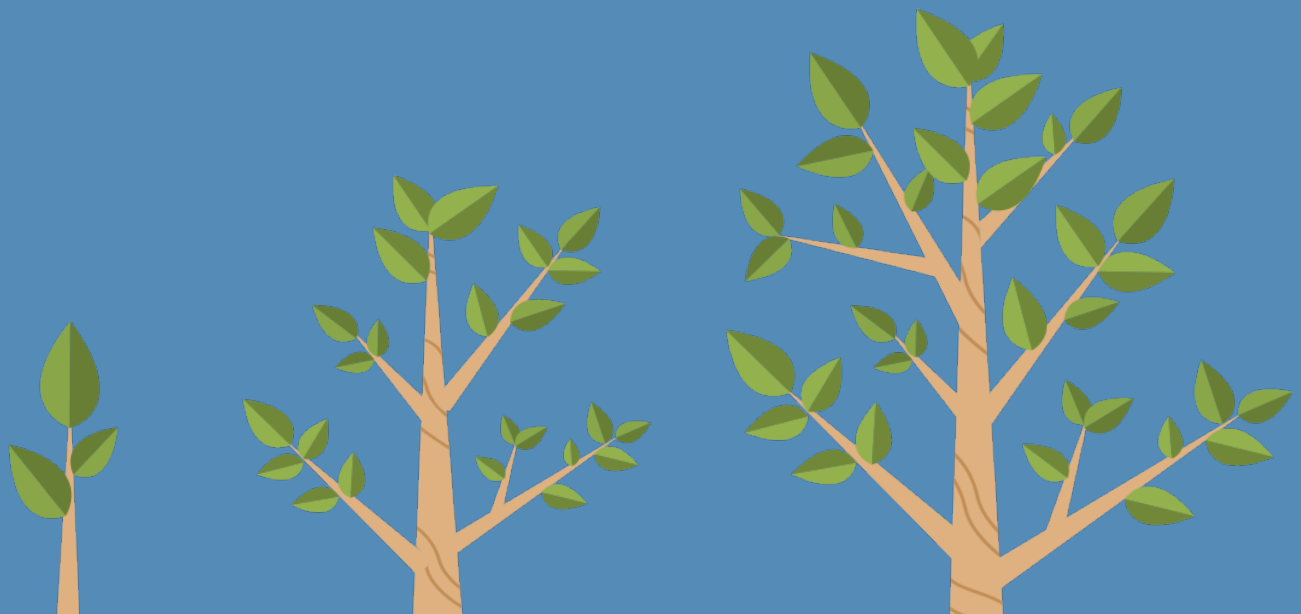


EPF Summer Training for Young Patient Advocates 2018



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1. Background Information

Young patients have an important place in EPF's work. We aim to empower young patients to strengthen their confidence and express their voices in order 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 an active role in developing policies and programmes at the EU level.

In 2012, EPF established the Youth Group and developed the Youth Strategy to address these issues in a systematic and organized manner. Since then, the Youth Group has 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 rights in accessing the health care system, as well as in all other spheres of their life.

In 2017, EPF ran a pilot Summer Training Course for Young Patient Advocates-Leadership Programme, with the aim of coaching a first cohort of trainees and strengthening their leadership and advocacy skills. In order to build on the results achieved and in continuity with the 2017 edition, EPF intends to keep a similar structure for the 2018 edition.

2. Rationale for a Leadership Programme

Our vision is to create a **platform where young patients' 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 the patients' movement across Europe and therefore maximize their advocacy impact within their countries.

The event is organised on an annual basis, and designed according to identified emerging needs.



3. Overarching Theme for the Training Course 2018

The Summer Training Course for Young Patients Advocates-Leadership Programme intersects with all EPF thematic areas and its focus is in line with EPF's strategic goals.

The previous edition focused on three topic areas: leadership, discrimination, and human rights from an advocacy and project planning perspective.

Based on the feedback received from trainees, EPF and the lead trainers agreed that each of these areas deserve more time and dedication to allow participants to develop a fuller and more thorough understanding.

Therefore, the 2018 edition will have **non-discrimination and stigma** as the overarching theme. In this way, the training course outcomes will complementarily contribute to the Youth Group's activities planned in the EPF 2018 Work Plan. Moreover, while the 2017 edition provided an overview of non-discrimination principles, the 2018 edition will look at concrete advocacy and communication actions to facilitate a meaningful impact on the societal and institutional levels.

We will explore concrete examples of how living with chronic conditions affects young patients' daily lives. Therefore, we will use testimonies of patients who faced discriminatory behaviours in access to healthcare, education, and employment. We will also investigate how discrimination is often an unwanted outcome of standardisation and consequently more difficult to eradicate. This is the case for equitable and affordable access to appropriate nutrition and healthy lifestyles. In this context, we acknowledge that maintaining a healthy lifestyle is not a choice for young patients, but a must to prevent the development of a chronic condition.

We intend also to address the **misperceptions often caused by the invisibility of many chronic conditions.**

Fatigue and chronic pain are part of young patients' daily lives but often they are misinterpreted as laziness or even abuse of positive discrimination. Together with the trainees, we aim at identifying avenues to improve awareness and public understanding of pain implications and explore how its burden and impact on society can be reduced.



4. Target group

- Capacity: 40 participants;
- Age range: 18 – 35;
- Nationality: participants must be from EU Members States and the Western Balkan Countries who have either the EU official candidate or potential candidate countries status.

The programme targets the following group of participants:

1. Employee or volunteer of a patient organisation;
2. Patient with a chronic and/or lifelong illness/condition who is affiliated with a patient organisation;
3. Patient with a chronic and/or lifelong illness/condition who is not affiliated with a patient organisation.

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 the young person and is actively involved in the patient's advocacy work.

It is preferable that all participants:

- Have an excellent level of English;
- Have basic knowledge about public health, advocacy, social justice and non-discrimination;
- Are passionate about advocating for patients' rights and non-discrimination;
- Are dedicated to engaging in patients' advocacy organisations;
- Are willing to be part of large patients' rights movement;
- Are able to transfer learning to peers in their community;
- Availability for the entirety of the training event.

