

EPF Regional Advocacy Seminar 2016

6-7 June, The Hague, the Netherlands

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1. About EPF

The European Patients' Forum (EPF) is an umbrella organisation that works with patients' groups in public health and health advocacy across Europe. Our 67 members represent specific chronic disease groups at EU level or are national coalitions of patients.

Our vision is that all patients with chronic and/or lifelong conditions in the EU have access to high quality, patient-centred equitable health and social care.

Our mission is to ensure that the patients' community drives policies and programmes that affect patients' lives to bring changes empowering them to be equal citizens in the EU.

EPF helps to empower patients' organisations through educational seminars, policy initiatives and projects. We coordinate best practice exchanges between patients' organisations at European and national levels. Our programmes also help to strengthen their organisational and advocacy capacity.

2. Introduction

2.1 BACKGROUND ON THE EPF REGIONAL ADVOCACY SEMINAR

Organising annual EPF Regional Advocacy Seminars is the approach EPF is pursuing to engage and work with national patient organisations and their national coalitions with a view to:

- Integrating national perspectives into the European debate to have a stronger patient voice;
- Feeding policy information and policy outcomes back into national realities and contexts;
- Developing and sustaining the advocacy capacity of patient leaders.

The value of this approach has been strongly confirmed by the success of the advocacy and capacity-building seminars for patient leaders held over recent years, for example in Romania (2011), Portugal (2012), Croatia (2013) and Sweden (2015).

While the core objective of strengthening patient leaders' advocacy capacity is the key feature of EPF's advocacy seminars, these events also represent an opportunity to address specific issues which we identify in close consultation with our members.

This year's EPF Regional Advocacy Seminar was held in The Hague, in the Netherlands on 6 and 7 June 2016 under the auspices of the Dutch Presidency. Its overarching theme was "Getting the patients' message across to the national and European level".

The participants in this seminar were representatives of national patients' organisations from Belgium, Germany and the Netherlands.

2.2 GENERAL OBJECTIVES AND STRUCTURE OF THE SEMINAR

The overall objective of the EPF 8th Regional Advocacy Seminar was to look at the important role that patient organisations can play in the European decision-making process and to provide participants with tools to advocate effectively at European and national level.

The Seminar had 4 specific objectives:

- Developing knowledge of the European Union, its institutional structure and its policies in the field of health;
- Increasing knowledge and awareness of how to get involved in policy-making, transposition and implementation of key EU health-related policies;
- Training patient leaders in order to develop effective advocacy skills to influence national and European health policies;
- Building mutual understanding and cooperation among national patients' organisations.

The methodology of the Seminar was based on interaction and active involvement of participants. Indeed, the seminar aimed to build on the knowledge of participants, and to be an environment for experience-sharing and cross-fertilisation.

The Seminar took place over two days. On the first day, the key elements of European decision-making logics and processes were framed during two parallel workshops on European decision-making and advocacy. The workshops included interactive sessions and were rerun to enable all participants to attend both workshops.

On the second day, participants had the chance to 'wear the shoes' of Members of the European Parliament during a simulation game on the adoption of a real piece of European legislation.

3. Setting the Scene

3.1 INTRODUCTION

The first plenary session was chaired by Dominik Tomek, EPF Board member. Dominik welcomed the 45 participants and thanked the Dutch Presidency of the Council of the European Union for hosting the event.

Dominik Tomek presented the objectives of the seminar and encouraged the participants to be active over the two days of the seminar: indeed, with this event, the European Patients' Forum also hoped to take stock of the issues that affect the patient community in the region and help national patient organisations bring them to the European level.

Dominik invited the participants to make the most of the unique networking opportunity, and to share, discuss and exchange views with their peers from other countries.

3.2 THE DUTCH MINISTRY OF HEALTH

Brigitte Zonneveld, Deputy Director Market and Consumer spoke on behalf of the Dutch Health Ministry.

