

HEAR MY STORY

Communications workshop for young adults
DUBLIN, 4TH-6TH OCTOBER 2019

WORKSHOP REPORT

So happy
that IBE made
this possible
for us!

I felt
comfortable
and confident
in talking and
discussing

I found the
whole
experience
super
motivating

Without IBE
none of this
would have
happened!

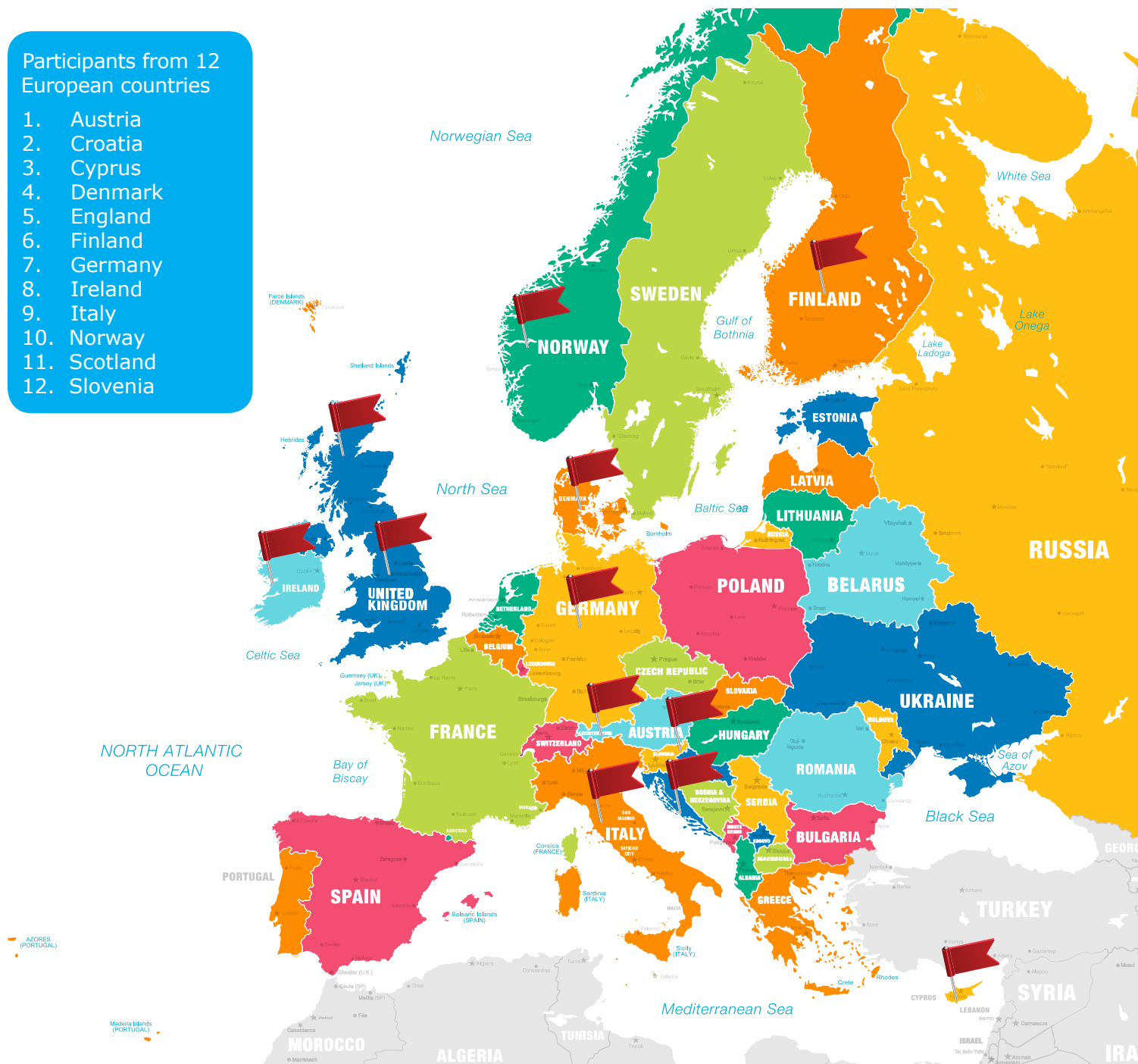
Thank you
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Workshop participants pictured with three members of the IBE European Regional Executive Committee (Shirley Maxwell and Natela Okujava, second and third from left standing) and Ljubica Vrabe (front left). Also pictured is Evaldas Rupkus (centre front), the workshop facilitator.

