

European Commission

Directorate-General Health & Consumers
B - 1049 Brussels
Belgium

Maastricht, 21 October 2013

Re: Position National Contact Points

Dear Sir/Madam,

The foundation EPECS, European Patients Empowerment for Customised Solutions likes to address you concerning the implementation of the National Contact Points. EPECS is a network organisation in Europe, which works to improve cross-border healthcare for patients and/or insured persons in Europe, and is connected with people and organisations in Europe.

Border regions are important areas of experience for our foundation. Especially concerning the development of cross-border procedures and the gathering of practice oriented experiences regarding a cross-border and Europe-focused healthcare. EPECS works with people in their role as patients - their needs, wishes and medical problems - when we deal with cross-border healthcare. In this context we are involved in various border-projects that will make use of mutual learn- and synergy effects to improve cross-border healthcare between participating Member States.

EPECS has also developed products and instruments to support citizens when they are dealing with cross-border healthcare. If citizens are considering making use of healthcare in another country than the one he lives in, it is important for them to know what is possible, what is allowed, what it means and what the limitations are. This supporting information is necessary for people to make the right decisions in light of the necessary highest quality of care.

In 2000 the fifth recommendation of the ministerial council of the European Union stipulated that "consumers and patients should participate in the process of defining goals for the health system"¹. This recommendation is also found in article 6, part 1 of Patient Directive 2011/24/EU regarding the instalment of National Contact Points. It is emphasised that Member States should consult patient organisations (among others) in the instalment of National Contact Points. EPECS has been following the developments regarding the instalment of National Contact Points and the consultation of patient

¹ Naiditch M. Patient organizations and public health. European Journal of Public Health. 2007;7(6):553-45.

organisations in this with interest.

To find out whether the Member States indeed consulted patient organisations in the instalment of the National Contact Points, EPECS has done a study in collaboration with Maastricht University, in June of last year. On the basis of this study among 13 Member States EPECS likes to present her findings:

- **Directive 2011/24/EU is not clear enough regarding the instalment of the National Contact Points.** In the view of EPECS, the Directive is not clear regarding the way patient organisations should be consulted in the instalment of the National Contact Points. This concerns the way the National Contact Points could or should look like, their content and tasks and their work areas and conditions.
- **Patient organisations are not at all or marginally involved in the instalment of National Contact Points.** The involvement of patient organisations has been marginal and there is a large variation in how patient organisations are involved. A number of Member States had only informed the patient organisations regarding the 'what', 'with whom' and 'how' of the instalment of National Contact Points. In some other Member States there had not been any contact with a patient organisation yet, even though the outlines of the National Contact Points were already clearly formed.
- **The recommendations of PWC² are not sufficiently taken into consideration.** The study by PWC gave Member States recommendations for the instalment of the National Contact Points. For various reasons however, the 13 Member States didn't use or only partly use the given recommendations. It was stated that the recommendations came too late in the development process, the costs of the implementation of the recommendations were too high, and the Member States thought the recommendations were not applicable to them for various reasons.
- **A website alone is not sufficient.** Many of the National Contact Points will only consist of websites. A website can be a good additional support, but regarding complex issues like cross-border healthcare, a website alone is not enough to inform citizens. EPECS fears that the only formal thing many Member States will do is launch a website on October 25th 2013. This will not be enough to provide people with the necessary and high quality patient-focused information.
- **Quality and safety standards and guidelines are not sufficiently integrated in National Contact Points.** Most National Contact Points struggle to provide information about the quality and safety standards and guidelines that the Directive describes in article 4, part 1b. There is a good chance that these Member States will not implement this, or will just direct clients to other websites.

² Price Waterhouse Coopers. Recommendation report: A best practice based approach to National Contact Point websites: a feasibility study 17 october 2012 [06.05.2013]. Report].

EPECS is of the opinion that the instalment of a National Contact Point in every Member State is a good way to provide citizens with information regarding their rights on cross-border healthcare and every thing that is connected with that. However, we are disappointed about the current state of affairs regarding the instalment of National Contact Points. EPECS would like to see more attention devoted to this theme. We are very willing to support the EU and her partners in the development of cross-border healthcare, in particular we are willing to support the implementation and further development of the Directive regarding for example the instalment of the National Contact Points.

With kind regards,



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