

Concept Note - Capacity-Building module on Empowering Leadership and Positive Organisational Governance

22/11/2018

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1. Introduction - EPF Capacity Building Programme (CBP)

The Capacity Building Programme (CBP) was designed in 2012 to respond to needs of the patient community which have been identified by our membership during previous activities of EPF. As such, it supports patient organisations to strengthen their role as equal players in the healthcare environment.

The target group is constituted primarily of representatives of EPF members: pan-European disease-specific organisations and national coalitions of patient organisations, including their members. EPF also targets other patient organisations representatives not affiliated with EPF following the principle of inclusiveness with the objective of growing the capacity of the patients' movement.

There are two main types of Capacity Building Programme activities:

- Core Capacity Building Programme modules (conducted at country level in the Central and Eastern European region, and EU level) which aim to increase the organisational capacity and advocacy skills of patient organisations;
- Thematic Capacity Building Programme modules (conducted at the European level), which aim at increasing the capacity of all partner patient organisations and their knowledge on specific topics such as patient safety, health technology assessment etc.

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 to and reflect EPF’s core values of patient-centeredness, 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

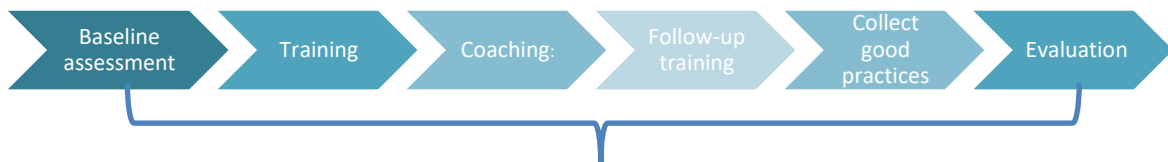
The “offline” CBP is a dedicated programme that combines **face-to-face tailored training workshops** with **individual coaching**. This approach allows beneficiary organisations to meet and exchange experiences and good practices with peer organisations, while offering the opportunity to address each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

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

The modules focus on:

- One specific aspect 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:



One module – (6 to 8 months)

Two face-to-face training sessions are organised with remote coaching 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 gained with the previous CB phases, EPF is tailoring its approach more and more to the needs of the patient organisations (POs) participating in the programme and to the theme.

Tailor-made training – achievements to date

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 to guide participants through using strategies and techniques that best meet the organisation's work.

NATIONAL PILLAR

Since 2012, the CBP has been 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

Since 2012 National CB chapters are complemented by a European programme dedicated to cross cutting topics that are of interest and benefit to all patient organisations. In the past years, EPF organised several Seminars as well Leadership Meetings for its members.

SUMMER TRAINING PROGRAMME FOR YOUNG PATIENT ADVOCATES

Since 2017, EPF organises a Summer Training Programme for Young Patient Advocates targeting young patients from 18 to 35 from across Europe, including EU Members States and Western Balkan Countries who either have an EU official candidate or a potential candidate country status.

The summer training programme aims at preparing the next generation of patient advocates by training young people in patients' advocacy and leadership capacity within the healthcare arena. The summer school is a 3-day course followed by mentoring, support and advice to each participant during the implementation of their advocacy campaigns.

1.2. EPF'S ONLINE LEARNING OPPORTUNITIES

Since 2017, EPF offers regular **Breakfast Briefings** and **webinars** (online or at our premises), which 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.

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

2. Why a Module on empowering leadership and organisational positive governance?

The overarching theme of this year (2019) European capacity-building module is Empowering Leadership and Positive Organisational Governance.

With **Empowering Leadership**, we understand the process of sharing information, rewards, and power with team members (either paid staff or volunteers) and board members so that they can take initiative and make decisions to solve problems and improve service and performance. Empowering leadership share several characteristics like trust, competency, consistency, commitment and creates a positive circle in the organisation.

With **Positive Governance**, we understand the process for making and implementing decisions. It is not about making "correct" decisions, but about designing the best possible process for making those decision. Positive decision-making processes, and therefore, positive governance share several characteristics like transparency, accountability, collegiality, quality, role clarification and good working relationships.

