.5	3.5	15.3	16.5	4.4
Belgium	17.4	17.0	3.7	16.8	17.7	4.6
Denmark	18.3	15.0	4.0	18.5	15.3	4.2
Finland	18.1	14.9	3.4	17.3	15.8	3.9
France	18.8	16.0	3.7	18.4	16.3	4.5
Germany	15.6	16.3	3.5	14.4	18.6	4.2
Greece	15.1	17.5	3.6	14.3	19.0	4.1
Ireland	21.5	11.3	2.6	20.4	11.4	2.8
Italy	14.3	18.1	3.9	13.9	19.6	4.9
Luxembourg	19.0	13.7	2.7	18.9	13.8	3.1
Netherlands	18.5	13.6	3.2	18.2	14.1	3.6
Portugal	16.7	15.6	3.0	16.6	16.4	3.6
Spain	14.6	16.8	3.6	14.0	17.2	4.4
Sweden	18.3	17.4	5.1	17.0	17.7	5.6
United Kingdom	19.1	15.9	4.1	17.9	15.9	4.4
Poland	19.2	12.1	2.0	16.4	12.9	2.5

<sup>96</sup> European Commission, *The social situation in the European Union*, Brussels, 2003.

<sup>97</sup> These are: Poland, Czech Republic, Slovenia, Estonia, Lithuania, Slovakia, Hungary, Latvia, Malta and Cyprus. These countries joined the Union on May 1<sup>st</sup> 2004. In 2007, Bulgaria and Romania are expected to join the EU; in that same year Turkey is also expected to join.

<sup>98</sup> European Commission, *The social situation in the European Union*, Brussels, 2003.

<sup>99</sup> *Idem*.

Czech Republic	16.4	13.8	2.3	14.6	14.2	3.1
Slovenia	15.9	13.9	2.2	13.9	15.4	3.0
Estonia	18.0	15.1	2.6	14.8	16.7	3.2
Lithuania	20.1	14.0	2.4	17.6	15.2	3.2
Slovakia	19.5	11.3	1.8	17.0	11.7	2.4
Hungary	17.0	14.6	2.5	15.5	15.1	3.1
Latvia	18.0	15.1	2.6	14.4	16.8	3.2
Malta	20.1	12.4	2.4	18.3	13.4	2.9
Cyprus	23.1	11.5	2.6	20.8	12.2	2.9

Source: United Nations Population Division, Database 2002

An ageing population must necessarily support greater costs in order to meet the growing demand for social and health care. Such demand could grow even further, as a result of the profound transformations taking place in the family structure in many countries. People get married less and later. Unions are more fragile and the number of divorces increase. EU statistics show a trend of increasingly smaller households, made up of a couple and, at the most, one child, or of people living on their own at all ages. There is also a strong increase in the number of single parent households, generally the mother, with one or more children. This family profile is quite common even in the new Member States, with the exception of Poland and Cyprus.

The awareness of the ageing process and of its impact in terms of social and economic policies has grown significantly in recent years. The EU is about to adopt measures to tackle these problems both at the national and European level. Action must be taken on different issues: improvement of public finance, employment, social welfare and healthcare, in a way that the respective social objectives can be met even when the pressure from the ageing process will increase. If the scenarios prepared by Eurostat should come about, public spending for healthcare could go from 0.7 to 2.3% points of GDP between 2000 and 2050. The ageing of the population, therefore, would determine an increase in spending, especially for long term care. To cope with such demands, healthcare facilities, their financing mechanisms, as well as the organization of services being provided, will necessarily have to evolve: there will be a greater need for more qualified personnel, since facilities and family networks, which are less numerous and more unstable, are no longer capable of providing support and solidarity<sup>100</sup>.

The second common challenge EU countries face is represented by the rapid progress of medical science, both with respect to the technical innovation of preventive diagnostic instruments and to the clinical and therapeutic strategies to be developed to cure many of this century's diseases. Such innovations could provide patients with many advantages in terms of reducing pathological risks, as well as for preventive treatments. Nevertheless, the implementation of these new technologies and therapeutic strategies presents costs that are higher than the current financing possibilities of the different healthcare systems, especially at a time when expenditure control represents the principal criteria when deciding the allocation of the available resources. For this reason, it has become necessary to encourage the development of transparent and efficient evaluation mechanisms in order to guarantee to the greatest number of patients accessibility to these new products or therapies<sup>101</sup>.

The third challenge concerns a critical issue: meeting patients' expectations. It is a challenge which has been effectively exemplified in the fourteen rights of the European Charter of Patients' Rights.

The available information at the European level, as well as the numerous studies conducted internationally on the demand for health protection goods and services, have emphasised the strong correlation among socio-economic status, citizens' level of education and that same demand. The different countries' healthcare services, therefore, should conduct more preventive actions and health education activities of the general population in order to increase the awareness of the avoidable risks and reduce the use of expensive treatment for diseases that otherwise could have been prevented in time. Citizens should then be allowed to take advantage of the information communication and diffusion systems on the available technological and therapeutic opportunities, so to freely exercise their right to choose among the different procedures and service providers<sup>102</sup>. In order for this to take place, it is necessary that the patient/citizen/end-

<sup>100</sup> Communication of the European Commission, *The future of healthcare services and care for the elderly: guarantee accessibility, quality and financial sustainability*, 5 December 2001, COM (2001) 723 def.

<sup>101</sup> *Ibid.*

<sup>102</sup> Fifth right of the European Charter of Patients' Rights, *the Right to free choice*.

user be recognised as the principal actor and active player in the healthcare system: strategies placing the individual at the centre of every prevention, assistance and treatment process should be encouraged.

With respect to these challenges, the European Commission has set three long term goals as part of its commitment in favour of health protection: accessibility, quality and sustainability<sup>103</sup>.

The development of a European cooperation on these goals is linked to the fact that the organisation of national health systems, the manner in which they are financed and the planning of the services being offered, are all aspects of public health which, though continuing to be the responsibility of the individual member states, are being tackled more and more within a general framework which is affected by a whole range of EU policies<sup>104</sup>.

*Access to healthcare services* is a right set forth by the European Union Charter of Fundamental Rights, and the different national governments are committed to maintaining universal and complete access to care, in contrast to and despite the increase of costs<sup>105</sup>. The national action plans promoting social integration aim at: encouraging prevention and health education; easing the spending burden for healthcare for people with low incomes; planning for measures to meet the health requirements of people belonging to disadvantaged sectors.

The *guarantee of quality services* poses, moreover, other critical issues in terms of the relation between costs and benefits. Setting quality standards is quite difficult, because of the diversity of existing healthcare systems, operating facilities and the levels services offered, as well as of the heterogeneity of the available technological and therapeutic instruments. A careful evaluation and monitoring activity in the field of health, through the definition and construction of a wide set of comparable indicators, would allow the identification of *best practices*, which would contribute to improving existing health systems. This is the direction which WHO's European Observatory on Health Care Systems has taken; a unique instrument for a qualified and expert analysis of the world's health systems. The Observatory produces, in fact, interesting information on: the allocation for health spending; the organisational structure and the management of the different systems; the method of financing of healthcare and the composition of this expenditure; the combination of the services being offered; the legislative reforms in this field. Nevertheless, as it will be clear later on, there is still no information which would allow to assess how much of the benefits generated by these systems actually do reach citizens, thus fulfilling their citizenship rights. There are rights, such as the right to information, to consent, to privacy, to free choice, to avoid unnecessary pain, to complain, as well as to respect the patients' time, for which very little is known, but which are the essence of a healthcare system created for individuals and citizens.

Finally, the *issue of sustainability*. Providing universal care at high quality standards requires adequate financial resources. The economic crisis of the nineties, which has affected all the European countries, together with the generalised increase in health expenditure, has led many Governments to launch the reform of their healthcare systems. These reforms have already impacted on the demand and supply side; in the first case, by increasing the contributions or costs to be covered by the end user; in the second case, by putting an end to the allocations to service providers and by contractualising the relations between citizens and service providers. The focus of the structural measures on the first or second area of reforms has produced new patterns in healthcare systems, by introducing arrangements such as managed competition, managed cooperation or competition-cooperation.

In order to illustrate how the issue of sustainability represents a critical problem common to the different national healthcare systems and, more generally, to European social protection models, one simply needs to observe that the spending for health is the second component, in order of importance, of total social spending, of which it represents 27%, equal to 7.4% of the overall Union-15 GDP (Tables 3 and 4). One should keep in mind that in the sixties, health spending in the OECD countries was 3.8% points of GDP, while in the nineties it had already reached 8%. However, the greatest increase took place between 1960 and 1980, with a positive percentage variation of 12.02%; while in the following period 1980-1997, the increase

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<sup>103</sup> This communication of the European Commission follows the conclusions of the European Council of Lisbon (March 2002), in which the need for a reform of the social protection systems to provide quality assistance was emphasised, and complies with the request of the European council of Göteborg (June 2001) to prepare a report for the European Council that was going to take place in the spring of 2002, containing recommendations in the field of healthcare and, more specifically, in the care for the elderly.

<sup>104</sup> *Ibid.*

<sup>105</sup> Communication of the European Commission to the Council, the European Parliament, the European Economic and Social Committee and the Committee of Regions on the "Proposal of a joint report – Healthcare services and assistance to the elderly: national support strategies to guarantee a high level of social protection", COM (2000) 774 def.

stayed below 7%; an effect of the resources' rationalisation policies launched at the beginning of the nineties<sup>106</sup>. More recently, in 2001, the increase, with respect to 2000, has been of 0.8% of the total social spending and of 0.2% of GDP. In fact, in recent years, there has been a further decrease in the growth rates of healthcare spending, as a result of the measures adopted by many Governments to control this component of overall social spending and the growth in importance of the private sector<sup>107</sup>. The incidence of healthcare spending on social spending continues to be, on average, lower in the Northern European countries (19.7% for Denmark and 23.7 for Finland), as well as in Greece and in Italy, where the private sector has expanded its role. Sweden represents an interesting exception; its healthcare spending, with respect both to total social spending (28.6%) and GDP (8.9%), is still today very high (see Tables 3 and 4). It is likely that Sweden's adoption of the already mentioned *ethical platform* and the explicit refusal of the efficiency criteria and of the economic evaluation of benefits, will make it more difficult to control public healthcare spending.

Levels of incidence higher than the European average (27%) are reported in Spain (29.3%), the Netherlands (28.4%), Portugal (27.5%), Germany (27.7%) and France (27.7%); in Ireland, healthcare spending receives the highest public budget allocation, reaching even 41% of the total social spending (see Table 3). In Ireland, whoever expresses the intention to settle in the country for at least a year is considered a resident and as such, on the basis of earned income and the means testing, can alternatively partake in two healthcare categories: one with total coverage, the other with partial coverage. Free medical care is guaranteed to those who have a low income, on the basis of means testing. Hospital services are provided at reduced rates even to those with high incomes.

Even in France, the healthcare system, which is included among the best European practices, has always cost a lot and continues to cost, even if for the first time, after many years, healthcare spending has dropped from 9% to 8.3% of GDP. As already mentioned before, France along with many other European countries, has launched spending control strategies. The same can be said for Germany, even if these two countries have two very different versions of the corporate model. France, together with Belgium, has the social oriented version, in which a set of non market services are institutionalised outside the family unit; Germany, like Austria, *has a more family oriented version, where ample space is left to a regulation of non market services, favouring the allocation of financial resources to women, so that they can take on their domestic role more easily*<sup>108</sup>.

**Table 3. Breakdown of social spending for category. Year 2001 (values in percentage of total social spending)**

	Illness & health	Disability	Family & children	Unemploy.	Social housing	Social exclusion	Elderly & Old people	Administrative spending	Other expend.	Social spending Total
EU-15	27.0	7.7	7.7	6.0	2.0	1.4	44.2	3.3	0.8	100.0
Austria	24.0	7.9	10.3	4.9	0.3	1.7	48.1	1.6	1.3	100.0
Belgium(1)	23.6	8.5	8.4	11.0	0.0	1.5	41.2	3.6	2.3	100.0
Denmark	19.7	12.1	12.9	9.7	2.3	3.6	36.9	2.9	0.0	100.0
Finland	23.7	13.3	11.8	9.5	1.1	2.0	35.5	3.0	0.0	100.0
France(2)	27.7	5.7	9.1	6.8	2.9	1.3	41.5	4.0	1.1	100.0
Germany (including former GDR from 1991) (2)	27.7	7.5	10.0	7.9	0.7	1.7	40.9	3.5	0.2	100.0
Greece	25.0	4.8	6.7	5.8	2.7	2.3	49.8	2.8	0.1	100.0
Ireland(2)	41.5	5.0	11.9	7.9	3.3	2.2	23.7	4.2	0.2	100.0
Italy(2)	25.1	5.5	3.8	1.5	0.1	0.2	59.8	2.9	1.1	100.0
Netherlands (2)	28.4	10.8	4.1	4.7	1.3	5.0	39.0	5.2	1.5	100.0
Portugal (2)	27.5	10.8	5.0	3.2	0.0	1.1	40.2	2.7	9.4	100.0
Spain(2)	29.3	7.4	2.5	12.6	0.9	0.7	44.2	2.2	0.2	100.0
Sweden(2)	28.6	12.1	9.4	5.5	2.0	2.2	38.3	2.0	0.0	100.0
United Kingdom (2)	27.1	9.1	6.5	2.8	5.4	0.7	44.9	2.9	0.6	100.0

Source: Eurostat

1= estimate

2= forecasted values

<sup>106</sup> Vicarelli, G., *Controllo, competizione e collaborazione nei sistemi sanitari europei. Politiche ed assetti organizzativi a confronto*, Facoltà di Economia dell'Università degli Studi di Ancona, Ancona, 2001.

<sup>107</sup> Zoli M., *I sistemi di welfare state nei paesi dell'Unione Europea*, Luiss Lab on European Economics LLEE, January 2004.

<sup>108</sup> Laville J.L., 1999, *Il terzo settore: un ambito di analisi per la sociologia economica*, in: "Sociologia del Lavoro", n.73, pp.209-229.

**Table 4. Breakdown of social spending for category. Year 2001 (values in percentage of GDP)**

	Illnesses & health	Disability	Family & children	Unemploy.	Social housing	Social exclusion	Elderly & Old people	Administrative spending	Other Expend.	Social spending Total
EU-15	7.4	2.1	2.1	1.6	0.5	0.4	12.1	0.9	0.2	27.5
Austria	6.8	2.2	2.9	1.4	0.1	0.5	13.7	0.4	0.4	28.4
Belgium (1)	6.5	2.3	2.3	3.0	0.0	0.4	11.3	1.0	0.6	27.5
Denmark	5.8	3.6	3.8	2.9	0.7	1.1	10.9	0.8	0.0	29.5
Finland	6.1	3.4	3.0	2.4	0.3	0.5	9.1	0.8	0.0	25.8
France (2)	8.3	1.7	2.7	2.0	0.9	0.4	12.4	1.2	0.3	30.0
Germany (including former GDR from 1991) (2)	8.3	2.2	3.0	2.4	0.2	0.5	12.2	1.0	0.1	29.8
Greece	6.8	1.3	1.8	1.6	0.7	0.6	13.6	0.8	0.0	27.2
Ireland (2)	6.1	0.7	1.7	1.2	0.5	0.3	3.5	0.6	0.0	14.6
Italy (2)	6.4	1.4	1.0	0.4	0.0	0.0	15.3	0.7	0.3	25.6
Netherlands (2)	7.8	3.0	1.1	1.3	0.4	1.4	10.8	1.4	0.4	27.6
Portugal (2)	6.6	2.6	1.2	0.8	0.0	0.3	9.6	0.6	2.3	23.9
Spain (2)	5.9	1.5	0.5	2.5	0.2	0.1	8.9	0.4	0.0	20.0
Sweden (2)	8.9	3.8	2.9	1.7	0.6	0.7	12.0	0.6	0.0	31.3
United Kingdom (2)	7.4	2.5	1.8	0.8	1.5	0.2	12.2	0.8	0.2	27.2

Source: Eurostat

1= estimate

2= forecasted values

The public component of health spending is greater in Denmark, Sweden and the United Kingdom: these are insurance based healthcare systems with a universalistic orientation, which have opted for managed competition – that in a number of cases, has burdened even more the share of public healthcare spending – while effectively working on controlling pharmaceutical spending, which is the lowest among the different European countries. Private integrated health insurance is more widespread in France (12.9%), where the increase in healthcare costs for citizens has led to its noticeable expansion, and in the Netherlands (16.5%), where managed competition strategies have revealed the difficulties of trying to combine market logic with equity of access to healthcare (see Table 5).

**Table 5. Public, private and pharmaceutical spending of the total healthcare spending. Public pharmaceutical spending as percentage of total pharmaceutical spending. Year 2002 (% values)**

COUNTRIES	Public health expenditure as % of total health expenditure (HFA2002)	Private insurance as % of total expenditure on health (OECDHdata2004) (year 2002)	Total pharmaceutical expenditure as % of total health expenditure (H4A2002)	Public share of pharmaceutical expenditure (OECDHdata2004) (year 2002)
Austria	69.9	7.4	16.1	74.9
Belgium	71.2	-	-	-
Denmark	83.1	1.6	9.2	52.5
Finland	75.7	2.5	15.9	53
France	76.0	12.9	20.8	67
Germany	78.5	8.4	14.5	74.8
Greece	52.9	-	15.3	71.5
Ireland	75.2	6.3	11	84.2
Italy	75.6	0.9	22.4	52.1
Netherlands	-	16.5	10.4	-
Portugal	70.5	-	-	-
Spain	71.4	4.0	21.5	73.6
Sweden	85.3	-	13.1	69.3
United Kingdom	83.4	-	-	-

Source: Health for All Database, 2002; OECD Health Database, 2002

### ***The challenge of the Charter of Patients' Rights: from proclamation to implementation. Unresolved issues***

Despite the solemn declarations on the “European Social Model”, there are still a great number of constraints preventing universal access to healthcare from actually being implemented<sup>109</sup>. National

<sup>109</sup> Preamble of the European Charter of Patients' Rights, Brussels, November 2002.

legislations announce rights that are often not guaranteed in medical practice and in everyday healthcare services.

In this context, information plays a critical role in constantly assessing the level of implementation and the effectiveness of citizens' rights of patients. In the last ten years, giant leaps forward have been made in constructing indicators to monitor the many aspects of existing healthcare systems in the different EU countries, with respect to their organisational and management structure, to the financing and allocation mechanisms of resources, to the system of assistance and services, as well as to the current reform strategies. These results have been reached thanks to the joint efforts of numerous international health organisations and national statistics agencies of many EU countries. The statistics compiled by Eurostat, OECD and WHO, and more specifically by the European Observatory on Health Care Systems, represent today the only source of structured and comparable information, which can be utilised when analysing the current transformations and the degree of implementation of citizens and patients rights.

More in detail, the data reported in the tables that have been selected to describe the different rights of the Charter come from Eurostat's database, WHOSIS Informative System, WHO's Health for All System, as well as from OECD's Health Indicators System.