*EPF will strive to achieve a balanced representation of nationality, age, condition, and gender.

5. Objectives

Overall aim: To contribute in building capacities of young patients/their representatives to be involved in patient organisations and advocacy work in their respective countries in a meaningful way.

Specific objectives:

- To increase participants' knowledge about the key attributes of patients' advocacy organisations led in an accountable and transparent manner;
- To strengthen participants' strategic communication and advocacy skills;
- To foster participants' future engagement in public awareness and advocacy efforts in their respective countries;
- To inspire young patients to challenge misperceptions and prejudices in their communities;
- To inspire young patients to conceive and promote anti-discriminatory measures in domains of life including healthcare, education, employment, and nutrition/ healthy lifestyle.

6. Training Design

The following section provides an overview of the main components of this programme, and will be used as a basis for the development of a detailed training methodology.

6.1.1 TRAINING COURSE

The programme will be delivered in English. Following the feedback and building on the 2017 edition outcomes, the Summer Training Course will keep the duration of three full days while topics will be streamlined to allow in-depth conversations and the absorption of key concepts. The following topics will be covered:

Topic I: Advocacy - Leading for influencing societal changes

Taking inspiration from testimonials and real-life experiences, participants will have the opportunity to practice how they can initiate changes to fight against discrimination practices and have impact at societal level.

Suggested methodology: speaker(s), interactive debates, individual/per country action plans.



Topic II: Communication - Development of an Advocacy Campaign Toolkit on Non-Discrimination led by Young Patients

Participants will learn about the most commonly used advocacy tools and techniques, such as policy monitoring and campaigns for policy change. After a brief theoretical session led by a communication/campaign expert, participants will be tasked to develop advocacy strategy and plan(s) in order to overcome discriminatory practices (ex.: work place, etc.).



Suggested methodology: lectures, group practical exercise, individual coaching, after-the-session group teambuilding games and exercises.

6.1.2 FOLLOW-UP

Following the Summer Training Course, the trainers will provide guidance, individual support and advice to each participant, upon request, in terms of their potential leadership capacities and/or specific advocacy issues they may have. It will also help the organisation committee to gather best practice cases and to provide recommendations for next year’s event.

7. 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 in public awareness and advocacy campaigns in their respective countries;
- Tools and recommendations developed by and with trainees will be integrated in the work of their organisations.

8. Indicative Timeline

Suggested implementation period	Activity
November 2017	Finalisation of the concept note
December 2017	Launch of the application process
By the end of January 2018	Set-up the Organization Committee and develop a detailed action plan
February 2018	End of application period

March 2018	Selection of participants by participant selection committee and notification to successful applicants
March to June 2018	Preparatory work (logistics and agenda)
By mid-July 2018	The training course event
August – October 2018	Follow-up Review of evaluation and recommendations
November 2018	Planning for the event in 2019

9. Programme development and lead trainers

Dan Moxon (Director) and Ed Moss (Associate) from People Dialogue & Change (PDC) will act as lead on-site trainers and will develop the programme along with EPF. PDC specialises in supporting organisations to use youth participation and youth engagement to listen and respond to the voices of young people.

PDC works with organisations in the public, voluntary, and academic sectors to provide research, evaluation, consultancy and capacity building services. PDC successfully developed and delivered the 2017 Summer Training programme in collaboration with EPF and other speakers, and they are keen to return for the next edition of the training event.

10. More information



Interested in our Summer Training Programme? For more information, please contact EPF Project Officer Danielle Flores (danielle.flores@eu-patient.eu).

Youth Advocates Summer Training: Participant and Trainer Evaluation

Dan Moxon and Ed Moss - July 2017



Summary:

Participants in the training course identified increases in their learning for all learning objectives within the programme. This included, understanding of advocacy, confidence as an advocate, ability to lead patient advocacy projects and a number of other areas. The most substantial changes reported by participants were in their understanding of patient rights and discrimination and the extent to which they felt empowered to make positive change as an advocate.

Participants satisfied with the programme was high, and all those who took part in the evaluation survey all rated it as either good or very good. The three highest rated aspects were, the trainers, the accessibility of the venue and the material received during the training. 88% of people who took part in the evaluation survey created a patient advocacy project.

This document contains more detailed results from the participant survey (section 1) and an evaluative reflection from the trainers (section 2)

Section 1: Participant survey results

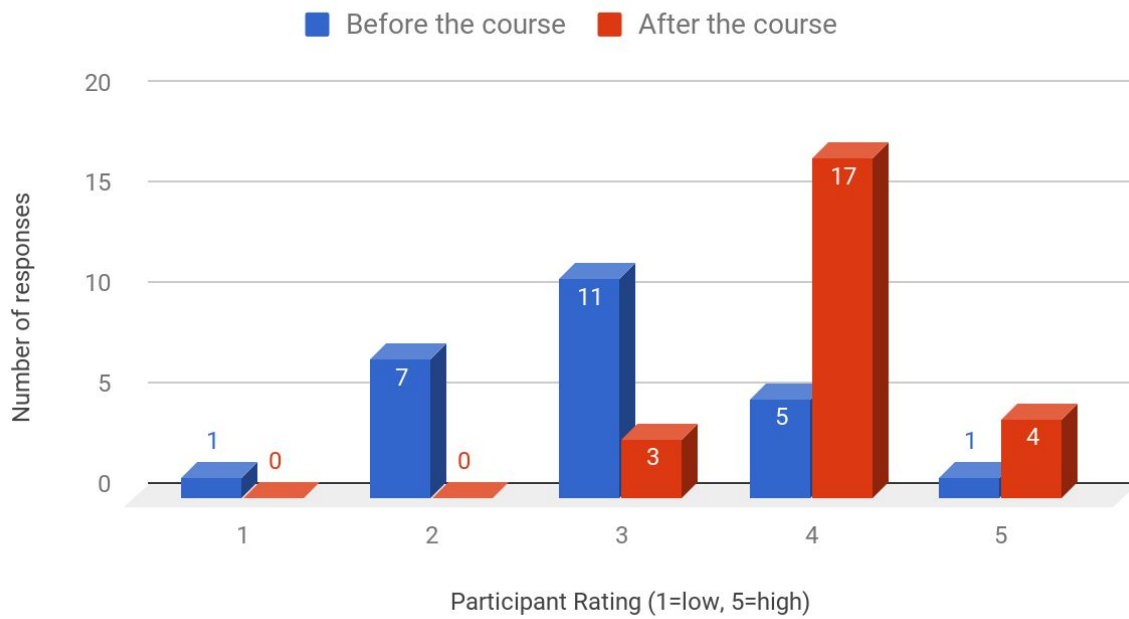
Participants in the EPF youth advocacy summer training course were sent an electronic survey immediately following the event. Of the 39 participants emailed, 25 provided responses. This section outlines the results of this survey



