

## **EPF<sup>1</sup> Breakfast meeting**

**European Health Forum Gastein, 4 October 2013**

### ***Meeting report***

**Tamsin Rose**, in her role as chair, welcomed participants and stated that, as a result of the dramatic impact of austerity on health systems, patients experience negative changes in their health systems. Patients are increasingly expected to better manage their own conditions, while on the other hand they expect health systems to be more patient-friendly. This means that the paradigm of health systems urgently needs to be changed. This meeting aimed to explore what that means in reality, for patients as well as other health stakeholders.

Key note speaker **Sylvain Giraud (European Commission, DG SANCO)** provided a brief overview of the background and content of the Commission's recent Staff Working Document 'Investing in Health', which is part of the broader policy framework outlined by the Social Investment Package. This brings together several health activities and setting them in the wider context of EU policies. While the principles of the EU health Strategy, adopted in 2007, are still valid, the Staff Working Document outlines an approach to consolidate these principles. Mr. Giraud underlined that health is a value in itself and highlighted three main aspects of the Staff Working Document:

The first relates to the fact that the title of the Staff Working Document not only refers to financial investment in health; rather, it underlines the need to engage in and commit to health. There is the dual aim to achieve efficiency gains in health on the one hand side while striving to have high quality and accessible health care on the other. If 15% of national budgets are dedicated to health spending, it makes sense to look at issues relating to efficiency. Health policy makers should strive to develop methodological tools to ensure that health systems function well and that they are accessible. While the EU's competence in the area of health is limited, Member States are ready to discuss these sensitivities and work together.

The second focuses on the idea that investing in health constitutes an investment in human capital as good health contributes to economic prosperity; healthy people are productive members of society. Policy action should therefore also focus on prevention and health promotion. Education plays an important role in ensuring healthy lifestyle choices; health literacy can support greater responsibility and participation. Clearly, the role of stakeholders – mainly consumers and patients – is crucial in this respect. As regards the concept of patient empowerment, it is not always clear what is intended. This is why the Commission would like to look into what is happening in this context at Member State level.

The third relates to the need to engage in addressing health inequalities and the contribution of health to social cohesion. It is clear that many EU citizens cannot access our health systems. The reasons for this are complex as many different aspects – e.g. housing education - have an impact. This is why the 'health in all policies' approach is highly relevant: it is the only way to tackle inequalities appropriately.

These three aspects are complementary.

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<sup>1</sup> in cooperation with Sanofi

## **Panel response**

The first speaker, **Nicola Bedlington (EPF)** welcomed the Social Investment Package and Staff Working Document. In relation to fostering sustainable health systems Nicola underlined the importance of meaningful patient involvement; EPF's Value+ model provides some useful guiding principles in this respect. Investing in human capital is linked to patient empowerment agenda: the patient should not be viewed as 'just' the problem but rather as an obvious part of the solution. Nicola also welcomed the Staff Working Document's references to taking action on health inequalities, as access to and equity in health remains a huge issue for many patients across the EU.

EPF also welcomes the Commission's planned mapping exercise of the many initiatives ongoing in the area of patient empowerment. EPF works to inject this concept in all relevant Commission health initiatives (e.g. Joint Actions on chronic diseases and patient safety) and all its other activities.

Furthermore, EPF has a strong focus on national level capacity building of patient organisations, and engaging these organisations at EU level. As far as inequality and social cohesion is concerned, it would be useful to create an explicit link between the work carried out in relation to health inequalities and the work on social cohesion and non-discrimination. This should be done in cooperation with other stakeholders, possibly by launching a cross-healthcare community partnership on access and equity. Nicola concluded by stating that the Structural and Investment Funds have proved to be important, also for buttressing health infrastructure in individual Member States such as Romania. However, patients have to be able to benefit from these Funds as well as only sustainable resourcing of patient organisations will make them as inclusive and effective as possible.

