europeanpatients'forum

VALUE+ EPF
Autumn Regional Advocacy Seminar for Patient Leaders

The politics of health policy making at EU level and meaningful patient involvement through VALUE+

SEMINAR REPORT

Vilnius, Lithuania
November 27-28 2008

The seminar was made possible thanks to an unrestricted grant from EFPIA.

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Introduction

On 27-28 November 2008 the European Patients' Forum (EPF) held its annual autumn advocacy seminar for patients' leaders. The seminar was linked to the project VALUE+, a project on patient involvement co-funded by the European Commission and that EPF is coordinating.

It was the first time that EPF organised an event at regional level. Evaluations of previous seminars held had highlighted the need to hold such seminars on a regional basis to enable a broader section of the patients' community to benefit. For this reason, the delegates invited represented patients' organisations mainly from Lithuania, Estonia, Poland, the Czech Republic and Latvia. Approximately 50 patient leaders attended the event.

The purpose of the seminar was to build knowledge and know-how on working at European Union level through and with EPF and explore initial findings from the VALUE+ project.

The first part of the seminar was dedicated to an introduction to EU policy-making and decision-making processes. The perspectives offered a comprehensive overview since the speakers came from the European Parliament, different bodies of the European Community, the patient community and the Czech Republic Government. The audience appreciated both the political and the practical and concrete insights the speakers brought from their experience and expertise.

The other main focus was VALUE+, which was introduced to the delegates. VALUE+ is conducting an assessment of patient involvement in health-related projects supported by the European Commission. The findings to date were shared.

In this report we record the seminar conclusions and recommendations and we make a summary of the presentations and of the workshop sessions.

Summary of Presentations

Welcome speeches

- *Ms Vida Agustiniene, Council of Representatives of Patients' Organisations of Lithuania*
- *Mr. Gintaras Vilda, Health Policy Center of Lithuania*
- *Mr. Rainald Von Gizycki, Board Member, European Patients' Forum*

Key points:

- Emphasis on the opportunities offered by the seminar: gaining new knowledge; sharing experiences; networking;
- Need for all participants to share experiences and contributions in order to succeed in formulating concrete recommendations to the European Union institutions and bring forward a patient-cantered approach in health-care policies;
- Benefits of working with and through EPF in the European health advocacy arena and in the context of the project VALUE+.

Presentation of EPF –
Ms Nicola Bedlington, European Patients' Forum

Key points:

- Membership: EPF is an umbrella organisation of currently 36 disease-specific European patients' organisations and national platforms;
- Vision and Mission: High quality, patient-centred, equitable health care in Europe;
- EPF Strategic Plan for five years and EPF key strategic goals: equal access for patients, patient involvement, patients' perspective, sustainable patient organisations and patient unity;
- Specific objectives for 2009: build capacity of EPF, strengthen EPF's policy impact and put patients at the centre of policies that concern them, build the patients' evidence base, extend membership, build powerful communications and partnerships, diversify the funding base;
- The EPF Manifesto – 150 Million reasons to Act: it was launched in September at the European Parliament;
- EPF strength consists in its members' expertise, experience and solidarity, in its unique patients' perspective and its commitment to partnership.

The role of the European Commission – Mr Kestutis Sadauskas, Representative from the European Commission office in Lithuania

Key points:

- Importance of the dialogue between the European Commission and EU citizens and the role of the Commission country office to be "the ears on the ground";
- According to Art 152 of the EC Treaty, Member States have the main responsibility for health policy and provision of healthcare - the EC role is not to duplicate their work, but to encourage them to cooperate efficiently and exchange information and best practices;
- EU citizens can exercise their rights to provide input to the Commission through responses to green papers, communications, public consultations;
- Final key message: the EU does care; EU institutions do listen and need the support from citizens.

The role of the European Parliament – Ms Jolanta Dickute, Lithuanian Member of European Parliament

Key points:

- The European Parliament is the only directly-elected body of the European Union and its work is important because in many policy areas, decisions on new European laws are made jointly by the Parliament and the Council of Ministers;

- The EP has the right to submit initiatives, written questions, written declarations and the political groupings are playing a key role;
- Concerning the way patients organisations can interact with Members of the EP, the key advice is to start from the very beginning of the legislative process, to understand it and to make timely interventions. Look carefully at MEPs CVs and identify those who may be interested in certain topics;
- When proposing amendments to a piece of legislation it is important to submit clear information based on evidence and to offer transparent and concise messages. Professionalism and persistence are key factors of success;
- For MEPs it is easier to maintain contacts with umbrella organisations that represent a multitude of organisations and have a single interlocutor in a specific area.