Participant learning

Participants were asked to rate their confidence as a patient advocate before and after the event. Using a scale of 1 - 5 where 1 is low and 5 is high the average before the event rating was 2.92 and the average¹ after event rating was 4.04. Responses are shown in the graph below:

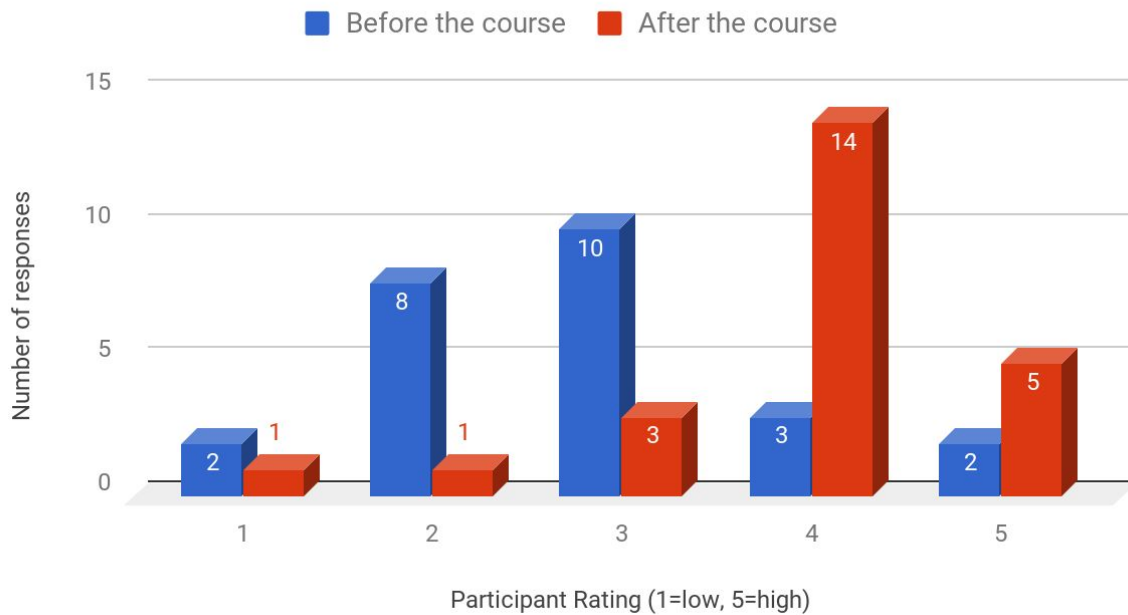
How do you rate your confidence as a patient advocate?



¹ Mean score

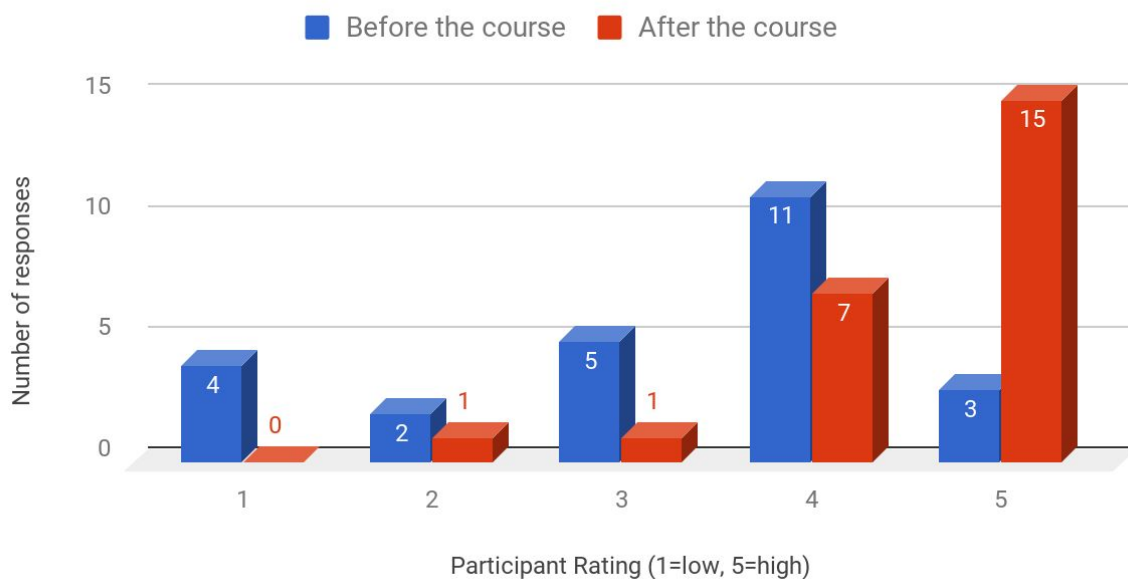
Using the same scale, participants were asked to rate their ability to lead patient advocacy projects. The average before the event rating was 2.80 and the average after event rating was 3.88. Responses are shown in the graph below:

How do you rate your ability to lead patient advocacy projects?