Participants from 12 European countries

1. Austria
2. Croatia
3. Cyprus
4. Denmark
5. England
6. Finland
7. Germany
8. Ireland
9. Italy
10. Norway
11. Scotland
12. Slovenia



THE REPORT

BACKGROUND

EpilepsyNext was established by IBE to acknowledge the voices of the youth around the world affected by epilepsy that need to be heard. Fifteen remarkable young adults from across Europe met in Dublin in October 2019 for a communications workshop entitled Hear My Story which was the inaugural event staged by IBE's European Regional Executive Committee under the auspice of EpilepsyNext.

Epilepsy is the most common chronic neurological disease which, according to the World Health Organization, affects more than 50 million people worldwide, with an estimated 2.5 million new cases each year. Epilepsy is one of the world's oldest recognized conditions, with written records dating back to 4000 BC. Fear, misunderstanding, discrimination and social stigma have surrounded epilepsy for centuries. This stigma continues in many countries today and can impact on the quality of life for people with epilepsy and their families and friends. For some people with epilepsy, the issues of stigma and discrimination are more devastating than the epilepsy itself.

THE PROBLEM

Despite the statistics, there has been much less public awareness and discussion about epilepsy compared to other conditions. This has to change and the future lies with the next generation.

There is wide recognition amongst IBE's chapters that young people are currently under-represented in their associations. This poses the risk of undermining the future potential of epilepsy associations or, at worst, putting their very future in jeopardy. It is also felt that the issues facing young people affected by epilepsy are not getting the public or political attention they should. Yet the diverse range of experience and the remarkable personal resilience that a large number of young people with epilepsy already demonstrate is going unnoticed, because many feel ill-equipped to report on their achievements.

THE PLAN

Maturing into adulthood is a difficult time for most people. For young adults with epilepsy, faced with the added issues that a diagnosis of epilepsy can bring, it can be an even more challenging time. Recognising this and in line with IBE's goal 'to provide resources for people with epilepsy and their families to maximise quality of life', IBE decided to offer a workshop especially for young adults with epilepsy in Europe and the

objectives of the workshop were agreed as follows:

- To offer a platform for young people to voice the issues they face and raise awareness of these issues;
- To provide young adults with epilepsy with the skills to become epilepsy advocates, in partnership with IBE's chapters in Europe;
- To hear how young people with epilepsy perceive patient organisations and how IBE, together with its chapters, can better adapt its operations to embrace the views and expectations of these young people with epilepsy;
- To harness the outcomes of the workshop towards building a political campaign that could be brought to national policy makers as well as those at EU level;
- To encourage the group to channel their results into a campaign for International Epilepsy Day 2020;
- With an ultimate aim of developing a youth commission within IBE.

Chapters across Europe nominated their shining stars and, in the end, twelve countries were represented: Austria, Croatia, Cyprus, Denmark, England, Finland, Germany, Ireland, Italy, Norway, Scotland and Slovenia. The workshop itself was led by Evaldas Rupkus from Germany, an experienced facilitator who is an associate with People Dialogue & Change, an international company with a strong track record in supporting Patient Representative organisation to train and support a generation of young patient activists. Epilepsy Dialogue & Change has long been working with the European Patient Forum, supporting the Summer Training for Young Patient Advocates programme, and has also worked with the European Platform on Multiple Sclerosis.

THE PROGRAMME

Bringing awareness to important issues such as the right to work, discrimination, social exclusion, access to treatments and fighting stigma, the opportunity to network and to work together on projects, as well as to get inspired were recognized as key factors for the group's attendance.