The role of the Council and the health priorities under the Czech Presidency –

Ms Lenka Ticha, Health Attaché from the Czech Republic

Key points:

- The Council of Ministers or Council is the EU main decision-making body, representing 27 Member States and meeting in 9 configurations. The configuration dealing with health is "Employment, Social Policy, Health and Consumer Affairs (EPSCO)";

- Decision-making procedure related to public health and medicines: acts adopted by „codecision“ procedure; two readings plus conciliation; qualified majority needed; subsidiarity of Member States in the area of health;
- Role of the rotating EU presidencies: a presidency lasts for six months but there is a programme for 18 months that is prepared with the previous and future presidencies; therefore there is close collaboration and the programming phase is started well ahead than the actual start of a specific presidency;
- The priorities for health of the future EU presidency of the Czech Republic are: eHealth for individuals, society and economy, microbial threat to patient safety in Europe and financial sustainability of health systems;
- With regard to patients' organisations' involvement in setting the EU presidencies' priorities, NGOs need to start contacting the health ministries and national governments at a very early stage, about two years before the EU presidency;
- Permanent representations can help, but people in charge there are diplomats and not experts on specific topics.

The role of patients' organisations – *Mr Thomasz Szelagowski, Federation of Polish Patients*

Key points:

- Introduction of the FPP and its goals: integration of patients' organisations, patient empowerment and advocacy, development of patient knowledge and their social awareness;
- FPP's main achievements in two years of existence: mainly a Treaty for integration of patients' organisations in Poland into a network;
- Example of a powerful patient input into national policy: through FPP work the government initiated a White Summit on the health system reform where FPP advocated for a patient-centered healthcare system reform, patient safety compliance and a patient' ombudsman;
- Future FPP plans: continue representing the patients' voice in the Polish Health Council, strengthen the work on health literacy, empowerment of and cooperation with local patients' organisation, extend the relations with media.

- Regarding action at EU level, being members of EPF is extremely beneficial and offered opportunities to make contacts and learn and to contribute to joint policy making;
- Patients' organisations should approach governments as an equal and constructive partner and be much more pro-active rather than only reactive.

Overview of evolving of patient involvement in EU policies and actions - the European Health Strategy and Europe for Patients –

Ms Antonie Egeland, European Commission Directorate General for Health and Consumers

Key points:

- The framework for the EU health policies is mainly represented by the Treaty of Amsterdam and the article 152;
- Overview of the role of the European Commission in relation to health;
- Main initiatives done at the EU level related to improving healthcare for all in Europe:
    - Directive on the application of patients' rights in the cross-border healthcare;
    - Commission Communication and Council Recommendation on a European action in the field of rare diseases;
    - Green paper on the European Workforce for Health;
    - Recommendation on patient safety including the prevention and control of healthcare associated infections;
    - Proposal for a directive setting standards of quality and safety of human organs intended for transplantation and others;
- The EC recently launched a "Europe for patients" campaign;
- DG SANCO is open to involve stakeholders; an example is the positive cooperation with EPF for the launch of the campaign as well as for the preparation of the patient safety package.

The health policy landscape from the perspective of patients –
Ms Roxana Radulescu, European Patients' Forum

Key points:

- EPF's work in monitoring and analysing EU policies relevant for patients, alerting patients' organisations about new EU policy developments, providing a strong patients' voice and promoting patients' organisations' views, in accordance with EPF vision of high quality, patient-centred and equitable healthcare in Europe;
- EPF specific policy input on the EU Legislation package on information to patients, pharmacovigilance and counterfeiting, on the Council Recommendation on Patient Safety & Health Care Associated infections, as well as on the proposal for a Directive on patients' rights in cross-border care and the recent EU Communication on telemedicine;
- Constructive work with the European Parliament for the adoption of a Written Declaration on Health Literacy calling for wider distribution of quality health information to patients, further training for health professionals to communicate better with patients and a meaningful patients' involvement in health related policies.

