EPF National Coalitions' Meeting
16-17 October, Brussels, Belgium

16/01/2018

Contents

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 74 members represent specific chronic disease groups at EU level or are national coalitions of patients.

Our Vision is that all patients with chronic conditions in Europe have access to high-quality, patient-centred health and related care.
Our Mission is to be the collective influential patient voice in European health and related policies and a driving force to advance patient empowerment and equitable access to care in Europe.

1.1 EPF NATIONAL COALITIONS' MEETING BACKGROUND

National Coalitions of patient organisations play a crucial role in a national context: they are best placed to monitor, understand and react to as well as to actively influence the national health policies of their respective countries.
For EPF, they are a vital partner, providing us with expertise on country-specific situations, and spreading our messages from and to the national and regional levels.

Strengthening the capacity of National Coalitions and improving the collaboration between them and with EPF has great political added value, both for the targeted countries and EPF. Indeed, to be effective advocates at European level, we need to have a strong patient voice in each of the European Union's member states.

On 16-17 October 2017, EPF organised the first edition of the National Coalitions' Meeting to raise awareness of the National Coalition's role in advocacy at EU level and to nourish the advocacy skills of our national members and create a common and coordinated strategy on advocacy.

1.2 GENERAL OBJECTIVES AND STRUCTURE OF THE EVENT

The overall objective of EPF National Coalitions Meeting was to stimulate synergies between National Coalitions as well as EPF to advocate effectively at European and national level.

The meeting had specific objectives:

- Developing the participants' knowledge of the European Union, its institutional structure and its policies in the field of health and how to get involved in policy-making decision process;

- Raising awareness on how to get involved in practice in a European advocacy campaign;
- Building mutual understanding and cooperation among National Coalitions on a regional and European level;
- Designing a roadmap for a coordinated and common advocacy framework for EPF and National Coalitions.

Furthermore, the present conclusions and recommendations made during the meeting will be integrated into EPF policy and membership work as well as in our current and future projects.

The methodology of the event was based on interaction and active involvement of participants. Indeed, the gathering aimed at building on the knowledge of participants, and to be an occasion for experience-sharing and peer to peer learning.

On the first day, the key elements of European decision-making logics and processes were framed, and different models of National Coalitions were presented.

On the second day, participants had the chance to participate to several workshops on advocacy tools, EU advocacy campaign and effective leadership.

2. DAY 1

2.1 INTRODUCTION

The first plenary session was chaired by Costin Radu Ganescu, EPF Board member. Radu welcomed the 30 participants and set the scene. He explained that EPF opened membership to national coalitions back in 2007 – when it realised it needed to have a relay in the different countries. He stressed that National Coalitions of patient organisations play a crucial role in a national context: they are best placed to monitor, understand and react to as well as to actively influence national health policies of their respective countries. National coalitions are the ears of the patient community on the ground.

Radu Ganescu then presented the objectives of the meeting and encouraged the participants to be active over the one day and a half gathering.

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

2.2 EXPLORING THE OPPORTUNITIES FOR NATIONAL COALITIONS IN ADVOCACY AT EUROPEAN LEVEL

Camille Bullot, EPF Operations and Engagement Director, presented the opportunities for National Coalitions in Advocacy on European Level. The session presented different ways of doing advocacy and how patient organisations do fit in the EU policy cycle.

In this framework, Camille explained the EU policy cycle and the role of its main institutions: the European Commission, the European Parliament and the Council of the European Union.

National coalitions of patient organisations play a crucial role in influencing the EU legislative process:

National coalitions can influence the **EU Commission** work in several ways, by:

- Monitoring the work of the EU Commission (legislative proposals, opinions, Work Programme, Calls for proposals…);
- Responding to public consultations, highlighting the patient perspectives;
- Raising awareness on what is missing;
- Meeting with the health ministers of each country sitting in the Council of the European Union and or health attaché;

National coalitions can influence the **EU Parliament** work by:

- Sending their positions;
- Sending amendments' proposals;
- Meeting Members of the European Parliament (MEPs) to discuss. Indeed, MEPs are elected on a national level. Therefore, they are keen on hearing from civil society groups coming from their own member state;
- Organising awareness-raising activities to highlight the gaps in European legislation from a patient perspective;
- Asking MEPs to ask questions to the Commission;

National coalitions can influence the work of the **Council of the EU**:

- Monitoring what's happening in the EPSCO Council: *'Emploi, politique sociale & consommateurs'*;
- Sending position papers / Sending amendments to legislative proposals;
- Targeting both National Ministries in the respective countries and Permanent representations in Brussels (Health attachés);

- Meeting with the EU Presidencies (here you can find the calendar of the upcoming presidencies);
- Organising events in the country of the Presidency.

National coalitions and European disease-specific umbrella organisations have a different and complimentary role to play in the EU legislative process.

During the presentation Camille explained how advocacy applies to both hard law [1]and soft law[2] legislative process.

Camille also shared some tips on advocacy:

1. **Become a database expert**: a lot of the advocacy can be eased through consistent database management. Organisations need to build a database including the contact details of the people they will be targeting: Members of the European Parliament (MEPs), Commission's representatives, Council's representatives (including Attachés from the Permanent representations). This will come very handy when organisations will need to act quickly and send messages to a specific target group, but it also helps the organisation building the institutional memory, and to keep all the knowledge developed when the staff members in charge leave the organisation. A practical tip, be as specific as you can, and divide them into subgroups.

2. **"Anticipate**!" Integrate legislation timelines or input needed for various consultations in your own organisation's calendar. Monitor regularly the Commission's websites for updates, and subscribe to their newsletters and RSS Feeds.

3. **Turn your network of contacts into your informers:** check regularly with people who have similar interests whether they know about important upcoming events.

4. **Curate your legitimacy**: make sure the positions you produce are elaborated in a consultative, researched manner. The decision-makers you are trying to influence are not going to take risks and will ask you for your sources, and how many organisations or individuals are behind your statements.

