

Opinion of the European Economic and Social Committee on 'Patients' rights'

(2008/C 10/18)

On 14 July 2005 the European Economic and Social Committee, acting in accordance with Rule 29(2) of its Rules of Procedure, decided to draw up an opinion on: *Patients' rights*.

The Section for Employment, Social Affairs and Citizenship, which was responsible for preparing the Committee's work on the subject, adopted its opinion on 17 July 2007. The rapporteur was Mr Bouis.

At its 438th plenary session, held on 26 and 27 September 2007 (meeting of 26 September), the European Economic and Social Committee adopted the following opinion by 108 votes to none, with two abstentions.

1. Justification and recommendation

1.1 For many years now, European countries and the European Community have addressed the question of the rights of health service users, establishing charters or a comprehensive body of legislation enabling the affirmation of such rights⁽¹⁾. These obviously depend on the quality of the health system and the way healthcare is organised. However, respect for such rights is also dependent on the behaviour and cooperation of health professionals and patients themselves; thus this might be expected to be an area where there is potential for rapid improvement.

1.1.1 In 2002, the Active Citizenship Network proposed a European Charter of Patients' Rights. These rights, which are based on the EU Charter of Fundamental Rights (Article 35), are important in European citizens' dealings with health systems in their respective countries. Despite this, a study carried out by citizens' organisations in 14 EU countries shows that the level of protection of these rights varies greatly from country to country. This calls into question the European Commission's commitment to guarantee all European citizens effective access to health services on the basis of the solidarity principle.

1.1.2 We are witnessing today an evolution in public policy where, increasingly, the tendency is to advocate citizens' involvement, with the development of participatory methods in various European countries: consensus conferences in Denmark; the setting-up of citizens' juries in several European States; general assemblies, etc. The Council of Europe and the European Parliament are promoting such participatory initiatives.

1.1.3 In the light of the European Charter of Fundamental Rights, the communication from the Commission *Consultation regarding Community action on health services*, the *Statement of common values and principles in EU health systems* adopted by the Health Council on 1 June 2006, the case law of the European Court of Justice in the field of patient mobility, the European Parliament report on patient mobility and healthcare developments in the European Union and the European Parliament resolution of 15 March 2007, the EESC calls on the European

Commission to take initiatives enabling the implementation of health policy which respects patients' rights. This requires:

- the gathering and analysis of comparative data on the regulatory and ethical obligations in force in each EU country,
- the devising, in the most appropriate form, of a Community course of action applicable to issues in this field,
- the planned evaluation of the application of the texts promulgated and policies decided,
- the dissemination of the results of this work to the relevant national authorities and representatives of the various socio-professional and user groups concerned,
- the establishment of a European Patients' Rights Day.

1.1.4 The European Economic and Social Committee is therefore addressing the issue of patients' rights in order to draw the attention of the European institutions to the need to respect these rights, particularly in the light of EU citizens' right of free movement between the 27 Member States and their equal opportunities to enjoy high-quality service in their country of origin or host country, and above all to encourage their practical application in all of the Member States. In addition, the reaffirmation of these rights implies the need for changes in relations between all health professionals and health care structures and patients on a day-to-day basis.

1.1.5 In addressing these issues there is often a need for ethical reflection where the responses are based on the political and social system of the country concerned. However, in spite of disparities in the way health systems are organised and the diversity of the debate, developments in health-related issues reveal a similar pattern in all European countries and a general and inescapable trend towards the assertion of the rights of people seeking care.

1.2 The tendency with regard to health needs and people's expectations, and beyond the health sector in the political domain, is to seek to give the individual an increasing say in health-related matters.

⁽¹⁾ Charter of Fundamental Rights of the EU, texts adopted by the Council of Europe, French Law No 2002-303 of 4 March 2002.

1.3 Advances in medical science and the introduction of social protection systems have led to a general epidemiological transition, which is reflected in fewer short-term care cases and, above all, in the rising incidence of chronic illnesses, a phenomenon accentuated by an ageing population. The provision of care for the chronically sick implies long-term care, as a result of which sick people accumulate knowledge through their experience of accessing the health care system and their experience of their illness.

1.4 The arrival of new information technologies, and in particular the development of the Internet, has reinforced this increase in patients' knowledge and improved their capacity to exchange views and to question professionals. In some cases, people sometimes have a thorough knowledge of their illness which must be taken into account. It is worth being taken into consideration by healthcare professionals.

1.5 Generally, patients' expectations vis-à-vis professionals are not limited solely to technical aspects of care but are also concerned with relational and human aspects.

1.6 Finally, living with a long-term illness or disability creates new needs and expectations on the part of the persons concerned. The challenge for treatment has changed: it is no longer a matter of seeking a cure at all cost, but more one of learning to 'live with' an illness in an ongoing effort to combat pain.

