

Summary reaction of cooperating patient organisations European Patients Empowerment for Customised Solutions (EPECS) to consultation

In the border area of The Netherlands and Nordrhein Westfalen (Germany) several regional patient organisations and pressure groups from both countries have been working together in the field of cross-border health care ¹. An increasing number of patients have been going to doctors across the border. Because of this we know much about the themes and problems related to everyday life in a border area. Commissioner Kyprianou rightly calls the patient the first of the stakeholders who must be consulted about cross-border patient mobility in Europe. The European Parliament describes, in its report about patient mobility and developments in the EU,² the position of the patient/citizen at this moment and what is most important in European health care.

Role of the European Union

We, the cross-border patient organisations participating in European Patients Empowerment for Customised Solutions (EPECS), agree that there is a structural problem in health care regarding enhancement of patient mobility in Europe: the focus has been too much on care providers, funding agencies, and authorities. The patients' concerns are subordinate. 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.

According to the Bowis resolution, the European Parliament is aware of this. We, as EPECS, fully support the resolution. Especially point 41 from this resolution is the foundation of EPECS:

“Emphasises that the focal point of the whole system is the patient, who has a natural interest in his or her own health and in the quality and accessibility of health care, who is the recipient of care and who pays for the care he or she receives, whether directly or through health insurance or taxation. Therefore, patients are fully entitled to be kept completely informed about their treatment and their state of health and are fully entitled to be involved in decision-making with regard to health care consumption.”

Advancement of the role of the patient will result in a future oriented, internationally competing and democratic development of European health care. It is important that certain European basic standards will be guaranteed.

We summarize our answers to questions of the EC as following:

We, as EPECS, agree that the EU must attend to the following points when working on cross-border health care in Europe:

- Quality: Implementation of best practices; implementation of European standards, prescription and distribution of medication; pre- and post care trajectory with treatment in another EU-member country.
- Transparency: More patient information about rights and duties of the patient, accessibility, quality and affordability of system of care.
- Complaints and liability: More clarity in liability and the initiation of a European office for grievances.
- Accessibility: More clarity about which cross-border care is available and accessible and under which conditions.

1 Cross-border health care includes both the care and the cure side of health care.

2 Report about patient mobility and developments in health care in the European Union (2004/2148(INI)), European Parliament, 2005

- Monitoring: Initiation of a monitoring system for cross-border health care activities.
- Empowerment: Advancement of patient voice in new developments and policy and decision making.

Role of the EU members

All EU members have their own national responsibility in the above mentioned points. By taking their responsibility they support the EU by making health care more effective.

In many European countries there is a movement towards more participation of the patient/citizen in the planning of health care services. This must be continued. The national patient umbrella organisations must and can play an important role in this. This will also improve the quality, transparency, accessibility, and participation/empowerment on a national level.

The EU members also play an important role in organising liability and financing of cross-border health care. This must be organised on a national level at first, a task EU members are well equipped for. This will give them autonomy which is necessary for organising national health care in a good way.

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 the patient/citizen 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.

The power of the EPECS initiative is in the fact that we are active in the Euregio in daily and practical exchange of information and advise to patients. We are especially familiar about cross-border care problems. EPECS is now researching which legal position is the best to form a powerful entity, that can mean a lot to citizens/patients in border areas but also can mean a great deal to the development of policies within the EU.

- We support the idea to implement pilot projects for improvement and simplifying cross-border care and cooperation, if the regional patient organisations who work in those border regions will be participants.
- We can offer the regional cross-border (basic) structure and capacity to act as an advisory body in this field for the EU and others
- We have realized for a while that the patient mobility in Europe is especially an emancipating process, in which the patient has to prove his/her position as most important stakeholder.
- Our primary concerns are the local and national possibilities for care, but we see the cross-border care as a necessary choice which we have the right to.
- We see as essential conditions for a good cross-border care the following: ICT (eHealth, EPD, epanel), accessible information service, quality of care; the right to gather data about quality of care, and satisfaction of clients and patient groups.
- We have regional and Euregional projects that can lead to best practice for the structural participation of the patient as primary stakeholder in the forming of cross-border care.
- We have cooperation structures with umbrella organisations of patients in the bordering foreign regions.
- Providers of care and funding agencies increasingly ask our advice. E.g., patient organisations in the Netherlands are participants in contract negotiations.

Based on above 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. We also feel that the development of empowerment of the cross-border patient should not be dependent on the arbitrary ideas of the separate EU members. The EU needs the resolve to generate conditions for the realisation of the rights of all European citizens.