The definition of what it is to be an advocate was discussed and consideration given to target groups, which ranged from national governments, MEPs at EU level, right down to patients themselves with media, schools, employers and the healthcare system also being identified.

Solutions were considered and the attendees split

into sub groups to develop concepts with different media products and how they might influence change. Education, employment, patient support and international networking were selected as the four projects that the group would develop after an initial prototype was conceived.

Additionally it was considered how to best utilise International Epilepsy Day to launch the projects with the support of IBE, which resulted in a fifth project for all of the group to work on together - a social media campaign that will feature each of the participants sharing personal stories about their own epilepsy journey that will include "A day in the life of..." and "Overcoming challenges that epilepsy has prevented me from trying before" or talking about the project that they are working on as a result of this workshop.

THE OUTCOME

This social media campaign will feature the next generation telling the world, in their own words, the struggles that they face in living with epilepsy and the barriers that they have overcome. Moreover, it will show that they are not afraid to be heard. Self-empowerment will be at the centre of this campaign. It will be a source of new perspectives, real life experiences, and outcomes that have the potential to guide epilepsy research and care, ultimately improving the quality of life of all people living with epilepsy.

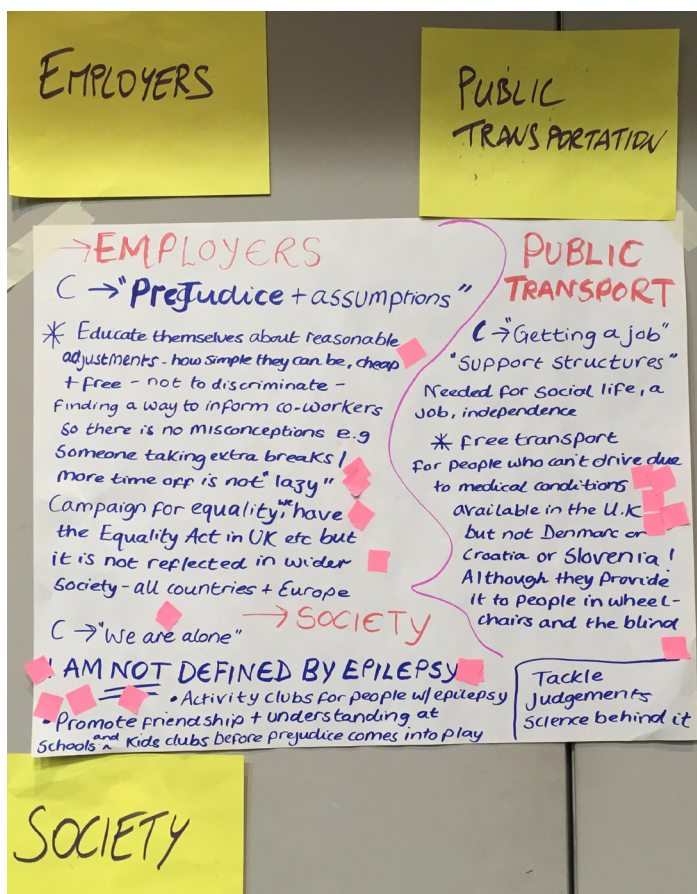
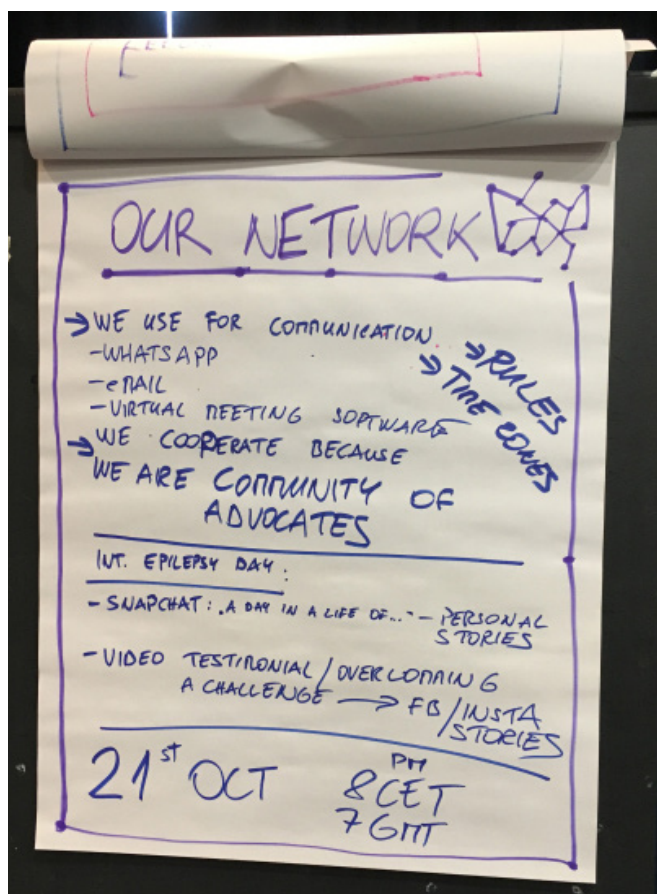
It was hoped that one of the primary outcomes