Such considerations induce people to play an increasingly active role with regard to the treatment they receive, with new needs and expectations.

1.7 People's evolving needs and expectations regarding their treatment are part of a more profound change in society which aims to promote a model based on respect for individual autonomy and the assertion of individual rights.

1.8 All of these factors lead to the conclusion that the paternalistic model of interaction between doctor and patient has run its course and consequently that there is a need to rethink the place of the patient in his interaction with the system, implying the recognition and introduction of new rights and obligations.

1.9 This opinion is focused on the rights of patients, i.e. people using healthcare systems, be they healthy or sick as defined by the World Health Organisation.

2. Background

2.1 Developments in medicine and in people's health needs and expectations give reason to consider a person in the context of his life, which implies not only taking an interest in the individual himself but also in his family, even his friends and the people he works with. *Living with an illness or disability* implies taking into account quality-of-life aspects, requiring the involvement of a range of professionals in addition to medical staff.

2.2 While the doctor retains a dominant role in the care of persons, the notion of a bond between the doctor and the

patient must be built into the functioning of the system, i.e. as an integral part of the entire body of healthcare, medical and welfare professionals.

2.2.1 The patient places his trust in the hands of health professionals and hence the doctor and nursing staff must keep a close watch on the patient, enabling them to adapt their views, treatment and assessment accordingly. This interactive process comprises listening, verbal exchanges and care provision. It enables a solid relationship to be built, which is essential for fighting the illness.

2.2.2 Thus, from the outset the medical response to these problems must be to design a real social procedure and, beyond the necessary and rigorous performance of technical acts, to meet people's demands for comprehensive care adapted to the needs of the individual.

2.2.2.1 Medical and welfare staff must act as an adviser to their patient, without, however, relinquishing their responsibility. Their task is therefore to provide care, information and support to the patient. They devise a therapeutic strategy based on hypotheses suggested by the patient's symptoms and the relationship with the patient. Thus the patient has a legitimate right to request health professionals for a personalised assessment of his condition, which must make it possible to propose a treatment that is the most suitable in technical and psychological terms.

2.2.3 Finding the best treatment and the outcome of the fight against the illness depend to a large extent on the links forged between the patient and the health professionals treating him. The outcome is as important for the healthcare staff as it is for the patient. This implies the need for mediation arrangements, so as to take account of social constraints (working life, financial factors, recognition of rights, etc.) and the challenges of emotional and family life. Family members and patient associations have a crucial role to play in this context.

2.3 Thus one can consider the advantages to be gained by a meeting between a patient organisation and an organisation of health professionals.

2.3.1 Some deplore the loss of trust that comes with the end of the doctor-patient bond as understood in its traditional sense. However, this development is to be seen more as a transition from a relationship based on blind trust to trust built up in a process of interaction and exchange between a person, his family and friends and health practitioners.

3. Inalienable rights

3.1 The affirmation of patients' rights is a human right and its objective is to promote their eventual autonomy. These rights are therefore often interconnected. The European Charter of Patients' Rights, drawn up in 2002 by the Active Citizenship Network, proclaims 14 rights, which the EESC welcomes and acknowledges. The EESC considers that three rights are linked horizontally or are preconditions for other rights.

3.2 Right to information

3.2.1 The information in question primarily concerns the patient undergoing treatment. It must provide details of the person's illness, how it may evolve over time, the courses of treatment possible, including the associated benefits and risks, the health establishments or professionals providing this treatment, and the effects of the illness and the treatment on the person's day-to-day life. The provision of such information is particularly important in the case of chronic illness, dependence, disability or long-term treatment leading to changes in the daily lives of the person and his family and friends.

3.2.1.1 Prevention is a key factor in improving the health state of the population. Information/awareness-raising campaigns should therefore be developed alongside the setting-up of structures with the capacity to provide appropriate examinations and care structures.

3.2.2 Information is not an end in itself but a means of allowing a person to make free and informed choices. For that reason, the ways in which information is provided are as important as the information itself. They are a part of a process which makes use of different information sources, including the Internet and telephone helpline services operated by associations, and where the patient can interact with a wide range of professionals, each of whom has his own role to play. The oral transmission of information is crucial. At regular intervals, the doctor must find out whether the patient understands the facts relating to his case and ascertain his level of satisfaction.

3.2.3 In addition, and irrespective of the person concerned, the patient's circle of family and friends must also be taken into account in the information process, all the more so if the patient is a child or a dependent elderly person. Obviously, the level of information provided will depend on the patient's state of health and capacity to decide for himself.

3.2.3.1 Every patient must be provided with information in his own language and his particular incapacities must be taken into account.

