

To:  
European Commission  
Directorate-General Health and Consumer Protection  
Consultation concerning health services  
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Belgium

## **Reaction of cooperating patient organisations European Empowerment for Customised Solutions (EPECS) to consultation**

Maastricht, January 15th, 2007

### **1. Preamble**

In the border area of The Netherlands and Nordrhein Westfalen (Germany) several regional patient organisations and pressure groups from both European Union countries have been working together in the field of cross-border health care<sup>1</sup>. An increasing number of patients have been going to doctors across the border out of necessity, even though the demands for the desirable and necessary mobility have not been met yet. Because of this we know much about the themes and problems related to everyday life in a border area. The problems that a German (potential) patient<sup>2</sup> encounters when going to a Dutch doctor are partly the same, partly very different than the problems of a Dutch patient wanting to see a doctor in Germany or who wants to be informed about it.

The cross-border activities of the patient organisations give us the opportunity to exchange information and knowledge and especially give practical recommendations when advising patients and the collaboration of health care organisations.

On the basis of encouraging experiences with collaboration, the patient organisations in the Euregio, Euregio Meuse Rhine, Rhine Meuse North and Rhine Waal decided to give there cooperation a more solid and permanent base. A formal cross-border collaboration will be organised.

The collaboration follows the joint essential views of the Dutch and German partners: considering the increasing mobility of patients, that is both necessary and desirable, especially in border regions, we want to be favorable towards and especially contribute to the development and improvement of the prerequisites for this cross-border patient mobility, in the interest of inhabitants of border regions and the citizens of the EU. One of our essential opinions is that the

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<sup>1</sup> Cross-border health care includes both the care and the cure side of health care.

<sup>2</sup> Patient also means a potential patient. Every citizen runs the risk of becoming a patient. On top of this, predicting medicine using DNA is getting increasingly important. Because of this someone can also become a potential patient.

collaboration will have to participate in political decisions that have an influence on patient mobility and the situation of patients. Because patients have a growing interest in cross-border health care and are not represented enough in European context, the collaboration wishes to be involved in this process. As long as the prerequisites for cross-border mobility or potential for mobility not have been met, there can be no mobility in the full spectrum of health care for the European citizen/patient.

A definite legal form for this collaboration, European Patients Empowerment for Customised Solutions (EPECS), has not been determined yet, but the first administrative steps have been taken. Now, when the European Commission wants answers to questions related to cross-border patient mobility, EPECS finds it appropriate to present commentary and suggestions about this issue, to the EC. Appropriately, commissioner Kyprianou rightly calls the patient the first of the stakeholders who must be consulted about cross-border patient mobility in Europe.

## **2. Introduction**

In a Europe in which free traffic of goods and services are valued and which has certain influence, seen the diverse arrests<sup>3</sup>, on health care, it is important to not loose the perspective of the citizen and thus that of the potential patient.

The patient organisations are independent parties in their own regions and are close to the patients. Patients are increasingly interested in the possibilities of health care in the neighboring country. This is true especially for patients in border areas, especially when there is not enough health care available for one reason or the other, e.g. when there are long waiting lists, or when there are top services available that are much farther away in the country of residence. Besides, more and more citizens and thus patients are aware that they don not only have obligations but also have rights regarding the use of health care. The quality, transparency and accessibility of health care are increasingly important for them, even when it means that in some cases they have to go to another country, or in another way make use of a foreign care system e.g. eHealth and telemedicine. We may also consider patients with a rare disease for which the top specialist works at an institute of care in another EU country.

A number of patients already makes use of this. The consequence is that we have an increasing number of questions about this. However, not only patients cause a higher degree of cross-border health care consciousness in patient organisations. Also the activities, projects and initiatives for collaboration that care providers and funding agencies have initiated in recent years, especially in our Euregios, have strongly increased consciousness in regional patient organisations dealing with patient mobility.

We, the cooperative patient organisations want to give our view on the report of the Commission of European Communities called 'Raadpleging over communautaire maatregelen op het gebied van gezondheidsdiensten' (Consultation about community measures in the field of health care services) from September 26th 2006. However we do not do this by answering separate questions, but by raising a number of points to illustrate the perspective of the citizen.

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<sup>3</sup> Kohll and Decker (1998), Smits and Peerebooms (2002) and Watts (2006).