Using the same scale, participants were asked to rate their understanding of the purpose of advocacy before and after the event. The average before the event rating was 3.28 and the average after event rating was 4.50. Responses are shown in the graph below:

How much do you understand advocacy and the purpose of a patient advocate?



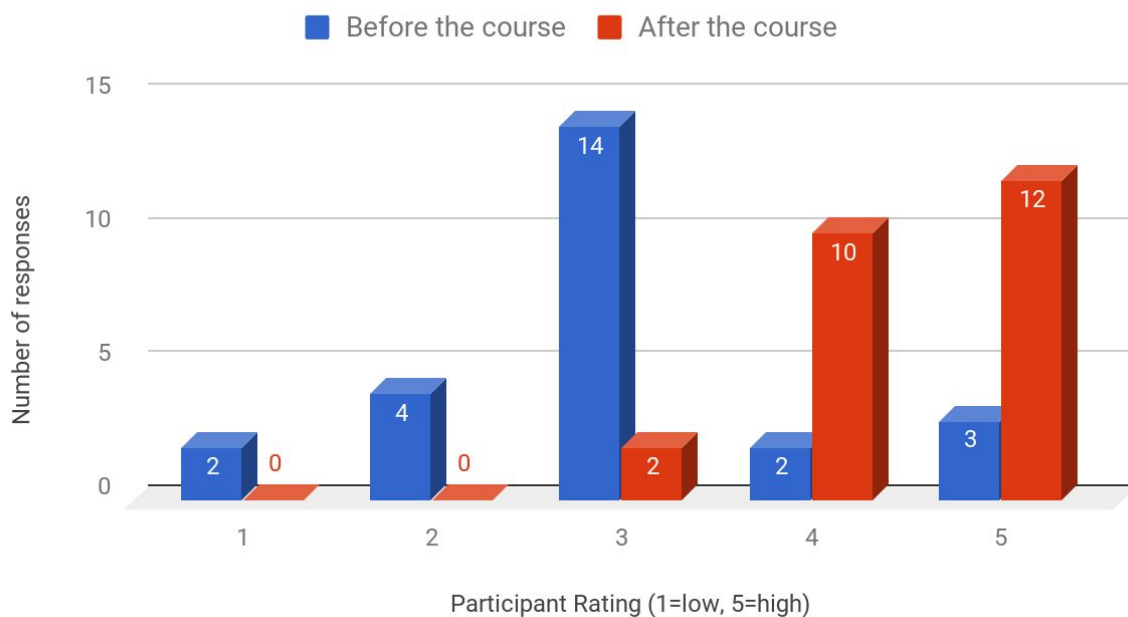
Using the same scale, participants were asked to rate their ability to speak up for patient rights. The average before the event rating was 3.24 and the average after event rating was 4.25. Responses are shown in the graph below:

How would you rate your ability to speak up for patient rights?



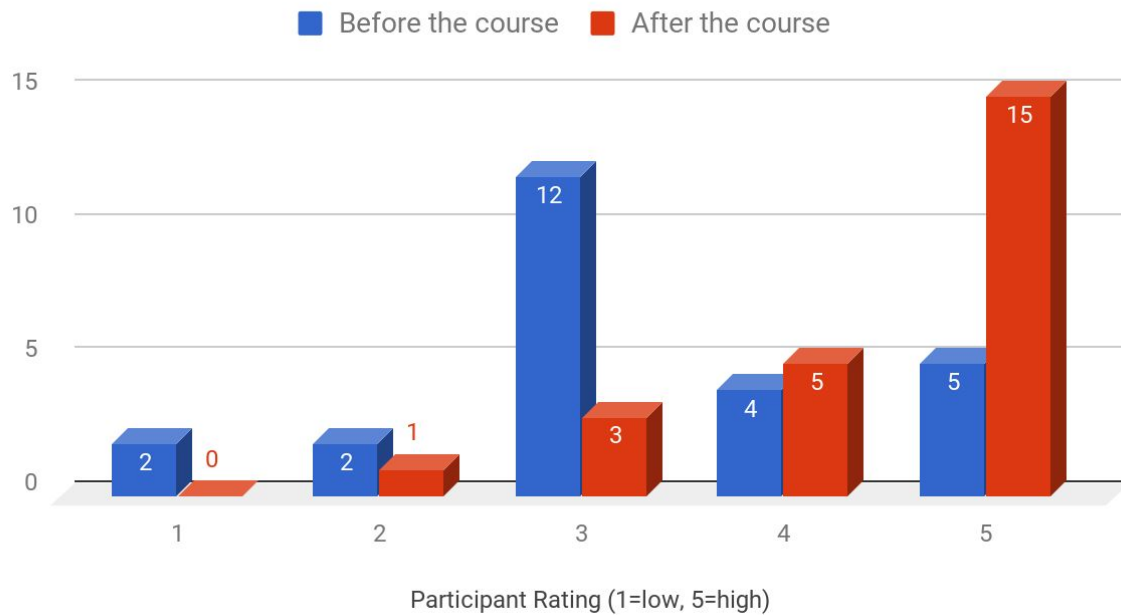
Using the same scale, participants were asked to rate their understanding of patient rights. The average before the event rating was 3.00 and the average after event rating was 4.42. Responses are shown in the graph below:

How would you rate your understanding of patient rights?



