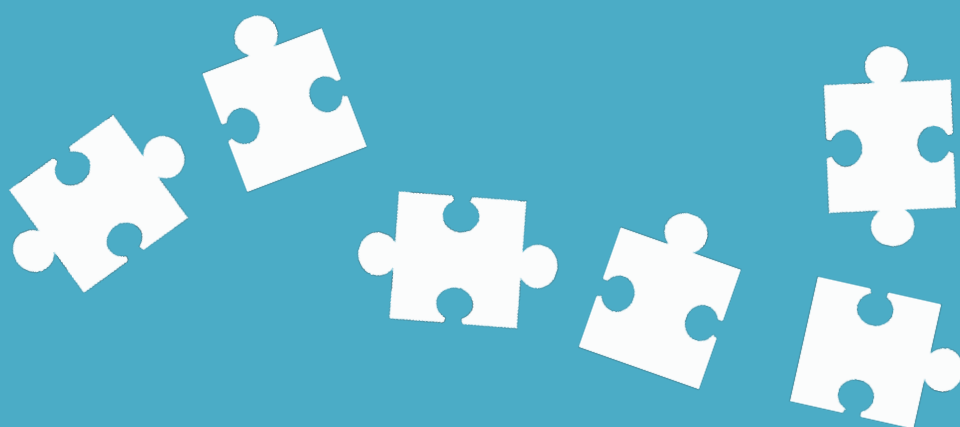


EPF CAPACITY BUILDING
PROGRAMME
2018



EPF Capacity Building Programme

November 2017

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1. About EPF

The European Patients' Forum (EPF) was founded in 2003 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 currently represents 74 members, which are national coalitions of patients' organisations and disease-specific patient organisations working at European level. EPF reflects the voice of an estimated 150 million patients affected by various chronic diseases throughout Europe.

EPF's vision for the future 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.

2. Background about the Capacity Building Programme

The Capacity Building Programme (CBP) is a long- term programme launched in 2012 to support the development of organisational capacities and advocacy skills of European patient organisations, to enable them to be more effective in:

- achieving their objectives and aspirations;
- feeding their experiences and expertise into the work of EPF and utilising the outcomes of our collective work in a national, and/ or disease specific context.

The CBP offers both online and offline (face-to-face) learning opportunities, as well as learning materials gathered in the EPF Resource Centre.

1.1. “OFFLINE” EPF’S LEARNING OPPORTUNITIES – TRAINING THE PATIENT COMMUNITY ON THE GROUND

The offline EPF Capacity-Building Programme was kicked off in 2012. Its activities contribute and reflect EPF's core values of patient-centricity, non-discrimination, health equity, health in all policies, independency, transparency, consultation, and inclusiveness.

Sustainable and collaborative approaches guide the work of the programme to ensure that participating organisations can use the knowledge acquired and continue to strengthen their work beyond the CBP activities.

METHODOLOGY

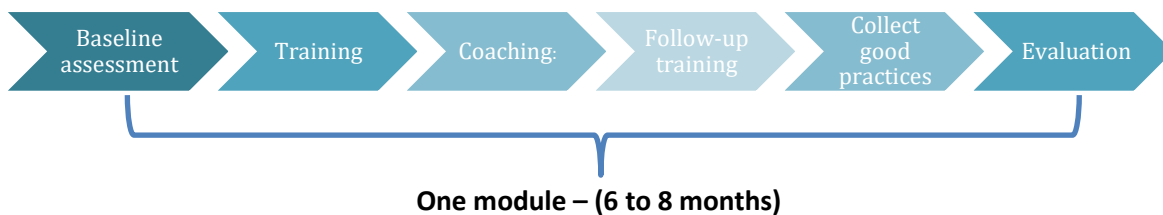
The “offline” CBP is a long-term programme that combines **face-to-face tailored training workshops** with **individual coaching**. This approach allows beneficiary organisations to meet and exchange experiences and good practices with other peer organisations, while offering the opportunity to address each organisation's individual needs.

The programme activities are implemented in **modules**. Each module represents one training topic, implemented over approximately six - eight months.