### 3. State of affairs within the European Union

The European Parliament, over the last few years, has rightly been questioning what the future role of the European Union (EU) could be regarding patient mobility. At the one hand because they are more or less forced by various verdicts of the European Court of Justice<sup>4</sup>, and at the other hand because European citizens demand further developments in this area.

The resolution of the European Parliament, also called Bowis' resolution, about patient mobility and developments in health care in the European Union<sup>5</sup> gives an excellent overview of the state of affairs within the EU and the points of interest. We, as EPECS, totally agree with this. Particularly point 41 in this resolution forms the foundation for the organisation of EPECS:

"emphasizes that patients as subject play a key role in the whole system, because they have a natural interest in their own health and in the quality and accessibility of health care available to them for which the costs are covered by them directly, or by means of health care insurance or taxes; because of this patients has the full right to all information about the care that has been given to them as well as over their state of health and the full right to decide whether they want to make use of the health care."

In addition, the following points from Bowis' resolution reflect, seen from our perspective, the core of what is important in European health care<sup>6</sup>:

- 'there should be clarity to enable patients/consumers to understand the cross-border and transnational health care and to participate in it',
- 'sees the lack of progress in the field of patient education as a severe threat to the development of health care in the EU and particularly to the realisation of patient mobility',
- 'criticizes the fact that a weighing of obligations and rights of patients/consumers has not found place yet',
- The European citizens 'subscribe to the viewpoint of patient mobility as an option'.

In addition Bowis describes, on behalf of the European Parliament, rightly a number of questions that have been asked by patients. Also in border regions patient organisations, but also other care providers and funding agencies are confronted with these questions.

The patient organisations not only are asked these questions, but also they ask these questions themselves on behalf of patients to other parties within health care to promote the patients' interests this way.

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<sup>4</sup> Arrests Kohll and Decker (1998), Smits and Peerebooms (2002) and Watts (2006).

<sup>5</sup> Report about patient mobility and developments in the health care in the European Union (2004/2148(INI)), European Parliament, 2005.

<sup>6</sup> Report about patient mobility and developments in the health care in the European Union (2004/2148(INI)), European Parliament, 2005.

#### **4. Role of the European Union**

The above mentioned points from Bowis' report need some extra attention.

We see a structural problem in health care regarding enhancement of patient mobility in Europe: the focus has been too much on care providers, political authorities, governments and insurance companies. Seeing the patient as a potentially mobile consumer only plays a subordinate role at this moment. Because of this the theme of patient mobility is a reflection of the need for further adaptations in the care system in Europe towards enhancement of the consumers' position. In the border regions these consumers are people who want to make use of cross-border care.

In our view, there must be a political and organisational change on both national and European level to a demand driven health care. Specific national and categorical characteristics and specific points of interest must not be forgotten. This must result in question focused, client focused acting by all that are involved.

Eventually the patient and thus the citizen must help decide which services will be available. Service providers in health care will agree that citizens/patients will be central in the European market. The EU is already conscious of this fact according to Bowis' resolution. New types of service and the development of the European citizen as an emancipated individual with her own responsibility will make it necessary that citizens are allowed space to participate actively from interests that are bigger than themselves. The enhancement of the role of the patient will contribute to a future oriented, internationally competing and democratically developing European health care. It is important that certain European basic standards will be guaranteed. These standards must take the emancipated citizen who can and will make her own choices regarding health care as an example.

The cooperating patient organisations within EPECS agree that the EU must attend to the following points when working on cross-border health care in Europe:

##### **1. Quality**

- Quality is without doubt one of the most important elements in health care. To guarantee and improve this attention must be paid to, among others, 'best practices'. At the moment when there are 'best practices' more attention must be paid to implement this in other regions in the EU. (question 1).
- Guaranteed quality of care institutions. This means that improvements in health care and social security systems must not be to the expense of good standards (question 6 and 7). Similar to European quality standards in other sectors of the internal market, the EU could take the initiative for specific certification and accreditation of care providers, care institutions, funding agencies, etc.
- Integrated care is very important for the quality of health care. Many countries already pay attention to this on a national level. The EU must as well. The aspects that obstruct the running processes for integrated care in European health care must be carefully examined.
- A very important point to which the EU definitely must pay attention is the problem that arises after a full or partial treatment with medication. The first concrete example is the prescription of drugs that are not available in the country in which the patient resides. The second example is

that in different EU countries different names for the same drugs are in use. This may make the drug appear unavailable to some.

