



## Consultation regarding Community action on health services

### Introduction

European Research Institute for Consumer Affairs (ERICA) welcomes the Commission's attempt to collect and co-ordinate the views of a wide variety of stakeholders on the need for legal clarity, certainty and transparency regarding the mobility of patients in the European Union. It is aware that the Commission's task will not be easy at a time when there are rapid changes not only in medical procedures but also in the development of related technology. Nor will it be easy to reconcile the differences between healthcare services as they exist in large cities and predominantly urban areas, and those in many parts of the European Union which are very rural and sometimes even isolated. It recommends that the Commission should make it clear that its final text deals both with the problems of people who are already in another country, particularly people who are working abroad, and when they need to have medical intervention and of patients who seek elective and optional medical intervention.

### Background of ERICA

ERICA is an independent, not-for-profit European consumer organisation founded in 1978 to improve life for Europe's consumers, particularly those who are disadvantaged and vulnerable, through research leading to action and through consumer education. In the past, its research has covered areas such as access to the Internet and digital TV for the disadvantaged, plain language and reaching less literate consumers with Internet education, transport for people with physical disabilities, protecting children using the Internet, and it continues to propose an action programme for the citizens of Europe. Its remit now includes issues of healthcare which affect all consumers including those of, for example, the elderly and disabled whose views are not only under-represented but unacknowledged. As a consumer organisation, ERICA is primarily concerned with patients, but it is nevertheless recognises the special significance of cross-border employment. Patients can benefit from the knowledge and experience that the interchange of healthcare professionals brings within the European Union. Nevertheless, in the patient interest, ERICA emphasises the importance of the mutual recognition of degrees and diplomas of a high standard, as well as avoiding the barriers created by language and cultural differences.

### Question 1

ERICA sees healthcare as inevitably tied in with other services, particularly access and transport in very large rural areas of many Member States. In such areas, local mobility is often the main problem, both for chronic illness and emergency treatment. Where poverty and ignorance are rife, such patient consumers are unlikely to aspire to

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treatment in another Member State unless adverse domestic conditions force them to seek work elsewhere as economic migrants.

As for speculation about the evolution of healthcare services, ERICA could foresee greater national integration of transport enabling easier access to a wider range of healthcare services. Movement Europe-wide is likely to depend on the continued availability of low-cost airfares and its effect on tourism. Services in other Member States are likely to be used to deal with national shortages (e.g. in dentistry), long waiting lists, or with the need for more complex diagnoses, treatments and procedures. Patients over time will become more familiar with the idea of moving further afield for access to a wider range of opportunities. There is likely to be a significant interchange of expertise available. It could also happen that commercial services as well as public services become increasingly involved with the development of tourist-type inclusive health packages for elective surgery.

## **Question 2**

Patients in all Member States need clarification and simplification of any relevant documentation so that they can understand their entitlement to cross-border health care. Any future communications must avoid vague implications in phrases such as "without due delay", or the use of "reasonable": What may seem reasonable to a healthcare professional or government official may seem most unreasonable to a patient who is suffering.

ERICA highlights the particular linguistic and legal problems relating to the need to obtain informed consent before a treatment or procedure can take place. This problem is becoming particularly significant since the accession of new Member States and the increased movement of workers and their families who have inadequate understanding of the language of their host country. Obtaining informed consent is essential from the patient's point of view but inevitably costly from the point of view of health services in terms of translation and interpretation that needs to be provided.

ERICA has found that, particularly since enlargement, care for new arrivals has placed linguistic burdens on the UK National Health Service, largely at primary level. Yet patients, actual and potential, need both general and specific information, presented in a way that they can best understand, that is, avoiding technical and medical jargon: they also need to be able to assess for themselves risks and benefits of particular treatments which may well be culturally as well as linguistically difficult when carried out in a Member State other than their own. Some patients may be able to take advantage of recognised national and EU websites, and further information could be distributed along with the European Health Insurance Card (EHIC) or disability driving permits.

It is quite clear that healthcare professionals will need the support of experts drawn from other areas of expertise in communications. Patients will need to be assured through them of the protection of clear legal certainty.

## **Questions 3 and 4**

The focus of these questions is much more on elective surgery and treatment rather than with the sudden misfortunes and maladies of patients as tourists. In cases of negligence or incompetence in these interventions, ERICA considers that legal redress and compensation for the patient should lie with the Member State providing the

treatment. If after care is needed, it is invariably in the patient's interest to provide this nationally, with costs being paid by the health and social services of the original State. Claims for redress and a clearly delineated scale of compensation should be settled promptly, possibly through a European arbitration scheme, and not allowed to span many years of legal confrontation.

### **Questions 5,6, and 7**

Patients must be able to see healthcare as being fair and equitable, both to permanent nationals, to visitors as tourists and to newcomers to their country. ERICA notes that a sudden influx of workers and their families can cause disruption to existing national health services, especially at primary care level. In the interest of harmonious relationships, it is essential that more is done to explain both entitlements and responsibilities to new patients on arrival, perhaps in the form of a simple leaflet on entry. A more detailed "welcome" pack could be available in doctors' surgeries which are likely to be the first places immigrants - or tourists - will contact. ERICA is of the opinion that such communications are better provided by professionals producing simple alternative language versions than attempting to translate essential facts into an enormous variety of other languages. In the UK such leaflets would be in English as a Second (or alternative) Language. Translation into other languages diverts funds from health and can take away the motivation to learn the language of the host country.

### **Question 8**

ERICA recognises the principle of subsidiarity under which health services operate in the European Union, but it also welcomes opportunities for European co-operation and collaboration. ERICA is also conscious that the future of healthcare will lie with other DGs as well as DG SANCO.

Research into rare diseases calls for shared investment and less competition between pharmaceutical companies to be first in providing effective treatment. The search for vaccines for potential pandemics (e.g. Avian flu) must also be done at EU level. The rapid advance of technology can increase the speed with which diagnoses are made and test results produced, data stored and retrieved for individual and collective benefit, and the register of organ donors expanded. Patients will undoubtedly benefit from the open and honest comparison of statistics in the Member States and from the stringent monitoring of best practice not only in medical techniques but also in administration and organisation.

### **Question 9**

ERICA considers that the best way to ensure legal certainty for patients would be by means of a legal binding instrument, universally comprehensible. This question also asks for suggestions which are non-legislative.

ERICA supports the growing concept of Public and Patient Involvement (PPI) not only nationally but in the European Union where people - as citizens - participate in the shaping of policies which concern them collectively as well as individually. Nevertheless, ERICA has certain concerns in that the expansion of patients' organisations and forums, often for those suffering from or caring for particular diseases, are not truly independent. It would seem that pharmaceutical companies now support some of these charitable organisations with desperately needed funds. At a

European level it would welcome a Forum which is truly representative of patients' interests and completely and transparently independent of any biased funding.

A sound starting point for the development of health services, particularly from the point of view of communications, is to work from existing successes, some of which are still inadequately publicised. The EHIC or the disabled drivers' card could be the means of conveying additional information about health services: both of these entitlements provide access to an existing database of names and addresses. EU Direct (which has the merit of being free) could be expanded to deal more specifically with health information by e-mail, telephone or in writing. And, as more homes in the EU achieve Internet access and broadband status, more programmes and indeed software could be developed which are exciting, informative and educational. Websites could be used for official warnings as well as advice.

Finally, we would like to thank you for the opportunity this consultation offers for ERICA to emphasise the importance of ensuring that the problems of the vulnerable and disadvantaged are included in the evolution of healthcare services across the EU.

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