

Epilepsy Community Outreach (ECO): Co-ordinating care through technology and workshops

Funded by the Scottish Government – Framework for Neurological Care 2020 - 2025

Delivery

Thanks to the Scottish Governments Framework for Neurological Care 2020–2025 Funding, Quarriers Epilepsy Community Outreach have delivered 2 strands of community-based epilepsy support, maximising existing resources, embedding multi-disciplinary working and embracing innovative approaches.

Strand 1 - Quarriers have rolled-out our virtual Annual Review Clinics for people with Epilepsy. Funding has enabled 16 clinics in collaboration with GP colleagues across North Aberdeenshire and Moray providing streamlined, multi-agency **support to 161 people living with epilepsy**. The accessible virtual clinics remove significant barriers to attendance and diagnose patients’ current needs and inform critical on-going support quickly and accurately.

Strand 2 - In partnership with Epilepsy Scotland and Lanarkshire Epilepsy, we have researched, developed and delivered a new, innovative, needs-led Epilepsy Awareness (EA) workshop. With the support of trainers at the world leading William Quarriers Scottish Epilepsy Centre (WQSEC) content was co-designed after desk-based research and community consultation to identify gaps in current provision. **10 workers from 3 different organisations were up-skilled** to deliver awareness raising workshops and support materials were produced including **unique video content from individuals on their real life experiences of living with epilepsy**.



<https://vimeo.com/862445077/fc12149df5?share=copy>

Our pilot delivery reached a wide a range of partner organisations and support agencies including Job Centre Plus, HSCP, Social Work Services, private companies, Citizens Advice, local councils, Housing associations, Mental Health services and NHS colleagues. During the funding period we delivered:

- **46 tailored workshops to**
- **32 organisations,**
- **293 individuals in**
- **6 local authorities** - Falkirk, Fife, Glasgow, Lanarkshire, Moray and Stirling.

Workshops were delivered in an accessible, flexible, bespoke and needs led way either online or in person with content adapted to best suit organisational needs. (IMAGE IF SPACE)



Impact

Our virtual Clinics and Epilepsy Awareness Workshops have established new community-based, co-ordinated care that maximises the experience and relationships established by Epilepsy Outreach and Fieldworkers.



Both approaches are multi-disciplinary and have strengthened partnership working between epilepsy partners, council departments, community organisations, social work teams, NHS and health care partners. In line with our anticipated outcomes delivery has **supported 161 people with epilepsy to remain safe by ensuring they can access critical annual reviews.**

Our virtual annual review clinics have:

- Provided **early intervention/prevention to 161 people living with epilepsy** across 16 clinics within Moray and Aberdeenshire
- **Reduced costs, transport, anxiety levels** associated with attending annual reviews
- **Addressed the lack of capacity within GP practices** to facilitate reviews

These critical reviews have helped to reduce the risk of epilepsy-related fatalities for people living with epilepsy. An additional 162 people have received preventative care that takes a “whole person” approach to controlling and reducing seizures including supporting individuals with wider lifestyle and health considerations with follow up care provided. (Annual reviews are desirable within primary care as detailed in the SIGN 143 Guidelines.)

106 individuals (of the 161 attending clinics) were further supported following their review by the Quarriers Epilepsy Community Outreach team either directly or via signposting to other services. This has included advice to seek further GP input on seizure activity or anti-seizure medication reviews, making referral to Neurology, pre-conception Clinics or other health related services. Signposting has been made to a range of community partners including Housing, Enable Works – disability employment support, Citizens Advice Bureau, local pharmacies for example. With our capacity to provide wrap around care we have also referred individuals to our own service for follow up help with benefits, food parcels and social support groups as well as providing information and advice regarding healthy lifestyles to help limit life threatening seizures. Feedback on the importance of the Annual Reviews has included:

“Feels good to get them, I feel looked after and it keeps in touch of how I am”

“.....it feels safe.”

“.... can see how I am doing with my medication”

Our staff report that delivering the clinics has improved joint working relationships with NHS staff, GP surgeries, local pharmacies and Epilepsy Specialist Nurses. The ECO worker is the lynch pin connecting the multi-disciplinary teams and providing consistent and reassuring support to individuals ensure they receive appropriate, timely, needs led support. “QUOTE – partner if possible”

Developing and delivering brand new Epilepsy Awareness Workshops:

In partnership with Epilepsy Connection and Lanarkshire Epilepsy we have:

- **Successfully embedded skills and resources across 3 key community-based Epilepsy Teams** that work across 12 Local Authorities.
- Upskilled **10 staff**, providing them with a unique toolkit to effectively inform key community partners.
- Increased the **capacity of 32 organisations to best support individuals with epilepsy to thrive** improving access to employment, education, and a wide range of community activities.
- **Resulted in 293 people** within the local workforce **being better informed** in epilepsy, its challenges, how it presents and how to support someone living with the condition.