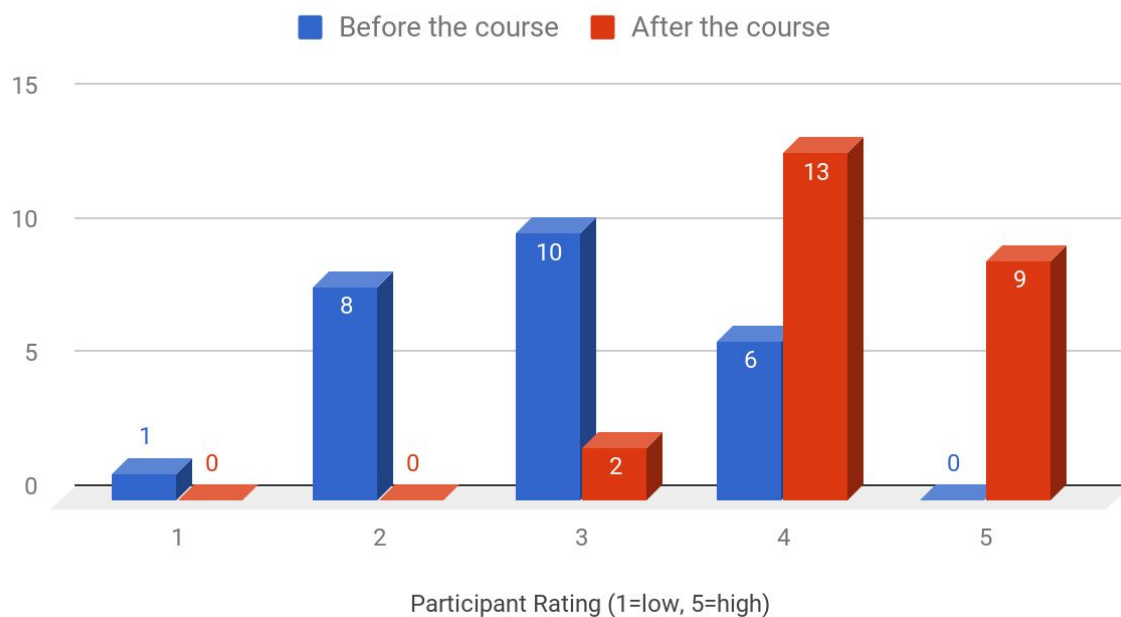
Using the same scale, participants were asked to rate their understanding of patient discrimination before and after the event. The average before the event rating was 3.32 and the average after event rating was 4.42. Responses are shown in the graph below:

How would you rate your understanding of patient discrimination?



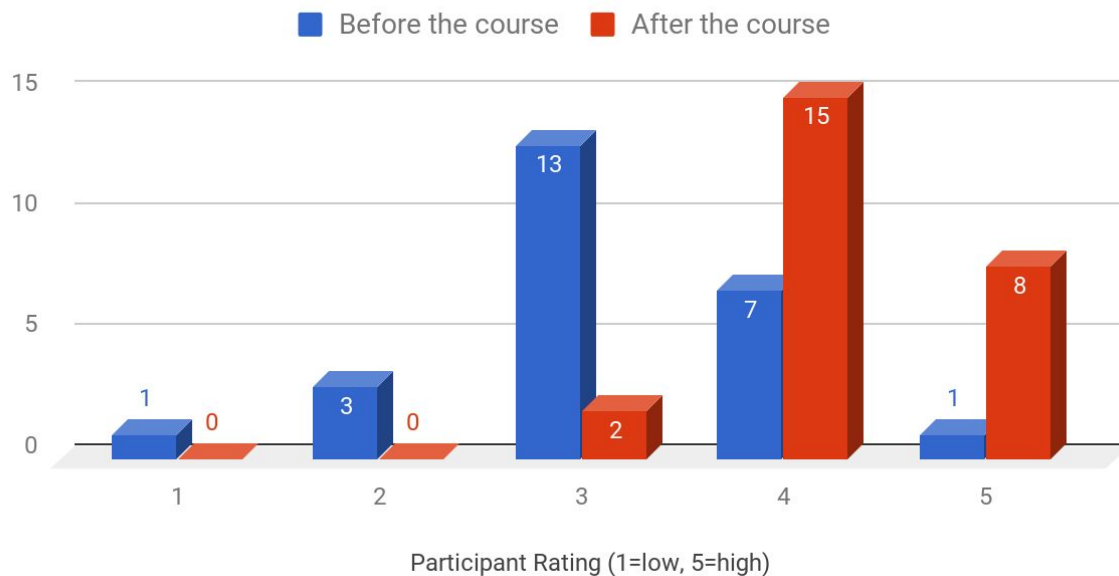
Using the same scale, participants were asked to rate how empowered they felt to make positive change. The average before the event rating was 2.84 and the average after event rating was 4.29. Responses are shown in the graph below:

How empowered do you feel to make a positive change as a patient advocate?



Using the same scale, participants were asked to what extent they had the necessary competencies to be a patient advocate (e.g. teamwork, communication skills). The average before the event rating was 3.16 and the average after event rating was 4.24. Responses are shown in the graph below:

To what extent do you have the necessary personal and cultural competencies to be a patient advocate?



Participants were asked “What were the key things you learnt within this training?” using an open text box. Responses were:

- “Leadership skills”
- “The process of writing a project and the importance of speaking out loud. Also, the importance of knowing right people in certain moment, and how to fight discrimination in different ways.”
- “Better knowledge of myself as an advocate and employee”
- “Patient rights, differences between countries, leadership styles, tools for projects”
- “Great projects occurs, as you keep on trying.”
- “How to properly communicate as a team and with your team, mainly due to the different ways people work. How to not lose the motivation needed to keep working on what you love.”
- “The extent of problems and issues....every country faces different ones. There is need for international cooperation.”
- “Leadership skills, rights Planning”
- “There are useful tools to that I can use in my personal development, and also as patient advocate the importance of structuring an "elevator" pitch. Answering to