3.2.4 Only informed consent and informed acceptance of the risks involved can be valid. Information is the outcome of the doctor-patient bond where only the best interests and well-being of the patient are taken into consideration.

3.2.5 This access to personalised information is a vital step towards reducing inequalities related to health disorders, illness and care provision and improving access to the health system for all citizens.

It is desirable that the information on a person's state of health, the diagnostic and therapeutic steps taken and the ensuing results be recorded in a 'medical file'. The possibility of the patient to access this file directly or through a doctor of his choice, according to his wishes, is also part of patient information and autonomy. In any moves to secure further information

and transparency, an appropriate legal framework should, however, ensure that when the data is being recorded, it is not used for any purpose for which it is not intended. Efforts should be made to make sure that extreme vigilance is exercised as regards the use of such data, especially where it is electronically stored and sometimes also when it is transmitted across borders.

3.2.6 It is essential to develop information about the system so as to make it clearer and more transparent. Patients faced with a proliferation of players may feel they have greater autonomy as individuals or, on the other hand, they may become totally dependent on their doctor, depending on the level of their knowledge and understanding of the system. There is then a danger here that this could give rise to misplaced claims on the part of users.

3.3 Right to free and informed consent

3.3.1 The right of patients to participate in decisions affecting them must be affirmed. This does not mean the transfer of responsibility from doctor to patient but rather the prospect of them interacting in a therapeutic alliance, each maintaining his own position, with his own rights and area of responsibility.

3.3.1.1 The patient's consent does not apply automatically to all medical acts, now or in the future. Consent is not given once and for all, but rather it has to be renewed before each important medical or surgical act.

The consent of a patient who has been informed in this way must be explicit, that is expressed objectively. After having been given the requisite information, the patient may either accept or reject the course of action which has been proposed to him.

As regards organ donations when the donor is alive, increased vigilance must be shown over information about the risks.

3.3.1.2 Where a new treatment is being tried out, the principles are the same as those implied when seeking the patient's consent to medical care. The patient's freedom must be respected and these principles are geared to the same end: shared responsibility and trust.

3.3.1.3 As regards clinical trials, including those involving persons who are not sick, a particular pedagogical approach is required. This approach, which must comply with well-established criteria, can only be contemplated if there is a stated desire to cooperate and it is accompanied by evidence of absolute consent.

3.3.1.4 In an emergency, some exceptions to this rule must be considered; the consent of the patient must be presumed and confirmed when he has regained his power of judgement.

3.3.1.5 The patient must have the possibility of choosing a person to represent him if he is subsequently unable to make his preferences known.

3.3.1.6 The consent of a child or a sick minor must be obtained for minor medical treatment once he has gained a certain degree of personal independence and is able to make a proper judgement. Involving children in health education from the earliest possible age helps to de-dramatise certain situations and improve cooperation with young patients.

3.4 Right to dignity

3.4.1 Under this heading must be included the right to privacy, the right to pain relief, the right to die in dignity, protection of the integrity of the human body, respect for private life and the principle of non-discrimination.

3.4.1.1 Everyone has the right to confidentiality of information about his health, the diagnosis made and treatment provided, as well as to respect for privacy during examinations, consultations and medical or surgical treatment. This fundamental right requires that the patient be treated with due respect and that he not be subjected to contemptuous remarks and attitudes on the part of healthcare workers.

3.4.1.2 People are weakened by sickness, disability and dependence. The more they feel belittled, the less they feel able to demand that they be accorded the minimum of respect. It is therefore up to professionals to be more attentive to the need to show respect to people who are particularly vulnerable because of their sickness or disability.

3.4.1.3 Recognition of the importance of time devoted to consultation, listening to people, explaining the diagnosis and treatment, both in hospital and elsewhere, is one facet of respect for people. This investment in time helps to strengthen the therapeutic alliance and save time elsewhere. Healthcare provision is about devoting time to people.

3.4.1.4 This applies especially to people who already suffer from lack of social recognition: elderly people in a precarious social position, people suffering from a physical, psychological or mental handicap, etc.

3.4.1.5 In terminal cases or where the patient is undergoing particularly difficult treatment, staff need to be even more vigilant. Respect for a person and his right to die in a dignified manner is achieved by providing universal access to palliative care designed to reduce pain and maintain a certain quality of life by guaranteeing the right of a patient to have his choices respected until the end of his life. Among other things, this means putting in place a procedure such as the designation of a proxy to ensure that the patient's wishes are made known.

3.4.1.6 Pain management through the provision of effective means and access to specialised facilities: information and training for healthcare professionals and information for patients and their family and friends need to be developed as this is about respecting the right of everyone to receive care to relieve pain.