### ***1. The right to preventive measures***

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

With reference to the right to preventive measures, there are indicators available on: vaccinations against the principal infant and non infant infectious diseases, preventive and screening tests for cardio-circulatory diseases, breast cancer and tumour markers, monitoring of hypertension, coverage for prenatal care, monitoring of lifestyles – such as smoking, alcohol and nutrition –, measures of healthy life expectancy at birth and at 60 years. Even the rates of incidence of a number of infectious (hepatitis, pertussis, measles, rubella, mumps, tuberculosis, HIV-AIDS) and tumoural (breast, lung, digestive track, colon, etc.) diseases can be considered indirect indicators of the spread of preventive measures adopted in the different countries. Health prevention includes measures aimed not only at avoiding the onset of a number of diseases, by controlling and reducing the factors of risk, but also at preventing their diffusion or reducing their effects once they have appeared. Primary prevention is conducted on healthy subjects to prevent the appearance of different types of pathologies. Vaccinations of the infant population falls within this form of prevention. In Europe, the survey systems for infant vaccinations are quite advanced and cover almost the entire population (see Table 7).

The percentage of coverage for almost all the types of vaccinations being considered, are greater than 90%. Usually, higher percentage values are reported for the so-called mandatory vaccinations, while lower values are associated with diseases for which preventive measures are optional. Second and third level preventive measures are instead aimed at stopping or slowing down the development of existing diseases, as well as the effects linked to them, through early detection and the introduction of appropriate therapeutic strategies. Third level prevention is also directed to reducing recurrent diseases and chronic processes. Secondary prevention includes manual and image diagnostics (i.e.: breast cancer), screening programs for heart check-ups and the monitoring of tumour markers. The prevention of breast cancer, unfortunately, still does not seem to be too widespread, especially in the older age categories, which are the most at risk (45-64 years). The most effective approach is provided by the diffusion of manual preventive testing, which represents the first measure adopted for the possible early detection of the appearance of this type of tumour. In a number of countries (Austria, Belgium and Germany), manual preventive testing is utilised by over half of the women between the age of 35-44, as well as by the younger ones (25-34 years), for which x-ray exams (mammography) are not recommended, unless otherwise clinically prescribed. Mammography is an invasive procedure and poses for women a series of problems, also of a psychological nature, therefore it is advisable to utilise it only when there is clear clinical evidence requiring a more thorough examination. Because older age represents one of the principal factors of risk for breast cancer, the use of image diagnostics (mammography) is more widespread among women between the age of 55-64 and in a number of countries (Finland and the Netherlands), 65% of them state that they make use of it. If one considers that while between the age of 30 and 40 the probability of becoming ill is 4-5%, after the age of 40 it increases as the years go by, to reach its highest level between the age of 50 and 70 (80%). Nevertheless, for this vulnerable age category there are significant variations in the spread of this form of prevention, so much that in Denmark and Germany only one out of five women utilise this type of exam; in Ireland and Greece, around 30%; in Belgium, Italy, Portugal, Spain and the United Kingdom, well over 40%; in Sweden, France and Austria, over 50% (see Table 6).

The only exception is Austria, where there is a highly efficient primary and secondary preventive system, guaranteed in all phases of the life cycle. Public medical care offers preventive programs, both for mothers and their children, as well as for school age children and, more in general, for adults. A number of general medical check-up services for adolescents (15-19 years) and adults (19 years and over) are provided as mandatory benefits which are covered by the social and healthcare insurance funds. The aim of these preventive measures is to strengthen the population's health and improve early detection diagnosis.

**Table 6. Secondary level indicators aimed at measuring the percentage of women utilising breast cancer preventive exams, through instrumental and manual diagnostic devices. Year 2002 (% value)**

COUNTRIES	% of women 25-34 reporting preventive examinations as mammo Breast by X-ray (mammography)	% of women 35-44 reporting preventive examinations as mammo Breast by X-ray (mammography)	% of women 55-64 reporting preventive examinations as mammo Breast by X-ray (mammography)	% of women 25-34 reporting preventive breast examination by hand	% of women 35-44 reporting preventive breast examination by hand	% of women 55-64 reporting preventive breast examination by hand
Austria	23.1	46.0	55.7	53.7	52.4	49.4
Belgium	7.2	16.0	45.0	37.8	45.3	41.7
Denmark	3.5	7.6	20.7	9.4	17.1	18.3
Finland	3.1	11.0	65.2	23.5	28.0	39.1
France	5.7	16.4	57.1	24.5	31.1	32.7
Germany	11.4	18.5	26.3	58.4	58.8	58.3
Greece	2.2	14.6	30.7	19.8	23.6	26.7
Ireland	1.8	7.0	31.7	27.0	23.3	39.7
Italy	6.5	30.0	48.6	22.8	35.0	36.5
Netherlands	4.3	7.3	66.7	8.7	10.0	16.1
Portugal	20.6	43.0	43.6	26.8	29.1	28.2
Spain	10.1	17.9	47.6	28.3	23.8	22.0
Sweden	4.9	10.5	51.2	2.9	8.4	18.6
United Kingdom	2.2	8.5	41.5	21.2	18.5	19.8

Source: Eurostat Database, Eurobarometer Survey, 2002

**Table 7. Indicators measuring the degree of diffusion of vaccinations for the prevention of a number of infant infectious diseases. Year 2002 (values in % of total)**

COUNTRIES	% of infants vaccinated against diphteria	% of infants vaccinated against tetanus	% of infants vaccinated against pertussis	% of infants vaccinated against measles	% of infants vaccinated against poliomyelitis	% of infants vaccinated against invasive disease due to Haemophil	% of infants vaccinated against mumps	% of infants vaccinated against rubella
Austria	82.6	82.6	82.6	78.5	82.5	82.2	78.5	78.5
Belgium	90.0	90.0	90.0	75.0	95.0	-	-	-
Denmark	98.1	98.1	98.1	99.0	98.1	85.7	99.0	99.0
Finland	98.1	98.1	98.1	95.8	95.3	95.6	95.6	97.0
France	98.0	98.0	98.0	85.0	98.0	86.0	84.0	84.0
Germany	96.4	96.4	96.4	91.6	96.4	90.8	91.4	86.1
Greece	88.0	88.0	88.0	88.0	87.0	-	-	-
Ireland	81.5	81.5	81.5	72.5	82.5	82.7	72.5	72.5
Italy	97.0	97.0	97.0	77.0	99.0	84.0	80.0	80.0
Netherlands	97.5	97.5	97.5	96.0	97.5	96.4	96.0	96.0
Portugal	93.8	93.8	93.8	91.9	93.8	93.9	91.9	91.9
Spain	96.2	96.2	96.2	96.6	96.4	92.0	97.1	-
Sweden	98.3	98.3	98.3	90.5	98.5	98.2	90.5	90.5
United Kingdom	91.0	91.0	91.0	83.0	91.0	91.0	83.0	83.0

Source: Health For All Database, World Health Organization, 2003.

**Note:** The data comes from the different national registries or notification systems. With respect to data completeness, in a number of countries, the data may be incomplete or not available; in reference to comparing vaccinations there is a problem linked to the denominator adopted to construct the indicator, which may differ from country to country. For example, the reference infant population that falls under mandatory vaccination may change

On secondary prevention, the Netherlands appears to be among the more sensitive countries with respect to developing a culture of prevention (at least in the age categories at risk): in more recent years, in fact, the spread of a number of risk factors, such as smoking habits, alcohol abuse and irregular dieting, when associated with hypertension, obesity and insufficient physical activity, has had a significant impact on the general health conditions of the population. In this country, there is the gate-keeping system, in which citizens can only access to the family doctor, who represents the main filter for passing on any health problem to specialists. In Austria and the Netherlands, around one fifth of the population, between the age of 25 and 54, reports having undergone heart check-ups and tests for the evaluation of tumour markers, while in most of the other EU countries not even one tenth of the reference population has done so (see Table 8).

**Tab.8 Secondary preventive indicators aimed at measuring the share of population which have undergone screening programs for the early detection of cardiac and tumoural diseases. Year 2002 (% values)**

COUNTRIES	% of population 25-34 participating preventive screening programme for heart check-up	% of population 35-44 participating preventive screening programme for heart check-up	% of population 45-54 participating preventive screening programme for heart check-up	% of population 25-34 participating preventive screening programmes for cancer test	% of population 25-34 participating preventive screening programmes for cancer test	% of population 25-34 participating preventive screening programmes for cancer test
Austria	9.9	1.0	11.8	10.9	2.0	13.5
Belgium	0.5	3.3	0.5	1.0	2.7	1.6
Denmark	2.3	5.3	5.8	2.9	11.8	6.5
Finland	3.1	2.4	4.2	2.5	2.4	6.0
France	2.7	8.6	0.6	0.9	4.9	1.1
Germany	4.5	1.8	9.4	11.9	1.4	13.1
Greece	1.7	1.1	-	0.6	0.5	-
Ireland	1.9	5.1	0.6	1.9	3.2	3.2
Italy	6.4	0.9	2.7	1.6	2.8	2.0
Netherlands	-	15.8	2.2	1.1	14.0	3.9
Portugal	0.6	2.6	-	0.6	0.6	1.4
Spain	5.1	0.7	10.4	2.5	4.8	3.2
Sweden	4.5	4.9	7.1	4.5	6.3	11.0
United Kingdom	0.4	-	1.0	1.8	1.5	3.5

Source: Eurostat Database, Eurobarometer Survey, 2002

Many pathologies can be easily kept under control by following life styles directed at an overall psychophysical wellbeing and health. The individual countries, the EU in its whole, and many international organisations, pay particular attention to encouraging healthy life styles, with the aim of promoting and maintaining high levels of health of the population. One can recall the recent no smoking campaigns conducted in many European countries, as well as those aimed at controlling the abuse of alcohol (especially in the countries of Northern Europe). Moreover, even eating habits, if not carefully followed, can lead to obesity and expose to the risk of critical metabolic, vascular, cardio-circulatory and blood pressure diseases. It is important, therefore, to promote health education programs in schools, as well as information campaigns for the populations in general, capable of reaching even those who are not aware of the consequences of certain life styles. Many studies conducted at the international level show how certain unhealthy behaviours, like excessive smoking, alcohol abuse and irregular diets are more widespread among the lower socio-economic sectors of the population. There is a need, therefore, to promote information where human resources are more fragile and vulnerable.

By taking all the necessary precautions, it is possible to observe how in a number of countries, where information campaigns on the harmful effects of smoking have been conducted with great intensity, the percentage of smokers is also quite low (Finland, Portugal and Italy), while problems related to eating habits interest more a number of "cold" countries of Northern Europe, characterised by a diet rich in fats which are accompanied by an excessive use of alcoholic beverages. This is the case of Germany (12% of the population has obesity problems), Finland (10.1%) and Austria (9.1%) (see Table 9), which are joined by a country of the Mediterranean area, Portugal, with a percentage of 12%.

**Table 9 Behaviour and life styles of the general and of the female population with respect to smoking (year 2001) and a balanced diet (year 1999).**

COUNTRIES	% population of present smoker	% women present smoker	% population 15-24 of present smoker	% population 25-34 of present smoker	% population 35-44 of present smoker	% population 45-54 of present smoker	% population 55-64 of present smoker	Obesity indicator BMI>30Kg/m2 (1) (% of total population) (year 1999)
Austria	31.3	24.2	45.7	38.5	40.5	35.6	21.4	9.1
Belgium	28.4	23.6	36.5	29	35.3	34.0	26.0	-
Denmark	34.2	32.1	28.9	36.2	38.9	40.6	33.3	-
Finland	24.4	18.5	26.7	30.2	29.3	30.6	22.1	10.1
France	-	-	-	-	-	-	-	-
Germany	29.1	23.5	36.4	36.8	38.5	36.9	22.3	11.5
Greece	48.4	38.9	40.1	59.2	59.8	55.5	43.2	-
Ireland	31.5	31.7	27.3	37	40.8	31.2	26.1	10.0
Italy	27.9	19.1	29.2	34.7	34.6	34.6	24.2	8.8
Netherlands	-	-	-	-	-	-	-	8.7
Portugal	21.7	10.2	19.8	32.4	30.1	23.3	15.4	12.8
Spain	32.3	23.8	33.8	43.9	47.8	33.7	22.8	-
Sweden	-	-	38.1	-	-	-	-	8.1
United Kingdom	-	-	-	-	-	-	-	20.0

Source: Eurostat Database 2003, ECHP European Community Household Panel, 2001

(1) The BMI (Body Mass Index) is calculated by dividing the weight of a person by his/her height. This index is recognised by experts at the international level as the best possible measure of obesity currently available for adults, when there is information only on the person's weight and height. An individual with a BMI between 18 and 20 is underweight and is critically underweight when it is below 18; a person with a BMI between 27 and 30 is overweight and is critically overweight if the value is over 30. A BMI value between 20 and 27 is considered normal.

## 2. The 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.*

With respect to the right of access, there are a number of indicators available on: public hospital facilities (number of beds per ward); personnel employed in these facilities (doctors, pharmacists, dentists, nurses, midwives also in relation to the labour force); hospital discharges for all the principal diagnostic categories according to the International Classification of Diseases (ICDIX last revision); time taken to reach hospital facilities, family doctors and healthcare centres (outpatients clinics); consumption expenditure of private households for health (at current prices and in percentage of total household consumption expenditure); social benefits for sickness and health care as far as for disability in percentage of total benefits.

It would, however, be helpful to obtain information on the investments made by individual Governments to remove architectural barriers in healthcare facilities, create adequate waiting areas for patients, or organise play areas for children who cannot access to wards during the visiting hours, etc.

One of the main indicators to measure a system's capacity to meet the demand for healthcare of its patients is represented by the available structural and human resources. Access to treatment is guaranteed through two principal ways: admissions in hospital facilities and general and specialist medical visits in outpatients clinics (including Day Hospitals). By analysing the number of hospital beds per 100,000 inhabitants, it is possible to understand the healthcare policy decisions adopted by a number of countries. In the countries of Northern Europe, for example, one can observe a significant reduction in the number of available hospital beds, as a result of the trend to increase outpatients' care and day surgery. In Finland, hospital beds were reduced by one third during the nineties, dropping to 747.8 (per 100,000 inhabitants) in 2001 (see Table 10); among the priorities in the Government's political agenda there is the commitment to de-institutionalise psychiatric patients, which can be observed in the reduction in the number of beds intended for this type of assistance.

A similar trend is taking place in Denmark, where hospital beds have dropped from 760.0 (per 100,000 inhabitants) of the eighties to the 422.6 in 2001. In this country, a series of policies have also been

launched, aimed at de-institutionalising psychiatric patients, observable in the significant reduction in the number of hospital beds assigned to this type of assistance (75.4 per 100,000 inhabitants).

In France, where hospitals are 25% publicly managed and 75% administered by the private non-profit and for-profit sector, the reduction in hospital beds (819.4 per 100,000 inhabitants) has been much less significant than what has happened in other countries. In fact, while the private sector is primarily responsible for minor surgeries, the public sector handles hospital emergencies, rehabilitations, long-term admissions (143.0 per 100,000 inhabitants) and psychiatric treatments (107.9 per 100,000 inhabitants), even though these are primarily taken care at the local level by multidisciplinary teams (see Table 10). Recently, new forms of assistance, such as hospitalisation at home and day-surgery, have been introduced at the experimental level. In Germany, the healthcare system is organised primarily around hospital admissions. There are a total of 2,260 hospitals, of which 790 public, 820 private not-for-profit and 420 private for-profit, for a total 572,000 hospital beds. Therefore, the number of hospital beds per 100,000 inhabitants continues to be very high (901.9), second only to Ireland (983.6) (see Table 10). Only the university hospitals have outpatients' clinical services<sup>110</sup>.

Many patients have, in fact, been discharged and directed to home or outpatients care provided by local services. Even in Sweden there has been a considerable reduction in the number of hospital beds, dropping from 1,200.4 (per 100,000 inhabitants) in 1990 to 500.2 (per 100,000 inhabitants) in 1997. At the same time, there has been an increase in outpatient and day hospital care services, as well as in the care for the elderly, disabled persons and psychiatric patients at the local level.

**Table 10. Number of hospital beds by type of admissions and number of doctors, pharmacists and nursing personnel per 100,000 inhabitants/residents. Year 2001**

COUNTRIES	Hospital beds rate per 100.000 inhabitants (1)	Psychiatric beds rate per 100.000 inhabitants (1)	Acute care beds rate per 100.000 inhabitants (1)	Long term nursing care beds rate per 100.000 inhabitants (1)	Number of physician or doctors* per 100.000 inhabitants (2)	Number of Pharmacists* per 100.000 inhabitants (2)	Number of nurses and midwives per 100.000 inhabitants(2)
Austria	853.6	66.0	615.8	180.1	323.7	56.4	934.4
Belgium	-	-	-	-	418.7	-	-
Denmark	422.6	75.4	340.8	516.6	342.7	51.9	1,489.2
Finland	747.8	101.2	237.9	408.7	310.9	149.7	2,174.0
France	819.4	107.9	415.7	143.0	332.0	102.2	698.2
Germany	901.9	127.6	627.6	-	362.1	64.7	-
Greece	-	-	-	-	454.3	85.1	-
Ireland	983.6	90.6	302.4	573.7	239.6	79.6	1,806.2
Italy	455.1	0.3(4)	437.4	17.4	603.1(3)	108.9	-
Netherlands	471.7	143.5	304.2	-	329.0	19.7	1,348.8
Portugal	374.7	78.6	12.7	-	323.8	81.6	-
Spain	364.8	50.2	283.3	31.3	-	-	519.8
Sweden	-	-	-	-	401.8	-	-
United Kingdom	-	-	-	-	-	-	-

Source:

- (1) Eurostat Database, National administrative archives. One should proceed with caution when comparing these data, as each national reporting system is affected by its own specific organisation. Moreover, the definitions of "hospital bed", "psychiatric bed", "Acute care bed" vary from country to country.
- (2) Eurostat Database, LFS Labour Force Survey, 2001.
- (3) It is interesting to note that in Italy, this figure, which refers to graduated doctors and to those practising the profession, is much higher than those in the other countries. However, if one examines the rate with respect to only those practising the profession (430.0), it is in line with the average European level. This fact would seem to highlight the gap between the number of persons that obtain a medical degree and those who are actually able to practice the profession.
- (4) This figure shows the effects of Law 180/78 which, in Italy, initiated a process of de-institutionalisation of psychiatric patients, by providing alternative forms of care to patients and their families at the local level, through the creation of Mental Health Departments. There are, however, after years of experience on the territory, quite a few doubts concerning the capacity of these organisations to meet the needs of patients and their families.
- (\*) Licensed, practicing or active according to different national definitions.

Among the countries of the Mediterranean area, Italy is the one which in recent years has gone through the greatest and more significant transformations. Currently, there is an extensive network of public, private and private services both for visits, as well as for clinical-diagnostic and therapeutic care. In Italy,

<sup>110</sup> European Observatory on Health Care Systems, *Health Care Systems in Transition: Germany 2000*.

there are 842 public hospitals (61% of the total) and 539 private not-for-profit hospital facilities. The number of hospital beds has dropped from 720.0 per 100,000 inhabitants in the nineties, to 455.1 per 100,000 inhabitants in 2001<sup>111</sup>. The reforms introduced during this last decade have, in fact, had the effect of improving the efficiency of services and the effectiveness of treatments; this, thanks to a more adequate rationalisation of resources and the launching of a managed cooperation system which has benefited the National Health System.