The modules focus on:

- One specific of organisational development: strategic planning, communications, fundraising, advocacy, reinforcing a national coalition...
- One thematic topic: digital health, patient safety, HTA...

In general, a CBP module consists of the following activities:



Two face-to-face training sessions are organised with remote coaching in-between sessions until the completion of the module. Each participating organisation selects a specific project or a common project which is relevant to the overall CBP theme and they design and implement it in a strategic manner with the support of the trainers. That said, thanks to the experience gain with the previous CB phases, EPF is tailoring more and more its approach to the needs of the POs participating in the programme and to the theme.

Tailored-made trainings

EPF works with experienced trainers who deliver the training on the ground. Activities are therefore conducted in the countries' languages or in English if more nationalities are involved. The role of the trainers is to facilitate processes, as well as help participants to navigate the strategies and techniques that best meet the organisation's work.

NATIONAL PILLAR

Since 2012, the CBP is being implemented in Bulgaria, Hungary, Romania, Slovakia, and since 2017 also in Poland. In addition, in 2017, EPF conducted a situational analysis of the patient movement in the Western Balkans. Targeted activities aimed at building the capacity of EPF member in Cyprus, the Pan-Cyprian Federation of Patients Associations and Friends, were carried out in 2014-2015.

EUROPEAN PILLAR

National CB chapters are complemented by a European programme dedicate to cross cutting topics that are of interest and benefit of all patient organisations.

SUMMER TRAINING FOR YOUNG PATIENT ADVOCATES

Target audience: young patients from 18 to 30 from across Europe, specifically EU Members States and the Western Balkan Countries who have either the EU official candidate or potential candidate countries status.

Objectives: preparing the next generation of patient advocates by training young people in patients' advocacy and leadership capacity within the healthcare arena.

Methodology: A 3-day course followed by mentoring, support and advice to each participant during the implementation of their advocacy campaigns.

1.2. ONLINE EPF'S LEARNING OPPORTUNITIES

Since 2017, EPF proposes regular **Breakfast Briefings** and **webinars** (online or at our premises) target the wider patient community and respond to a double objective:

- Increasing patient organisations' awareness and familiarity of the EU health policy stakeholders and developments and discussing potential actions for the patient community;
- Providing concrete advice and practical recommendations for patient organisations on a more regular basis.

The online meetings can be followed via [EPF's YouTube channel](#) in streaming. They are recorded and are also made available as podcasts.

1.3. EPF RESOURCE CENTRE



Over the years and throughout the trainings, EPF has developed expertise and produced many learning materials on organisational development, cooperation, legislative processes, and policy issues. We want to build on this expertise and are currently collecting and mapping the learning materials produced over the past years.

Our goal is to build an interactive, thematic Resource Centre for the patient community by 2021. By pooling together the considerable training and information resources accumulated over the years and enabling the patient community to access them, we hope to multiply the impact of our advocacy and capacity-building work.

EPF members and the wider patient community are encouraged to appropriate these tools, making them their own, and to share them further.

Objectives:

- Making organisational development tools developed by patient organisations available to the wider patient community;
- Increasing our outreach in **raising awareness** about patient issues;
- Contributing to patients' **health literacy** by communicating on complex policy and topics in a patient-friendly manner, and inspire others to do so;
- Enabling self-learning.

Format: factsheets, toolkits, Power Point presentations, videos, position papers, briefings...

Dissemination: to increase the impact of the materials developed, we disseminate them through the broad range of communications channels (social media, newsletters, face-to-face meeting, EPF

CONNECT, EPF website). Furthermore, when possible, our materials are translated into further EU languages.

Examples:

- EPF National coalitions toolkit: http://www.eu-patient.eu/globalassets/library/toolkits/epf-toolkit_nationalcoalitions.pdf
- EPF Fundraising toolkit: http://www.eu-patient.eu/globalassets/library/epf_broch2016_v5blow.pdf
- EPF Factsheets: <http://www.eu-patient.eu/library/factsheets/>

3. Key Achievements 2017

CREATION OF THE ONLINE LEARNING OFFER

- Creation of the “EPF Breakfast Briefings” concept;
- **8 Breakfast Briefings** on 8 different topics filmed and uploaded as podcasts on EPF YouTube channel. Topics: EPF Access Campaign, Transparency & Ethics, European Solidarity Corps, Anti-microbial resistance, Added-value of patient organisations, Future of health collaboration, Health Technology Assessment.
- 580 single views in 2017.