Patient organisations and patient organisations' leaders are becoming more and more visible actors in the healthcare arena. This is an important and positive change. Nevertheless, it also brings new and bigger challenges:

- Organisations leaders exchange more frequently and more intensively with several stakeholders at the same time;
- Instable political situations and rapid changes in governments put extra pressure on patient organisations;
- The growth in visibility is not linked to a growth in financial and human resources of patient organisations, therefore they face more challenges and increasing demands from external stakeholders with small teams, mostly of volunteers and limited financial resources;
- Leaders of patient organisations are very charismatic and committed but, in some cases, are lacking practical business knowledge necessary to run an NGO successfully.

During the module, participants will gain insight into the complexity of these issues and address them through interactive debates, group exercises and concrete action plans.

In 2019 EPF will organise the second edition of the CB module on Empowering Leadership and Positive Organisational Governance strong of the success of the first edition (2018) that saw 24 patient organisations' leaders from 18 different countries passionately engaging in the learning process and increasing their leadership potential.

3. Target group

Our objective is to involve around twenty-four (24) leaders of patient organisations.

The programme targets preferably 1 high-level representatives per each organisation of:

- The EPF Member organisations at European or national-regional level mainly based in but not only in Slovakia, Bulgaria, Romania, Poland, Hungary, Western Balkans to continue the capacity building efforts that EPF carried on in the past years in these targeted countries and to stimulate high-level exchanges among patient advocates leaders;
- A cross-section of EPF Member organisations' membership;
- Other European or national-regional patient organisations not affiliated with EPF who have expressed an interest in participating in this capacity building module.

As a general eligibility rule, organisations participating in the CBP are the patient organisations who are:

- Legally registered association/NGO working for the direct benefit of targeted, disease-specific population in a specific geographical scope;
- National coalitions of patient organisations;

- European disease specific associations, federations or networks mandated to defend the interests of a population affected by a specific disease;
- Disease specific organisations active at national/regional level;
- The organisations participating in the module and its representative should commit to take part to the module during its whole duration by signing an enrolment contract presenting the duties and benefits of the programme;
- Participants should have a proficient level English written and spoken;

4. Objectives

The overall objective of this module is to strengthen patient organisations by enhancing their leaders' leadership skills and consequently enabling positive organisational governance in their organisation, with the final objective of supporting patient organisations in positioning themselves as legitimate stakeholders, strong advocates and reliable partners on the national and European health policy environment.

Specific objectives:

- To improve participating patient organisations leaders' leadership skills;
- To provide tools to support organisations' leaders in setting strategic priorities and planning for their NGO in a constantly changing environment;
- To explore the different but complimentary roles of the Board of Directors of and of the Executive staff and/or volunteers to foster positive governance;
- To strengthen the ability of patient organisations and their leaders to develop and maintain collaborative and influential relationships with a growing number of stakeholders in the national and European healthcare area (ex. government, policy makers etc.) by boosting their empowering leadership skills;
- To support the participating organisations in developing an efficient and easy to implement internal and external communications flow to boost their external visibility and the organisation's internal coherence;
- To boost the collaboration and networking opportunities as well as the exchange of practices among participants;

5. Outputs and Outcomes

5.1 EXPECTED OUTPUTS

By the end of the module, the following outputs will be delivered by the participating organisations, with the support of the experts:

- 24 pre-&-post knowledge assessment tests that demonstrate an improvement of the participating organisations' knowledge and skills in empowering leadership and positive governance. The output number will depend on the final number of participating organisations (at least one participant per organisation);
- 24 completed self-assessment report in which participating organisations will define how they can improve the leadership and governance of their organisation;
- 24 action plans or mini projects developed that suit the participating organisation's organisational abilities;

5.2 EXPECTED OUTCOMES

At the end of the module participants will have more confidence in their leadership skills, they will acquire strategic skills and better knowledge to EPF and external resources on the topic.