Spain and Portugal present, in some respects, a similar scenario. Both countries have the lowest rate of hospital beds per 100,000 inhabitants: respectively 364.8 and 374.7 (see Table 10). However, there are also some differences. In Spain, this lack of hospital beds has led to an increase in waiting time and of more people sharing the same hospital room. The health sector has tried to respond to these problems by intensifying the use of the available resources: reducing admissions periods, accelerating patients' turnover. In Portugal, on the other hand, between 1970 and the end of the nineties, there has been a steady decline in the number of hospital beds, with a 65% reduction: this in conjunction with the progressive ageing of the population and the decreased capacity of families to take care of and assist the weakest members<sup>112</sup>. Nonetheless, the structural resources continue to be inadequate and not evenly distributed on the territory.

With reference to the medical personnel employed in the different healthcare systems, one can observe how in Sweden, in 1997, the number of doctors were 10% lower than the European average, while in 2001 they reached a rate of 401.8 per 100,000 inhabitants, well above the EU-15 average of 390.0. However, the number of doctors is still lower than the actual demand, especially in rural areas. The same can be said for the nursing personnel<sup>113</sup>. In Finland, the number of doctors is significantly lower than the European average (310.0 per 100,000 inhabitants), while the rate of nursing personnel is the highest in the Europe-15 (2,174.0 per 100,000 inhabitants) (see Table 10). Moreover, it is expected that the ageing of the population will lead to an increase in the demand for care and, subsequently, for medical and nursing personnel<sup>114</sup>. In Denmark, in the last twenty years, the number of doctors has grown by 30%. 60% of them work in hospital facilities, while 23% are general practitioners. However, the most critical problem continues to be the recruitment of nursing personnel<sup>115</sup>.

What concerns France, instead, is the slow but progressive reduction in the number of medical and nursing personnel. Currently, the healthcare system employs some 1.6 million health professionals, equal to 6.2% of the active population. The number of doctors, which has stabilised in recent years, following the limitations imposed on the enrolments in Medical Schools, is expected to continue to drop in the next ten years. This will aggravate a problem, which is already perceived, of an uneven distribution of medical personnel in the territory, as their presence is not homogenous in the different regions of the country<sup>116</sup>.

In the Mediterranean area, Spain and Italy present a number of similar problems, while Portugal is a case on its own. In 1998, Spain was the second nation, after Italy, to have the highest number of doctors per 100,000 inhabitants, as well as the highest number of chemists, while having the lowest rate of nursing personnel. The same can be said for Italy. In 2001, Italy continued to have the highest number of doctors per 100,000 inhabitants of the Europe-15 (603.1), and Spain the lowest rate of nursing personnel (519.8). Italy is second only to Finland in the number of chemists (108.9 as opposed to 149.7)<sup>117</sup>. In Spain, the redundancy of medical personnel and of medical graduates has led to a rise in unemployment in this particular economic sector. A common problem continues to be the lack of highly qualified nursing personnel. These are countries in which the ageing of the population has already raised critical issues in terms of domestic care and assistance, for which appropriate strategies have yet to be implemented to confront the problem. Even in Portugal, a policy aimed at increasing the number of health operators in the medical and nursing profession has been launched. Despite these efforts, the rate of medical personnel remains the lowest in the Europe-15

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<sup>111</sup> European Observatory on Health Care Systems, Donatini, A., Rico, A., D'Ambrosio, M.G., Lo Scalzo, A., Orzella, L., Cicchetti, A., Profili, S., *Health Care Systems in Transition: Italy 2001*.

<sup>112</sup> European Observatory on Health Care Systems, *Health Care Systems in Transition: Hit Summary on Portugal, 2004*.

<sup>113</sup> European Observatory on Health Care Systems, *Health Care Systems in Transition: Hit Summary on Sweden, 2002*.

<sup>114</sup> European Observatory on Health Care Systems, *Health Care Systems in Transition: Hit Summary on Finland, 2002*.

<sup>115</sup> European Observatory on Health Care Systems, *Health Care Systems in Transition: Hit Summary on Denmark, 2002*.

<sup>116</sup> European Observatory on Health Care Systems, *Health Care Systems in Transition: Hit Summary on France, 2004*.

<sup>117</sup> European Observatory on Health Care Systems, Donatini, A., Rico, A., D'Ambrosio, M.G., Lo Scalzo, A., Orzella, L., Cicchetti, A., Profili, S., *Health Care Systems in Transition: Italy 2001*.

(323.8 per 100,000 inhabitants), well under the European average (390.0). Even the number of nursing personnel is the lowest, while the number of chemists has increased<sup>118</sup>.

Hospitalisation is particularly high for tumours, which usually represent the principal diagnosis for admissions, and for complications arising from child-births (see Table 11).

This is a very sensitive issue, which draws the attention to the need of intensifying awareness activities on preventive measures: a proper monitoring of pregnancy and a correct information on the effects linked to certain life styles could reduce the impact of a number of pathologies. The low rates of hospital discharges for pathologies, such as Parkinson and multiple sclerosis, highlight the tendency of treating highly invalidating diseases outside hospital facilities. These are pathologies that can be better followed by keeping the patient in his/her family environment, surrounded by the loved ones. In order to avoid, however, that the impact of the reduction of admissions for these diseases falls totally on the families, it would be useful to have at ones disposal comparable information on the spread of family assistance services and assisted healthcare residence facilities, in order to monitor the progress of these patients.

**Table 11. Hospital discharge rates for all the diagnosis and for certain types of diagnosis, per 100,000 inhabitants. Year 2001**

COUNTRIES	Total hospital discharges by main ICD diagnosis (A00-Y89) per 100.000 inhabitants	Total hospital discharges for virus infections (incl.HIV) (A80-A99, B00-B09, B15-B34) per 100.000 inhabitants	Total hospital discharges for malignant neoplasms (C00-C97) per 100.000 inhabitants	Total hospital discharges Parkinson's disease (G20-G21) per 100.000 inhabitants	Total hospital discharges for multiple sclerosis (G35) per 100.000 inhabitants	Total hospital discharges for complications of pregnancy, childbirth and puerperium (O00-O99) per 100.000 inhabitants
Austria	29,245.6	160.2	3,144	80.9	62.7	1,480.5
Belgium						
Denmark						
Finland	26,146.1	105.1	1,907.1	91.2	52.8	1,599.8
France						
Germany						
Greece						
Ireland	13,055.5	180.7	692.4	15.4	20.1	2,042.6
Italy	15,192.6	109.1	1,006.5	18.3	15	1,339.7
Netherlands	9,158.7	29.6	775.5	9	13.4	859
Portugal	7,885.3	79.8	545.4	3.1	5.5	1,160
Spain	7,401	56.8	474.6	3.9	5.5	918.1
Sweden	16,079.5	95.8	1,369.6	27.6	18.2	1,234.7
United Kingdom						

Source: Eurostat Database, National administrative archives. One should proceed with caution when comparing these data as each national reporting system is affected by its own specific organisation.

An indicator which can be obtained from the European Community Household Panel Survey (ECHP) looks at the segment of the population which turns to general practitioners and specialists more than a certain number of times. These are consultations conducted by way of ambulatory medical examinations and are an indication of the possibility of the patient/citizen to consult on issues concerning health. In countries like Austria, Belgium and Italy, over 50% of the population, in the 12 months preceding the survey, went to the general practitioner more than three times. (see Table 12). In these countries the relationship between patient and general practitioner is based on trust and often represents the most efficient form of prevention within the primary healthcare system. With respect to specialists consultations, it can be observed that in the countries in which access to these services is subject to and dependent on the prescription from the general practitioner, the percentage of those who access to this level of care is much lower than the others.

<sup>118</sup> European Observatory on Health Care Systems, *Health Care Systems in Transition: Hit Summary on Portugal, 2004*.

**Table 12. Percentage of people who in the 12 months preceding the survey consulted the general practitioner or a specialist 3 or more times. Year 2001**

COUNTRIES	% of population who had three or more consultations of general practitioners over the past 12 months	% of population who had three or more consultations of medical specialists over the past 12 months
Austria	54.0	25.3
Belgium	56.3	22.7
Denmark	34.4	11.2
Finland	29.0	11.1
France	-	-
Germany	-	-
Greece	21.8	20.2
Ireland	39.4	6.4
Italy	51.6	16.7
Netherlands	35.5	18.7
Portugal	40.5	16.9
Spain	38.8	18.8
Sweden		
United Kingdom	39.6	

Source: Eurostat Database 2003, ECHP UDB European Community Household Panel, 2001

Moreover, the right of access is not fulfilled solely by providing adequate health facilities and high level professionals to citizens, but also by making it easier to access to the treatment centres in reasonable time and without too many difficulties. The proximity of services, especially at a certain age, can make the difference in making it possible to take advantage of the treatment and assistance opportunities offered by healthcare systems. In general, the following scenario seems to be emerging: general practitioners or the reference centres of family units represent proximity services. Most of the population, including the elderly over the age of 65 (around 80%), is able to reach their general practitioner or the local ambulatory clinic in less than 20 minutes (see Table 13).

Things are somewhat different for hospitals. When asked how much time it takes to reach the nearest hospital, the percentage of those taking less than 20 minutes, both among the general population and the elderly, drops, on average, to less than 50% (see Table 14). The tendency, therefore, would seem to be one aimed at strengthening the local support network for patients, through the regular contact with general practitioners, who provide a proximity service to individuals and family units. Nevertheless, the data on the time taken to reach the nearest hospital can also be seen under a different perspective: an excessively prolonged time makes it more difficult to visit hospitalised relatives or loved ones, increases the time of first aid in cases of emergency.

**Table 13. Distribution of the general population and of the elderly one (65+), according to the time taken to reach their general practitioner. Year 1999**

COUNTRIES	% of population who takes less than 20 minutes to go to their general practitioner/health centre	% of population who takes between 20 and 59 minutes to go to their general practitioner/health centre	% of population who takes 1 hour or more to go to their general practitioner/health centre	% of population of 65 years and over who takes less than 20 minutes to go to their general practitioner/health centre	% of population of 65 years and over who takes between 20 and 59 minutes to go to their general practitioner/health centre	% of population of 65 years and over who takes 1 hour or more to go to their general practitioner/health centre
Austria	80.0	19.2	0.9	78.9	20.4	0.7
Belgium	87.7	11.6	0.7	77.6	21.8	0.6
Denmark	90.9	8.7	0.4	91.4	7.8	0.8
Finland	74.4	24.7	0.9	74.7	24.1	1.2
France	89.2	10.0	0.8	88.5	11.5	
Germany	81.3	17.6	1.1	80.4	19.1	0.5
Greece	55.9	40.9	3.2	50.8	44.6	4.6

Ireland	76.1	22.3	1.5	69.9	29.5	0.6
Italy	88.7	11.0	0.3	90.3	9.7	
Netherlands	90.7	7.3	2.0	90.8	9.2	
Portugal	61.4	36.4	2.2	60.3	37.3	2.4
Spain	89.7	9.7	0.6	90.8	8.6	0.6
Sweden	88.2	11.7	0.1	78.4	21.6	
United Kingdom	87.0	12.6	0.4	82.7	16.1	1.2

Source: Eurostat Database, Eurobarometer Survey 52.1, 1999

**Table 14. Distribution of the general population and of the elderly one (65+), according to the time taken to reach the nearest hospital. Year 1999**

COUNTRIES	% of population who takes less than 20 minutes to go to the nearest hospital	% of population who takes between 20 and 59 minutes to go to the nearest hospital	% of population who takes 1 hour or more to go to the nearest hospital	% of population of 65 years and over who takes less than 20 minutes to go to the nearest hospital	% of population of 65 years and over who takes between 20 and 59 minutes to go to the nearest hospital	% of population of 65 years and over who takes 1 hour or more to go to the nearest hospital
Austria	40.1	52	7.9	35.8	51.4	12.8
Belgium	65.9	31.4	2.7	54.5	42.3	3.3
Denmark	62.3	36.5	1.2	45.7	51	3.4
Finland	50.3	46.5	3.1	48.1	47.7	4.2
France	53.2	43.3	3.5	47.8	49.2	3
Germany	50.9	44.8	4.3	48.9	45.5	5.7
Greece	37.7	55.5	6.7	29	61.9	9.1
Ireland	38.4	50.5	11.1	37.6	50.4	12
Italy	65.7	31.4	2.9	62.7	33.8	3.5
Netherlands	70	29.6	0.5	57.3	42.7	
Portugal	37.6	52.2	10.2	31.4	53.8	14.8
Spain	41.5	51.9	6.7	35.9	55.8	8.3
Sweden	52.8	39.7	7.5	45.3	45.2	9.4
United Kingdom	44.7	51	4.4	41.6	52	6.5

Source: Eurostat Database, Eurobarometer Survey 52.1, 1999

### 3. 4. *The right to information and to consent*

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

*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.*

On the right to information there are indicators on: population that uses internet to look up information on health, diseases, injuries and nutrition, divided by type of activity (active population, students and by age categories); spread of the use of telemedicine; use of the web to set up appointments with practitioners and specialists; on-line drug prescriptions requests.

There is no information on: the degree of implementation of this right in terms of patients' likelihood to be informed on their illness, taking into account the possible linguistic difficulties, religious beliefs and reference cultural models; the actual possibility of accessing to their own medical records (clinical file) and asking for their correction in case of errors, etc. There is the need to find indicators capable of providing adequate information on these health practice aspects, which are too often disregarded or underestimated. There is also the need to study survey tools which will allow the gathering of data and production of information useful for putting pressure when such rights are violated or neglected.

Moreover, the right to information can also be guaranteed on another level: that of the right to be informed in an accurate and continuous manner about the services available on the territory, their location, the hours and access procedures, the services being provided, the potential costs, the possibility of taking advantage of partially/totally free health care or of insurance covered reimbursements; as well as everything

concerning scientific research, therapeutic innovations introduced by technological advancement, new drugs and anything else that might help patients be informed in a transparent and reliable manner.

On this issue, many steps forward have been made: most of the countries have information systems assisting citizens/patients on the territory, helping them find those healthcare services which are available and operating. These tools, however, are found on the web and can be accessed only by those who have a computer and an internet connection. Even though the use of new technologies is quite widespread in many of the EU countries, it is worth remembering that the more fragile and vulnerable segments of the population belong to the weaker socio-economic strata, and do not have such tools, or are too old to learn how to use them. Therefore, it will be useful to study information diffusion strategies under other forms, with the aim of reaching those sectors of the population “excluded” from the usual information channels and lacking the social support networks and the human resources to rely on.

**Table 15. Percentage of people in general, of different type of workers and of students who use Internet to search for information on health, diseases, injuries and nutrition. Year 2003**

COUNTRIES	% of individuals who used Internet for seeking health information on injury, disease or nutrition	% of employees, self-employed, family workers who used Internet for seeking health information on injury, disease or nutrition	% of students who used Internet for seeking health information on injury, disease or nutrition
Austria	5.4	6.9	7.8
Denmark	34.6	38.0	45.3
Finland	32.0	36.0	52.2
Greece	2.7	3.8	6.1
Ireland	6.5	7.7	:
Sweden	20.8	23.3	21.7
United Kingdom	28.8	32.7	50.4

*Source: Community Survey on ICT – Target Population: individuals between the age of 16 and 74. Year 2003*

A number of indicators from the Community Survey on Information Technologies (ICT), highlight the fact that young people, students in particular, are the ones who take advantage of the opportunities provided by internet and the new technologies to research information on medicine, nutrition, injuries and diseases. Youth, associated with a good education level, favours the free exercise of this right of the citizen. There are differences among the EU countries: in the countries of Northern Europe and in the United Kingdom, where internet is also used to take care of a number of administrative and bureaucratic obligations, the percentage of students using internet to acquire health information is greater than 50% (see Table 15), while in the continental and the Mediterranean countries the percentage drops to just above 6%.

Among people engaged in work activities, the research of information on internet is quite widespread. Nowadays, most jobs require the ability to use computers and navigate the web: it is likely, therefore, that who belongs in the working world may find it easier to be informed through the use of these channels.

The possibility of easily accessing to news dealing with health services, therapeutic opportunities, risk factors, scientific advancements in fighting certain diseases and new drugs acts as a “conveyor belt” for promoting the so called informed consent. Therefore, knowledge promotes rights and freedom. However, this is not enough to guarantee the right to information. For this to happen, health service providers and professionals need to use a language understandable to all patients who, in most cases, do not have the necessary technical knowledge to decipher the semantic codes contained in diagnostic and therapeutic formulations. In this respect, at present, there is no available data to evaluate how the right to an informed consent is being implemented. Moreover, it is not feasible to monitor the actual possibility for a patient to refuse a particular treatment or medical care.

#### **5. 6. The right to free choice , to privacy and confidentiality**

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

*Every individual has the right to 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 and*

*her privacy during the performance of diagnostic exams, specialist visits, and medical/surgical treatments in general.*

Indicators capable of assessing the degree of implementation of these rights of the Charter have not yet been identified.

European health systems have adopted different mechanisms in implementing the right to free choice. In some systems, gate-keeping procedures have been introduced, so that patients have to go through mandatory gates or filters before accessing to certain specialists or therapies; in others, citizens/patients are free to turn to general practitioners, specialists, ambulatory or hospital services in full autonomy. In any case, while in some systems, where there is a gate-keeping mechanism, the choice of the general practitioner or of the local healthcare centre is at total discretion of the citizen/patient (Denmark); in others, the possibility of patients to exercise the right to free choice is reduced even more, as the health system assigns part of the population to multidisciplinary medical teams (Finland). In these countries, reforms aimed at strengthening patients' right to free choice are currently being carried out. An in-depth study of the different healthcare systems would allow to evaluate, at least in theory, the level of guarantee recognised to the right to free choice; nevertheless, it is always difficult to verify its implementation in the field.

Monitoring the implementation of the right to privacy and to confidentiality is even more difficult. The privacy of the person must be respected even during medical-surgical treatments, which must take place in an appropriate environment and in the presence of only those who absolutely need to be there. It goes without saying, that for some of the rights examined above, more than studying quantitative survey systems for the indicators considered appropriate for this monitoring activity, it would be useful to turn to qualitative information gathering tools, such as direct observation.

### **7. *The right to respect of patient's time***

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

On the official data banks there are no indicators capable of providing a measure of the degree of implementation of this right. The only information available, and which is being presented in this paragraph, have been extracted from the Hit Summary of the European Observatory on Health Care Systems or from national reports. One hopes, therefore, that an information survey system will be set up, for example, on the length of waiting lists for the access to healthcare services, for type of service (clinic, day-hospital, admission by specialisation, surgery, transplants, etc.).

This right deals specifically with the issue of waiting lists and time: a problem which concerns many European health systems<sup>119</sup>. It is in fact the duty of healthcare systems to establish waiting times, within which certain services must be provided, on the basis of specific standards and in relation to the urgency of the individual case. In this sense, this right is linked to the one on personalised treatment and assistance more in general. Services must guarantee, within the limits set forth by norms on the respect of privacy, citizens/patients' right to consult and sign up on waiting lists. In case the healthcare system is not able to provide services within established terms, it must allow patients to seek alternative services of the same quality and at no additional costs.