NATIONAL PILLAR

2017 saw the successful implementation of all trainings offered in the frame of the Capacity Building Programme.

Bulgaria: training module on Fundraising – successfully completed in summer 2017, including the additional training and coaching. Also, EPF translated its Fundraising toolkit into [Bulgarian](#).

Hungary: extension of the training module on Strategic Communication and finalisation of a situational analysis on the healthcare sector in Hungary.

Poland: the first module of the capacity building programme on Strategic Planning was launched in spring 2017.

Romania: the revision of the mid-term planning was concluded in March and the training on Strategic Communications is currently taking place.

Slovakia: A new module on Advocacy skill will kick-off in the second part of 2017.

Western Balkans: a situational analysis was conducted in spring 2017.

In total, around 70 organisations from 5 countries participated in activities ranging from: assessments, face-to-face trainings, coaching and individual projects which contributes in building professional and sustainable patient organisations across the EU.

EUROPEAN PILLAR

2017 saw successful implementation of two new learning formats:

EPF Leadership Meeting - conducted in April 2017. 74 participants from 28 countries. 80% of the participants found the event very good or excellent.

National Coalitions' Meeting- conducted in October 2017. 30 participants from 29 countries 85% of the participants found the event very good or excellent.

SUMMER TRAINING COURSE FOR YOUNG PATIENT ADVOCATES

The 1st edition of EPF's Summer Training Leadership Programme for Young Patient Advocates took place in Vienna, Austria, (3-5 July 2017). 40 young people from 21 countries. 100% of the participants rated the training as either very good or good.

4. EPF Capacity Building Programme 2018

In 2018 EPF will take a step further in the development of its capacity building programme. It will integrate a learning component in its whole annual programme creating synergies with other EPF working areas and a more effective use of resources.

To do so EPF will offer three types of learning experiences:

ONLINE LEARNING OFFER

In 2018 EPF will organise 6 online learning opportunities (webinars) on the following topics:

- Crisis Communications
- Social Media for Patient Organisations
- Pro bono legal support
- Fundraising
- Transparency guidelines
- EU Institutions



“OFFLINE” EUROPEAN PILLAR – STRENGTHENING THE EXPERTISE AND ADVOCACY SKILLS OF EUROPE’S PATIENTS

In 2018 EPF will address the patient community’s learning needs providing them with the following learning formats.

- A **capacity-building module dedicated to organisational positive governance** will be organised for patient organisations from several European countries with a special focus on organisations based in Bulgaria, Hungary, Poland, Romania, Slovakia and the Western Balkans. This module will be organised according to the EPF methodology: Initial face-to-face training (I), Coaching, Face-to-face training (II), Evaluation.
- **The EPF Leadership Meeting** is a one-day event aimed at empowering EPF members’ leadership through high-level discussions and exchanges. The event will provide EPF members with the opportunity to shape strategic direction of EPF and the patient movement in Europe. In 2018 the event will be linked to EPF Annual General Meeting taking place in April 2018 to ensure a high level of participation.
- With the **Patient Advocates’ Seminar (PAS)**, to be organised in the second half of the year, EPF will aim to stimulate exchanges between EPF members as well as with EPF to advocate effectively at European and national level. This interactive event will be an opportunity to inform patient organisations of EU health policy developments, engage members in EPF’s advocacy work, and build mutual understanding and cooperation among members on a regional and European level.
- In 2018 we aim to reinforce the links between our capacity-building and advocacy work. Thus, we will organise **thematic trainings on digital health** and other relevant policy areas, to strengthen the expertise of our members and their ability to feed in our policy and advocacy activities.
- **Second edition of the Summer Training for Young Patient Advocates:** the 2018 edition will have non-discrimination and stigma as overarching theme. Specifically, this edition will look at concrete advocacy and communication actions to facilitate a meaningful impact on the societal and institutional levels.