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[1] Hard law refers to actual binding legal instruments and laws. Hard law gives member states actual binding responsibilities as well as rights.

[2] Soft law refers to rules that are neither strictly binding in nature nor completely lacking legal significance. In the context of international law, soft law refers to guidelines, policy declarations or codes of conduct which set standards of conduct. However, they are not directly enforceable.

5. “**Meeting is easy as a coffee”**: many NGO representatives, especially when not based in Brussels, tend to think that the people sitting in the institutions are not approachable. This is not true. Decision-makers are not experts on every topic. To feed in their own reports, and to be able to make informed decisions, they are looking for expertise and for different points of view, which your organisation can offer. Use your phone, write a simple and polite email and ask the Commission’s representative, the Member of the European Parliament (or their assistants) for a meeting. Also, meeting in person is always best to start a relationship. The decision-makers will be much more receptive to your online communications and phone calls after they have met you.

6. “**Know your stuff”**: this is very much in line with the previous points. Decision-makers don’t have time. Get ready for 20-minute meetings and learn to speak “bullet points” and unpack your positions in a short and structured way. Be concise, to the point, and send the details per email.

7. **Find allies and work together**: NGOs are great at doing this. Building partnerships is precious in advocacy. It allows you to spare resources and not to duplicate efforts. When proposing amendments to the Parliament, for example, coordinate with your allies and divide the list of MEPs to approach according to your respective affinities.

8. **Tailor your communications**: this is going to be easier if you have become a database expert. Make sure the messages you send out are fit for their recipients, and will resonate with their role and personal sensitivity.

9. **Trust your worth**: a lot of NGOs walk in meetings with decision-makers feeling like the “weaker” interlocutor in the discussion. You are not there to beg for a favour, but you are offering expertise and a perspective that the decision-maker currently doesn’t have. You’re bringing something at the table therefore trust your worth and walk in as equal partners.

Camille’s full presentation is available here.

2.3 DISCUSSION

Camille’s presentation triggered some exchanges with the members.

Robert Johnstone, (National Voices, UK) commented that the EU policy cycle is absolutely mirrored at national level. Nancy Van Hoylandt (ME, from Belgium) said that the EU level is sometimes a way to overcome inertia or barriers at national level. Birgit Dembski (BAG Sebsthilfe, Germany) agreed with this point, adding that the resources, knowledge and potential pressure from the EU level are an untapped potential.

Tunde Koltai, (BEMOSZ, Hungary) stressed that to be successful in advocacy, patient organisations at EU and national level need to understand this is a two-way, continuous conversation. Therefore, to her, the key is building good contacts at national level that understand the added value of EU advocacy and can be key interlocutors for EPF.

To move forward in developing a common and coordinated advocacy framework for EPF and National coalitions participants suggested the following actions that will be taken into account by EPF secretariat:

- Marc Paris (France Assos Santé) proposed to identify and share good practices describing concretely how some countries managed to push through some successes;
- Sofia Karlsson (Swedish Disability Rights Federation, Sweden) suggested preparing a "diary of European/EPF consultations", so that EPF national coalitions know when to provide input;
- Other participants suggested to have a tool explaining the "natural connection" between the EU and national levels in advocacy to disseminate the knowledge further.

Finally, Camille reminded the participants of existing EPF tools to interact, exchange good practices and be informed of upcoming events and consultations:

- Weekly Insiders' – EPF's members-only mailing sent every Tuesday;
- EPF CONNECT – EPF's online community dedicated to EPF members only;
- "Weekly Coffees with EPF"- EPF's one to one communication channel with it members;

2.4 NATIONAL COALITIONS: A COMMON GOAL BUT DIFFERENT MODELS - CHALLENGES AND OPPORTUNITIES

This session presented three different models of National Coalitions in three different countries: France, Sweden and Bulgaria.

2.4.1 THE FRENCH MODEL: FRANCE ASSOS SANTÉ

Marc Paris presented his organisations **France Assos Santé**.

France Assos Santé vision is "Nothing about us without us" and their mission is representing patients and health system users; the organisation is advocating for a more patient-centric healthcare system in France as well as doing capacity building activities for patients and patient organisations.

The association was created in 1996 as an informal group named Collectif Interassociatif Sur la Santé (CISS). In 2004 CISS changed its legal status into an NGO and in 2017 the CISS changed name into France Assos Santé.

France Assos Santé currently represents 72 national patient organisations. The organisation's governing bodies consist of the General Assembly that meets once a year, of a board, made of 82 representatives and of an executive board made of 10 members.

France Assos Santé is mainly supported by public funding. As a rule, France Assos Santé does not to receive money from the pharmaceutical industry.

With regards to transparency, they created an Internal ethics committee and they published a Charter of Values as well as they designed a strong transparency policy.

In Marc's opinion, such a structure comes at a cost and the organisation risks become too institutionalised. A lot of efforts has to be invested in the "inter associative work" and in stimulating constructive internal debate with all the 72 members to preserve members' involvement. On the other hand, being a big organisation brings the advantage of being more representative and a bigger player in the healthcare arena.

Marc also presented a new initiative of France Assos Santé "**Santé Info Droits"**, a free helpline that try to answer to any social / legal questions and difficulties that patient or healthcare users might face.

You can find more information on France Assos Santé website: http://www.france-assos-sante.org/

2.4.2 THE SWEDISH MODEL: THE SWEDISH DISABILITY RIGHTS FEDERATION

Sofia Karlsson presented the case of Funktionsrätt, the Swedish Disability Rights Federation.

The organisation's vision is a society for all, as it is defined in the UN Convention on the Rights of Persons with Disabilities.

The Swedish Disability Rights Federation's mission is to improve the possibilities for persons with disabilities and chronic diseases to study, work and access to good health care.

The Swedish Disability Rights Federation was founded in 1942 as an NGO, to create a united voice for the Swedish disability & patient movement in relation to the government, the parliament and national authorities.