3.4.1.7 The requirement to treat a person with respect does not cease to apply after death. This implies ensuring that, whenever a hospitalised patient dies, his family and friends and the healthcare professionals who tended him at the end of his life receive appropriate psychological support and that the wishes and beliefs of the deceased are strictly respected.

3.5 Some other individual rights need to be enforced as part of a public health initiative; this requires that the system, as currently organised, comes up with an appropriate response.

3.5.1 *Right to access to care for all*: i.e. not just access to rights and social protection but to the full range of healthcare services and professionals without discrimination on the grounds of a person's social or economic position. This is not part of a move to open up the health sector but rather of a proactive public health policy, on the understanding that the practical implementation of this right differs greatly across countries, depending on the responsibilities that are taken on and the forms of funding existing in each country.

3.5.2 *Right to high-quality care*: every person, taking into account the state of his health, has the right to receive the most appropriate treatment and access to the best therapies and medicines offering the best cost-effectiveness ratio (promotion of generic drugs). The right to high-quality care also implies the right to screening and therapeutic education, which calls for investment in resources and funding, and adequate availability of properly trained professionals.

3.5.3 *Right to prevention and safety of care*: citizens want the health system to be built around and for people. They want to know more about the therapeutic strategies proposed to them, take part in personal and collective prevention efforts, and ensure that social choices, behaviour and consumption do not harm health.

4. Recommendations for implementing patients' rights

4.1 The affirmation and application of these rights is a source of concern for many professionals, patients, health policy-makers and user associations. There is an urgent need to move away from confrontation between the rights of some parties and the obligations of others. Respect for patients' rights also means a new distribution and balance for the obligations and responsibilities of professionals.

4.1.1 As the medical profession is no longer alone in taking decisions involving people's futures, it can no longer be alone in assuming full responsibility for them.

4.2 In the interests of the common good, it is the collective responsibility to help professionals respond to these expectations:

- by including ethical aspects and respect for the individual and his rights in their training, so that they understand the dynamics involved and the resulting implications, and so do not see patients' rights as a further constraint,

- by establishing forums and meeting places between professionals and between professionals and users,
- by creating new ways of delivering information to the sick involving all stakeholders in the health system,
- by developing new pedagogical procedures for dealing with consent, leading to a therapeutic alliance,
- by creating and bringing into general use new organisational and pedagogical solutions designed to minimise stress suffered by children when undergoing treatment, especially when they are in hospital,
- by setting up clinical ethics committees in health establishments, thereby facilitating support for professionals and respect for the rights of the sick,
- by including protection and promotion of patients' rights in ethical codes and codes of conduct for professionals,
- by making the system easier to understand for users whilst enhancing the position and role of health professionals as a whole,
- by devising new forms of collective practice involving doctors and other health professionals:
 - group practices, medical health centres
 - links between medical, welfare and social professionals,
- by rethinking the role of patient, user, consumer, family and citizen associations:
 - including users' representatives in representative bodies
 - recognising the role of certain associations in therapeutic education, prevention, provision of information to the sick, etc.
 - building links between the structures of associations and those of professional bodies, etc.
 - equipping associations with the means to carry out their activities and put across their views (training, representation leave, etc.)
 - creating neutral and convivial spaces in hospital establishments where patients can voice their concerns and

prepare for discussions with professionals with the support of user associations

- involving associations on the same footing as professionals in the analysis of complaints and in defining ways of improving the quality of care.

5. Conclusion: towards an affirmation of collective rights

5.1 How effective individual rights turn out to be in practice will depend to a large extent on the collective responses which are made to support this initiative. That is why it is necessary to work for the adoption of health democracy, implying the collective involvement of users and their representation in different parts of the system.

5.2 Patients' rights are one expression among others of human rights, but by no means a separate category. They are the manifestation of the desire that no patient wants to be considered as a being apart and, above all, as someone on the margins of society.

5.2.1 There is a need to acknowledge that users of the healthcare system are becoming more vocal in making known their feelings about healthcare conditions on the basis of their own experiences and also because they are receiving increasingly more information.

5.3 Consequently, it is appropriate to ask about the position of the patient in the process of making decisions which concern him, in the interests of transparency of procedures and respect for individuals.

5.4 The issue at hand is not about adopting a legalistic consumerist approach but rather about recognising that the patient is sufficiently mature to take part in decisions affecting him on the basis of respect for his rights.

5.5 Giving a voice to users and their representatives is all the more necessary as health issues extend into other areas: methods of production, lifestyle, working conditions, environmental protection, etc. This implies social, economic and ethical choices which go beyond the sole responsibility of health professionals.

Brussels, 26 September 2007.

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of the European Economic and Social Committee
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