

## 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 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> )	Indirect indicator: <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.