Regarding membership, the Swedish Disability Rights Federation members consists of 41 nationwide disability associations, patient organisations, organisations for small disability groups and youth organisations. Organisations that would like to join the federation must agree with the principles and statutes of the Swedish Disability Rights Federation. Each member organisation determines its own activities but on issues on which all member organisations agree, common actions are taken.

Regarding the governance of the organisation, the Swedish Disability Rights Federation has a board of 9 people appointed by the members. To ensure the daily work of the forum the organisation as a secretariat of about 10 people.

The Swedish Disability Rights Federation has a strong advocacy role and it's represented in most of the relevant authorities in Sweden – by representatives of the federation member organisations, by board members or officials. As they are well represented in most of the relevant authorities, the Federation mainly answers to referrals instead of producing policy papers. The Federation is not only active in Sweden but also in international fora like the European Disability Forum & EPF.

With regards to funding, the Swedish Disability Rights Federation is supported by public funding.

2.4.3 THE BULGARIAN MODEL: NPO - NATIONAL PATIENTS' ORGANISATION BULGARIA

Stanimir Hasurdjiev presented the Bulgarian National Patients' Organisation (NPO). The National Patients' Organisation - Bulgaria was founded in 2010 and is currently the largest patients' umbrella organisation in the country with 80+ member organisations from across Bulgaria.

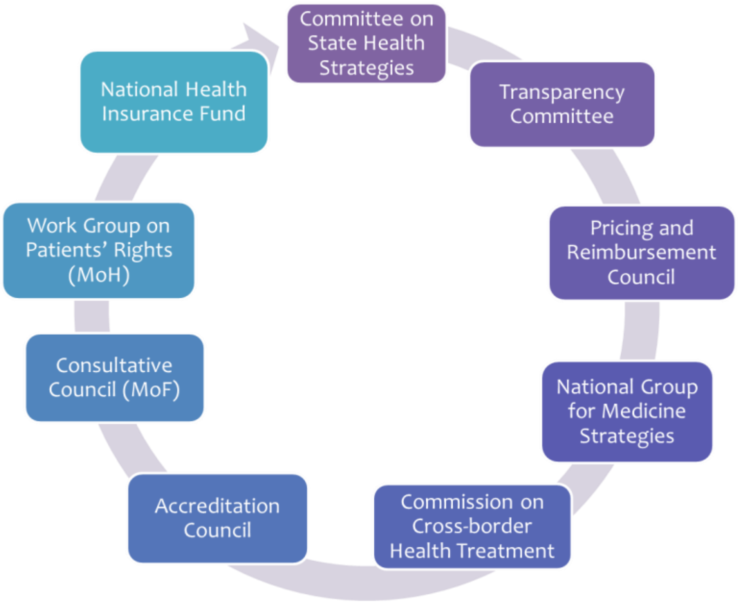
Following a decision of the Minister of Health of Bulgaria from 2010 (reconfirmed in 2011), the National Patients' Organization is now recognised as a national representative organisation for the defence of patients' rights in Bulgaria. Before the creation of NPO, the Bulgarian patient movement was not united and it took a lot of effort and time to build such a national coalition.

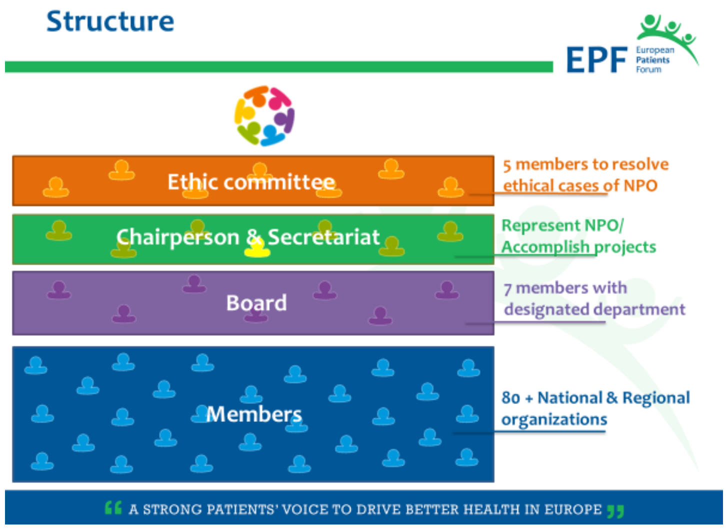
The National Patients' Organization rests on values such as understanding, democracy and high morals. In this respect, the National Patients' Organization pursues with dedication the core objectives of the EU health policy, namely ensuring citizens' empowerment, reducing inequalities in health and promoting scientific-based policy.

During the presentation Stanimir highlighted the key success factors of NPO:

- **A strong Code of ethics** (inspired by EPF code of Ethics and EFPIA Code of Practice;
- **Being a patient-centric organisation;**
- **Being a transparent organisation** making sure information related to the organisations' activities, sponsors and finances are easily available.

To ensure a high level of transparency NPO created several committees and advisory groups, you can find a summary here below:





Structure

Ethic committee – 5 members to resolve ethical cases of NPO

Chairperson & Secretariat – Represent NPO/ Accomplish projects

Board – 7 members with designated department

Members – 80 + National & Regional organizations

A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE

NPO works on several projects and activities around three key pillars:

- **Patient centred**: the patients are at the centre of all NPO's activities.
- **Patient rights**: to ensure patient rights NPO launched the Patient Satisfaction Platform and created the position of the Access Officer
- **Awareness**: NPO regularly organises screenings, Campaigns, disease-specific events and create information materials.

NPO wants to be a vibrant network and to do so organises several meetings during the year. It also provides capacity-building opportunities to its members and ensure a constant and constructive communication flow within the network thanks to the website as well as produces a monthly newsletter.

NPO also conducts advocacy activities at national and European level. The organisation created the advisory group "Partnership for Health" in 2015. This advisory group is made of patient organisations, unions of medical professionals, hospitals, caregivers, industry and governmental institutions, and is chaired by the Minister of Health. It recently became a permanent consultative body to the Council of Ministers. On the International level NPO contributes to the work of EPF and IAPO.