Promoting and delivering workshops has begun to reduce the stigma often associated with Epilepsy. Workshops have given partner organisations and their staff more confidence and understanding around the everyday challenges associated with Epilepsy. Building this capacity and raising awareness has helped remove barriers to people with Epilepsy ensuring they receive appropriate care and support when accessing health and community services, from housing support and financial advice, for example.

Those attending training are better prepared and more confident to provide support for someone with epilepsy. Care home staff, nursery, primary school and college staff, job centre staff and social work

colleagues all report feeling “very well prepared” post workshop. This extended to NHS and Nursing colleagues who also reported having learnt something new and feeling more informed.

Marketing materials have also provided wider profile-raising opportunities and stimulated discussions across the community. Quarriers ECO Worker said:

“Its great to now have marketing and promotional material which created new opportunities to start conversations about Epilepsy and to have Epilepsy visible and with a positive profile in community spaces (e.g. supermarkets, churches and cafe notice boards). Raising awareness and generating discussion has helped to tackle the stigma and misinformation often associated with Epilepsy”

As part of the workshop co-production process, consultation was undertaken with local delivery partners and of course people we support. This feedback shaped the content and format of the new workshops and has resulted in the inclusion of a video from people living with epilepsy talking openly about their experiences and the impact this has had on them throughout their lives (link attached above). This powerful, often emotional, element has enhanced the workshop content and brings to life the challenges that many people with epilepsy face. The process has been empowering and has amplified the voice of people we support.

Evaluation

We have used qualitative and quantitative measures to evaluate the impact of the project, including:

- Targeted questionnaires
- Surveys
- Partner consultations
- Regular anecdotal and verbal feedback from multiple stakeholders

Workshop participants, organisations, community workers and people living with epilepsy have all informed the development process and learning captured as part of the delivery of this funded work.

Feedback

Virtual Annual reviews

- **233 people with Epilepsy were offered a virtual annual review clinic**
- **161 people attended their review**
- **106 people were supported by Quarriers ECO team as a result of their review**

Following their review people living with epilepsy have reported to staff that they feel healthier, their condition is more stable, they are financially better off, and feel their support needs are being met. As a result of this support their confidence has increased, they felt better able to attend appointments, and felt positive about seeking out employment, education, training and community activities.

Epilepsy Awareness Workshops

As detailed earlier in this report during the pilot deliver period we delivered both in person and online workshops to:

- **46 tailored workshops to**
- **32 organisations**
- **293 individuals in**
- **6 local authorities** - Falkirk, Fife, Glasgow, Lanarkshire, Moray and Stirling.

97 people who attended workshops completed survey questionnaires post-delivery and we recorded the following encouraging results:

- **98% “agreed” or “strongly agreed” that they had learnt something new**
- **74% agreed they felt “very well prepared” to support someone with epilepsy after the workshop**
- **92% of those asked scored the workshop 4 or 5 out of 5**

Participants made the following comments prior to attending the workshop:

"I know very little about Epilepsy".

"I have no idea how to support someone with Epilepsy".

As a result of the workshops being delivered participants were able to share the following statements:

"I have more knowledge and awareness to put into practice".

"The session was very relaxed, questions could be asked at any time, the session was very informative".

"The videos allowed me to prepare for what it looks like".

"I feel I would certainly have more confidence now".

"Learning about all the different types of seizures and it's not just about convulsing".

"I feel everyone in healthcare would benefit from this course".

Delivery staff also had a positive view of the development and delivery process as well as the benefits of the toolkit and the impact it has had and its potential for the future:

Feedback on the development and training process:

"Good to have full day, then time for reflection and practice. It gave staff confidence. Appreciate the in-depth notes that can be adapted as needed."

"The unique opportunity to come together with other outreach teams itself was a great chance to share experience and best practice and better understand partners current delivery models."

"Attending the WQSEC was beneficial – as it was away from our normal environment, it was interactive and in-person which allowed for you to be fully absorbed in the content and process."

Delivery:

"Great to have training pack to distribute."