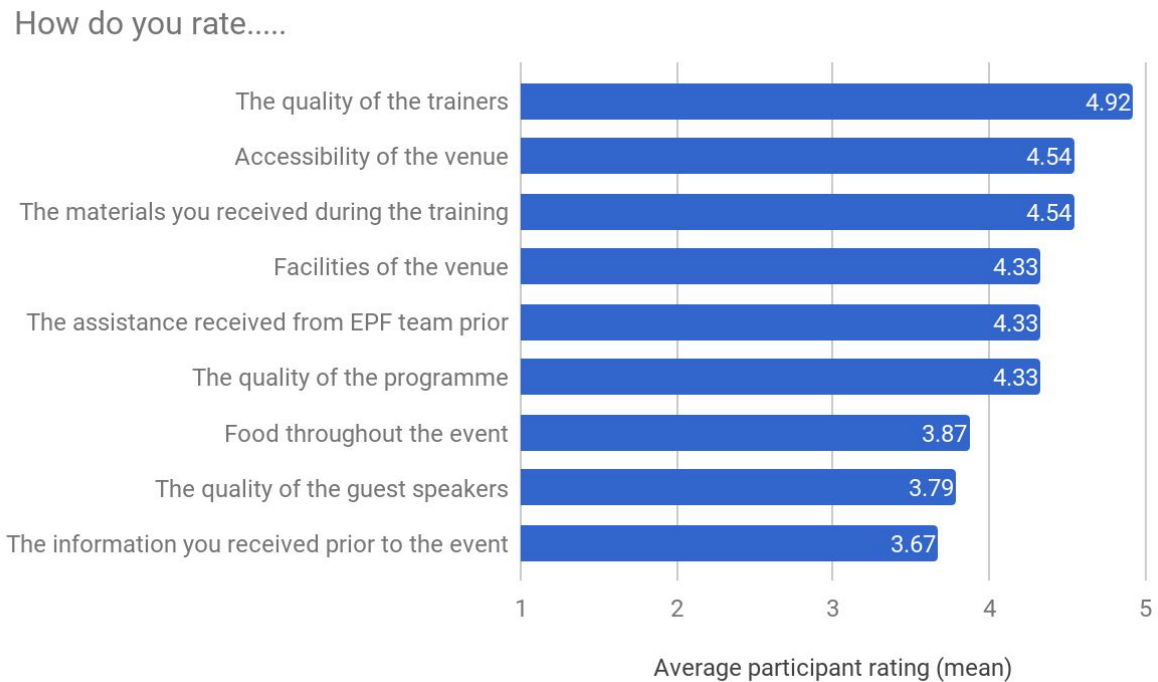
simple but big questions "why?", "what?", "how?" No one hears the ones in the second row - is important to speak up, to dare"

- "Change takes time and that you shouldn't give up, no matter how many difficulties you face on your way."
- "We have to help ourselves. Yes we have rights but we have to take responsibility and use them."
- "To believe in myself while advocating and to have a good plan and how to make the plan work."
- "Human rights, Leadership skills"
- "human rights in more detail and how to use them in our advocacy work; basically it is something that I can start with every time;"
- "How I work and how others work and how to communicate with them"
- "How to create a project."
- "That most of the patients across every disease undergo some sort of discrimination at a point, either positive or negative, and they all need to feel like they can have a voice. I learnt mostly about other conditions and was surprised to notice the similarities."
- "Different ways of thinking, reflecting on personal skills and attributes as a leader, understanding of rights, activities of other young advocates and support opportunities that are available."
- "Personal stories of other patients"



Participant experiences

Participants were asked to rate different aspects of the event on a 5 point scale, where 1 = very bad, 2 = bad, 3 = neutral, 4, = good and 5 = very good. Average responses are shown in the graph below:



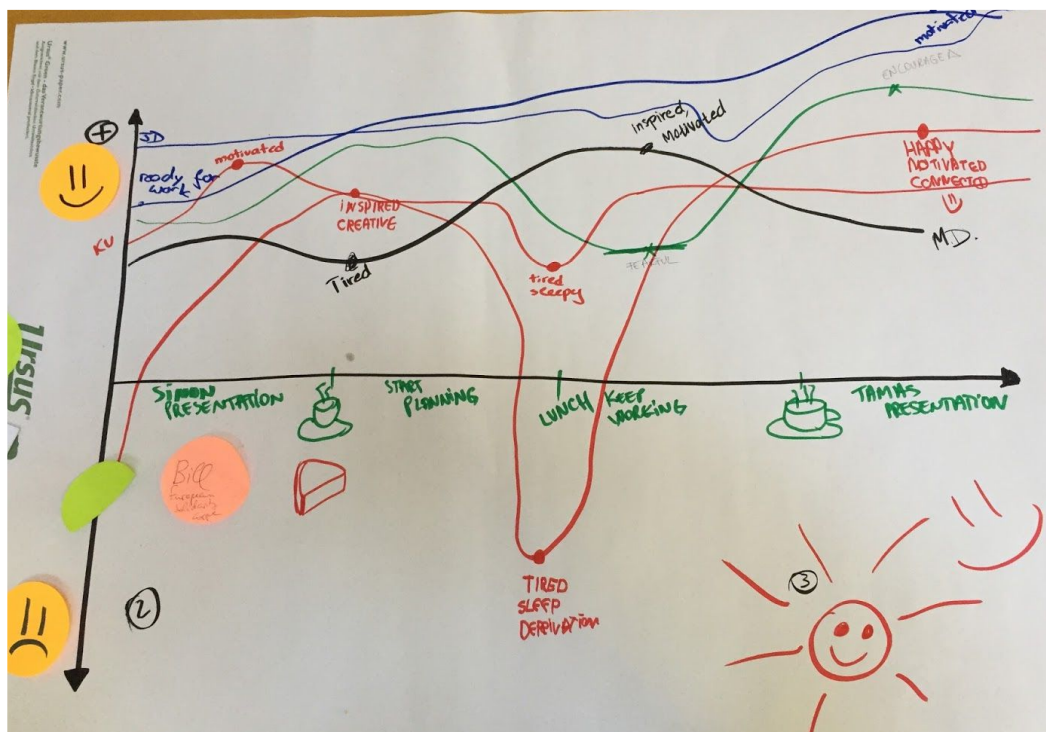
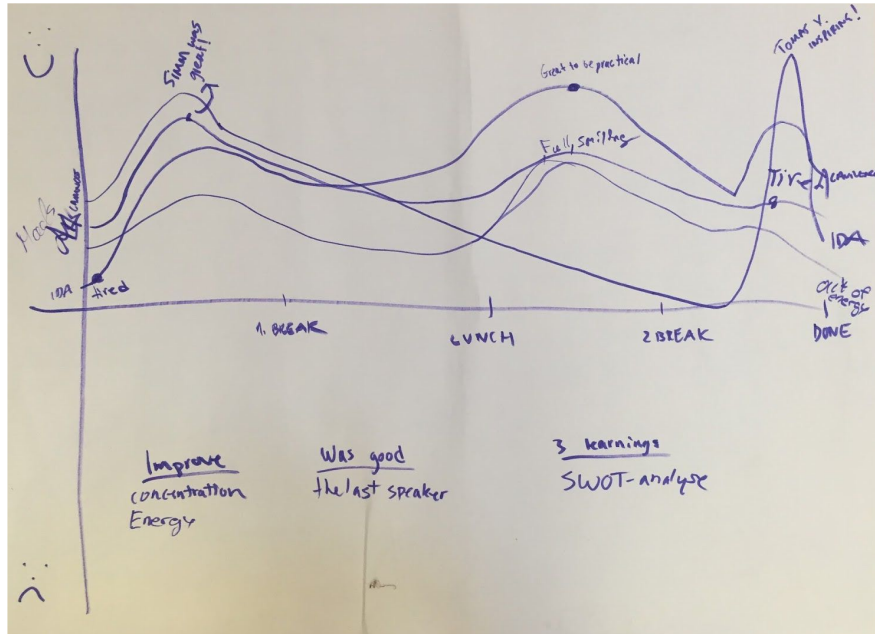
Participants were asked how relevant the training course was to their day to day role as a patient advocate. Answering using a sliding scale of 0-100 where 0=*not at all relevant*, 50=*Neutral* and 100=*highly relevant*, the average response was 80.0