With regards to funding NPO receives funding mainly from the pharmaceutical industry both as core funding and projects. NPO would like to receive public funding as well but so far it has not been possible. Thanks to its transparency guidelines, NPO can ensure independence and autonomy from their funders.

NPO, as many other patient organisations, is facing several challenges, such as meeting the expectations of a growing and diverse membership base, managing the relationship with the press, delivering on a growing amount of activities while having a very small secretariat and little resources and finally diversifying their source of funding.

2.5 NETWORKING SESSION- DISCUSSION PER MODEL

During the networking session participants were divided in three groups and each group joined one of the speakers that hosted a debate around key questions linked to the model of their organisation.

Session objectives:

- peer-to-peer learning in an informal setting;
- creation of connections & ideas of cooperation between NCs;
- inspire the creation of new NCs or revision of the strategies of the existing ones;

2.5.1 HOW TO DEFINE MEMBERSHIP CRITERIA FOR A NATIONAL COALITION, HOW CAN WE ENSURE TRANSPARENCY?

The first table was chaired by Sofia Karlsson from The Swedish Disability Rights Federation and the discussion was around the question "**How to define membership criteria for a National coalition, how can we ensure transparency?**"

Main points from the discussions:

- **Membership criteria:** we see different approaches among the national coalitions present:
    - Acceptance of regional vs. national-level only members;
    - Acceptance of individual members;
    - Dealing with informal, web-based platforms: this is an unresolved question for EPF. The Dutch coalition (NPCF) has also noticed the emergence of these new stakeholders and started working on this issue, and on a definition of a "patient organisation 2.0";
    - All the organisations present seem to agree that foundations should not be accepted as members;
    - Some organisations tolerate the membership of healthcare professionals and healthcare providers. For them, this is a way to improve the communication with these stakeholders and a way to implement patients' rights effectively;
    - Review of compliance with membership criteria: not all coalitions have an effective system in place. NPCF, the Dutch coalition, has recently recruited a Membership Manager whose role it is also to review members' compliance with membership criteria.

- **Renewal of patient organisations** – overall there seems to be a disinterest for traditional patient organisations, due to their rather inflexible structure and their rigid membership criteria: most organisations require the organisations to be legally registered to become members.
  There are also sometimes misunderstandings between generations: young people, who are often advocates in their free time, would prefer not to exchange with older advocates.

- **Inclusion of disability organisations vs. patient organisations only:** some national coalitions do gather under their umbrella disability organisations (Sweden, Latvia, Finland, Estonia), while in some other countries, this is unimaginable. Birgit, from Germany, explains that her organisation focuses on what the two movements (disability, patient) have in common, rather than on what divides them. There can be common topics on which patients and people with disabilities need to advocate: access to specialised care for example. There is also a natural link between the two movements: some chronic diseases can lead to a disability.

- **Funding structure** - this is also a topic where the approaches from the different national coalitions differ: while some organisations are completely funded by public funding (Sweden), some other are funded by industry only (NPO, Bulgaria). One of the outcomes of the discussion on funding is that this is very often a pragmatic decision: in countries where the state is not willing to support patient organisations, these turn to alternative sources of funding, and very often towards sponsorship from pharmaceutical companies. Another outcome is that the funding structure very often influences the nature of the organisation: in Bulgaria, where the state provides no funding, the advocacy work of the organisation is often directed at the government, whereas in Sweden, where the state provides most of the funding for patient organisations, the way they work is more collaborative.

2.5.2 “WHAT IS THE BEST WAY TO CONSULT YOUR MEMBERS?”

The second table was chaired by Marc Paris and the question discussed was the following: “**What is the best way to consult your members?**”

The main outcomes of the discussions were the following:

- Consulting your members is not easy but it is essential for the life and legitimacy of the organisation;
- There is no magic recipe that would fit all national coalitions;
- Some organisations use mailings, other more frontal meeting or surveys.

France Assos Santé presented one of their engagement tools which is the monthly meeting: the purpose of the monthly meetings is to gather the members, brainstorm with them. Not all the members can attend each meeting but thanks to this format all the members have the possibility to exchange and contribute, also because France Assos Santé organises the meetings and covers travel expenses. For what concerns the discussions topics, these are chosen upfront by the members and participants vote to select the discussion topic of the week.

Some organisations commented that this is a brilliant way to consult and work with your members as it strengthens the community. However, not many organisations would have the financial means to organise monthly meetings.

2.5.3 "WHAT ARE THE INGREDIENTS FOR AN EFFECTIVE ADVOCACY STRATEGY AT NATIONAL LEVEL? WHO ARE THE STAKEHOLDERS THAT WE NEED TO TARGET AT NATIONAL LEVEL?"

The last table was chaired by Stanimir from NPO Bulgaria. The question posed at this table was: **"What are the ingredients for an effective advocacy strategy at national level? Who are the stakeholders that we need to target at national level?"**

At this table participants realised that there is no magic recipe and definitely not a one-size-fit all but they did agree that some key elements are essential for an effective advocacy strategy at national level:

- Define your advocacy priorities (select few);
- Anticipate the political agenda and keep a close eye on the latest political development;
- Create and update regularly your database of contacts and target your communications;
- Curate your legitimacy and transparency;
- Meet and create relationships with policy makers, potential allies and stakeholders;
- Trust your worth and act for the best of your patient community;
- Learn and study your dossiers and always present solutions when highlighting a problem.

Participants liked the possibility to discuss with peers and exchange different experiences around topics that are close to their daily work.

3. DAY 2

3.1 WORKSHOP: DEVELOPING A COMMON AND COORDINATED ADVOCACY FRAMEWORK FOR EPF AND NATIONAL COALITIONS – THE EXAMPLE OF THE EPF ACCESS CAMPAIGN

The workshop's objectives were:

- Raising awareness on how to get involved in practice in a European advocacy campaign;
- Exploring synergies between the national and EU level;
- Creating a useful and effective workflow between EPF and national coalitions;
- Understanding what constitutes a successful coordinated and common advocacy framework dialogue;
- Getting ideas and experiences from other members.