In a number of healthcare systems, like for example the Finnish one, where policies have focused on strengthening and improving those services provided to families by medical teams, which have been assigned a territorially limited and well defined sector of the population, waiting times have been significantly reduced. However, as already mentioned, problems persist with respect to exercising the patient's right to free choice. Even in Denmark, where there is a gate-keeping system, the issue of waiting lists and waiting times for medical services has been raised by the media, thus prompting actions at the political level. In the nineties, a series of surveys were conducted aimed at understanding and defining the problem; subsequently, a number of concrete initiatives were taken, such as allocating additional financial resources to the counties and establishing maximum waiting times allowed for specific treatments. In July 2002, a law was adopted in Denmark, which sets at two months the maximum period within which patients must be able to utilise the service requested. Waiting times represent a problem also for the Swedish healthcare system, where primary healthcare is less developed than in other European countries: 46% of all ambulatory visits are conducted in hospital facilities and not in local healthcare centres. This has led, in the eighties, to an excessive increase in waiting times and a shift of end-users to private sector providers. In

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<sup>119</sup> The data contained in this paragraph is extracted primarily from the Hit Summary of the European Observatory on Healthcare Systems or from national reports.

order to limit this phenomena, in 1997, waiting times for services were established, with the objective of encouraging primary and specialist healthcare to provide their services within a determined time period, after which the service could be provided by another county. In light of the ties existing between general practitioners and specialists in the Swedish system, measures have been introduced to strengthen the relations on the territory and the cooperation between these two levels of assistance. In Germany, the issue is quite difficult to pinpoint, because of the peculiarity of the country's healthcare system, where the manner in which health services and assistance are provided (thus including also time) are negotiated between medical associations and the individual insurance funds. In Belgium, waiting lists do not seem to represent a problem: the country's healthcare system, though fragmented, has gone and is going through a season of reforms in which the principal results have been an increase in the services' quality levels, the citizen's freedom of choice, the almost universal coverage of the population, the reduction of waiting times for medical services.

Among the EU-15 countries, the Netherlands is the nation which has tackled the waiting list problem in the most systematic and decisive manner. As a result of the growing awareness of the problem's importance and urgency during the nineties, specific political initiatives were launched in 1997; among them the allocation of an additional fund of € 7 million to reduce unacceptable waiting times and the creation of an ad-hoc commission to study a series of measures to confront the problem. Among the measures adopted, worth mentioning is: the introduction, as an integral part of the package offered by insurance mutualities, of an explicit reference to the time taken to provide certain services; the allocation of additional financial resources to healthcare service providers who can demonstrate that they are offering high quality services (performance related payment) and, hence, within a determined time; the improvement in the organisation of the system to provide healthcare services; the introduction of strategies aimed at increasing the number of medical students, as well as recruiting nursing and auxiliary personnel. In 2000, in the Netherlands, there were 150,000 patients signed up in waiting lists for healthcare services; of these, 92,000 had been signed up for over a month. In 2001, the number had increased to 185,000: the waiting lists concerned primarily orthopaedic specialties, general and plastic surgery, ophthalmology. Plastic surgery had the longest waiting list and the longest waiting times; 12 weeks (three months) for the diagnosis; 23 weeks (around 6 months) for the treatment. In 2004, the Dutch Government, following the implementation of the measures recommended by the ad-hoc commission, was able to record an improvement in the situation: 68% of those signed up in the waiting lists is able to receive today the required service within 4-5 weeks.

Portugal, which in the nineties had introduced a number of reforms, whose impact has been primarily in terms of an improvement in the health conditions of the general population, finds itself still having to confront a whole range of challenges and unresolved issues. Among these, the capability to respond and provide treatment in an acceptable time for patients. Since 2002, the reform agenda has been focused on improving access to treatment: to this end, measures have been adopted to reduce waiting times for surgery services. In Spain as well, the waiting list problem has represented one of the most important challenges of the health sector: In order to reduce them, a strategy has been adopted since 1996, which has led to an average 70% reduction in waiting times in the ten regions administered at the central level. In Spain, in fact, the devolution process which had been launched, has been completed in only seven of the country's regions. This has meant and means that among the regions there are still a number of inequalities in the healthcare system's capability to respond.

In Italy, despite the efforts made with the recent reforms<sup>120</sup>, waiting lists continue to be long and crowded: The lengthening of waiting times pushes the population, especially those with a complementary health insurance coverage, to turn to the private sector. Even in Great Britain, the speed at which waiting lists are handled is considered an important indicator of the health system's efficiency: an indicator to monitor this has been calculated, which measures the number of patients on waiting lists per 100,000 inhabitants (the figure is not available).

#### **8. 9. 10 The right to the observance of quality standards, to safety and to innovation**

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

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<sup>120</sup> Decree of the Prime Minister DPCM of May 27 2002 on "Guidelines on the priority criteria for the access to diagnostic and therapeutic services and on maximum waiting list times" (*Decreto del Presidente del Consiglio dei Ministri DPCM del 27 maggio 2002 su "linee guida sui criteri di priorità l'accesso alle prestazioni diagnostiche e terapeutiche e sui tempi di attesa"*).

*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.*

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

On the right of access to high quality healthcare services and innovative procedures there are indicators on the spread of organ transplants. At present, there is no available official and comparable information at the intra-European level on other innovative intervention procedures. To this end, it would be useful to collect data on the individual governments' investments on scientific research and technological innovation in the field of health, as well as on safeguarding admissions spaces and services for patients in health facilities.

The respect of the right to high quality services requires the setting of standards which health facilities and professionals should abide by, both from a technical-scientific point of view, as well as from a human and relational one. The tools needed to report on the actual adoption of quality standards and, more so, on their application in medical practice, as well as the patients' satisfaction with the humanisation of treatments is not easily measurable, if not through the analysis of existing legislation and customer satisfaction surveys. Unfortunately, when these surveys are conducted they remain isolated experiences and thus lose their effectiveness, which can be guaranteed only through constant observation aimed at evaluating the effects in time of the policies and choices made. In recent years, the setting of quality standards, often different from country to country, has been one of the main items on the political agenda of many Governments, even if not always easy to resolve, because of the simultaneous need to "balance the book" of public budgets. However, economic and financial concerns, though representing an unavoidable constraint for certain choices, should not in any way influence or jeopardise the right of patients/citizens to access to technologically innovative and often costly procedures (Right n. 10). On this issue, one cannot forget the Swedish "ethical platform", an example of how to guarantee medical services, without having to take into consideration any economic criteria. This system, while presenting problems in the governance of public spending (healthcare spending is the highest among the EU-15 countries, with 8.9% of GDP), is extremely respectful of the dignity and human rights of each individual.

An appropriate indicator to monitor the access to highly innovative services is the one on the number of transplants carried out per million of inhabitants (PMP). Nowadays, transplants represent a highly sophisticated therapeutic option which should however be considered a "normal" opportunity and not an extraordinary or extreme one. Scientific progress, the improvement in operating procedures, the breakthroughs in contrasting organ rejection, the increase in post-transplant survival, are some of the great achievements of scientific research in this delicate area of medical science. The average patients' survival rate five years after a heart transplant is 80%, for lungs it is 50-60%, for kidney between 70 and 90%, for liver 70%<sup>121</sup>. In Spain and Austria there is the greatest number of kidney, liver and heart transplants with PMP rates of around 50. In most of the other continental welfare model countries, rates are around 30 PMP, while in the Mediterranean countries they drop to 20-26 PMP (see Table 16).

**Table 16. Number of organ transplants, by typology, per million of inhabitants (1 Mio inhab.). Year 2001**

COUNTRIES	Organ transplantation of kidney per millions of inhabitants	Organ transplantation of heart per millions of inhabitants	Organ transplantation of liver per millions of inhabitants	Organ transplantation of lung per millions of inhabitants	Organ transplantation of pancreas per millions of inhabitants
Austria	51.0	8.1	15.8	7.0	2.3
Belgium	36.3	7.8	18.8	4.3	2.0
Denmark	30.3	5.8	6.0	5.4	-
Finland	32.6	2.5	7.3	2.5	-
France	34.3	5.8	13.6	2.0	0.9
Germany	28.5	5.0	9.2	1.8	2.4
Greece	15.4	0.5	1.7	-	-
Ireland	-	-	-	-	-
Italy	26.7	5.5	13.7	1.1	1.1

<sup>121</sup> Italian Health Portal, *New drugs that make transplants safer*, Health Service Web, by Didamed, 2004 (*Portale sanitario italiano, Nuovi farmaci che rendono più sicuro il trapianto*, Servizio Sanitario Web, by Didamed, 2004)

Netherlands	31.3	2.2	6.9	1.6	1.4
Portugal	35.6	1.7	17.9	0.1	0.4
Spain	48.0	8.5	24.2	3.6	1.4
Sweden	34.6	2.8	11.5	2.4	0.6
United Kingdom	28.4	3.3	11.1	1.4	0.8

Source: Eurostat Database, 2003

Less widespread are lung and pancreas transplants: rates decrease quite significantly, dropping for lung cancer to values between 1 and 7 PMP; for pancreas, between 1 and 2.4. In the Netherlands, the Health Insurance Fund also provides coverage for certain tissue and organ transplants. There is also a commission for the evaluation of new technologies to help select those which will ensure high quality standards.

However, the greatest obstacles revolve around the issue of organisation: policies aimed at strengthening and spreading a culture of organ donation still encounter difficulties in most countries. On this, Italy is still lagging behind Spain, Portugal, Austria and Belgium, if even if its rate of organ donors in 2002 was above the European average (16.5 PMP – current donors index 2001) with a value of 18.8 PMP<sup>122</sup>.

Even for transplants there is a problem concerning waiting lists: in Italy, at December 31<sup>st</sup> 2001, 9,971 patients were on the waiting list for organ transplants: 7,597 for kidney; 1,362 for liver; 770 for heart and 242 for lung<sup>123</sup>. In the same year, 1,80 kidney, 818 liver, 329 heart and 60 lung transplants had been carried out (including transplants with other organs or mixed). These figures testify to how much more needs to be done in this field in order to effectively implement the right of access to the opportunities which scientific innovation is able to offer nowadays.

### **11. The 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/her illness.*

With respect to the right to avoid suffering, no comparable indicators have been identified on the spread of palliative cures or access to such treatments. There is, however, a ranking of 65 countries worldwide (of which 12 of those considered for this study, with the exception of the Netherlands) on the average amount of morphine per person utilised for therapeutic purposes, prepared in 1995 by the International Narcotics Control Board, on the basis of a survey conducted in collaboration with WHO and 65 national Governments.

This right includes both palliative treatment, as well as pain therapies. Palliative treatments take care, in an active and complete manner, of patients affected by a disease that no longer responds to specific treatments. According to the definition of the National Council for Hospice and Palliative Care Services WHO-OMS of 1990, modified by the ministerial commission for palliative care in 1999, palliative treatments celebrate life and regard death as a natural event; they do not accelerate nor delay death; they bring relief from pain and other ailments; they integrate the psychological and spiritual aspects of care; they help patients to live actively until the time of death; they support families during illness and mourning. A number of palliative treatments can be adopted earlier in the course of the illness, in addition to the oncological therapy. WHO provides very precise guidelines on the pharmacological approach to be adopted: the first step calls for the use of analgesic non steroid drugs (FANS); when these are no longer enough, one needs to integrate them with mild opiates (codeine, oxy-codeine); when this also fails, one moves on to strong opiates (morphine and methadone). The whole treatment must be carried out according to a rigorous personalisation of dosages: in this sense the right to avoid suffering is associated with that to personalised treatment.

Moreover, palliative treatments still represent today a desire rather than a reality: in many countries it is not easy to access to these therapies or to centres specialised in pain relief. The more appropriate facilities and healthcare services to provide this treatment are the hospital palliative treatment units and hospices. The obstacles preventing an effective diffusion of palliative care lie primarily in: the insufficient economic resources available; the cultural factors which impose a vision of pain as an inescapable and

<sup>122</sup> National Transplant Centre, *Donation and transplant activities in Italy*, January-April 2002 (*Centro Nazionale Trapianti, Attività di donazione e trapianto in Italia, gennaio-aprile 2002*). For Italy, these are annual projections based on the data of April 30 2002.

<sup>123</sup> *Ibid.*

inevitable event; the inadequate preparation of doctors on this issue; the opposition to the use of opiates, etc. in many countries.

### **12. 13. 14 The right to personalised treatment, to complain and to compensation**

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

*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.*

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

With the knowledge available today on the workings of the different healthcare systems, it is very difficult to identify indicators which can provide evidence of the actual implementation of the right to personalised treatment. Each patient is a case on its own and it is not easy, therefore, to set standards against which to evaluate the degree of adherence of a treatment, in its entirety, to the individual. Nevertheless, these aspects could be studied through ad-hoc surveys on patient's satisfaction.

On the other hand, on the basis of the information on the functioning of healthcare and hospital facilities, it is possible to identify a number of indicators on the fundamental orientations inspiring treatment: the priority or not, for example, of economic criteria over those of citizenship which are based on rights.

For some time now, in a number of EU countries, policies have been implemented with the goal of shifting care to the patients' home, in order to guarantee for his or her stay within the family unit, close to the loved ones. In many countries, therefore, policies to cut back the number of hospital beds have been introduced, which have been accompanied by a reduction in the length of stay, aimed at increasing patients' turn-over. Italy, together with Sweden, is one of the countries where the length of stay in hospitals is the shortest (less than a week); Finland, Austria and the Netherlands, where it is the longest (from 8 to 10 days) (see Table 17). It is worth recalling how difficult it is to conduct comparisons with these figures, among countries where there is no unambiguous definition to indicate which type of facilities can be considered hospitals and what is intended for hospital bed; or on the possible different effects of the implementation of policies aimed at reducing the length of stay in hospitals. For a more comprehensive analysis, it would be necessary to dispose of data on the facilities and services activated to support families, who are usually the ones taking care of and assisting patients, with significant repercussions in terms of reducing the time available to conduct work activities (women are the most penalised) and decreasing the family unit's income generating capacity.

Along with these measures, in a number of countries, it has been possible to introduce efficient systems for home care, to encourage, especially for long admittance and chronic patients, the stay in a family environment; something very important to help in handling the psychological and emotional effects which some illnesses may have. In some countries, like Italy for example, where home care is still something quite novel, if not unheard of, efforts have been made to create an extensive network of assisted healthcare residences and social support centres for long admittance patients covered either by national health system or private arrangements. Istat estimates lead us to predict that the number of admissions in these type of facilities will increase: they are highly specialised centres, where different health professionals come together to provide the more appropriate and specific care and treatment to patients.

Finally, what has been stated above can be applied to the right to complain and to compensation. It would be useful, on one hand, to examine strategies for the survey of this right's violations (in this sense, Cittadinanzattiva's Tribunal for Patients' Rights could be an important form of surveillance), on the other, to promote the creation of a judicial statistical information on health: making it possible, for example, to "count" the number of compensation requests measures for reasons related to health rights violations or for damages caused by healthcare malfunctions, as well as their outcomes. This information would allow to better define the limits of citizens' capability to react when facing these violations, along with the capacity of the existing judiciary system to support them in a fair and equitable manner.

**Table 17. In-patients average length of stay for all diagnosis and for specific types of diagnosis. Year 2001**

<b>COUNTRIES</b>	In-patient average length of stay for total hospital discharges by main ICD diagnosis (A00-Y89)	In-patient average length of stay for virus infections (incl.HIV) (A80-A99, B00-B09, B15-B34)	In-patient average length of stay for malignant neoplasms (C00-C97)	In-patient average length of stay for Parkinson's disease (G20-G21)	In-patient average length of stay for multiple sclerosis(G35)	In-patient average length of stay for complications of pregnancy, childbirth and puerperium (O00-O99)
Austria	8.7	6.9	6.4	16.6	12.8	5.5
Belgium	-	-	-	-	-	-
Denmark	-	-	-	-	-	-
Finland	10.4	7.1	7.8	30.9	25.5	3.5
France	-	-	-	-	-	-
Germany	-	-	-	-	-	-
Greece	-	-	-	-	-	-
Ireland	7.3	4.4	13.7	19.2	10.6	3.8
Italy	6.9	8.0	11.3	10.9	8.1	4.3
Netherlands	8.2	8.4	10.6	23.0	8.1	4.3
Portugal	7.4	11.8	13.2	12.4	6.7	3.5
Spain	7.7	8.3	11.7	14.1	6.7	3.6
Sweden	6.2	3.7	7.8	10.9	11.3	3.1
United Kingdom	-	-	-	-	-	-

Source: administrative sources

Note: The data comes from a number of administrative records, created for specific objectives which differ from country to country. Therefore any comparison should be conducted with great care.

## C. Citizens as Actors in health services monitoring and auditing: the Italian experience

### 1. Civic evaluation as a standard practice of active citizenship

#### 1.1. Scene-Setting

*Cittadinanzattiva*<sup>124</sup> attributes high strategic value to the process of enabling citizens to produce their own, technically structured evaluation of the quality of public services. The following document uses two examples, which refer to the public health sector, and which have produced the most significant methodological developments in the civic evaluation process. These two examples focus upon Hospital Safety and the activities of public health agencies (the Civic Audit). They also serve as examples of civic evaluation; an innovative form of public involvement in public policy.

This particular type of evaluation could also be carried out as civic analysis, which is understood to be, “*production and use of information by the public in order to bring their own policies to life through their involvement in public policy-making both during the defining and implementing stages of the evaluation process*”<sup>125</sup>.

The public has been directly involved in public life for at least three decades, in a process of research followed by public action,

*in which enhanced consciousness and the modification of reality are systematically intertwined. In concrete terms, civic action is demonstrated by means of:*

- *data collection, as people acquire information concerning the problem;*
- *mobilization, as people learn to share the problem;*
- *efforts to maximise use of constructive skills as people work to resolve the problem*<sup>126</sup>.

This collective way of worked is put into practice in very different ways: local committees, national and international non-governmental organizations; groups which target one specific problem or take action in numerous sectors of public life. The common factor linking these forms of involvement is the practice of active citizenship (*cittadinanza attiva*), this being “the capacity to organize (civil society) in various ways, so as to mobilize human, technical and financial resources and to respond formally and with diverse strategies in order to defend rights by exercising powers and responsibilities intended to care for and develop common assets.”<sup>127</sup>

The more recent forms of active citizenship tend to combine the traditional aspects of mobilization and intervention with the development of sectional skills to elaborate, interpret and analyse data.

As Aaron Wildavsky maintains, citizens are becoming *analysts*<sup>128</sup>. That is to say that they learn to assess efforts against results and the relevance of policies through their own personal experience. Citizens can specialize in their own particular field of interest whilst gradually developing their general skills as active

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<sup>124</sup> *Cittadinanzattiva* (“Active Citizenship”) is a non-governmental organization, founded in 1978 under the name of *Movimento federativo democratico* (“Federal Democratic Movement”), which works to defend civil rights and to encourage civic participation. It maintains a nationwide presence, having over 200 branches. In 1980 it founded the Tribunal for the Rights of the Sick, which was specifically designed to defend rights to public health. In 2001, with the support of 70 civic organizations in 30 member or candidate countries of the European Union, it put in place an Active Citizenship Network (ACN) to digest experiences and reinforce discussion with other national and European institutions.

<sup>125</sup> Moro G., *Manual of Active Citizenship* – Carocci edited), Rome 1998, p. 135.

<sup>126</sup> Rubin H., Rubin, I., *Community Organizing and Development* – MacMillan Publishing Company, New York, 1992.

<sup>127</sup> Moro G., *op. cit.* p. 48.

<sup>128</sup> Wildavsky A. – *Speaking Truth to Power. The Art and Craft of Policy Analysis* – Transaction Publisher, New Brunswick, 1993, pp. 252 – 279.

citizens in the domain of public policy. Citizenship is not only a matter of loyalty to one's own government, it is also a matter of active, informed and influential civic presence in public life.

