

From: **Patient and Public Forum in North Yorkshire**

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The EU Commission,
DG SANCO
Health & Services Consultation B232 8/102

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Dear Sir,

As chairman of the Patient and Public Forum responsible for primary health care in Harrogate, Craven and Rural Areas, I have pleasure in submitting our response to your consultation.

I hope you will find our comments useful and informative.

Will it be possible for us to access your co-ordinated findings and be appraised of any action which results?

Yours sincerely,

Ivan Lester (chairman, PPI Forum)

EU CONSULTATION regarding Community action on health services.

RESPONSE from the Patient and Public Involvement (PPI) Forum representing the localities of Craven, Harrogate and Rural Districts of North Yorkshire.

Preamble

The PPI Forum welcomes the Commission's initiative in attempting to collect and collate disparate views on the need for legal certainty, clarity and transparency regarding the mobility of patients in the European Union and their cross-border care. It endorses the need to take into account the links between health and social care. The Forum also recognises the enormity of the task in view of the very differing health and social care systems in the Member States with their right to operate under the principle of subsidiarity. It is also mindful of the difficulties in planning for an era of change in medical practices exemplified by rapid developments in new technology and communications.

Background of the Forum

The Commission should be aware that the Forum is a group member of an independent national organisation of *patients* as well as the public. Therefore it confines itself to responding only to those questions which have direct implications for patients as users and not to healthcare employees. It accepts, however, that cross border *employment* should be welcomed and supported because of the desirable interchange of experience and expertise that it can bring. But in the patient interest there must be stringent adherence to the mutual recognition of degrees and diplomas, to the need for linguistic fluency in the language of the host country, and to the understanding of cultural differences.

This particular Forum is located in a predominantly rural part of North Yorkshire and is therefore confronted by its own local problems of patient mobility in both transport and access to many different forms of even the most basic healthcare. To many inhabitants elective cross border treatment would seem as remote a possibility as a journey to the moon!

The Forum points out, therefore, that it is essential to make a clear difference between treatment in another country, which is likely to be optional, elective and non-urgent, and treatment which concerns tourists on holiday who may need sudden, emergency medical intervention. There is also a new dimension in that more families are investing in a second home in the EU and may choose to live there for a substantial part of the year using two different and possibly interactive health services.

Relevant national implications

- The United Kingdom in general does not, in its insularity, have the same problems of *transfrontaliers* as many other EU Member States where as many as 10% of the population live and work and get ill in adjacent countries.
- Its National Health Service (NHS) has recently embarked upon a system whereby patients offered treatment in hospital are now increasingly offered a choice of five

truly “informed” and understood across the language barriers.

Patients need to be able to make informed choices about treatments and their providers in other Member States and therefore require legal clarity and linguistic simplicity as cornerstones of progress. Choice, particularly concerning treatment, where there can be an emotional as well as a practical and financial dimension, is as always a complex subject. Nevertheless, better information at a national level could lead to the revelation - and the take up - of other options which could reduce both shortages of healthcare staff and patient waiting times. Patients need information and the necessary assessment skills to be able to weigh up for themselves the risks and benefits; one of the major factors is the need for legal certainty about liability in the case of a mishap, and the consequent provision of medical and social aftercare.

Practical details about possible choices could be available through sources such as recognised national and EU websites and FAQs, through enclosures with EHIC forms and explanations issued with disabled driving permits.

Questions 3 and 4

These questions deal more with elective surgery and treatment rather than with the illnesses, accidents and injuries incurred by patients as tourists. As for carelessness, incompetence or negligence, the Forum is of the opinion that no-quibble legal redress and compensation for the patient should be with the original Member State providing the initial treatment. Follow-up after care should be the responsibility of the home country with transferred restitution of costs. There should be an EU-wide recognised scale of compensation set out clearly, simply and transparently, as is the case in much commercial private insurance. Claims must be promptly settled, perhaps with arbitration, and not allowed to continue over a lengthy time span in law courts. Individual cases with significant *general* implications must be independently investigated and results widely publicised in order to prevent future similar incidents.