The workshop kicked-off with a presentation by Ophélie Martin from Mental Health Europe (MHE) who presented how to create an impactful communication workflow.

In her opinion advocacy is a smart mix: 50% communications, 50% of policy, what is necessary is to break down policy and communications silos, when this is done any campaign will have more impact and power.

Advocacy campaigns, she continued, are about strategy, planning, team work, objectives, and a little bit of creativity.

Budget are always an issue in the patient community but there is a lot it can be done with little or no budget. For example, the MHE Anti-stigma campaign was led with a budget of 180 euro. Ophélie presented such campaign to show first, that patient organisations could create powerful advocacy material with very limited budgets as well as translating complex messages into simpler ones.

Even if Ophélie stressed that **there is no a magic recipe for successful campaign** she believes that there are some tips that could really help in achieve some results, such as:

- Before starting a campaign, ask yourself what you want to communicate, why, and what is the purpose of our message;
- Who is our audience? Why do we need to reach this audience?
- What is your message and what can you do to make it as accessible as possible?
- Is your idea too culturally specific or is it built on a universal theme?
- Be S.M.A.R.T! (Specific, Measurable, Achievable, Relevant, Time-Framed);
- Plan again, and again;

- Use surveys to identify needs and objectives;
- Once defined, understand your audience;
- Combine channels and tactics to spread your message;
- Call for action in a straightforward way;
- Sometimes, better to focus on quality than quantity;
- Think of impact measurement and evaluation.

Ophélie illustrated her presentation with the MHE campaign Anti-stigma. In her opinion, the key success factors were the following:

- Successful fundraising;
- Translation of the campaign in 10+ European languages;
- The campaign was replicated by members at national level (Greece, Italy and soon Malta);
- The campaign had a well-defined target: the public and decision-makers;

Replicating a campaign in different countries, as MHE Europe did, it is possible if you keep in mind that:

- It is important to analyse the possible impact based on country's specificity;
- You are creative;
- Target groups may react differently to the same content in different countries;
- You need to identify what is needed in your case to replicate the campaign;
- Campaign material must be easy to translate and replicate;
- You need to have a common and clear basis, a key message and objectives;
- It is important to allow freedom for replication.

The second presentation was dedicated to identifying the key elements that need to be considered when developing a common and coordinated advocacy framework. Katie Gallagher, EPF Policy Advisor, provided a short outline of the EPF Access to Healthcare Campaign, how it was developed and executed. With the access campaign EPF tried to give its members the opportunity to engage with the campaign in their own context. Some members organised events in national Parliaments and in the European one to increase outreach and strengthen the impact of the campaign.

After the discussion participant were split into groups to brainstorm and define together dos' and don'ts for a common and effective advocacy strategy. Each group selected one rapporteur to tag their post-it on the flip charts and explain each element while placing it on the flipchart. The list below are the Do's and Don'ts. You will find the result of the discussion here below:

DO's

Methodology and Tailoring

- Make patient-friendly surveys! (possibility to pause the survey, etc.);
- Improve the information stream between EPF and its members;
- Focus on specific issues at national level when replicating;
- Members' role of gathering best practices and communicating to EPF;
- NC to approach national political representatives;
- Videos with no words (leaving NCs the possibility to record words over in their language / add subtitles in their language) (graphics are good for this);
- Ask members to put campaigns in their agendas;
- Anticipate and build synergies together – EPF and NC;
- Adaptable material, tools, templates (for example video);
- Region specific;
- Find the right media;
- Plans and goals;
- Give choice in visuals;
- Involve policy-makers and find partners;
- Set time respect frames, deadlines;
- Spent time – elaborate and explain for members;
- Strong and simple message;
- Find the right media;
- Set time and respect the deadlines;

Topic and content

- Make the topic specific;
- Choose a topic relevant in all countries;
- Identify targets;
- Strong + simple message;
- Ready to go material, visual, easy to translate;
- Relevant to local situation;
- Take care in the choice of words;

Building Capacity + Implementation

- Access to journalists, lists for national coalitions;
- Do: joint initiatives;

- Consult members on implementation also – do workshops with members to prepare campaigns etc. (prior to them being launched);
- Educate and empower: make people aware that they have a voice;
- When tailoring to different countries – countries and national coalitions can put pressure / support other MSs (collaboration between national coalitions);
- Good collaboration of national coalitions with stakeholders at national level;
- National policymakers need to work with MEPS (NCs to close that gap);

Early Involvement of Members

- Inform members face-to-face ie. workshops, group skype workshops;
- Members to review implementation strategies – reference group;
- Inform members via a short video of 5 minutes + visual (graphic), more contact with national coalitions before launching campaign;
- NCs need to know in advance, so that it isn't one additional think to do but already planned for the years' work programme, preparation and planning is key;
- Resource packs per region / categories of initiatives based on maturity of member state;
- Joint member-EPF calendar (google calendar) synchronised, timeline with milestones;

DON'TS

- Importance of data: don't always assume that members at national level have better data, don't assume members have the data / fully understand the situation in their country;
- Don't make too general surveys – what happens if the national coalition does not know the answer? How do you fill this gap?
- Don't send long email in an initial instance, clear headings;
- What works in English may not work in other languages (e.g. 5 Es / 5As);
- Don't forget face-to-face communication;
- Don't target all audiences at once: the wider public might not be receptive to "cross-cutting issues";
- Don't forget your own members – it starts with the patient organisations;
- Avoid general EU messages, don't use too many acronyms, don't be theoretical;
- Don't always think of quantity, but quality;
- Don't translate words by words - > more by meaning, be sensitive to culture and language, don't overlook country specifics, don't think it's always universal;
- Don't rely on national coalitions for translations;
- Don't be confused and confusing;
- Don't overuse 'best' practice, make them adapted to situation;

3.2 DON'T BE TOO CONFRONTATIONAL.WORKSHOP: ADVOCACY TOOLS

Strategy without tactics is the slowest route to victory. Tactics without strategy is the noise before defeat. Sun Tzu

This workshop was facilitated by Kaisa Immonen, EPF Policy Director, and Roberta Savli, The European Federation of Allergy and Airways Diseases Patients' Associations (EFA) Director of Strategy and Policy. The workshop aimed at reflecting on the tools at the disposal of patient organisations to get their message across at national and European level. the workshop's objectives were:

- To understand what advocacy is and what is not, the different approaches to influence change;
- To build capacity on how to develop an influencing strategy;
- To get examples about Do's and Don'ts of advocacy;

During the first part of the workshop Roberta introduced the concept of advocacy and how patient organisations can use it.