There are numerous independent interpretations and analyses produced by civic organizations, which tend to focus upon the way in which public services function, the defence of common goods such as the environment, awareness and management of social phenomena, such as immigration and poverty. These three examples can also be mentioned in order to underline potential diversities:

- *The links between environmental concerns of international non-governmental organizations, such as WWF or Legambiente*<sup>129</sup>; (the "Environmental League") in Italy.
- *Regular immigration studies by Caritas Italy*<sup>130</sup>.
- *The guide to civic work in Vancouver's local communities*<sup>131</sup>.

In the belief that the development of independent means of assessment is a prerequisite for civic empowerment, *Cittadinanzattiva* has always strived to develop civic analytical skills. Some key stages in the development of this process since the late 1970's may be singled out.

The first stage was the production of the Charter of Patients' Rights, which was drawn up in the early 1980's. The Charter was not a declaration of ethic principles, but rather a reflection of the Italian's citizens view of the service delivered by the Italian health service. After the National Health Service was established in 1978, *Cittadinanzattiva*<sup>132</sup> promoted the *Tribunale per i diritti del malato* (Tribunal for Patients' Rights) and launched an awareness-raising campaign to improve the conditions of hospitalized citizens. Organized groups of citizens went into hospitals, observed the structures in place and interviewed the patients, thereby collecting a tremendous amount of information. Committees were established which analyzed data, identified and classified various cases of "unnecessary suffering", caused not by illness but by cultural prejudice, malfunctioning of the health service or behaviour of staff. The Charter of Patients' Rights was the result of this process civic analysis and evaluation<sup>133</sup>, and the development of the Tribunal for Patients' Rights, and commitment in other policy areas (notably civil defence), provided an opportunity to develop civic technical data collection, analysis and interpretation skills whilst mobilizing citizens.

The second key stage in this process was our "Report on the State of Civil Rights in the National Health Service" which was written in cooperation with the Ministry of Health between 1990 and 1991. This undertaking involved thousands of citizens, who interviewed 16,000 people, including both patients and healthcare providers, and observed the activities of over 1,000 departments and services. With the help of a scientific team, significant methodological systems were brought up to date. Hundreds of indicators and standards were drawn from the Charter, and various other sources and civic inquiries were carried out with the necessary technical equipment (check-lists and questionnaires). This produced an accurate and documented picture of the Italian public health facilities, which resulted in health concerns being placed on government and health sector agendas; an issue which had been disregarded until that time.<sup>134</sup>

The Report on Rights changed the working practices of *Cittadinanzattiva* and those of the Tribunal for Patients' Rights<sup>135</sup>.

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<sup>129</sup> Ref. p.es, Legambiente – "A Green Train Fighting Pollution: Active Citizen's Manual regarding Protection from Traffic, Smog and Noise", Rome 1996. (*Un treno verde contro la mal'aria. Manuale per i cittadini attivi per la difesa da traffico, smog e rumore*).

<sup>130</sup> Ref. to the file of statistics on themes presented on the Italian Caritas web-site, [www.caritasitaliana.it](http://www.caritasitaliana.it)

<sup>131</sup> Dobson C. – *The Citizen's Handbook. A Guide to Building Community in Vancouver* – Vancouver Citizen's Committee, Vancouver 1995.

<sup>132</sup> At that time the name was still *Movimento federativo democratico* ("Federal Democratic Movement"), (ref. Note 1).

<sup>133</sup> Moro G.; Petrangolini T., "Undermining the health of the government". in *Democrazia diretta*, n. 4 -5, 1987.

<sup>134</sup> CE.R.FE (ed.), *Report on the State of Citizens' National Public Health Rights*, Il Pensiero scientifico editore, Roma 1992.

<sup>135</sup> The Tribunal for Patients' Rights is an initiative of the Federal Democratic Movement which came into being in 1980 to defend citizens' rights to public health and support, and to ensure a more humane and rational organization of the Health Service. The Tribunal is made up of normal citizens but also of healthcare workers and professionals who undertake this mission voluntarily.

Structured monitoring of the various features of healthcare is now becoming standard practice. The regulations introducing the Charter of Health Services establish that standards of quality and commitments be defined in collaboration with citizens.<sup>136</sup> These standards are not always applied, but collaboration with two public health agencies in Turin (Sant'Anna-Regina Margherita and San Giovanni Battista) have brought about significant results. A system was tested whereby standards could be assessed directly by health care users<sup>137</sup>.

Both the quantity and quality of assessments altered, thus requiring a new regulatory framework, which established a number of stages of assessment: firstly, collection, classification and standardisation of tools used by citizens to carry out their work.<sup>138</sup> The following stages were the planning of the two programmes – “Hospital Safety” and “Civic Audit” – which are outlined below.

The building of the project's methodological basis, as illustrated in the following paragraph, has paved the way for civic analysis of other issues, such as Safe Schools,<sup>139</sup> and the implementation of the Tribunal for Patients' Rights<sup>140</sup> in fourteen EU countries<sup>141</sup>. The Civic Audit project was officially recognised by the Civil Service Department as a means of evaluating public services from a citizen's perspective<sup>142</sup>. It is also being tested on issues pertaining to transport, water supply and postal services.

## ***1.2. Theoretical References and Methodology***

The development of civic assessment projects in the public health sector was determined by the need for concrete empowerment of citizens, thereby overriding two main types of bias; the first having been that service users were merely a principle of professional ethics, and the second stemmed from the notion that rights protection was an automatic result of a good organization of work and its structures. Citizen-centred practices, instead, require the definition of criteria to plan services and policies, and an accurate technical approach to assess the quality of public health services.

So far, the traditional tools used to measure customer satisfaction have produced unsatisfactory results and are generally considered inadequate by most experts. In recent years, several health service agencies have successfully developed innovative programmes on perceived quality of services<sup>143</sup>. But this is not enough to solve the problem. In fact, *the methodology used to date concentrates on paying heed to citizens, but without considering them capable of independent assessment*<sup>144</sup>.

To better understand the scope of this question, suffice it to observe that the expression “representing the citizens' point of view” has two very different, though complementary meanings.

The *first* meaning stems from the geometry of perspectives, where the “point of view” is the *point from where a specific reality is observed*, which defines a mathematically determined representation of reality. Thus considered, the citizen's point of view is not simply an expression of his or her individuality. It also

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<sup>136</sup> Decree by the President of the Ministerial Cabinet, 19 May 1995 – The Public Health Service Charter.

<sup>137</sup> Ref. “Oirm-Sant'Anna” Public Health Establishment – *Documentation of Hospital Services* – Turin, 1997 and “San Giovanni Battista of Turin” Public Health Establishment - *Documentation of Hospital Services* - Turin, 2005.

<sup>138</sup> Ref. Chapter 4, “Civic Analysis”, in G. Moro, ref. pp. 135 – 167, written in cooperation with A. Terzi.

<sup>139</sup> Ref. programme “Learning safety” <http://www.cittadinanzattiva.it/content/view/374/268/> (consulted on 5 January 2007).

<sup>140</sup> On 15 November 2002, the European Charter on Patients' Rights was acknowledged by 15 civic organizations in member countries of the European Union belonging to the Active Citizenship Network, the European political network promoted by *Cittadinanzattiva*. [www.activecitizenship.net](http://www.activecitizenship.net)

<sup>141</sup> Health and Social Campaigners' Network - *Patients' Rights in Europe: a Citizens' Report (Summary of Meeting Organised by Active Citizenship Network at the European Parliament, Brussels 28 February - 1 March 2005)* - Oxford Vision 2020, March 2005.

<sup>142</sup> Public Services Department, *Customer satisfaction with the Public Administration* – Cantieri Hill, Rome 2003,

<sup>143</sup> Ref. Cinotti R., Cipolla C., *Quality Divided between public health services and citizen*, Franco Angeli, Milan, 2003.

<sup>144</sup> Altieri L. (edited by), *Hearing and involving citizens in Public Health*, Franco Angeli, Milan, 2002.

identifies a way of observing (and thus representing) the public health services, from those for whom such services are intended.

In other words, representing the citizen's point of view does not only mean collecting a body of opinion, but rendering the way in which the service appears factually visible to those using it in various moments of their experience. So defined, the citizens' viewpoint acquires equal dignity as other viewpoints in the health system (such as those of directors, doctors, nurses, regional administrators, etc) and, thereby constructs a picture of the whole organization, and enhances our understanding of the real situation.

The second meaning of "point of view" is *to act in the name and on behalf of citizens*, thereby making one's own judgement of the quality of services relevant. It is indeed the turning point for civic organizations when they highlight particular cases or force public agencies to face major problems.

In this context, civic assessment provides citizens with the technical services needed, thereby linking the two meanings of the term "point of view", for it:

- identifies, formalizes and makes measurable the key characteristics of the citizens' experience;
- defines a consistent body of information collection and processing tools;
- singles out the moments in the assessment and decision processes when the citizens' representatives must be present in order to table and enforce their interpretation of the issues at hand.

The civic assessment process is not the sole means of ensuring civic representation in the public health service. It provides the groundwork for the successful integration of civic assessment processes and other methodological tools, notably state-of-the-art practices in the field of perceived quality analysis.

Civic organisations can collect data independently through direct observation of health structures, by consulting documents, by requesting information to provide information to users, and through interviews of experts.

Based on these general points, a structured assessment process has been designed and tested, where citizens are active subjects and not only objects of the assessment.

### ***1.3. The Evaluation Process Structure***

In order to envisage the whole process, one could say that the structure of the civic assessment process is designed to offer both "analytical" information, to describe very concrete aspects of the real situation, and "synthetic" information on more general aspects of the real situation being analysed. To this end, the process has been divided in three: components, assessment factors, indicators.

Firstly, the *components*; a term used to refer to any core aspects of the situation being examined, such as the public health "facility", the "personnel", or the "organization", as in the case of the "Safe Hospital" initiative, or even general thematic areas such as the "information to citizens" in the Civic Audit processes.

Each component is then divided into *assessment factors*, that is to say, "key areas for the perception of citizens" or even "the main points qualifying the relationship that citizens develop with the situation being assessed"<sup>145</sup>.

Ultimately, at a more analytical level, each assessment factor includes a group of indicators: *i.e.* quantitative variables or qualitative parameters enabling the formation of a judgement on the factor. Each factor is thus linked to a cluster of indicators enabling the observation of basic events which reveal the operating ways of the reality being examined, its compliance with rules, good practices etc.

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<sup>145</sup> These definitions were formulated and based upon the Presidential Decree of the Ministerial Council (D.P.C.M.) of 19 May 1995 and upon a publication by the Minister of Health entitled, "How to Define and Use Quality Standards", Notes from the Charter of Public Health Services, 1996.

#### **1.4. Index of adequacy of standards and benchmarking**

Indicators are drawn from published sources, regulations, documents produced by civic organizations, scientific societies etc, and they are selected on the basis of four criteria:

- *relevance; that is the degree to which they relate to themes and are assessed from the citizen's point of view;*
- *sensitivity; that is the capacity to register the changes (for better or worse) of the event observed;*
- *precision; that is the capacity to precisely express only the event being registered;*
- *detectability; that is the availability of timely and cost-effective information, which may be detected by citizens.*

The quantitative treatment of the data collected using key indicators makes it possible to draw an initial picture of the reality observed.

By means of the Index of Adequacy of Standards (IAS) it is possible to supply information of a more general nature on factors and components taken into consideration. The IAS expresses how far the values gathered for a set of indicators grouped into an assessment factor correspond to their “expected value”, that is to say, to the reference standards set by rule norms, citizens’ charters, documentation produced by scientific societies, etc. In cases where standards are not available, reference values may be drawn from the original data analysis.

The steps required to calculate the IAS of an assessment factor are:

- a. the definition of the indicators for the factor being analysed;
- b. a comparison between the actual value of each indicator and its expected value;
- c. the allocation of a value from 0 to 100 to every indicator; where 100 means the actual value is identical to the expected value and 0 means the opposite;
- d. any weighing of indicators, according to their relevance;
- e. the calculation of the mathematical average of values attributed to the indicators.

*Subsequently, if necessary, the IAS can be calculated from a series of evaluation factors, belonging to a single component and, still, the IAS of the component parts is thus reflective of the observed reality (for example a hospital).*

Calculating the IAS has enabled civic evaluation to be used to practice benchmarking methodology and thus encourage comparative evaluation of the individual realities observed in the civic evaluation process, with a view to:

- providing the opportunity to interpret the results of the civic evaluation process in a wider context, and thus to separate potential areas of excellence or delay in relation to other similar realities;
- encouraging an examination of the technical and organizational solutions that enabled better levels of *performance* to be achieved.

The way in which this methodology has been used in the 2 Civic Audit experiments and in the Safe Hospitals campaign will now be examined.

## **2. Civic Audit**

### **2.1. How and When Civic Audit Came to Be**

The Civic Audit involves critical, systematic analysis of action taken by the public health concerns promoted by civic organizations. This initiative implemented by *Cittadinanzattiva* is based upon the experience of the Tribunal for Patients’ Rights and makes up one element of the cooperative agreement with AstraZeneca, which has been in place since 2000.

The Civic Audit methodology – developed in the context of a cooperative project, initiated between *Cittadinanzattiva* and AstraZeneca in 2000, and still in place today – was applied for the first time in 2001, with an initial experimental phase which was finally defined and tested for its theoretical grounding and methodology, and ultimately implemented in cooperation with 12 health agencies. A second experiment

carried out in 2002, in cooperation with 13 health agencies later enabled the tools to be tested and to establish that the methodology could be applied generally to all health agencies and not only in a small set of circumstances specifically oriented towards the development of civic participation and good methodological processes. Since 2003, the possibility to adhere to Civic Audit has been used extensively in the world of public health agencies. Since 2004, following the establishment of a particular convention with the Emilia Romagna Regional Health agency, the first regional programme involving systematic application of the methodology was launched. In 2005 and 2006 other conventions were drawn up with Council offices on transparency, active citizenship and with the Public Health agency of the region of Puglia, with Council offices on public health for the Lazio region, and with the regional public health agencies of the Abruzzo and Friuli Venice Giulia regions. The total number of agencies involved in the Civic Audit process amounts to 134, approximately one third of the total number of Italian public health agencies.

All in all, from 2000 to 2005 the public health agencies that had already completed at least one Civic Audit cycle amounted to at least 94<sup>146</sup>, of which 60 were local public health agencies and 34 hospital concerns, this meaning that 106 would be audited<sup>147</sup>. During the course of this process, the following agencies have been observed:

- 156 hospitals;
- 136 district health offices;
- 137 regional outpatients' clinics;
- 134 specialised, regional and semi-residential services (Mental Healthcare Centres and Services for Drug Addicts)<sup>148</sup>.

The decision to provide civic organizations with their own tools with which to evaluate public healthcare activities effectively responds to three types of, often challenging, problems experienced by the Tribunal for Patients' Rights. The first type of problem is linked to the double requirement to render a citizens' point of view central to public health services in concrete terms, for whilst this is invoked by all, it is in fact practised by few. There is hence a need to *promote effective forms of participation* by citizens to the management of public health services.

A second series of questions is connected to an insistence to render the activities of public health services *transparent and accountable*. This stems from the substantial experience of Cittadinanzattiva in fighting battles through the Tribunal for Patients' Rights, in order to counter the self-referral process in the health services and to ensure that the signs be taken into consideration in order to produce the necessary improvements. The distinction between the civic groups and the management of public health agencies in structured procedures such as the Civic Audit can, in this context, become a "realization" by the local community of the results achieved by the management of the health services not only in budgetary terms (as is often the case), or as in the best case scenario, in terms of the fight against illness, but rather in the wider context of *promoting health*,<sup>149</sup> and of frequently overlooked aspects of the public health agenda; such as *interpersonal relations* and *comfort*<sup>150</sup>. To this regard it is interesting to note the considerable time gap between the implementation of Civic Audits and the compilation of the first social balances on the Italian public health agenda.

The third main reason to test an evaluation process based upon homogeneous, comparable criteria is the need to *avoid the risk that the increased autonomy of regional and local governments might translate into diverse citizens' rights agendas or standards of service*, this resulting in a series of Class A citizens, with enhanced rights and higher quality standards, and Class B citizens, with a lesser degree of rights and

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<sup>146</sup> There is a difference of 40 public health establishments, compared with the Civic Audit. This can be attributed to the regional and national development cycles which were being developed.

<sup>147</sup> 1 hospital and 11 local public health establishments had carried out the Audit twice.

<sup>148</sup> The data referred to in these paragraphs was updated in January 2007.

<sup>149</sup> "Promotion of health is the process of rendering groups or individuals capable of improving their control of factors which determine and improve health." (Ottawa Papers for the promotion of health by WHO, 1998, p. 2).

<sup>150</sup> A. Donabedian, *The Quality of Public Healthcare Support: Principles and Method of Evaluation*, La Nuova Italia scientifica, Rome, 1990

services. To this regard the link with the benchmarking standards is not only a methodological choice, but is also a matter of strategic value for it facilitates comparison of different agencies' performance on the basis of basic criteria linked to citizens' rights and to socially acknowledged standards.

The Civic Audit cannot replace the activities of civil society organizations, or organizations representing patients, to improve public health services, nor can it replace external audits, quality insurance or accreditation procedures. However, experience does demonstrate that it plays a significant role in enhancing both civic activities and the administration of the public health services. For example, it:

- provides a forum for active cooperation between citizens and public health agencies;
- produces information which is not available by other means; data which bridges the gap between various evaluation procedures;
- it helps highlight critical areas of concern and favours the implementation of viable, corrective processes by individuals.

The development of the Civic Audit process in cooperation with regional and local public health administrations is ultimately an example of the implementation of the last subsection of Article 118 of the Italian Constitution which cites that: "States, regions, provinces, cities, towns and town councils prefer citizens to take independent individual or collective initiatives in order to develop activities of common interest, based on the principle of subsidiarity".

### **2.3. The Four Civic Audit Questions**

As is well-known, the quality and efficiency of an audit depend upon the questions, to which the audit itself is intended to respond, being appropriately formulated. The planning of Civic Audits has thus come about as a result of 4 simple, fundamental questions which demonstrate the average citizens' core experience regarding public health services.

