Online self-management – Evaluating Epilepsy and you

Epilepsy Action identified a need to go beyond simply providing epilepsy information. We wanted to work with people with epilepsy and professionals. Our aim was to activate people to learn about their condition, develop their active coping skills and enable shared decision making.

What is Epilepsy and you?

It is an innovative online self-management programme for people with epilepsy. It can be accessed online from a computer, tablet or smartphone, at any time.

Over 8 weeks, participants are supported to:
- Access high-quality information and become an expert in their own epilepsy and
- Understand shared-decision making and
- Try out new self-management skills, including goal setting and action planning and
- Achieve a better quality of life through self-care

Working together

Design
We used the evidence from the literature review in a Delphi consensus process (Dulley 1969) with 45 people with experience of epilepsy, including health professionals. They rated content and delivery approaches that would be most helpful in an education programme supporting people to manage their epilepsy.

The Delphi process also created the learning outcomes that informed the design of eight learning modules:
1. Active self-care management 5. Your feelings
2. Epileptic seizures 6. Memory, sleep and stress
3. Managing your seizures 7. Work and daily activities
4. Safety, travel and your independence 8. Relationships

The programme supports participants to set and achieve goals, and incorporates an online gratitude journal and a participant forum. A workbook can be downloaded or posted.

Production
We co-produced Epilepsy and you with people with epilepsy, GPs, neurologists, nurses, psychologists and commissioners. It’s evidence-based, meets Information Standard and QSMET requirements.

Evaluation and analysis
To measure the outcomes of the programme an evaluation is being undertaken by Coventry University using the following measures:

Demographics and epilepsy status
Quality of Life: (EQ-SD, QOLIE-31) (PHQ-9, GAD-7)
Patient Activation: (PAH) (PHQ-95)

Ongoing analysis includes:
- The extent of participants’ quality of life, self-management behaviour, knowledge and confidence, and psychological well-being
- To what extent are any changes in these factors maintained over time?
- Which groups benefit most and least from the programme? (We are looking at gender, level of education, levels of income, ethnicity and seizure control).

Where are we now?

Sixteen people with epilepsy completed Epilepsy and you for our 2015 feasibility study. This demonstrated the programme was accessible to them. To complete the end of programme survey and six participants in semi-structured interviews by telephone.

The findings from the study and feedback from the participants informed the full pilot. The pilot programme is now underway, with 208 people having completed the pre-programme survey. We are monitoring how many of these go on to complete the programme and achieve their goals.

Why online?

In 2013, Epilepsy Action carried out an extensive literature review of what has worked in the design and delivery of self-management programmes for long-term conditions. It showed:
- Limited evidence of the effectiveness of different ways of delivering self-management education
- A gap in the provision of online self-management education

Group sessions were reported to be beneficial because participants compared themselves with others and were motivated to change the way they managed aspects of the condition. Barlow (2005). However Loing (2004) noted that “large numbers of patients will not or cannot attend group education programmes”. And there are logistical difficulties in getting groups together.

Feedback

The full evaluation will be published later this year. Feedback received so far is very promising:

Feedback from participants
- “I thought it was great and I wish I could have done it ten years ago.”
- “I am thinking more positively and am just trying to be me again, and not that man with epilepsy.”

Feedback from professionals
- “People with epilepsy get a bit from this type of content as it helps them to realise they are not alone in their thoughts and feelings.”
- Edel Dowhurst – Cognitive Behavioural Psychologist
- “I feel this is an excellent way to encourage people to have ownership of their condition.”
- Janet Rigby – Epilepsy specialist nurse

What’s next?

Social return on investment
Coventry University will conduct a Social Return on Investment evaluation. This will seek to understand the nature, extent and range of the potential social returns of the programme. For example, changes in employment/volunteering, increases in social networks, pursued learning and reduced visits to healthcare professionals.

For every £1 spent on this project, Coventry University will work out how many £s of social value is created.

Evaluation of different delivery methods
This will inform decision making when considering offering self-management education programmes to different groups of people. The outcomes of the evaluation will inform our work with commissioners and providers of services for adults with epilepsy.

Finally...

Online programmes for diabetes, heart disease, arthritis and respiratory problems have already been commissioned. Why not epilepsy?

There is a potential health inequality when people with some conditions, living in some areas, can access targeted self-management, and others cannot. Epilepsy Action is working with others, to increase access to self-management programmes for all.

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References

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