The word "advocacy" comes from the Latin "advocare" and literally means "to call out for support". Today it is used to describe a specific 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 because you believe in, and trying to change people's lives to build a better world.
When it comes to advocacy, strategy is everything, therefore Roberta presented in a concise way few key tips on how set up an impactful advocacy strategy.

3.2.1 SIX QUICK STEPS TOWARDS ADVOCACY

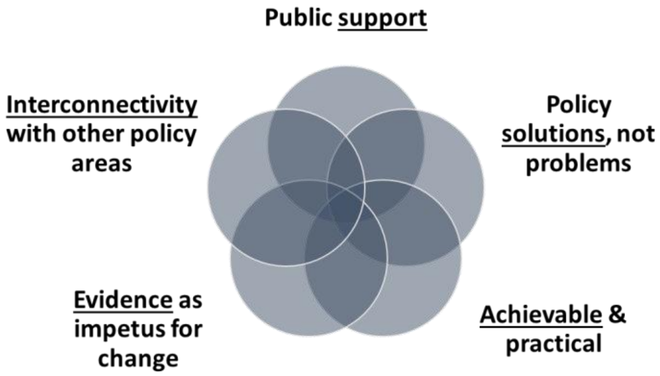
1: Identify your key issues and asks
Find out what issues the members of your patients' group care about.

2. Plan, prepare and create an action plan
Planning and preparation is crucial to ensure that your advocacy campaign will "perform" at its best. The plan can be tackling one big issue or working towards one common goal or it can be smaller issues over a given period.

3: Assess the broader context of the issue
Find clear answers to the questions "what", "who", "when" and "how". It doesn't matter if you are working at national level or at the European one having clear answers to these

questions will make your campaign more impactful.

Step 3: Understand what policy-makers need



Step 4: Use different communication channels
Once you understood who are your target groups you need to use the most effective communication channel to reach the right target group. Keeping in mind that no matter the target audience the message should be concise, clear, credible, coherent and finally relevant to your audience.

Step 5: Set S.MA.R.T. objectives
To measure the progress of your work, define objectives that are Specific, Measurable, Action-Oriented, Realistic and Time-Sensitive.

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.

3.2.2 USING SOCIAL MEDIA TO INFLUENCE POLICY

Roberta Savli also gave some tips on how to use social media in advocacy.
When talking about EU politicians' latest statistics say that 61% of the members of the European Parliament follow social media conversations every day (you can find here a complete list of MEPs on twitter).

When using social media to communicate you need to keep in mind that**you are one of many voices competing for space in the EU healthcare debate**. To break through the noise, you need to deliver concise messages in a way that resonate with your audience. Clear and concise messaging delivered in the right way will consistently grow your share of voice in the debate and mobilizing members to contribute to that share of voice will make it even stronger.

You can try to engage in a conversation with policy makers directly using:

- "Soft touch tweets" that are designed to deliver individualized messages to key stakeholders in an unobtrusive way that creates value for those stakeholders;
- The tweets directly target a key stakeholder by either sending a message to him/her, or relaying a message that they have delivered, for example at a conference or in an article. Doing this will a) shows the policy-maker that you are engaged in their work, and b) draws their attention towards you

As it is key to give ourselves SMART objectives is important measure the success of your work on social media focusing on three points: reach, engagement, action:

Reach: Bi-weekly **reports** that detail how many people the campaign has reached: if you are using twitter you can use Twitter impressions to track your progresses;

Engagement: To understand who the campaign is **engaging** and how we will look at: key institutional stakeholder engagement, Media engagement Video views, click through rates;

Action: To understand who is taking action and how: sharing, commenting, and liking our material across social channels;

After the presentation, participants were split in two groups and worked on a hypothetical advocacy plan based on the toolkit that the speakers prepared for them. After an animated discussion in both groups, each group shared the outcomes of its discussion: learnings, questions arising, "Dos and don'ts" from everyone's experience.

3.3 WORKSHOP STRENGTHENING NATIONAL COALITIONS

The workshop objectives were:

- To strengthen National Coalitions strategic thinking and resilience;
- To Provide a self-assessment tool for their organisations looking at legitimacy, membership involvement, transparency and strategy;
- Stimulate peer-to-peer learning and dialogue among National Coalitions;

Participants were split into two groups and they were invited to think of the key value of a national coalition and the benefits for patient organisations and for other stakeholder to have a national coalition in their country.