In addition, **national modules** will be rolled out in Bulgaria and Romania with various thematic training modules, in cooperation with the National Coalitions, our members and partners on the ground.

OFFLINE NATIONAL PILLAR - TRAINING THE PATIENT COMMUNITY ON THEIR GROUND

EPF will continue to strengthen the capacity of patient leaders rolling out two thematic training modules in Bulgaria and Romania, in cooperation with the National Coalitions, our members and partners on the ground.

CAPACITY BUILDING PROGRAMME IN ROMANIA 2018

EPF will continue offering thematic trainings in Romania with the support of its member and partner on the ground COPAC. In 2018 EPF will develop a module on Advocacy skills. The overall objective of

this module is to contribute to position the Romanian patient organisations as legitimate stakeholders, strong advocates and reliable partners on the national health policy environment.

Specific objectives:

- To improve patient organisations knowledge and skills on advocacy;
- To strengthen the ability of patient organisations to develop and maintain collaborative and influential stakeholders in the national healthcare area (ex. government, policy makers etc.) by using an appropriate advocacy strategy;
- To support the participating organisations in developing a sustainability advocacy strategy and plans that best suit their capacities, priorities and resources, as well as the demands from the external environment;
- Strengthen the role of COPAC as an advocacy leader in Romania and improve collaboration among Romanian patient organisations;

CAPACITY BUILDING PROGRAMME IN BULGARIA

EPF will continue offering thematic trainings in Bulgaria with the support of its member and partner on the ground NPO. In 2016-2017 EPF rolled out a capacity building module on fundraising strategies. 17 fundraising strategies have been developed. Nevertheless, fundraising is a complex topic that can be fully learnt by practicing all fundraising techniques in real life.

Therefore, in 2018 EPF will develop a new module on fundraising and ideation techniques with the aim of further supporting organisations in developing their operational fundraising plan and support their first grant applications processes.

NATIONAL COALITIONS BUILDING

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.

For EPF, they are a vital partner, providing us with expertise on country-specific situations, and cascading our messages from and to the national and regional levels.

Supporting the constitution of national coalitions 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.

In 2018, EPF will continue to facilitate the creation of national coalitions of patient organisations in countries where they do not exist yet. We will focus our efforts on **Austria through the organisation of a workshop** and continue supporting the efforts initiated in Portugal and in the Czech Republic.

5. EPF Capacity Building Programme Target Audience

The EPF CB programme is dedicated to patient organisations based in Europe. EPF CB programme targets mainly but not only EPF members and members of EPF members.

Find here below a breakdown of the target audience for each capacity building activity.

Online/Offline	Activity	Description	Audience		Indicative Timeline
			EPF Members	Open to non-members	
Online	Breakfast Briefings	Web-streamed interviews and briefings	✓	✓	All year long
Online	Webinars	Online trainings on policy/organisational development issues	✓	✓	All year long
Offline (Physical meeting)	Leadership Meeting	One-day meeting with high-level patient representatives to reflect on advancing the patient movement	✓		April 2018
Offline (Physical training)	Patient Advocacy Seminar	Interactive event: how to advocate effectively at European and national level	✓		Second semester 2018
Offline (Physical training)	Summer Training for Young Patient Advocates	2-day event + coaching: preparing the next generation of patient advocates	✓	✓	July 2018
Offline (Physical training)	CB module on Organisational Positive Governance	Face to face meetings, coaching for 24 patient leaders (focus on Central and Eastern Europe) Production of one toolkit on organisational positive governance	✓	✓	April 2018 – November 2018
Offline	Thematic Workshops (Digital health x2, vaccines, incentives...)	One-day physical trainings	✓		All year long
Offline	National CB Modules	Bulgaria, Romania, Poland (tentative)	✓	✓	TBD
Offline	National Coalition building	Organisation of a workshop in Austria		✓	Second semester 2018
EPF Resource Centre	Production of learning materials	Infographics, leaflets, toolkits	✓	✓	NA

6. More information?



For more information on EPF's Capacity-building programme, please visit [EPF's website](#) or contact EPF Membership & Capacity-Building Officer Elena Balestra at elena.balestra@eu-patient.eu.