The second speaker **Rebecca Mueller (GAMIAN-Europe)** provided the perspective of mental health patients on the Staff Working Document. She particularly welcomed the explicit references to the concept of patient empowerment, which is increasingly being used by health professionals as well. To GAMIAN-Europe, the concept relates to putting patients at the heart of the health care process. As everybody is a potential patient, investment in health is important; and the current crisis is making itself felt more and more in terms of its impact on mental health. While GAMIAN-Europe welcomes the positive notions contained in the Document, the organization regrets the lack of specific references to mental health. As there is no health without mental health this is an important omission. Policy efforts are still needed to provide good information on and increase awareness of mental health and fight the attached stigma. Better informing and involving all people – not just health stakeholders - would prevent health problems as well as create more openness about mental illness. Health inequalities remain very prominent in the field of mental health.

Rebecca also informed the audience of a recent GAMIAN-Europe survey on mental health in the workplace. This revealed that, despite common perception, the willingness of mental health patients to work is strong; they want to be healthy and part of society. Patients want to recover and resume a 'normal' place in society. When a person is affected by a mental illness, many societal roles are lost. Getting back into a normal situation is a hard and long process for many patients and policy measures should take this into account. Empowering patients and asking what they really need is important in this respect.

The third speaker, **Katrin Fjelstedt (CPME)** stated that, as a doctor, her main interest has been the doctor-patient (or patient-doctor) relationship throughout her career. Welcoming the Staff Working Document, she underlined the need for any good health service to have a solid foundation in order to function effectively. GP's are part of this solid foundation, providing accessible and affordable primary care services.

According to Katrin, patient empowerment and health literacy all hang together with addressing social inclusion, unemployment and poverty; health cannot be separated from other crucial societal aspects. All stakeholders have a role to play in this complex situation and patients and doctors are natural strong allies. In this respect, Katrin underlined the importance for her organization to work with EPF; both organisations can contribute to EU policy debates in a non-conflicting manner and enhance each other's activities and points of view. Katrin made a strong plea for the need to reinforce the patient-doctor relationship on the one hand side while strengthening links with policy makers and other medical and health stakeholders on the other.

Speaking next, **Marianne Olsson (EHMA)** underlined that the consumer approach and the patient empowerment approach are often confused: patient choice will not by itself deliver patient empowerment. A paradigm shift is happening and this will profoundly change the way health care is being delivered. This shift is being driven by many factors, but it is clear that the challenges of the future cannot be met without patient knowledge; people inside the system rarely have the capacity and right knowledge to be truly innovative. Therefore, patients are needed to deliver this innovation. Europeans of today are not prepared to accept the traditional paternalistic approach and there is a demand for partnership at all levels between health professionals, health managers, policy makers and patients. While the messages from Brussels are very positive, they often miss a link with the micro (and often the mesa) level. If these ideas are to become a reality, a link between policymaking and practice is needed. Policy should be put into practice and practice into policy. The focus should be on developing an understanding of this link. Working with patients is important in this respect. This is why funding for patients -transparent funding- is crucial. If patients are required to act as partners we need to ensure that they can speak for the patients. Partnerships are not yet evident in health systems, so systems need to be changed. Ways to integrate patients into steering mechanisms of health systems need to be found, as patients are currently better represented in 'Brussels' than at the clinic.

The next speaker, **Karin Kadenbach MEP**, advocated the need to integrate the patient agenda into the policy agenda. How to make patient empowerment a reality is the crucial challenge. The European parliament needs to be involved in this work and the notion of health in all policies can make a change. Karin welcomed the recently launched EPF European Election Manifesto<sup>2</sup> as a good example of how patients can involve and engage with policy makers. The Manifesto will help assess what the candidate MEPs truly stand for and their true commitment and dedication to the issue of patient involvement and empowerment. MEPs can amend Commission proposals and welcome input from the outside as outside expertise is often needed. However, it is important to bear in mind that the momentum needs to be kept at national level: the EU-level can only set broad policy frameworks. The Staff Working Document is a positive paper but it will be difficult to implement its ideas in times of austerity. Budgets are being consolidated across the EU; as part of the European Semester there will be many recommendations that could influence social and health budgets. We will need to keep a close look on where the impact of these recommendations will be.

The final speaker, **Milena Richter (Sanofi)** welcomed the fact that patient groups are increasingly looking beyond their specific disease areas and are addressing the broader policy framework, e.g. prevention, health promotion, impact of austerity, health systems reform and many other issues. The patient voice is essential in these discussions.