3.3.1 BENEFITS OF NATIONAL COALITIONS

The first group focused their discussion on the benefits of having national coalitions in a country

They listed the benefits from the perspective of patient organisations:

- Patients have one strong voice;
- The patient community is stronger;
- The patient movement is more legitimate, credible;
- A well-managed national coalition can provide:
- Better, more effective communication;
- Cooperation of resources and funds;
- More visibility;
- More ideas;
- Bigger outreach;
- Capacity-building of members, education, training;
- The national coalitions can be a model for other smaller organisations (statutes, leadership);
- For national disease specific organisations it means be able to be part of networks (national, EU…)
- Opportunity to get funding from EU;
- Data collection;
- Stability and continuity;

And from the perspective of other stakeholders:

- One contact point;
- More transparent relations with partners;
- More effective communication;
- Easier to involve patient in the legislative processes;
- Easier to involve patient organisations in national health strategies including long-term strategies;
- Benefit from the data collection conducted by national coalitions;
- More legitimacy for the institutions who involve the national coalition;

3.3.2 THE KEY VALUES OF NATIONAL COALITIONS

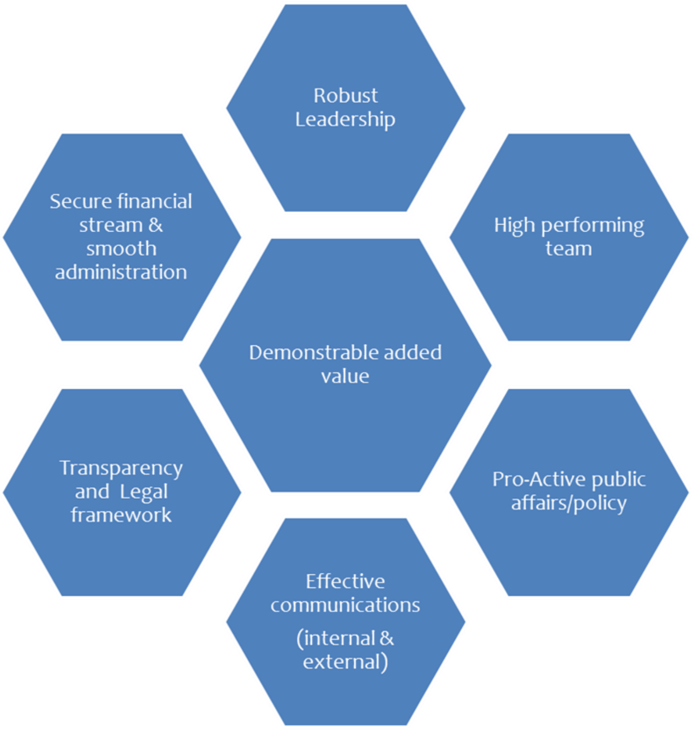
The second group focused their discussion on the key values of national coalitions of patient organisations.

- Mission-driven;
- Ethical;
- Sense of community;
- Independence;

- Transparent;
- Supportive (value of solidarity);
- Sharing knowledge;
- Strength;
- Unity;
- Respect for each other and each other's differences;
- Representativeness;
- Credibility/Trust;

After the exercise Elena Balestra, EPF Membership and Capacity-Building Officer, presented few key elements of the EPF Toolkit on building coalitions of patient organisations focusing on three key points Louder together, Smarter together and Stronger together.

After this recap Elena Balestra focused on how National Coalition could overcome challenges and ensure a path towards sustainability and engagement. She presented the model below and its key areas.



Each participant took a moment to assess how important each block of the graph was for his/her organisation and how well they were performing in that area. Below you will find an explanation of each block of the model presented and the feedback of the participants:

Leadership is a challenge for many national coalitions, as one common fear is that one of the stronger organisations may want and take the **leadership of the coalition-** as well as use its visibility to defend its own interests. This legitimate fear can be addressed by ensuring the representativeness of the coalition and its governing bodies, and putting in place strong governance rules. Some "older" and well-established organisations sometimes face the difficulty of refreshing their leadership and this challenge could be addressed also with strong governance rules.

High-performing team: all participants agreed that they have a very dedicated team but they also recognised that this challenge is mostly faced by young national coalitions or by national coalitions that needs to rely on fluctuating private funding and volunteers. This challenge can be addressed involving more volunteers, or paid staff in case this is financially feasible, and provide them with clear and well-defined tasks.

Proactive policy/public affairs: most participants defined their organisation as quite or very proactive in public affairs but some defined themselves as mostly reacting to policy development in their country more than being an agenda setter. A possible way to overcome this challenge is to define your advocacy strategy with long, medium and short-term goals as well as knowing your audience and defining key messages for each target group.

Effective communications (internal and external): most participants said that effective communications is quite challenging. They linked it with members' engagement and the difficulties of having competing priorities within the membership. On another level, the relationship with the media is sometimes challenging as it's time intensive to engage them. These challenges can be addressed focusing first on your communication strategy. Within it itis key to know your target audience as you do not use the same arguments or the same tone to invite a patient organisation to join the coalition or to convince the Ministry of health to meet with you. **Segment your audience, adapt your messages and develop specific material for each of your targets.** Itis also key to streamline your communications as each of the people involved with your organisation may have a different reason why they are engaging with you, and all of them will surely speak about your organisation and the work you do with third parties, be it in an informal context, at a networking event or when doing a speech at a conference. You also need to make sure that the persons who are going to speak about your coalition to external stakeholders will give the same view of your organisation. Indeed, when promoting the work of your organisation, you should be speaking with a unique voice.

Within effective communications we cannot forget to mention that it is key to **invest in internal communication:** a great mistake would be to invest all your efforts in external communication. Membership-based organisations are complex associations whose members are not sitting together regularly. An open and transparent communication with members is key to ensure the organisations' transparency and democracy. To ensure ownership and commitment, you need to put in place user-friendly communication tools that facilitate the internal information flow.

Examples of internal communication tools include websites, intranet, social media groups (Facebook group), printed or online newsletters for members only, physical meetings, trainings, seminars, emails, phone calls, teleconferences.

Transparency and Legal framework: during the debate participants representing well established organisations thought they were performing well on this regard but people representing coalitions to be found challenging to define transparency guidelines as well as defining the right legal framework for them. Therefore, if you wish to read EPF practical tips on how to overcome these challenges you can find them here.

Regarding **transparency,** ethics and transparency are an absolute priority for patient organisations. This applies to every aspect of an organisation's structure and activities (from membership to governance through communications). However, this is especially crucial when it comes to funding. To protect their independence and their credibility, national coalitions must follow some principles that can be found here.

Secure financial stream & Smooth administration: this point was recognised as a challenge from most of the organisations and only the one receiving constant public funding are not concerned. Below you will find few tips on how to ensure better funding. You may want to check EPF's Toolkit on Fundraising for patient organisations for a more comprehensive overview).