- a. The first point is that the citizen is a service user, involved in a process of prevention, diagnosis, cure and rehabilitation as a result of his or her own personal or family problems, and the question in this context is: *In concrete terms, what action taken by public health services ensures that citizens and their needs are central to public health concerns?*
- b. The second point relates to the citizen suffering from a serious or chronic illness and the question is the following: *Do public health agencies prioritize any public health or social policies in particular, such as risk management, pain management or support of the chronically ill?*
- c. The third point relates to exercising civil rights, obliging us to raise the question: *Is civic participation considered a necessary resource for improvement of the public health services by the public health services, or is it promoted (if it is indeed promoted at all) as a mere bureaucratic fulfilment of certain legislation?*
- d. The fourth point relates to the citizen and the community in which he or she lives and the question is: *How did the public health agencies respond to a problem considered urgent by the local community?*

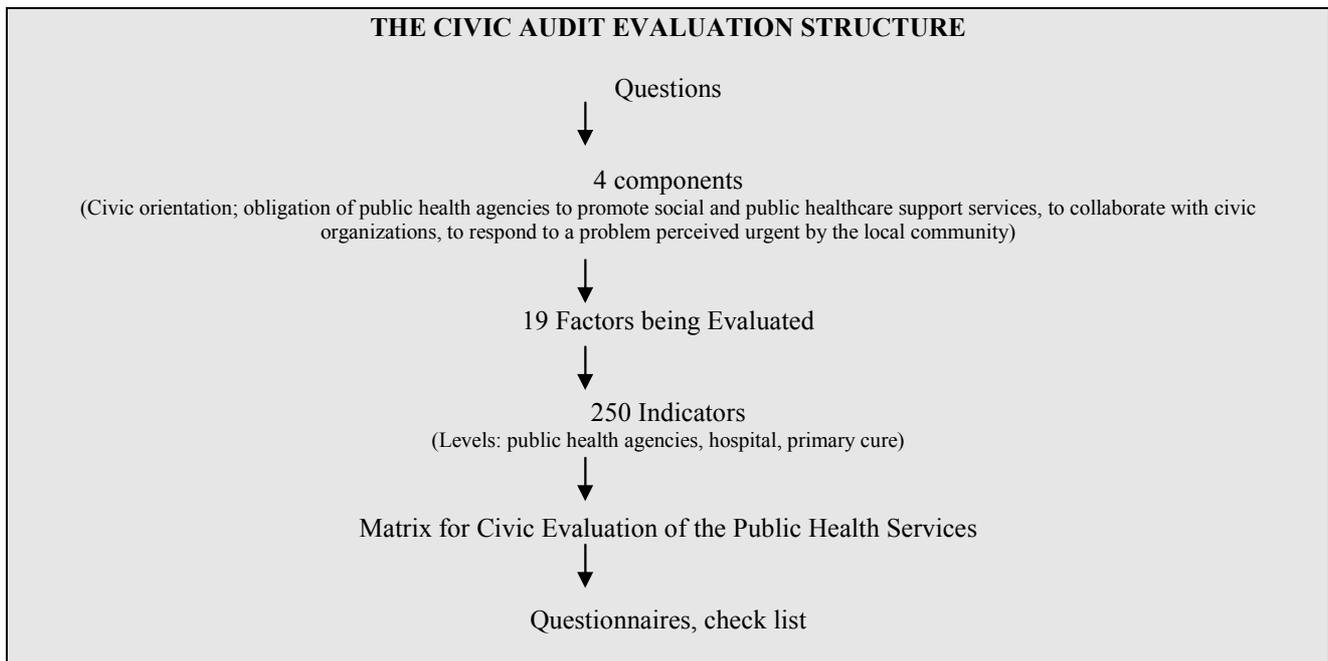
Naturally, the vast and complex nature of these questions makes it impossible to provide a complete, systematic response. However, they do facilitate the selection of core considerations for the Civic Audit and for data collection purposes

When presented with the first question regarding the focus of public health agencies upon citizens themselves, the agencies must indicate the measures they are taking to guarantee their provision of good information on services which respect the rights of the sick, ensure the provision of comforting, welcoming surroundings in public health services and provide support for the families of the seriously ill, etc. As far as the second question is concerned, the safety of hospital facilities and systems can be analysed, as can the relative allowance for individual requirements and potential, adverse conditions, measures in place to manage patients' pain and measures which would also facilitate the use of services by the chronically or terminally ill. Treatment of the third question on the public health body's capacity to actively involve

citizens and civic organizations in their policy management is of less immediate concern. Thus, the Civic Audit facilitates a process of clarification of some legislative arrangements in place, intended to encourage the participation of citizens voluntarily seeking new means of interaction with their local community and, ultimately, it seeks to render the relationship between citizens and public health services of strategic value. The fourth question is deliberately value as it is considered impossible to foresee which problems a specific community may consider to be urgent, but the Civic Audit provides a forum through which interactive consultations with various actors (hospital administrations, medical personnel, nursing staff, citizens etc) can be carried out and ultimately become a public initiative.

#### 2.4. The Civic Audit Evaluation Structure

Alessandro Lamanna and Alessio Terzi's "Technical Working Group for Civic Auditing<sup>151</sup>", demonstrated below, forms the basis of the Civic Audit Evaluation process, establishing a clear structure with components, factors and indicators.



Firstly, 4 *components* were defined which each correspond to the core questions previously referred to. The components are:

- a. *Orientation towards citizens*, that is the attention demonstrated by the agencies in areas frequently considered to be problematic by public health service users, who could help establish ever-increasing faith in the SSN if effectively cared for (SSN: performance, respect of personal, cultural and social identity etc.);
- b. *The public health agency's duty to promote certain social and public health policies*;
- c. *The involvement* of civic organizations in the definition of public health policies;
- d. *The public health body's capacity to respond* to a concrete problem perceived as urgent by the *local community*.

The *first three components* have been developed from a *national* perspective, are centrally structured, focused upon managing certain thematic areas and subsequently encouraging *benchmarking* and diffusion of good practices.

<sup>151</sup> The Working Group, drawn up in 2000, was made up of experts from the *Istituto superiore di sanità*, (Higher Institute of Health), the *Istituto per il marchio di qualità* (Imq/Csq), (Institute for Quality Brands), of hospital establishments in Caserta, Turin (San Giovanni Battista), Monza (San Gerardo), local, public health bodies in Northern Bologna Nord and Legnago, and representatives of Astra Zeneca, as well as local and national representatives of *Cittadinanzattiva*.

These three components are broken down into *factors being evaluated*. That is to say:

**a. Focus upon the Citizen:**

- Access to services;
- Respect for personal, cultural and social identity of the sick;
- Social relations;
- Information;
- Personal assistance;
- Comfort – hotel services;
- Support for the sick and their families;
- Health care documentation and communication with doctors;
- Rights protection;
- Quality improvement programmes.

**b. The Obligation of the Public Health Services to Promote Certain Social and Public Health Policies:**

- Management of clinical risk;
- Safety of structures and installations/services;
- Chronic and terminal illness;
- Pain management.

**c. Involvement of Civic Organizations in Policies of Public Health Services:**

- Institutions encouraging participation of SSN (*Servizio Sanitario Nazionale* / National Public Health Services in rigorous accordance with the law;
- Other forms of civic participation and interaction between citizens and public health bodies.

Each factor is demonstrated by a series of indicators, collected together in a matrix for *civic evaluation of public health services*. The matrix, which currently contains approximately 250 indicators operates on 3 levels:

- The first level includes the indicators which apply to the public health services as a whole (*establishment level*);
- The second level includes indicators which relate to hospitals (*hospital assistance level*);
- The third level includes the indicators pertaining to family medicine, home care, specialist medicines, mental health and drug-addiction (*primary care level*).

The *fourth component*, as has already been stated, is studied by means of a local approach and relates to concerns raised by the team at a public health agency level and considered most urgent at local community level.

The data collected by various teams composed of a mixture of citizens and public health workers who participate in the Civic Audit.

Data is collected using the following means:

- 5 types of questionnaire addressed to the management of public health bodies affected by Civic Audit;
- 1 questionnaire addressed to representatives of voluntary groups present in some Committees of Public Health Establishments<sup>152</sup>;
- 5 different checklists intended for the direct observation of the public health structures by auditors (citizens or public health workers).

## 2.5. Benchmarking

One element of the Civic Audit is the development of a comparative evaluation (benchmarking) of performance relating to the three component factors of the evaluation process, that is “focus on citizens”,

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<sup>152</sup> Italian legislation makes a provision for the existence of certain committees at the public health establishment level (Ethics Committee, Committee on Good Use of Blood, Conciliatory Committee etc.) and participation of representatives of these Committees in civic organizations is also foreseen.

“the duty of the establishment to promote certain social and public health policies” and “the involvement of civic organizations in policy agendas”.

Basically, benchmarking involves designing a graph to demonstrate the value of adequate standard indices (IAS) which each public health services received for every factor evaluated.

Each graph is accompanied by:

- a concise judgement based on a scale of excellent / good / fair / poor quality / very poor quality, which is based upon an average rating of the IAS for all healthcare agencies;
- The highest scores reflect the positive performance.
- The lowest scores reflect the negative performance.

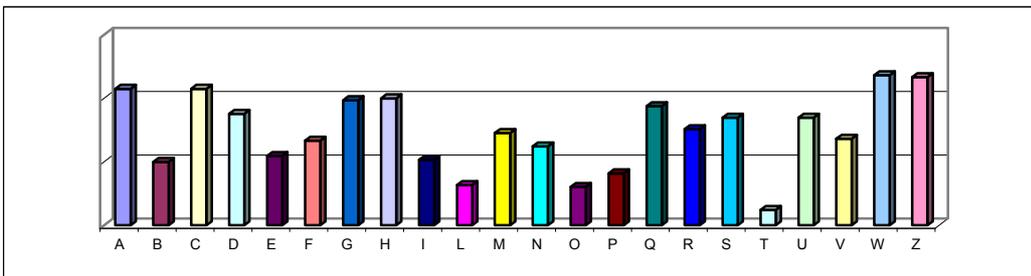
Whenever possible, an indication is provided of when standards have not been reached by any public health agency.

The results of the Civic Audit, organized in this way, are discussed at “benchmarking meetings” in which teams from various establishments participate. During the course of these meetings, it becomes possible for every member of the team to:

- Interpret the results of his or her own Civic Audit in a wider context;
- Segregate potential areas of excellence and critical areas of concern, which are specific to each performance;
- Promote the study of technical and organizational solutions which have make it possible to improve performance.

Hereafter are some graphs which were included in the Civic Audit Reports of 2003 and 2004.

**Quality Concern: Information –Level of Assistance in Hospitals. Civic Audit 2003**



Key: A B C D E F G H I L M N O P Q R S T U V W Z = the health care services involved in the Civic Audit.

**Result: fair**

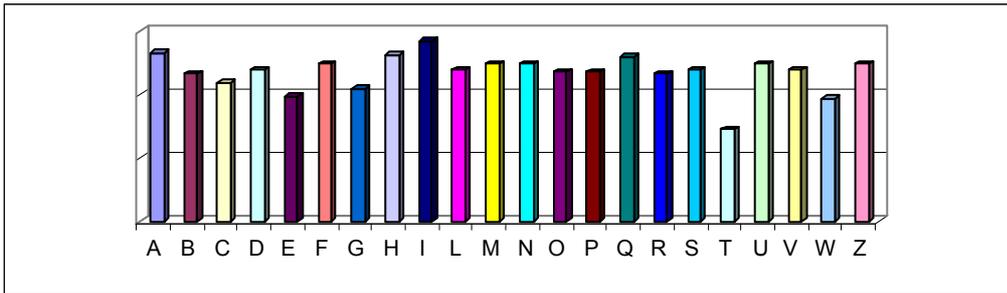
*Factors Which Justify the Best Results :*

- A high percentage of healthcare workers of whom a poster indicated hours/schedules
- A high percentage of healthcare workers of whom a poster indicated their names and doctors’ qualifications
- Availability, at the time of entry into the healthcare service, in an information pamphlet on patient rights
- Availability, at the time of entry into the healthcare service, in an information pamphlet on hospital presidency and the hospital rules regarding patients

*Factors Explaining the Worst Results:*

- Low percentage of those from hospital departments in which there was a poster indicating arrival times of personnel
- No means of informed consensus regarding invasive acts
- No public information service close to the main entrance

**Quality Concern: comfort – level of assistance in hospitals Civic Audit 2003**



Key: A B C D E F G H I L M N O P Q R S T U V W Z = the healthcare agencies involved in the Civic Audit.

**Result:** excellent

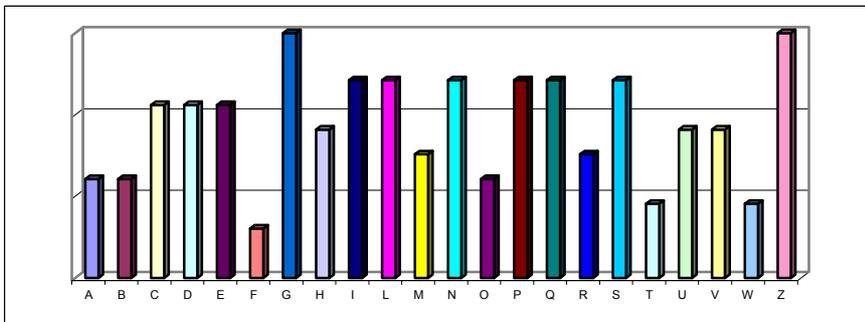
*Factors Which Justify the Best Results :*

- There is a car park specifically for the service.

*Factors Explaining the Worst Results:*

- A run down communal areas and operations’ rooms of hospital structures (crumbling walls, windows that do not close, rubbish or other abandoned materials, cobwebbed ceilings and/or walls)
- Low percentage of hospital sections with toilets with seats, alarm bells or systems which indicate whether the toilet/bathroom is occupied or available for use
- Low percentage of outpatient clinics with disabled toilets close to the premises
- Low percentage of toilets/bathrooms in the clinics with mirrors, shelves or waste bins
- No waiting room in the first aid/emergency area of the hospital premises
- Low percentage of beds with recovery rooms with private hygiene services available only to in-patients using that room
- No possibility to choose between two or more hospital meals
- Nowhere for hospitalized patients to buy magazines or newspapers

**Quality consideration: risk management – Public Health Agency level. Civic Audit 2003**



Key: A B C D E F G H I L M N O P Q R S T U V W Z = Public Health Agencies involved in the Civic Audit

**Result:** Good

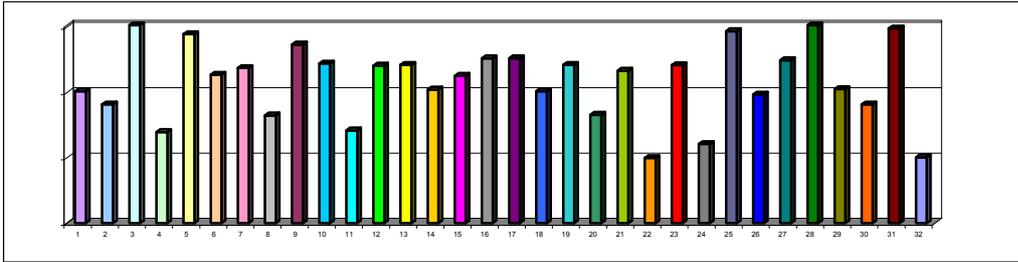
*Factors which Justify the Best Results:*

- The availability on every level of the establishment of an office / person / service charged with risk management
- The existence of a map of clinical risks

*Factors Explaining the Worst Results:*

- The lack of a Committee on prevention of hospital infection
- The lack of risk management training courses

**Quality Concern: Rights protection – Public Health Agency Level. Civic Audit 2004**



**Result: good**

*Factors Which Justify the Best Results:*

- Response to all complaints made by citizens
- Establishment of official service standards and involvement of citizens in the process

*Factors Explaining the Worst Results:*

- Lack of periodic analysis of complaints received by the Public Relations Office

**2.6. The Impact of Civic Audit**

At the end of the first four years of Civic Audit, least three effects of the process are apparent. The first is cognitive, as it provides a sort of “control filter” of the action taken by public health services and of their impact upon the quality, humanization of public healthcare assistance and citizens’ involvement in establishment policy. The second effect of Civic Audit relates to its impact upon the premises, that is to say the collective result of improvements carried out by public health concerns as a result of the Audit. The third effect relates to new practices which have developed in public healthcare services subsequent to the Civic Audit.

Moreover, benchmarking has made it possible to identify three types of concern. Firstly *good practice*, that is the good practices that distinguish a small percentage of public health establishments from the rest, this being linked to their sensitivity to problems as they arise, or at least those of recent concern in Italy. Besides these, the following points can also be listed.

**Tab.1 – Key List of “Good Practices”**

- Communication of the name of the doctor in charge of hospitalized patients to those patients
- Provision of support services and procedures to the bedridden and their families in case of death of their loved ones, financial need, transfer to hospital facilities for the long-term bedridden or to residences with healthcare assistance, or monitoring after hospital discharge
- Introduction of the ISO 9000 quality control system throughout the entire hospital complex
- Introduction of the ISO 9000 quality control system in one or more services of the public health system
- Survey of the degree of user satisfaction (and that of their families and friends) with district offices, walk-in clinics and other areas of the public health service
- High percentage of hospital departments in which at least one survey of level of user and family satisfaction has been carried out (in the last 2 years)
- High percentage of hospital departments in which there is evidence of action being taken to improve facilities or procedures after consultation with in-patients
- Records of errors, quasi-errors, incidents caused by organizational/duty issues
- Drawing of the clinical risk map
- Drawing up of the plan to manage clinical risks
- Development, in the last three years, of projects intended to create a system of evaluation/recognition in hospitals by introducing clinical controls and collecting data on patients in pain
- Training courses to measure clinical control and collect data on patients in home care living in pain
- Occasional consultations (at least every 4 months) of civic organizations with the management of public health care establishments
- Contracting of work which foresees quality control of the services provided by the users.

The second type of consideration is omissions, specifically speaking, these are actions taken in the majority of agencies, and which but a few are determined not to carry out. The following provide examples of such omissions:

**Tab.2 – List of the Main “Omissions” Noted**

- |   |
|---|
| <ul style="list-style-type: none"> <li>• No institutional telephone number through which to provide the public with information</li> <li>• No public relations office (URP)</li> <li>• No institutional website</li> <li>• No public services or information at the main entrance (which would lend itself to being an information or welcome point etc)</li> <li>• No appointments, or checks/diagnosis service through a single, central reservations service (<i>Centro Unico di Prenotazione</i>, CUP)</li> <li>• Impossible to make telephone reservations through CUP (details above)</li> <li>• No specific point at which to make appointments for medical visits or tests with queue control/regulation</li> <li>• No sign in the main hall summarizing the services available in the walk-in clinic</li> <li>• No information booklets explaining services and rights in walk-in clinics</li> <li>• Impossible to drop off service users with difficulty walking at the main entrance</li> <li>• No street sign outside the establishment premises indicating the site layout</li> <li>• Wards with hospitalization rooms, this including confinement rooms with more than 4 beds each</li> <li>• Lack of clinics with disabled toilets</li> <li>• Lack of periodic, qualitative/quantitative analysis of complaints received from the Public Relations Office (three monthly, annual reports etc)</li> <li>• No Committees focused on the prevention of hospital infection</li> <li>• No palliative care facilities</li> <li>• Little use of charts with which to monitor pain</li> <li>• Lack of protocol regarding relationships with civic organizations</li> </ul> |
|---|

- To conclude, benchmarking has facilitated identification of obstacles, that often means basic practices of particular concern to citizens, which are often not implemented in most public health agencies. Below is the main list of problems/obstacles to be overcome.

**Tab.3 – Table of main obstacles to be overcome**

- |   |
|---|
| <ul style="list-style-type: none"> <li>• Appointment/test calendars on all doors and implementation of a queue control mechanism.</li> <li>• Dinner distribution to patients after 1900</li> <li>• Number of day hours during which visitors can see patients on bank holidays (besides the 6 hours per day)</li> <li>• Patient register from his/her time of admission to hospital (sufferers of second degree wounds and worse)</li> <li>• Respect for privacy of terminally ill patients and their families, who should have their own room reserved</li> <li>• Provision of advice on rights regarding free choice of the patients’ place of care</li> <li>• Signs throughout the hospital indicating names and qualifications of doctors</li> <li>• Availability of pamphlets indicating the services available at the entrance of walk-in clinics</li> <li>• Availability of documents or advice on how to communicate comments, suggestions or complaints immediately upon entry to public health establishments (notably hospitals, district offices and other services)</li> <li>• Summons of the Public Health Service Establishment Conference of the previous year</li> <li>• Presentation of the quality control survey results to the Service Conference</li> </ul> |
|---|

This informs each team of its own organization’s “good practices, “obstacles/problem areas” or “omissions”, and proves to be the preferred means of clarifying the issues to be addressed as priorities.