The Dutch Presidency's priorities

She gave some background on the political context, stating that health policy is not central in the new European Commission's Working programme, nor in the Dutch Presidency's programme. Still, many health issues require European cooperation. Therefore, the health agenda of the Dutch Presidency is aimed at influencing the legislative agenda in Brussels, with a particular attention for cross-border issues.



The Dutch healthcare system and cooperation with patient organisations

After having presented the Dutch healthcare system, Brigitte Zonneveld explained how the Dutch Ministry of health cooperates with and supports patient organisations.

Patient organisations are supported through a grant programme made of different strands:

- **Operating grants for disease-specific organisations** (200 disease specific organisations, with grants from 25 000 to 35 000 euros)
- **A voucher system for disease-specific organisations**, aimed at fostering cooperation between patient organisations: in order to benefit from these vouchers, patient organisations have to work together (at least 7 organisations, the vouchers are worth 18 000 euros, 1 voucher per organisation).
- **Operating grants for national umbrella organisations** (total available: 6 million euros annually)
- **Patient organization support desk**: for structures providing information, advice, training and assistance to patient organisations (total: 4 million euros annually).

Patient involvement in health-related policies

Ms Zonneveld reported how patient organisations are regularly invited to contribute health-related policies, for example,

- Developing quality guidelines in healthcare
- Providing expertise on medicines, therapies, options
- Being involved in programmes measuring quality from a patients' perspective.

The full presentation of Ms Zonneveld can be accessed here:

http://www.eu-patient.eu/globalassets/events/2016-ras/brigitte_zonneveld_getting_the_patients_message_across_june_2016.pdf

3.3 THE EUROPEAN PATIENTS' FORUM

Dominik Tomek then gave the floor to Nicola Bedlington, EPF Secretary General.

The role of patient organisations in the EU decision-making process

Nicola presented EPF's vision and mission, and its Strategic objectives for the period 2014-2020. She then focused on the role patient organisations can play in the EU decision-making process, giving a few examples of successful patient advocacy (Directive on cross-border healthcare, Directive and regulation on pharmacovigilance)

She made clear that the role of European disease-specific umbrellas differ from national coalitions: while European umbrellas (such as EPF) are in a better place to influence the initial proposal by the Commission, to meet with Members of the European Parliament (MEPs) from the different Committees as they are monitoring their activities quickly. On the other hand, national coalitions of patient organisations are best placed to approach to MEPs from their own member state, or to the Council. Finally, they have also a privileged position to monitor the implementation of the piece of legislation, and to give feedback to European umbrellas.

The case for strong patient organisations and the need for capacity-building

Nicola called for strong patient organisations as balanced views from across the spectrum of health stakeholders are needed to achieve balanced policies. The capacity for strong civil society organisations need to be built, from the local level, to the national level, to the European level.

Nicola gave an overview of the activities EPF undertakes to support its member organisations and the patient community at large:

- **EPF's Capacity-Building Programme** aims to strengthen the organisational capacities and advocacy skills of national and European level patient organisations. It is currently deployed in Hungary, Romania, Bulgaria, Poland, Cyprus and Slovakia.

- **EUPATI, the European Patient Academy on Therapeutic Innovation** is an unprecedented collaboration between patient organisations, health professionals, health tech experts, health NGOs and the pharma industry. Its objective is to build competencies and capacity among patients and public in the area of medicines' research and development.

Outstanding challenges ...



Nicola concluded that although the EU competences in health are limited, they are real opportunities for creating change at EU level for the benefit of patients. It is a fact that the EU legislation has an impact on policies in Member States. Patient organisations can play a role in the EU decision-making process, and this role is different according to the nature of the PO (EU vs. national). Dialogue and exchange of information between patient organisations are the key to complementary and successful advocacy actions.