"Promoting patients' involvement in EU supported health-related projects – VALUE+" –
Ms Liuska Sanna, European Patients' Forum

Key points:

- The project is funded by the Public Health Programme for a duration of two years and is coordinated by EPF;
- Purpose of project: To exchange information, experiences and good practices among key stakeholders in relation to the meaningful involvement of patients' organisations in EU supported health projects at EU and national level;
- The focus of the project is to assess patients' involvement in EU supported health-related projects to identify barriers and success factors;
- The project aims at developing tools to help different stakeholders realize meaningful patient involvement.

The role of the Executive Agency for Health and Consumers – Representative from EAHC (replaced by Ms Liuska Sanna, EPF)

Key points:

- Within the mandate of the EAHC there is the implementation of the two Public Health Programmes (2003-2008 & 2008-2013);
- The objectives of the current Health Programme are:
  - Improve citizens' health security;
  - Promote health – including the reduction of health inequalities;
  - Generate and disseminate health information and knowledge;
- The Call 2009 will be launched in February with deadline for proposals in May;
- The Call will co-finance different types of actions: projects, operating grants for European NGOs, conferences, joint actions by Member States.

VALUE+ preliminary findings –
Ms Liuska Sanna, European Patients' Forum

Key points:

Focus: assessment of level of patient involvement in health projects supported by the EU in the period 1998-2008;

- Sources of information: literature review, questionnaires, focus group with patients and patients' representatives;
- Main findings of literature review:
  - Three main levels of involvement identified
  - Barriers to patient involvement: lack of legislation and policies; poor commitment; lack of mechanisms and tools; scarce resources; communication;
- Main findings of questionnaires sent to projects' representatives:
  - Patients/patients' organisations involved in most projects; low to medium degree of involvement in development and management of the project;
  - Patients/patients' organisations are mainly invited to projects for their expertise and to get better results;
  - Barriers to involvement: resources; attitudes; communication;
- Main findings of focus group:
  - Barriers to involvement: stigma and attitudes; resources; communication;
  - Recommendations: provide resources and training; acknowledge patients as experts and equal partners; make patient involvement an eligibility criterion for project funding.

Summary of Workshop Sessions

WORKSHOP 1: How to get involved in a consultation process at EU level:

Moderator: Ms Roxana Radulescu, European Patients' Forum
Rapporteur: Mr Gintaras Vilda, Health Policy Center of Lithuania

There can be different mechanisms and approaches to be involved in consultations at EU level. The workshop explored some of these from the perspective of patients' organisations with a focus on challenges, good practices and impact.

Key points:

- There is little direct involvement of patients' organisations in Commission consultations. A higher degree of involvement is achieved by working through European organisations including EPF;
- Here is some experience in working with MEPs, but it is not enough;
- Patients' organisations have lot of experience in working at national level with Ministries and National Parliaments.

Recommendations:

- Patients' organisations need training in different areas: leadership, management, lobbying, working with media, negotiation skills, etc.
- Being a member in a European organisation is good for continuity of work;
- It is important to set up partnerships with the Ministries;
- Building relationships with members of the National Parliaments can help influence Ministries;
- Cooperation with health professionals is beneficial to integrate a patient perspective.

WORKSHOP 2: Patients' organisations as partners in policy-making:

Moderator: Ms Kaisa Immonen-Charalambous - Thalassemia International Federation
Rapporteur: Ms Anne Veskimeister - Estonian Patient Advocacy Association

What are the premises, basis, elements patients organisations need to have to be credible partners to the government? And vice versa what are the premises, mechanisms, approaches governments need to have/put in place to allow patients' organisations to be active interlocutors and to be properly consulted? The workshops addressed challenges and good practices as well as the type of support patients' organisations need.

Key points:

- Lack of understanding or recognition by governments of the value and importance of patient involvement;
- Lack of resources for patients' organisations – human, financial;
- Need for an independent and professional representation of patients at national level.

Recommendations:

- Creation of national bodies representing all patients' interests;
- There should be a code of ethics linked to mechanisms for funding in order to stress the independence and transparency of how patients' organisations operate;
- Evidence of the benefits of patient involvement (e.g. study) and sharing good practices;
- The European Commission should issue a recommendation on involvement of patients in health policy-making.

WORKSHOP 3: Information to patients – how to apply at national level the deliverables of the European Pharmaceutical Forum

Moderator: Ms Nicola Bedlington - The European Patients' Forum

Rapporteur: Ms Liene Sulce - Patients' Ombud Office of Latvia

The European Commission Pharmaceutical Forum has concluded its three-year process and, on 2 October, put forward several recommendations addressing the many challenges facing the pharmaceutical industry, public health interests and national healthcare systems.

