

EPECS

European Patients Empowerment
for Customised Solutions

Statement of opinion
concerning the
proposal of the Commission of the European Communities
for a
directive of the European Parliament and the Commission
concerning
patient rights in transnational
healthcare

KOM (2008)/0142 final

2008/0142 (COD)

Concerning EPECS – who gives their view?

For nearly two decades now, self-help groups and patients' organisations have been working together on a transnational basis along the border between Germany, the Netherlands, Belgium and Luxembourg, especially in the regions near the border and border regions in addition to the Euroregions.

Based on the experiences and the confidence derived from this cooperation, the significant umbrella organisation and committed personalities engaged in self-help and patient work established the foundation EPECS according to Dutch law in the year 2007.

The aim of the foundation is to promote transnational collaboration of self-help and patients' organisations through a new standard and quality of cooperation. The practical commitment of affected sick and handicapped people and of those threatened by illness and their will to cooperate and integrate over the border, forms an essential basis for EPECS. EPECS will give the patients in border areas, both male and female, a voice on a transnational and a European level and will incorporate their concrete experiences and wishes into the process of improving the health care systems in Europe. Especially with respect to cross-border accessibility, quality and safety.

As EPECS, we are involved in everyday life in the concerns and requirements of citizens, the healthy ones as well as those needing or seeking health care in their own country or over the border. An example of our involvement in everyday life concerns patient safety. This is one of our key priorities. EPECS supports all efforts that are made on national and European level to make healthcare as safe as possible. In a cross-border setting 'infectious disease control' is a crucial topic. EPECS is therefore a partner in a project called 'Eurosafety Health-net' along the Dutch-German-Belgium border. In this project hospitals and other (public) health care services are in a cross-border setting fighting against antibiotic resistance. This is very important for the improvement of the quality and the safety of (cross-border) healthcare.

Consequently, we do not consider ourselves as an anonymous lobby bureau, but instead as a committed network that, according to our vision, will someday operate throughout the whole of Europe.

General assessment of the proposal of the European Commission

In view of the fact that around one third of the citizens in Europe live in regions near the border of the national Member States of the European Union, given further increasing mobility in Europe and considering the development in terms of health management of healthcare in Europe, EPECS welcomes the Commission's proposal.

With the Commission's proposal, the process of tuning of the health systems in Europe is making a major step forwards, which is in the interests of all European citizens. It is of special importance for those who live in the regions near the borders and for the patients who, owing to their residence in another Member State of the European Union (must) make use of the health services of this Member State.

EPECS welcomes the proposal calls for further opening up of national healthcare for European citizens. EPECS therefore considers the proposal as an essential and necessary improvement with regard to the current situation, in which the legal framework for cross-border health and its application is above all remodelled by the single case decisions of the European courts. The Commission's proposal is well suited to improving the certainty of the law of the citizens of the national Member States.

EPECS is convinced that in view of the demographic change, Europe requires a vision and a long-term strategy for shaping transnational healthcare. The Commission's proposal may have long-term positive effects for high quality and payable transnational healthcare in Europe.

In addition EPECS urges that the citizens of Europe be able to contribute as influential "stakeholders" in transnational healthcare, in order to be able to exercise their options and liberties. Healthcare in Europe must be geared to the fundamental rights of the

patients who wish to be able to freely choose their health service in Europe and who claim a high level of quality.

Consequently, from the EPECS' standpoint, it is necessary to make provision in the proposal for efficient cooperation and participation of the patients in shaping the healthcare systems of the national Member States. Currently, the patient only plays a subordinate role in many Member States and too little attention is paid to his/her concerns in organising care.

The conception of EPECS is that in the medium and long-term the people of Europe will above all be able to have access to a high quality and internationally competitive health service system,

- Provided that patients can play a decisive role as third parties in this system (in addition to the healthcare providers and those bearing the costs) and
- They should be involved more directly with their needs and interests in shaping a sustainable healthcare system.

In the view of EPECS, it is therefore also necessary that patients should receive in everyday life suitable relevant, transparent and understandable information concerning the health systems of the European countries. Especially in emergency situations the patients are frequently dependent on information from experts that they must be able to verify.

The Commission's proposal requires that especially the national regulations and information regarding quality of care in addition to regulations for reimbursement of the costs for the patients should be transparent, so that the patient is placed in command in the decisions concerning his/her own health and treatments.