Nicola Bedlington's full presentation is available here: http://www.eu-patient.eu/globalassets/events/2016-ras/nicola_bedlington_setting_the_scene_june_2016.pdf

3.4 THE DUTCH FEDERATION OF PATIENT ORGANISATIONS (NPCF)



Dominik Tomek introduced **Dianda Veldman, Director of the Dutch Patient Federation.**

Dianda presented the Dutch Patients' Federation (NPCF). NPCF was founded in 1993 and currently counts 35 member organisations. NPCF has three main foci:

- **Advocacy actions towards the media and decision-makers**, on topics such as shared decision-making, accessibility, affordability, quality of care, patient safety...)
- **Improving the cure and care sectors** in partnership with other stakeholders (medical professionals, hospitals, health insurance companies, and the government)
- **Changing the system with their own products** (such as Zorgkaart, which is a kind of "Tripadvisor" for the healthcare

sector). With more than 140 000 professionals listed on Zorgkaart and 325 000 reviews, Zorgkaart is now a reference for patients across the Netherlands.

Dianda Veldman gave examples of NPCF's projects in the field of patient-centred care ("My quality of Life") and shared-decision making.

Finally, she presented NPCF's work on the value of personal health records for patients.

The full presentation of Dianda Veldman is available here: http://www.european-patient.eu/globalassets/events/2016-ras/diandra_veldman_patients_federation_netherlands_june_2016.pdf

3.5 DISCUSSION

A Dutch patient representative stated that while the intentions of the Dutch government to involve patients and give them the resources to be a key player were commendable, it is still difficult to have an equal partnership.

Another participant asked whether there is a national cancer plan in the Netherlands.

Brigitte Zonneveld from the Dutch Ministry of Health replied that there is currently not a national plan but many actions including prevention, early detection, and guidelines for patients and healthcare professionals. There is also a strong link with ICT development, standardisation and collection of data.

Cees Smit, patient representative, complemented Brigitte Zonneveld's answer by stating there was a national plan 5-6 years ago.

A participant representing a Dutch patient organisation congratulated the Dutch Ministry on planning the review of guidelines by patients, and asked whether and how the implementation of these guidelines are monitored.

Dianda Veldman, Director of the Dutch Patient Federation (NPCF), said that there is currently no system in place to monitor the implementation of guidelines, and that patients should report whenever they feel the guidelines are not correctly implemented. Specifically, they should push doctors' associations, she said.

Nicola Bedlington was asked about the future of the EUPATI programme, (the European Patients' Academy on Therapeutic Innovation), and whether there would be a new training in 2017. Nicola Bedlington replied that the future of EUPATI was currently discussed, and that the focus for now was making the most of the tools available, including the [EUPATI Toolbox](#).

She also clarified the funding structure of EUPATI. EUPATI is currently funded through the Innovative Medicines Initiative, a public-private partnership.



4. Workshop: Decision-making in the European Union

This workshop was held by Sara Massini, Consultant for Start Easy Ltd and aimed at exploring the European health policy arena.

4.1 OBJECTIVES OF THE WORKSHOP

- To develop knowledge of the European Union, structures, as well as the role and priorities of the EU institutions in healthcare;
- To raise awareness about the EU decision- making process, the stakeholders, the role of NGOs and influencers;
- When and where can patient organisations act in the decision-making process?

4.2 PRINCIPLES AND VALUES OF THE EUROPEAN UNION

In a first exercise, participants were split into groups and asked to answer a multiple choice quiz on the principles of the EU and its core values.

According to the Treaties that rule the European Union, **the main objectives of the Union** are to promote peace, the Union's values and the well-being of its peoples.

These general objectives are supplemented by a list of more detailed objectives:

- an area of freedom, security and justice without internal frontiers;
- an internal market where competition is free and undistorted;
- sustainable development, based on balanced economic growth and price stability, a highly competitive social market economy, aiming at full employment and social progress, and a high level of protection and improvement of the quality of the environment;
- the promotion of scientific and technological advance;
- the combating of social exclusion and discrimination, and the promotion of social justice and protection, equality between women and men, solidarity between generations and protection of the rights of the child;
- the promotion of economic, social and territorial cohesion, and solidarity among Member States.

