

What was issue?

Young adults (aged 16-24), like other adults with epilepsy, can find living with epilepsy a challenge. As well as the effects of seizures, they are at higher risk of anxiety and depression, cognition and memory problems.

Some issues previously identified as relevant to the age group included:

- Transition to adult health services
- Social pressures – going out, drinking alcohol
- Fear of seizures and stigma from peers can lead to isolation and loss of confidence.
- Gaining independence / moving away from home
- Further/higher education and employment
- Contraception

Opportunities or limitations of activity? (Time, resources, impact etc)

Opportunities: Use of social media is high and helped to generate interest. A small core group of 16 attended workshops but a wider group gave feedback online.

Limitations: Access to actively interested young people who follow epilepsy topics on social media was easier than access to the less interested who may be a more difficult to engage group more in need of support to manage their epilepsy. Sustaining engagement over time to deliver a project.

Which children or young people?

Regional demographic	Diversity Information	Occupation
Shipleigh	3 Male / 13 Female	6 Full time employment
Halifax	3 Mature students
Glasgow	1 Black/British	2 University Students
Surrey	1 British/Pakistani	2 College Students
York	2 White/Scottish	
Farnborough	12 White/British	
Lancashire	
Hereford	1 Atheist	1 Learning provision for those with disabilities
Cornwall	1 Muslim	
London	1 Hindu	1 Unemployed/volunteering
Hertfordshire	2 Christian	
Winchester	11 No religious belief	1 Expectant mother

Recruitment plan?

- We contacted voluntary organisations, schools, further and higher education institutions, our social media channels and health service contacts.
- We focused on Yorkshire as we were planning the youth advisory group meetings in Leeds, but we had interest from across the country. 21 young people expressed an interest, though some couldn't make the dates of the meetings or had to withdraw for personal reasons. 16 joined us

What did you (professionals) hope to achieve?

We set out to develop an online programme/toolkit that young people could access via their smartphones. We aimed to:

- Provide young people with the knowledge, skills and confidence they needed to manage their epilepsy
- Cover topics important to young people such as alcohol, staying safe when going out, talking to friends, independence and transition to adult services
- Base the resource on extensive user research so that all the content was relevant and engaging
- To do this, we worked with a youth participation worker to engage young people in the design and testing of the resource (discovery phase)

We used the findings to develop a mobile-accessible programme/tool

What did children /young people hope to achieve?

They gave views for what the self-management tool should achieve

- Be accessible to as many people as possible
- Be mobile-friendly because we are all on the phones all the time
- Have 'top tips' with short information
- Show lived experience it's really important so you can see what others do when they go on nights out etc
- Offer top tips and connect to Epilepsy Action website for people who want to know more
- Long-term maintenance – keep updating blogs and vlogs, we thought this content might create a community. Needs to be current as there are always things coming up with the science
- Use videos. I saw a video from epilepsy action with a real-life experience of an absence seizure and that was really good
- Manage the security side of things to make it safe. Making sure no one is getting bullied

How did you do it? (method)

Three workshops with creative activities, feedback between session via What's App and email. Additional input to testing content and design from more interested young people.

How did it impact change?

In 2020 6,794 people used the Epilepsy Space following launch in May.
In 2021 15,864 people had used the resource up to the end of September.
We have collated feedback comments from users and added stories.

What worked, what didn't, limitations?

We were able to build a resource that was well received we were not able to resource a moderated forum that connected young people in a safe way.

How did you celebrate / reward young people input?

Paid for travel and meals out. We offered media opportunities and featured some in videos others learned about developing online content and IT security issues. Some gained confidence from coming to the group and reported being able to tell others about epilepsy.

For more information please go to <https://epilepsyspace.org.uk/>