The Pharmaceutical Forum's initial mandate, set out in 2005, was "to discuss the competitiveness of the European pharmaceutical industry and related public health considerations, with a specific focus on information to patients on disease and treatment options, relative effectiveness assessments and pricing and reimbursement of medicinal products". The process resulted into a series of recommendations to member states, industry and other relevant stakeholders and specific tools and instruments in the three areas. The workshop looked into ways and opportunities on how to apply at national level the deliverables of this Forum.

Key points:

- Information is a central instrument/tool for patients;
- Information is the right communication at the right time.

- The concept of health literacy is crucial;
- Importance of the quality, reliability, accessibility of information;
- Importance of resources and of the cooperation between all health care actors and patients' representatives;
- The national governmental involvement and support is fundamental.

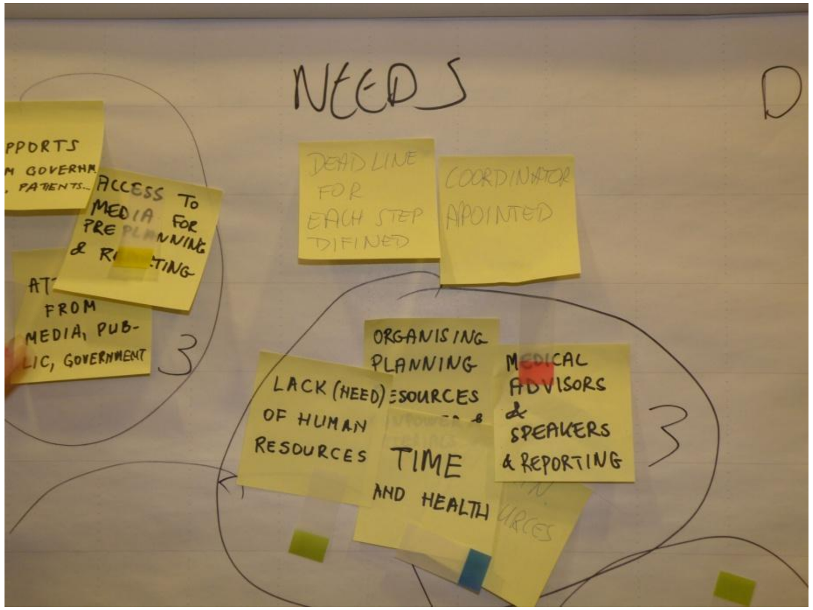
Recommendations:

- Patients' organisations should choose the most appropriate quality principles, ideas and recommendations for improving information to patients – prioritise them and point them out at national level;
- Use of best practices (international, cross-border) should be made;
- Use the political commitment existing at national level and the political momentum created by the Pharmaceutical Forum.

WORKSHOP 4: Assessing the needs for patient involvement and best practices:

Moderator: Mr Rainald Von Gizycki - European Patients' Forum
Rapporteur: Ms Kim Wever – Dutch Genetic Alliance

The workshop looked into what patients and patients' organisations need to be meaningfully involved in health-related projects and policies. The concept of "meaningful" was explored and good practices discussed.



Key points:

- Patients' organisations want to be involved in all aspects of projects: problem finding, planning, management, getting results, disseminating results etc.

- Needs of patients' organisations to be meaningfully involved (prioritized):
    - Training and acquiring the right skills;
    - Financial and human resources;
    - Teamwork and networking.

Recommendations:

- Training should be provided:
    - Taking into account the needs of patients' organisations;
    - Training related to a concrete project on all aspects;
    - Training should be provided by the right trainer;
- Teamwork should be stimulated:
    - By acknowledging patient as equal partners;
    - By making patient involvement obligatory in all health related issues in the EU;
- Make one central point for information on funding in Europe;
- Change the rules of project funding to pre-financing instead of post financing.

WORKSHOP 5: Patient involvement in projects: how project outcomes feed into policy development and advocacy – the EUNetPaS project:

Moderator: Mr Juozas Galdikas – State Health Care Accreditation Agency of Lithuania
Rapporteur: Ms Roxana Radulescu, European Patients' Forum

The expected outcome of many projects is to feed into advocacy and policy development. This workshop looked into how it is possible to do it in practice starting from the project concept and design through to the implementation phase and making best use of the projects outcomes and deliverables.