EPECS is a competent partner in this shaping of the active role of the European patient.

Regarding the individual provisions of the proposal

Article 1

EPECS shares the fundamental objectives of the directive.

Article 2

EPECS welcomes the fact that the directive will be applicable to any healthcare, particularly whether provided publicly or privately.

Article 4

EPECS welcomes the clarifications made through the definitions of the concepts. With the definition of the concept “patient” under letter f), it simultaneously becomes clear that male and female patients are not only natural persons who actually make use of health services in a Member State, but are also such persons who would like to make use of these health services. Consequently, the meaning of the term “patient” for example also covers the meanings “male and female citizen”.

Article 5

EPECS expressly welcomes the regulation in paragraph 1, letter d).

At the same time, it becomes clear in paragraph 1 that the conception of the commission regarding a target-oriented organisation of the national health system according to paragraph 1 of the proposal does not include the cooperation and participation of patients.

From the point of view of EPECS, it is necessary to substantially improve this in the proposal.

Article 6

Implementation of paragraphs 1 and 2 requires in particular the information and knowledge of the patients concerning the respective level of reimbursement of costs: it is important in this case to supplement regulations that increase the transparency of the reimbursement provisions. The regulation in paragraph 5 is to be concretised: patients require, particularly in case of complaint procedures, not only access to the files, but issue of material (e.g. copies) that they can take with them.

Article 8

In paragraph 3, a prescription is lacking concerning transparent verification of the necessity of a system of preliminary verification, particularly of the regulation according to letter b) subitems i) and ii). In view of the regulation in paragraph 4, national and European patient organisations should be included in this verification.

It is essential in the patients' interest that, according to number 33 of the proposal, they should "receive a decision concerning transnational healthcare within fifteen calendar days". At the same time, it is necessary to provide sanctions in case this deadline is not observed.

Article 9

The application for the use of healthcare in another Member State must be processed according to the directive within a specific period. In the patient's interest, EPECS suggests that the directive in paragraph 4 should establish this deadline period. As in article 8, a period of fifteen calendar days is proposed.

Article 10

The regulations in paragraph 1 are too vague for target-oriented formulation of the information obligations of the Member States. This also applies to the provisions of paragraph 2,

according to which the information should be “readily accessible”.

EPECS feels that paragraph 3 should be reformulated from a “can” into a “must” regulation and that these obligations are clearly established by the Commission.

At the same time, provision is to be made for the possibility of informing the patients through organisations which they trust – these involve independent patient organisations operating on a national or a European level.

The provision of article 15, paragraph 3 number ix) offers an example of a corresponding formulation of the guideline.

Article 12

Regulations concerning the obligation of the national contact bodies to collaborate with patient organisations operating on a national level are lacking. This applies particularly during drafting of the directive according to paragraph 3 letter c).

The provision of article 15 paragraph 3 number ix) offers an example of a corresponding formulation of the directive.

Article 13

EPECS supports the appeal to Member States to render mutual assistance where this is necessary for the implementation of the directive. EPECS would welcome the addition, that neighbour States shall formally publish their mutual agreements in this respect.

Article 17

With regard to the new health technologies, EPECS asks itself the question as to whether the currently applicable provisions for data protection in view of national experience (e.g. in Germany) are sufficient and can be controlled with an adequate degree of efficacy.

Only effective data protection will create the necessary acceptance among the patients for transnational, technologically effectuated delivery of data.

Article 18

The provisions should be supplemented by regulations concerning publication obligations and information rights on the part of the male and female European citizens.

Article 19

EPECS demands that the Commission secure the cooperation of representatives of European patient organisations for implementation of its missions. This should be adopted in the wordings of the directive.

The provision of article 15 paragraph 3 number ix) offers an example of a corresponding formulation of the directive.

Final remark

EPECS is well aware, that the political resistance against the present draft directive is substantial. Especially Member States may consider the proposal to go too far beyond the codification of the ECJ rulings or to conflict too much with their own competences and responsibilities as laid down in the Treaty. If such resistance would indeed lead to considerable weakening of the proposal, EPECS would support the creation of pilot regions, where cross-border patient mobility and cross-border cooperation of care providers can be practiced to the level of the present proposal and to the full benefit of the population in the respective border areas. Such pilot regions have also been proposed in Amendments of the European Parliament to the directive.