Milena also welcomed the EPF Election Manifesto; she underlined that patients are at the centre of health care delivery. Therefore, they are the best judges as to what health care services and delivery

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<sup>2</sup> <http://www.eu-patient.eu/whatwedo/EPFCampaign2014Elections/>

mean in their daily lives and what their requirements are. Stakeholders all need to be brought together to debate the current issues in health care. Therefore, Milena welcomed the recent trend towards the formation of well-governed multi stakeholder platforms that can help progress the health policy dialogue. Such platforms allow for mutual dialogue and can focus on and assess values in innovation as well as foster economies of scale. It goes without saying that the voice of patients is crucial within such fora. Milena provided three more examples of multi-stakeholder models, in line with the main focus areas of patient groups: The recently launched network of national HTA authorities provides for stakeholder representatives to take part in its meetings. The European Innovation Partnership on Active and Healthy Ageing (within which one work stream seeks to address adherence and compliance), the European Patient Academy for Therapeutic Innovation (as part of the IMI) which seeks to educate patient about medical R&D in order to facilitate their involvement in these debates. The patient's voice should be heard in systematic way and the EU can lead by example.

### **Audience debate**

In the audience debate that followed the issues below were raised:

*Leadership:* it was remarked that, while all panelists seem willing to progress matters and ensure greater patients empowerment, they all seem to be fighting their little corners; there seems a lack of connection between them all. Leadership is needed to make this happen.

*The need to fund patient groups:*

This idea resonated well with the audience; it cannot be the case that patient groups are expected to work and contribute to policy development and not be funded.

*Positive side of patient involvement:* it was remarked that it is far more gratifying and fulfilling for doctors to involve patients and work in partnership. Involvement of patients helps doctors as well, for instance in terms of their patients' compliance to treatment.

*Patient involvement with policy involvement:* It would be useful for patients to be involved with the actual implementation of the policies that they are advocating. This will help them take responsibility and will create an even stronger engagement.

*National level/EU level:* Patients are very well represented in Brussels; the EU level seems to be much more open to engage with patient groups than the national level. In many cases, national level patient groups are only heard when policy makers see the need, for instance, when a medical guideline needs to be changed. There are no rights or requirements to consult at the national level; this means that the power of patient groups at national level could be far greater.

*Online posting of patient experience:* there are projects where patients can directly post their health care experience to their providers. This can be quite illuminating.

*Patients part of the system or not:* Questions were raised as to what extent patients should become part of the system, or be educated to become an instrument in health systems.

### **Panel Responses**

Responding the questions the panel made the following comments:

- The ‘leadership’ concept is used on many occasions but its meaning is not always clear. In order to get to the desired innovation in the paradigm underpinning health systems, people outside the systems are needed. Educate patients to become part of the systems is not desirable as their real stories are needed. Health systems should be open to other players - that is the kind of leadership required. ‘Leadership’ as a term conjures up paternalistic notions, whereas all players should be on an equal footing.
- It was remarked that it is not always easy to discern which group is representing who or what and where their messages emanate from. In addition, there are many competing patient groups. This is not easy for politicians. Creating more homogenous organisations would be helpful – EPF is a good example.
- There are huge differences between Member States with respect to the level of organisation, funding and support of patient groups. Policy makers should be more aware of the contribution of these proactive patients who basically help themselves; it is not always easy to speak with one voice. National groups struggle and this should be recognised and addressed; patient groups should be enabled to engage as they play a massive role in self-care which is low cost and beneficial.
- A sound framework for funding is essential and transparency is clearly very important as well. Being a patient group at this time is extremely challenging as not only do these groups have to navigate their own disease areas and seek to improve that; they also need to deal with all the changes in the health systems as well as with changes imposed by the EU that impact on health budgets.
- Clearly, the EU cannot regulate the dialogue between patients and doctors. However, the current EU activities -such as the various Joint Actions and health programme- can hopefully lead to the development of tools and instruments that can be implemented to foster this dialogue. Other useful initiatives are the EU research programme (Horizon 2020), the Directive on cross border patients’ rights, the pharmaceutical legislation and the clinical trials regulation.

In her closing statement, **Nicola Bedlington (EPF)** underlined the membership focus of the EPF. Strict membership criteria are in place and transparency is a key operational concept. EPF concentrates on the input of its members into the EU level policy debate. The EPF election Manifesto constitutes a powerful advocacy as well as engagement tool in this respect