### *Local Outcome of the Civic Audit*

To date, analysis of results of the Civic Audit has been carried out by 13 public health agencies<sup>153</sup>.

In these establishments and in accordance with the Civic Audit, 235 improvements have been noted. These can be categorized as follows:

- 58 improvements to comfort, access to medicine and safety of systems and structures;
- 26 improvements relating to risk and pain management;
- 53 improvements relating to chronic illness, support for the bedridden and their families, assistance to the sick person, documentation of his/her state of health, involvement of institutions with legislative obligations to intervene, and other forms of participation;
- 98 logistical and sanitary improvements, respect for identity and social relations, rights protection and improvements to the quality of service

There are various types of improvement, such as those listed in the list below:

- **Structural improvements**

A new oncology department, the opening of a bar, opening of an in-house shop, building of disabled toilets in three hospitals, general improvements to comfort of certain hospitals etc

- **Organizational improvements**

Opening of two appointment centres for visits and tests and a system of telephone reservations: use of an operative scale of urgency by one Emergency Services Unit; distribution of mobile phones throughout hospital departments; improvement to the visiting hours of hospitalized patients, adoption of a personalized appointments system for walk-in visits, billposting of evacuation plans

- **Institutionalization of improvement groups**

On safety in operating rooms, on risk and pain management

- **Implementation or strengthening of information channels to citizens**

Opening of information points, updating of posters both inside and outside the public health structures, printing and distribution of information

- **Activation/Implementation of new services and public health establishments**

Cultural mediation service, ethical committee, mixed consultative committee

- **Occasional, new consultation procedures of civic organizations.**

### *New Practices*

Ultimately, application of the Civic Audit has brought new practices into operation.

In some cases the indicators not meeting the required standards have been pinpointed very punctually, and in each case the possible line of corrective action indicated and subsequently checked as to why standards were not met. In other cases, **a progressively more intense involvement of civic organizations in establishment policy has been noted.**<sup>154</sup> Ultimately, **discussions on the data collected through the Civic Audit process has encouraged intervention in general.**

## **3. The Hospital Safety Campaign**

### ***3.1. The Starting and Development of the Campaign***

The Hospital Safety campaign came into being in response to two grave events, which took place between the end of 1997 and the beginning of 1998, and which were concerned with hospital safety. Although sophisticated legislation was in place and a considerable amount of national funds were available, it was possible to lose one's life or one's health in Italian hospitals as a result of circumstances that could

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<sup>153</sup> *San Giovanni Battista di Torino* Hospital, Caserta Hospital, Palermo Walk-in Clinic, *S. Antonio Abate di Trapani* Hospital, Local public health agencies in Chiavari, Nuoro, Legnago, Lucca, Salerno, Piacenza, Turin 1 and Turin 4., Provincial Public Health Services for the Trento Region.

<sup>154</sup> Ref. A. Passerini e C. Corposanto "Communal Building of the Public Health Service Documentation – The Experience of Apss in Trento", Franco Angeli, 2004.

undoubtedly be avoided. Something had to be done to enable citizens to play an effective part in this situation.

The complexity of the matter required a systematic comparison of the citizen's point of view with that of the rest of those concerned. Consequently the suggestion of a *Round Table on the Safety of the Health Service* was made to representatives of scientific institutions, to those of public health establishments, and to professionals and producers in the public health field. Participants were both numerous and qualified.<sup>155</sup> On the one hand, the scientific and professional aptitude of those at the Round Table resulted in the evaluation structures and of the system of indicators for the Hospital Safety Campaign being perfected; on the other and it allowed features of the system to be brought together to develop a common safety culture.

In 1998, the first experimental campaign drew public attention to the problem<sup>156</sup>, allowed the suitability of the indicator system to be tested and the evaluation structure to be fully defined. This was followed, at the end of 2003, by another five campaigns and the last evaluation cycle is currently in progress.

A total of 224 evaluations of 165 hospitals were carried out. The evaluation mobilized 535 citizens, who were defined as *civic safety operators*, and who had complemented the *direct observation* with interviews with:

- 2.360 healthcare workers (doctors, nurses, technicians, auxiliaries);
- 165 Prevention and Protection Service managers;
- 108 doctors responsible for the safety of their work;
- 108 nurses responsible for preventing infection.

### ***3.2. The significance/impact of citizens' intervention in hospital safety politics***

The birth of the Hospital Safety Campaign has resulted in repeated incidences of prejudice in public health being overcome. Indeed, it has been suggested that safety can simply be aligned with the number of surgical operations carried out, in order to meet the required norms. The subject matter was left to technical specialists and administrative leaders. The healthcare workers and citizens using the service did not play an active part in this process, and had to limit themselves to respectfully working around the experts.

It is quite easy to observe that this approach is essentially inadequate. By definition, hospitals are areas of concentrated risk, due to their ailing populations, invasive treatment, the complexity of structures and sophisticated technology that should function perfectly. Management of such a complex system requires a high level of awareness and involvement from all parties present.

In civic organizations this problem has been of long-standing significance. The National Protocol on the Health Service (*Il Protocollo nazionale sul servizio sanitario*) defined the right to safety by way of an announcement on the Patients' Rights Day in 1995:

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<sup>155</sup> The Round Table of the Higher Institute of Health (*Istituto Superiore di Sanità*) included participants from: The National Research Council, the Institute of Quality Control (*Istituto per il Marchio di Qualità/CSQ*), of Certified Quality (*Certiquality*), the National Society of Prevention Workers (*Società nazionale degli operatori della prevenzione*), the Italian Association of Physics for Medicine (*Associazione italiana di fisica per la medicina*), the Italian Association of Clinical Engineers (*Associazione italiana degli ingegneri clinici*), the Association of Healthcare Engineers and Architects (*Associazione degli ingegneri e degli architetti*), the Association of Operation Room Nurses (*Associazione degli infermieri di camera operatoria*), the National Association of Nurses for the Prevention of Hospital Infection (*Associazione nazionale degli infermieri per la prevenzione delle infezioni ospedaliere*), the National Association of Electrical Industries (*Associazione nazionale delle industrie elettriche*), the Biomedical Association (*Assobiomedica*), the Chemical Federation (*Federchimica*: sensitive and medicinal gas products), the Italian Federation of Healthcare and Hospital Establishments (*Federazione italiana delle aziende sanitarie e ospedaliere*), doctors adhering to "Fimmg" and the "Anao Assomed" Medical Association, and the Italian Private Hospitals Association (*Associazione italiana dell'ospitalità privata*).

<sup>156</sup> The final reports on the Secure Hospital permanently echoed daily or weekly press reports, as well in V. Ferla (edited by), *The Italy of Rights (L'Italia dei diritti)*, Cultural peace editions, Calenzano (Fi), 2001 and 2002.

*Whosoever finds him or herself at risk to his/her health has the right to the care necessary for his/her condition as well as the right not to suffer further ill as a result of ineffective functioning of structures and services.*<sup>157</sup>

The issue of the right to safety was taken up and brought up to date by the European Charter of Patients' Rights, presented in Brussels on 15 November 2002:

*Each individual retains the right to remain unharmed by any ill-functioning of the public health services, by malpractice or medical error, and has the right to access public health services and treatment which guarantee a high standard of safety.*

In order to guarantee this right, hospitals and public health services must constantly monitor risk factors and ensure that electronic healthcare measures are kept in good condition and that healthcare workers receive the necessary training. All healthcare professionals must be fully responsible for safety in each stage of medical treatment. Doctors must be able to foresee potential errors by monitoring previous cases and by continuous training. Members of staff who report risks to their superiors and/or colleagues should be protected from any possible adverse consequences of their actions.

Thus, the concept of safety is no longer a simple matter of meeting standards, but has instead become a risk management regime; *the term 'regime' being used to mean a system of norms, values, resources, information, procedures, codified behaviour which forces all parties concerned to warn of present dangers and thereby limit any damaging effects.* In this context, the ability to observe, developed through experience of the Tribunal for Patients' Rights, proves itself a highly valuable resource.

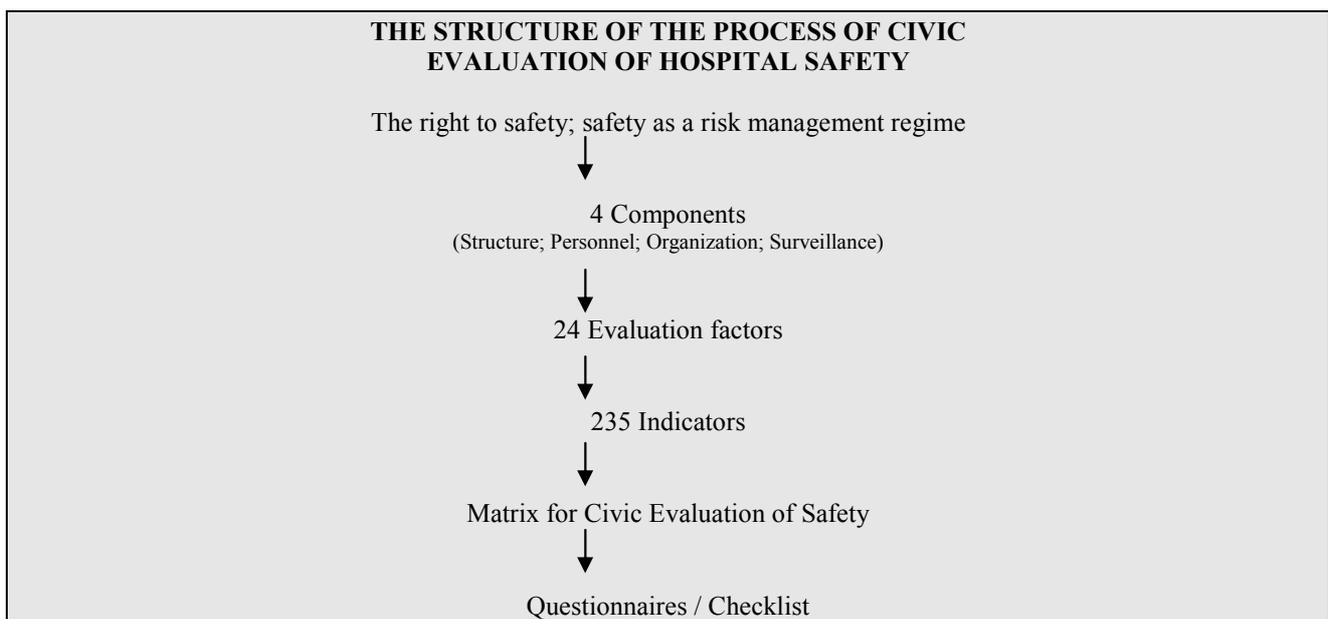
### **3.3. The Structure of the Civic Evaluation of Hospital Safety Project**

The structure of the evaluation project stemmed from the belief that safety can be defined by:

- the conditions of the *structures* in which public health activities are carried;
- the capacity of the *personnel* to recognise and manage the real risks of the workplace;
- the *organization* of risk control activities and procedures;
- the *surveillance*, notably of safety-related concerns.

Each of the four components, as defined above, was considered a factor for evaluation, of which there are a total of 23.

The structure of the civic evaluation of safety is summarized in the table below.



<sup>157</sup> Petrangolini T:- *Health and Citizens' Rights* – Various Editors, Rome, 2002.

Regarding the *structures*, the following points are taken into consideration:

- Readiness of the *communal structures* for these purposes;
- Readiness of the *emergency services/first aid*;
- Adequacy of the *electrical installations*;
- Adequacy of *fire prevention* measures in place;
- Adequacy of *air conditioning* fittings;
- Adequacy of *medicinal gas* installations;
- Adequacy of *hydraulic installations*;
- Impact of *building sites* on site;

The *personnel's* capacity to recognise and manage the real risks in the work place and to evaluate these with four levels of assistance:

- The level of formalization and precise information given to *personnel* on potential risks in the workplace;
- The extent and type of safety *training activities* encouraged or officially recognised by the public health establishment;
- Their *knowledge* of the organization and its safety procedures;
- Their *operational knowledge* of the means of indicating risk and managing emergencies.

The evaluation of the organization of activities and risk control procedures considers 8 key points:

- *General* management and planning *foresight*;
- *Hygiene safety*;
- *Management of hospital stays*;
- *Upkeep and control* procedures;
- *Safety measures* at work;
- *Technology management* procedures;
- Procedures to *manage medicinal gas installations*;
- *Laboratory analysis management* procedures.

The fourth component is *surveillance*, and is made up of four factors:

- Surveys of events which demonstrate that inappropriate *behaviour* is taking place;
- *Surveillance* measures;
- *Information* to the public and to workers with ID cards and instructions;
- The state of the *system of safety signs*.

235 indicators used to analyse the factors identified above.

### **3.4. The Development of the Annual Campaigns**

Setting up the Hospital Safety project required integrated development of both national and local activities.

The national level takes care of all technical and methodological issues, as well as the practical coordination of the campaign.

The data collected by a team of citizens required the following tools:

- a **check list** to monitor stable **structural points** which tend not to change with time;
- a **check list of momentary events** which vary (such as obstacles blocking fire exits), which should be controlled by 4 different types of inspection, each carried out at least a week from the last;

- **five questionnaires by qualified managers** (Prevention and Protection Service, Doctor Responsible for Safety at work, Prevention of Hospital Infection, Hospital Pharmacy and Laboratory Analysis Managers),.
- **a questionnaire for healthcare workers** regarding their knowledge of safety procedures.

### 3.5. Benchmarking

To date, a strength of the campaign has been the publication in the final report, of hospital merit ratings, compiled on the basis of the comprehensive Index of Adjustment to Standards (IAS).

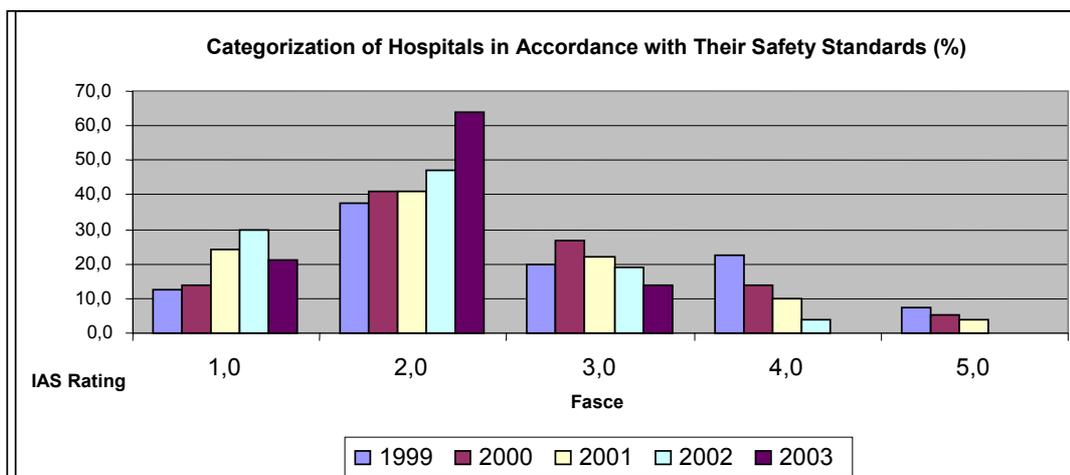
There are five groupings used:

- the first grouping is made up of hospitals with an IAS rating of 80 or above, which demonstrates their general tendency to provide a satisfactory level of safety;
- the second is made up of hospitals with an IAS rating between 70/100 and 79/100, which indicates that there is a fair level of safety though general management roles are underdeveloped;
- the third grouping, with rating between 60/100 and 69/100 suggests that overall safety is problematic;
- the fourth grouping brings together hospitals in dire straits with regard to safety, with ratings between 50/100 and 59/100;
- the fifth grouping (with an IAS lower than 50/100) reflects situations in which safety management is practically non-existent and could present an impending danger.

Publication of the index has always had relevant echoes of the reality on the ground<sup>158</sup>, resulting in some inevitable controversies whilst also having numerous positive effects.

For the best hospitals, positioning at the top of the ratings served as a deserved acknowledgement of the crucial work they had carried out, which tends not to be noticed. For those which fell into the intermediary bandings, there was a drive for improvement. When establishments fell into the critical category, or that of impending danger, they were strongly driven to take responsibility. The controls carried out in these hospitals at one year intervals almost always demonstrated slight improvements. The Nuoro hospital was exemplary to this regard for in less than 12 months its rating moved from critical to the second credit banding, and it shrewdly proceeded to become a genuine leader of the civic evaluation process.

General improvements to hospital safety are reflected in the graphs in figure 1, which demonstrate the percentage of hospitals in each of the five groups at the end of each campaign between 1999 and 2003.



Group 1 : IAS >= 80/100; Group 2: 70/100 = <IAS > 80; Group 3: 60/100 = <IAS > 70; Group 4: 50/100 = <IAS > 60; Group 4: IAS < 50/100

<sup>158</sup> Ref. to note 33.

There is an evident move towards the higher bands and fortunately cases of potential danger have virtually disappeared.

The comparative evaluation of the IAS is obviously applied to each single component and to every single point of concern. Moreover, median, minimum and maximum values are made available to local groups, and the best and worst situations experienced are identified for their benefit. This service has been frequently used at a local level to identify critical areas of concern and methods of improvements.

Ultimately, diachronic examination of the data from the five campaigns carried out to date helps improve understanding of the safety processes in place in Italian hospitals.

### ***3.6. The slow but constant improvements to the public health structures***

The Index of Adequacy of Standards (IAS) of buildings rose relatively regularly from 71 in 1998 to 82 in 2003. This is the result of an intense use of national funds having been allocated to public health structures between 1998 and 2003. The facility improvement process is intrinsically slow and an increase of approximately 15% of the IAS over a six year period can be considered a positive result.

### ***3.7. A strength: Surveillance***

The surveillance component demonstrates the greatest adjustment to standards of the IAS (87/100) as well as the greatest index increase compared with the initial situation (+ 50%). Together the four factors demonstrate a very favourable course:

- The IAS of the behaviour of personnel went from 70/100 to 89/100, with an increase of 27%;
- The Surveillance IAS jumped from 60/100 to 87/100 with an increase of 45%
- The Index of public and public health worker information access moved from 55/100 to 90/100 with an increase of 64%.
- The Signposting IAS went from 46/100 to 89/100 with an increase of 93%.

In the years being considered attention towards the theme unquestionably increased (and the Hospital Safety campaign could well take some credit for this). This simple fact has prioritized a large number of simple, yet neglected, concerns, including, for example, the need to indicate a room's purpose at the entrance, or to warn of danger with posters designed for the purpose.

In an outline of the situation, which is favourable overall, there are, however, at least two alarm bells ringing. The first is that there are still hospitals almost totally lacking any surveillance measures, with an IAS of 33/100 for behaviour, 25/100 for surveillance, 43/100 for provision of information and 33/100 for signposting. The second alarm bell is the scarce availability of evacuation plans. The average IAS on this point is in fact 63/100 and in some hospitals there are absolutely no plans. As will soon be seen, As will soon be seen, this is not a mere matter of carelessness.

### ***3.8. A critical area: hospital personnel***

Since the beginning, the IAS of these components registered the lowest levels. 48/100 in 1998 and 58/100 in 2003. Results are only fractionally better in a limited number of excellent hospitals with the highest ratings. The comparison of this data with that of the previous paragraph demonstrates that, for the most part, a communal culture of sharing has not yet developed.

