SUMMER TRAINING COURSE FOR YOUNG PATIENT ADVOCATES

Shaping the future of Patient Advocacy

CONCEPT NOTE

2020 EDITION

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A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE

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Background Information

Young patients have an important place in EPF work. We aim to empower young patients to strengthen their confidence and express their voices to be treated on an equal footing with others. We promote better cooperation between younger and adult patients, and greater partnership between young patients, their families and carers, and the wider community. In this way, we encourage young patients to take active role in developing policies and programmes at the EU level.

In 2012, EPF has established the EPF Youth Group (a group of young patients representing different chronic conditions and nationalities) and developed the Youth Strategy to address these issues in a systematic and organized manner. Since then, the Youth Group organized meetings and engaged in youth projects to share first-hand experiences and good practices with young patients from all over the EU. They continuously work to raise awareness about the challenges young patients face in their daily lives and advocate with policy-makers and stakeholders. Nevertheless, it is evident that young patients still need to become more aware of their rights and to exercise those in accessing health care system as well as all other spheres of their life.

In 2017, EPF has run a pilot Summer Training Course for Young Patient Advocates-Leadership Programme, with the aim to coach a first cohort of trainees and strengthen their leadership and advocacy skills. To build on the results achieved and in continuity with the 2017 edition, EPF kept a similar structure for the 2018 (second) edition of the Summer Training and kept the overarching theme of overcoming discrimination and stigma and expanded it to inclusion.

In 2019, EPF has organised the third edition of the Training Course and as its previous two editions, it offered a tailored high-quality training to young patient advocates. The third edition - where an essential role was played by the EPF Youth Group members- looked at topics that are central to the patient community as a whole and represent a key priority for the new generation of advocates. The overarching theme was “Shaping the future of patient advocacy” with a dedicated emphasis on advocacy at individual and community level. Dedicated sessions focused on the different pathways patient advocacy may take through individual patient advocates, emerging online patient communities, more formalised entities such as patient organisations, and looked at how they differently uniquely contribute to patient advocacy and how they do complement each other. The course offered the opportunity to learn about **powerful** and **thorough advocacy** involving aspects such as ethics, roles, responsibilities, challenges and opportunities before young patient advocates in an era where patient involvement is evolving and adding more complexity, and potential to the patient advocacy environment.

Rationale for a Leadership Programme

Our vision is to create a platform where young patient advocates would empower, inspire and learn from each other. We aim to gather young patients and/or their representatives from different organisations and different countries. They will discuss and explore common issues relevant for young patients' and patients' movements across Europe and therefore maximize their advocacy impact within their countries. The Summer Training Course is organised on annual basis and designed according to identified emerging needs.

EPF makes sure participants are fully supported before, during and after the Programme and at the same time their professional development is closely followed-up. EPF is in contact with alumni trainees and is trying to involve them as much as possible into the current workflow.

Theme for the Training Course 2020

The Summer Training Course for Young Patients Advocates-Leadership Programme intersects with all EPF thematic areas and its focus is in line with EPF strategic goals. Building on last year edition, this year's topic will be dedicated to investigating how patient advocacy is evolving and facing emerging challenges and opportunities while keeping a strong ethical approach. Patient involvement in healthcare systems and in the R&D medicines lifecycle provide tremendous opportunities to have patients' voices heard and their input embedded in the design of services. Young patients' voices are increasingly heard by regulatory bodies such as EMA, HTA bodies, industry, and policy makers, to ensure that their perspective is not missed to inform the decision-making process. these opportunities are a positive indicator of the increase involvement of patients in the healthcare systems, nevertheless it raises questions around the **representativeness** of those bringing the patient perspective, their potential **conflict of interest** or risk of **bias** depending on the role patient advocates play in which context. EPF believes that in its evolution patient advocacy must build strong safeguards to avoid pitfalls and misperceptions. **Transparency** is acknowledged as an absolute precondition to advocacy[1], therefore it applies also when it comes to involving young patients either as individuals or as young patient communities in advocacy work. There is an identified need to keep building and nurturing a culture of **ethical advocacy** and **trust** to facilitate constructive interactions within and outside patient communities. Young patient advocates or patients that want to star their advocacy journey are not fully equipped to navigate such a complex and uncertain environment.

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[1] European Patients' Forum, *Transparency Guidelines,* 2017 http://www.eu-patient.eu/globalassets/library/toolkits/epf-transparency-guidelines.pdf as well as the EPF Advocacy Code of Conduct created during the 2019 Summer Training.
https://www.eu-patient.eu/globalassets/who-we-are/yg/stypa-2019---advocacy-code-of-conduct.pdf

Therefore, EPF Summer Training Course for Young Patients Advocates will have the following objectives:

- To develop a common understanding of what constitutes an ethically sound patient advocate and the legitimacy criteria patient organisations and patient advocates representing them should fulfil;
- To reflect on the accountability of patient advocates, and how to demonstrate it;
- To establish guidelines and principles for cooperating with other stakeholders, with a focus on donors;

Through the training course, EPF will raise awareness among the new generation of young patient advocates on current challenges, obstacles, opportunities and will share good practises for ethical patient advocacy in complex environments.

Target group

Capacity: 40 participants
Age range: 18 – 30
Nationality: the participants should be based in continental Europe.