In addition, the Union respects cultural and linguistic diversity and ensures that Europe's cultural heritage is safeguarded and enhanced.

The fundamental principles of the Union: Article I-4 of the Constitution guarantees the free movement of persons, goods, services and capital within the Union (the famous "four freedoms") and strictly prohibits any discrimination on grounds of nationality.

More information on the objectives and principles of the European Union can be found here: http://europa.eu/scadplus/constitution/objectives_en.htm

4.3 WHO ARE THE MAIN STAKEHOLDERS IN EUROPEAN HEALTH POLICY AND WHAT ARE THEIR RESPECTIVE ROLES?

In the second exercise proposed by Sara Massini, participants were invited to review the different European institutions and their respective roles.

The European Parliament is the EU's law-making body. It is directly elected by EU voters every 5 years. The last elections were in May 2014. The Parliament has 3 main roles: legislative, supervisory, and budgetary. There are currently 751 MEPs sitting in the European Parliament. They are directly elected from the European citizens.

The European Commission is the EU's politically independent executive arm. It is alone responsible for drawing up proposals for new European legislation, and it implements the decisions of the European Parliament and the Council of the EU. The European Commission proposes new laws, manages EU policies and allocates EU funding, enforces EU law and represents the EU internationally.

The European Council brings together EU leaders to set the EU's political agenda. It represents the highest level of political cooperation between EU countries. One of the EU's 7 official institutions, the Council takes the form of (usually quarterly) summit meetings between EU leaders, chaired by a permanent president. This President is currently Donald Tusk.

The Council of the European Union gathers government ministers from each EU country. They meet to discuss, amend and adopt laws, and coordinate policies. The ministers have the authority to commit their governments to the actions agreed on in the meetings. Together with the European Parliament, the Council is the main decision-making body of the EU. Not to be confused with: (1) the European Council - quarterly summits, where EU leaders meet to set the broad direction of EU policy making; (2) the Council of Europe - not an EU body at all.

The Court of Justice interprets EU law to make sure it is applied in the same way in all EU countries, and settles legal disputes between national governments and EU institutions. It can also, in certain circumstances, be used by individuals, companies or organisations to take action against an EU institution, if they feel it has somehow infringed their rights.

As the EU's independent external auditor, **the European Court of Auditors (ECA)** looks after the interests of EU taxpayers. It does not have legal powers, but works to improve the European Commission's management of the EU budget and reports on EU finances.

More information on the EU institutions and bodies: <http://europa.eu/about-eu/institutions-bodies/>

4.4 WHAT KIND OF LEGISLATION DOES THE EU PRODUCE?

Sara explained how the aims set out in the EU treaties are achieved by several types of legal act. Some are binding, others are not. Some apply to all EU countries, others to just a few.

A regulation is a binding legislative act. It must be applied in its entirety across the EU.

A Directive is a legislative act that sets out a goal that all EU countries must achieve. However, it is up to the individual countries to devise their own laws on how to reach these goals. One example is the EU consumer rights directive, which strengthens rights for consumers across the EU, for example by eliminating hidden charges and costs on the internet, and extending the period under which consumers can withdraw from a sales contract.

A Decision is binding on those to whom it is addressed (e.g. an EU country or an individual company) and is directly applicable. For example, the Commission issued a decision on the EU participating in the work of various counter-terrorism organisations. The decision related to these organisations only.

A Recommendation is not binding. It allows the institutions to make their views known and to suggest a line of action without imposing any legal obligation on those to whom it is addressed.

An Opinion is an instrument that allows the institutions to make a statement in a non-binding fashion, in other words without imposing any legal obligation on those to whom it is addressed. An opinion is not binding. It can be issued by the main EU institutions (Commission, Council, Parliament), the Committee of the Regions and the European Economic and Social Committee.

4.5 THE ORDINARY LEGISLATIVE PROCEDURE: CO-DECISION

Sara Massini proposed to the participants to watch a video to review the European ordinary legislative procedure.