This component of the survey reflects the limitations of taking an approach which strives to simultaneously adopt measures, provide information and involve personnel. The relative indicators of organizational and operational awareness are in fact very low.

- 40% of interviewed workers do not know who is responsible for hospital safety;
- 45% do not know the meaning of symbols or the branding of hospital equipment;
- 45% do not know the fire procedures;

- As many as 29%, claim not to know safety codes.

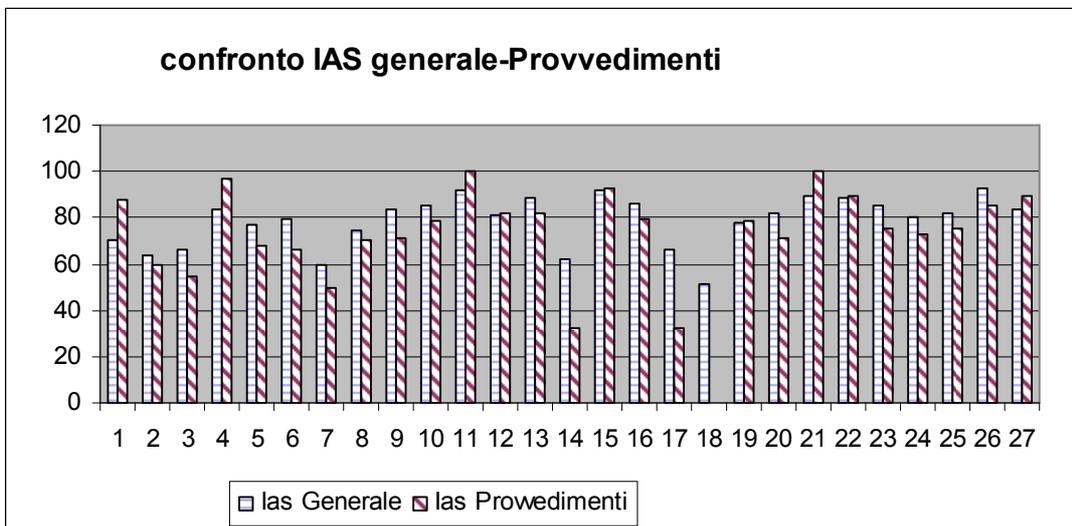
Knowledge of accident reporting procedures, service management and checks also appears to be very limited, but in this case, as will become apparent, the problem is a total absence of procedures, and in spite of this, the training initiative, which was aimed at monitoring maintenance, addressed or had little impact upon operational culture, or if it did, it affected a small group of specialist workers such as the fire squad.

### 3.9. *The Slow Process of Organizational Adjustment*

The relative IAS of the various components of the organization indicates a less dynamic movement, for the level of improvement noted moved from 70/100 in 1999 to 76/100 in 2003. The IAS of the factors pertaining to maintenance and controls was almost unaltered (74/100 in 2003 as opposed to 69/100 in 1999), as was the index of technology management (76/100 as opposed to 73/100). There are also almost no procedures in place to indicate accidents. One emblematic factor is that in 2003 all public health establishments claimed to already have the risk evaluation document, but only 66% also had an evacuation plan. The first document, required by the law of safety at work, can be drawn up in generic terms by only formally adhering to this legislation. The second of course needs to be compared with the real situation. In concrete terms, a culture of formally respect of norms has permeated the system, but does not impact upon reality, safety remaining a mere marginal concern, addressed by technical experts, and not impacting upon general organizational processes.

### 3.10. *Good news: lessons learnt*

A relative comparison of a sample of 26 hospitals reveals very interesting data. The first graph shows the relative state of the IAS in the hospital as a whole; the second index shows factors relating to the general management and planning measures in place.



It is noted that in the majority of the hospitals the difference between the general IAS value and the relative IAS value with regards to organizational measures adopted are very low. Those who took the legislative advice seriously and worked hard to apply it to the norms of their own real life situation intelligently achieved the best results. This means two things: the first is that the legislation available is appropriate to current circumstances, the second is that in various real life situations a virtual risk management regime is being installed, which makes a significant wealth or experience and competence available to the Italian health system.

#### 4. Conclusions

The spread and success of civic evaluation of quality and safety challenge closed-minded discussions of citizens “lack of the necessary ‘skills’ to carry out public business because it them to draw on certain knowledge”<sup>159</sup>. Similar perceptions overlook two simple, undisputable facts, which are:

- The level of teaching and professional experience of active citizens are not usually inferior to those of the policymakers and the service managers carrying out the civic intervention process;
- Systematic action to protect policy and service rights and services produces information and knowledge and thus provides a true, proper “civic competence” training programme.

The thesis put forward by some writers,<sup>160</sup> who suggest that citizenship itself be considered a learning tool, thus appears to carry weight. The itinerary summarized in the opening paragraph helps to understand how, with increasing impact, citizens intervened in certain areas of public policy-making, by specifying their point of view as intended in the double accession process discussed in Paragraph 1.2. Basically, this is a learning exercise, and a development of specialist areas, upon the basis of which it has been possible to build the foundations of the civic evaluation process.

The core innovation, which grew from the planning and implementation of the two projects described in this document, has been the consideration of civic evaluation as a discipline, a coordinated, formal structure made up of operational concepts, procedures, calculation techniques and interpretation criteria. Its complete development still requires much more work, but adoption of this approach has already produced significant results:

- Thanks to more precise, methodological support, the quality and relevance of monitoring campaigns carried out by *Cittadinanzattiva* have improved;
- Channels of communication and interaction between civic evaluation and other forms of evaluation used by national public health services have been opened.

Notably, conclusive reports of the Civic Audit and of Hospital Safety have been recognised as valid documents for accreditation procedures in public health structures, this including direct services of the Joint Commission on Accreditation of Healthcare Organizations in the Lombardy region<sup>161</sup>. Civic evaluation is now considered integral to the third part of the evaluation process, concerning the viewpoints of service users. Direct participation of citizens writing the evaluation report is considered a point of strength. In classical approaches to customer satisfaction and perceived quality, citizens simply remain data sources to question with the most appropriate tools, whilst the choice of indicators and data interpretation remain the experts’ prerogative.

Turning our attention from general considerations to more operational matters, the concept of factor evaluation can be seen as the stronghold of the civic evaluation process. This in fact allows for an association of the aspects which characterize the real situation being evaluated with a group of detail indicators which analytically describe the situation being examined. The calculation of Indices of Adjustment to Standards (IAS) enables the link between the real situation and the expected outcome to be analysed approximately.

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<sup>159</sup> Ref. Moro G., *Civic action*, Carocci, Roma 2005, p. 37; Id., “Citizens’ Evaluation of Public Participation”, in Caddy J. (ed.), *Evaluating Public Participation in Policy Making*, OECD, Paris 2005, pp. 109-126.

<sup>160</sup> Ref. Donolo C. – “The good governance dream. Praise for the democratic regime” – Anabasi, Piacenza, 1992.

<sup>161</sup> per le procedure regionali che richiamano esplicitamente l’Audit civico si possono consultare: <http://www.regione.puglia.it/index.php?page=curp&opz=display&id=1127>; [http://asr.regione.emilia-romagna.it/wcm/asr/piano\\_programma/pp2006/pa2006\\_accREDITAMENTO.htm](http://asr.regione.emilia-romagna.it/wcm/asr/piano_programma/pp2006/pa2006_accREDITAMENTO.htm); <http://www.asrabruzzo.it/area%20accredita%20mento.htm> (ultimi accessi 10/1/2007). Il Programma triennale per l’implementazione del sistema di valutazione delle aziende sanitarie pubbliche e private della Lombardia ha il supporto tecnico della Joint commission; i rapporti di Audit civico presentati da due aziende ospedaliere di sono stati accettati come documenti validi.

Analysis of the absolute value of the IAS, and of the benchmarking tables, favours a move towards rapid characterization of critical factors. Studying the checklist, on the other hand, facilitates characterization of indicators which do not meet the standards or carry out the necessary operations to raise the adequacy of their standards. In local real-life situations these characteristics have enabled:

- Civic organizations to develop their capacity to enter into dialogue with the management of public health agencies;
- Encourage concrete changes to take place, and often at low cost, to guarantee continual processes of improvement.

Ultimately, by adopting a unified evaluation system and through systematic benchmarking processes, public health concerns have expressed a preference for the circulation of best practices and the development of criteria both for evaluation and corrective action planning. This is particularly true in regions which have officially adopted the Civic Audit. In these cases regional groups have developed with (both civic and management of any truly involved parties) which evaluate the reports of projects in operation. The analysis and discussion of the check list of indicators associated with the factors, the definition of implementation criteria, discussion of the benchmarking tables provide opportunities for informal meetings and precisely because they add operational value because by sharing standards and solutions, they easily act in accordance with their respective realities. It is quite easy to note, for example, that a slight increase of attention to little known, or hidden, phenomena of great relevance to citizens. A particularly noticeable example in terms of its merit and improvement to logistical information.

In conclusion, it seems fair to affirm that the development of the civic evaluation process has produced, on the one hand, a considerable reinforcement of the role of citizens in public health governance, which makes them available as more powerful analytical tools both as a new means of participation and interaction with public health institutions, and on the hand an increase of information, monitoring and evaluation of the quality of public health services, to the unquestionable advantage of operational bodies and the efforts to improve the services and their workers.

## **D. List of organizations and persons involved in the monitoring process**

### **1. Partner organizations**

<b>Country</b>	<b>Organization</b>
Austria	Women's Health Center Graz
Belgium	National group of Europe Donna
Denmark	National Danish Association against Breast Cancer (Europa Donna)
Finland	Patientförbund (Finnish Patients' Association)
France	Missions Publiques en Europe (OMIPE)
Germany	Deutsche Gesellschaft für Versicherte und Patienten e. V. (DGVP)
Greece	Forum For Health and Health Services
Ireland	Age Action and Adelaide Hospital Society
Italy	Cittadinanzattiva / Tribunale per i diritti del malato
Netherlands	Stichting Fonds P.G.O: National Foundation for Patients, Handicapped and Elderly
Portugal	“Sempre Bem” – Association for the promotion of the welfare
Spain	Confederacion de Consumidores y Usurarios (CECU)
United Kingdom	The Patients Association
Sweden	Bröstcancerföreningarnas Riksorganisation-BRO (Europa Donna)

### **2. Experts**

#### **Participants in the expert meeting in Novembre 2004:**

Margrethe Nielson, Danish Consumer Council, Denmark; Martin Rusnak, International Neurotrauma Research Organization, Austria; Albert Jovell, Biblioteca Josep Laporte, Spain; Louiza Mavrommatis, KIDDA, Cyprus; Mariadelaide Franchi, BIQO, Italy; Alessandro Lamanna, Cittadinanzattiva; Fiorenza Deriu, University of Rome “La Sapienza”; Simona Sappia, TDM-Cittadinanzattiva; Giovanni Moro and Melody Ross, ACN-Cittadinanzattiva, Italy

## E. List of hospitals observed and monitoring teams

### Austria

Monitoring Team: Sylvia Groth,  
Eva Rasky

Hospitals:

1. Krankenhaus der Stadt Wien-Lainz
2. Kaiser Franz Josef Hospital
3. SMZ Ost-Donauspital

### Belgium

Monitoring Team: Nadine Cluydts,  
Odette Klaes

Hospitals:

1. Centre Hospitalier Universitaire/Universitair Verplegingscentrum Brugmann
2. Cliniques Universitaires Saint-Luc/Universitaire Klinieken Saint-Luc (U.C.L.)
3. Centre Hospitalier Universitaire St-Pierre/Universitair Medisch Centrum Saint-Pieter

### Denmark

Monitoring Team:

Susanne Knoth Clausen; Lis Truels  
Jensen

Hospitals:

1. Rigshospitalet, Copenhagen
2. Frederiksberg Hospital, Frederiksberg
3. Hvidovre Hospital, Hvidovre

### France

Hospitals :

1. Avicenne (Assistance Publique Hôpitaux de Paris)
2. Hôpital Européen Georges Pompidou
3. Hôpital Saint Antoine (Assistance Publique Hôpitaux de Paris)

### Germany

Monitoring Team: Barbel Keim-Meermann

Hospitals:

1. Vivantes Klinikum Am Urban
2. Helios Klinik Am Buch
3. Charité Campus Mitte

### Greece

Monitoring Team:

Anastasia Christoforidou, Vivian  
Andria and Panagiota Kalou

Hospitals:

1. Ippokratio Hospital, Athens
2. Alexandras Hospital, Athens
3. Asklipiou Boulas, Athens

### Ireland

Monitoring Team: Avril Bailey,  
Caitlin Gaffney

Hospitals:

1. Beaumont
2. St. James
3. Tallaght

### Italia

Monitoring Team:

Simona Sappia, Francesca Goffi,  
Francesca Moccia, Maria Vitale, Melody Ross

Hospitals:

1. San Giovanni - Addolorata, Roma
2. Policlinico Umberto I
3. San Camillo Forlanini

### Netherlands

Monitoring Team: Dinant

Haslinghus and Eva Volten

Hospitals:

1. Academic Medical Centre
2. Slotervaartziekenhuis
3. Free University Medical Centre

### Portugal

Monitoring Team: Carla Marques

Hospitals:

1. Egas Moniz Hospital, Lisbon
2. Santa Maria Hospital, Lisbon
3. São Francisco Xavier Hospital, Lisbon

### Spain

Monitoring Team: Ana Etchenique,  
Carmen Casado, Adriana Escardò

Hospitals:

1. Hospital de Mostoles
2. Hospital Ramón y Cajal
3. Hospital Clinico San Carlos

### Sweden

Monitoring Team: Ingrid Kössler,  
Kerstin Wähleman

Hospitals:

1. Södersjukhuset AB, Stockholm
2. St. Görans hospital, Stockholm
3. Danderyds hospital

### UK

Monitoring Team: Melody Ross,  
Jane Clayton

Hospitals:

1. Royal London Hospital
2. University of London Hospital
3. St. Thomas Hospital., London

## F. List of key persons interviewed

### **Austria**

#### *Ministry of Health*

Dr. Iris Stamm and Dr. Dr. Reinhild Strauss,  
Federal Ministry of Health and Women,  
Adviser to Chief Medical Office

#### *Health Expert*

Dr. Claudia Wild, Institute of Technology Assessment  
of the Austrian  
Academy of Sciences, Senior Researcher

#### *Health Expert*

Dr. Odo Feenstra,  
Department of Public Health, Styria, Chief Medical  
Officer

#### *Journalist*

Mag. Annemarie Happe,  
Austrian Press Agency, Journalist science, education,  
and health

#### *Nurse representative*

Monika Klampfl Kenny,  
Styrian Department of Public Health, Chief Medical  
Nurse

#### *Doctor representative*

Dr. Reinhard Doerflinger,  
Physician's Chamber of Vienna, Representative

#### *Third Party Payer*

Dr. Gert Klima, Dr. Michaela Pogantsch, Styrian  
Health Insurance

### **Belgium**

#### *Ministry of Health*

Professor E. Coche  
Cellule "Santé"

Ministère de la Santé, de l'Enfance  
et de l'Aide à la jeunesse

#### *Health Expert*

Dr. Myriam De Spiegelaere (Fr), Directrice scientifique  
– Médecin de santé publique

Observatoire de la Santé

#### *Journalist*

Mrs Leen Baekelandt, Journalist,  
Plus Magazine - Redactie

#### *Nurse representative*

Mrs Daphné Van Beek, Professor  
Nurse school in Flemish Region

#### *Doctor representative*

Dr. Luc Bleyen, Head of the Screening Centre  
Centrum voor Preventie en

Vroegtijdige Opsporing van Kanker  
- Universiteit Gent - RSC Gent

#### *Third Party Payer*

Mr Van Robaeys, Coordinator insurance rights  
Responsible of Sickness Fund, based in Brussels

### **Denmark**

#### *Ministry of Health*

Gertrud Backer,  
Embedslægeinstitutionen for Region IV, Chief of  
Department

#### *Health Expert*

Helena Alring, H:

S Bispebjerg Hospital, Copenhagen, Patient Consultant  
*Journalist*

Birgit Brunsted, Brunsted

#### *Nurse representative*

Ingrid Schultz, H:S Amager Hospital, Copenhagen,  
Nurse

#### *Doctor representative*

Dr. Michael Dupont, Organisation of General  
Practitioners, Chairman

#### *Third Party Payer*

Vibeke Krog, Topdanmark Livsforsikring A/S, Chief  
of Department

### **Finland**

#### *Ministry of Health*

Mervi Kattelug,  
Ministry of Social Affairs and Health, Senior Legal  
Officer

#### *Health Expert*

Irma Kiikkala, The National Research and  
Development Centre for Welfare and Health, Manager

#### *Journalist*

Mardy Lindquist, Hufundstidsbladet

#### *Nurse Representative*

Mervi Flinkman, The Union of Health  
and Social Care Professionals, Officer

#### *Doctor Representative*

Markku Aarimaa, Finnish Medical Association,  
Chief Executive Officer

#### *Third Party Payer*

Maija Sakslin, Social Insurance Institution, Researcher

### **France**

#### *Ministry of Health*

Denis Ducasse, Health Ministry,  
Hospital Organisation Officer

#### *Doctor's Representative*

Maurice Catinat, Ordre National des  
Médecins, National board member

#### *Third Party Payer*

Jean-Claude Poirier, Ile-de-France Regional  
Health Insurance Centre, Assistant manager

#### *Health Expert*

Ruth Ferry, CRIPS Ile de France, Chargé de Mission  
*Journalist*

Eric Favereau, Libération

#### *Nurse representative*

Robert Caballero, EPS Maison Blanche, Director of  
Nursing

### **Germany**

#### *Health expert*

Dr. Ekkekard Bahlo,

#### *Journalist*

Heike Rösch, Journalist of the Berufsverband der Arzt,  
Zahnarzt- und Tierärzthelferinnen e.V.

#### *Third party payer*

Nina-Beata Björklund, BKK für Heilberufe

## **Greece**

### *Ministry of Health*

E. Prosykli, Ministry of Health and Social Solidarity,  
Head of the Independent office of Patients' Rights

### *Health Expert*

T. Garani, National School of Public Health,  
Researcher

### *Journalist*

Lora Pipili, Journalist of various Newspapers on health  
issues

### *Nurse representative*

Dr. B. Margaritidou, Retired professor of nursing

### *Doctor representative*

Dr. G. Patoulis, Association of Physicians, Member of  
Board

### *Third Party Payer*

Ms. I. Antonopoulou, IKA, General Director of Health

## **Ireland**

### *Doctor Representative*

Dr. Ciaran Donegan, Beaumont Hospital, Dublin,  
Consultant Physician

### *Health Expert*

Stephen McMahon, Irish Patients Association,  
Chairman

### *Journalist*

Dr. Muiris Houston, The Irish Times, Medical  
Correspondent

### *Third Party Payer*

Sean Murray, BUPA Ireland Health Insurance,  
Director of Marketing

### *Ministry of Health*

Des Treacy,  
Department of Health & Children Services for Older  
People,

Community Health Division General Medical

### *Ministry of Health*

Nuala Redmond,  
Department of Health & Children Services for Older  
People,  
Health Promotion Unit Mental Health

## **Italy**

### *Ministry of Health*

Francesco Taroni,  
Agenzia Sanitaria Regionale Regione Emilia Romagna,  
Director

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