

The outcomes of online self-management education for adults with epilepsy

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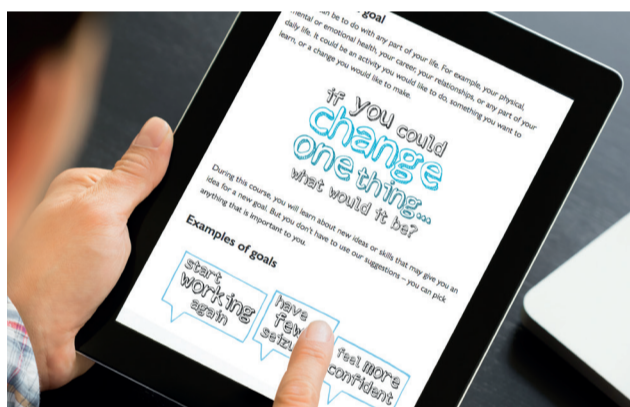
Epilepsy is a complex condition and people with epilepsy require support to actively self-manage.

Epilepsy and you is an online self-management course designed to increase patient activation, thereby improving health outcomes and quality of life. The programme was co-produced with patients and professionals, and has QISMET and NHS England Information Standard accreditation. The programme demonstrates significant value to participants at relatively low cost.

The programme

It can be accessed from any computer, tablet or smartphone at a time and place that suits participants.

The programme is designed to impact on patient activation, medication adherence, psychological wellbeing, coping skills and behaviour change. This is achieved through a structured programme of information and activities, including weekly goal setting and action planning.



Design

Epilepsy and you is evidence-based and was co-produced with people with epilepsy, professionals and commissioners. It has QISMET and NHS England Information Standard accreditation.

Learning outcomes and delivery method were chosen through:

- An extensive literature review
- A multi-round Delphi survey completed by 45 professionals and people with epilepsy

An initial feasibility study (n=17) was followed by a pilot (n=62) and evaluation, to assess programme outcomes and economic and social impact.

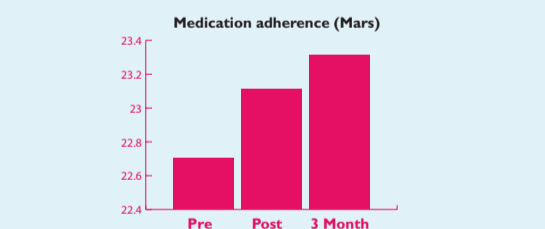
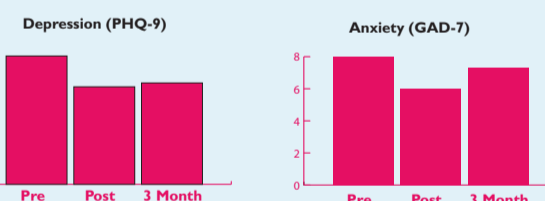
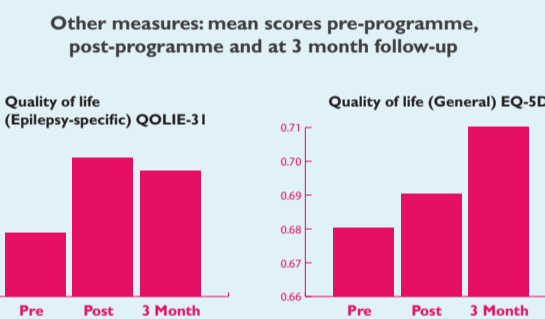
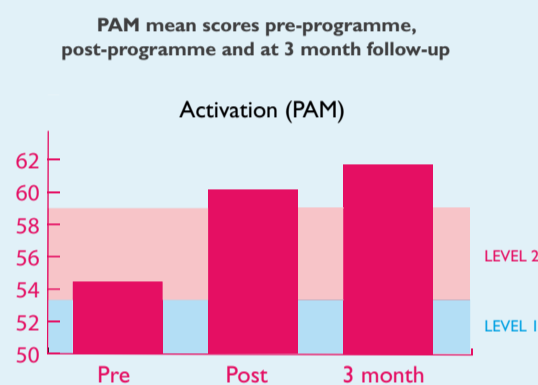
Evaluation methods

Independent evaluators from Coventry University used:

- A quantitative online survey using standardised outcome measures administered pre-programme, post-programme and at 3-month follow-up (n=62, 37 and 31 respectively)
- A Social Return on Investment (SROI) study using telephone interviews with programme participants (n=10) to identify and value programme outcomes experienced

Results

Participants moved, on average, from level 2 activation – “lacking knowledge and skills for self-managing” – to level 3 activation – “beginning to take action to self-manage”.



Economic and social impact

For every £1 spent to develop and deliver Epilepsy and you, £18.15 of value was generated for programme participants.

£ The Social Return on Investment ratio = £1: £18.15

Participants reported a range of outcomes, including a reduction in social isolation.

Conclusions

Participation in the programme provides meaningful benefit to people with epilepsy.

- Increased knowledge, skills and confidence (activation) in participants to manage their epilepsy, maintained at 3 months after completion
- Improvements in patient activation that compare favourably with other self-management programmes
- A range of social and economic outcomes including increased social interaction, reduced isolation and fewer seizures
- Evidence that participants experience less social isolation after completing the programme
- The programme demonstrates significant value to participants for relatively low cost

Participants reported that an online programme had benefits over taking part in a face-to-face programme, including flexibility, being able to take part at a time and place that suits the individual and avoiding the need to drive to a location.

Feedback

“Better sleep and going back to being my happy, positive self - something that has been missing since I experienced my first seizure nearly 7 years ago.”
Course participant

“It’s given me confidence I’ve never had. I’ve increased my physical activity and worked on my relationship with my neurologist and epilepsy nurse.”
Course participant

“I feel this is an excellent way to encourage people to have ownership of their condition.”
Janet Rigby – Epilepsy specialist nurse

“People with epilepsy get a lot from this type of content as it helps them to realise they are not alone in their thoughts and feelings.”
Edel Dewhurst - Cognitive Behavioural Psychotherapist

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