Participants were asked if the programme met their expectations. Answering using a sliding scale of 0-100 where 0=*not at all*, 50=*Neutral* and 100=*completely*, the average response was 80.0

Participants were asked to what extent the program provided the opportunity to network with other patient advocates. Answering using a sliding scale of 0-100 where 0=*not at all*, 50=*Neutral* and 100=*a large amount*, the average response was 90.0

88% (n=22) of survey participants indicated that they create an advocacy project on this training course.

During the training, participants also used emotion/experience graphs (shown below) to illustrate how their experience changed throughout the course of each day. These indicated that participants generally found the experience positive and rewarding, though it was intense with long days.



General feedback

On the survey, participants were asked what the best aspects of the event were using an open text box. Responses were:

- “Meeting others with similar experiences for the first time in my life.”
- “Networking with other patient advocates”
- “The connection between young people all over the Europe, and the whole process of writing a project”.
- “Dan and Ed, of course”
- “Networking and learning from others”
- “The freedom to go anywhere to work (not being confined to the same room for the whole duration). The constant availability of the trainers for questions and personal help.”
- “The talks.”
- “Leadership skill planning”
- “Motivational speech, useful tools, networking”
- “The people that I met.”
- “The opportunity to meet patient advocates from across Europe and hear about the similarities and differences between the health services of different EU member states was invaluable.”
- “The training sessions!”
- “Very relevant and useful chats with colleagues that I have made”
- “Meeting lots of new people”
- “Connecting with other advocates and new skill.”
- “The possibility to network with other patients. I feel that we all had the opportunity to have amazing discussions on various relevant subjects that made us all think and reconsider our positions on previous ideas we had.”
- “Networking”
- “The opportunity to network with other young patient advocates.”
- “Definitely the trainers, I really want to thank Ed and Dan! You are the best!”

Participants were asked what aspects of the event could have been improved responses were:

- “The hotel, food”
- “Maybe more shorter days than fewer long ones to help with concentration and participation. Catering was absolutely awful.”
- “Maybe the part of human rights, to make it even more interactive.”

- “The par of guest speakers was boring as hell and I got easily distracted”
- “No Skype lecture; this was too much monotone and not all relevant. It would've been nice to have given the EPF youth people a certain role in the programme, like doing something in co creation with the trainers”
- “More interactive guest speakers; i.e. asking questions to the group.”
- “Less drama.”
- “Day 2- rights and discrimination”
- “Maybe better sound system for online sessions”
- “Probably this is one of the most common answers, but I wish I was longer.”
- “The use of Skype for guest speakers. It wasn't always obvious what they were saying.”
- “The Skype lecturers. It is more motivating to hear and see the person in real life.”
- “Creating a two groups of younger and older PAs because sometimes it seemed to me as a too big age gap among young PAs”
- “Don't invite people to speak when they shouldn't be speaking in public, when they don't understand when people can't listen anymore and still go on for another 20 minutes”
- “Less speakers and more time work[ing]. I think that program should be more oriented to the developing new skill.”
- “I think we should have had more time to network and to discuss ideas, even during the day while working. The time given to discuss and develop ideas and projects was very short.”
- “No skype sessions too many topics covered, would have been nice to focus on one topic and to get a deep knowledge have more exercise such as the elevator pitch, how to make a speech, how to deal with tensions within our organisations, how to make sure your voice is being heard more concrete exercises the presentation of the Youth group, still being unclear what the purpose of it, how to join, if I have to apply, the selection process, the workload...”
- “The Skype sessions, not necessarily because of the format, but because of the content of discussions which were not entirely applicable. It is a minor comment, but may have been better spent doing something else.”
- “I missed some organised event outside the facility”

