Including Experts by Experience (EbE) as Co-facilitators of a Psychological Wellbeing After Stroke Group: Reflections and Impact

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NHS
Gloucestershire Health and Care
NHS Foundation Trust

Background

- Emotional changes following stroke are common and can negatively impact recovery outcomes (Liu et al., 2025).
- The Gloucestershire Community Neurology Service introduced an online Psychological Wellbeing After Stroke (PWAS) Group in May 2024 to support post-stroke adjustment using Acceptance and Commitment Therapy (ACT)
- Although the group provided opportunities for peer connection, 18% of participants did not attend and 29% dropped out.
- Patient feedback suggested that involving Experts by Experience (EbE) to co-facilitate the group could improve relevance and reduce isolation.
- Peer support and EbE involvement have been shown to promote psychological wellbeing through building community, increasing motivation and shared experience (Clarke et al., 2020; Van Erp et al., 2025).
- EbEs were introduced as PWAS co-facilitators in January 2025, working alongside a qualified psychologist and Assistant Psychologist to share their experiences and support patient outcomes

Aims

- To evaluate the effectiveness of the PWAS group
- To assess the impact of EbE co-facilitation on patient outcomes and engagement
- To explore the impact of EbE involvement on patient experience and retention

Method

- The project was registered as a service evaluation with the NHS Trust Research Department.
- EbEs were recruited and trained in collaboration with ReConnect Gloucestershire.
- Since the PWAS groups have been running:
  - 27 patients have attended
  - 9 have dropped out
  - 22 have declined the group
- Outcome measures (OM) were collected pre and post group attendance:
  - Depression (PHQ-9)
  - Anxiety (GAD-7)
  - Psychological flexibility (AAQ-II)
- Patients also completed a feedback questionnaire.
- Anonymised data was collated from service records of ACT group attendees before the introduction of EbE co-facilitators (*n* = 9) and compared to those attending since their introduction (*n* = 18).

Results

Symptoms of depression and anxiety significantly decreased and psychological flexibility increased across patients attending groups with and without an EbE. There was no significant effect of EbE presence on outcome measure scores. Before the introduction of the EbE, patients were 1.96 times more likely to drop out. Patients report finding it helpful having the EbE cofacilitate the group. Feedback from all EbEs indicated that their involvement in the group had a positive impact on them.

Conclusion

- Depression and anxiety symptoms decreased, while psychological flexibility increased following the ACT group intervention
- The EbE co-facilitator had no measurable impact on OM
- Dropout rates decreased following the introduction of an EbE, though this was not statistically significant
- Patient feedback was positive, with suggestions for longer sessions to allow more group discussion
- Findings are limited by the small sample size, inconsistency in completion of OM, a change in the Clinical Psychologist running the group and incomplete outcome data; Qualitative research could further explore the perceived benefits of EbE involvement from patient and EbE perspectives

Taking ACTion Together - A qualitative research study exploring psychological adjustment in EbE. For more information contact Megan Letch: ml01570@surrey.ac.uk

Onboarding and my Involvement

1. **Recruit**
   Liaised with ReConnect to identify potential EbEs
2. **Prepare**
   Supported EbEs through role-specific training
3. **Collaborate**
   Roles and responsibilities discussed and established with Clinical Psychologist, AP and EbE
4. **Facilitate**
   Supported delivery of Weeks 1-6
5. **Reflect**
   Gathered feedback and reflected on the impact of EbE involvement

My Learning
Collaboration . Communication . Service Development . Valuing Lived Experience . Group Facilitation . Balancing Roles .

The role of the Expert by Experience:

The role of the EbE was created as an opportunity to co-facilitate the PWAS group. Weekly responsibilities included:

- Facilitate group discussion
- Share their experience of their stroke and recovery
- Promote connection
- Shape content of the group

What the EbEs have to say…

"it was very rewarding. It felt like we spoke the same language; I could identify what issues the group members were dealing with and I found I could pick up on things they weren't saying because I have been through it myself."

"It was absolutely brilliant. It felt nice to feel valued, and that my opinion counted."