<https://www.youtube.com/watch?v=BUMyiwCMzSI>

<http://europarlament.touteleurope.eu/understanding/decision-making/print.html>

Participants were then asked to reflect on where in the policy cycle can patient advocates contribute most efficiently. During the discussion, the following proposals came out:

- Influencing the processes before the Commission's proposal, by contacting and meeting with Commission's officials, raising awareness about your cause;
- During the first and second reading, contact Members of the European Parliament (strategy by nationality or by party);
- Create coalitions with other patient groups to increase your impact;
- Contact representatives of the Council (Ministry of health or other competent ministry) and share your views;

- Generally, it is easier for national and local patient organisations to contact Members of the European Parliament from their country, while European umbrellas have an easier access to the Parliament’s Parties’ Secretariats and to the European Commission.



To conclude the workshop, Sara Massini invited the participants to take a silent walk looking at posters where the current health priorities of the European Union were displayed and to express their comments on post-it notes.

5. Workshop: Advocacy

This workshop was held by Ilaria Esposito, Consultant for Start Easy Ltd. Its objective was to reflect on the tools at their disposal to get their message across at national and European level.

5.1 OBJECTIVES OF THE WORKSHOP

- To build capacity on how to develop an influencing strategy
- To understand what advocacy is and what is not, the different approaches to influence change

- To get examples about Do’s and Don’ts of advocacy
- Advocacy strategies and the Advocacy & Campaigning cycle

5.2 WHAT IS ADVOCACY?



“Never doubt that a small group of thoughtful, committed people can change the world. Indeed, it is the only thing that ever has.” Margaret Mead

The word “advocacy” comes from the Latin ‘advocare’ and literally means “to call out for support”. Today it is used to describe a particular democratic process, where individuals or groups of people take different actions to try to influence those who make decisions that affect our lives. Advocacy is also about standing up for an issue or cause you believe in, and trying to change people’s lives to build a better world.

Advocacy = Raising awareness + Educating decision-makers + Taking actions

5.3 WHAT ADVOCACY IS NOT?

Whatever the issue, advocacy is about taking a stand and working for positive change.

Advocacy is not a single activity. Some activities may be part of your advocacy initiative, but none of them alone will be enough to influence decision-makers to introduce changes which will improve people’s lives.

These activities, for example, are not advocacy if they stand by themselves:

- Producing leaflets about your organization
- Participating in a training on advocacy
- Raising awareness and bringing about behaviour change in individuals
- Fundraising for your initiative
- Informing the government about EPF/ local national association
- Promoting your Association

Combined, these activities can become advocacy.

5.4 SIX QUICK STEPS TOWARDS ADVOCACY

To conclude the workshop, Ilaria Esposito and the participants reviewed the process of starting an advocacy action.

Step 1: Identify your key issues and asks

Find out what issues the members of your patients' group care about. They might want better facilities in the local community, to set up a local council so that patients are consulted on issues affecting them in the community, or they might want to take action to protect the environment, or help people living in poverty.

Step 2: Assess the broader context of the issue

The group researches the problem to identify how many patients might be affected and who is making the decisions on this issue.

Step 3: Decide on a project

Based on their research the group brainstorms. They identify potential solutions to the problem and define their advocacy goals.

For example, should they try to change local rules or laws or should they try and train their families or educational bodies on the issue they are concerned with?

Step 4: Create an action plan

Next, the group needs to create a detailed action plan to decide how they will achieve their goals. They should think of activities to help them reach their target audience, identify possible partners, and identify what their key message should be.

Step 5: Putting the plan into action

Next, the group needs to implement the activities identified – writing a letter to the local mayor, launching a petition, arranging a visit to the local council.

Step 6: Review progress

Remember, the group needs to keep checking if they will achieve their goals or if they need to change their plans. When the project is completed, look at what worked and what didn't. Record the lessons that can be learned for the next project.