of this workshop would be the development of a programme that would assist young adults living with epilepsy to become epilepsy advocates, with the added potential to be replicated at a national level through IBE's chapters and with the possibility of adaption for use in other IBE regions. Unquestionably, this has been achieved.

The group had the opportunity to evaluate the workshop and one summarised the highlights of it as "support from peers, open honest discussion, positive participation, the planning element for the future, the social aspect and meeting others as well" which certainly are among the results for which IBE had wished.

The success of the project is still evident in the continued active engagement of the young people in rolling out their social media project and in their interest in further evolving the group. It was inspirational to witness how this group of young people felt that their capabilities and skills as advocates had improved as a result of the workshop. Each one returned home with the strong belief and confidence that they could make a difference.

IBE's realisation was achieved in helping young people to grow in independence with one of the attendees saying "Very often 'Thank you' is the only words that come to mind but I believe that we are all capable of making a huge difference in relation to the understanding and experience of people with epilepsy."



THE FUTURE

Without doubt, connections have been established and a network of experience has come together to create a community of advocates for people living with epilepsy. For IBE, this is a great foundation for the future and addresses IBE's goals of awareness, advocacy, empowerment and communication. Since the end of the event, the participants have been staying in touch using Social Media as well as Zoom video calls, as they continue to work on their project for International Epilepsy Day and the longer term projects that the teams proposed during the workshop.

