To:
Health & Consumer Protection
Directorate-General

Response by the cooperating patients' organisations "European Patients Empowerment for Customised Solutions" (EPECS) to the discussion document "Health in Europe: A Strategic Approach"

Maastricht, 7 February 2007

What is EPECS?

In the border area of the Netherlands and North Rhine-Westphalia (Germany), regional patients' organisations[1] from both EU countries have been working together for some time in a structured manner on cross-border healthcare[2]. In view of their encouraging experience of cooperation, patients' organisations in the Euregios Maas-Rhein, Rhein-Maas-Nord, Rhein-Waal, etc. decided some time ago to strengthen the basis for their cooperation and put it on a long-term footing.

The partners from the Netherlands and Germany in the EPECS alliance (European Patients Empowerment for Customised Solutions) share the following basic convictions:

- We take an overall view of citizens in the border regions and elsewhere as responsible citizens, who wish to exercise responsibility and equal rights, particularly when they become patients, in their relations with social insurance institutions and service providers (medical practices, hospitals, etc.) and not to be the passive "objects" of decisions taken by experts.

- Moreover, ever-increasing numbers of citizens and hence patients are becoming aware that as patients they do not only have duties but also rights in healthcare matters. Quality, openness and accessibility of healthcare are thus becoming increasingly important, and this also applies at European level. The information available on the Internet is making more and more patients aware of the options afforded by the European health sector, e.g. for patients with a rare disease, who consult specialists in a particular medical discipline in another EU country.

- Specifically because of our experience in the border regions, we should like, in the interests of the people living there, to help create a better basis for cross-border and European-minded provision. Above all, we wish to contribute to the development and improvement of the framework for a European health system.

- Our particular aim in the alliance is therefore to play our part in political decisions and measures at European level.

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[1] Also referred to as "patients' interest groups".

[2] In speaking of cross-border healthcare, we mean both the "care" and "cure" aspects.

The role of the European Union and EU members

We are glad that the strategy paper includes among the key issues for a European health strategy the need to "support citizens and patients, including by making more healthy choices available and improving information to patients".

At the same time, we feel that the paper does not do justice to the actual importance of citizens and patients to a new European health strategy.

The healthcare sector in Europe suffers from a particular structural problem: acting and thinking in this area has so far been dominated by the viewpoint of the providers of health services — the political sphere, the public authorities and insurers — whose outlook is primarily national. The perspectives and interests of patients as customers are at present only a secondary consideration. We believe citizens and patients, since they are central to the European market, must be involved in deciding how the supply of services should be organised in the health system.

Increasing mobility in Europe will make cross-border provision one of the key areas in which the wider problems of healthcare in the Member States and a genuinely European approach to healthcare will be reflected.

We are convinced that strengthening the role of customer/patients can help to ensure that healthcare in Europe can develop in future in a manner that is both internationally competitive and democratic. A major prerequisite is to ensure that certain fundamental European requirements are satisfied.

Health strategy in Europe must therefore be centred on the concept of the responsible patient, who takes his own healthcare decisions and accepts responsibility.

The context of healthcare provision must therefore be so shaped by the European Union that responsible citizens are able to participate and exercise self-determination:

- Patients must have a voice in new developments, in the addressing of new issues and in policy decisions. Patients' organisations, as the representatives of citizens and patients, should be properly involved in these processes and be allowed a role in steering them. To this end, it is important to recognise patients' organisations as entities.

- Citizens' ability to obtain information on the services delivered by health systems in Europe and on cross-border provision, without being constrained by the interests of social insurance schemes or service providers, must be sustainably improved and further developed. A precondition for autonomous decision-taking by citizens or patients is adequate information of assured quality.

- Impartial national and European contact points that serve patients' interests must be set up as a place to which the public can turn with its comments, wishes, difficulties, objections and complaints in healthcare matters. This would provide insights into patients' problems, which may be fundamentally different from those of the authorities, care providers and funders and can provide pointers to policy desiderata.

No use, or not enough use, has so far been made in Europe of such a bottom-up method and of patients' knowledge and experience, especially in the areas mentioned in the discussion document.

However, major past developments in healthcare have already been based in part on initiatives taken in the regions and by committed citizens, who above all know the public's concerns and needs. They are among the stakeholders that should be involved in considering policy decisions and strategies in Europe. They are also in a position to provide the various national and European decision-making levels with information allowing structured representation and comprehensive coverage of the field.

Support provided by patients' organisations

Hitherto, it has mainly been the disabled, the chronically ill and those with rare diseases that have organised at European level to promote their interests. These organisations are of considerable importance for the health system.

At the same time, we believe that a European-level organisation is needed to represent the experience of patients' organisations that deal with patients' more general concerns and interests and which have as much practical expertise as possible in the field of cross-border provision.

Such largely local and regional patients' organisations can represent patients and citizens because of their contacts with them: they are familiar with the needs of this "market operator" in general terms and not merely as a specific group. They adopt a bottom-up approach and know what is happening in the (border) regions and in healthcare provision. They also have quick access to patients in the border regions and so can grasp their wishes and expectations. They are thus the basis for structured cooperation shaped by and for citizen/patients.

Our EPECS initiative engages in everyday, practical cross-border information and advice activities for patients in the regions designated by the EU as Euregios, where we mainly deal with (cross-border) problems in the border regions.

EPECS is on the point of acquiring legal personality: a first step towards creating an effective entity that can be very useful to the EU.

- We offer a (basic) regional cross-border structure and have the necessary capacity to act as a fully–fledge advisory body for the EU.

- We have long been aware that patient responsibility within Europe in itself represents an emancipation process, although the starting point is the local situation of the citizen. The regional patients' organisations linked with EPECS act accordingly, so far as their (financial) circumstances allow.

- We work on regional and euregional projects which, in combination, are a good basis for European cooperation (best practice). This basis must of course be enhanced with local wishes and needs in order to exploit fully the potential of each individual region.

- We are part of (extensive) cooperation arrangements with the umbrella organisations in the adjacent regions in other countries. (Some such organisations are also represented in the "Silver Economy" network, which is concerned with demographic development and the resulting opportunities for development.)

- We use information technology, since it is an excellent means of providing the public with independent information.

- It is also increasingly common for our advice to be sought by healthcare providers and funders.

We will expand EPECS to include further patients' organisations from other European regions which adhere to a Europe-oriented approach to healthcare and thus lend support to the European philosophy.

Postal address:
Ms Brigitte van der Zanden
EPECS coordinator
Calvariestraat 12
NL – 6211 NJ Maastricht

@: info@epecs.eu

Tel.: 0031 (0)6 – 36062039

Contact EPECS Germany: Mr Klaus Bremen
Contact EPECS Netherlands: Mr Martien Overkemping