Questions 5, 6, 7

The system of healthcare in action in each Member State must be seen to be fair: for example, an sudden overload of workers and their families from another EU State must not diminish the existing entitlements and expectations of permanent residents particularly at primary care level. There is already a perception of unfairness in the UK with regard to what is called “the post code lottery” where patients living in different (and sometimes adjacent) areas are not given the same level of treatment. Resentment and antipathy are not conducive towards harmonious and necessary relationships which themselves relate to the well being of citizens. Much more could be done by preparing a health “welcome pack” for new arrivals in an appropriate language (maybe specially written in the UK in English as an Alternative Language), explaining rights and responsibilities. Such a communication could be available in doctors’ surgeries - which are likely to be the first medical contact point for immigrants - as well as at the point of entry to the host country. Undoubtedly, there will be communications and cultural problems and the consequent need - and cost - of providing interpretation whether through individuals or a recognised telephone service. There is a significant role here for voluntary organisations, such as the Council for Voluntary Services in the UK, in helping with familiarisation and

acclimatisation.

The Forum is concerned about the migration of key healthcare professionals to other countries, including the UK, where salaries are higher. It is not within its remit to suggest solutions but it again stresses the need for balance and fairness. It is neither balanced nor fair for one Member State to be deprived of its own much-needed medical services to supply the needs of another.

Question 8

The Forum recognises that there are certain advantages in European co-operation even though the main focus of health and social care remain inevitably localised - for example in the extension of a Europe-wide register of potential organ donors.

Concentration of combined resources - for example the research and the treatment of rare diseases calls for shared action, as do provisions for an outbreak of Avian flu. Indeed in the latter case, as in many other situations, combination rather than competition would be a cost-cutting asset in the search for effective immunisations. Avoidance of duplication of effort cuts costs at all levels. There is also a strong case for Europe-wide co-operation in medical and technological research supported by central funding, for example, in diagnostic techniques and the speeding up of analysis of test results. These are increasingly the concern of other EU Directorates General in addition to DG SANCO.

These are the sorts of measure, together with the ability to monitor and appraise best practices and compare healthcare data, that would bring benefits to patients as results filter down into national and finally local healthcare.

Question 9

The Forum is not qualified to comment on the range of possible tools for action at Community level, though it feels that legal certainty for patients would be best ensured by a binding legal instrument.

At the non-legislative level the Forum has certain suggestions. It would like to see strong Europe-wide representation of patients in an *independent* forum or federation which is openly and provably seen to be free from the support and influence of pharmaceutical companies. The ultimate aim should be the active involvement of patients not only as responsible partners in their own health care but also in the progress and development of collective health and well-being. This Forum is well aware of the difficulty of actively involving patients who profit from actions on their behalf rather than taking action themselves. European examples of ways in which hard-to-reach and disadvantaged groups became active participants concerned with current issues should be studied: in the introductory stages of the euro, the *Eurofacil* project succeeded in achieving peer group organisation and participation, for example, involving older people and consumers with special needs who were enabled to devise their own resource materials.

Health is a subject of interest and concern to all, both individually and collectively, and is

therefore a potential inducement to encourage the concept of European citizenship - if adequate measures are taken at EU level. Popular and successful starting points - such as the EHIC or disabled driver's card - where a data bases of names and addresses are already available, could be developed as the means of supplying and updating information. EU emergency numbers could be provided credit card style. Europe Direct could have a cross border component specifically on health issues (cf NHS Direct in the UK and the widely-used Doctor Foster website) and inter-active phone ins could be arranged. As more homes have access to the internet, more eye-catchingly popular websites could be produced in clear, simple language with diagrams, to provide advice and warnings, even to highlight "unpopular" illnesses such as mental health or podiatry.

These ideas emanate from existing sources as a relatively easy way of developing non-legislative improvements in empowering patients through knowledge. But it must not be forgotten that the EU's proper functioning is supported and stimulated by its enormous variety of non-governmental organisations - or NGOs. This Patient and Public Involvement Forum covering a semi-rural part of North Yorkshire is but one of these NGOs making its contribution.

This paper represents the views of its author on the subject. These views have not been adopted or in any way approved by the Commission and should not be relied upon as a statement of the Commission's or Health & Consumer Protection DG's views. The European Commission does not guarantee the accuracy of the data included in this paper, nor does it accept responsibility for any use made thereof.