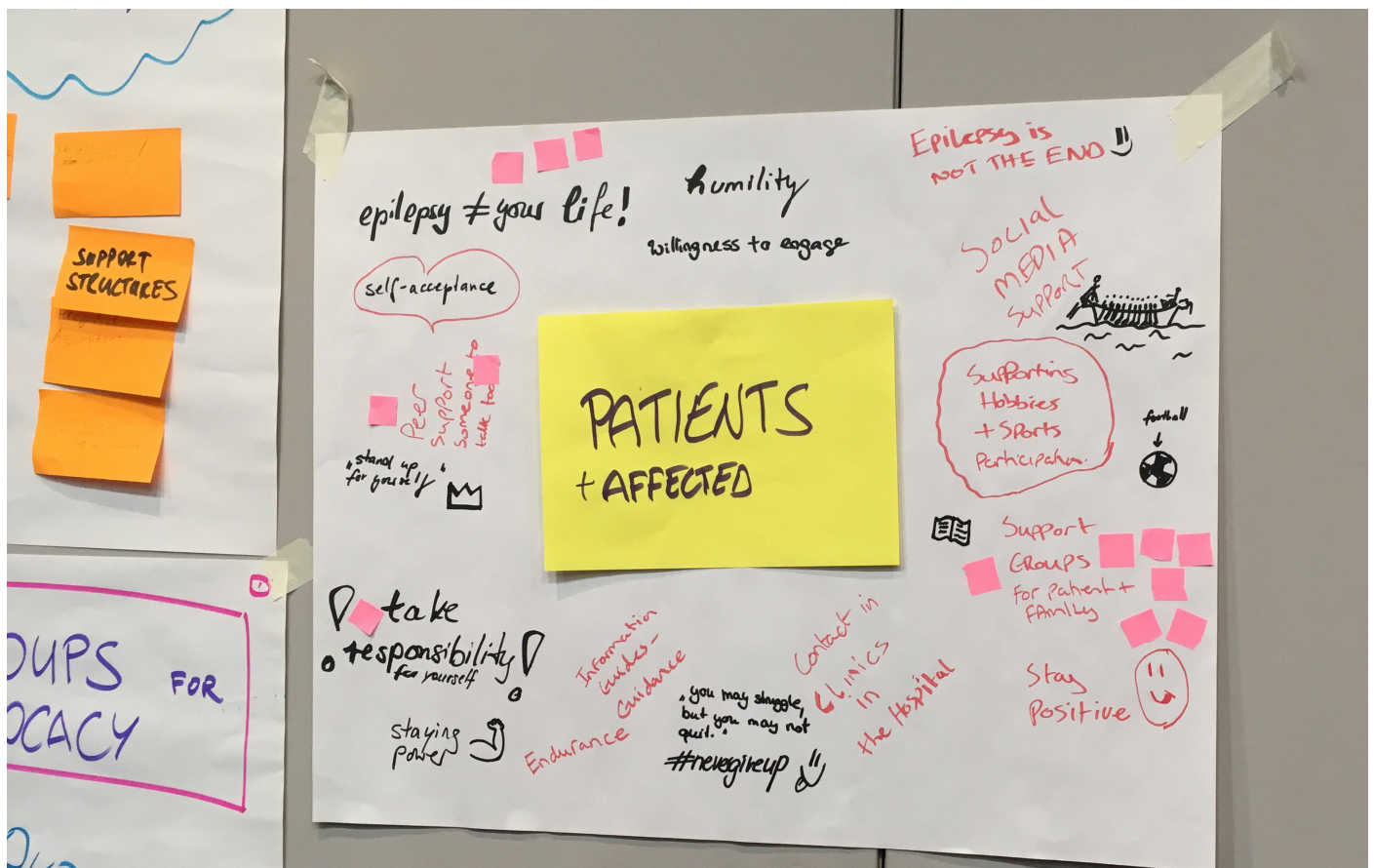
We now look to rolling out the initiative in other regions with the possibility of engaging the young adults from the Dublin workshop in our future endeavour.

WORKSHOP SURVEY - what the participants said

What were the best aspects of the workshop?

- I found the whole experience super motivating just to be in the same room as people with similar passions and aims
- I felt comfortable and confident in talking and discussing. It was easy to express myself
- Talking with others, support from peers, open honest discussion, positive participation, the planning element for the future, the social aspect and meeting others as well

- Thank you for everything & this opportunity that comes once in a lifetime
- I had a really great time, everyone was so great and I also learned a lot from each person
- I'm very glad that everyone has to talk about their own story and that there was nearly no self-pity
- **What were the key things you learnt in this workshop?**
- The divide between countries in terms of the support for people with epilepsy despite being covered by common European law
- More motivation and inspiration for projects - talking more to persons
- Importance of networking across the borders
- Disparity of epilepsy care in the EU difficulties in other countries the network that exists with the IBE supports IBE can provide inspiration and motivation from others
- The challenges others are facing, different ideas how we can aware people about epilepsy, how to start working on a project
- About other people's experiences of epilepsy in their own country
- There are a lot of differences between the European countries
- How to speak out more about epilepsy and to make a difference
- Our differences and getting some ideas and what to improve back home

