

Enabling Good Health for All: A Reflection process for a new EU Health Strategy

Comments by the European Patients Forum

Introduction

The European Patients Forum (EPF) welcomes David Byrne's initiative to launch this Reflection on a future EU health strategy and is happy to take the opportunity to share its views and ideas.

EPF was set up with the aim to

- facilitate an open and inclusive Patients Forum enabling all pan-European patients' groups to exchange information and points of view in the area of EU Health Policy and all other EU initiatives of interest or concern to patients.
- to share experiences of health care and examples of good practice in order to strengthen the role and voice of European patients' organizations.
- to voice the views of patients, as stakeholders in the European healthcare debate, by means of a broad, truly representative and independent patient group resource.
- to provide a forum for patients' organisations to develop common positions on European health policy issues and to lobby on behalf of those organisations, giving them a central position in the provision of healthcare in Europe.
- to become the natural first point of reference for the European Commission and other European institutions when seeking the opinions of patients and/or when seeking to consult patient groups.
- to co-operate in the formation and execution of joint projects aimed at improving health outcomes and the quality of life of European patients.

Comments:

EPF fully endorses Commissioner Byrne's view of the future, i.e. a Europe where high-quality health care is equal, accessible and affordable and where there is reliable information on health, illness and treatment options. In addition, there should be a Europe where all health stakeholders, including patients, are proactively involved in shaping the policies and initiatives that influence their health and treatment options, and where accessible health education becomes a priority.

Enabling Good Health for all

EPF agrees with the Commission's view of the vital role of good health to economic growth and sustainable development, and the need to tackle the health gap across the EU. We welcome the change of emphasis from treating ill health to promoting good health.

Good Health as a shared responsibility

Different actors need to work together

EPF shares the Commission's stance on the need for different actors to work together to foster good health. Therefore, we believe that a true European health

strategy will need to actively address and involve all health stakeholders in a proactive fashion. Such a strategy will clearly outline the roles and responsibilities of these stakeholders and the ways in which they can support and help develop better health for all across the European Union.

Consultative bodies should be more representative and include all stakeholders

The Commission has already created a number of bodies have been created to foster this cooperation; bodies in which stakeholders meet and exchange information, experience and views, such as the European Health Policy Forum and the Open Forum. While we appreciate these initiatives and the possibility for EPF to be formally part of these we do feel that their precise role and influence is unclear as well as limited. For instance, consultation of these often occurs at the last moment and is therefore less effective than it could be.

The fact remains that other bodies, usually composed of representatives of national governments are in a position to concretely influence and shape policy decisions (e.g. the Public Health Framework Programme Committee, the High Level Group on Health and the recently created High Level group on Health Services and Medical Care). While we recognise the importance of the involvement of Ministries in the design and implementation of EU programmes and initiatives –particularly in an area where EU competence is limited - we would urge the Commission to consider involving other health stakeholders in these influential Committees and Groups as well. A good example was set by the High Level Reflection Process on Patient Mobility, where several interest groups participated alongside national governments.

Patient organizations should be enabled to play its part

Another issue concerns the availability of EU financial support to actually enable stakeholders to work together in order to foster good health. The EPF, as a united EU-wide and representative patient organisation and important stakeholder, should be able to benefit from EU funding, as is already the case for a number of other EU wide interest groups (e.g. those active in the social domain). Patient organisations have crucial experience and knowledge to share, and should be supported in playing their part. Prudent health policies cannot be developed without the input of patient organizations.

A more patient-focused Public Health Framework Programme

The 2004 Public Health Framework Programme work programme did not really address patient issues. It proved to be impossible to submit a funding proposal which would meet the themes and priorities outlined in this year's call for proposal. As a consequence, the EPF application was rejected (despite an explicit mention to EPF in the 2004 EU budget). Therefore, we would like to urge the Commission and the Framework's Programme Committee to ensure that next year's work programme is more 'patient-friendly'. Since this Programme is such a vital part of the EU health strategy, it is crucial that patients can participate and help develop future strategies as well as concrete projects

Information needs education

The Commission maintains that 'all citizens need reliable and user friendly information about how to stay in good health and the effects of lifestyle on health. When ill, they need information about their condition and treatment options. Enabling citizens to make the right choices is indispensable.'

While we agree with this statement in principle, there are some aspects that need to be taken into account. It is clear that today's patients have a different attitude towards their involvement in decisions that affect their treatment and quality of



life. The old 'doctor knows best' adage no longer applies. Patients are better informed and want to have a say in treatment options. However, EPF feels that the focus on providing information per se is not sufficient. Information without education remains limited. Concrete efforts will need to be made towards educating patients as well. To this effect, synergies with other Commission DG's (INFSO and Education) should be sought. This would also be in line with the idea to mainstream health into all other EU policies and initiatives.

Health generates Wealth

Investing in health brings long term benefits

EPF fully endorses the Commission's emphasis on substantial benefits for the economy that investment in health would bring. Unfortunately, investing in health is often viewed as a short-term cost, not as a long-term investment. We agree that, with the increasing heavy disease burden, improving health must become an economic priority. If one thinks investing in good health is expensive, maybe one ought to consider the cost of ill health.

Health technology assessment should keep the patient benefit as its main criteria

While we agree that new health technology and medicines must be used efficiently, assessment of technology/treatment should never lose sight of the benefit for patients – in the widest possible sense. Quality of life is an important indicator in this respect.

The right balance: prevention, health promotion, care and treatment

EPF welcomes the Commission's focus on health promotion and illness prevention, but would like to stress that treatment, care and quality of life (both for patients as well as their caregivers) should keep its proper place in the equation.

Conclusion

EPF once again would like to thank the Commission for this Reflection initiative, and express the hope that Commissioner Kyprianou will take account of its outcome. We would welcome the opportunity to have a discussion on a new EU health strategy and future cooperation.

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