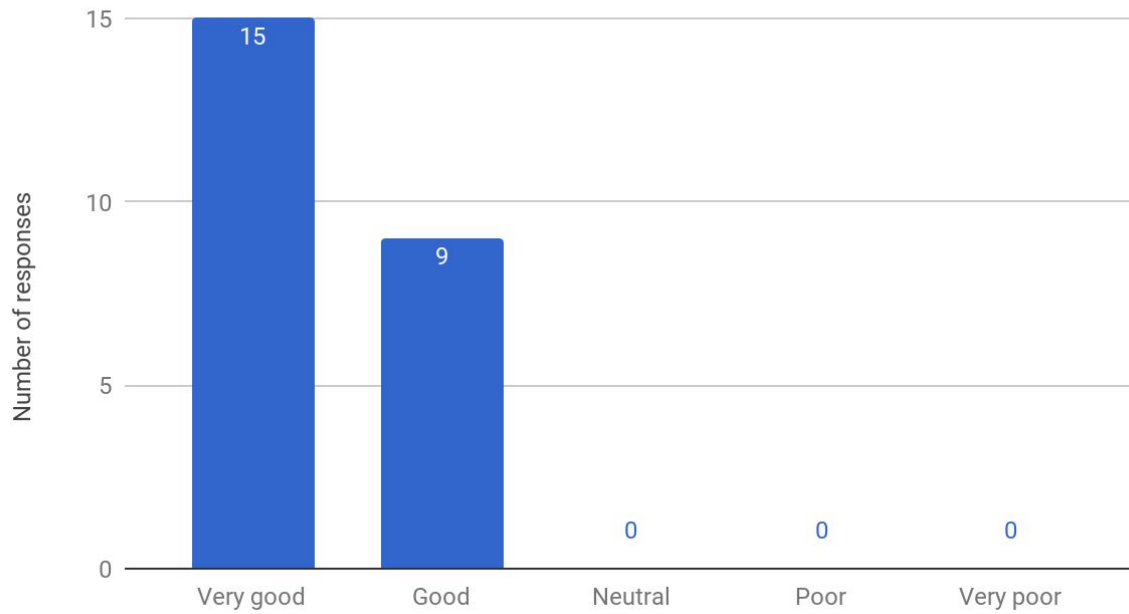
Participants were asked to share feedback on the organisation aspects of the event, responses were:

- “All EPF staff were fantastic and helpful. The trainers were absolutely brilliant too.”
- “It was well organised event with lot of interactive parts which is very good for sharing experiences and finding out patients problems in other countries”

- “To know upfront that we were sharing rooms Taxi's back to the airport was very nice!!”
- “No complaints! Everything was nicely organised in my opinion,”
- “More time on rights and discrimination”
- “Great venue, great organisers”
- “I'm glad that we managed to cover everything that was planned and that we stuck to the time schedule, it was a pleasure for me to be part of this amazing event.”
- “Notification of room sharing in advance.”
- “The organisation was overall quite good. There was however some difficulties receiving information in advance of the event. for example the information pack, i received it just a few days before, because they had forgotten to send it to me somehow.”
- “Perfect food, amazing surrounding - quiet for the thinking - that was absolute TOP for me! Being surrounded by trees and squirrels even though we were in the middle of the city”
- “Tell us the times it starts and when it stops for us to book flights, so you don't have to leave early”
- “Everything was perfectly nice organised.”
- “I wish, as a young adult, some of us did not feel discriminated by the adult staff. This was a sad thing to notice and to be discussed during the evening outings - the way we felt adults at the organisation were sometimes rude or condescending towards the young participants. This is something that really needs to be addressed. Other than that the young staff of the youth group is honestly amazing and very empowering, not only as individuals but as a group. Kudos!”
- “It would have been nice to be informed before the event that rooms would be shared”
- “If you have a bigger argument, please take it somewhere where no other people can see you. It is really bad atmosphere even for people who are not part of it”

Participants were asked “Overall how did you rate this event” responses are shown in the graph below:

Overall, how do you rate this event?



Section 2: Trainer reflection



This section contains the trainers' feedback and comments, based on their experiences of facilitating the program:

“Overall we were satisfied that the programme was delivered as intended, and the generally very positive feedback from participants above and within the event indicates that it has delivered the intended learning in a positive manner. Each of the training workshops we planned were delivered as intended, particular highpoints were seeing the use of the leadership tool by participants throughout the following two days.

The guest speakers remained the weakest part of the programme for us. Whilst some were excellent, and clearly brought value and inspiration to the young people, others were very poor, and did not speak in an engaging manner or follow the speaker briefing. In addition the number of speakers and time length allowed to them made it hard for many participants to concentrate. In future events we would recommend reducing the number of speakers to 3 or 4, only inviting speakers which EPF have previously seen speak, and avoiding skype links. It is important to recognise that a presentation from a speaker, (effectively very similar to the giving of information by a teacher) whilst valuable at times, is a method of education generally avoided by youth empowerment programmes, which instead focus on experiential learning and groupwork.

Looking at the programme in hindsight we feel it could be improved by give more time for participants to explore each of the three topic areas (leadership, discrimination/rights, project planning) in more depth - though it is clear that would not be possible in a three day course. For future events it be beneficial to reduce the number of topics, and work in greater depth on one or two areas to allow participants to develop a full and thorough understanding, or extend the length.

The tensions within between EPF staff and Youth Group members, created some challenging situation to deal with within the programme, and we found ourselves engaged in one to one conversation with a number of people on all sides involved in this. Whilst this did not derail the programme some participant comments above indicate it was noticed by others and created some tension. Despite this, we do view it as a positive progression for EPF and the youth forum. Whilst not a pleasant experiences for those involved this kind of

conflict it can also be seen as a sign of the [storming](#) stage of group development, a necessary step for groups to begin working together effectively. To move the group (and by group we mean both Youth Group members and EPF staff) to the next stage of development we recommend that EPF gives some thought to the purpose of the Youth Group and its approach to working with young people. This should involve considering what successful youth participation and empowerment would look like within EPF and how that compares to similar projects in other organisations, particularly when it comes to communication and collaboration between volunteers and staff. Through these key roles, expectations and communication channels should be identified. This will enable EPF to engage more effectively in conversation with its existing and future youth forum members about future direction. We would be very happy to provide advice and guidance through this process.

In practical terms, the venue and organisation was very effective and we found that we had all of the information and equipment necessary to complete our role as trainers. The recruitment of participants was excellent and we found them in generally to be highly motivated, clear about the purpose of the course and the right target group. In fact as a group we found them to be much more committed than other youth groups we have worked with. Support from EPF staff to ourselves was very good and we appreciated the space and trust we were given to undertake the training sessions.”