The Programme targets following categories of participants:

1. Patient with a chronic and/or lifelong illness/condition who is affiliated with a patient organisation
2. Patient with a chronic and/or lifelong illness/condition who is not affiliated with a patient organisation
3. Employee or volunteer of a patient organisation who identify as a patient representative or advocate
4. Alternatively, a family member or carer of a patient with a chronic and/or lifelong illness/condition can take part in the course, if she or he accompanies a young person, and is actively involved in the patients' advocacy work. The Programme can sponsor only one family member/carer per participant.

It is preferable that all participants:

- Have excellent level of English (C1 as a minimum);
- Have basic knowledge about public health, advocacy, role of patients in developing new legislation;
- Are passionate about advocating for patients' rights;
- Are dedicated to engaging in patients' advocacy organisations;
- Are willing to be part of large patients' rights movement;
- Can transfer learning to peers in their community;

- Availability for the entirety of the training course;
- Have valid travelling documents.

*EPF will strive to achieve a balanced representation of nationality, age, health condition, gender and social-economic background.

Objectives

Overall aim: To contribute in building and strengthening the patient advocacy capacities of young patients and youth groups and transfer their acquired knowledge and values to their respective constituencies.

Specific objectives:

- To strengthen participants' strategic advocacy skills;
- To inspire young patients to engage in patient advocacy in a transparent and ethical manner;
- To foster participants' future engagement in public awareness and advocacy efforts in their respective countries;
- To inspire young patients to change misperceptions and prejudices about patient advocacy in their communities and to make sure young patients are involved in a meaningful way;
- To familiarise participants with the EPF code of conduct for young advocates.

Training Design

The following section provides an overview of main components of this programme and will be used as a basis for development of a detailed training methodology and programme. The selected trainers, EPF Secretariat and the EPF Youth Group will be the three main contributors to the design, execution and implementation of the Training.

Summer Training Course

The programme will be delivered in English. Following the feedback and building on the previous three editions' outcomes, the Summer Training Course will keep the duration of three full days and there will be two main topics/modules to be discussed during the duration of the course:

PROGRAMME

A. Preliminary virtual meetings:

Two months before the face to face meeting, participants will gather on a virtual platform to get to know each other and connect with trainers. Preliminary information about the training topics will be shared.

B. Face to face meeting:

Taking inspiration from testimonials and real-life experiences, the training course will kick off with an interactive exercise showing the different paths a patient advocate can take, which experiences, or interactions may enable or obstacle new potential collaborations.

Module I: Ethical Advocacy

Module One will offer the opportunity to debate around **ethics** in the field of patient advocacy. Trainers and participants will look at the broader ecosystem and how patient advocates may navigate and contribute to the decision-making in the health system. The dimensions that will be considered entail European and national level, formal and informal patient groups, individual patient advocates.

Module II: Transparency and Ethical Advocacy

Module Two will be around **transparency** and how it can be approached by youth groups, patient organisations, informal communities and individual patients. Potential challenges around conflict of interest will be analysed and participants will have the opportunity to practice how they can play an essential role in patient advocacy, respecting well-established ethical good practices and at the same time having an impact at societal level in their local communities.

Suggested methodology: speaker(s), interactive debates, individual/per country action plans and creation of a supporting toolkit.

C. Online mentoring and team project development.

In this phase the trainers will split participants in teams. Each team will be led or co-led by members of the EPF Youth Group or returning STYPA participants (depending on their availability). Trainers will provide teams with both collective and individual guidance and support, in terms of their potential leadership capacities and/or specific advocacy issues they may have. At the end of the Programme, trainers will organise a final closing virtual event (October 2020) and nominate the team that has most advanced on the tasks and integrated the learnings of the training course. This follow-up phase will also help the organisation committee to gather best practice cases and to provide the recommendations for the 2021 edition of the Summer Training Course for Young Patient Advocates.

Key expected outcomes

Following the training course:

- Trainees will transfer and facilitate the uptake of their learning to local patient communities
- Trainees will be able to use their learning to engage into public awareness and advocacy actions in their respective countries
- Tools and recommendations developed by and with trainees will be integrated in the work of their organisations
- Trainees will acquire awareness, knowledge and expertise of representativeness, transparency and ethical principles and how they can be applied in their day-to-day advocacy/professional activities

Indicative Timeline

You can find the timeline of the Summer Training below:

Suggested implementation period	Activity
November 2019	Finalisation of the concept note for 4th edition
January 2019	Launch of the application process
By the end of January 2020	Set-up the Planning Committee and develop a detailed action plan with check points
End of February 2020	End of application period
March 2020	Selection of participants by participant selection committee and notification to successful applicants
Mid-March to June 2020	Preparatory work (logistics, content and agenda)
May 2020	Online pre learning phase launched. Participants take place in webinars and online learning tasks
By 6-8 July 2020	The training course event
August – October 2020	Review of evaluation, recommendations and next steps Follow on phase – participants work in teams on advocacy projects and take part in online learning
End of October 2020	Closing Celebration Event (Online)
November 2020	Planning of the Summer Training 2021 kicks off

More information?

For more information on EPF's Summer Training Course for Young Patient Advocates please visit [EPF's website]() and contact Elena Balestra Membership and Capacity Building Manager at elena.balestra@eu-patient.eu .