"..importantly we have made contact and are now a familiar face to help with relationships and raising awareness within the community, to encourage referrals and additional support or queries"

"Videos were a good addition, packs were also great but had to be adapted to a whole range of audiences with different time slots and focus. We often had to be "nimble" and able to "pivot" during workshop delivery to provide the most meaningful and relevant content for each group."

"Its great to have a video now showcasing real life experience and to have standardised content and continuity across all Community Outreach/Fieldwork Teams."

"On promoting the new, free of charge, workshops there was significant interest and feedback was really positive."

"The majority of workshop delivery was in-person. This provided more opportunity for interaction, to gauge understanding and respond to reactions as well as keep the audience fully engaged."

"Groups of no more than 12 mean its easier to build rapport and also supports peer connections".

Challenges:

Delivering the Epilepsy Awareness Workshops, we have established that it is necessary to make the clear distinction between training and workshop – several organisations took the funded pilot as an opportunity to receive free input for staff where it would have been more appropriate for them to attend the formal epilepsy and rescue medication training this included Nurses and Health Improvement teams. It is also worth noting that incompatible IT devices limited some staffs access to the video link which was a particularly powerful element of the new workshop.

We are still working closely with GP partners to establish 2 new virtual annual review clinics. Progress has been delayed due to challenges with staff capacity, across the Quarriers ECO team and within surgeries. We have continued to strengthen relationships with our GP partners and are in regular communication with a surgery in Fife who are committed to working in partnership. We have been held up by technical challenges getting Quarriers staff access to NHS Honorary Contract required to access the NHS systems to carry out reviews in the most efficient and cost-effective way. We have reached out to existing partner surgeries for support and next steps require the GP to connect with NHS I.T. department. This process has been slow and feedback from practice managers is that they continue to be working beyond capacity due to the ongoing impact of the pandemic and have had to continually prioritise other core delivery

ahead of resolving this technical difficulty. In NHS Grampian Quarriers have had 2 vacant staff posts during the funding period and this has impacted the total number of reviews delivered overall. One post was quickly filled the other currently remains vacant.

Future Plans (scalability, sustainability, awareness):

The approaches developed and delivered as part of this funded work represent “best-practice” for epilepsy support within the community and have the potential to be adopted across a wider geographic region.

This project has embedded skills across 3 key community-based Epilepsy Teams that support more than 1500 people living with epilepsy across 12 local authorities. Each organisation has the knowledge and material to continue to deliver tailored workshops where staff capacity allows and a fully funded and well-resourced team is in place. Sustainable long term funding remains a challenge for all 3 organisations. Feedback from Quarriers and Epilepsy Connections staff to date, suggests that it has become one of the regular offers made by community outreach and fieldworkers as part of their role. Since the end of the pilot we have delivered to staff within social work and mental health services as well as to a group of 80 teachers and support staff at a local Primary in Falkirk.

Annual review clinics utilise existing infrastructures and, once NHS access is provided, offers a simple and accessible alternative to in-person reviews and has demonstrated can free-up capacity for GP surgeries and NHS colleagues, relieving the pressure on already stretched services. Partnership working with GP practices is not without challenge at this time but we believe this is a replicable model for other Neurological Support Services.

Feedback from people we support continues to highlight that early intervention has reduced the likelihood of more intensive and costly medical support, as epilepsy has been well managed. With a better-informed workforce people with epilepsy are receiving improved support and services and are better connected to employment, education, training and community opportunities and activities.

“I feel so much better going into work now.....I feel safer.” Individual with epilepsy whose employer and colleague received Epilepsy Awareness Workshop.

Staff really enjoyed delivering the workshops and saw it as a great awareness raising campaign but also a great opportunity to mix with the wider community – with occasions to get together still more limited than prior to Covid, staff felt the benefit, ***“I loved doing it and mixing with everybody”***.

Quarriers ECO team will continue to track and share the impact of both these delivery models with the wider epilepsy and neurological communities including as part of our role on the Epilepsy Consortium Group, Local Authority and Voluntary Sector Steering groups.

Financial Breakdown:	AMOUNT
ITEM	
Quarriers salaries – x4 Community Outreach Workers, x1 Project Manager, x1 Administrator	£35,265
Workshop Training Development Session inc. accommodation and subsistence	£489
Training the Trainer Delivery Session	£4,278
Staff Travel	£2,400
Epilepsy Connections research, delivery and evaluation costs.	£5,000
Lanarkshire Epilepsy research, delivery and evaluation costs.	£3,200
IT Equipment, print and design, workshop video content development	£940
Quarriers Internal Training	£983
Quarriers Overhead and running costs	£3,352
Total Cost	£56,260