- Another point that needs attention is the pre- and post care trajectory of a treatment that takes place in another EU country. There are many problems regarding this issue. When a patient received a partial or full treatment in another EU country, it has to be clear to the care providers and care organisations what exactly has been done and what still needs to be done after the patient returns. This is not always clear yet. Also when there are complications, it has to be clear where the patient can go; to a doctor in his/her own country, or to an appropriate doctor in the other EU country. What should be done in case of complications does not only have consequences for the quality of care, but also for the financing of care and liability. The DBC's or a similar system which are already used in a number of EU countries make it even more complex.

## 2. Transparency

- Disease, impairments and accidents are not bound by borders. From a cross-border perspective it lacks, according to the experience of patient organisations, transparency of accessibility, quality and affordability of the care system (question 1). Patients find it difficult to obtain correct information about their possibilities when they want to make use of the care system in another EU country. In addition, the education of patients about their rights and about rules regarding cross-border health care has the highest priority. There are only a few market parties that pay enough attention to this. In his report, Bowis subscribes to the view of lack of patient education regarding patient mobility and developments in health care in the European Union.<sup>7</sup>

- There must be more transparency regarding the rights and obligations of patients in Europe. When a patient makes use of a care system in another EU country, voluntarily or out of necessity, it is often not clear to the patient and people surrounding him what his rights and obligations/duties are in such a situation. The patient organisations that are participating in EPECS explicitly insist that the basic rights and obligations of each citizen must be written down in European patient rights. Right to information, right of self-determination and right to privacy will at least have to be included (question 2).

## 3. Complaints and liability

- Transparency should clarify the different responsibilities on national and European level. There must be clarity about liability and it should be clear to the patient who is liable for what when the treatment takes place completely or partly in another EU member country. It speaks for itself that this is not only good for the citizens, but also for the care providers, funding agencies and professionals working in health care.

- Also needed will be an office for grievances (which serves the interest of the patient) which patients can go to for signals, wishes, difficulties, complaints and objections regarding cross-border health care. In this way insight is gained in the problems that are experienced by patients. These problems can be different from problems that governments, care providers or funding agencies experience and can serve as signals for desirable policy.

## 4. Accessibility

- There has to be clarity regarding which care systems are accessible and which are not and under which conditions. Uniform care is important.

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<sup>7</sup> Report about patient mobility and developments in health care in the European Union (2004/2148(INI)), The European Parliament, 2005.

- Not only has to be looked at which care is accessible also attention has to be paid to the pre- and post trajectory, as mentioned before under 'quality'.
- For a safe, effective and high-quality care abroad it is a prerequisite to work with cross-border accessibility and exchange of medical data.

#### 5. Monitoring

- Patient organisations from border areas who often deal with patients who use care systems in neighboring countries will have to be involved in the monitoring of various cross-border health care activities. Not only because in this way citizens will be involved in the activities independently, but also because the patient organisations are close to patient groups and can inquire with them about questions, ideas, etc. Patient organisations will have to be involved in evaluation studies and the like.
- Also the EU should be able to inquire about certain European health care issues. Patient organisations should give independent advice to the European Union about this, supported by patients, who are central in this.
- There should be a European office with e.g. telephone and a website where citizens can go if they have questions about the European health care system, possibilities and complaints regarding European health care. People with questions for and complaints about national issues should be directed to the responsible national authority (see question 4).

#### 6. Participation/Empowerment

- The patient as a party is increasingly important within health care. This is an observable trend in an increasing number of EU countries. This has to be taken into account in the developments that the EU wants to implement. Patients will need to participate in new developments and policies. They will need to participate in various decision making organs. E.g., contract negotiations between the different care providers and funding agencies, or when governments are making new policy, laws, and guidelines. Patient organisations, as representations of patients, must to be involved in these processes and must participate in decision making.
- To be able to improve patient participation and the choices made by patients in Europe, it is important to acknowledge patient organisations that deal with European issues, as NGO's (question 9). This means that patient organisations will be acknowledged as entities, and also that they can claim subsidies that are necessary to maintain their independency.

Gathering and signaling using a bottom-up method and making use of that knowledge and experience regarding above mentioned points within health care has almost not been used within Europe. The developments in health care are partly determined by initiatives from the regions and care organisations. They know what is important among their citizens and what they need. They are also the ideal parties to be involved in policy and strategies in Europe. In addition, they are able to provide information that complements the shape and organisation of the field on different levels for development of policy on both national and European level.

