



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

Final Report  
January 2007

*Edited by Alessandro Lamanna, Giovanni Moro, Melody Ross  
and Ilaria Vannini*

*In cooperation with*



## Index

Foreword

---

### FIRST PART

---

1. Background of the project

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

1.3. The European Charter of Patients' Rights

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

1.5. Rationale of the project

2. Project Methodology

2.1. The Civic Information Approach

2.2. Methodological questions

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

2.4. Sources of information and technical tools

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

2.6. Development

2.7. Value and Limits of the Research

3. European Health Systems between new demands and financial constraints

---

### SECOND PART

---

4. Analysis of available statistic data

5. Information coming from National Legislations

6. The Civic Audit Information

6.1. Right to Preventive Measures

6.2. Right to access

6.3 Right to Information

6.4. Right to consent

6.5. Right to Free Choice

6.6. Right to Privacy and Confidentiality

6.7. Right to Respect of Patients' Time

6.8. Right to Quality

6.9. Right to Safety

6.10. Right to Innovation

6.11. Right to Avoid Unnecessary Suffering and Pain

6.12. Right to Personalized Treatment

6.13. Right to Complain

6.14. Right to Compensation

---

### THIRD PART

---

7. Conclusions

7.1. Main Findings

7.2. An Overview

7.3. The question of information on patients' rights

7.4. Degree of attention on patients' rights

---

7.5. Improvement Priorities

---

7.6. Policy priorities

---

APPENDIXES

---

A. Matrix of Patients' Rights

---

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

---

C. Citizens as Actors in health services monitoring and auditing: the Italian experience

---

D. List of organizations and persons involved in the monitoring process

---

E. List of hospitals observed and monitoring teams

---

F. List of key persons interviewed

---

G. References

---

## **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>1</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.

---

<sup>1</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>2</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>3</sup>.

---

<sup>2</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>3</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.

---

(C-368/98, 12 July 2001), IKA (C-326/00, 25 February 2003), Müller-Fauré & van Riet (C-385/99, 13 May 2003), Inizan (C-56/01, 23 October 2003), Leichtle (C-8/02, 18 March 2004) and Watts (C-327/04, 16 May 2005).

## 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>4</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>5</sup>. In order to do this, the population's health conditions and

---

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

5 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>6</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>7</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.

---

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

7 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>8</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

<sup>8</sup> 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>9</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>10</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>11</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

---

<sup>9</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>10</sup> Zoli M. (2004).

<sup>11</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>12</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>13</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>14</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.

---

<sup>12</sup> Sgritta G.B. (2004).

<sup>13</sup> Inpdap (2003).

<sup>14</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>15</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>16</sup>: human rights (human dignity); need and solidarity; and cost-efficiency<sup>17</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>18</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>19</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

---

<sup>15</sup> European Observatory on Health Care Systems, Hit Summary, Sweden (2002).

<sup>16</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. (1999)).

<sup>17</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>18</sup> European Observatory on Health Care Systems, Hit Summary, Sweden, (2002).

<sup>19</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>20</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>21</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>22</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>23</sup>.

---

<sup>20</sup> Inpdap (2003).

<sup>21</sup> European Observatory on Health Care Systems, Summary, Austria (2002).

<sup>22</sup> Implementation of Agenda 21: *Review of progress made since the UN Conference on Environment and Development 1992*, New York, aprile 1997.

<sup>23</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>24</sup>, which opened the way to the entrepreneurization of health facilities, introducing private management rules and competitive mechanisms among service providers. In 1999<sup>25</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>26</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>27</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>28</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.

---

<sup>24</sup> with legislative decrees n. 502 of 1992 (De Lorenzo Reform) and n. 517 of 1993.

<sup>25</sup> with legislative decree n. 229 of 1999.

<sup>26</sup> Zoli, M. (2004).

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

<sup>28</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>29</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%.

---

<sup>29</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>30</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>31</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>32</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>33</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>34</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

---

<sup>30</sup> European Commission (2003).

<sup>31</sup> European Commission (2001).

<sup>32</sup> *Ibid.*

<sup>33</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>34</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>35</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.

---

<sup>35</sup> Zoli M.(2004).