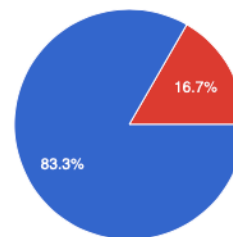


WORKSHOP SURVEY

The results in graphics

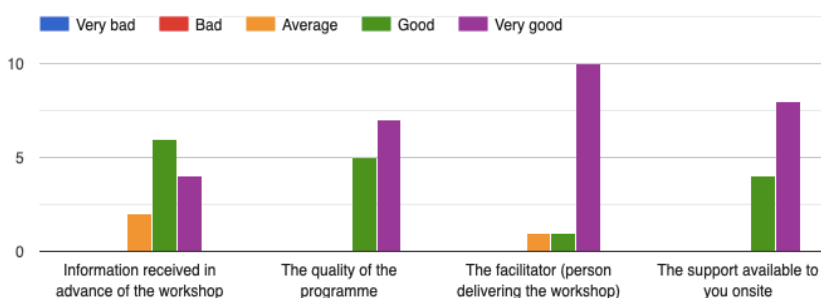
Overall how would you rate this workshop?

12 responses

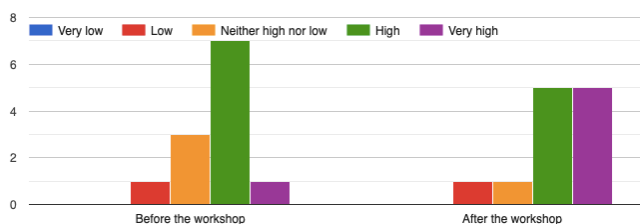


- Very good
- Good
- Neutral
- Bad
- Very bad

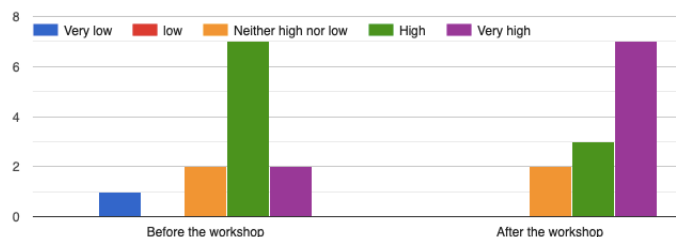
How do you rate:



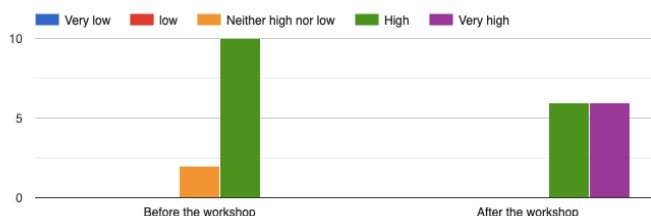
To what extent do you have the necessary personal and cultural competencies to be an epilepsy spokesperson? (e.g. communication skills, teamwork abilities)



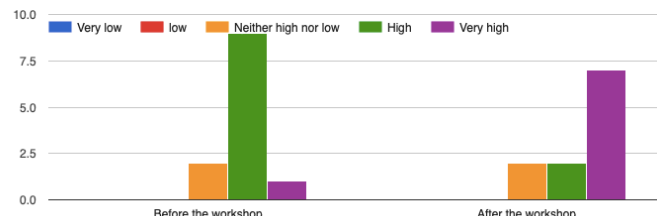
How much do you understand advocacy/speaking out and the purpose of advocates?



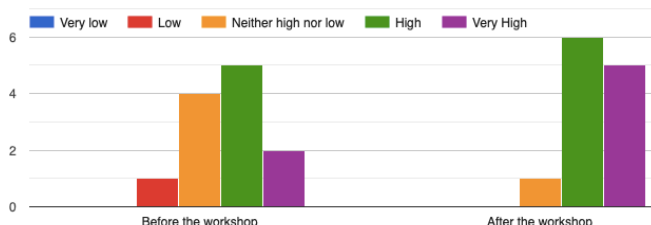
How would you rate your ability to represent the views of other people living with epilepsy?



How empowered do you feel to make a positive change on epilepsy awareness?



How do you rate your confidence in working on an epilepsy project?



How do you rate your skills in working on an epilepsy project?