Afterwards, participants gathered and shared their experiences. During the debates, some common aspects emerged and Elena Balestra, referring to the EPF toolkit, proposed few possible solutions based on EPF's Toolkit on Fundraising for patient organisations and Toolkit on building National Coalitions of Patient Organisations.

Workshop Conclusions

The success of patient organisations is more than the sum of a clear vision, well-thought strategic and operational plans, committed sponsors, a clear vision and dedicated individuals. Patient organisations also should foster a positive atmosphere and a culture of learning, sharing, documenting and communicating openly. Keeping your organisation's activities and governance open and transparent is essential to build trust and inspire individuals to volunteer their time for your organisation.

It's important to always keep a fresh eye and regularly go back to the organisation vision, mission and values to ensure that the work the organisation is engaging in, the institutions the organisation is partnering with are in line with your identity. Organisations participating in the workshop found essential to review the current environment from time to time to ensure that their mission and vision are still fit for the challenges patient organisations face in their country. Finally, participants highlighted that participatory processes take time, just as establishing a good relationship with institutional stakeholders or building your organisation's reputation. Another key point is to invest in evaluation, check your organisation's achievements against your initial goals, repeat what worked well and try out new activities, always making sure they fit your organisation's mission and vision.

Elena's full presentation is available here.

4. Conclusions

Elena Balestra, EPF Membership & Capacity Building Officer, 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:

- Even more practical examples on advocacy tools;
- As following step to move from ideation to implementation;
- Even more examples and best practices from the members.

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 all over Europe.

EPF is determined to keep working and co-developing strategies to stimulate synergies between National Coalitions as well as EPF to advocate effectively at European and national level.

5. List of Annexes

- Agenda of the event
- List of participants with contact details


Demonstrable added value
High performing team
Transparency and Legal framework
Pro-Active public affairs/policy
Effective communications (internal & external)
What did we learn?
EPF
A STRONG PATIENTS'
EUROPE

5.1 NATIONAL COALITIONS’ MEETING AGENDA

16-17 October, Brussels, Belgium

Agenda

Day 1 – Monday, 16 October 2017

12:30-13:30	**Welcoming lunch**
13:30-14:00	**Registration**
14:00-14:30	**Welcome** Radu Costin Ganescu, President, National Coalition of organisations for patients with chronic conditions of Romania (COPAC) and EPF Treasurer
14:30-15:00	**Exploring the opportunities for National Coalitions in advocacy at European level** Camille Bullot, Director of Operations and Engagement, EPF *The role and influence of National Coalitions in the EU decision-making process (including the importance of agenda-setting vs. reactive approach to policy-making; getting involved in a consultation process at EU level)*
15:00-15:30	**Q&A and discussion**
15:30-16:00	**Coffee Break**
16:00-17:00	**National Coalitions: a common goal but different models - challenges and opportunities** • Marc Paris, Communications and Membership Engagement, France Assos Santé; • Sofia Karlsson, Responsible for Equal Health, Swedish Disability Rights Federation; • Dr. Stanimir Hasurdjiev, Chairman, Bulgarian National Patients’ Organization (NPO) • Moderator: Elena Balestra, Membership and Capacity Building Officer, EPF *Interactive presentation of three different models of National Coalitions highlighting the challenges and opportunities peculiar to each model.*

17:00-18:00	**Networking and discussion per model** Elena Balestra, Membership and Capacity Building Officer, EPF *Moderated group discussion on the different models of National Coalitions*
18:00-19:00	**Free time**
19:00-21:00	**Networking dinner**

Day 2 – Tuesday, 17 October 2017

09:15 -09:30	**Welcome to day 2** Elena Balestra, Membership and Capacity Building Officer, EPF
09:30-10:30	**Parallel workshops** **W1 – Advocacy tools** Kaisa Immonen, Director of Policy, EPF & Roberta Savli, Director of Strategy and Policy, EFA • *What is advocacy? Different approaches to influence change* • *How to develop an influencing strategy* • *The Do's and Don'ts of advocacy* • *Advocacy strategy and the Advocacy & Campaigning cycle* **W2 –Developing a common and coordinated advocacy framework for EPF and National Coalitions– The example of the EPF Access Campaign** Katie Gallagher, Policy Advisor, EPF & Ophélie Martin, Communications Manager, Mental Health Europe • *How to create an impactful communication flow* • *Key elements of a common advocacy strategy* • *Best practices* • *Translate European level campaign into a national contest: the example of the Universal Access to care campaign*
10:30-11:00	**Coffee Break**
11:00-12:00	**Continuation of workshops**
12:00-13:00	**Lunch**

13:00-14:00	**W1 – Strengthening National Coalitions** Camille Bullot, Director of Operations and Engagement, EPF & Elena Balestra, Membership and Capacity Building Officer, EPF • *How to develop an effective leadership and governance* • *How to involve and broaden your membership* • *Achieve legitimacy through transparency* **W2 – Developing a common and coordinated advocacy framework for EPF and National Coalitions – The example of the EPF Access Campaign (rerun)** Katie Gallagher, Policy Advisor, EPF & Ophélie Martin, Communications Manager, Mental Health Europe • *How to create an impactful communication flow* • *Key elements of a common advocacy strategy* • *Best practices* • *Translate European level campaigns into a national context: the example of the Universal Access to care campaign*
14:00 - 14:30	**Coffee Break**
14:30 - 15:30	**Continuation of workshops**
15:30 - 16:00	**Closing and next steps towards a common advocacy strategy** *Participants will share the main highlights of the workshops and define together the common steps towards a common advocacy strategy*
16:00	**End of the event**

Disclaimer: This meeting arises from the EPF 2017 Work Programme, which has received funding from the European Union, in the framework of the Health Programme. The content of this meeting reflects only the author's views, and the Executive Agency is not responsible for any use that may be made of the information contained therein.

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