6. Role play simulation

6.1 PREPARATION OF THE ROLE PLAY – BEFORE WE START!

On the evening of the first day, Ilaria Esposito explained the setting of the role play that was to take place the following day: the objective of the session would be to **debate and decide on the 7 key health priorities for the European Union for the coming years.**

Participants were attributed cards with roles to play during the role play. They were either:

- Members of the European Parliament (from 8 different parties),
- Representatives from patient organisations
- Representatives from the pharma industry.

The cards stating their roles also indicated their party's "line" and interests.

A document with potential health priorities was also distributed to the participants. Participants were advised to review their profiles carefully and to already make a first decision on what they thought should be the health priorities (they had to choose seven out of thirteen) according to their "role" in preparation of the role play.

6.2 THE ROLE PLAY

On the second day, participants put on the shoes of Members of the European Parliament and civil society representatives.

The session was broken up in different rounds:

Round 1 – MEPs debated and agreed on priorities in their own party. Civil society representatives also met with their peers: patient organisations' representatives decided on the most important health priorities for the patient community. Representatives from the pharmaceutical industry met together and agreed on a strategy.

Round 2 – The ENVI Committee met. One MEP from each party was sent to the ENVI Committee to exchange views with the other parties and to agree on common priorities.

Round 3 - Patient organisations representatives and representatives from the pharma industry met with the ENVI Committee to try and influence their position.

Round 4 – The ENVI Committee gave its position (priorities on which they agreed). All MEPs returned to their respective party.

Round 5 – Each party discussed again their priorities and prepared for the vote. At this stage, representatives from the pharma industry and Patient organisations representatives were able to meet with each of the political fraction and influence the vote.

Round 6 – Each party put forward their 7 priorities.

Round 7 – The Consultants Sara and Ilaria playing the European Commission announced that the priorities were to be “weighed” according to factors such as the difficulty to implement them and their cost. Each priority “cost” 1 to 3 points, and the list of 7 priorities put forward by each party could not overcome 11 points. Some parties had to revise their copy and adjust their priorities’ list to match the maximum total of 11 points.

Round 8 – Each party presented their final list of priorities and their arguments in favour or against one or the other priority.

Round 9 – VOTE! Each political party had one vote. The priorities who obtained more votes in favour than against were accepted.

6.3 FEEDBACK ON THE ROLE PLAY

After the role play, participants were asked on their impressions on the simulation. Some participants reported having had difficulties to put themselves in the shoes of a member of the Parliament with views that contrasted with their own.

Some explained the frustration of having to compromise and to prioritize their political group’s preference over their individual choice.

Participants also reported experiencing the pressure from stakeholders’ groups, including civil society and industry.

7. Conclusions

Camille Bullot, EPF Membership & Stakeholder Relations’ Manager, moderated the final session. She gathered impressions from the participants on the two-day seminar.

Participants thanked EPF for organising the seminar and made recommendations for similar events in the future:

- More practical examples of how to prepare for a meeting with an MEP;

- Introduction session (maybe one day earlier) and sharing of expectations;
- Inviting MEPs to have the opportunity to ask them questions directly.

Going back to the objectives of the seminar, Camille explained that, while there is almost no new European piece of legislation on health-related issues at the moment, there is still a need to advance on implementation, to work towards creating an enabling environment, and to prepare our demands for the next programming period.

In order to do that, umbrella organisations such as the European Patients' Forum need the support of the local and national levels. The voice of patient organisations at local and national levels is therefore very much needed in European debates.

While the stated goal of this seminar was to strengthen patient organisations' capacity to become more empowered actors in the national and European health policy arena, the interactive format of the meeting also allowed for extensive networking between patient leaders from the region.

This meeting will be evaluated by an external evaluator. The results will be incorporated into EPF's evaluation for our activities 2016.

8. List of Annexes

- List of Participants
- Agenda of the meeting
- Pre-reading material (sent to participants two weeks ahead of the meeting)



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