Thanks to the pre-&-post knowledge assessment tests that the trainers will carry on we will be able to measure the impact of the module and the following key outcomes indicators:

- At the end of the module, 70% of the participants feel at least 30% more confident and resourceful in terms of their internal and external organisational capacities, with a focus on empowering leadership skills and positive governance;
- At the end of the module, 70% of the participants feel 30% more empowered and have better strategies for managing their organisation and key stakeholders;
- At the end of the module, 70% of the participants know where to find relevant information on positive governance and empowering leadership.

6. Methodology and planned activities

This section outlines the proposed methodology for the delivery of this module. The precise and detailed methodology will be proposed by the trainers.

The training methodology shall take into consideration the different natures of the organisations, namely their stages of development, size, and membership base, and their different sustainability levels. The proposed methodology should reflect these differences.

The proposed training will also attempt to strike a balance between theoretical frameworks and the practical aspects through coaching.

6.1 KNOWLEDGE ASSESSMENT

A comprehensive assessment should be conducted at the beginning of the module by the experts. Its purpose is to assess the organisations' current knowledge-base, skillset and capacity in positive governance and empowering leadership. The assessment report will include a clear set of

recommended measures on how participating organisations can improve their capacities. These could then be addressed by the experts during the face-to-face trainings and the coaching phase.

6.2 KICK-OFF MEETING

The CBP module for all representatives of participating organisations will start with the Online Kick-off session (duration of 2 hours), with the aim to:

- Present the programme objectives, benefits, duties;
- Verify the commitment and expectations of participating organisations;
- Increase awareness about the role and value of empowering leadership and positive governance and enhanced cooperation, as well as on the importance of collaboration and coordination with like-minded organisation;
- Identify leadership and governance issues which organisations can better address together while becoming stronger as a single organisation, and make sure the module can meet participants expectations.

6.3 1ST FACE-TO-FACE TRAINING

The CB module objectives, outputs and outcomes are usually used as a basis for developing learning objectives and detailed methodology for the 1st face-to-face training over two-day long training.

Suggested methodology: presentations, presentation handouts, plenary sessions, individual and group exercises, practical tools, involvement of the participants as speakers and use of additional resources etc.

By the end of the training, each patient organisation should select a project related to developing an empowering leadership attitude and positive governance plan in which they require coaching support, and define how they prefer to collaborate with the experts.

6.4 COACHING PHASE

Between the two face-to-face trainings, the local experts will provide guidance and mentoring, individual support and targeted advice to each participating organisation with regards to implementing their action plans and coaching projects. The coaching phase should help participants to become more confident and skilful in leadership and positive governance and in forging relationships with the key internal and external stakeholders (ex.: decision-makers, member organisations, team members, board of directors, executive team etc.).

6.5 2ND FACE-TO-FACE TRAINING – FOLLOW UP

While the first face-to-face training will be organised at the beginning of the capacity building module, the follow-up training will be organised once the first coaching phase is completed. Its purpose is:

- To consolidate the learning of the first face-to-face training, if needed;

- To address questions and topics that emerged during the coaching phase and have not been fully addressed during the first face to face training;
- To give the opportunity to participating organisations to present and discuss the development and/or implementation of their coaching projects and what they have achieved so far and create a positive peer-to-peer feedback loop;
- To gather success stories which can be disseminated it via EPF communications channels.

6.6 EVALUATION

Both face-to-face trainings should be followed by a comprehensive training report including a description of presented and discussed topics, used methodology, participants' engagement, main outcomes, key issues/challenges faced during the training, including the recommendations, as well as an evaluation including direct participants feedback.

The final evaluation will be conducted by EPF at the end of the 2nd face-to-face training. EPF will use this opportunity to ask participants about the topics for the next capacity building module, including their satisfaction with the provided support. The trainers will also provide EPF with key data from the knowledge assessment and final evaluation as well as selected data from the evaluation questionnaire that will be compared and aggregated by the EPF staff.

7. Timeline

04/12/2018	Launch registration process
30/01/2019	Registration process closing
1/02/2019 10/02/2019	Application selection
End of February	Online Kick-off meeting
February	Knowledge/Needs Assessment
March	1 st face to face meeting + Evaluation
March 2019 September 2019	Coaching
September 2019	2nd Face-to-Face training + Evaluation
September-October 2019	Final evaluation and closing