"I have more of an ambition to reach out online to people, and I have more of an incentive to get more qualifications and become more trained. This has been a step in the right direction for my future."

"I do feel very positive that so much time is being taken to listen and learn from users of the service. I'm sure that other areas of the NHS could benefit from similar approaches."

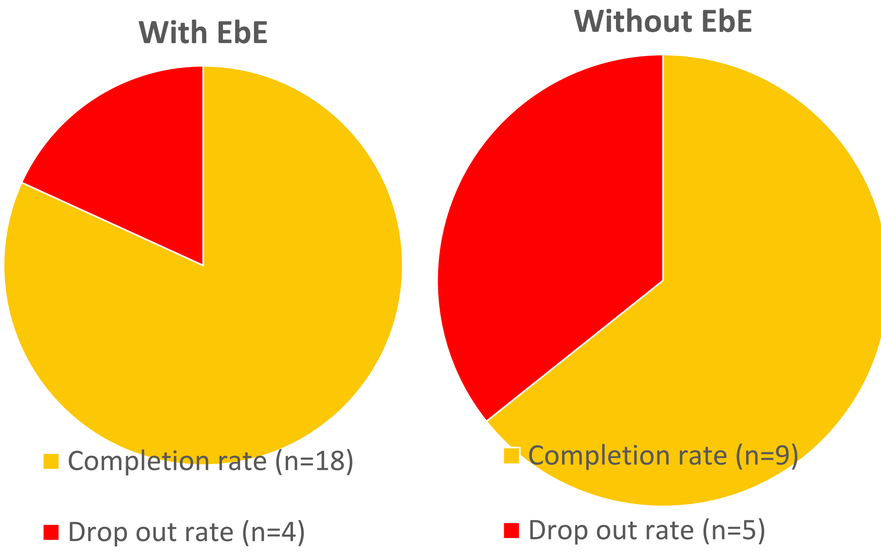
ReConnect Gloucestershire

Who are ReConnect?
ReConnect supports stroke survivors across Gloucestershire through peer befriending, support and group activities.

Our collaboration...
We partnered with ReConnect Gloucestershire to recruit and support EbE's. ReConnect provided volunteers with information about the EbE role and ongoing support throughout their involvement.

PWAS Group Structure	
Week 1	Psychological Challenges After Stroke
Week 2	Ways of Coping
Week 3	Developing Awareness
Week 4	Dropping the Struggle
Week 5	Identifying what is Important
Week 6	Overcoming Barriers and Bringing it Together

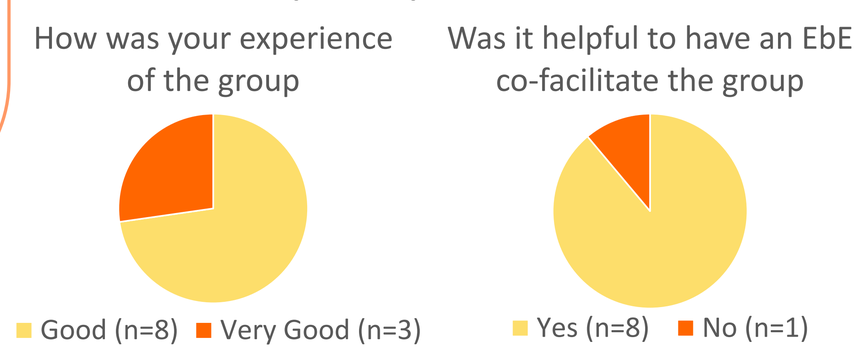
Completion rate of group participants with and without co-facilitation of an EbE



My Reflections

The project provided me with valuable experience of service development and collaborative working as an Assistant Psychologist. I developed confidence in recruiting, preparing and supporting Experts by Experience, as well as co-facilitating psychological group sessions and supporting patients in between sessions. Working alongside EbEs highlighted the unique contribution of lived experience and encouraged me to reflect on how professional and personal perspectives can compliment one another. I learned that successful involvement requires clear communication, defined roles and ongoing support. Overall, the experience has increased my confidence in group facilitation and reinforced the importance of involving people with lived experience in the development and delivery of psychological services.

Group Participant Feedback



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