Key points:

- EUNETPAS project – European Network Union for Patient Safety – all Members states, health professionals, stakeholders;
- The Commission's forthcoming Recommendation on Patient Safety and the EUNETPAS project are an opportunity also at national level;
- Lithuanian experience:
  - Started setting up a Lithuanian Network on Patient Safety;
  - The fact that there is a new minister is an opportunity to push for patient safety;
  - Need to revise the law: move from a Court system to a more open culture on patient safety – claims resolved by administrative procedure.

Recommendations:

- Focus advocacy and lobbying activities around the evidence collected through projects;
- Organise conferences and information days on the project outcomes;
- Seek for partnerships with other patients' organisations to have a stronger voice;
- Promote the use and development of eHealth solutions to improve communication and avoid medical errors;
- Lobby for using Structural Funds for patient safety actions;
- Lobby for use of Public Health Funds – for patients' organisations specifically and for less complicated application procedures.

WORKSHOP 6: The role of patients' organisations in European campaigns – EPF Patient Manifesto:

Moderator: Ms Nicola Bedlington, European Patients' Forum

Rapporteur: Ms Zuzana Candigliota – League of Human Rights Czech Republic

How can patients' organisations participate in campaigns at European level? A concrete case was presented through EPF Patient Manifesto.

Key points:

- Possible actions for an EPF manifesto campaign at national level: translations of manifesto; use of banners on websites; integrate the manifesto in other campaigns; recruit a celebrity and hold targeted media events;
- European Rights Day – possible themes to promote: EPF Manifesto; information to patients; health literacy; access to and affordability of medicines; gender and health equality.

Recommendations:

- Actions recommended to EPF for providing support:
  - Coordination: campaign updates, newsletter, letter templates, press release templates ;
  - Cooperate with the Baltic “network” coordinated by Lithuania;
  - Provide resources for translation into each of the languages and a “format” for the design of the manifesto brochure;
  - Attend campaign events and high level meetings with member organisations;
  - Communicate directly with Ministries as EPF, in close collaboration with national patient organisations.

Overall Conclusions

The seminar had a number of successful outcomes that can be summarized as follows:

- The seminar was a valuable experience for individual participants who will relay their knowledge to fellow patient leaders at national level;
- It lead to further networking among and between patient organisations in the region;
- It was very valuable for EPF in order to enhance EPF's relationship with national umbrella patient platforms and coalitions in the region and encourage further cooperation and possible membership;
- It helped to raise awareness about the project VALUE+, as a precursor to dissemination of the deliverables in the region, and provided a platform to examine outcomes of the project to date with grass- roots patients' representatives and harness their views and recommendations.

It is envisaged that a similar event will take place in Sofia, Bulgaria in late summer 2009 that will convene representatives from the South East part of the European Union and Applicant Members.

About the European Patients’ Forum

The European Patients’ Forum:

- Was set up in 2003 to become the strong and united collective patients' voice at European level and to put patients at the centre of EU healthcare policy and programmes;
- Adopts a holistic interpretation of healthcare, to include prevention, and the social, economic, environmental, cultural and psychological aspects of health;
- Has both a proactive and reactive role by acting as a catalyst and consultative partner for positive change in EU healthcare systems and as a “watchdog”, closely monitoring EU policy and legislative initiatives;
- Is a credible and professional partner for cooperation, dialogue and negotiation with a broad range of EU level health stakeholders;
- Facilitates exchange of good practice and challenging of bad practice on patients' rights, equitable access to treatment and care, and health-related quality of life between patient organisations at European level and at Member State level;
- Offers a resource for member organisations on EU healthcare intelligence, information dissemination, baseline patient-rights policy responses to the EU Institutions to enable them to focus on disease specific responses;
- Is open to European patient organisations and national umbrella organisations that fulfill criteria relating to legitimacy, representation, democracy, accountability and transparency.

EPF has currently 27 member organisations.

Our **vision** is to establish patient-centred, equitable healthcare throughout the European Union. In order to achieve this, EPF demonstrates the solidarity, power and unity needed for an effective EU patients' movement.

Our **core values** emphasise a patient-centred approach to healthcare, inclusiveness, non-discrimination, patient empowerment, consultation and independency and transparency.

For more information on the European Patients' Forum: www.eu-patient.eu