### **5. Role of the EU members**

The role of the EU members in supporting European health care must not be underestimated. On all above mentioned points the EU members have their own national responsibility, which they cannot and must not pass onto the EU. By taking their own responsibility they also support the

EU with the effectuating of health care on a European level. We want to emphasize a number of responsibilities.

In 'Patient mobility in the European Union; learning from experience'<sup>8</sup> is mentioned that there is movement towards more participation of the citizen/patient in planning of health care services in many European countries; "The involvement of patients is equally important in border areas".<sup>9</sup> This trend must be continued in EU countries, but the EU itself also must take responsibility for furthering patient participation. Kypriano's advice to the EU on September 4th, 2006 was for the EU to ask citizens for advice regarding patient mobility. On a national level, the national patient umbrella organisations can and must play an important role in this. This will also improve the quality, transparency, accessibility and participation/empowerment on a national level.

Another important point for EU countries is financing. The national financing systems must remain most important for the EU countries. This will have to stay that way in order to preserve norms and values that individual countries have for social security and health care.

## **6. Support by EPECS**

On European level, primarily people with impairments, people with a chronic condition, and people with a rare disease are organised. Regional patient organisations will have to be organised on a European level as well. Eventually, the local and regional patient organisations represent patients/citizens by direct contacts. They also know the wishes of the market. They work bottom-up and know what happens in the border region regarding cross-border health care. They also have the best and quickest access to map the wishes and expectations of patients in the border regions. They are at the base of a structured cooperation that is formed by citizens/patients.

At the moment there is no collaboration between patient umbrella organisations in the border regions: the power of the EPECS initiative is in the fact that we are active in regions that are called Euregios by the EU, in daily and practical exchange of information and advice to patients. We are especially familiar about cross-border care problems. EPECS is about to get a legal position, with which we could make a first step in the forming of a powerful entity, that can mean a lot to the EU.

- We agree with the fact that pilot projects within various different European subsidies are done in border regions. Certainly because these are the first concrete steps to solutions for earlier mentioned problems. We prefer this being done in regions where there is a lot of experience with cross-border traffic and where there is enough engagement in the projects. Projects in the field of quality, contracts, ICT, EPD's, transparency, data traffic, participation, eHealth and telemedicine are advisable. However in these pilot projects regional patient organisations who work in the mentioned fields should be involved, to guarantee the patient perspective. The EU should make this a prerequisite for these pilot projects.
- We can offer the regional cross-border (basic) structure and capacity to act as a full advisory body for the EU.

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<sup>8</sup> Rosenmoller, McKee and Baeten, 2006, p.187.

<sup>9</sup> Rosenmoller, McKee and Baeten, 2006, p.187.

- We have realized for a while that patient mobility in Europe is especially an emancipating process, in which the starting-point is the local situation of the citizen. The regional patient/consumer organisations belonging to EPECS live up to this view, as far as their (financial) limits make this possible.
- We are ahead on a European and national level in a number of fields:
  - ICT; consider epanel which is used by patient organisations as basic support for the citizen, or of the intensive collaboration of patient organisations that work on care and information technology; for which the patient is starting-point within the present and future digital highway.
  - Accessible information service: consider places where citizens and pressure groups that are connected to patient organisations can get support and where availability of good (choice supporting) information is central.
  - Quality of care: collecting of data on quality of care and client satisfaction.
  - Support groups: the good and structural organisation and support of all self help activities for European citizens.
- We have regional and Euroregional projects which, when combined, can be a good basic structure for European collaboration ('best practice'). The basic structure will have to be supplemented with local wishes and needs as to fully make use of the possibilities of the region;
- We already extensively collaborate with umbrella organisations in the bordering foreign regions. In addition a number of umbrella organisations are part of the 'Silver Economy' network, which works with demographic development and the consequent possibilities for development.
- Already we are involved in projects within the ICT and within projects in the medical technical field.
- In addition other care providers and funding agencies increasingly ask us for advice. We are already involved in contract negotiations.

Based on above mentioned points, the patient organisations that are part of EPECS are very much suitable for participating in the development and planning of the European health care in the area of cross-border quality, transparency, complaints and liability, accessibility, monitoring and participation and empowerment. We find it worthwhile to extend EPECS and work together with patient organisations from other border areas of Europe.

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 European commissioner Markus Kypriano once mentioned about the growth regarding cross-border commerce that "Brussels' vision of a borderless market is forming". We hope that, in a number of years, a similar statement can be made about health care. We hope it will say: "Brussels' vision of health care with involved citizens, care providers and funding agencies is forming".

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